

***“What about motherhood?”:***

***Women’s journeys through HIV and AIDS.***

Submitted by

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**The “stories told *about* women with AIDS  
are usually not the same as the stories told *by* them”**

**(Cameron, 2001:8)**





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## *Table of contents*

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<i>Statement of authorship</i> .....	vii
<i>Acronyms</i> .....	ix
<i>Acknowledgements</i> .....	xi
<i>Introduction</i> .....	1
Chapter 1.....	14
<i>HIV-positive women and reproduction</i> .....	14
Women in the epidemic .....	14
Mother-to-child transmission and biomedical research.....	16
Prevention of mother-to-child transmission in Australia.....	18
Epidemiological research on HIV-positive women and reproduction .....	21
Chapter 2 .....	26
<i>Narrative theory and method</i> .....	26
Part I – Narrative theory .....	27
Part II – Method.....	33
Chapter 3 .....	48
<i>Motherhood and HIV</i> .....	48

Motherhood and narrative .....	48
Diagnosis disrupts the plot of motherhood .....	52
Being an HIV-positive woman.....	64
Motherhood and HIV.....	70
Loss.....	74
Summary .....	81
Chapter 4 .....	82
<i>The journey after diagnosis</i> .....	82
Revising after diagnosis .....	85
HIV, motherhood and uncertainty.....	94
HIV is an overwhelming barrier .....	96
HIV is not a barrier to motherhood .....	105
Summary .....	106
Chapter 5 .....	108
<i>Mothers and medicine</i> .....	108
Justification.....	110
Conception .....	113
The role of treatments during pregnancy.....	116
Caesarean or “natural” delivery .....	121
Treatments for babies .....	126



Breast or bottle? .....	131
Summary .....	134
Chapter 6 .....	136
<i>The impact of stigma on women's accounts</i> .....	136
HIV-positive women, stigma and discrimination .....	137
Private accounts .....	147
Public accounts.....	159
Public and private accounts of childlessness.....	163
Summary .....	166
Chapter 7 .....	167
<i>Living with uncertainty</i> .....	167
Illness .....	174
Treatments .....	184
Summary .....	198
Chapter 8 .....	200
<i>The journey continues</i> .....	200
Appendix A: Notice calling for volunteers .....	206
Appendix B: Consent forms .....	210
Appendix C: Interview schedule .....	218
Appendix D: Demographic information sheet.....	222

Appendix E: Newsletters .....	226
Appendix F: <i>Common Threads</i> cover page .....	240
Appendix G: Women’s narratives .....	<b>Error! Bookmark not defined.</b>
References .....	429

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## *Summary*

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This thesis explores the impact of an HIV-positive diagnosis on the meaning of motherhood in women's lives. Narrative methodology was used to examine how HIV-positive women understand their experiences of an HIV diagnosis during their childbearing years and the impact this has on their identity as mothers (both present and future). In-depth interviews were conducted with 34 HIV-positive women living around Australia in 2001. Interviews were transcribed and edited and then returned to the women so they could confirm the story used was the same as the one they had jointly constructed with me.

The women in this study found their HIV diagnosis to be extremely traumatic and for most it shattered their sense of self and future, and their plans and intentions. Not only were these women faced with their own morbidity and mortality, but for those who intended to become mothers, motherhood seemed unobtainable. Women who were already mothers were faced with the devastating possibility of dying before their children became adults or independent.

The metaphor of the journey was used to explore how women give meaning to their diagnosis and move beyond this initial devastation. With time many women were able to revise their future narrative to include motherhood. However, this decision brought to the fore other complex decisions about the use or rejection of medical interventions to reduce the risk of vertical transmission. Women also faced difficult decisions about disclosure, with the threat of stigma ever-present.

Most women narrated their HIV infection as only one small aspect of their lives. They usually wanted to continue with the life they had planned before their diagnosis and for most this included becoming a mother or mothering existing children. Despite the

initial overwhelming shock of their HIV diagnosis, most women were determined to pursue their quest for motherhood.

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## ***Statement of authorship***

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Except where reference is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis submitted for the award of any other degree or diploma.

No other person's work has been used without due acknowledgment in the main text of the thesis.

This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

All research procedures reported in the thesis were approved by the relevant Ethics Committee or Safety Committee or authorised officer.

Signed: .....Date: .....



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## *Acronyms*

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AIDS	Acquired Immunodeficiency Syndrome
ARCSHS	Australian Research Centre in Sex, Health and Society
ARV	Antiretroviral treatment/therapy
AZT	Zidovudine
CARG	Commonwealth AIDS Research Grant
CDC	Centers for Disease Control and Prevention
CMV	Cytomegalovirus
GRID	Gay-related immune deficiency
HCG	Human chorionic gonadotropin hormone
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
MTCT	Mother-to-child transmission
NCHECR	National Centre in HIV Epidemiology and Clinical Research
NHMRC	National Health and Medical Research Council
PACTG	Perinatal AIDS Clinical Trial Group
PCP	Pneumocystis Carinii Pneumonia
PLWHA	People living with HIV/AIDS
PTCT	Parent-to-child transmission





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## *Acknowledgements*

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I first decided I wanted to become a social researcher when one of my undergraduate sociology lecturers, Dr Len Eastop, told a vignette about a former student whose research had led to the introduction of video camera evidence for victims of sexual assault so they could avoid their alleged offender. Thank you, Dr Eastop, for the story that led to my career. As a result I embarked on a Master's Degree in Applied Social Research, whilst working full-time in market research and, after this was completed, "I was never going to study again!" So when I started as a research assistant at the National Centre in HIV Social Research at the Centre for Sexually Transmissible Diseases at La Trobe University, I never imagined this journey.

I would like to thank my first work supervisors, Michael Bartos, Dr Douglas Ezzy, and Diana McConachy who encouraged me to forge a niche within their program of research on People living with HIV/AIDS and their Carers. They encouraged my interest in working with HIV-positive women in Australia. I would particularly like to acknowledge Michael's role for providing me with support to overcome my fear of public-speaking and become the 'public face' of my work.

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<sup>1</sup> The NHMRC did not stipulate research goals, methods, or desired outcomes.

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## *Introduction*

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### **Background to the research**

My first social research job was at the National Centre in HIV Social Research. Ten months after I started I was sent out into the field for my first interview on a project about sex and relationships of people living with HIV/AIDS. Although the sample consisted mostly of gay men, a nominal number of women were included in the sample. As the only woman interviewing on the project I was sent to interview all of the women who volunteered to participate. The first woman I met with, Jane<sup>2</sup>, had requested a “support person” be present with her during the interview when she was invited to participate. This request probably should have suggested to us that it was likely this interview was going to be particularly difficult for Jane.

Within minutes of commencing the interview it became obvious to me that I would not be using the interview schedule. The woman sitting in front of me wanted to tell me a story, her story, which would not fit the mould of an interview schedule. Jane had met a man overseas, fallen in love, fallen pregnant and returned to Australia to have her baby. Within months of the birth of her son it was obvious that there was something wrong with him. He was constantly sick and his weight gain was poor. Paediatricians tested her son for all sorts of conditions; eventually a friend of Jane’s, who was also a doctor, suggested she consider testing her son for HIV. She did. The doctor who tested Jane’s son rang her at 5:30 p.m. on Friday evening and advised Jane her son had AIDS. Jane was an intelligent woman and knew enough about HIV to know that if her baby was HIV-positive then she too must be. Jane and her son were

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<sup>2</sup> As with all of the women written about in this thesis, ‘Jane’ is a pseudonym.

home alone, without support, without services, with a death sentence. Jane's son had died six months prior to the interview – he was 18 months old.

This interview was incredibly painful for Jane. Jane, her support person (who turned out to be a woman who was assigned to Jane from the AIDS Council not long after her son's diagnosis) and I cried often. Several times I offered to terminate the interview but Jane was determined to have her story heard and included, hopeful that no other woman would ever have to endure her experience of diagnosis. I left Jane's place emotionally exhausted but inspired to help Jane make a difference.

During the course of that project (and others) I interviewed around 20 women and it soon became apparent that these women wanted to tell a different story from the one that we were requesting from them about their sexual practices or work-related issues. Instead many women wanted to talk about what their diagnosis had meant to their desires to become mothers, their existing roles as mothers or their loss of the role of mother. A common theme in their stories was the sense that their experiences were lost in the bigger picture of the Australian epidemic but that they continued to participate in the research projects in the hope that their story may reach one other woman out there who also might think she was alone. The research projects in which these women were participating were designed with the larger Australian epidemic in mind, that of gay men; therefore there was little scope within these projects to explore issues around motherhood. I recognised that research needed to be devoted to women's experiences and I wanted to be able to devise a method that would allow for all of the women's accounts to be heard.

Two years after my interview with Jane, she was invited to participate in another project being undertaken by our research centre that I was not involved in. Jane wrote a letter to the director declaring her dissatisfaction with her prior participation and emphatically stating she did not wish to be involved in any further research. She wrote that she did not feel her story was reflected in the report findings that she had been sent (based on a quantitative survey she had also participated in) (Ezzy, de Visser, Bartos et al., 1998; McDonald et al., 1998) and that she was disappointed that she had not received a transcribed copy of her interview. Jane also believed that I should have contacted her the day after the interview to inquire after her well-being, considering

how upset she had been. I was mortified to think that I had let this woman down. I immediately wrote to Jane explaining to her that the report she had been sent did not have the scope to reflect her story but that I had included her story in conference presentations I had given, and that journal articles were being prepared. I also informed Jane that her experience had inspired my PhD research which at that stage I had just started to conceptualise. I also explained to Jane in the letter that I was not ethically permitted to contact her again after the interview but with hindsight I wish I had made an exception. I invited her to contact me if she wished to discuss the matter further but, not surprisingly, I did not hear from her again. The director of our centre also wrote to Jane expressing her regret at Jane's disappointment and confirming the ethical restraints researchers are bound by.

My experience with Jane and her dissatisfaction with the research process made me determined to avoid such pitfalls with my PhD research. I decided that each research participant would receive her transcript back after it was edited and that the version approved would be the one I used. I also sent yearly newsletters updating women on the progress of my work and any conferences I had attended. However, I did not assume that each woman would want further contact and stressed it this was up to her if she wished to continue hearing from me even after she had approved her edited transcript. I did lose contact with some women over the years, but this was because they moved rather than requesting I no longer contacted them (my method was inspired by that of Maggie Kirkman, 1997, and is covered in detail in Chapter 2).

### ***Common Threads***

One of the ways I believed I could overcome a repeat occurrence of Jane's unsatisfactory experience with the research process was to ensure that the women who participated in my PhD research saw their participation turn into something that would directly reach the affected population. I also wanted to ensure that the women did not feel excluded from this process and could participate in the process of dissemination if they so wished.

I was inspired by several previous resources released in Australia that were aimed

specifically at HIV-positive women. The first, and most influential, was the resource *Positive Women: Women with HIV/AIDS Speak Out* (Positive Women Victoria, 1992). This resource was the first to include women's stories in the text. Since then, other resources such as *Your Child and HIV: Be Positive about Being Positive* (Sydney Children's Hospital, 1999), *A Positive Guide to Child Care* (Blegg, 1999), *Treat yourself right: Information for women with HIV and AIDS* (Positive Women Victoria & AFAO/NAPWA, 2001) and *Unravelling the Law: A Resource for Women Living with HIV/AIDS* (Cameron & Puls, 2004) have all produced significant resources for HIV-positive women. Although there have been some informative fact sheets produced for HIV-positive women concerned with pregnancy and one resource focusing exclusively on pregnancy called *Positive pregnancy* (Goode, 2001), these particular resources did not contain the stories of a diverse group of women with a range of experiences. Thus evolved the resource *Common Threads: Positive women discuss pregnancy, parenting and living with HIV* (McDonald, 2006a) (See Appendix F). This resource was a lengthy one that contained the stories (or part thereof) of all the women who participated in my PhD research. Its main foci were the decisions regarding pregnancy, including conception, treatment, birthing choices, the stay in hospital, and care of the new baby. However, it also contained chapters on diagnosis during pregnancy, parenting a positive child, disclosure, being an HIV-positive woman and a mother, as well as finding support and information.

Once this project was conceptualised, I approached the director of Positive Women Victoria to ask for the organisation's assistance in seeking funding. Together we acquired funding from the Reichstein Foundation, The AIDS Trust of Australia, the National Association of People Living with HIV/AIDS and the Department of Human Services (Victoria). Like the narratives used in this thesis, the women were consulted on the use of their narratives in the resource and were given editorial opportunities. Whilst this was being done, a designer and artist were employed. There were a number of delays in this project, including the birth of my first daughter, shortfalls in funding and the resignation of the consultant initially employed to write the resource (which led me to write the resource). However, the resource was finally completed and launched in February 2007.



## **My journey over the course of this research**

During the course of this research I had several significant experiences which affected my understanding and interpretation of the stories told to me by the women who participated in this project.

The first was the birth of my older daughter, Juliette, in January, 2003. This occurred after I had completed all of the interviews (2001) but before the detailed analysis took place. I had not always been sure that I wanted to become a mother but, like many of the women in my research, I assumed it was something I could do if I chose. Having my own daughter to care for and protect provided me with new insights into the expressions of love and the need to shield their children from harm shared by the women whom with I spoke. Whilst I had previously appreciated their desires to protect their children and had an intellectual understanding of their mother–child love, becoming a mother myself meant I now embodied such knowledge and could share mine with them. Further to this, in Juliette’s first year she suffered infantile eczema. I found myself resistant to using the cortisone creams prescribed by doctors. Experiencing the trauma eczema caused Juliette, I began to find myself in a similar – albeit different – dilemma to that of the women in my study who were confronted with treatment choices for their newborn children. My own narrative of motherhood has made me vulnerable in my readings and interpretations of the women’s stories (Behar, 1996). Whilst interpreting the women’s accounts, I have become aware of my own accounts and, like Behar (1996: 33), I am one who has “come to know others by knowing herself and who has come to know herself by knowing others”.

The second event which had a profound impact on me as a mother and researcher was the miscarriage of what I believed was my second pregnancy at six weeks’ gestation. I was diagnosed with a non-viable pregnancy, most likely a blighted ovum. During this time I had a lot of abdominal pain which my obstetrician thought was contractions. She told me I had two options: a dilation and curette, or wait for the miscarriage to occur “naturally”. I opted for the second, believing less intervention was preferable.

Logically I accepted the miscarriage; I knew around one-third of pregnancies ended in miscarriage. But as I waited for the miscarriage over the next four weeks I rode a roller-coaster of emotions coupled with physical pain. I still had morning sickness and even looked pregnant. I felt very hormonal and at times I wondered if a mistake had been made with the ultrasound. However, after four weeks my obstetrician said I needed to have a curette to avoid additional medical complications. Perhaps to put my mind at ease, she performed another ultrasound – there was definitely no baby. I had the curette the following day at the same hospital where my daughter was born. I remember feeling very sad that I was there to remove what should have been Juliette’s sibling.

After the curette my obstetrician said I should wait a cycle before attempting to conceive again. But four weeks later she rang me and told me that the pathology results from the curette revealed I had had a hydatidiform mole. This disease is the abnormal growth of the placenta and is also referred to as a molar pregnancy and Gestational Trophoblastic Disease. In 5% of cases this disease metastasises into highly malignant choriocarcinomas (Diagnostic Products Corporation, 2007). I had experienced typical symptoms whilst waiting for the miscarriage but its rarity meant that a diagnosis was not made. My obstetrician reassured me that treatment was very successful; however, I would have to wait at least 12 months before I could attempt to conceive again. I was devastated. All I could think about was the difference in age between Juliette and her future sibling. All of the women around me at playgroup and within my social circles had already had their second children.

The disease monitoring for a hydatidiform mole at the time I was diagnosed required months of weekly testing which reduced in frequency when hormonal levels returned to “normal” and then continued monthly for a period of one year. During the period of monitoring, pregnancy is contra-indicated. Ironically, the tests are looking for the presence of the Human Chorionic Gonadotropin hormone (HCG) which is significantly elevated in both pregnancy and trophoblastic tumours. So, of course, if I was pregnant the tests would no longer be reliable. Because I do not live near a major hospital it was easiest for me to drop my sample at the Royal Women’s Hospital each week on my way to work. I remember the first couple of months entering the hospital

and being acutely aware of all the pregnant women and babies – it compounded my grief.

During my search for information I discovered a disbanded support group. After speaking to one of the group leaders I requested that the group reconvene because I had an overwhelming urge to hear other women's stories. When I did eventually meet with these women I found comfort in their stories, particularly those most like mine, where the woman had gone on and completed her family after this diagnosis.

After nine months of undergoing tests, of which the last six months revealed normal levels of HCG, I made an appointment with the oncologist and told him I did not wish to wait any longer as Juliette was three years old. The oncologist requested I do one more month of testing and then continue testing until I became pregnant, because it was unlikely I would conceive immediately. I agreed to this and did provide one more sample. I conceived in the second month but I did not undergo a test in the month I did not conceive. I was satisfied this disease was no longer present and I wished to move on and put it behind me.

When I did conceive my second child, the experience was very different from my first pregnancy. I worried about a repeat occurrence of a molar pregnancy (twice as likely) which could not be ruled out until a heartbeat could be detected at seven weeks' gestation. Then I worried about miscarriage and chromosomal abnormalities (although I decided against chorionic villus sampling or amniocentesis). Even the three ultrasounds I had did not allay these anxieties. With hindsight I did not really relax until I reached 26 weeks when I knew the baby was "viable".

This experience of disease and disease monitoring coupled with loss, grief and desiring something that was temporarily unavailable, deepened my understanding and compassion for the women who participated in my research. I had some similar experiences of medicine intervening in my reproductive choices, on-going medical tests and, like many of the women in my research, I did not regard medicine as the final word. I am not claiming I can "know" what it is like for a woman living with HIV, but I came to have a clearer sense of their desires to become mothers and how disease can interfere with that quest.

The events that I have described have undoubtedly affected this research. My disclosure represents part of my endeavour, from conceptualisation to analysis and the writing of this thesis, to be vigilant to the principles of reflexivity, scrutinising my own “positions and interests ... in order to produce less distorted accounts of the social world” (Hertz, 1997:viii) of women living with HIV/AIDS in Australia.

### **The HIV epidemic: where do women fit in?**

The first cases of PCP (pneumocystis carinii pneumonia) were reported in 1981 among young gay men in the United States of America (CDC, 1981). In these early stages this unknown disease was referred to as GRID (gay-related immune deficiency) and was spoken about as a “gay man’s cancer or gay plague” (Lewis, 1998). It was a year before the disease was named Acquired Immunodeficiency Syndrome (AIDS) and GRID then became widely known through its increasing use by health-care professionals and the media. This led to the belief that there was an inherent link between homosexuality and the disease.

In the early years of the epidemic there was little recognition that women in Western countries were also living with (and dying from) AIDS (Long & Ankrah, 1996). The first woman was diagnosed with AIDS in the United States in 1981 (Wiener, 1991) and in February, 1984 in Australia (NCHECR, 2007b). Several years later it was discovered that a Danish female doctor who had been working in Africa and was thought to have died from PCP in 1977 had in fact died from AIDS (Shilts, 1987). Yet women have remained largely invisible in the epidemic of the developed world despite the epidemic having profound implications for some populations of women in the developed world. In the United States of America, women account for 26% of people living with HIV/AIDS (CDC, 2006b). The CDC estimated 120,000 to 160,000 women were infected with HIV and 80% were of childbearing age (CDC, 2004).

In reality the HIV epidemic in Western countries has mostly affected gay men. This has resulted in the majority of resources being directed to assist this population and the little attention HIV-positive women has received has tended to present women as

victims (recipients of infected blood products or partners of bisexual men) or vectors of disease (HIV-positive pregnant women and sex workers) (Anastos & Marte, 1989; Bayer, 1991; de Bruyn, 1998; Gorna, 1996).

Today more than 33 million people are infected with HIV worldwide and almost half are women. Current projections are for the ratio of women to men infected by this virus to continue increasing. Sub-Saharan Africa bears the greatest burden of this epidemic, with almost two-thirds of the world's people infected with HIV/AIDS; 61% of those infected with HIV in this region are women (UNAIDS & WHO, 2007). Severe population decline is predicted due to the large numbers of women of childbearing age who will die as a result of HIV infection. Approximately 30% of all pregnant women aged 15 to 24 in this region are known to be HIV-positive (UNAIDS & WHO, 2006).

Australia's epidemic is comparatively small. As of 30 September 2006, 25,981 people have been diagnosed with HIV, 9,940 have been diagnosed with AIDS and 6,658 people have died from an AIDS-related condition (NCHECR, 2007a). Whilst the number of HIV-positive women living in Australia still remains relatively low (n = 1539 (NCHECR, 2007a)), the consequences of an HIV-positive diagnosis are highly significant, particularly when considering that the median age of women diagnosed between 1996 and 2005 was 30 years (NCHECR, 2006b). HIV-positive women have a double burden of health and reproductive decision-making, both of which are framed by the medical discourse of HIV. This accentuates the need for greater understanding of women's reproductive desires and the choices they make about their reproductive health.

## **Research goals**

My principal goal was to examine the meaning of an HIV-positive diagnosis on the role of motherhood in women's lives. Secondly I wanted to present HIV-positive women's stories about how they understand their experiences of an HIV diagnosis during their childbearing years and the impact this has on the role of motherhood

(both present and future). I also wanted to explore the decision-making processes through which HIV-positive women go in their pursuit (or not) of pregnancy and motherhood, including the use or rejection of medical interventions to reduce the risk of vertical transmission. In addition I sought to investigate how HIV-positive women make decisions about disclosure and how stigma impacts on these decisions and on their daily lives as both women and mothers. Finally I wanted to explore HIV-positive women's concepts of future, hope and longevity.

There is a plethora of research theorising motherhood and it is not my intention to critique this work. Instead this thesis contributes to the literature on women living with HIV and what an HIV-positive diagnosis means to women who intended to become mothers or were already mothers. I am also interested in the way HIV-positive women and their bodies are seen within the epidemic. Historically the medical focus of HIV-positive women has been vertical transmission. Consequently women have become vectors of disease and little attention has been paid to their desires as mothers and as sexual beings. Although the focus of this thesis is Australia, and notwithstanding cultural differences, it has wider applicability for HIV-positive women in countries where antiretroviral therapy is available.

Even though HIV-positive women are now discussed at international gatherings and in the literature published about the pandemic, scant attention is paid to their stories and their experiences. Instead, vast amounts of time are dedicated to discussing the reduction of mother-to-child transmission (MTCT) or, more recently, parent-to-child transmission (PTCT), the goal being an HIV-negative baby. Where women's experiences are presented they are usually discussed in medical literature as case studies of risk for vertical transmission, with success or failure being the salient point. I do not wish to malign these discussions, but little consideration is given to the women themselves and their desires and hopes for motherhood: their stories. Without this understanding we cannot hope to understand what motivates HIV-positive women to utilise or reject medical technologies that help reduce vertical transmission.

## Outline of the thesis

My intention with this thesis is to take you, the reader, on a journey: to provide insight and understanding of how women living in Australia give meaning to and interpret their experiences of being diagnosed as HIV-positive. From diagnosis and disruption, the devastation women felt was not only because most assumed imminent death but also many believed they could no longer pursue their dream to become a mother. Those who were already mothers faced the possibility that they would not see their children into adulthood and beyond. With time, many women were able to revise their narratives of the future to include children, however, HIV impacted on all facets of their mothering experience. Framed by the stories of women living with HIV in Australia, the following chapters examine these experiences.

Chapter 1 reviews research on HIV-positive women and reproduction. This research has been undertaken by a number of disciplines, dominated mostly by epidemiological and clinical research. Within these disciplines women's stories are silenced and it is their bodies that are the focus; the principal goal is eliminating vertical transmission (from mother-to-baby) of HIV. The social research that does exist is predominantly conducted in the United States where women of minority groups are over-represented (particularly African-American, injecting drug-users and economically disadvantaged women). Australia's pattern of HIV infection in women is quite different and hence the cultural implications are as well.

In Chapter 2 I introduce the concept of narrative theory which influenced the analysis and presentation of my research. "Stories are fundamentally about the vicissitudes of human intention organized in time" (McAdams, 2003: 190) and narrative is the way people with illness make sense not only of their illness or disease but also of their life affected by illness (Frank, 1995; Good, 1994a). In this chapter I also explain my method and expand on what I did and why.

Chapter 3 deals with the women's narrative identity of motherhood and the impact of an HIV diagnosis on that identity. The influence of the canonical narrative of motherhood is explored for women who are not yet mothers, those who are diagnosed

whilst pregnant and those who are already mothers. The role of HIV in women's shifting identities is explored, and issues pertaining to motherhood, including loss and grief, are examined.

Chapter 4 explores the post-diagnosis journey. An HIV diagnosis is a biographical disruption that leaves many women unable to make any plans or progress towards their future. This uncertainty can last months or years and during this time many women can be thought of as living in the subjunctive mode. Eventually most women are able to reconstruct their future to include motherhood. However, for some, HIV presents an overwhelming barrier to motherhood and they must revise their accounts of the future as childless women.

In Chapter 5 I explore women's interaction with medicine as they pursue their quests to become mothers. I look at what aspects of medicine women are prepared to embrace or reject both for the health of their babies and themselves; including treatments, conception, birthing choices and feeding their babies. The rhetorical aspect of justification in the women's accounts is examined as women explain their choices as responsible and caring mothers.

Chapter 6 examines the impact of stigma on women's accounts and the role stigma has played in women's lives. I argue that HIV-positive women are vulnerable to a unique form of stigma because of their child-bearing capabilities and their role as mothers. I also explore perceived and enacted stigma and the complex decisions of disclosure. Women's decisions to construct private and (sometimes) public narratives are examined.

Chapter 7 explores the women's accounts of their future. I suggest that when women were diagnosed (before or after Highly Active Antiretroviral Therapy (HAART)) influences their accounts. I also examine the role of HAART in their thoughts about the future and how they envisage motherhood. Women were at various stages in their journey with HIV and whilst many were hopeful of longevity and the continuation of improved treatments, the uncertainty of HIV was ever present, with little chance of cure or reprieve.



The final chapter concludes this thesis and reflects on the metaphor of “journey” to examine the accounts of women living with HIV in Australia and the impact an HIV diagnosis had on the identity of motherhood.

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# Chapter 1

## *HIV-positive women and reproduction*

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Women in Australia have inhabited several roles during the course of the HIV/AIDS epidemic, most of them secondary to the experience or, in the case of HIV-positive women, hidden and paid little attention. In this chapter I will sketch the representations and positioning of HIV-positive women in the HIV/AIDS epidemic as well as their representation in relation to reproduction in both medical and social research (which encompasses psychosocial, anthropological and nursing research). Crucial to this discussion is mother-to-child transmission; that is, the transmission of HIV from mother-to-baby. I will describe how mother-to-child transmission occurs, what medical intervention is currently recommended to prevent it and the role of treatments in preventing mother-to-child transmission. I will then describe some of the epidemiological and psychosocial research that has been undertaken and which encapsulates this area of research.

### **Women in the epidemic**

Early in the epidemic in Australia women were considered involved only in so far as they were caregivers or mothers, sisters or friends of the gay men affected by HIV/AIDS. As the first few women were diagnosed, they were either “innocent victims” infected by “bad blood”, a haemophiliac husband or medical malpractice, or were somehow deserving because of their engagement in deviant behaviour such as sex work, substance abuse or promiscuous behaviour (Lawless, Kippax & Crawford, 1996). Of course this “deviant behaviour” and “self-infliction” was not exclusive to women infected with HIV and frequently defined the gay men affected by this

epidemic (Alonzo & Reynolds, 1995). However, once the “bad blood” was taken care of by the introduction of screening by the Australian Red Cross Blood Services in 1985, this left only the so-called “deserving” women and gay or bisexual men – deserving, that is, of HIV infection but not apparently the interest, compassion or support of general society.

However, there was to come another infected (or potentially infected) group: the babies born to HIV-positive women. If *ever* there were “innocents” in all this horror, it was these babies and so developed a new identity for HIV-positive women who chose to continue with their pregnancies as vectors of disease (Anastos & Marte, 1989; de Bruyn, 1998; Gorna, 1996). Bayer (1991:193) summed it up:

we have become all too familiar with the capacity of American society – and of other societies as well – to distinguish between the ‘innocent’ victims of the epidemic and those who, however unwittingly, have been implicated in their own unfortunate state. Unable to protect themselves from the decisions of their mothers, HIV-infected babies provide the paradigmatic case of past and future undeserved suffering. But even for those who have rejected as morally irrelevant, and socially divisive, the question of how individuals have become infected and the distinctions between individuals who had become infected before the first cases of AIDS were recognised and those whose behaviours exposed them to risk after much was known about the possibilities of self-protection, the plight of children born to disease and early death continues to be especially poignant, warranting special urgency.

Very early in the epidemic, before prophylaxis was known to reduce the risk of mother-to-child transmission, it was initially assumed to be inevitable. In reality, the chance of mother-to-child transmission was actually between 20–30% (Stratton, Mofenson & Willoughby, 1992). In 1985 the Centers for Disease Control and Prevention in the United States published its *Recommendations for Assisting in the Prevention of Perinatal Transmission of HIV/AIDS*. Its purpose was to assist health-care providers, state and local health authorities in developing procedures to prevent mother-to-child transmission (Lawless & Sponberg, 1995). However, at the time little was known about transmission rates and a suggested figure was 65% (CDC, 1985).

The recommendations in relation to women's reproductive choices were vague, suggesting that women be counselled to "consider delaying pregnancy until more is known about transmission" (CDC, 1985: 725). Although not explicitly stated, "delaying pregnancy" implied terminating existing ones and health-care professionals voiced their concerns in letters to the Journal of the American Medical Association for women who did want to carry their pregnancies to term, fearing women might be coerced into having unwanted terminations (Gunn, 1988).

In 1989 the World Health Organization (1989) produced a report following the United Nations International Conference on the Implications of AIDS for Mothers and Children. In conjunction with a discussion of research priorities and policy and program implications, the report outlined the need to support women in making informed choices about their reproductive lives. Despite this, with the availability of antiretroviral prophylaxis which reduced mother-to-child transmission to less than 2%, HIV-positive women who chose to have children continued to be viewed as selfish, irresponsible and even immoral (Anastos & Marte, 1989; Bradley-Springer, 1994; McDonald, 2002; Patton, 1994; Sherr, 1993).

### **Mother-to-child transmission and biomedical research**

In the short time that the HIV/AIDS epidemic has taken to grip minority populations in the developed world and to have devastating consequences for those infected in the developing world, much has been discovered about the virus by scientists worldwide, including about the dynamics of mother-to-child transmission.

Mother-to-child transmission can occur throughout pregnancy – in any trimester, as well as the intrapartum and postpartum periods (Burgess, 2001). It is thought that intrapartum transmission in utero is transplacental (Courgnaud et al., 1991), however, the baby may contract the virus during delivery from contact with infected maternal blood, cervicovaginal secretions by skin, tracheobronchial exposure, or by ingestion (Ait-khalid, Lyall & Stainsby, 1998; Loussert-Aika, Mandelbrodt & Delmast, 1997). Postpartum transmission occurs via breastfeeding. Breast milk is known to contain

viral particles and transmission via this route has been reported since 1985 (Senturia, Ades & Peckham, 1987; Ziegler et al., 1985).

Clinical practice has revealed that the probability of mother-to-child transmission is not equally distributed and there is clinical evidence that strongly suggests that mother-to-child transmission predominantly occurs during labour (65%) (Krist & Crawford-Faucher, 2002), delivery (Burgess, 2001) and during breastfeeding (Coutsoudis et al., 1999; Gorna, 1996).

### **The role of treatments in reducing mother-to-child transmission**

In 1994 the Pediatric AIDS Clinical Trial Group (PACTG)<sup>3</sup> 076 revealed that a three-part zidovudine (AZT) regime could significantly reduce the chance of mother-to-child transmission from mother-to-baby by up to two thirds (Conner et al., 1994). This study indicated that mother-to-child transmission from mother-to-baby could be reduced from 25.5% to 8.3%. This finding had an enormous effect on the lives of HIV-positive pregnant women and provided many with great hope.

The HIV/AIDS epidemic was further (radically) altered with the availability of new treatments, known as combination therapy, available from 1996. These treatments significantly improved prospects for the clinical management of HIV and attendant diseases for many people living with HIV/AIDS (PLWHA). Death from AIDS-related conditions in Australia dropped from 670 in 1995 (NCHECR, 1997) to 91 in 2005 (NCHECR, 2006a). Yet these treatments have not been without complications. The HIV Futures Studies (1–5) have all revealed the complexities involved in taking combination therapy including side-effects, physical changes and strict regimens that can have dire consequences if not adhered to (Ezzy, de Visser, Bartos et al., 1998; Grierson, Thorpe & Pitts, 2006; Grierson et al., 2000; Grierson et al., 2004; Grierson

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<sup>3</sup> The Pediatric AIDS Clinical Trial Group (PACTG) was a multi-centre national clinical trials network, first funded in 1987 in the United States of America. “The PACTG developed and implemented phase I, II and III studies designed to test and optimize therapies to prevent and treat HIV infection and its sequelae in infants, children and adolescents, and new approaches for the interruption of mother-to-infant transmission” (National Institute of Allergy and Infectious Diseases, 2000).

et al., 2002). In particular, women in these studies have consistently demonstrated less willingness and less confidence in the efficacy and safety of these treatments (McDonald, Bartos & Rosenthal, 2001; McDonald, Misson & Grierson, 2002; McDonald et al., 2000; McDonald et al., 1998) although this has lessened with time (McDonald, Thorpe & Grierson, 2005; Thorpe, McDonald & Grierson, 2007).

However, the introduction of combination antiretroviral therapy antepartum and intrapartum to the mother, followed by prophylaxis (Zidovudine mono-therapy) to the infant, further lowered the rates of mother-to-child transmission. In conjunction with other medical interventions such as caesarean delivery and avoidance of breastfeeding, these treatments have reduced the chance of mother-to-child transmission to less than two per cent (Perinatal HIV Guidelines Working Group, 2006). Even in developing countries when maternal HIV status is known and where access to combination antiretroviral therapy is limited, a single dose of treatment (Nevirapine) during labour to the mother and to the baby before day three can reduce the chance of mother-to-child transmission and is able to reduce the transmission rate by half even in breastfed babies (The HIVNET 012 trial)<sup>4</sup> (Guay et al., 1999).

## **Prevention of mother-to-child transmission in Australia**

Preventing mother-to-child transmission from an HIV-positive woman to her baby can be achieved via a number of medical interventions. Several of these interventions focus on the risk of intrapartum transmission. The first is by reducing the maternal viral load<sup>5</sup> which is believed to reduce the risk of placental transmission as well as

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<sup>4</sup> There has been a considerable debate about the ethics of using treatments to reduce mother-to-child transmission, particularly for women living in developing countries. This debate has questioned whether it is ethical to give treatments to a woman only at the time of delivery to reduce the chances of her baby becoming HIV-positive and then to deny her access to further treatment, thereby increasing the likelihood that her child will be orphaned before he or she is 10 years old. There is also scientific evidence to suggest that women who take Nevirapine during delivery build a viral resistance to this treatment, thereby rendering the treatment useless for future treatment options should treatments later become available (such as medical trials or cheaper generic treatments).

<sup>5</sup> Today there are two primary measurements of the progression of HIV. The first is the viral load test which measures the amount of HIV in the blood and gives an indication of the activity of the virus; that is, the amount of viral replication. Viral replication is also an indication of immune function damage. The second measure is a CD4/T-cell test which counts the number of CD4/T-cells, which co-ordinate the immune system's response. These tests are used in the clinical management of HIV to make

reduce the infectivity of the mother's blood and bodily secretions. This is achieved through the use of combination antiretroviral therapy (discussed later in this chapter) taken by the mother (McDonald et al., 2001).

The second intervention involves reducing the baby's exposure to HIV during the course of labour and delivery. Some research has indicated that babies should be delivered within four hours of membrane rupture in order to reduce exposure. The only way to ensure this is to deliver the baby via caesarean section and is recommended for HIV-positive women in developed countries (Hughes, 1999; McDonald et al., 2001). More specifically, two studies revealed significant differences between those women who had vaginal versus caesarean deliveries. The International Perinatal HIV Group (1999) reported that mother-to-child transmission for women who took antiretroviral therapy and had a vaginal delivery was 7.3%, versus 2% for women who took antiretroviral therapy and had a caesarean delivery. The European Mode of Delivery Collaboration (1999) also reported a slightly higher rate of mother-to-child transmission among women who took antiretroviral therapy and had a vaginal delivery versus those women who took antiretroviral therapy and had a caesarean delivery. Note that these women took antiretroviral therapy for all three periods (antenatally, during labour and postnatally to the infant) of the PACTG 076 protocol. However, the most recent research found no difference in the transmission rate between the two delivery modes for women who are taking highly active antiretroviral therapy (HAART) and have viral loads below 1000 copies/mL (Perinatal HIV Guidelines Working Group, 2006).

The postpartum interventions include a course of ARV prophylaxis to the baby and avoidance of breastfeeding. Prophylaxis involves giving the baby Zidovudine for the first six weeks of life. This is usually administered every 12 hours.

Breastfeeding was identified early in the epidemic as a vector of HIV transmission from mother to child and the risk of transmission was estimated to be between 13 and 16% (Ziegler et al., 1985). In 1998 the World Health Organization, UNICEF and

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decisions about treatments and additional medical treatment or tests.

UNAIDS drafted recommendations that support the use of alternatives to breastfeeding and emphasised the mother's right to be informed of the risks of breastfeeding and to choose an alternative method of feeding (UNAIDS, UNICEF & WHO, 1998). However, there has been considerable controversy about the perceived benefits of alternative feeding over the known disadvantages of not breastfeeding. More recently it has been recommended that, where there is no safe way of preparing or providing artificial breast-milk substitutes, exclusive breastfeeding for three months is preferred. It is believed that mixed feeding (breast and formula) increases the risk of transmission, because contaminants and allergens may be present and damage the baby's gut lining, providing an entry point for the virus (Coutsoudis et al., 1999). There has also been considerable scientific research investigating the "safest" method of breastfeeding for women living in developing countries who do not have access to formula and clean water (Chantry et al., 2000).

Ann McDonald and her colleagues (2001) reported that, in Australia between 1982 and 1999, 204 children were born to 162 women whose HIV infection was diagnosed by the end of 1999. Among the 50% of women who were diagnosed antenatally, use of antiretroviral therapy increased from 14% for women whose babies were born in 1982–1993 to 88% for women whose babies were born in 1994–1999. Similarly caesarean deliveries increased from 3% to 21% between the two time periods. Almost all of the women diagnosed antenatally avoided breastfeeding. Mother-to-child transmission occurred in women diagnosed antenatally at 25% during 1982–1993 and 19% during 1994–1999. The rate of mother-to-child transmission was significantly lower among women who used antiretroviral therapy in pregnancy (11% versus 36%). Of importance for this study were the 52 women who were diagnosed antenatally and whose exposed children were born between 1994 and 1999. Of these women, only 11 made use of all three recommended interventions (antiretroviral therapy during pregnancy and prophylaxis to the baby, caesarean delivery and avoidance of breastfeeding). All of these women's babies were HIV-negative. Since 1996 (after the introduction of the PACTG 076 protocol which reduced the risk of vertical transmission from mother-to-baby), more than 150 HIV-positive women have given birth to more than 200 babies. Most of these women were diagnosed before the birth of their baby and less than 1% of these babies were HIV-positive (NCHECR, 2006b).



## **Epidemiological research on HIV-positive women and reproduction**

Prior to the introduction of the PACTG 076 protocol, epidemiological research focussed mostly on mother-to-child transmission and the progression of HIV disease in pregnant women. A few studies examined the reproductive choices of HIV-positive women; although this was limited to comparing live birth rates and termination rates among general populations and HIV-positive women within those populations (Stephenson, Griffioen & The Study Group for the Medical Research Council Collaborative Study of Women with HIV, 1996; Thackway et al., 1997). Such research usually relied on HIV-positive women's medical records to describe the characteristics of the reproductive choices and then referred to other research to interpret their findings rather than speaking to the women themselves (Bedimo, Bessinger & Kissinger, 1998; Thackway et al., 1997).

Thackway and colleagues, for example, reported that women with HIV-1 infection had a birth rate of about one half of Australian women and that they also had higher rates of pregnancy termination. The authors speculated about these findings, suggesting that the lower birth rate of HIV-positive women was due to the likelihood of increased condom use as either a risk-reduction strategy or for contraception after deciding to avoid pregnancy. As another possible explanation for the lower birth rate, they also noted that there was often less sexual activity in women with advanced HIV disease. Thackway and colleagues characterised the reproductive choices of HIV-positive women as complex:

There is now increasing recognition that decisions relating to conception and continuance of pregnancy are varied and complex, and that maternal HIV status is only one of the multiple factors that influence reproductive decisions (Thackway et al., 1997: 666).

Bedimo et al. (1998) also acknowledged their research was limited by the use of only medical records and that psychosocial characteristics were not recorded. The authors noted that research using medical records cannot take intention into account and that motherhood can be part of women's social identity and self-esteem:

HIV and childbearing are not just issues of health; they touch upon almost every aspect of a person's life. From sexuality to economics to motherhood to morality, the disease influences every spectrum of society in which we operate. More research is needed to fully comprehend this complex decision-making process (Bedimo, Bessinger & Kissinger, 1998: 177).

Some epidemiological research has examined the factors associated with reproductive decision-making among positive women (see, for example, Kline, Strickler & Kempf, 1995). However, much of this research acknowledges that reproductive decision-making is complex, involving both psychosocial and cultural factors (as well as biomedical) (Williams, Watkins & Risby, 1996).

### **Social research**

Quantitative social research on HIV-positive women and motherhood has tended to focus on reproductive decision-making, including the likelihood of termination (Barbacci et al., 1989; Stephenson, Griffioen & The Study Group for the Medical Research Council Collaborative Study of Women with HIV, 1996; Wiznia et al., 1989). A number of these studies have found that HIV status may not necessarily influence future fertility behaviour (Ahluwalia, Devellis & Thomas, 1998; Johnstone et al., 1990; Kline, Strickler & Kempf, 1995; Selwyn et al., 1989b; Sunderland, 1990; Sunderland et al., 1992). These studies concluded that women's reproductive decisions are based on their life circumstances or particular contexts, such as the number of children living at home, partner influences and psychosocial factors, such as the need to love and the desire to leave a legacy as well as religious and cultural beliefs (Green, 1994; Ingram & Hutchinson, 1999; Johnstone et al., 1990; Kline, Strickler & Kempf, 1995; Pivnick, 1994; Sowell et al., 1996b; Squire, 2003). Some of this research was conducted before it was known that zidovudine (AZT) could reduce mother-to-child transmission, but the risk of mother-to-child transmission was rarely reported as a significant variable in reproductive decision-making among women in these studies.

The HIV Futures Studies 1–5 have revealed a number of significant differences between men and women in the experience of living with HIV/AIDS including the issues of child-bearing and rearing (2002; 2000; McDonald et al., 1998). The HIV Futures 4 Survey (conducted in 2003) recruited approximately 10% of the total estimated number of women then living with HIV/AIDS in Australia, and found that one half of the sample of women had dependent children. These data revealed that women were living with children ranging from less than one year to 18 years. Just over half of these children were aged five years and under and almost a third were two years old or younger. This study also found that nearly 20% of the women were considering having children in the future, or actively trying to get pregnant. Twenty-two women had given birth to children born after their diagnosis and one woman was pregnant at the time of the study (McDonald, Thorpe & Grierson, 2005).

Qualitative research has been able to provide more insight into what motherhood means to HIV-positive women. Interviews from the HIV Futures Qualitative Studies touched on the importance of children in women's lives and the impact an HIV diagnosis had on their decisions about motherhood (McDonald & Bartos, 1999; McDonald & Hurley, 2002). Although the issue of motherhood was only a minor focus of the study, it was notable that most women discussed various concerns around choices of having children as a positive woman. For most of these women, children were an important part of their life. Women who had children often spoke of their sense of future in relation to their children and their obligations as mothers.

I feel like I've still got a full life ahead of me, because I've got a job to fulfil. I've got my son, I've got to – I don't think anybody else will be good enough to look after and rear my son. So the way I figure it is I'm, I'm going to kick on to be able to rear him as much as I can, or as long as I can to sort of give him the ideas that, you know, steer him in the right direction – that type of thing. [Jessica, aged 32, diagnosed 1996, child aged four years].

Similarly, another woman said:

I want to be here for my kids to grow up. And I am determined that I will be [Melissa, aged 28, diagnosed 1995, three children aged two, five and nine years].

These themes are consistent with other qualitative research conducted with HIV-positive women in the United States of America. Ingram and Hutchinson (1999) interviewed 18 women, all of whom had children. They identified what they call *defensive mothering*, which generally referred to three areas: preventing the spread of HIV and stigma; preparing their children for a motherless future; and protecting themselves through positive thought control (1999: 246). Ingram and Hutchinson also suggested that children became “a reason to live and a focus on life” (1999: 253). This research was a useful contribution to the knowledge about HIV-positive mothers, but they too note that research is needed on HIV-positive women’s decisions about whether to become pregnant. The qualitative research that has been conducted in the area of HIV-positive women and reproductive decision-making has tended to focus on minority groups of women, such as African–American women or injecting drug-users (Pivnick et al., 1991; Sowell & Misener, 1996a) and is not of immediate relevance to populations of other HIV-positive women.

All of this research suggests that HIV-positive women make decisions about pregnancy and reproduction in much the same way that HIV-negative women do (Anastos & Marte, 1989). Their religious beliefs, cultures, identity and desires all play a role in what many would describe as the most important and fulfilling role of a woman’s life. Yet the fear of mother-to-child transmission from mother-to-baby has continued to prevail over the care of the HIV-positive women as a human being (see Bezemer, 1992) and has been the focus of most research. The women’s stories that give meaning to and interpret their experiences are almost never present in biomedical research. Medical and epidemiological research papers on HIV-positive women and reproduction presented at international conferences and published in journals discuss the results of randomised control and placebo groups and yet conclude with comments like, “More research is needed to understand the decisions made by HIV-positive

women.” However, despite the now substantial volume of literature examining HIV-positive women and their reproductive decision-making, little of this research gives meaning to these women’s experiences. Furthermore, only qualitative research is really capable of achieving this, yet results from qualitative studies are given little credence in biomedical scientific forums.

This chapter reveals the considerable research that has preceded this project about HIV-positive women and reproduction. However, most of the data collected has focused on socio-demographic identifiers when trying to explain how HIV-positive women make decisions about pregnancy and motherhood. Little research has focused on the meanings women ascribe to motherhood (Wesley et al., 2000) and how these permeate all of their reproductive decision-making, antenatally and postpartum. To understand these decisions I think it is necessary to examine all aspects of women’s lives, including accounts of their thoughts and feelings about motherhood prior to their diagnosis, as well as their hopes and desires for their futures.

Much has been written about how chronically ill people seek meaning in their lives to help explain and make sense of the circumstances in which they find themselves (Charmaz, 1991; Kleinman, 1988; Nelson, 1996). Cheryl Mattingly (1994a: 812) argued that “Locating ourselves within an intelligible story is essential to our sense that life is meaningful.” In the following chapter I describe how narrative methodology can assist in interpreting and explaining how HIV-positive women make sense of their HIV diagnosis and are then able to make decisions about their reproductive lives.

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## Chapter 2

### *Narrative theory and method*

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I went to bed that night, living in a book with characters everywhere, and noise, and hustle and bustle, and I woke up on a blank page: Ann O’Neill (McRobert, 2004).

Ten years previously Ann O’Neill’s estranged husband, Norm, broke into her house and shot her and their two children, Kyle (aged six) and Latisha, (aged four), who were sleeping beside her. He then shot himself. Ann was the only survivor. Her leg had to be amputated because of the injuries sustained in the shooting. In describing this terrifying and devastating event, Ann O’Neill used the metaphor of a book to help explain her loss to others on the Australian Broadcasting Commission’s television program, *Australian Story*.

It is by telling stories that we humans understand our lives and its vicissitudes. Through stories we establish, maintain and revise our identities (McAdams, 1989, 1993, 2003; Riessman, 1993) and justify our actions to others (Bruner, 1990; Mishler, 1991b). Our stories help us make sense of events that happen to us and around us (Riessman, 1993). These stories are understood, framed, and interpreted within the cultures in which we live (Andrews, 2002; Denzin, 1989b; Ricoeur, 1991a).

In the first part of this chapter I briefly outline the breadth of disciplinary application of narrative with a particular focus on illness narratives. I then consider its applicability to understanding and interpreting the stories told by HIV-positive women about their reproductive decision-making and motherhood. In the second part of this chapter, I explain the methods I employed to gather and then analyse the

narratives told by 34 HIV-positive women who were diagnosed in their child-bearing years.

## **Part I – Narrative theory**

Narrative theorising can be found across a broad range of disciplines, including philosophy (MacIntyre, 1981; Polkinghorne, 1988), sociology (Somers, 1992, 1994, 1995; Somers & Gibson, 1994), anthropology (Garro, 1992; 1994; Good, 1994a; Rosaldo, 1989), psychotherapy (Spence, 1982; White & Epston, 1990), psychology (Bruner, 1986; Kirkman, 1997; McAdams, 1993; Sarbin, 1986b), linguistics (Labov & Waletzky, 1967) and medicine (Kleinman, 1988).

Many scholars from numerous disciplines believe narrative to be the organising principle for human action (Bruner, 1986; Cronon, 1992; Rosaldo, 1989; Sarbin, 1986b; Schaefer, 1980, 1992). Jerome Bruner (1986) argued that human beings have two modes of thought. The first is the paradigmatic mode, which is the traditional understanding of thought as logical induction. The second is the narrative mode, where by context and intentions are understood via the stories constructed to make sense of human experience. It is the narrative mode of thought and the “vicissitudes of human intentions” (Bruner, 1986: 16) that I focus on to understand and interpret the ways in which HIV-positive women comprehend the vicissitudes of their own lives.

There are four particular concepts of narrative theory that I will briefly outline here and which will be the focus of much of my analysis presented later in this thesis. These are narrative identity, time and revision of one’s narrative, canonical narratives and the rhetorical function of justification in narrative.

### **Narrative identity**

Narrative identity refers to the stories we tell about ourselves (both to ourselves and to others). By telling stories about ourselves we tell others who we are and who we

would like to be. “We express, display, make claims for who we are – and who we would like to be – in the stories we tell and how we tell them. In sum we perform our identities” (Mishler, 1999: 5).

Individual narrative identities are developed within the cultural influences, dominant discourses and canonical narratives available to the individual. Narrative identity formation requires individuals to either position themselves within, or in opposition to, these available stories. This is an ongoing process and something we do all of our lives. As Riessman (1990b: 1195) put it, “We are forever composing impression of ourselves, projecting a definition of who we are, and making claims about ourselves and the world that we test and negotiate in social interaction.”

Other researchers have written about the ontological assault of chronic illness (see, for example, Charmaz, 1991; Frank, 1995; Garro, 1992; Mathieson & Stam, 1995), and the disruption caused by the inability to perform previous social roles and identities (Williams, 1987), as well as the strategies employed to maintain some semblance of normality or adjustment (Strauss & Glaser, 1975). Chronic illness fundamentally disrupts the taken-for-granted world of everyday life (Berger & Luckman, 1966; Crossley, 1998a; Garro, 1994) and in turn calls for a new narrative to be told or an existing narrative to be revised. Women who are diagnosed as HIV-positive are usually both devastated and traumatised. Their existing identities and imagined futures are shattered and they must learn to incorporate a new identity into their life story; as a woman with a chronic and potentially life-threatening illness (Davies, 1997; Doyal & Anderson, 2005). Furthermore, they must do this within a society that both stigmatises and ostracises them because of the disease with which they live (McDonald, 2006b).

### **The journey: revision and time**

Researchers who adopt the metaphor of narrative have noted the dynamic nature of autobiographical narratives (Bruner, 1987; Fivush & Buckner, 2003; McAdams, 2003; Ricoeur, 1981b). Kirkman and her colleagues (2001: 281) noted, “The



emplotment of one's life undergoes constant revision as new experiences suggest new meanings for the life already lived and the life to come." Josselson (1996) found, as she listened to her participants, that there were many stories: the one being lived at the present time and others that would be lived in the future.

It is via narrative that we are able to describe lived time (Ricoeur, 1991b). Sarbin (1986a) noted that the way we understand Western stories – beginning, middle and ending, or what Frank (1995) called past, present and future – is dependent on time in human activities. A detailed discussion of Ricoeur's theses on time and narrative (1984–8) is beyond the scope of this chapter; however, of relevance is Ricoeur's notion of narrative identity in which the temporal nature of human experience is emphasised. Narrative shapes our identity as well as our experience of time and "we never cease to reinterpret the narrative identity that constitutes us, in light of the narratives proposed to us by our culture" (Ricoeur, 1991a: 32).

Jerome Bruner (1987) and Byron Good (1994a; Good et al., 1994b) further developed Ricoeur's theories on narrative and time to consider subjunctivity. To be in the subjunctive mode is "to be trafficking in human possibilities rather than in settled certainties" (Bruner, 1986: 26) or considering multiple prospective plots (Kirkman, 1997) when one is still living her or his story. In particular, Good and his colleagues (1994b) identified subjunctivising in the narratives told by chronically ill people who still have hope and see possibilities for their future. Revision and subjunctivity were evident in the narratives told by many of the HIV-positive women who spoke with me, as they considered multiple pathways for their future.

### **Canonical narratives**

I have already claimed that culture and society are inherent in individual identity and life-story construction. Archetypal plot structures are also available to individuals in the construction of their own story. Literary critic Northrop Frye (1957) described four archetypal plots for construing experience: romance, tragedy, comedy and satire. Byron Good (1994a), from his research into epilepsy in Turkey, proposed that several

prototypical plot types could be identified among the illness narratives which have a distinctive cultural form. Furthermore, prototypical plot types “are available as cultural resources for those in the midst of illness attempting to make sense of their experience” (Good, 1994a: 46). Good, amongst others, also established that there is a range of culturally-specific prototypes of plots which act as scaffolding for the life stories told by people immersed in that culture. Jerome Bruner (1986; 1987) described this range of culturally specific prototypes of plots as canonical life narratives.

Maggie Kirkman (1997; Kirkman et al., 2001) argued that being a mother is a canonical narrative for women in Australian society and that those who choose otherwise are expected to justify their actions because being a mother is an expected role for women. Within the canonical narrative of motherhood, some women are deemed inappropriate for motherhood. These women include teenagers (Kirkman et al., 2001; Perales, 1999), single women (Schnitzer, 1998), lesbians (Benkov, 1998), drug-users (Paltrow, 1999) and HIV-positive women (Gorna, 1996; Wyche, 1998). The narratives of HIV-positive women I interpret in the following chapters reveal the cultural importance of motherhood and the women’s awareness of how HIV violates the canonical narrative of motherhood.

### **Justification of lives led**

Autobiographical narratives not only explain particular actions or sequencing of events but they also provide a rationale or justification for particular actions. The telling or re-telling of one’s story also takes into account the listener and will be tailored to persuade the listener of “their point of view, of the value or legitimacy of their claims” (Mishler, 1991b: 106) or that the action taken was the correct or necessary one (Farmer & Good, 1991; Garro, 1992; Garro, 1994; Kirkman et al., 2001).

Furthermore, a particular self (the protagonist) is constituted within the narrative told to the listener and typically the moral character of the protagonist is assured (Riessman, 1990b). Bruner argues that the rhetorical strand within a story serves to

persuade the listener “*not* causally, but morally, socially, psychologically” (1990: 121). The accounts given by HIV-positive women in this study wishing to become mothers without exception contained strong rhetorical justification (morally, socially and psychologically) of their motherhood desires and decisions about their reproductive lives. As their narratives will reveal in subsequent chapters, this is usually because listeners (including health-care professionals) often explicitly oppose their desires.

### **Illness narratives and HIV**

Social research, particularly anthropology, has developed a substantial body of work around illness narratives, which attempt to understand the way in which individual women and men deal with the experience of chronic illness. Individuals facing autobiographical disruption due to illness will reconstruct a coherent self via narrativisation (Bury, 1982; Frank, 1995; Riessman, 1990a, 1990b; Williams, 1984). Illness often disrupts the everyday life that is taken for granted, and within the illness narrative the individuals will often attempt to make sense or meaning of what has happened, adapt to this adversity, describe any actions taken and why, and explain how the illness has affected them (Garro, 1994; Gergen & Gergen, 1993; Good, 1994a). Linda Garro (1994: 775) wrote:

The experience of illness may also change the way individuals think about themselves, their present and their future as well as the past. In personal narratives of illness, often what is being told cannot be seen simply as the story of an illness but rather the story of a life altered by illness.

Narrative theory is especially suited to the study of illness because of the “essential temporal quality of narrative, its unfolding in time, its working through of a plight to a resolution” (Good, 1994a). Narratives are central to understanding the experience of illness from both individual and cultural perspectives, because narratives are structured in cultural terms and use cultural forms (Frank, 1995; Good, 1994a).

Since the beginning of the HIV epidemic the community sector, advocacy workers and some people living with HIV/AIDS have pleaded with researchers to hear the stories from those people affected, as opposed to just the percentages, people's lives reduced to epidemiology (see Rule, 2003; Willis, Grierson & Hurley, 2001). Social research has provided one vehicle for some of these voices to be heard and, in doing so, some social researchers have recognised the value of narrative method and analysis as one of the best ways for stories to retain their integrity and form. Viney and Bousfield (1991) recognised the value of narrative research with HIV-positive men back in the early 1990s, acknowledging the interviewees' "expertise" making the research more ethical and potentially empowering to participants. Other researchers have also claimed that narrative theory is best suited to explaining the lives of people living with HIV/AIDS (see, for example, Crossley, 2000; Ezzy, 2000).

### **Narrative, HIV-positive women and motherhood**

Patti Lather and Chris Smithies (1997) were among the first to collect and present the stories of women living with HIV/AIDS in the United States of America. Since then a few researchers have employed narrative theory to interpret the stories told by women living with HIV/AIDS (see Berger, 2004; Cameron, 2001; Gurevich et al., 2007; Stevens, 1996; Stevens & Doerr, 1997).

I propose that narrative theory is ideal to explore the reproductive decision-making of HIV-positive women because it is concerned with the interaction between the individual and society. Like all women, HIV-positive women make their decisions to have children in cultural contexts and must also deal with decisions (made by them or made for them) against having children in those same cultural contexts. Kirkman's (1997) research into infertile women used narrative theory and method and found that being a mother is an expected role for women in Australian society. Narrative methodology appealed to me because it emphasises individual experience which enabled me to examine the complex issues arising from the personal circumstances, social context, and individual choices of each woman. Narratives also allow for diverse ways of telling about a particular experience and counter the tendency to

objectify the research participants (Riessman, 1993). Furthermore, narrative theory allows for stories that are rendered inaudible by cultural influences to be heard (Rosenwald & Ochberg, 1992; Thomas-MacLean, 2004).

Focusing on individual autobiographical narratives of women living with HIV/AIDS avoids making the assumption at this early stage of research that HIV-positive women have similar experiences relating to motherhood or are indeed a homogeneous group. HIV/AIDS is a relatively recent disease and the knowledge of this disease changes rapidly as more is discovered about the disease's aetiology, pharmacology and the psychosocial aspects of living with HIV/AIDS. A narrative approach allows for the tradition of language and storytelling to be studied consistent with postmodernism whilst still recognising the everyday lived experience of the individual (Crossley, 2000).

## **Part II – Method**

This part of the chapter focuses on how I conducted the research and why I chose the methods I did: finding the women who participated in this project, negotiating the stories they were prepared to tell of being diagnosed as HIV-positive, interpreting their stories and maintaining contact over the course of the project. I complete this chapter with a brief description of the demographic profile of the women who participated and a brief discussion concerning the limitations of the methods.

### **The participants**

The participants were women who had had an HIV-positive diagnosis during their childbearing years. This included women who already had children (either before or after their diagnosis) and women who had not had children. They included women who were waiting for more treatment options before making a decision or proceeding with pregnancy; who had children who were HIV-negative but who were born to an HIV-positive woman; who had children before they were diagnosed as HIV-positive;

who were advised against pregnancy or who had terminations and who were now either too ill or too old to have children, and one woman whose child was HIV-positive.

## **Recruitment**

A notice calling for volunteers was distributed to organisations that support and provide services for HIV-positive women and AIDS Councils in Victoria, New South Wales, South Australia, Western Australia, Queensland and the Northern Territory (a copy of the notice can be found in Appendix A). I also spoke with each of the relevant people in these organisations about the research and asked them to distribute the notice. This was usually done by including the notice in newsletters or handing them out at appropriate gatherings of HIV-positive women. Potential volunteers were given my contact details and contacted me either directly or via an employee of the organisation to arrange an interview time.

The notice calling for volunteers said the research was about motherhood and HIV-positive women which included the decision to have (or not to have) a baby. As recruitment relied upon women self-selecting for the study, it is not surprising that motherhood was important or had been considered as a possibility by all but one of the participants. It is for this reason that I refer to women without children as “childless” as opposed to “child-free”. Only one woman, Louise, had chosen a life that was child-free and I explore Louise’s reproductive choices (see pages 49-50, 163). The remainder of the women who did not have children were either still intending to have children, or considering this as a possibility, or had decided not to have children because of their HIV status which was a source of considerable grief for them.

It was inevitable that some snowball recruiting would occur. Some of the women interviewed also worked in roles of peer support and thereby their assistance with recruitment included being able to tell a prospective participant what the research was about and what it entailed. In each instance when a woman suggested another woman

as a potential participant, I suggested that she contact the woman and tell her about the interview and then invite her to call me if she was interested.

In total I interviewed 34 women living in Australia. Because of the anticipated difficulty with recruitment I was aiming for between 20 and 30 interviews. I thought this number of interviews would provide me with a diverse range of experiences. The number 34 was obtained more easily than I could have hoped for, with volunteers presenting at each location I visited. Indeed I could have conducted more interviews (and would have loved to have continued to meet with more women and hear their stories), but my supervisors and I agreed I had enough data for this project.

I had met with a number of the women on previous occasions. I had interviewed three women for an earlier project about sex and relationships when I was employed as a research assistant on the Living with HIV Program at the Australian Research Centre in Sex, Health and Society (ARCSHS). One woman had been part of a focus group I conducted for a discussion about quality of life and living with HIV as part of a project undertaken by ARCSHS for the World Health Organization. Three other women I had met briefly before at work-related functions, such as seminars or conferences. I think that being known by a number of the women assisted with recruitment, as they were able to “vouch” for previous research in which I had been involved.

### **Interview location**

All of the women chose a location for the interview. This was usually at their home (18) or at an organisation that provided support for HIV-positive women (13). One woman came to my motel while I was interviewing interstate, because she insisted it would be easier for her to find me than the other way round! I also interviewed two women at their workplaces. For each interview I provided morning or afternoon tea.

## Confidentiality and ethics

Participants' confidentiality was protected with the use of pseudonyms and by disguising identifying details. Research with HIV-positive women is intrinsically personal and sensitive. Particular attention was therefore paid to issues of privacy and confidentiality. To this end, the data collection process, the storage of raw data, and the dissemination of results was carried out so as to maintain strict confidentiality. All hard-copy data (including tape recordings and interview transcripts) were stored in a locked filing cabinet at the City Campus of La Trobe University. Computer-generated transcripts were kept only on the password-accessed file server or my home-computer hard drive, which also required password access.

The women signed consent forms before they participated in the research. The consent form was a plain-language statement explaining the research purpose and data management, including issues of confidentiality and privacy (see Appendix B). The consent form included a sunset clause, which informed participants that they were free to withdraw from the project for a period of up to one month after their interview. Participants were also told that withdrawing could include withdrawing their interview from the project if they wished. They were also reminded that allowing me to use their interview would not commit them to any further participation.

An additional consent form, approved by La Trobe University Human Ethics Committee, was sent to the participants in 2005 (see Appendix B) requesting their permission to use their edited narratives in three further ways: included in the appendices of the thesis (see Appendix G), in a booklet of narratives for each participant and used in the event that a book contract be sought and secured after the completion of the thesis. The consent offered three possibilities for each request: the narrative could be used as it was without any further editing; the narrative could be used but further editing was required; or the narrative could not be used for any of these three requests. (See Appendix B for a copy of the consent form.) Initially I had decided against including the women's narratives in the appendices of this thesis because I was concerned about the possibility of women being identified. However, when I wrote *Common Threads* I realised that I could use all (or almost all) of the women's narratives with little likelihood of this occurring. Nevertheless, it was



necessary to seek the women's permission and highlight this risk as a possibility. Fifteen women returned the second consent form. They all consented for their narrative to be used in the appendix of this thesis (see Appendix G). Fourteen women agreed to the use of their narrative in a booklet for other participants. Fourteen women agreed for the use of their narrative if a book contract was sought and one woman said that the request required further thought. Four women said they would like to edit their story further and one woman said she wanted to provide another update.

I was not surprised that not all of the women wished for their narrative to be used in these ways and the original design of the project took this into account. However, the narratives are so powerful that I felt even a small selection of them would benefit the readers of this thesis. The booklet would give something back to the women (as the resource book was largely targeted at newly diagnosed women or women considering pregnancy for the first time as a positive woman), and the possibility of a book was the idea of my supervisors.

Because it was possible that participation in the research process may have raised questions about treatment options and pregnancy choices, information about counselling and referral services was offered to all participants.

Due to the small number of women living with HIV in Australia and the even smaller number of women who frequent the support organisations and services for HIV-positive women, a large proportion of women in this project knew one another, or of one another. In a few instances, women knew intimate details of other women's stories. This may be because they were members of the same organisation or support group or had attended a conference or family camp together. This did not pose any problems for me during the interviews. If I was asked about whether I knew a particular woman I answered truthfully, but we never discussed any details of the other woman's story. It is pertinent to point out that the HIV-positive women I have encountered understand the importance and significance of confidentiality better than most people, and all of the women I spoke with demonstrated respect for the confidentiality of other HIV-positive women.

## **The interviews**

After taking each woman through the consent form and asking her permission to record the interview, I asked her if she had any questions before we commenced the interview. Occasionally a woman wanted to ask a few questions about me or the project before the interview, but in most cases these were reserved for the end of the interview. I then commenced the interview by saying, “Can you please tell me your story of how being diagnosed with HIV has influenced your thoughts and feelings about motherhood?” By asking for a story, I was encouraging a plot and sequence of events (Kirkman, 1997), although a couple of women did ignore this request, implying this approach was not too prescriptive. In some instances, women found it difficult to start from this point and asked for further guidance. I then suggested they start with their diagnosis or with the birth of a child (if this was appropriate). Most chose to start with their diagnosis. This question and subsequent probes also helped provide the “scaffolding” for the women’s stories to be told (Bruner, 1986; 1987; Cazden, 1983).

## **Transcription**

The minidisks of all interviews were copied to tape and fully transcribed; half were completed by me and then other half by a transcriber used by other researchers at the Australian Research Centre in Sex, Health and Society at La Trobe University, who had signed a statement of confidentiality. I listened to each interview at least twice as I made corrections and punctuated the interviews to allow meaning to be read. I also changed all names and other potentially identifying information.

## **Creating the narratives**

When recruiting women for this study I informed them from the outset that, if they agreed to participate in this study, their interview would be edited to retain a focus on their account of HIV and motherhood and returned to them to allow them to expand,

clarify or edit parts of their story. This method was undertaken by Kirkman (1997) in her research into the experiences of infertile women and was found to be highly successful both ethically and in validating the women's stories; it enabled the women to negotiate their stories and remain involved in the research process if they chose to do so.

I stated at recruitment and on the consent form that the version of the interview that both each woman and I agreed on would be the one used in this study. I was committed to allowing women to have ongoing involvement in the research if they wished. This commitment arose from a previous experience when I interviewed an HIV-positive woman as part of a larger project I was employed on as a research assistant (which I discussed in the introduction to this thesis), as well as previous projects where women have requested copies of their transcripts and expressed a general interest in research outcomes.

My method differed from Kirkman's (1997) in that I did not re-order narratives, nor did I remove much of the interview. Most of the stories were left in their original form, with the exception of repetitions where the storyteller re-told part of the story. I also did some grammatical editing to remove false starts, hesitations (um, ah), or repetitive fillers (you know, I mean). I preferred the participants to focus on their story, what they had included (and perhaps excluded), rather than on their grammatical speech, and I did not want them to reject their story because they were embarrassed by speech patterns or use of repetitive fillers.

Although I retained the woman's words, I occasionally altered the beginning of the paragraph to incorporate the question or prompt that was initially my voice. The removal of my voice was not to pretend I was not there, for storytelling does not exist without a teller and a listener (Riessman, 1993) and to tell a story is "a joint production" (Mishler, 1986b:82). Other researchers have pointed out that illness narratives are dialogically constructed with those involved with the person who is ill or affected by disease, which includes family members, health-care professionals and, of course, researchers (Frank, 2005; Good, 1994a; Mathieson & Barrie, 1998; Riessman, 1993). Mattingly (1994a: 812) suggested that, "Even the notion of a 'life story' is a misleadingly individualistic construct, as though we lived our stories by

ourselves.” There is certainly no confusion about my role in the meaning-making that occurred to create these narratives. I requested women to “tell me their story” and so they did. However, for the purpose of the research, it was not relevant to include my voice. Further, I wished to provide the women with a document that was a part of their story at a particular point in time. To include my voice in this document would have distracted from their story.

Like Reissman (1993), I am cautious about earlier feminists’ claims to “giving voice” to participants. However, having heard in previous interviews with HIV-positive women both requests for copies of transcripts and musings about possible future autobiographies, I wanted to present the women with transcripts that “read well”, both to meet the needs of the women and to avoid rejection of their story because of concerns with speech and representation. Even with this level of editing I still received comments from participants about their speech patterns and their embarrassment about this. For example, Clare, in a letter written to me when she received a copy of her edited transcript, wrote,

Thank you for the transcript of our conversation, I had nearly forgotten all about it. I must admit I had a bit of a laugh when re-reading it, it sounds just like me!

There are no adjustments in the transcript that I need to alter, maybe just the punctuation of some of my sentences and slight grammar changes, but you don’t have to change anything really. I didn’t realise I said, “I don’t know” and “stuff” so much – but if that’s what I said, that’s what I said!

Participants were also told at the time of recruitment that I hoped a resource book discussing pregnancy and motherhood in HIV-positive women would arise from this study which would be distributed to participants and organisations that support and care for HIV-positive women. This resulted in, *Common Threads: Positive women discuss pregnancy, parenting and living with HIV* (McDonald, 2006a: described in my Introduction). Participants were advised that, if quotations from their stories were included in this book, their confidentiality would be maintained and changes would be made to any identifying details. (See Appendix F for details of the resource book.)

## **Consulting women about their narratives and maintaining contact**

The process of editing and returning the women's narratives was interrupted by the birth of my first child. Some women received their narratives only several months after participating in the interview, but for the majority there was a time lag of two or so years. This caused me some concern because I was worried that women might want their narrative altered, possibly re-written or, at worst, withdrawn. In fact this did not happen, although many women wrote letters or postscripts commenting on where they had come to in their journey (which I encouraged them to do). I examine the issue of revising one's account in Chapter 4.

Each woman was sent a draft copy of her narrative with an accompanying letter requesting that she read her transcript thoroughly, note any corrections, edits or deletions clearly and, if she wished, update her story. This method was chosen to ensure women were satisfied with their story going into the public domain. I hoped this process would allow women to speak freely in the interview knowing they would have a chance to edit or remove parts of their story they did not wish others to know.

The interview sent back excluded my voice (as explained above) and included pseudonyms and changes to possible identifying information. I assigned pseudonyms to women; however, I invited women to change any pseudonyms as well as any potentially identifying information. A few women changed their pseudonyms or those of their children or partners, but most women were satisfied with the names I gave them and two even mused that they preferred their pseudonym and would use it should they ever write their autobiography.

Despite the length of time between the interviews and the transcripts being returned, I did stay in contact with the women over this period with research updates. I sent participants a newsletter each year to advise them on the state of my research, the progress of the resource book and the funding for the resource, as well as any other relevant information from conferences I attended, such as the World AIDS

Conference (see Appendix E). I also sent Christmas cards each year. This regular contact not only served to maintain contact with participants but also reinforced my commitment to the research and allowed for women who had moved to advise me of their new contact details.

In total, 21 women returned the edited narrative I sent to them, some with corrections or alterations but mostly untouched. A further six women did not send their transcript back; however, they contacted me later when a draft of the resource book was sent out or when the second consent form was sent out and approved their edited narrative. Twelve women moved during the course of this research and five of those women provided me with forwarding mail details. For a further two women I was able to forward narratives, newsletters and information via other contacts, although I cannot be certain they reached the intended recipient. Three women were lost to follow-up and two women did not respond to requests for input or the additional consent form.

Only two women expressed the desire to pull out of the research project. However, this was well after the sunset clause included in their consent form (which advised them they could withdraw from the project for a period of up to one month after the interview). Whilst this sunset clause protected my use of the data, the very point of returning transcripts to the participants was to ensure they were satisfied with the way they presented themselves in their narratives and to allow them speak freely at the interview, knowing they could withdraw parts of their story if they chose to do so when they received the transcript. Olivia rejected her transcript, apparently commenting that she did not recognise herself as the woman in the story as so much had changed for her. I was told of Olivia's wish to withdraw her story by another participant, Samantha, who had introduced her to me. Samantha told me that Olivia no longer felt the way she did when she spoke with me. I suggested to Samantha that Olivia either contact me or write a brief postscript describing what had changed for her and that I would acknowledge these changes in my writing about her story. Olivia did not contact me nor provide a postscript and, as a consequence, I was cautious with the use of her story in *Common Threads*. Joy expressed concerns about part of her narrative becoming public and asked if she could withdraw from the project altogether. After a discussion about what part of her narrative she was concerned with, I suggested we remove that particular part of her story, to which she agreed.

It is important to note that our stories are not static; that is, they are time-bound and therefore constantly revised as circumstances change and time passes. Some women recognised this when they received their edited transcript back, writing things like, “Things are a bit different now,” and then providing a brief update of their story. It is with this understanding that I have used Olivia’s story, recognising that it arose from a past identity.

### **Limitations of the method**

Despite my best efforts, I did lose touch with some of my respondents. This was probably due in part to the time-delay between interview, transcription and editing. As a result I did not receive updates from all participants, nor did all participants endorse their accounts. Therefore a methodology that was longitudinal in style and involved repeat interviews over time would enable analysis of the development of narratives over time. However, I do not believe this research was compromised by most participants being interviewed only once, and those participants who did provide updates or thoughts about their interviews provided additional rich data that was a direct result of my attempt to remain in contact with the research participants and my intention for participants to verify their accounts.

An additional limitation was that the sampling relied upon self-selection and some snow-balling. As a result there are only a few CALD participants with the majority being Anglo-Saxon Australian-born. I was contacted by one woman who was a recent African migrant about potential participation but after talking with her I was unable to allay her fears that the interview was completely confidential and that her community would not find out about her participation. As a result there are no recent migrants in this sample and future research should attempt to address this.

Finally, this was a complex and time-consuming project that may not be affordable to many research projects. The editing and negotiation of the women’s accounts took many hours of transcription and organisation. However, as a result of this

commitment, I believe I was able to avoid any participation dissatisfaction whilst collecting rich and diverse accounts of HIV-positive women's experiences of motherhood and their decisions about their reproductive lives.

### **Analysis of the narratives**

The process of transcribing, cleaning and editing the women's narratives resulted in me knowing the women's stories very well. The act of creating themes and then subsequently writing the resource book in 2005 further enhanced my intimacy with their stories. I did consider the use of qualitative software to assist in the management of the data, but I did not want to segment the text and my knowledge of the women's stories made it seem unnecessary. Instead I chose to focus on the particular theme I had identified and then I read each narrative, organising relevant aspects of the women's narratives as I went. I repeated this process for each theme.

To assist with the thematic analysis I created spreadsheets that contained demographic characteristics of the participants (see Appendix D). I then expanded these spreadsheets as themes emerged to conduct a content analysis of the themes that emerged. For example, I counted the frequency of women's concerns about the potential toxicity of treatments during pregnancy. I look looked for similar themes such as previous or current antiretroviral use, side-effects, the influence of other peoples' opinions on antiretroviral toxicity and adherence or non-compliance. The most compelling finding from this analysis was the few women who did not comply with the recommendations for antiretroviral use during pregnancy or the use of prophylaxis for their babies.

I commenced my analysis with 10 themes, which were the interview prompts I had used to conduct the interview (see Appendix C). These 10 themes were: *Diagnosis of HIV; Motherhood identity; Achieving motherhood as a positive woman; Sense of self; Antiretroviral therapy; Possibility of future illness; Partners/husbands/family/friends; Disclosure; Power and control; Time and revision*. Additional themes emerged from close reading and re-reading of each woman's account. These additional themes include *denial; normalcy; discrimination; hope; future; terminations* and



*sterilisations; loss and grief; birthing choices; and breastfeeding*). I incorporated these additional themes into the 10 broader thematic branches listed above.

To avoid fragmenting the women's stories I then considered the themes I had identified within the metaphor of narrative. For example, *Narrative Identity* could accommodate *motherhood identity, diagnosis, childlessness, loss, terminations, miscarriages* and *sterilisation*. Additional aspects of identity (that I had not considered) emerged from the data, such as *no plot of motherhood*. These were incorporated into *Narrative Identity*, (which became Chapter 3: Motherhood and HIV).

I knew from previous interviewing how devastating an HIV diagnosis is and how people often assume their life and all their plans for the future are over. By considering the narrative metaphor of revision and rewriting I was able to explore the women's narratives as they explained how they initially considered death to be imminent and motherhood to be lost (or their children to be without a mother) and how over time they came to revise and rewrite their stories of motherhood (although not all women were able to do this). The metaphor of revising and rewriting became Chapter 4: The journey after diagnosis.

For those women who were able to revise their story to include motherhood, medical protocols recommended that HIV-positive women adhere to treatment, (sometimes) have a caesarean delivery, provide prophylaxis to their baby and avoid breastfeeding to reduce the risk of vertical transmission. I examined the women's interpretations of these protocols in their quests to become mothers, their awareness of the canonical narrative of motherhood and the rhetorical effect of justification evident in their accounts (see Chapter 5: Mothers and medicine).

Because stories are dialogically constructed, I wanted to explore the role of the wider community (family and friends, health professionals, peers) in the construction of the women's narratives. Stigma and discrimination were important and prevalent themes within the stories and this encompassed the metaphor of public and private accounts (see Chapter 6: The impact of stigma on women's accounts).

Women living with HIV face a great deal of uncertainty. The advances in treatments have enabled many people living with HIV/AIDS to expect and hope for a longer future. Two themes that recurred in women's accounts of future were control and hope. Treatments had allowed some women to revise their account of the future and enabled others to subjunctivise again (see Chapter 7: Living with uncertainty).

### **Demographic characteristics of participants**

At the completion of each interview I sought demographic information (see Appendix D). This information assisted with my interpretation of the women's narratives as well as assisting with my capacity to remain in contact as the project progressed.

Of the 34 women, 10 were from Queensland, eight from New South Wales, six from Western Australia, five from Victoria, four from South Australia and one from the Northern Territory. All women were interviewed in their state of residence in person.

The majority of women were Australian-born, with five born overseas. One woman identified as an Indigenous Australian. The women's ages at the time of interview ranged from 25 to 48 years. Women were diagnosed between 15 years and one year prior to the interview. CD4 T-cell counts ranged from 180 to 1,000 copies m/L and viral loads from undetectable to 236,000 copies m/L. Twelve women were taking combination antiretroviral therapy and six women were also co-infected with hepatitis C. Information about mode of transmission was not asked of the women, but most reflected on the event or individual from whom they believed they contracted the virus. Most women said they were infected via sexual intercourse. Five women were also injecting drug-users at the time of diagnosis or presumed infection.

Like other studies of women living with HIV in Australia, the women in this study reported high levels of education (2002; 2005; 2000; McDonald et al., 1998). Fourteen women had tertiary education, six women had completed year 12 and the remainder had completed years 9 or above. Twenty-two women were married or in de facto relationships. Five women had lost partners or husbands to an AIDS-related illness.

Twenty-seven out of the 34 women had children (51 children in total). Two women were pregnant at the time of interview and follow-up interviews were conducted with these women after the birth of their babies (one face-to-face, the other over the phone). Sixteen women had 23 of these children after they became aware of their HIV status. All but two of these children were born after 1994 (and the introduction of the PACTG 076 protocol). Only one child was HIV-positive and this child was born in 1994.

A table of the demographic characteristics can be found in Appendix D (page 221).

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## Chapter 3

### *Motherhood and HIV*

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When women are diagnosed as HIV-positive they find it to be an extremely traumatic event, and for most it is shattering to their sense of self, their sense of future and their plans and intentions. Not only are these women faced with their own morbidity and mortality but for those who intended to become mothers (or have more children) the role of motherhood seems unobtainable. Women who are already mothers are faced with the devastating possibility of dying before their children become adults, or are considered old enough to cope with such a loss. This chapter will examine the impact of an HIV diagnosis on women's desires to become mothers and address the differences between the life they imagined and the life that eventuated.

#### **Motherhood and narrative**

I'd always thought about having kids; even when I was at school I always babysat. I did childcare courses and I did my work experience in the children's hospital, so my life revolved around children. It was really always something when at school, people said, "What do you want to do when you leave school?" I'd say, "Get married and have kids." So it was all I could see my future being really and I never thought of a life without children [Layla].

Layla's certainty about her future as a mother exemplifies the narrative accounts of self-as-mother reiterated by most of the women who told me their story about

motherhood and HIV. Many of these women had narrated their future lives around motherhood and assumed it was a natural and rightful role. Most women constitute their futures within the canonical narrative of motherhood in Western society (see, for example, Kirkman, 1997). This was the same for most of the women in my study; motherhood was an essential component of their identity.

Western societies have largely embraced individualistic values and self-determination. It is the common values, goals and attitudes that allow a society to exist and the most common and socially accepted role for a woman within society is motherhood (Josselson, 1996). The discourse of motherhood within Western culture has been confirmed by many researchers and theorists (Birns & Hay, 1988; Boulton, 1983; Busfield, 1987; Griffin, 1985; Marshall, 1993; Phoenix & Woollett, 1991; Urwin, 1985). The common theme to their work is the recognition that, for many women, motherhood is seen as an important identity and a valued role for women (Ingram & Hutchinson, 1999, 2000; Leifer, 1980). Other social research has confirmed that an HIV-positive diagnosis does not alter the significance of the identity of mother (Murdaugh, Russell & Sowell, 2000). The women in this study narrated their identity of motherhood in the same way. In fact for some women, such as Georgia, diagnosis brings their motherhood identity to the fore:

I think the reason motherhood suddenly became important when I was diagnosed was a combination of everything. I think where I was in life, I guess that by the time I was diagnosed I decided yes, I was having children but I just hadn't decided when. So that made you think well you may not be around forever but I guess your priorities change ... I just wanted to experience unconditional love, which I didn't feel I'd ever had really. I mean I get it from my mother, but I don't think I, even now, have really truly, honestly given it to anybody else. Also one of the reasons was because I wanted Tim to have a child, regardless of whether I was here or not.

## **Narrative accounts of motherhood**

Most of the women's accounts of the self-as-mother could be described in two ways: those for whom a motherhood identity was one that they had imagined since childhood, and those for whom this identity became important over time for numerous reasons, which included growing older, being diagnosed as HIV-positive or even finding themselves unexpectedly pregnant.

### ***Motherhood imagined since childhood***

Many of the women in this study explained that having children was something they always assumed they would do. Yvette summed it up for many when she said, "I always thought I would have children one day." Certainly many of them had other important roles as career women, travellers or students, but they still envisaged a future for themselves which included having children. Women narrated in various ways "knowing" that motherhood was part of their identity. For some, like Layla, it was something they had envisaged since they were little girls. Most of these women could not imagine life without children. Janice explained, "Like when you were a kid and how you always thought you will have a baby and they will be just like you."

Reaching one's thirties or describing a new awareness of their "biological clock" was a significant event for some women. Monica was one for whom having a baby was always part of her future when she was younger, but for various reasons she kept delaying it until she reached an age where she started to believe she was never going to achieve her life goal:

I always wanted to have a baby and in my twenties I remember thinking, if I'm not married or whatever by the time I'm 30, I'll just go and have a baby anyway. Then I would up that age as I went along, and at the age of 36 I started thinking, well I'm not going to have a child and whilst I wasn't happy about that I started to accept the thought and then I got pregnant. So I feel very lucky.

### ***Motherhood becomes important later***

Not all women gave accounts of motherhood as their imagined destiny. Several women, including Georgia, claimed, “I hadn’t always wanted children, to be honest with you, but as I turned 30 I had started considering it.” Women provided other reasons for not embracing the canonical narrative of motherhood throughout their lives. A few women in my study were previously injecting drug-users. Lily was one who interpreted her rejection of a motherhood identity as based on her experiences as an intravenous drug-user:

I had no intentions of ever having children in this world. I was so against bringing a child into this world. I mean I’m an ex-junkie too so being in that drug world really opened my eyes to how horrible this world is.

Some women planned lives in which, although motherhood was seen as inevitable, other roles were the focus of their younger selves, such as developing a career or travelling. Kate explained motherhood as something that comes after one’s education or career, “that if you do have a family, it is later.” Career had taken precedence for a few women. Isabelle spoke of a highly successful and rewarding career that had led to living overseas and a significant amount of travel. She reflected, “I wasn’t sure if I could lose that kind of freedom and to continue doing that for the sake of a child, or whether I would resent that.” However, Isabelle admitted that having a child was something that she still occasionally thought about, saying, “I still like to think about what [our child] would have looked like with our racial mix. My partner is tall and good-looking so you kind of daydream.”

Despite many women providing accounts of other important roles in their lives, such as career or travel, motherhood was implied as an identity that was taken for granted: a likely choice; something one would, or could, pursue at some point. In fact, most women reached a point in their lives at which motherhood did come to the fore and became central to the way they thought about themselves and their futures.

### ***Motherhood has no personal relevance***

Only one woman in this study rejected an identity of motherhood completely. Louise and her partner had decided not to have children long before she was diagnosed with HIV, and Louise had terminated a pregnancy years before based on this choice. When her doctor at the time suggested her symptoms might be signs of pregnancy, Louise explained to her, “Well I’d have to have an abortion. I don’t want children.” Louise went on to say, “I know that personally I’ve never felt maternal at all in my life. Maybe with the exception of when I thought I was pregnant.”

Louise is not extraordinary in her rejection of motherhood identity; rather, she is not typical of the group of women who self-selected to participate in a research project about women, HIV and motherhood. In her initial inquiries about the project she asked me if it was appropriate for her to participate because she did not have any intentions of having children but that she felt her story was an important contribution as an HIV-positive woman. I told Louise I would like to hear her story.

### **Diagnosis disrupts the plot of motherhood**

Women who are diagnosed as HIV-positive during their childbearing years often initially believe that the option of having a(nother) baby is no longer available. Given that so many HIV-positive women are diagnosed during their 20s and 30s, the diagnosis not only disrupts the plot of their lives (Kirkman, 1997) but disrupts the motherhood identity that most women in this age bracket assume as natural and rightful. Previous research on infertility amongst women has documented the significant distress and devastation that women experience when they receive their diagnosis (Greil, 1997). Similarly, a qualitative study of women living with ovarian cancer during childbearing years found that some women found the loss of childbearing ability harder to deal with than being told they had cancer (Schaefer et al., 1999). Likewise, many women in this study also explained that, upon diagnosis



(or shortly after), the belief that they would be unable to have children was more devastating than being diagnosed with a life-threatening illness.

Before the introduction of the 076 protocol, when it became known that vertical transmission could be significantly reduced, the American College of Obstetricians and Gynecologists recommended that HIV-positive women avoid pregnancy and that HIV-positive pregnant women be counselled about the risks of vertical transmission and informed of termination options (Kass, 1991). This was evident in the accounts of the women in my study who were diagnosed before the 076 protocol. They reported that health-care professionals often considered them as unworthy, undesirable or undeserving mothers and recalled being told they should not get pregnant. Yvette said, “I was told I had a year to live and I couldn’t have children. ... So I would say for about the first two years after I was diagnosed the time that I was crying was actually over the fact of not having children and having that taken away from me.”

Yvette was certainly not unique in her experience of diagnosis and the subsequent loss of a predicted life that would have included children and motherhood. HIV intervened in their imagined motherhood story for nearly all of the women in this study. To adequately describe the experience of how an HIV diagnosis disrupted the plot of motherhood, the next part of this chapter is divided into three sections: those women who were not yet mothers when they were diagnosed, women who were pregnant when they were diagnosed, and women who already had at least one child when they were diagnosed.

### **Women who are not yet mothers**

Common in many women’s narratives when recounting their diagnosis is how they first thought of their desire to become a mother and how that dream was suddenly crushed. Despite many women explaining they knew little about HIV/AIDS and assuming imminent death, motherhood was at the forefront of the many losses that women perceived when they were first diagnosed. Evident in Stephanie’s narrative

was the loss and grief she felt when she was diagnosed and believed that motherhood was no longer available to her:

When I was first diagnosed it was very, very upsetting. I was 29 years of age and I was always planning to get married and have a stable relationship with children, and so to think that I couldn't have a baby – it was like, 'Oh, my God'. The dream of my life – I couldn't really ever see it through.

Even women for whom motherhood is not at the forefront of their identity found that their unexpected diagnosis took away the possibility of motherhood which they had assumed was their choice. Brooke explains how motherhood came to the fore when she was informed of her HIV status, even though motherhood at the time was not an urgent quest for her:

My very first thought when I was diagnosed was, "HIV, oh I can't have kids." Even though I didn't know much about how it was transmitted and stuff. I just thought I can't have sex again and I can't have kids. And that was the most devastating part of it. Even though I hadn't really thought about kids. ... I wasn't one of those people who from the time they are 12, or whatever, wanted to have kids. Because I was 27 when I was diagnosed so it's just that age that maybe you start thinking and it comes up more.

The perceived loss of motherhood also left women at a loss as to what they would do with their lives, irrespective of how long they perceived their life to be, given their HIV diagnosis. Carol described how her diagnosis left her without any imagined future and at a loss as to what she would do with her life:

Being told I couldn't have kids and couldn't travel again was, at first, all that I heard. There wasn't even what being positive might have meant, it was just that I wouldn't be having kids. That was the main thing because then I thought, well what am I going to do with my life and the plans I had? I will be without kids and I can't travel so what am I going to do? Sit around in Australia? It wasn't like oh, but I'm going to be sick.

This loss was just as profound for those women who did not immediately assume they could no longer pursue motherhood when they were diagnosed. Over time, as they began to absorb their diagnosis, to find out more, and to speak to health professionals, some women started to believe that motherhood was no longer an option. Like Stephanie, Layla had envisaged a future for herself and her partner that included marriage, and “having kids would obviously be part of that.” Once she was diagnosed she said to her partner, “Well I’d understand now if you don’t want to marry me because of this.’ He said, ‘No, it doesn’t matter to me, it’s you I want to marry’. And it wasn’t until it all started to sink in that I really started thinking about having kids.” Layla went ahead with her marriage and said, “I don’t remember anyone telling me when I was diagnosed that I couldn’t have children.” However, the loss of potential motherhood became apparent when she spoke with her doctors:

I remember a little while later talking through my prognosis and at that point in time they weren’t looking past five years and when I did broach the subject of children I was told that, for a start you couldn’t be guaranteed that I would be around to raise a child. The main thing that stuck with me was that there was no way of knowing what the impact of a pregnancy would have on my health and the doctor said, “We would advise against a pregnancy, not knowing those things.” So I basically just went along with that. I was really devastated. The more I thought about it, the more devastated I became. I realised that it was something that had been taken away from me.

An HIV diagnosis for women who were not yet mothers often brought to the fore an assumed life trajectory that had not previously required articulation. Many women in this study told of their visions for themselves as mothers; others had taken for granted motherhood as a possibility which only came to be articulated once it looked like being denied them.

### ***Exclusion from the motherhood group***

An HIV diagnosis can leave many women feeling alienated from personal expectations and excluded from the world of motherhood. The canonical narrative of motherhood in Western societies (and, perhaps, all societies) can leave women who are unable or unwilling to fulfil the expectations of this narrative feeling excluded from the world of motherhood, the world of adult females, notions of the family (see Kirkman, 1997) and even other HIV-positive women. It was during this time while Layla was grappling to come to terms with this loss that she found she, "... really hated other people who had children. I couldn't be happy if friends had kids and even when people went past with strollers on the street I'd look away. I didn't want to get close to children at all, which was very unusual for me."

This sense of isolation can also occur within support or peer groups of HIV-positive women. Other women choosing to have children can be painful for some women and reinforce their loss. Yvette felt isolated even in the presence of other HIV-positive women at peer support meetings, as her identity as mother now seemed inactionable:

Most of the issues discussed are around pregnancy and children and you just feel not part of it. ... Almost every second meeting someone else is pregnant or had the baby or whatever. And it's like oh fabulous, congratulations or whatever and it's just like all the women had either had children before their diagnosis or they've had children since. I can only think of a few women who haven't actually had children. So I am very pleased and happy for them but I feel quite ripped off.

### **Women who are pregnant when diagnosed**

Women who are diagnosed as HIV-positive while they are pregnant are faced not only with how HIV will affect their life, but also that of their unborn child. What should be (for most women) a very exciting time becomes a time of great confusion and anxiety.

Not only must they digest the news that they have a potentially life-threatening condition, but there is also chance their baby may be infected with HIV.

Early in the epidemic, the shortened lifespan predicted for HIV-positive women, as well as the belief that 65% of all babies born to women infected with HIV would also be infected, resulted in the *Recommendations for Assisting in the Prevention of Perinatal Transmission of HIV/AIDS* issued by the Centers for Disease Control and Prevention (CDC) (MMRW, 1985). This document recommended that HIV-positive women should be counselled to “consider delaying pregnancy until more is known about transmission” (MMRW, 1985: 725). Lawless and Sponberg (1995) asserted that, although “such a statement euphemistically avoids the mention of recommending termination ... its intention is exactly that.” They also point out that there had not been any official policy around the issue of HIV-positive women’s rights regarding reproduction and, because of this void, the issue had been left in the hands of individual doctors and health-care providers.

Five women in this study were pregnant when they were diagnosed as HIV-positive. Only one of these women proceeded to termination, although three others had considered it as a possibility. Two women, Denise and Sophie, were diagnosed before HAART and the 076 protocol were introduced and both of these women were advised to terminate their pregnancies. Denise was diagnosed with HIV in 1987 and at the same time was told that she was pregnant. It came as a great shock to her, as she had not expected either event. Her son was five years old and she described being pregnant as the bigger issue:

Like the HIV was, “Oh, wow.” I didn’t really have a lot of information and this is back in 1987 and I knew no other positive people. So my partner was tested; he was also positive. We were told we had two years to live. ... But the hardest thing was the decision about the pregnancy. They said, “Well you’ve got to have a termination.”

Even when a termination is not interpreted as forced it can still be regretted. Denise interpreted the termination she had as her decision, but understood this decision as

influenced by her health-care professionals. In retrospect, with a healthy daughter in her life, she wished that she had continued with her earlier pregnancy:

Now I say that I made that decision but I was greatly influenced. I regret what I did then but they said to me, “You’ve got a six-year-old son, who’s going to look after him? You’re going to get sick, your baby may be sick.” And I remember asking them, standing in the corridor there ... “Isn’t there another woman in the whole of Australia who’s ever been in my situation?” And they said, “Oh, not that we know of.” But they gave me an A4 sheet about women in Africa and I can just remember thinking to myself I couldn’t connect that situation with my situation and I had like zilch knowledge about HIV.

Sophie was also diagnosed as HIV-positive and pregnant at the same time. She had been feeling unwell and a doctor suggested they do some blood work including an AIDS test which, for Sophie, “wasn’t a concern because I had never been overly promiscuous. I had never shot up drugs or – ” Sophie returned “to be told that I was HIV-positive and the reason I’m sick is because I’m pregnant but don’t worry about that because he’s already arranged for me to have a termination.” Fortunately Sophie had an HIV-positive friend who recommended she go to a hospital with HIV specialists and after going through all of the “pros and the cons ... they said my chances of having a positive child would be one in 27 or something around that. So we ummed and we ahned, ... I’d booked for the termination but I couldn’t go through with it; I got up and I left.”

When women are diagnosed as HIV-positive during their pregnancy they often assume that their lives are over and therefore it would be irresponsible to bring a new baby into the world. Olivia was one who immediately thought her life was over and therefore she would have to terminate her pregnancy: “My first thought was that obviously I’m going to die and then I thought I was not going to go through with the pregnancy.” However, Olivia had another shock in store for her when she had her first ultrasound and she identified this discovery as her reason for being unable to proceed with a termination:

When we went in for a scan the doctor actually said that my uterus was bigger and my dates were wrong and that's when we found out it was twins. And for some reason I thought, no I can't do it. It shouldn't have made any difference but having twins, it did. So we went through with it all.

Mary was also diagnosed in her first trimester of pregnancy and, whilst she did not "agree" with induced abortion, it was something she felt she had to consider. She narrated this time as a week-by-week proposition as her doctor re-ran her HIV test to confirm the results. Mary's doctor advised her 10 weeks into her pregnancy that there was a problem with the result of her HIV test, which was part of a routine antenatal screen, and that he wished to conduct the test again. Her HIV diagnosis was confirmed 13 weeks into her pregnancy.

The reduction of vertical transmission as a result of the 076 protocol is not common knowledge and consequently most people still assume that, if the mother is positive, so too will be the baby. The women in this study who were diagnosed whilst pregnant made this assumption. Like other women in this study, Mary's primary concern was for her unborn baby. She remembered asking the doctor:

"What about the baby? Does it affect the baby?" He didn't know. He didn't know anything and he wanted me to wait for another appointment he made for me to see someone three weeks later or something like that. I knew the time was coming short if I had an abortion, and I don't agree with that but I knew that time was coming up.

Mary then decided she could not wait any longer and went to the phone book. "I looked up a clinic that deals with HIV and I went down the next day. Well, that's how good I've handled it. I haven't cried since. It doesn't worry me. I don't worry about it." Mary went to the clinic and had more blood tests and, on the basis of these results, started treatments and continued her pregnancy. Mary presented herself as a normal woman who had "handled" and coped well with her diagnosis.

Only one woman who was diagnosed during her pregnancy did not consider termination as an option. Polly was living overseas at the time and she found it difficult to find information that made sense to her and receive the medical support she would have liked. Polly had been “waiting for about four years for this child” after deciding she wanted to have a child and then suffering several miscarriages. Although Polly was devastated by her diagnosis, her identity as mother was stronger than her new identity as a woman with a life-threatening illness and she was determined not to let this shocking news override her joy of becoming a mother:

As time progressed, it was coming closer to the stage but I didn't want this to take away the joy of my being pregnant for the first time and so I tried I put in the back of my mind. I was very confident that I would get through. I was in shock but I put it in the back of my mind.

Polly, Olivia and Mary all employed techniques to minimise the impact of their HIV diagnosis on their lives. This coping strategy enabled them to focus on their pregnancy and not become overwhelmed by anxiety. (Coping strategies upon diagnosis are also covered in Chapter 4.)

### **Women who are already mothers when diagnosed**

An HIV-positive diagnosis for those women who were already mothers presented another devastating possibility: that their child or children might also be HIV-positive. For women whose children were born to them before they were aware of their status, their diagnosis opened a Pandora's Box of terrifying possibilities. Like the women who are diagnosed during pregnancy, those who are already mothers immediately think of the ramifications of their diagnosis on their children. Usually these women are more concerned about their child's HIV status than their own. Sarah's account of her diagnosis is a powerful example of what these women experienced. She was breastfeeding her six-week-old daughter on the couch when Cameron, her baby's father, rang her to say that he had AIDS and that she and the baby needed to be tested.



Sarah described how she “just lost it” and was forced to call the number that he had given her:

So I ended up ringing her and losing it on the phone to the counsellor and she didn't realise there was a little baby involved. So I informed her and she said, “We virtually need you in here straight away if you can.” ... So I had my test done that night and then my biggest worry was Lila. I said, “How do you pass it on to your baby?” He said, “It could have been done at birth; we don't really know if it is in-utero, it could have been done while she was in your womb or breastfeeding.” And because I was on the couch breastfeeding when I got the call I was a mess and I didn't know what to do there and then. Should I keep breastfeeding my baby? Should I stop feeding her right now? There was no preparation. I suppose you could normally wean babies gradually.

The hospital staff suggested that Sarah ring the breastfeeding counsellors at the hospital where Lila was born and ask them for advice about breastfeeding because her diagnosing doctor said, “Although we deal with HIV we couldn't really tell you whether you have to stop now or whether another feed or two is going to – ?” Sarah said, “They really didn't know a lot about that side of it.” She rang the hospital where Lila was born and recalled the women she spoke with saying that, “she didn't know a great deal, but she said, ‘If it was me I probably would stop.’” Sarah found herself in an impossible situation and “was just feeling very lost as to whether – you know – is it too late? Have I already passed it on to her? Is another feed going to kill her? But she was only six weeks old. Would she be upset not being on breast milk, like cut off right there and then, that minute, or – ?” Sarah decided she could not take the risk; her brother went to buy some formula milk because Lila was due for a feed while they were waiting for results. Sarah recalled her shock being replaced with fear:

I know everyone thinks it can't happen to them, but when we first had the blood taken I had this feeling that I didn't and then to suddenly be told that I was: it was a big shock and I suppose it is for anyone. My biggest fear was then Lila. I didn't give a shit about myself. Cameron and I had got ourselves into this

situation but she was an innocent in it all and I was feeling very angry and upset with both him and myself: that we may have passed it onto our daughter. It was pretty scary and then they informed me that it would take six months of testing before we would know that she was in the clear, and I lost it again. That was the hardest six months of my life.

Seven other women had older children whom they had to have tested after they were diagnosed and it became apparent that they (and therefore their baby) could have been at risk. Samantha described the four-week period between her positive diagnosis and receiving her children's negative results as a "period of living hell"; Joy described this wait as "heart-wrenching". Laura's husband had haemophilia and they were diagnosed in 1990. She described that moment:

Motherhood was the first thing I thought of when I was diagnosed. I was diagnosed four days after my husband was. He was given his diagnosis on the Monday night by his GP and then on the Tuesday, they took bloods from me and my daughter, because she was born after he would have been positive, so she could have been at risk. They made an appointment at the hospital, so it was pretty quick, the whole process of having bloods done. There was certainly no time to assimilate his diagnosis and the repercussions of all of that. ... Then about midday it was when they called me in and you know that it's not very good when the social worker is sitting in the room. So the first thing that they told me that my daughter was negative, that was how they broke it. They thought, give her the good news first and then they said that I was positive.

Adele recalled her moment of diagnosis and said that her doctor also gave her daughter's negative test results first but then failed to provide any support for this devastating news, despite her diagnosis occurring in 1997. Even five years since her diagnosis Adele was still perplexed and upset that her doctor failed to provide her with any support:

First of all she said, “Briana is fine.” And I said, “That’s fine.” And she said, “And you’ve got HIV.” And I was just stunned. And she said, “I will be making you an appointment with an HIV specialist and you need to take more blood tests,” and at that point I just got up and said, “Fuck off” and walked out. There was no counselling involved. She didn’t say anything about it and I just lost it.

### **HIV impacts on family size**

Little has been written about HIV usurping women’s reproductive intentions. Wesley and her colleagues noted some HIV-positive women feel unable to have the number of children they desired or had originally planned. In my study there were women who were already mothers when they were diagnosed who had not yet finished their families. They had planned to have more children; to provide a sibling for an existing child when their HIV diagnosis disrupted this goal. Helen had one daughter and “would have liked more children.” Brianna also had one child and had “always wanted two.” Some women were still unsure about whether they would have another child. These women felt “lucky” to have had one negative child and that this luck may not extend to future children. Sarah explained this indecision when she said, “So it’s very hard, because although I would like to give [my daughter] a brother or a sister, I wonder now am I, I don’t know, playing with fate?”

Women who were diagnosed before HAART (which offered PLWHA some hope of longevity as well as reduced perinatal transmission) often felt that HIV was an insurmountable barrier to having more children. Leanna described the overwhelming anxiety of caring for one child as a mother living with an uncertain future and how this prevented her from completing the family she had always wanted:

I just couldn’t bear the thought of bringing another child into the world when I had so much anxiety over the fact that was I going to live long

enough to see Michael grow up. And to me it was something that I just felt that I wasn't able to do. But I always wanted to have more children.

Even some women who proceeded to have children after they were diagnosed narrated their decision about their family size in relation to their HIV diagnosis. The experience of discrimination and stigma that endured during the pregnancy and birth of her first child led Layla to wait almost six years before attempting to have another baby. Fortunately this was a far better experience and Layla said, "I'm actually really glad I didn't have this experience with the first one otherwise I would have had a few more children by now!"

These women's narratives reveal that an HIV-positive diagnosis was not only devastating but also hijacked their intentions for the future. Nicola exemplified this when she said, "but when you're diagnosed you think, oh? You've got your life plan set out and suddenly it's like maybe you can't do what you always thought you could." Women who were planning to have children suddenly believed they could not pursue this life choice and women who were already mothers were distressed by the thought of dying before their children are grown up and independent.

### **Being an HIV-positive woman**

Motherhood was invariably central in the identity construction of most of the women in this study. Not surprisingly, but to lesser and varying degrees, HIV also played a role in these women's identities. By commencing all interviews with the question, "Can you tell me your story of how your HIV diagnosis influenced your thoughts and feelings about motherhood?" I directed women to focus on how HIV had affected their life, particularly motherhood, and most of them did just that. Yet although the centrality of HIV in women's lives was accepted by some women as central to their sense of self, most compartmentalised HIV and relegated it to a small part of their lives. The significance of this identity was fluid: at certain times an HIV-positive identity could be central and at other times it was just one component of women's social identity.

## **HIV is central to self**

For some women HIV was all-encompassing and no alternative narrative seemed available. Lily, the only mother of an HIV-positive child in my study, told her story as consumed by HIV, affecting as it did both her child and herself. Lily explained how every aspect of their lives was governed by HIV: where they lived, stigma they have experienced as a result of unwanted disclosure, treatment and side-effects, meals which had to coincide with treatment, and day-care where disclosure was an important issue for Lily: “I tell all of his teachers or carers about our status. Any scenario where he is there and I am not: for their sake and Zach’s.” Lily envisaged a future that would continue to be consumed with HIV:

I am scared of disclosure, scared from the experiences I have had. Disclosure scares the shit out of me, particularly in relation to Zach. What’s going to happen when he gets a girlfriend? If they were educating kids about it now then he might have a girlfriend in the future who will have grown up with it, but instead his disclosure will probably scare the shit out of them. It’s torment for a Mum, it really is. Those sorts of things worry me as a mother. He has already lost his best friend because of his HIV. The children are scared of us. They have been taught fear and hate. It’s wrong. Maybe one day people will learn. But what can you do? You just have to get on with it.

For Lily there was little choice but to accept HIV as defining her sense of self and this was likely to be true for women who were unwell or for whom the side-effects of treatments, such as lipodystrophy<sup>6</sup>, had significantly altered their body shape and reinforced HIV as ever-present. Joy explained:

Another really hard thing that I have had to get used to is the physical changes; my body changing with the medication. ... I can see everything

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<sup>6</sup>Lipodystrophy is a disturbance in the way the body produces, uses and stores fat. There are two kinds of lipodystrophy. The first is lipoatrophy which is also known as fat wasting. Fat is lost from particular areas of the body, especially the arms, legs, face, and buttocks. The second is known as hyperadiposity, which involves fat accumulation. Fat builds up in particular parts of the body, mostly around the belly, breasts, and back of the neck (The Body, 2005).

changing. I don't have a waist any more and I have boobs coming out everywhere and no fat on my face and no fat on my legs, no bum. And the physical things like that are hard to get your head around as well. It reminds you every day. You look in the mirror and you think, 'that's right.' You can't get away from it.

A few women came to accept their diagnosis and embraced the identity of an HIV-positive woman. These women tended to be those who had been diagnosed for a considerable period, usually 10 or more years. Denise, Leanna and Yvette were diagnosed in the early years of the epidemic. They told stories of believing they were the only HIV-positive women in Australia and their narratives of those years are of isolation and fear. Yet with time and sheer survival these women decided to become involved in the organisations that support and advocate for PLWHA. Leanna was a board member of her state-based PLWHA organisation, part of the Positive Speakers' Bureau (a program designed to educate the wider community about HIV/AIDS via personal storytelling)<sup>7</sup> as well as other committees set up to support the lives of PLWHA. Similarly, Denise was involved on national and state Positive Speakers' Bureaux and her employment was as a peer-support officer for HIV-positive women. Several other women were active advocates and supporters, and most often this was expressed as a desire to help other women and ensure that women's issues remained "on the agenda" of the organisations that were established largely to support the needs of HIV-positive gay men.

Layla interpreted the birth of her child as the point at which her HIV identity became central. She said, "before I had Ella, HIV was a very small part of who I was. But then when we decided to have a baby it became a focus only because we needed to talk about it and to take things to reduce the transmission to her." Layla's experience of discrimination and stigma during her pregnancy and birth of her first child led her to "realise afterwards that a lot of people need a lot of education." This resulted in taking

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<sup>7</sup> The Positive Speakers' Bureaux [PSB] are run by the state-based PLWHA organisations. The PSB provides to schools, professional and community groups the opportunity to hear first-hand the experiences of people living with HIV/AIDS. The aim of the PSB is to "encourage understanding, dispel myths about people with HIV/AIDS and counter ignorance, fear and discrimination." Speakers are diverse people with HIV/AIDS who have been trained in presentation skills (PLWHA (NSW), 2007).

an active role in educating health professionals and “speak[ing] to midwives as a positive mother”, so “that hopefully the other women would benefit by these people having a better understanding about the needs of positive mothers.” Layla described her involvement in this work as “really empowering.”

Yvette’s account was evidence of how the positioning of HIV in one’s life can change. She had founded a positive women’s group in [her] state, organised retreats for positive women and was involved in the Positive Speakers’ Bureau. However, since going back to work full-time and being less involved with other HIV-positive people, Yvette said that there were more days where she felt, “it is not a big part of your life” but at the same time, “even when you are having what I call a *good AIDS-free day* where nothing has happened, then something will happen” where she is reminded that HIV is always there:

Sometimes HIV is not a part of my life much at all, but then when you think it’s not part of your life all these things keep on cropping up that eventually spiral back to that. Whether it’s about the child issue and people asking, “Why don’t you have kids?” Or going to Bali, for instance. You just want to go on a holiday, but because they wouldn’t even let Magic Johnston in to play basketball there is that little fear of what if they were to find out somehow? Because you don’t know how computers are linked up and everything. The other thing is getting travel insurance. If I come down with something and they relate it to HIV they are not going to cover it, so even the most simple thing somehow can spiral back. Just a lot of things where theoretically it shouldn’t have anything to do with it but in some way or another, maybe four or five steps down, but it does take it back to that.

### **HIV is one part of self**

HIV was not central to most of the women in this study. These women deliberately narrated HIV as a minor aspect of their identity. After the shock and intensely focused period following their diagnosis, most women wanted to reduce the impact HIV had

on their lives and deliberately constructed stories to achieve this. Minimalising HIV was especially the case for women with children, women with negative partners, women who were not on treatments and had not been ill, and women who had been diagnosed since the introduction of HAART. Brooke explained:

At the start, HIV is everything, because of the shock for the first few years at least. But as I have gotten more used to it and more comfortable with it, it has become just a little aspect of my life. ... And it helps that Simon doesn't have it too – so it's not always everywhere.

Later, Brooke said, "Occasionally I think it's a drag; I'm over HIV, I've done HIV."

Carol had two passions in life, children and travelling, that she understood as lost when she was diagnosed. Carol explained that her husband played an important part in the role HIV was to have in her life and attributed to him her redefinition of HIV as not fundamentally changing her identity:

He said, "Well how do you feel different today than you did last week when you didn't know?" So apart from the shock of how they were telling me my life should or would become, I then realised that it wasn't any different; that I didn't feel any different and that apart from their predictions of the kind of life that I should live from then on, that it wasn't any different. So I have just always focused on that as well; that until such a time that it would be affecting my health, life goes on!

Despite the small possibility of passing HIV on to her daughters, Carol believed the only reason HIV had become a part of her self identity was the experience of having treatment forced on her new baby when she and her husband had decided not to give her the recommended prophylaxis (see Chapter 5).

But really, I mean if we hadn't gone through this with Scarlet, I probably wouldn't even be talking to you today, because it's not a big issue in my life. It always has been a non-issue and it was only now that it transferred



over to another person in my life; that now they have had stuff inflicted on them, that I realised okay, this is a really big thing being positive!

The desire to see their children into adulthood and beyond also played a part in many women relegating HIV to a minor part of their lives. Helen explained that HIV had only changed her as a person because, as a mother, she was concerned for her daughter when she becomes sexually active. Aside from this issue, Helen understood her “positive attitude” as protecting her from adverse changes to her identity and even to her life from HIV. In her journey her personal strengths had helped her along the way despite the obstacles created by diagnosis. She went on to claim, “I’m going to be here forever ... So nothing’s really changed.”

A few women claimed that HIV played a small role in their self-identity but then went on to describe all of the things they now did because of HIV. Audrey said, “I don’t think about HIV. I don’t want to even be bothered thinking about it because I’ve got too much happening in my life to think about it.” Later in the interview, Audrey described her involvement in the Positive Speakers’ Bureau for the last three years. She explained how important she thought this work was in helping to “make a difference.” In addition to this, she said was committed to volunteer work with her state AIDS Council and regularly organised get-togethers with other HIV-positive women. It was not that Audrey was pretending HIV did not matter but rather she refused to let it define her identity.

It was more common for women to claim that HIV was only a small part of their life (as opposed to a significant part of their identity). This was usually so even when it involved the daily commitment of treatment, regular medical appointments and for some a level of activism or community commitment. It is likely that this was due in part to the small numbers of women living with HIV in Australia and the sense that there is less community organisation on the part of women. This is quite different from the HIV-positive community that exists for gay men, who have been largely able to mobilise the gay community for their cause (see Bartos & McDonald, 2000). In addition, the events that occurred as result of being HIV-positive (such as taking treatment) were often not incorporated into the women’s narrative identity.

## **Motherhood and HIV**

Regardless of when women are diagnosed in their life trajectory, HIV has a significant impact on their experiences of motherhood. During the interviews and subsequent conversations, letters, and telephone calls, women conveyed a range of emotions including at the birth of a baby, the love they felt for their children, the anxiety and grief that HIV had imposed on their roles as mothers, and their feelings about potential or actual impact this had on their children.

### **Diagnosis pre-HAART**

An HIV-positive diagnosis before effective treatments were available meant almost certain death with a short life expectancy. Once again, at the forefront of women's accounts of that time was what their diagnosis meant for their children. Leanna and her partner were diagnosed in 1985 when her son, Michael, was only three. Leanna said, "from the outset my biggest anxieties were over whether I was going to live long enough to see him grow up." She and her partner were told they had "one to two years possibly." She recalled "seeing people who were diagnosed and die within three weeks or three months. And everything you saw on the news and written in newspapers was all bad news; there was no good news at all. If anything, they just seemed to be finding out more ways every day that people were dying."

At this point the most difficult thought for Leanna was not being there to watch her son grow into adulthood. "I found that, really, I could not bear the idea of not being there for Michael and not seeing him grow up or having to make a decision to rescind his care over to somebody else." Similarly Laura's daughter was six years old when she was diagnosed. When told of her positive status, "the first thought that I had, and I think the first thing that I said, was, 'She will be all alone'." Joy life's "flashed before my eyes" and "all I could think of was my two kids because at that stage, Jane, my daughter, had just turned four and Michael, my son, was five." Like Leanna and Laura, Joy was diagnosed in a time when treatment options were limited and HIV was a death sentence:

I did a lot of crying and every time I looked at my kids it just broke me up because at that time – I mean we have come along way since then – I said to my doctor, “Well, what does this mean?” And he said, “A minimum of two years and a maximum we don’t really know.” And I thought, oh God. ... my biggest fear; who was going to look after them?”

### **Bargaining for time**

Many women were reluctant to plan too far into the future, particularly those diagnosed pre-HAART. Yet some women found themselves ‘bargaining for time’; setting small temporal goals and then, upon reaching that goal, setting another. These goals were usually in relation to surviving their children’s various milestones: the completion of primary school or high school or reaching a certain age. Bargaining for time was more likely among women whose partner had died, or women who were single mothers and could not imagine anybody else being able to care adequately for their children. Leanna and her husband were diagnosed in 1985 and her husband died nine years later. As a result of her drug use, Leanna had become estranged from her mother and siblings, so her son “didn’t have any close links with any other family members.” Leanna did not believe her son “would have been happy” in anyone else’s care but hers.

I just felt that really there was no answer – that I just had to survive at all costs. But I could only look ahead in blocks of time of two to three years. When I was diagnosed I said, “Please let me live until he is six.” I started to do this bargaining thing where I would bargain for another two to three years. And then when he was six until he was nine and then until he was 12. And then he was 14 ... I remember going to the doctors and saying, “How about it?” I think that was probably not long after Tom died. ... The idea about whether I was going to live long enough. My benchmark was always when he turned 18. Because I felt like at least if he was 18 and he had lost both of his parents that he may have been able to cope far better than if he had been 12 or 14. ... I remember saying to the doctor then and he saying,

“Yes definitely”, he could assure me I would definitely be alive by the time he was 18. He couldn’t say how good my health would be but at that stage my health was still fine and had remained stable all those years.

Even women who were diagnosed post-HAART, when treatments offered the prospect of longevity, tended to set milestones for their health in relation to their children. Adele’s daughter was two when she was diagnosed and her estranged husband died shortly after. Adele set a goal to survive until her daughter commenced secondary school but then, as time passed and she continued to stay well, she set a new goal: “I want to be around when Briana finishes school and she is independent.” Getting children to an age where their mothers thought they would cope without them was a key component to their stories. Some women also set about trying to provide their children with the necessary skills to survive as a motherless or orphaned child. Mothering was changed by HIV for many of these women as women placed a particular emphasis on creating independence in their children.

### **Creating independent children**

Some women felt they could not focus on their own lives until they had equipped their children to make the journey through life without them. The fear of dying and leaving their children without the skills they would need after the death of both or one of their parents consumed a few women. This was particularly so if the women’s partner was also diagnosed as HIV-positive or if they were diagnosed before the introduction of HAART. These women felt impelled to make arrangements for their children in the event of their death. Laura was told she had around five years to live when she was diagnosed, so she set out to provide her daughter with the necessary skills she would need as an orphaned child. She also organised for her daughter to be financially independent and for a network of carers to be available. Laura understood this as “making sure that if anything happened to me there was someone to take care of her and she would also be able to take care of herself.”

Some women reflected on how being HIV-positive had led them to place emotional distance between themselves and their children. This tactic was an attempt to protect both themselves and their child from potential or inevitable emotional distress. Denise had her second child before treatments were available to reduce vertical transmission, when transmission was thought to be around 30% and parents were told their baby's status would not be known for two years. The anxiety of this wait was overwhelming for Denise and she consciously made the decision to go back to work when her daughter was six months old because she "was afraid to get close to her." Leanna, like most women diagnosed pre-HAART, believed her son would be orphaned and later realised that she had been trying to create emotional independence for him:

One of the things that I became very aware of when he was about nine years old was that – and when I think about it now it absolutely breaks my heart because for about three or four years I had literally been holding him, not physically at an arm's distance, but I think emotionally and psychologically at an arm's length. I'd almost been trying to sort of convey to him, 'Don't get too close to me, don't get too attached to me. Be more self-sufficient because I might not be there for you'. I wasn't really aware that that was something I was doing consciously until he was about nine and it suddenly dawned on me. ... I took steps then to redress that and to make sure that I didn't do it any more. But I think that just the fact that probably from the time he was about five to the time he was about nine he had that sort of lack of emotional closeness with me.

### **Anxiety about transmission**

As so little is known about HIV in general Australian society, many women who are diagnosed find themselves paralysed by the fear that they may pass the virus onto their existing children. Adele explained how she was "nervous about too much contact in case I transferred it" to her daughter. Women worried about things like their children wanting to have a bath with them or getting into bed with them while they were menstruating. When Eliza was diagnosed she was living in Australia but she did not know any English, so it took her longer to establish what was safe for her

children. At first she thought, “maybe I cannot cuddle my kids. I cannot kiss the kids.” However, with time and information, most women reached a point at which they felt comfortable with their children’s safety from HIV transmission, although they remained diligent about personal hygiene items like toothbrushes and razors.

Women who were diagnosed as mothers and also had to have their children tested for HIV endured an anxious wait to discover their children’s HIV status. Despite their obvious elation and relief from a negative test result, some women found they could not accept the first result and subsequently retested their children for what they described as “peace of mind”. Joy was one of several women who had to endure having her children tested, but their negative results did not provide her with the comfort it should have. Joy continued to harbour anxiety about her children also being HIV-positive, “because I still had my theories that something was going to go wrong; that they were going to be positive. So now, it’s 2001, and I’ve had them tested three times.” The women who retested their children tended to be unsure of when they were infected and their children were often born in this period of uncertainty. Despite the initial test confirming their child’s negative status, uncertainty plagued them and caused them to doubt this good news.

## **Loss**

Ingram and Hutchinson (1999) have written about the grief and worry that consumes the mental energy of HIV-positive mothers in the United States of America. They found that HIV-positive mothers “grieve multiple day-to-day losses and future losses” (p. 255). Furthermore, these women experience “disenfranchised grief” due to the stigmatised nature of their disease, which often prevents others from knowing what they are going through. Evident in many of the stories women told me is a great deal of pain, loss and grief. Fundamental to these feelings were powerlessness and a sense of losing control of one’s life. As Laura explained, “It doesn’t feel like you’ve given it over of your own volition; it feels like it is taken away from you.”

The losses imposed by HIV were reinforced in all aspects of women's lives. Layla, when talking about motherhood in the first few years after her diagnosis, explained that, "Not really a day went by without thinking at some point or something happening that would make me think of what I wasn't going to have." Several women had chosen careers which involved caring for children and sometimes this work was too much to bear, as women were reminded daily of what they believed they would never have. Yvette was a child health-care worker and part of her practical training involved work at maternity hospitals shortly after her diagnosis. On her last day there she found herself in a broom closet, crying because she was "never going to go through this." Eventually Yvette left that area of work. Some women sought counselling to help them deal with these losses and most women described these sessions as revolving around the loss of their dream of becoming a mother.

### **Induced and spontaneous abortions**

Women continued to experience considerable loss and grief around abortions for many years. These experiences were also felt by women who had abortions before contracting HIV. Nine women in this study told of having abortions, some before their diagnosis but most after. Yvette was one woman who had an abortion before she was diagnosed. She had obviously spent a great deal of time considering what this abortion was to mean to her after her diagnosis:

I was 25 [when I was diagnosed] and I had had a termination when I was about 18, so of course that brought up all those issues. I still stand by that decision because it was right at the time but I still thought if I hadn't had that termination at least I would have one child. But if I had had that child my lifestyle wouldn't have been what it was and probably I wouldn't be positive.

Most women who were diagnosed during a pregnancy and after the availability of HAART reported they were able to find support from health-care professionals to continue their pregnancy. However, some women who were diagnosed before they

became pregnant were not so fortunate. Even after it was known that antiretroviral treatment could significantly reduce vertical transmission, some pregnant positive women were still advised to terminate their pregnancies. Central to the stories women told about their abortions was a sense of a lack of control: of being influenced or even coerced by their doctors. Brooke constructed her decision to terminate a previous pregnancy as largely influenced by her doctor's reaction and advice. Brooke felt unsupported and confused when she went to investigate the then newly available viral load test which she felt could help "determine whether I will have the child or not." Brooke interpreted her doctor as "pessimistic" when her doctor told her, 'Let's face it; maybe you're not going to be here. Maybe you'll die'." Brooke then proceeded with an abortion.

Some women were able to resist the pressure they felt from their health-care professionals and continued with their pregnancy. Lily was unaware of her pregnancy until she was four months along. Lily "booked an abortion; the doctors were virtually begging me to get rid of it. They made my decision to abort." However, when Lily saw her son's image on the ultrasound, she found she was unable to go through with the planned abortion.

The loss and grief women felt around their inability to pursue motherhood or have additional children after they were diagnosed were sometimes exacerbated by other women's decisions to have abortions. Laura was the only woman who reflected on the emotional pain she endured when assisting her sister, and later her daughter, through their own abortions. She explained that knowing "I can't have any and I have assisted another woman to not have any and the whole sort of head-mind-fuck about that is amazing." When her daughter had an abortion, Laura recalled being acutely aware that "this was my own grandchild and this was probably the only way that I was going to have another child in my life and that was like, oh my God."

Enduring a miscarriage can also cause profound sadness that may resurface for the rest of a woman's life. For women who are HIV-positive, a miscarriage may represent not only a lost baby but a lost possibility; some women assumed that was the last chance they had to be pregnant and have a baby. Tara described falling in to "a really



deep depression” after her miscarriage. She had “wanted another kid for so long” and then her HIV diagnosis led her to believe “oh, that’s it for having kids.”

So then to lose it and find out that I *was* pregnant was just devastating. It was really upsetting to think that I had something that I really wanted and possibly can never have again and then I lost it before I knew I had it; it was really horrible.

Joy attributed her three miscarriages to her HIV infection she had over a 12-month period. She felt significant grief over her miscarriages and described a “very hard, very haunting time” when she tried to reconcile herself to both the spontaneous and induced abortions she had been through since her HIV diagnosis. Joy had to “deal with this guilt that I had that there were five lives out there; three have been taken from me and two I decided to take myself.”

## **Adoption**

Two women in this study revealed underlying grief and pain from putting their children up for adoption before they contracted HIV. Celia was 34 years old when she was diagnosed and at that point she discounted the idea of ever having another baby “because I couldn’t live with the thought of having a baby and having that baby have HIV.” However, later in the interview Celia revealed the adoption of her son when she was a teenager, which she interpreted as the underlying reason for why she “never thought that another opportunity would come up that I would probably want another baby” because “having to give up a baby when you are very young, ... you think oh, if I have another baby, that it’s going to be taken away from you.”

Celia had constructed her journey as a successful career woman who was “so set in my ways” and therefore probably unable to accommodate a child in her life. Yet there was a parallel journey of a virtual mother, as Celia had “vowed” to find her child “from the day that my son was taken from me in the hospital”, which she did when he

was 18 years old. Whilst she “missed out on his growing up”, Celia found consolation in knowing that “I have a son that I can ring up.”

Tara adopted out her second-born child. When she left her husband she left her first-born in her husband’s custody. After leaving this child, she “didn’t feel like it was right ... to then go and have another child and bring that up when I’d left one.” She justified her decision because she had “sacrificed my family” to be able to pursue other goals and she “wasn’t going to jeopardise it.” Tara found herself unable to have an abortion, despite having several earlier in her life, because “once you’ve had a kid and you have gone through the whole pregnancy and given birth and breastfed, it is just a lot harder.” Although Tara accepted the decision to adopt her second-born child as her own, the pain of the separation was obvious. Tara later had a third child and, at the time of interview, she shared custody of this child with her ex-husband. However, her ex-husband was pursuing sole custody of this child which Tara was contesting. When I spoke with her she was hoping to have one more child with the use of donor sperm: “I don’t want to have another partner. I’m over that. I want a kid that’s mine! That nobody can take away from me!” The disembodied biological contribution of an anonymous sperm donor and the absence of a relationship with her imagined child’s biological father removed any threat to Tara’s future parenthood.

## **Sterilisation**

There is little research about HIV-positive women and sterilisation. Of the relatively few studies that have been undertaken, HIV-positive women have been found to be more likely to undergo tubal ligation than HIV-negative women (Bedimo, Bessinger & Kissinger, 1998; Lindsay et al., 1995). However, much of this research speaks of “women’s choices” or “women opting for sterilisation”. Australian research has revealed that some women have been bullied into these decisions by threats of non-treatment (Lawless, Kippax & Crawford, 1996).

Two women in this study, Laura and Audrey, stated that they were advised to undergo sterilisation after their HIV diagnosis. Both women consented at the time but, on

reflection, they described this experience as one during which they felt powerless and were influenced by their health-care practitioners. Although they may not have intended to have more children, there was still loss and anger following a decision that they interpreted as being out of their control. Audrey was the mother of six children when she was diagnosed and she had recently remarried. At her first appointment with her HIV doctor, Audrey recalled he told her, “We would like to sterilise you.” Audrey interpreted this statement as a “command” and, although she consented, she said, “it hurt because I thought, well, they’re not giving you a choice; they are kind of giving you a command.”

Laura was 29 years of age when she was diagnosed in 1990. She and her husband had one daughter who was five at the time, and Laura remembered, “Within a month of diagnosis I was sent to a gynaecologist.” Four days later “they sterilised me.” Laura could not recall receiving any counselling or support, “apart from some really patronising nurse telling me that I was doing the right thing. I remember that because it was the pat on the back; you know you’re doing the right thing, Love.”

Laura consoled herself with the thought that she “was really lucky because I had a child who was negative who was my partner’s child, so I would have something of him when he did die.” But she went on to explain that her survival and wellness led her to wonder if she had done the right thing when she lived beyond her prognosis of five years. She wondered if she were to “get another partner and they want children, what can I do here? I really don’t think that I would be able to find a gynae that would take off those clips.” The pain she felt over her loss of choice was still evident after more than a decade when Laura concluded, “But the idea of not actually having another baby – sometimes it hurts, though.”

## **Guilt**

In Australia and the USA today, a great deal of pressure is felt by many women to be “perfect” mothers (see for example, Douglas & Michaels, 2004; Nolan, 2007; Warner, 2005). Mothers are pressured to respond to their child’s every need, provide a stimulating and educating environment, and put their family’s needs ahead of their

own. It is hardly surprising, then, that many of the women I spoke with carried a significant amount of guilt and grief around their HIV infection and their roles as mothers. Women felt guilty for not being the kind of mothers they wanted to be or felt they ought to be.

Examples of the guilt experienced by the women in this study included the painful blood tests inflicted on their children to test them for exposure to HIV. They also felt guilty because they were unable to breastfeed their babies or because they felt an innate need to create emotional distance between themselves and their children. Some felt guilty because they had not purchased a house, believing they would not be well enough or live long enough to continue the repayments.

Denise summed it up for most women when she explained the anxiety and guilt she endured every time her daughter had to be tested in the first two years of her life:

The hard thing was all that emotional stuff, like looking at her and thinking, is she positive; isn't she? Taking her for blood tests. Every three months they would give her a blood test and the first one was just horrific because they couldn't find a vein and they were like jabbing her everywhere and in the end they took blood out of her head. And I was just standing there, like, sobbing, and lots of guilt, lots of feelings of guilt went along with that period. Also the fear of not knowing her status and the uncertain road ahead, full of emotional pain.

Eighteen months after we met, Denise sent me a letter updating some of her story including her disclosure to her daughter. During her interview she also said that, at public-speaking engagements in schools, children asked her, "If you had your life over again, like what would you do differently?"

I can't say, "Well, I suppose I wish I didn't get HIV." But it's more than that. For me, what I regret, or what I wish I had, was good health, wellness. I say to them, "You've all got that now and you probably take it for granted. I remember how I felt at 15 and looked and I thought I would feel like that

forever.” I say, “So I regret that loss of having good health and having the energy to like take my daughter to the playground and go bike-riding and do all the things that I should be doing with her.” I think a part of that pattern was set up when I went back to work, it was so subtle, about not wanting to get close to her and now it’s like, “My God, she’s 12!”

## Summary

The canonical narrative of motherhood influenced women’s decisions to become mothers but then, paradoxically, after they are infected with HIV, deemed them as unsuitable for this role. Most of the women in this study had assumed motherhood as natural and rightful, something they could choose and undertake when they wished. For some, motherhood was a childhood dream; for others, it became important later, often brought to the fore by other events, including their diagnosis.

Despite an HIV diagnosis being an overwhelming and devastating experience, the identity of motherhood was sustained for most women. For those women who were not yet mothers, diagnosis could shatter this dream whilst also reinforce motherhood as integral to their future journey. Women who were pregnant not only had to grapple with the magnitude of this news, but also make important and life-altering decisions about their pregnancy. An HIV-positive diagnosis for those women who were already mothers was usually accompanied by a great deal of anxiety, pain and loss.

In the next chapter I explain how, as women assimilate their diagnosis, they are often able to see alternative journeys to the one they first assumed when diagnosed, including motherhood.

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## Chapter 4

### *The journey after diagnosis*

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An HIV-positive diagnosis will often result in one being halted in one's tracks with no obvious future direction. In the months, or sometimes years, following their diagnosis, people living with HIV/AIDS may have to reframe their identity and revise their future narrative. Some may continue with plans or goals while others will change their direction altogether. This chapter explores the post-diagnosis journey. I consider the uncertainty that most women experience post-diagnosis that can last for months or even years. During this time many women can be thought of as living in the subjunctive mode where multiple pathways are possible. Eventually most women are able to reconstruct their future to include motherhood. However, for some, HIV presents an overwhelming barrier to motherhood and they must revise their accounts of the future as childless women.

Most of the women in this study assumed that illness and death framed the only likely future. As a consequence, many found themselves unable to consider anything beyond one day at a time. It was not possible to make plans or to look too far ahead (if at all). This experience lasted variable amounts of time (years, for some), depending on many factors, including the support network the individual had as well as her own coping skills. An HIV diagnosis not only disrupted their envisaged journey but also left some women unable to see an alternative to their impending death. This was particularly so for women who were diagnosed pre-HAART. Denise recounted how, when she was told that she and her partner only had two years to live, they did not see a point in making any plans for the future:

So basically our way of coping with that was, like, just to use more drugs. It was like, “Why put all this effort into life if we are not going to have a life to live?” And we didn’t really talk about it and I just continued like being a mother to my son, living day-to-day with no courage to think about any future, since we didn’t have one.

Denise was virtually paralysed by her HIV diagnosis, unable to make any progress towards her future. Even women who were diagnosed within the era of treatment when an HIV-positive diagnosis was not likely to mean imminent death, found themselves unable to envisage their future as they originally intended or make any plans. Like others in this study, Brooke spent “the next few years generally depressed” after her diagnosis, devastated by the belief that she was unable to have children.

### **Diagnosis and denial**

Other researchers have documented the buffering effects of denial as an important part of psychological well-being and self-preservation, particularly among individuals facing life-threatening situations (Kübler-Ross, 1969; Lazarus, 1983; Russell, 1993). Denial, as a defence mechanism, has previously been identified as a necessary part of the coping process when a woman is diagnosed with HIV (Davies, 1997; Sunderland, 1990).

Most of women I spoke with talked about the experience of denial when they were first diagnosed. Unable to accept that they had contracted HIV, these women tended to busy themselves in other activities to try and prevent having time to think about what their diagnosis meant. Despite being diagnosed whilst pregnant and then discovering she was pregnant with twins, Olivia decided to “just get through the pregnancy” and to focus on her impending wedding which “kept my mind off it.” Part of her coping strategy included avoiding other HIV-positive women because, as Olivia understood it, she “was in denial” and “didn’t want to talk to anybody about it.”

Clare also believed that avoiding other HIV-positive women would help her cope in the initial years after her diagnosis.

I am not up to getting into a room full of other women who are positive. It just gets back to that, “Look at me, I’m actually positive.” I know I am and I’m not in denial, but when you have to say it to the rest of the world it brings it home that you are and it would be nice .... You just want to float into the community as though you are just like everyone else on the street. That you’re not different, and I know I’m *not*.

Julia was diagnosed while she was working overseas. She did not receive any support or counselling and the only person she told was her brother who was a doctor. He felt it was likely that the result was false-positive and told her, “Oh, don’t worry; a friend of mine got diagnosed and it was bullshit. It wasn’t true and that’s what has happened to you. Don’t tell anyone.” So she did not tell anyone and, as time went on, she too believed the diagnosis to be incorrect. Upon reflection Julia said, “I was in denial, I suppose, for three and a half years, and in that time I’d got myself married and pregnant. So I went off for tests; all the initial tests that they do at another hospital. I had really, really believed that I was negative. So I was diagnosed again.” Later Julia characterised this period of denial as an opportunity to “have a normal life, in that way, with a husband and a child.”

In the remainder of this chapter I consider the role of revising one’s future after the shocking and life-altering effect of an HIV diagnosis. I demonstrate how women were able to revise their lives to include a sense of future as well as, for many, the quest of motherhood. The women in this study were at various stages of their journey through HIV and motherhood. Some women were mothers before their diagnosis, others had completed their motherhood narrative and had children since their diagnosis, some were yet to live out their revised narrative of motherhood or were still in progress, and a few found themselves unable to revise their narratives to include motherhood (or more children) due to their diagnosis.



## **Revising after diagnosis**

Following a life-changing event such as chronic illness, including an HIV diagnosis, a woman is unlikely to ever quite be the same again. This kind of experience will usually result in the woman rethinking her biography and self-concept and she will do this by narratively reconstructing or reinventing herself (Bury, 1982; Denzin, 1989a; Josselson, 1996; Mathieson & Stam, 1995; Williams, 1984). As Arthur Frank (1995: 54) put it, “Disease happens in a life that already has a story, and this story goes on, changed by illness but also affecting how the illness story is formed.”

Kirkman makes the important distinction between revising one’s narrative and making decisions. She points out that rewriting is “not an over-elaborate synonym for making decisions about the future” but rather it implies having to alter one’s goals and sense of who one is (Kirkman, 2002: 67). Being diagnosed with HIV requires constant revision and adaptation of the life journey. Most people diagnosed with HIV assume that the life they had predicted for themselves is lost. The process of revision allows for many people living with HIV/AIDS to revise their personal narrative to incorporate the diagnosis of a potentially life-threatening illness which may involve returning to the life that was intended before diagnosis, or planning an alternate one.

## **Death postponed**

Donna Barnes and her colleagues found that women equated their HIV diagnosis to “a death sentence” (Barnes, Alforque & Carter, 2000:19). Similarly, the women in this study assumed that death was imminent when they were first informed of their HIV-positive status, regardless of the level of professional support they received. Women who were diagnosed pre-HAART were not, of course, given positive or long-term prognoses; however, even after the introduction of HAART the prevailing belief remained that HIV/AIDS was a speedy and inevitable death sentence. Olivia, who was diagnosed in 1998, recalled, “My first thought was that obviously I’m going to die” and Adele also believed, “okay that’s it, I am dead”, despite being diagnosed six

months after the introduction of HAART. With hindsight she knew that, “diagnosis didn’t mean death but I still thought that because I didn’t have all the information ... I still didn’t have the proof; it was only new.”

However, women’s ability to revise their journey from imminent death depended on when they were diagnosed. If they were diagnosed in the 1980s and early 1990s and had witnessed the ravaging effects of AIDS on many young Australians infected with HIV, women were more likely to be sceptical of the efficacy and safety of HAART (McDonald, Bartos & Rosenthal, 2001). Women who were diagnosed after the introduction of HAART were more likely to embrace the hope that combination antiretroviral therapy would make HIV a chronic manageable illness, and therefore not unlike other illnesses, such as diabetes, which require considerable health maintenance but a good chance of longevity.

The one thing all women had in common in reassessing the inevitability of early death was the passing of time. Once the initial shock and devastation of their diagnosis dissipated, women were often more willing to consider the future, even if it was in small blocks of time. Adele found herself unable to envisage any future for herself except illness and death. However, as time passed and she became more knowledgeable about HIV and treatments, Adele found she was “more comfortable” with her diagnosis and able to envisage a journey that included motherhood, albeit as a mother who was living with a chronic illness.

### **Wanting to be normal**

Most of the women’s journeys following diagnosis and the assumption of impending death included striving for a sense of normalcy. Essentially this is because she no longer feels normal, so for a time she strives to regain her sense of herself; her sense of normalcy (see also, Crossley, 1999; Schaefer et al., 1999). This can be understood both in broader terms of illness and wanting to continue with the life that was planned but also within the context of HIV, where women suddenly find themselves with a condition that society highly stigmatises. Women who were already mothers tended to focus their attention on their children and tried to minimise the presence and effect of

HIV in their families' lives. Women who were not yet mothers, but who had always assumed they would be, re-focused their attention on this desire and sought ways to achieve it, believing this to be a way of participating in society as a "normal" woman. In pursuing normalcy whilst coming to terms with their diagnosis, women can be understood as attempting to revise their life goals and trying to reframe their sense of self.

A number of studies have identified normalcy as an important attainment for many chronically ill people (for example, Crossley, 1999; Ohman, Soderberg & Lundman, 2003; Schaefer et al., 1999). Related to this theme is trying to understand, or seek explanation, for their illness and ultimately make sense of the illness experience. In striving for normalcy, chronically ill people will often learn to integrate the changes caused by their illness and find new ways to live. For some this will include comparisons of their own situation with others whom they view as being in a more dire predicament (Morse & Carter, 1996; Morse, Bottoriff & Hutchinson, 1994).

The canonical narrative of motherhood in most Western societies in effect encourages reproduction and emphasises motherhood as one of the few valued and esteemed (and attainable) roles for women. Other researchers have argued that babies also represent sources of love, acceptance and a legacy for the future for HIV-positive women (see Ingram & Hutchinson, 1999; Squire, 2003). Most of the women in this study had a profound sense of motherhood. It seemed they had a double sense of finding value for themselves; both as women and women living with HIV.

Having a baby and becoming a mother for many of the women in my study was also linked to restoring normalcy in one's life; having the life one would have always had and being just like any other woman. As Hutchinson and Kurth (1991) put it, "wanting to take a pregnancy to term may spring from her need to assert her 'normalcy' in the face of a diagnosis of HIV-positivity." For many women it was also about asserting control over one's life, future, and body. I would add that because HIV is such an ostracising and stigmatising disease, many women want to relegate HIV to a minor part of their life. Many even try to forget its foreboding presence, albeit for only brief periods of time. Continuing with one's life as planned, which for most included motherhood and having a baby, is part of achieving this goal. Carol

recalled that her diagnosing doctor informed her that she should not have children and should not travel. This left her at a loss as to what she would do with her life. After a short time Carol considered her options and decided she should continue with the life she had planned, and she subsequently had two daughters.

Clare was one of the few women who were not sure whether or not she actually wanted children, and her HIV status complicated this choice. However, being HIV-positive made Clare feel different from other people and she thought that choosing not to have a child might lead to further ostracism:

You feel that maybe you would be more normal if you do have a baby and you will have the whole family thing and people will say, “Why didn’t you have kids?” You feel a bit freaky now anyway that you are not fitting into society, so if you try and do everything you can and have a baby and a family and the perfect house, you will feel more normal.

Other women gave accounts in which they attempted to normalise their HIV infection in an attempt to reduce the stigma that they perceived or had experienced (stigma is explored in Chapter 6). Some women compared it to cancer, others to diabetes or asthma. Adele claimed that she was “luckier than someone who has got asthma or who’s got diabetes.” She said that she worked with someone who was required to test his insulin levels several times a day and, because of the burden of this testing, she felt “luckier than him because that’s treatable but it never goes away.”

### **Women who were already mothers**

An HIV-positive diagnosis for women who were already mothers resulted in enormous concern and anxiety as they envisaged their children’s futures as motherless or even orphans. Women took various steps to address these concerns but for many the passing of time was the ultimate comfort, as they survived and their children grew.

Women who were already mothers were more likely than other women to contradict themselves when discussing whether or not they were able to plan or think very far into the future. These women were living in the subjunctive mode, in which more than one possible future was possible. They had constructed opposing accounts of the future, one in which they had limited prospects of a future or longevity and in which illness and death were likely, and another in which they would live to see their children become independent adults. Once again, those women who were diagnosed pre-HAART were more likely to deny the ability to plan very far into the future. However, they did extrapolate on their children's future, which often included their intention to be present at particular milestones or significant events. These women tended to frame their entire sense of future around motherhood. For many, it was their entire motivation for staying well, taking treatments (when they became available and if they were deemed necessary) and refusing to believe they would succumb to HIV.

### **Motherhood becomes a possibility**

For the remainder of the women in this study who were not mothers when they were diagnosed, time allowed them not only to revise their belief that their diagnosis was a death sentence, but also to revise their future journey (to varying degrees), which for many included the quest of motherhood. Revising their future to include motherhood for most of the women in this study was often influenced by the availability of antiretroviral treatments, which could dramatically reduce the risk of vertical transmission. Layla was diagnosed in 1991 and was told that the effects of pregnancy on her health were unknown. She was therefore advised not to have children. However, once she became aware of the 076 trials she began to reassess the possibility of motherhood:

A few years later, in 1993, I started reading about a study on using AZT during pregnancy. I went and saw my doctor about it. I think I'm very lucky to have a doctor who's in touch with a lot of this information fairly quickly. So my partner and I discussed the possibility and I read up as much as I possibly could and we decided that we would try and have a child.

Viral load tests also provided women (and their specialists) with a clearer sense of disease progression and it soon became apparent that viral load was directly related to vertical transmission. Most women discussed their viral load in relation to perceived “risk” of vertical transmission. Carol’s decision not to take treatment during either of her pregnancies was based on her low viral load. (Carol’s story is covered more fully in Chapter 5.) Brooke, when trying to decide whether or not to proceed with a pregnancy, thought that she “should have a blood test and find out what my viral load is and my T-cell count and that will determine whether I will have the child or not.”

However, despite the availability of HAART, many women were still informed when they were first diagnosed that pregnancy was something they should not consider. Despite being distraught by her diagnosis, and even told by her doctor that she should focus on her health and not on having a baby, Stephanie refused to abandon her quest. Stephanie started looking for information from other states in Australia and found an article about a woman with a similar clinical profile to hers who had given birth to a healthy baby. She took this article to another doctor, who agreed it was possible for Stephanie to have a baby.

However, not all women gave up the possibility of motherhood, even in the absence of treatment. Several women in this study decided to have a baby before treatment was available and the results of the 076 trial demonstrated a reduction of vertical transmission. Miranda gave birth to her first baby in 1992 and believed she was the first positive woman in her state to do so. Miranda’s husband, who was also HIV-positive, asked Miranda if they could have a child together. At that point Miranda “didn’t think it was possible” so she decided to talk to HIV specialists and other positive women. Eighteen months later Miranda became pregnant because she “felt that if I was going to have a child, I wanted to do it early so I’d be around longer.”

Even a couple of women who were diagnosed in the era of HAART did not interpret the risk of vertical transmission without the availability of HAART as a barrier to pursuing their quest of motherhood. Nicola was eight months pregnant at the time of interview. She had suffered two miscarriages on her journey to motherhood (one before diagnosis and one since diagnosis) and Nicola’s desire to become a mother was

something she believed would not have been influenced by HIV, despite the availability of treatments:

It is great that the treatments are there for me but I definitely think that, no matter what, I would have still tried to have a baby. I don't think I could not, because I think the worse thing you can ever do is have regrets. But then if you're just going on advice, and the advice available at the time was not to have children, well, what can you do? You put yourself in the specialist's hands, but I suppose I've come along at a good stage; it has been around 20 years before I was diagnosed.

Nicola went on to say that she would definitely have more children. She hoped there were "no complications with the virus" but said "I don't think that would even stop me." Nicola had considered the possibility of her child being HIV-positive and thought that even if this eventuated, medical technology could provide solutions:

I don't think it's a death sentence now and because medications are getting changed and updated and they are researching all the time. I was thinking about it the other day, the 2% chance that I have a child that's positive; it's not a death sentence.

Similarly, Carol, who was told when she was diagnosed that she should not get pregnant, also believed she would probably have pursued motherhood despite the risk of vertical transmission. She remembers being told when she was pregnant that, without any medical intervention, the transmission rate was estimated to be around 25%:

And that blew me away. I said, "Is that all?" Because I thought, I had to plan on having a positive baby, from all the hype I had heard in the general public. I said, "Oh I thought it was like more than 50."

Two women, Layla and Kate, who had children in the first couple of years after they were diagnosed, reflected that knowing less about the risks of vertical transmission made the decision to have a baby slightly easier. When Layla spoke of her first pregnancy, she thought that not being well connected to other people living with HIV and not knowing a great deal about HIV and vertical transmission were beneficial. “Looking back on it, I read as much as I could, but I didn’t know a lot about HIV. I didn’t know much at all then and I think it’s probably a good thing because there was less to be concerned about.” Kate also had her only daughter a few years after she was diagnosed. She too thought the decision to continue with her pregnancy was made less difficult by several factors, including her limited knowledge about HIV and vertical transmission, her young age and what she referred to as her naivety – she was 21 when she had her daughter, and did not know many other HIV-positive women at the time. Kate went on to say, “I think perhaps my age sheltered me from the harsh reality.” Ignorance was seen as beneficial to this journey because it helped reduce their anxiety.

Layla describes her first and second pregnancy as very different experiences. Whilst her first pregnancy progressed without incident, early in her second pregnancy she experienced some vaginal bleeding, which was diagnosed as a “suspected” miscarriage. Along with her increased knowledge of HIV and vertical transmission, this led to greater anxiety:

I felt like after that I could never really enjoy the pregnancy; that I couldn’t invest too much in it, in case things didn’t go well. And, funnily enough, I was more concerned about the baby’s status this time, even though I knew that the infection rate was much lower than it used to be. It was suggested that I start antiretrovirals as soon as I found out I was pregnant, but I wanted to wait until the end of the first trimester before I started, just in case there were any problems. So even though I had all that information and I knew that there had been no positive babies born to women who’d been on treatments, for some reason I just had greater fears for this pregnancy.

As revealed by Layla’s account, the women’s anxiety about vertical transmission tended to increase the longer they had been diagnosed which, in part, was due to their



increased knowledge about HIV and the suffering of others from AIDS that they may have witnessed.

## **HIV, motherhood and uncertainty**

Many HIV-positive people find themselves living with various possibilities for their future, due to the uncertain nature of HIV disease progression, including the many years of asymptomatic disease and the changing landscape of medical treatment. Others have referred to this as being in the subjunctive mode (Bruner, 1986; Good, 1994a; Good et al., 1994; Kirkman, 2002); when one is in the midst of one's illness with an uncertain future in which any one of a range of outcomes is possible.

The availability of combination therapy has led many people living with HIV/AIDS to reassess the future: from impending death to the management and maintenance of a long-term chronic illness. This involves considering the life planned before diagnosis, and balancing various possible outcomes whilst taking into account disease progression and treatment success. Clare had spent most of her twenties thinking she probably would not become a mother because it was not something she "really wanted." Since her diagnosis, she had established a relationship with a man who already had children and now felt that there was no pressure arising from her relationship for her to have a child. Clare was uncertain about her own desire for motherhood and envisaged two equally possible roads into the future:

It's not as if I am with a guy who wants to have a family and all that stuff, because he's been through that and he has still got his kids around him. But I do feel that I am at the age that all my friends are having babies and we're all 30 now and I am just getting that biological clock ticking thing or whether it is society saying I should have babies. And my parents want grandkids, and I don't want it to be me and my boyfriend growing old together and that's it. But then the whole HIV thing: that's the other part of it all.

## **Women who might have more babies**

A few women in this study considered alternative possibilities as to whether they would have any more children. All of these women expressed a desire to have at least one other child in their family, but many also struggled with the uncertainty that lay before them, not only in relation to their own health but the idea that their next baby may not be as fortunate in avoiding HIV. Sarah described this concern as “playing with fate. ... The fact that from two positives [parents] came Lila, who is a negative.” Sarah interpreted her lack of awareness of her HIV status as ultimately the reason for her daughter’s existence, because she had asked herself:

Would we have decided not to keep the baby had we known at the time of my pregnancy that we were both positive? So sometimes I think she was really meant to be here in the fact that things may have been very different had I known. It might have been too nerve-racking to go through with the pregnancy.

Sarah went on to say that she and her partner had talked about having another child and that, although she felt there were many reasons why they should not, if she were to find herself pregnant, “I honestly don't know if I could get rid of the baby in the fact that I have had one grow inside of me now.” Although she frequently acknowledged her gratitude for Lila’s presence in her life, as well as for the fact that her daughter was HIV-negative, Sarah still felt “cheated” from having more children due to her HIV status. Whilst Sarah believed she may well have aborted her first pregnancy if she had known she was HIV-positive, the love that she felt for her daughter made her rethink this possible course of action should she find herself pregnant again.

Several women spoke of the stress and anxiety they experienced during their pregnancy. Whilst they yearned for another baby, they were doubtful about whether they could go through it all again. The anxiety did not end with the safe delivery of their baby. All women recalled the anxious wait after the birth while the baby was cleared of HIV infection. Stephanie said, “It was very stressful until we knew he was free of everything.” However, most of these women continued to live in the

subjunctive mode. As Stephanie put it, “But the desire for another baby surfaces regularly. So I think I will wait a couple of years and then decide again if I will have another baby or not.”

### **HIV is an overwhelming barrier**

Any risk of vertical transmission, as well as the uncertainty of their own health and longevity, was too much to bear for four women, despite their yearnings to become a mother (or have another baby). These women’s accounts did not contain elements of subjunctivity; rather, HIV was presented as an overwhelming barrier to a future baby. HIV as a barrier to having a child was not restricted to women diagnosed pre-HAART, although women who had been diagnosed for longer were wary of how much time they might live. Even with the use of medical intervention to reduce the risk of vertical transmission to less than 1%, a few of the women did not view this as an acceptable risk. For a couple of women, the anxiety of having to wait so long to know their baby’s HIV status was thought to be too difficult to endure. A few women felt that being a mother whose health status and longevity was uncertain, as well as the use of medical interventions in pregnancy such as caesareans and treatments, were uncondusive to their ideal of motherhood.

### **Women who wanted more children**

HIV infection presented an overwhelming barrier to completing the family they envisaged for eight of the 12 women who already had children. Despite the reduction in vertical transmission over the years, for some women any risk was too much risk. Helen “would have liked more children but I wouldn’t now.” For Helen the risk of vertical transmission was just too great:

I just don’t think it’s fair because of the chance of it being positive. ... The fear of it is just overwhelming but, on the other hand, too, I suppose, if I think it’s that bad, I would have either had my tubes tied or I would have

made Brian go have the snip. But no, I still would prefer not to [get pregnant], although I would love another baby. But I wouldn't. I just know I wouldn't. I would be too scared.

Many women spoke wistfully of the children they might have had, had they not contracted HIV. Some women had intentions that included "a brood" of children. Faye said, "When I was young I wanted to have six children"; Julia and Polly both said they wanted five children. Some women factored the length of time they had been HIV-positive when deciding not to have the additional children they desired. Kate's husband, who "wanted a brood", started "showing signs of being fairly well ... and had overcome a few major illnesses." Kate found herself "very reluctant" to have another baby because she expected her own illness to progress during her journey:

A part of me would have loved to have had another child but the other rational part of me was like, well this doesn't fit the picture. And the rationale that I had for making that decision was around, if I have a child now, I have been diagnosed for that many years, the likelihood of me getting this child to adulthood is very minimal, so that is what I based my decision on. I thought, I don't want to leave a parentless child at a young dependent age, I suppose.

Julia was one who was concerned about the medical intervention required to reduce the risk of transmission. In particular, she was "nervous" about having a caesarean. She, like the other women, had already experienced the months of waiting to find out her child's HIV status and was reluctant to have to experience again the worry and months of wondering, "Are they going to be positive?"

The loss of not having more children was represented by a couple of women as a loss for the child they did have. Leanna was 25 years old when her first child was born and 28 when she was diagnosed. Evident in Leanna's account was how her diagnosis disrupted all of her intentions, which affected not only her own desires to have more children but also robbed her child of the chance of siblings:

The other way that I think that he really missed out was that I always planned to have other children and from, like I said he was only three and a half, and it was around about the time that I was considering having another child. ... We'd bought a house; we basically thought we had our life just beginning.

HIV was not the only consideration in the decision to have more children. Like other women in society, some women in this study had other concerns such as their age or relationship status which could also present a barrier to having another baby. Monica was influenced by her age, as her only child was born when she was 36. She had started to believe she was never going to achieve her quest of motherhood and she described herself as, "very lucky" to have had one child:

When I had my baby I felt I'd never want another baby; she was perfect and I could never love anyone else. Now I'm starting to feel, not so much I want another baby, but I'd like a sibling for her. But because I'm 40 and single it makes it tricky! And HIV: I mean, it all just adds up. I don't consider it completely impossible. I could meet somebody tomorrow and it could all just happen, or it might not. I just think it would be nice for her to have a sibling, but it could also happen that her father might have a baby with someone and give her a sibling that way. So it's something that I don't dwell on and I don't freak out about, but I just think about. It would be nice.<sup>8</sup>

Adele also had not completed the family she had intended and she empathised with women who were diagnosed without children. "It would be tough to have been diagnosed without any children. I have asked myself the question of whether I would do it now because I always wanted two children." Adele had become pregnant a second time before she was diagnosed, but she miscarried. After separating from her husband, she looked into "maybe using a donor to have another child. But then when I was first diagnosed I thought, no that is it, and since then I think there have been two incidences where I got really clucky and I thought, oh I would love another baby."

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<sup>8</sup> Monica sent me a note with her second consent form saying that she was pregnant again and had "managed to fulfil my dream."

Since being diagnosed, Adele had explored the risks of vertical transmission, but having turned 40 just prior to her interview, she described herself as “past that!” Despite yearning for a second baby on several occasions, Adele was able to find consolation in having one child who was past the infancy stage. She also described turning 40 as a “milestone” most probably because she was still well after living with HIV for more than five years; Adele was no longer subjunctivising about motherhood. It is also likely that she, like other women in this study, viewed turning 40 as the point at which motherhood was no longer a possible route and one path could now dominate her future journey.

Celia had given her baby up for adoption when she was much younger but assumed she would have more children. However, once diagnosed with HIV, she decided motherhood was no longer an option. Celia found the risk of having a positive baby too much to bear. Celia did get pregnant in her late thirties, but terminated this pregnancy. She attributed this decision to a number of factors, including the lack of support from the man with whom she was in a relationship, the reaction she believed her family would have had, and her anxiety around vertical transmission:

I only married Brian in 1999. I met him after I came back from overseas and I guess sometimes I think to myself it would have been nice to have a baby, but I am 43 now and I think to myself, no, that’s too old. But even discounting that, I block it out because I couldn’t live with the thought of having a baby and having that baby have HIV.

It was not uncommon for women who had only recently had their first child to feel that they would be “tempting fate” or “pushing their luck” to try to have another baby. However, with the passage of time, some women were able to reassess this possibility. Layla recalled thinking after the birth of her first child, “I was so lucky and I didn’t want to risk it again, in case I wasn’t so lucky. That one beautiful child should be enough, really.” However, Layla’s desire to have more children regularly surfaced and, nearly seven years later, she gave birth to her second child.

## **Finding benefit in adversity**

Other researchers have noted the importance of finding benefit in adversity for one's well-being and chance of a satisfactory life (Kermode, 1967; Kirkman, 2002; McAdams, 2003; Mendola et al., 1990). Kermode (1967) referred to a consoling plot as one that allows for the interpretation of adversity in a way that makes it bearable. The women in this study also framed their decisions to not have any more children around their "luckiness" of having one or two negative children and "not risking" having any more should this luck run out. Julia said, "So I've got one and he's really just wonderful, so I think in that way I'm extremely lucky." Joy was pregnant twice after she was diagnosed but said she was unable to proceed with the pregnancies, deriving consolation from having two negative children:

I thought I was blessed with having two kids that were negative and I just didn't want to take that risk of having a baby born with HIV. It would have just destroyed me. So when I weighed it up it was probably easier to have a termination.

Mothers of only children who had planned to have more than one child harboured some concerns for their child as an only child. They worried about their child being lonely and having to endure the burden of having a parent (or parents) who was HIV-positive. Julia found a way to address what she believed was her son's loneliness through regular access to his cousins. Her son had asked her to "buy a baby for him." Julia said they call his cousins "brother and sister," so that when he "feels very hard done by, I tell him how he's actually got seven and that helps a lot."

## ***Women without any children***

Of the six women who did not have any children, three (Rachel, Yvette and Isabelle) interpreted their childlessness, or decision to remain childless, as resulting from their HIV status. Despite the advances in medical treatments and reduction of the risk of vertical transmission to less than 2%, HIV remained a barrier to motherhood and these women described the multitude of factors that presented a barrier to motherhood.



Rachel could not see a future with children now that she was HIV-positive. The uncertainty of her future as a woman living with a potentially life-threatening illness eliminated motherhood from her future journey:

I'm 31 and I'm in a good relationship, so if it weren't for the HIV I probably would think about having kids. But because of the HIV I think, no, it's too hard. ... If it wasn't for this I probably would. I'd definitely be thinking, yeah, let's have kids. ... But it just seems too complicated and a bit disadvantageous for the child, too, ... later on in life, if parents do die younger than they might have otherwise. I mean a friend of mine, her parents died when she was in her early twenties. And even though she was an adult, it was still really devastating for her.

Rachel explained her decision to remain childless as beneficial to her health as well. She was concerned about the demands of motherhood and the impact that it would have on her health and she was resistant to the amount of medication intervention recommended for HIV-positive pregnant women:

I guess I think, oh yeah it would be nice. But no, I know the reality of it too well. In my early twenties a girlfriend of mine had a child and the reality is really, really hard, especially with the HIV. I just think, oh gosh. Looking after your own health as well and just so many questions come into it, ... like being on treatments including the impact that they would have on the baby. Not being able to breastfeed a baby and the baby having to be on prophylactic medications for quite a while. Plus having to get the tests and not knowing for a couple of years and the *very* slight chance of the baby being positive.

Yvette was the only childless woman who described her diagnosis and subsequent loss of motherhood as devastating. Yvette explained the reasons for her decision not to have children as threefold: the advice she was given when she was diagnosed, her prognosis at that time and, more recently, her age. However, Yvette still felt a

profound sorrow despite interpreting childlessness as her choice. “I have still elected not to have children but I feel very ripped off. Hide the tissues!”

Yvette was diagnosed in 1986 at 25 years of age. There were certainly no treatment options for the mother or the baby, and women were strongly advised to avoid getting pregnant or to terminate any subsequent pregnancies. Despite advances in the reduction of vertical transmission, Yvette thought her age became an additional barrier to her dream of becoming a mother:

By the time treatments became available to reduce transmission from mother-to-baby I was also diagnosed with hep C. I was also a lot older and I had been positive for a lot longer. So I still had the attitude that it was good that I will live longer and I had a positive outlook for the rest, but you think, well, the longer I live, then is the lifeline getting shorter? And it is okay for the ones coming up because they have got 10 years to go. But there was still the decision based on, well, if my health does go down, who is going to look after my child? And, because I was older, I was thinking, do I really want to have my first child at 37?

Yvette was 40 when I met with her and aware of additional risk factors in pregnancy to consider. She said to me, “Do I want to have my first child at 40 and it’s not only HIV but also other possible deformities the child could have which is a risk for women anyway, especially older women?” Yvette envisaged a time when her age would eliminate the choice and motherhood as an alternative route would finally be blocked; however, this was not something she viewed with equanimity:

I am very pleased for women today but I am just pissed off and ripped off and jealous – that’s all! Perhaps if I was 60 I wouldn’t feel that because I would be past that child stage but because it is right at that time when women, at 40, start to think the clock has nearly finished ticking so if I am going to do something I will have to do it quick. And I have had that thought but I don’t want to get wrapped up in that ‘because of the clock ticking’

thing. I need to look at my whole life, not just the issue of having children. But I am pleased for women today and I am a little bit sad, too.

Isabelle had also decided to remain childless. Whilst Isabelle felt some sadness about her decision, she understood this decision as more complex than just being HIV-positive. Prior to contracting HIV, Isabelle had been in a couple of long-term relationships, “where I thought about having kids if we had actually gone on to get married.” However she was 38 years old when she was diagnosed in 1992, “so there were a number of other factors already that made it unlikely that I would become a mother.” Isabelle’s career was an important part of her identity and she explained that having children would have required her to make sacrifices in relation to her career:

So there were so many things that kind of added up against motherhood for me. I mean I still kind of think about it. I guess by the time I was diagnosed one of the things that made me go for a test was that I’d already achieved a lot in my life and I travelled and lived overseas and I could be pleased that I’ve achieved a lot. I wasn’t sure if I could lose that kind of freedom to continue doing that for the sake of a child, or whether I would resent that, because I mean that is a 20-year period. It was hard.

Rachel, Yvette and Isabelle all talked about achieving other things that they would not have been able to do with a child in their life. For example, career advancement, travelling or working overseas, volunteer work, and a life in which the focus was on the individual and her health. Yvette described some of her friends’ children as, “the kids I am not going to have. So I spoil them and all that but it is still not the same.” However, over the years Yvette had revised her plans and life goals and now she narrated her present and future in terms of all that she can achieve because she was childless:

In some aspects when I am travelling or like today someone said to me when I was telling them all of the things I’ve got coming towards the end of the year, “How can you do all that?” I said, “Because I don’t have a boyfriend and I am not married and don’t have kids.” So one part of me has got used to

the life and thinks would I really want my life tied down with kids? But the other part of me thinks I am missing out on so much. And when I do public-speaking I say there are a lot of women out there who can't have children for a whole heap of reasons but they have a lot more choices and that's the big difference.

### ***Meaning-making***

Much has been written about meaning-making in chronic illness (Charmaz, 1991; Goffman, 1974; Kleinman, 1988; Mattingly, 1994a; Nelson, 1996). The women in this study found meaning in their HIV diagnosis as a “wake-up call” or an opportunity to embrace life fully. Rachel believed herself to be “directionless before HIV” and had changed her attitude to life, saying she did not “take it for granted.” She viewed her life post-diagnosis as a “second chance” to really appreciate life. A few women described pursuing interests they had previously delayed or been unable to find time for. Helen, assuming she would be dead within five years of her diagnosis, found herself thinking, “Where’s that list of things that I wanted to do?”:

I’ve always wanted to learn and play the saxophone and I was vacuuming out the car one day and I thought, right, that’s it. I just turned everything off, went upstairs and looked through the phone book and found a number to ring. Got on to them; about two days later or something, I went and bought a brand new saxophone, joined a band, and I’ve been playing for the last two years!

Isabelle said she found relief knowing that her “biological clock had kicked on” and that she no longer had to make a decision about having a child. She also found consolation in the things she could do as a childless woman, which included advocacy work for positive women:

I’m glad now at the moment that I don’t have a child, because of things I wouldn’t have been able to do, like my post-grad studies. I wouldn’t be able to get much more involved in Pos Women, as I have been, and I actually

want to increase my involvement more in terms of things like advocacy and education. If I had a child, and particularly if I was a single mother, I just couldn't do it.

### **HIV is not a barrier to motherhood**

Georgia and Faye were the only women in this study for whom HIV did not present as a barrier to motherhood. Other researchers have found that HIV infection is not a major determining factor in reproductive decision-making and that risks were personally evaluated (Barbacci et al., 1989; Bernstein et al., 1989; Sunderland, 1990; Wesley et al., 2000). The potential loss of motherhood can be shocking for women diagnosed as HIV-positive. Occasionally this potential loss instigates an urgent desire to become a mother (Almond & Ulanowsky, 1990). This was certainly the case for Georgia. When I met with her she was trying to conceive. She had been diagnosed four and a half years previously. Georgia and her partner had tried artificial insemination, she had undergone exploratory surgery in relation to her fertility, and they were about to explore IVF options. Whilst Georgia had not always identified herself as a potential mother, a combination of her age and her diagnosis led to her revising her life goals. In relation to motherhood and her HIV diagnosis, Georgia said:

I guess that your perspective on life changes quite considerably about everything, and I realised what was important to me at the time, which was your friends and your family which are probably the most important thing on earth, especially when you're sick. As you get better, these things do change again. But one of these things was to have a child, and I don't know why, but it was just so strong after that diagnosis and so, ever since then, I've been researching how I can.

Faye had been diagnosed 13 years previously and had one son who was 20 years old. Her first baby was stillborn and Faye had always longed for six children. After the birth of her son, Faye haemorrhaged and had to have a hysterectomy. For years she had concluded that there would be "no more children". But her ovaries were not removed, which Faye saw as promising, "that if I wanted to, I could still have children but it would be a very difficult process." Faye went on to explain to me that whilst she

had not had any discussions with HIV specialists, she did have an HIV-negative friend who was willing to act as a surrogate mother and a gay friend who was willing to donate sperm. Faye said she only had one child because of her hysterectomy and never having met the right man. HIV did not appear to be a barrier to Faye pursuing her desire to have another child, despite the enormous obstacles that she would have to overcome to have another child.

Faye appeared to have little information about vertical transmission and no awareness of the potential for her ovaries to be reservoirs for HIV. I think she participated in the interview because she was hoping to find out whether she would be able to proceed with her plans of surrogacy. At the conclusion of the interview, I told her that I was not a medical expert and that she would need to discuss her plans with her HIV specialist.

## **Summary**

Most of the women who were not mothers when they were diagnosed were able to revise their plans to include children. For many, time played a crucial role as they revised their imagined journey after diagnosis from one of imminent death to one that could include children and some sense of future. The influence of the canonical narrative of motherhood was evident in the women's accounts as they described having children and becoming a mother, as representing a "normal" life.

The women who were already mothers before diagnosis mostly found themselves unwilling to "tempt fate" or "push their luck" by having additional children. Consequently, many women did not "complete" their families with the number of children they had intended prior to being diagnosed. These women experienced complex feelings of gratitude and loss. A few women were in the subjunctive mode considering various possibilities for their future; motherhood was one of those possibilities. Those women who were unable to revise often felt cheated, but most were able to find consoling plots which helped lessen their grief.

The journeys of women who have pursued or considered motherhood since the PACTG 076 protocol are usually also shaped by the inclusion of clinical markers, antiretroviral treatments and medical intervention in the prevention of vertical transmission. The following chapter considers the role of medicine in the prevention of vertical transmission and how women incorporate (and sometimes reject) the medicalisation of the HIV-positive pregnant woman.

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## Chapter 5

### *Mothers and medicine*

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Despite medical advances reducing the risk of vertical transmission, HIV-positive women's desires to become mothers have continued to meet opposition because they clash with what society deems to be a suitable or "good" mother (McDonald, 2002, 2006d). This opposition comes not only from the woman's own network of family and friends but also from health-care professionals. Levin and colleagues (cited in Kass, 1991) interviewed 247 neonatal health-care workers when the risk of vertical transmission was approximately 30% and found that 65% of those interviewed believed that HIV-positive woman should avoid pregnancy. Comparably, only 25% thought pregnancy should be avoided when the risk of disease was Tay-Sachs, and 15% when cystic fibrosis (Kass, 1991; Williams, Watkins & Risby, 1996). This was at a time when HIV/AIDS was almost certainly a death sentence for both mother and child; however, the prognosis for a baby born with Tay-Sachs disease was also a certain death sentence by the age of five. Kass (1991) suggests the most likely explanations for the difference in attitude were the inevitability of the mother's future illness, the threat to public health posed by HIV/AIDS, and the fact that, in the United States (where the study was undertaken), HIV/AIDS affects mainly minority and socio-economically disadvantaged women.

The introduction of the 1994 PACTG 076 protocol demonstrated that vertical transmission of HIV from mother-to-baby could be significantly reduced by a three-part Zidovudine (AZT) regime. This protocol resulted in the increased role of medicine in the management of HIV-positive pregnant women. The additional benefits of HAART and its role in reducing vertical transmission, introduced in 1998,



only served to increase medical intervention in the pregnancies and deliveries of HIV-positive women in Australia.

This chapter explores the women's accounts, as women with HIV, of their quests to become mothers and their journeys from conception to birth and beyond. I examine the women's interpretations of the protocols recommended to reduce the risk of vertical transmission. I also explore women's encounters with the medicalised construction of a woman with HIV, and the extent to which individual women position themselves within or outside this construct.

Researchers have previously identified the differences between health-care professionals and their patients' ways of knowing and understanding illness (Bell, 1988; Frank, 1995; Good, 1994a; Kleinman, 1988; Rudebeck, 2000). Elliot Mishler describes the two voices present in the medical consult which he called the "voice of medicine" and the "voice of the lifeworld" (1984: 90). The voice of medicine represented the biomedical model or the medical perspective, whilst the voice of the lifeworld referred to the patient who sometimes talked about problems in their lives that resulted from their illness. Mishler says there is sometimes a struggle for control between these two voices, but typically the voice of the lifeworld is suppressed whilst the voice of medicine acquires dominance.

After Stephanie was diagnosed, all she could think about was her dream to become a mother. She told me that she frequently asked her diagnosing doctor about the possibility of having a child but that her doctor always gave her the same response: "No, just concentrate on your health and forget about it. No, no, no". Layla recalled being very frustrated by her obstetrician, believing that he was judging her as irresponsible:

I was really upset by the way I was treated. I think he had decided because I was positive that I must be a junkie mother. I felt that the whole time I saw him during that pregnancy he was judging me and not listening to things I wanted because he knew better than me which frustrated me.

## **Justification**

Justification is intrinsic to narrative. The protagonists not only recount their story but also justify their actions as understandable under the circumstances. The rhetorical effect of justification in storytelling has been identified by other researchers and theorists (see, for example, Bruner, 1990; Farmer & Good, 1991; Mishler, 1991b). Justification was evident in the accounts of the women in my study of their decisions to proceed with a pregnancy or to become pregnant, particularly when health-care professionals advised them not to. The rhetorical effect of justification within the women's accounts was to convey to me, the listener, that their actions, interpretations or conduct were correct or necessary (Bruner, 1986; Garro, 1992; 1994; Kirkman et al., 2001).

Like many of the women in this study, Layla spent the first couple of years after her diagnosis devastated by the thought that she would not be able to have children as she had intended. After hearing about the 076 study and gathering information about it, she and her husband decided they would try to have a baby. She explained to me that her decision to become pregnant was careful and considered, as she “read up as much as I possibly could” and had “put a lot of time and thought into the pregnancy. It was extremely important to me and I wanted to do everything I could to make it the best it possibly could be.”

## **Medical technology and clinical markers**

In the accounts that most women gave, clinical markers and medical technology were utilised to support their justification to have children. These included low viral loads and/or high CD4/T-cell counts, the availability of treatment, caesarean sections and avoidance of breastfeeding. For more than a decade after HIV was first identified, the only way of assessing disease progression was the CD4/T-cell count. Prior to the 076 protocol, many health-care professionals advised women not to get pregnant or to have abortions if they did. Despite this, some women proceeded with their

pregnancies, often explaining to me that they had a high CD4/T-cell count and therefore believed they had limited immune system damage. A couple of women told of investigating interventions being used overseas in the hope that their specialist would employ any such techniques to reduce the risk of vertical transmission.

Sophie's pregnancy was discovered before the 076 protocol and at the same time as her diagnosis with HIV. Her diagnosing doctor recommended she terminate her pregnancy but Sophie chose to continue. Central to her account of her decision to continue with her pregnancy was her high CD4/T-cell count, the only clinical marker then available to monitor disease progression:

We went through all the pros and the cons and how I had only recently acquired it and how my T-cells were better than the average person's and my health was just A-1 and they said my chances of having a positive child would be one in 27 or something around that.

In addition to the use of CD4/T-cell counts to monitor disease progression, viral load testing became available in 1996 and was soon identified as playing a key role in the risk for vertical transmission (CDC, 1998, 2006a; Perinatal HIV Guidelines Working Group, 2006). The women who had considered motherhood after the availability of viral load testing usually gave accounts of deciding to become pregnant or continue with a pregnancy that included "a low viral load". As more information became available about the role of the mother's viral load and CD4/T-cell count, as well as the role of antiretroviral treatment in vertical transmission, women's accounts gave greater significance to test results and the availability of treatment. Stephanie was encouraged to pursue her quest of motherhood when she read about another woman "who had similar health conditions ... the same viral load, similar T-cells ... similar age ... She had a baby and the baby was negative." Because this other woman had a similar clinical profile and had given birth to a healthy HIV-negative baby, Stephanie utilised what Goffman referred to as an "exemplary moral tale ... illustrating a desirable code of conduct" (1963: 37) to explain to me that her decision to become pregnant was based on sound knowledge that could result in a healthy HIV-negative baby.

The women in this study were very aware that others in Australian society deemed HIV-positive women to be inappropriate candidates for motherhood. By using medical technology and clinical markers they presented themselves as women who had taken all possible steps to behave virtuously. By incorporating viral load, CD4/T-cell counts and ARV therapy, the women justified their decision to proceed with a pregnancy or their intention to become pregnant was one that was well-considered, well-informed and therefore deserved.

### **Persuading others**

Even with the knowledge that medical intervention could significantly reduce vertical transmission, some women found that friends and family who knew of their HIV status still did not react positively to their pregnancy. Layla reported experiencing a number of very cautious reactions to the news of her pregnancy, which she believed was because people assumed her pregnancy was an accident. Consequently, she told people, “I am pregnant and I’m really happy about it”, explaining that it was “so that they could react in the way they should.” At one point her family made decisions that affected Layla and her husband without consulting them:

My family were really shocked about my decision and weren’t very supportive. They were concerned that the impact on my health would be too great. I found out after I had the baby that they had had a family meeting about who would look after the baby when I died, which would have been nice to include me.

Not all women felt they would be able to justify their decision to family and friends. Two women, Isabelle and Celia, included their families’ disapproval of HIV-positive women becoming pregnant as influential in their decision not to have any (more) children. A few women avoided this scenario by not disclosing their HIV status and one woman, Miranda, opted to lie about the conceptions of her sons to her family and friends who knew she was HIV-positive, describing her pregnancies as “accidents”.

Miranda thought people would find an accidental pregnancy more acceptable than a planned one.

## **Conception**

Planning the conception of a baby was often complicated for the HIV-positive women in this study. If she and her partner were serodiscordant (he was HIV-negative), the woman had to consider the risk of HIV transmission to her partner. If she and her partner were seroconcordant (he was also HIV-positive) there was risk of superinfection, including the possibility of sexual transmission of treatment-resistant virus. As Clare put it, “It’s not just ‘Go out and have a nice romantic dinner and have sex.’” Conception for Clare and her partner was complex, not only because her partner was HIV-negative but because he had had a vasectomy:

I don’t want to have unprotected sex with him, because it would just kill me if he got it. So do you reverse the vasectomy ... and then ... turkey-baste? I don’t know how it all goes; or can you just take his little spermies and then put them in me? ... It doesn’t seem worthwhile for him to have his vasectomy reversed.

## **Serodiscordant couples**

Eight women in my study deliberately conceived 11 children with HIV-negative partners by having unprotected sexual intercourse. For some of these women, condom use was fraught with difficulty within their relationships; their partners often refused to use them. When she was first diagnosed, Brooke and her partner, Simon, “gave condoms a try but he hates them”, and so now they never use them. Carol stopped taking the contraceptive pill after she was diagnosed because she assumed that she and her HIV-negative husband would use condoms. Despite being told by her doctor

that she should avoid pregnancy, their condom use “started to dwindle off” and she became pregnant, which was “great news.”

Miranda and her partner conceived their child “naturally.” Miranda had a caesarean section, during which she had a tubal ligation. With pregnancy no longer a risk, she and her partner “occasionally” had unprotected sex, despite the risk of HIV transmission. Miranda interpreted these episodes as informed decision-making on her partner’s behalf, but she still worried about them. From her account, it seemed unlikely that unprotected sex was entirely pleasurable for her:

I just lie there and just think, oh my God, what if, what if? But he’s a grown-up and that’s his choice and I say to him, “Well that’s your responsibility. If you get HIV, it’s not my fault, so don’t say that it is, because it’s not. I’ve asked you to wear a condom and you don’t want to wear one and you still want to have sex, so that’s your responsibility.”

Miranda justified these acts of unprotected sex by demonstrating that she is doing the best she can. She has requested that her partner wear a condom and expects him to accept responsibility for protecting himself against HIV.

The few women for whom condom use was not a regular feature of their relationships felt they were able to live with the “small risk” to their partner of unprotected sexual intercourse. They all interpreted their partner’s willingness to participate as “informed decision-making”. Many of the women’s accounts included stories about their partners being tested either regularly as a precautionary measure, or after they achieved pregnancy. Some women also told of their partners’ reluctance to participate in regular testing and their need for “convincing”, which was often explained as providing peace of mind for the woman. Despite most doctors advising against unprotected sex because of the risk of HIV transmission to the negative partner, women were generally aware of the smaller risk of transmission from woman to man than vice versa. Janice said that they got pregnant “by doing it the old fashioned way”. She understood this to be a low-risk act “because my viral load had got so low and everything. It’s quite a lot harder to give it to a man than a woman.” She also said that she and her husband talked about it “all the time, and he has his tests every six months

to make sure he hasn't got it. Touch wood: so far so good. But it just gets so frustrating having to use a condom every time.”

### **Artificial insemination**

Only two women, Georgia and Stephanie, spoke of an intention to conceive a child with their partner by artificial insemination. Stephanie gave a detailed account of discussing artificial insemination with her doctor and agreeing they would try this method. However, after 10 days of ultrasounds to monitor her ovulation, Stephanie and her husband “abandoned the syringe and had normal sex.” She justified this by emphasizing that, apart from this one episode, they were always responsible: “This was the only time we had done this since finding out I was positive, before or since; and it worked.”

Georgia did attempt artificial insemination at home with her partner. She also tried temperature monitoring, ovulation kits and the Billings method: without success. “You name it; I’ve tried everything.” She and her partner then decided that the risk to him of contracting HIV via unprotected sex was “10,000 to one” because Georgia’s viral load was “undetectable”. So for a couple of years they had been having unsafe sex when Georgia was ovulating and using condoms when she was not. At the time I met with Georgia, they had still not achieved a pregnancy. After recent exploratory surgery to investigate her fertility, she had just begun to consider assisted reproduction.

Despite both women being very knowledgeable about their ovulation cycle and receiving considerable assistance from their health-care professionals, neither had managed to conceive this way. Both women had opted to conceive “the old-fashioned way”. Their rhetorical justification was evident when they stated emphatically that they “only” had unprotected sex at the times it was likely they could conceive and that they used condoms at all other times.

## **Seroconcordant couples**

Four women (Kate, Nicola, Miranda and Denise) were in seroconcordant relationships when they had decided to have a baby. Miranda and Denise both had their babies before treatment was available or before it was known to reduce the risk of vertical transmission. At this time few people were on treatments and little, if anything, was known about viral super-infection (the possibility of being infected with a different strain of HIV). Similarly, at the time Kate's baby was conceived, neither she nor her partner was on treatment and they did not use condoms. Both Kate and Denise were using illicit drugs at the time their babies were conceived and neither expected to get pregnant.

Nicola and her partner planned her pregnancy and their first child was born in 2001. Despite having the same serostatus, Nicola and her partner ordinarily practised safe sex to avoid transmitting viral resistance to treatment, because Nicola's partner was on antiretroviral treatment and she was not. Nicola explained how they "had to get our timing right" to avoid having a lot of unprotected sex. She went on to say:

With the unprotected sex, it sort of worries you at first but then you want the baby more, so it is a trade-off and it really does get pushed to the background. You stop thinking about, well what can I get from him? I mean, I've already got what I don't want! Anything else is just nothing now. And I got pregnant easily, no problems there.

All of the babies conceived by the women in this study resulted from having unprotected intercourse despite the risk of HIV transmission to HIV-negative partners or the risk of super-infection for seroconcordant couples. Several women in this study who engaged in unprotected intercourse despite the serostatus of their partner justified it with accounts of informed decision-making, "undetectable" viral loads, and the lower risk of transmission from woman to man.

## **The role of treatments during pregnancy**



The 076 protocol recommends that all pregnant HIV-positive women not already being treated begin antiretroviral treatment in the second trimester. Most women in this study expressed gratitude for access to antiretroviral therapy and acknowledged its role in improving health and longevity for many PLWHA as well as in reducing vertical transmission. Their gratitude, however, was coupled with anxiety about the toxicity of the treatments for themselves and potential detrimental effects on the development of their babies.

As the HIV Futures Studies have shown, HIV-positive women in Australia have demonstrated notable scepticism about the efficacy and safety of combination antiretroviral therapy (McDonald & Kirkman, 2002; McDonald, Bartos & Rosenthal, 2001; McDonald et al., 2000; McDonald et al., 1998). Although this scepticism has gradually and slowly decreased over time (McDonald, Thorpe & Grierson, 2005; Thorpe, McDonald & Grierson, 2007), the women in this study were unconvinced and remained wary of antiretroviral therapy. Women tended to frame treatments as experimental and referred to themselves and their children as “guinea pigs”. Many of them described either experiencing treatments before pregnancy or hearing about the (sometimes) debilitating side-effects on other PLWHA. In particular, some women were suspicious about the drug Zidovudine (AZT), and were aware that dosages in the past had led to toxic morbidity and even mortality among some PLWHA. This suspicion has been found in other research with HIV-positive women (Siegel & Gorey, 1997). Brooke, who took AZT during her pregnancy, put it this way: “I’m still a little bit wary of AZT. It’s just got this bad name.”

### **Accepting treatments**

Despite their concerns about the toxicity of antiretroviral therapy and the effects on their bodies, most women reported that they were prepared to take antiretroviral therapy during pregnancy. Women who had already had children in the era before HAART usually embraced the opportunity to reduce the chance of vertical transmission from around one third to less than 8% (depending on when their

subsequent children were born). Miranda's second child was born in 1998 and, despite still worrying about the possibility of vertical transmission, she found the experience much easier, because "When we decided we wanted to have Jack, I knew about all the medication and the triple therapy so I did that, and had a booked-in caesar and it was much better." Similarly, Sophie had given birth to one HIV-negative child and was pregnant with her second child when she heard about the role of AZT in the reduction of vertical transmission and that AZT was about to be made available in Australia. Sophie said that she seized this opportunity to increase the chances of having a second negative baby and immediately contacted the hospital to begin treatment.

Most women revealed that taking treatments was psychologically distressing: a daily reminder of a serious and stigmatising illness. This has been found in other studies of people with HIV (see, for example, Wrubel et al., 2005), as well as people living with other chronic lifelong illnesses such as epilepsy (Conrad, 1985). Most of the women in this study viewed treatment as something to be "saved" for the final stage of the journey when the body could no longer contain the effects of HIV (this is explored in more detail in Chapter 7). To overcome these feelings as well as concerns about treatment and toxicity, some women found it helpful to focus on the outcome of having a negative baby. Monica's account demonstrates how a health-care worker was able to help her put her fears aside:

During the last two trimesters of my pregnancy I was on AZT and Videx (ddI) and one other. They were introduced one at a time, slowly, and I didn't notice any effects of those at all, no side-effects whatsoever. I found it very difficult to actually start the treatment. ... [It] was like a real hurdle because that was almost like admitting that I had it. One of the lovely nurses in the clinic that I would go to, we had a chat and she said, "Well, you know, you're not doing it for you, you're doing it for the baby", and so that's what enabled me to actually start it. So that worked well. I took my last tablet the day before the birth and I haven't taken anything since.

Some women are advised to commence treatments before they conceive and some combinations are apparently safe in early pregnancy. However, if the woman's viral load is not high, treatment commencement is recommended after the first trimester because all major organ growth and brain development has occurred in the foetus by this stage. There is also less risk of the woman developing viral resistance to treatment if she experiences nausea and vomiting during early pregnancy. However, women who have high viraemia are considered to be at higher risk of vertical transmission, so these women may be advised to start treatment before conceiving.

Women worried about the effects the treatments might have on their unborn children. Mary was pregnant when diagnosed with HIV and had commenced treatment while pregnant. She worried during her pregnancy that the treatment "would affect him" and she felt that if she were to have another pregnancy she would prefer to commence the treatment before she was pregnant. She went on to say, "Not that I want to; I don't want to be on medication." Mary's logic contradicts what is currently known about the teratogenic effects of HAART. Her viral load before starting treatment was only 3,000 copies/mL, so high viraemia was not her concern. She was possibly concerned about the introduction of strong drugs to her body while she was pregnant and therefore thought that by taking them before conception, she would avoid introducing potentially toxic drugs to an otherwise "clean environment".

In the context of pregnant women being advised to try to avoid most medications, recreational drugs and alcohol, as well as some foods, it is not surprising that many women worried about the potential for antiretrovirals to harm their unborn babies. In addition, some women expressed concern about the paucity of information of the long-term effects of antiretroviral treatment on babies. Olivia said, "They don't know what the drugs are doing, because the kids are still small. So the girls may be infertile. I don't know." The women in this study each wanted to be the best mother they could possibly be, and integral to this was protecting their babies from harm.

## Rejecting treatments

The potential of antiretroviral therapy to harm their babies was more likely to dominate the accounts of the few women who rejected treatments or part of the recommended treatment regime. Such malign interpretations of the effects of treatment appeared to influence the women's effective use of antiretroviral therapy. For example, Lily said that she had no faith in the treatments either during her pregnancy or for her baby after the birth, and she did not trust the health-care workers providing her with information. She justified her non-compliance of antiretroviral treatment by saying her baby's welfare was foremost in her decision:

Once I knew I was pregnant and that there was only five months of the pregnancy left, there were just really heaps of doctor's visits, heaps of lectures about treatments. Being told, "You've got to do it." They gave me the medicine and I took it home but I wouldn't take it. Because they weren't listening to me; they were just giving it and ordering me to take it. So I was just doing what I was told but not taking it, because they weren't listening, they weren't listening to the refusals, so I just shut up, did what I was told, took it home and threw it out. I did take it for a little while but it made me sick and I told them that, but their attitude was just, "Bad luck." I was saying, "I've got a baby in my body. Look what's it's doing to me – what's it doing to him?" But they weren't listening; they were just talking at me. I was worried that it was going to make him deformed but all they focused on was the HIV. But they couldn't be sure and as far as I knew AZT was a killer for lots of people with HIV and they wanted me to take it.

Carol had given birth to two children as a positive woman since the availability of HAART. She also disagreed with her doctor's advice to take HAART during both of her pregnancies. She had a low viral load, which she continued to monitor during her pregnancies, and therefore decided that treatment was unnecessary for her babies and herself. She said, "During the pregnancy, they respected my decision not to take treatments. They would always re-hash: 'Are you still not wanting to go on treatment?' But that was really about it." Carol believed she was allowed to act on

her own judgement and that the risk of toxicity from the treatments to her unborn children was greater than the risk of vertical transmission:

That's why I didn't go on treatment when I was pregnant. I said, "If it just affected me and lowers the risk because it would lower my viral load, that would be something that I would consider doing, but if it meant that it was already going through to the baby, I just found that too scary.

Polly was living overseas, and was diagnosed at 20 weeks' gestation. Although treatment was advised and available, she decided it was too expensive and preferred to spend her money on "good food" for herself and her growing baby. Despite being told by a doctor about a government agency that supplied free treatment during pregnancy and reading fact sheets on vertical transmission and the recommended interventions, Polly interpreted treatment as "pretty toxic" and probably harmful. She said, "Am I going to give this sort of toxicity to my child, with some repercussion for her?"

Rejection of treatments during pregnancy was more likely among women who were extremely distrustful of treatment and the medical establishment that advocated its use. This finding is similar to that of other studies, which have found that the belief of treatment efficacy affects adherence of PLWHA (Adam, Maticka-Tyndale & Cohen, 2003; Goode et al., 2003; Malcolm et al., 2003; Wrubel et al., 2005).

### **Caesarean or "natural" delivery**

There continues to be debate among HIV specialists about the benefits of elective caesarean section versus vaginal delivery. Caesarean delivery is thought to limit the baby's exposure to the mother's blood and bodily fluids. However, this coincides with an increased risk of morbidity and mortality for the mother. Evidence for elective caesarean in preference to vaginal delivery has existed since 1999 (The International Perinatal HIV Group, 1999), although earlier trials identified this as a possible intervention. More recent studies have found that women who are on HAART and have viral loads below 1,000 copies/mL have transmission rates between 1.2 and 1.5%, regardless of the mode of delivery (Perinatal HIV Guidelines Working Group., 2006)

The most recent guidelines from the National Institutes of Health in the United States recommend that women with viral loads greater than 1,000 copies/mL consider elective caesarean and those women with viral loads less than 1,000 copies/mL be, "counseled regarding the low baseline rate of transmission, the uncertain benefits, and the known risks of elective caesarean delivery" (Perinatal HIV Guidelines Working Group, 2006: 30).

Previous studies have identified the risk associated with a longer duration of ruptured membranes and vertical transmission (see The International Perinatal HIV Group, 2001). Initial studies found that membrane rupture greater than four hours posed an increased risk of vertical transmission; however, it is now thought that the increased risk of vertical transmission and the duration of membrane rupture are dependent on maternal health; that is, women with AIDS are at greater risk than women without AIDS.<sup>9</sup>

Three women in this study each gave birth to a baby after their HIV diagnosis but prior to the introduction of the 076 protocol. Two babies were delivered vaginally and one by caesarean section. Sixteen women had 19 pregnancies that resulted in live

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<sup>9</sup> The International Perinatal HIV Group did not define maternal AIDS in their article. However, the CDC defines AIDS as CD4 cell counts below 200 or diagnosis of an AIDS-related illness such tuberculosis or Pneumocystis carinii pneumonia (PCP) (CDC, 2005).

births after the introduction of 076. Twelve of these pregnancies resulted in caesarean deliveries, including two twin pregnancies and one emergency caesarean (for which the benefit of reducing the baby's exposure is no longer applicable).

## **Caesareans**

Most women said they were advised that caesarean section was the safer delivery method and were happy with this decision. Nicola said she was told from the outset of her pregnancy quest that she should have a caesarean. However, when I met with her, just weeks before the birth of her first child, she said another specialist had recently told her that she could have a natural delivery if she wanted to because, as she understood it, "the transmission risk between caesarean and natural birth is so minute because I'm on medication now." Because she had spent so long believing she would have a caesarean and exploring the advantages and disadvantages, Nicola did end up choosing caesareans for the delivery of both of her children. Similarly, Mary was given a choice of delivery mode but "chose a caesar ... because ... I knew the risk was a bit lower."

Two women, Miranda and Layla, had actually wanted caesareans for the delivery of their first babies because they had read that it reduced the risk of vertical transmission. However, the women said that their obstetricians thought there was little difference in the risk of vertical transmission and therefore advised a vaginal delivery. Miranda had tried to convince an obstetrician to perform a caesarean section in 1993 because she had "heard somewhere, some French study, saying that a caesar was a safe way to deliver" but "couldn't find anyone who wanted to give me a caesar; no obstetrician would." Both women then chose caesarean deliveries for their second babies and spoke positively about their second birthing experience. Layla's first child was born in 1994 and her second in 2001:

The first pregnancy ... I had a natural delivery which was absolutely horrendous. It was dreadful. Really long and horrible and I'd been reading that a caesar can reduce the rate slightly as well, so I decided this time that I

was having a caesar. My obstetrician had other ideas. He really wanted me to have a natural delivery since I had one the first time. But I managed to convince him by the end of the pregnancy that that was what I really wanted. And that felt good to be able to make a decision and for someone to respect that decision.

Other studies have found that women often feel a sense of sadness or failure as a result of having a caesarean (Fisher, 2002; Rizk et al., 2001). However, none of the women in this study expressed any feelings of great sadness or inadequacy from the caesarean delivery choices that they or their obstetrician had made. Of course, the obvious difference between the women in this study and other studies is that the women in this study mostly expected a caesarean and were well prepared for the surgery. Like taking treatments, any negative feelings about a caesarean delivery could be overcome by focusing on what they believed was best for their baby. Most women gave accounts that focused on the benefits such as avoiding long and painful labours and their partner being present.

### **Vaginal deliveries**

Of the nine children delivered vaginally after their mother's diagnosis, seven were born after the introduction of the 076 protocol; only one of these babies was born after the 1999 study that recommended caesarean section as further reducing the risk of vertical transmission (see The International Perinatal HIV Group, 1999).

Lily, Sophie and Layla all had their babies around the time of the introduction of the 076 protocol. Only Sophie and Layla took the recommended treatment while they were pregnant but all three received AZT intravenously during their labour. Polly and Julia had their babies overseas in developing countries. Julia took the recommended three-part AZT regimen but Polly refused to take any treatment at all.

The remaining two babies were born to Carol. She told of having the support of her obstetrician for a vaginal delivery with her first daughter in 1997. She described it as



very straightforward, involving a six-hour labour and membrane rupture as her daughter was delivered. She assumed that she would be able to do the same with the birth of her second daughter in 2001, although by this time she had moved to another state. Carol reported that the obstetrician consulting on her second pregnancy advised her to have a caesarean because the risk was “lower”. However, Carol interpreted this advice as “pressure” and not to her benefit, despite being presented with evidence that caesarean delivery further reduced the risk of vertical transmission.

They were very pushy about caesarean here, whereas we didn't have that with Lucy at all. And so that was something I didn't realise that I would have to deal with, repeatedly saying, “I don't want a caesarean.” Even when I turned up in labour, they were saying, “Everything's set up, we can still whisk you off”! So Lucy was a six-hour labour and Scarlet was a four-hour labour. So that was really good and recovery was instant. So just dealing with those pressures of people that aren't in that situation. As I said, for all those days after, I would have been flat on my back and I'd have stitches from here to there and this was what they were promoting for me to do. It just didn't sit right.

Brooke was pregnant with her first baby during our first interview and planned to have “a normal delivery because I want to be there.” She said she had the support of her obstetrician, but she was “a bit worried” about how long her labour might take and whether it would increase the risk of transmission. When I met with her again four months after the birth of her baby, Brooke told me that her labour was nearly 24 hours and, because she had still not fully dilated, her obstetrician decided to perform a caesarean.

It is important to note that nearly all of the women who had vaginal deliveries did so with the consent of their consulting doctors. Most of these women had their babies shortly after the introduction of the 076 protocol and at the time many obstetricians and women agreed that the side-effects of surgery and recovery seemed to outweigh the benefits of caesarean section. Many women in this study recounted being given a choice about their preferred mode of delivery, despite evidence at that time suggesting

caesarean section as the most effective delivery method to reduce vertical transmission. Only Carol actively defied the advice of her health-care professionals.

### **Treatments for babies**

The 076 protocol and NIH guidelines adopted here in Australia recommend that babies born to HIV-positive women be given a course of AZT for six weeks, followed by six weeks of prophylaxis to prevent PCP (Pneumocystis Carinii Pneumonia) should the baby be HIV-positive. The women in this study reported that most of the babies coped well with the treatment and experienced only small side-effects like minor diarrhoea. A few women said their babies disliked the prophylactic treatments. All but three women gave their children all of the recommended treatment, although some expressed concern about toxicity and potential long-term side-effects.

### **Accepting treatments for babies**

Most women accepted that giving the treatment was one of the final steps in pursuit of a healthy and negative baby. The accounts given by the majority of women did not dwell on their thoughts and feelings about giving their baby AZT (and, in some cases, other treatment in combinations, such as 3TC). Mary's account was typical of most women when she explained that "Joel was really good with the medication. Because in the beginning we had to put it through a teat and he'd take it all right like that." Even women who had not disclosed to their family members found inventive ways to explain the medication with little or no questioning from their family. For example, Monica told her mother, sister and in-laws that the AZT vials were a "new vitamin that they recommend you use for babies who are not breastfed."

Even most women who were adamantly opposed to or sceptical of treatment for themselves were willing to comply with treatment advice for their babies. The explanation for this apparent contradiction was that they did not have enough knowledge to challenge the advice they were being given and, because it was not their

own body, they could not act upon how the medication was making them feel. Lily, the only mother of an HIV-positive child in this study, had vehemently refused treatment for herself because it made her sick, but when it came to her son she understood this decision as not hers to make:

My body was my responsibility but as far as Zach was concerned, a child with HIV, I did not have knowledge so I had to go along with the doctors. So Zach has been on constant medication for his five years.

### **Rejecting treatments for babies**

Whilst most women were prepared to comply with recommended treatment regimens during their pregnancy, this acquiescence did not always extend to giving their babies prophylaxis after birth. Brooke's account demonstrates both her suspicions of the suitability of treatment for infants and her interpretation of AIDS care as an inexact science.

[After a six-week course of AZT] I was supposed to give her Bactrim which I didn't actually do, but I said that I did because I couldn't be bothered explaining to them why I didn't want to give it. Bactrim doesn't stop them from getting HIV anyway. I didn't want to be put in the "non-compliant" category by doctors, so I just pretended to comply! They give Bactrim to them in case she is positive to stop her getting PCP but she might not get PCP even if she is positive, so it's a real like, if, if, if. So I just thought, 'Oh no, she's not going to have it anyway, I am pretty sure.' And it was scary with the AZT. Why is it six weeks you have to give it to her, why is it not four or why not eight? Apparently it's just from previous tests that have worked, so why change it if it works; but I was thinking, "Oh, maybe I should skip the last week", but then when it comes to it I was a bit scared to do it; yeah it's a big step. In the end I just skipped the last day. Part of me worried about any bad effects from the AZT, that she might not need it anyway – who knows, she might have been negative without the AZT. But

another part of me thought, it's best to take all the precautions they advise. In the end, the most important thing is to have a negative child.

It is clear that Brooke interpreted treatment as only equivocally beneficial. In her desire to do what is best for her baby, she made judgments that are at odds with the explanatory tools of scientific medicine. Miranda and Olivia's thoughts were similar. Miranda gave her son the treatment but did not give him any of the prophylaxis, saying, "I didn't even get the script filled ... In the end, I just thought, oh, he is having enough." Olivia recalled how much her babies had hated the prophylaxis, spitting it out. She felt very uncertain about how she would proceed if she were to have any more children:

So, yeah, if I had another child ... I'd have to think really carefully about what we did. ... I wouldn't want to give them the drugs, especially the Bactrim. ... I don't know what I'd do, I really don't. It's just that they're so toxic. That's why I stopped mine; I just didn't want a bar of it.

When Carol was pregnant with her second baby, she and her husband decided not to treat their newborn baby. She and her husband believed the risk associated with the treatment was greater than the likelihood of their baby being HIV-positive. Despite preliminary discussions with her specialist, Carol understood this decision as hers to make. This disjunction between maternal and medical assessments of her baby's welfare resulted in legal proceedings and the involvement of community services in the administration of treatment to Carol's baby twice a day at her home for the first six weeks of her baby's life:

On the day of her birth, we actually ended up in court. The hospital were forcing treatment on her, so she was actually treated through a court order and we had hospital staff coming around twice a day to administer the AZT. ... It was four hours after she was born and we were ready to go home and they walked in with the detention order to detain her.

Carol also decided against giving her daughter the PCP prophylaxis, thinking it was extremely unlikely that her daughter was HIV-positive. To avoid further medical or legal scrutiny, Carol filled the prescription, but didn't administer the medication.

Carol's account is an ideal illustration of the effects of interpreting antiretroviral therapies using an explanatory structure that is at odds with medical protocols. One significant feature of this account is the power vested in the nameless "they", who seem not to cede any role to Carol in making decisions about her baby. This very powerlessness may be the factor that ultimately undermines effective treatment.

But just that whole feeling now of, like, safety. I don't feel like we can protect our kids from anything. It's become broader than that. It's like any time they think we are not doing the right thing, they can just do whatever they want. So that's really the biggest impact of being positive. Because I always thought, 'Well, I'm positive, and as long as the kids are OK and as long as I am healthy, it won't be an issue.' But to then realise that it impacted on my second baby particularly because we didn't want her to have treatments. ... And just their interest, or their over-interest, in whether I would have more children. ... Whereas now any future pregnancies: they would either be here without anyone knowing, but most likely overseas to avoid intervention and those sorts of things.

From the women's perspective, it makes sense not to let their babies become experimental subjects. Taking the treatments during pregnancy and giving them to their babies represents a threat, not a solution. AZT still carries its reputation from the late 1980s and early 1990s, when excessive doses killed people living with HIV/AIDS. When this is added to the psychological implications of initiating HIV treatment, at a time when women are most conscious of their health and their bodies as safe vessels for their babies, you have a powerful force of resistance against antiretroviral treatment (McDonald & Kirkman, 2006).

## Testing babies

Before the availability of viral load testing, babies born to HIV-positive women were tested at birth, 24 hours, one week, four weeks, six weeks, three months, 12 months and 18 months. Because it takes around 18 months for a baby to clear all of the mother's antibodies, women had to wait all this time to find out if their baby was HIV-negative. Since the availability of PCR (polymerase chain reaction) testing, the agonising wait to discover a baby's HIV status has been considerably reduced. Whilst women are still encouraged to continue testing their babies until 18 months of age, mothers are told that, if their baby's PCR tests are negative at the first test, there is a good chance their child is negative.

All of the women in this study tested their babies and many described the range of emotions they experienced during this time, including, stress, guilt and anxiety, at having to put their babies through the months of tests required to determine their child's HIV status. For some it was like taking treatments: a constant reminder of their own status. They were conscious that their baby's distress resulted from their HIV status. Kate explained the guilt she felt each time her daughter was subjected to another blood test, saying, "The thought always came back to that: this is because of me that you have to have this."

Despite the tests becoming more sensitive and accurate, women still found the waiting time a considerable burden and the imposition of pain on their baby especially traumatic. To avoid some of this trauma, Miranda "missed a couple" of the tests and Brooke declined a test she was requested to repeat, saying she preferred to wait until the next one was due. Similarly, Polly, whose baby was born overseas, "had heard that you couldn't be sure until 18 months." Polly decided to "try and hang out till that time" and not undertake any of the earlier tests. However, her parents and her doctor continued to ask Polly to test her daughter and eventually she agreed when her daughter was 14 months old. That test came back negative and Polly said that the doctor advised that her child be re-tested at 18 months, to which Polly said she agreed at the time. However, Polly described the process of her daughter being tested as "abhorrent" and did not return for the test, saying, "I just didn't see the point. She's negative."

Janice decided that it was better not to go with her daughter when they took her blood because she felt that her daughter would get upset from seeing her distressed. She described how, at the last test, the paediatrician had to put “the needles in her arm, in her other arm, in the back of both of her hands and in her feet to get about a mil of blood” because the “veins always seem to collapse.” Janice devised a strategy of sending her sister with her daughter because she knew her aunt well and then, after it was over, Janice was able to comfort and calm her. Yet, despite this strategy, Janice described being able to hear her daughter crying and “bawling my eyes out.”

Testing their babies was a painful experience for the women in this study. It reinforced their own status and was often accompanied by guilt, sadness and anxiety as they awaited the outcome of each test.

### **Breast or bottle?**

Breastfeeding has been known since 1985 to increase the risk of vertical transmission by approximately 15% (Senturia, Ades & Peckham, 1987; Ziegler et al., 1985). Therefore, women who live in developed countries and have access to safe drinking water and sterilising equipment are advised not to breastfeed. All but one woman in this study complied. Most women interpreted the decision not to breastfeed as a small sacrifice that would benefit their baby. Sophie said, “[breastfeeding] would have been nice. I think having a healthy child is nicer.” To compensate, when she was home alone, she bottle-fed her babies while they lay against her bare breast to imitate the skin-to-skin contact experienced by breastfeeding mothers.

Carol explained that, had she gone against advice and breastfed, it would have provoked such great anxiety that it would have interfered with her relationship with her baby. In spite of her resistance to treatment for her second baby, Carol did not breastfeed either of her babies:

I guess I felt that the risk was too great, and that it would then be an on-going thing each time I fed her, and I would be more focused on that than on the nurturing or feeding, and hoping that it wasn't transferring to her.

Carol said that her attitude made it easier to accept not breastfeeding her second baby.

Some women in this study experienced a range of negative emotions including sadness and guilt from being unable to breastfeed. Stephanie described foregoing breastfeeding as:

The hardest thing, because I would have really loved to breastfeed him but I couldn't, for his sake. It really upset me in the first couple of days in the hospital, because the baby was looking for my nipples and I was feeling so guilty. I cried a couple of times when he was looking everywhere. I just said, "No, no, no," and I would give him his bottle.

Not being able to breastfeed compounded the feeling of abnormality for some women. Brooke speculated that the other mothers in her maternal-child health group wondered, "Is there something wrong? Or they might be thinking that you are a bad mother or something", because she was not breastfeeding. These feelings are not just paranoia on behalf of the women. Layla described bottle feeding her baby in a taxi when the driver said to her,

"Oh, you're not breastfeeding." I said, "No", and he said, "Well you should, it's better for the baby", and I thought, who the fuck are you to tell me what to do? I think that it is like that when you're pregnant and when you have a baby that people feel that they can.

Layla felt that the pressure on women in general to breastfeed is also experienced by HIV-positive women. She thought, "I suppose it would make you feel more like a normal mother having a child if you were able to breastfeed."

Only Polly chose to breastfeed because she disagreed with the advice she was given. She was offered formula and told that breastfeeding posed a risk to her child. Polly said she felt "the power ... they had over my child" when a doctor warned her that there could be legal implications if she chose to breastfeed. Polly said the doctor concluded their discussion by telling her, "Well, we're just doing our job and we have



told you all of that now and we really strongly urge you to protect your daughter.” Polly said the doctor then “put it on” her, “Do you or don’t you want to be responsible for your daughter having HIV?”

However, Polly did not believe what they were telling her, and even at the time of the interview continued to believe HIV was “a germ warfare”. Although she admitted to having doubts about whether she should breastfeed in the first 24 hours after her daughter’s birth, she ended up breastfeeding her daughter when a nurse on staff appeared to not know what was going on and did not provide any formula for the baby. Polly explained that she was “so glad for the first time in my life to suckle my child. ... I couldn’t wait for [the paediatrician] to come and see Fatima suckling on my breast, but at the same time I was a little bit apprehensive.” Polly said that, although the paediatrician was very disappointed and said to her, ““Oh, you’ve done it now,”” she also believed that the doctor felt that it was now “out of her hands”, for which Polly was grateful, “because if people were actually emotionally convinced of their ideals it would have been hard.” Polly was unable to reconcile the advice that was being given to her and her knowledge of the benefits of breastfeeding:

Breast milk is supposed to build the immunity of the child, so that’s something I know. So why would I go with something I don’t know, and not breastfeed her? Give her toxic drugs with the hope of her not becoming sick?

Later, Polly said:

I’m not going to live my life by the hypothesis of the worst-case scenario. I refuse to. I mean, I proved my point. She came out negative and I breastfed her for four months and I got her tested. I had a natural childbirth. I didn’t take any drugs through pregnancy, and this one came out negative, so why can’t other babies come out negative?

During her interview, Polly spoke of being given fact sheets with transmission rates and the different ways HIV can be transmitted from mother-to-baby. However, she said she found these facts to be “nonsensical” and believed her doctors to be “trying to rob me of my natural experience.” From Polly’s perspective, everything she was

being told conflicted with her ideas of being the best mother she could be. She did admit she knew very little about HIV at the time of her daughter's birth but she did not give any indication that she since understood her daughter to be part of the 67% of children who do not vertically acquire HIV from their mothers.

## Summary

Generally, women constructed accounts that presented themselves as informed, responsible and deserving mothers. They rejected the medicalised construction of the HIV-positive woman, although most embraced aspects of medicine, such as clinical markers, to explain and justify their choices.

Although women were largely willing to follow protocols to reduce the risk of vertical transmission, most of the women in this study explained antiretroviral therapy as not unequivocally benign for either themselves or their babies. They described experiencing or being aware of debilitating side-effects and those taking antiretroviral therapy discussed the lack of scientific explanation for many of their experiences with the treatment. It is not that these women did not understand the scientific discourse that drives the protocols for mother-to-child transmission. Rather, these women identified for themselves a primary role as protectors of their children, including protection against the medical fraternity. The history of antiretroviral therapy is not one of clear and consistent efficacy and most were very aware of the trial and error that has preceded the antiretroviral therapy treatment that is available today (McDonald & Kirkman, 2002).

Kathleen Nolan (1989) noted that the imposition of unwanted advice can violate the patient's autonomy as well as paradoxically driving the patient into a defiant rejection of the health-care worker's advice. Acknowledging the role of the mother in the care of her baby, rather than excluding her from decision-making, is likely to be one of the crucial steps in bringing about the best outcome for all concerned.



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## Chapter 6

### *The impact of stigma on women's accounts*

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People with HIV are often blamed for their infection; many people believe that HIV could have been avoided if better moral choices had been made (Brimlow, Cook & Seaton, 2003; Ciambone, 2001). (For a comprehensive discussion about stigma and morality, see Scambler, 2006.) Although now mostly treatable, HIV remains, like other terminal illnesses, an incurable disease. People living with HIV are stigmatised by the implication of physical deterioration as well as other people's ontological fear of contagion and death (Bennetts et al., 1999; Siegel, Ravies & Karus, 1994; Sontag, 1989). HIV transmission is often poorly understood by the general population (Brimlow, Cook & Seaton, 2003). Within the Australian context, because it is an almost entirely gay-epidemic, HIV is both stereotyped (as a disease that affects only gays, injecting drug-users or sex workers) and absent (because it is considered irrelevant or something that affects others) from mainstream society (Persson & Richards, 2008). Thus HIV continues to be a highly stigmatised disease which few HIV-positive people publicly disclose.

Assumptions are often made about an HIV-positive woman and the "type" of woman she must be to have contracted such a disease. It is not surprising, then, that most of the women in my study chose to keep their HIV status private. All of the women had constructed a private account of their HIV infection in an attempt to gain some meaning and understanding of their predicament. Most used this version to share with their health-care provider, their partner, selected family and friends, and me. Some women also created a public version which they shared with the wider public in an attempt to educate others and improve the lives of other HIV-positive people.

Sometimes a woman's private and public accounts were the same, but in most cases they were different. The public version was usually "sanitised" and edited to protect the protagonist and, if applicable, her children, from potential stigma and discrimination.

Implicit in the discussion of public and private accounts of HIV is disclosure. Much has been written about HIV-positive women and disclosure, including the steps leading to disclosure. These are identified as: adjustment to diagnosis; the decision about whom and when to tell; having the motivation to disclose; and consideration of the recipient's circumstances, possible reaction and ability to cope with the information (Kimberley, Serovich & Greene, 1995; McDonald, 2006a, 2006c; Trathen, 2001). Disclosure of one's HIV status is also believed to be positively related to one's physical and psychological health (Sowell et al., 2003).

In this chapter I consider disclosure in the context of motherhood and how perceived stigma influenced women's constructions of their private and public accounts of living with HIV. I also explore women's accounts of disclosure or non-disclosure to their children.

### **HIV-positive women, stigma and discrimination**

The prevalence of HIV/AIDS-related stigma and discrimination has been widely documented (see, for example, Alonzo & Reynolds, 1995; Bennetts et al., 1999; Herek, 1990, 1999; Sandelowski, Lambe & Barroso, 2004; Wiener, 1991). Even before HIV was identified, there was societal stigmatisation of certain groups of people such as homosexuals, sex workers, injecting drug-users, and those with cultural and linguistic differences. The emergence of this disease has only served to heighten the stigmatisation of these minority groups (Malcolm et al., 1998). Women who are HIV-positive are often assumed to be sex workers or injecting drug-users and their stigmatisation is compounded if they are from ethnic minority groups (Lekas, Siegel & Schrimshaw, 2006) or do have a history of sex work or drug use (Barnes, Alforque & Carter, 2000; Berger, 2004). Reidpath and Chan (2005) referred to this as "layers" of stigma. Not only do these women have a feared, contagious disease, but

they also are assumed to have deviance in their personal traits. HIV-positive women encounter additional stigma because of their childbearing capabilities (Gurevich et al., 2007; Lekas, Siegel & Schrimshaw, 2006; Sandelowski, Lambe & Barroso, 2004) as well as their roles as mothers; women who express their desire to pursue pregnancy are sometimes accused of being selfish, inconsiderate, uncaring, and even immoral (McDonald, 2002, 2006c). Sandelowski and her colleagues found that “stigma was virtually synonymous with the experience of HIV infection in women” (Sandelowski, Lambe & Barroso, 2004: 124).

HIV-positive women in the Western world have also experienced further stigmatisation in the context of a “gay” epidemic. That is, they felt they had both something and nothing in common with HIV-positive gay men (Sandelowski, Lambe & Barroso, 2004). Many of the women in my study thought that the majority of services, information, research and funding had been targeted at gay men. Yvette remembers attending a support group meeting in the early years of the epidemic, at which she was the only woman and was mistaken for the facilitator. She recalls “bringing up women’s issues in that group. All the guys would be looking out the window – that sort of thing! Sometimes I even felt guilty for wanting to do it.” Eventually Yvette solved this problem by founding the first women’s group in her state. At the same time, Yvette acknowledged that gay men had made an important contribution to the plight of HIV-positive people, saying, “if it weren’t for gay men I wouldn’t have the choices I’ve got now.”

### **Perceived and enacted stigma**

Two kinds of stigma within the context of illness have been identified: perceived and enacted (Jacoby, 1994; Scambler & Hopkins, 1986, 1990). Scambler and Hopkins (1986) argued that perceived stigma usually occurs before the experience of stigma; stigma is felt before it is enacted by others. Kleinman (1988) noted that the label of stigma imposed by societal reaction to the disease comes to be expected by the stigmatised person, even in the absence of enacted stigma. Kleinman (1988: 164) went on to argue that, “The stigma begins not with the societal reaction to him [sic],

but rather with his [sic] own acceptance of a stigmatized identity” and that individuals position themselves within the dominant discourse and accept what Goffman (1963) called a spoiled identity.

Accompanying an HIV-positive diagnosis is often a high level of fear and anxiety that one’s status will become known, resulting in detrimental action against one, such as rejection by loved ones. The fear or anticipation of stigma for HIV-positive women has been identified by other researchers (Lekas, Siegel & Schrimshaw, 2006; Sandelowski, Lambe & Barroso, 2004) who have argued that women “blur” perceived and enacted stigma because of their internalisation of the dominant, stigmatising discourse about their illness. Such blurring has contributed to HIV-positive women feeling dirty, diseased and deficient (Lawless, Kippax & Crawford, 1996). This was certainly true for the women in my study, many of whom felt stigmatised and rejected because of the dominant discourse about HIV, even if stigma had not been specifically enacted against them.

Despite most women admitting they knew very little about HIV when they were first diagnosed, many recalled the *Grim Reaper* advertisement launched by The National Advisory Commission on AIDS (NACAIDS), April 1987, intended to educate the community about the risk factors of HIV/AIDS. The advertisement shown on national television featured a “Grim Reaper” bowling over human “pins” in a bowling alley and included provocative images of women holding babies and the hands of small children. An evaluation of the campaign found that it raised the anxiety level among low risk heterosexual persons, especially women (Morlet et al., 1988).

Goffman (1963: 45) noted that “persons who have a particular stigma tend to have similar learning experiences regarding their plight, and similar changes in conception of self – a similar ‘moral career’”. Career, as defined by Goffman (1961: 119), refers to “any social strand of any person’s course through life.” A similar moral career could be identified for the women in my study. All of the women in this study were acutely aware of the stigma attached to an HIV-positive diagnosis and the stereotypes that are associated with HIV-positive women. The first stage of their “plight” or journey included making decisions about disclosure. HIV-negative people often positioned HIV-positive women as “discreditable” by warning them to refrain from

telling many people in the first few weeks of their diagnosis, thereby confirming their spoiled identity. Denise remembered, “The other thing that the STD clinic said when we were diagnosed was, ‘Don’t tell anyone’.” Even family members tried to limit women’s disclosure, fearing ramifications. When Helen disclosed to her mother, “she didn’t want me to tell my two sisters,” and “the first thing” Brooke’s mother said was, “Don’t tell Dad; whatever you do, don’t tell Dad”, because he had cancer and her mother was “concerned it would make him worry and make him sicker.” So the fear of stigma was ever-present even if it was not actually experienced.

### **Stigma and health-care professionals**

Stigma about and discrimination towards HIV-positive women from health-care professionals has been well documented (see, for example, Barnes et al., 1996; Gorna, 1996; Lawless, Kippax & Crawford, 1996; Sowell et al., 1996b). Most of the stigma and discrimination experienced by the women in my study had come from their encounters with health-care professionals. Women often felt obligated to disclose their status in health-care settings to ensure that proper protection measures were implemented. Helen disclosed her status when she went to the dentist “because at the bottom of the form it says, could you be HIV-positive?” Helen found herself in a dilemma but decided, “I’ve got to be honest, so I put yes”, because “How would I feel if that was my husband or my brother?” As a result of her honesty, the dentist and the nurse wore two pairs of gloves and, when the nurse asked if she should place the steel tools that had blood on them (after a tooth extraction) into the steriliser, the dentist told her to put it in the bin. He then said to Helen, “Look, I’m really sorry, I really am. ... You’re the first patient. I’m 45 and you’re my first ever patient. ... I’m scared, I’m sorry’. At that point he walked out of the room.” On another occasion when Helen presented at a local doctor and requested a pap smear, the doctor told her to go to another doctor. Although Helen found these experiences stigmatising, she told me that she understood the attitudes of these health-care professionals, saying that, before she was diagnosed with HIV, she too would have avoided contact with people living with HIV:



To be totally honest with you, and I am being honest, if you had come to my house as a friend or a visitor and you said, “Oh guess what, I’m HIV-positive”, I’d be like, “Oh, okay, gee, what’s the time? Oh, I’ve got to go out now.” I would be; I would be. I know I would’ve been. ... I would’ve just been like, “Don’t breathe my air”, and that’s really ridiculous, but I would’ve been. So I know how he feels. I know exactly how he feels.

Almost half of the women in my study told of encountering health-care professionals who openly opposed or advised against their desires to pursue pregnancy. However, most of the women who had their babies after the 076 protocol were able to find a supportive doctor to care for them during their pregnancy and birth. Similarly, most women concluded that the majority of the staff they encountered in the hospital were very considerate of their confidentiality. Particularly notable were the stories from women who had had two children since they were diagnosed, and the differences they reported between the two experiences. Some women even received apologies from staff who remembered how the women were treated and how much procedures had changed to try to ensure that women did not feel stigmatised.

For example, when Layla had her first baby in 1994, she was put in a room with three other women and their babies. Layla was not allowed to use the communal laundry bag provided for sheets and towels in her shared room. Instead, she was instructed to use the one next to her bed that had a distinctive “yellow contaminated waste bag”. There were “yellow stickers” all over her medical folder and, “when I went to the nursery I noticed they were putting gloves on to change my baby’s nappy, which they were not doing for other babies”:

Every time I went to the nursery to feed the baby I felt like I was having to educate the nurses so that I was being treated like a human being, otherwise they were making assumptions about who I was and what my life was like.

Layla’s second baby was born in 2001 and she went back to the same hospital. This time, “I felt like my status wasn’t an issue at all. ... They just were wonderful and they went out of their way to be helpful.” Layla did notice at her first appointment that her old file “still had yellow stickers on it” but this time she was given a private room

and they did not leave her charts at the end of the bed, “so they were not there for everyone to see.” Layla interpreted this effort as the staff being “conscious of my privacy and confidentiality.”

However, some women still felt stigmatised by health-care professionals during their hospital stay and this was usually in the form of unwanted questions from curious nurses and breaches of confidentiality. Olivia’s twins were born in 1998. She said her stay in hospital was “great” until the sixth day:

The night shift staff left messages for the morning shift and they had the volume up too loud for the Dictaphone. I had my door open and, although I was right out in front of them, everyone else could have heard it as well. And they’ve said my room number, my name, and my status. They’ve said, “HIV-positive,” and I’ve called the nurse and I said, “I just heard that.” I said, “I don’t know how many other people heard it.”

Janice said that “the only people I’ve ever been rejected by would be probably the people in the medical industry.” Janice remembered a nurse who “put three sets of gloves on” to take her blood and “doctors telling me not to have a baby.” When Janice was in hospital after the birth of her daughter, the midwives asked her a lot of questions, such as, “Are you sure she’s going to be all right? How did you get it? And how long do you think you’re going live for?” Whilst Janice interpreted their questions as curiosity, she was “bothered” because she felt they should have known the answers to the questions they were asking.

### **Stigma and motherhood**

HIV-positive women have a compounded experience of stigma because they are seen to place “innocent” children at risk. Additionally, the stigmatisation of HIV-positive mothers is intensified because of the assumed association of HIV-positive women with “deviant” behaviour. As a result, the canonical narrative of motherhood in Western society does not consider HIV-positive women as worthy mothers. Like

other marginalised mothers such as women in prison, drug-using women, and teenagers, HIV-positive women have found it difficult to position themselves within the dominant discourse of worthy and good mothers instead of selfish and immoral women for desiring motherhood (McDonald, 2006c; Wilson, 2007). Stigma is often experienced and nearly always feared by women whose life experience falls outside culturally accepted norms of motherhood, including teenage mothers (Kirkman et al., 2001) and mothers who use recreational drugs or are HIV-positive (Ingram & Hutchinson, 2000).

Health-care professionals were not the only people openly to oppose women's desires to pursue motherhood and to reject these women as worthy mothers. Friends and family also objected to their desires to become mothers because of their HIV status. Isabelle recalled that, when she was considering motherhood at one stage, she spoke to her brother about her thoughts:

He is a doctor, actually, and he said, 'It would be irresponsible. What if the child is positive?' I actually sort of agreed with him. I was really in two minds with it. I wasn't really pursuing the subject really seriously; I was just sort of sounding it, to see what people's reactions were.

Isabelle was one of two women in my study who were of Asian origin. Isabelle's cultural heritage played a role in her construction of whether her family would accept her as a mother. As both an HIV-positive woman and an unmarried woman (although in a long-term relationship), she believed that her parents would be very upset if she pursued motherhood.

Miranda interpreted her decision to terminate her first (wanted) pregnancy as a result of the lack of support she had from family and friends, who said things to her such as, "How could you? You won't be around to bring the child up. What if the child's sick?" Miranda then constructed a public account of her next two pregnancies that she believed her friends and family would find more acceptable: telling them they were both "accidents," explaining:

People accept it better if you say, ‘Oh, I accidentally fell pregnant and now I’m going through with it,’ rather than saying, ‘Oh, this is my situation and I want a child,’ because they consider that selfish. ... When I was pregnant with Jack, people, even family, were a bit like, ‘Oh, how could you do it again? You should just be happy that you have one child that is well. How could you go through the whole thing again?’ It’s like they think it’s a bit greedy. So again I said it was an accident. There is this sense of shame. I felt guilty and ashamed when I was pregnant, like I couldn’t really enjoy it because pregnancy is supposed to be this real spiritual thing, but I felt embarrassed when I was pregnant.

As Isabelle and Miranda made clear, stigma is often enacted by the very people from whom many women expect support and understanding. Such unsupportive and even antagonistic responses result in most women becoming very selective about to whom they told their accounts, and what they actually told them.

### **Managing unwanted disclosure and stigma**

Around one in four women had experienced unwanted disclosure. This was either in the form of people they had told telling others, health-care professionals being indiscreet, or well-meaning family members insisting on another family member being told even when it was not what the woman herself wanted. When Polly disclosed to her mother, she asked her mother not to tell her siblings because Polly thought “they wouldn’t react in a good way.” Her mother ignored her request, telling her, “your sister has two children and they have to protect themselves.” She was very angry about her mother’s decision because Polly did not believe there was any risk of her sister or her sister’s children contracting HIV. Polly’s concern about the ramifications of disclosure was proven correct when her sister physically assaulted her. A few other women felt they were pressured into disclosing to a parent by another family member who “thought they had a right to know.” The consequence to this disclosure was often a very anxious parent who required a great deal of support

from his or her daughter. This was often difficult because she was either still grappling with her diagnosis or perhaps lived too far away.

Unwanted disclosure caused additional angst when it directly affected their children. Lily was forced to leave the town in which she and her son were living when an ex-lover told a lot of people, including her neighbours, that she and her son were HIV-positive:

The discrimination and the abuse we received meant that we were just ostracised from everybody. Nobody talked to us any more. Zach lost all his playmates and it was just him and me existing, and when we were out we were stared at and talked about and people called out names and abuse. ... [My ex-lover] told people that Zach and I had AIDS and that if they touched us they would get it.

Even women who had not actually experienced unwanted disclosure feared the consequences of it. Monica had not told any of her family about her diagnosis. She did tell her partner who went on to father her child, but after their separation she worried that he would disclose her status against her wishes. She was “concerned” about him because they had “had some really awful times recently” and she was aware that it was “a very good tool for him to use as a mode of threat, which he has done.” Adele had not yet disclosed her HIV status to her daughter, but one of her neighbours found out about her status from a previous sexual partner who was contact-traced<sup>10</sup> and subsequently worked out it was Adele. This woman had already disclosed Adele’s status without her permission to some of their neighbours, and consequently Adele had “a fear that she would tell somebody that was connected with the school. She is not connected with the school in any way but I have that fear that it would come out at the school.” Adele had given considerable thought to how she would handle such a scenario because she believed “a lot of people ... would be quite narrow minded”:

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<sup>10</sup> Contact-tracing involves partner notification and is the process of identifying the relevant contacts of a person with an infectious disease (such as HIV) to ensure their awareness of their exposure (Donovan et al., 2006:2). Although the confidentiality of the infected individual is maintained, sometimes it is possible for the individual who is contact-traced to guess her or his identity.

I would try and get somebody else who is experienced and can talk to a group – to stand up in front of a parent meeting – if it came to that, to put my side forward. I couldn't do it because I would get too emotional and I would get too angry. But I think education would be the answer because I don't want to take Briana out of school. I don't think that would be the way to go, but it would depend on how hard a time she got from the other kids, which would come from the parents because the kids don't know. The teachers and the principal I don't think would be a problem. I get on with them well and I think they are open enough to ideas. It would be parents that are narrow and I guess the only comeback would be that there is nothing wrong with Briana. It's only me.

One act of unwanted disclosure for Adele had resulted in considerable distress for her. Adele's greatest concern was the impact further unwanted disclosure might have on her daughter and consequently she had put a considerable amount of energy into imagining a situation where unwanted disclosure occurred and how she would deal with it when, or if, it did.

HIV-positive women have previously been identified as employing a variety of strategies to manage both perceived and enacted stigma which also enhanced normalcy (Joachim & Acorn, 2000). The women in my study also worked to manage stigma, which included maintaining identities as normal women; women who were mothers prioritised minimising harm to their children. Goffman (1963) noted that those individuals who became stigmatised later in life often have difficulty in re-identifying themselves. One way some of the women in my study minimised the imperative for taking on a spoiled identity (Goffman, 1963) was to limit the contact they had with other positive women. The women who employed this strategy justified this decision by explaining that their lives were too busy to attend the events that were organised for positive women. By avoiding interactions with other HIV-positive women, they could live their lives "passing" (Goffman, 1963: 58) as ordinary women. Nicola explained, "You've got to still live your life as normally as possible because you don't grow another head. People can't tell when you walk down the street and it doesn't affect your everyday living unless you're ill."

Other studies have found that perceived stigma of an HIV-positive woman is exacerbated if the woman is (or has been) a drug-user (Barroso & Sandelowski, 2004; Berger, 2004; Herek, 1990). In the early years of her diagnosis, Denise worked very hard at passing as a normal woman to the outside world in the hope that it would protect not only the secret of her HIV status but also that of her drug use:

I was always working part-time in child care and studying and running the house because I always thought if I, like, kept my house really clean and spotless and was on every parent committee that existed, no one would ever know that my family, my partner and I, used heroin.

Being a drug-user and HIV-positive meant that Denise was doubly discreditable and she worked vigilantly to avoid becoming discredited.

### **Private accounts**

The women in my study had constructed a private account of their HIV infection to help understand and gain meaning from being diagnosed with a disease most knew little about and certainly did not expect. Women's private accounts often included how they contracted HIV, how devastated they were by their diagnosis and how, over time, they dealt with this shocking news. Stigma was at the forefront of most women's minds when first diagnosed and they often faced the dilemma of wanting to share the most significant event of their lives contrasted with the need to protect themselves from rejection and stigma. Some women told of wanting to tell everyone, feeling the need for widespread support and understanding. After disclosing to her parents, Clare's "next reaction" was "just to go out and tell everyone, I got this – and feel sorry for me – "my life is over" type of thing; get all the sympathy. And then you just think, 'Don't be stupid; you can't do that.'" Rachel explained how, after her diagnosis, she found it difficult to be around people who did not know, because it was such an important part of her life:

I was very sensitive at first, or I felt like a few layers of skin had been removed. So when I was with people, I think I needed to tell them because I thought they would sense there was something wrong anyway. ... I felt like there was this big gulf between me and everyone else.

By not disclosing her status, Rachel felt others could not really know her and how she was feeling. The “normal” Rachel whom her old acquaintances knew no longer existed, as HIV was consuming her identity. By sharing her status, the “real Rachel” could be known.

Despite the “gulf” that women felt between themselves and everyone else, most refrained from telling very many people because of the stigma associated with being an HIV-positive woman. Women differed in their approaches to protecting themselves (and any children) from stigma. Avoiding disclosure and thereby keeping one’s status a secret was the surest way not to attract stigma and discrimination and ensured that women could “pass” as normal. Person and Richards (2008) also found that non-disclosure was key to normalcy amongst a heterosexual sample of PLWHA in Australia. Disclosure was also recognised by many women as a part of their life they could control when so much of the rest of their lives seemed chaotic and out of control. Laura explained:

I think one of the few things that you feel that you have left when you are first diagnosed is whom you tell. There are a whole lot of things that seem to be taken away from you but one of the few things that you do have left, that you have some control over, is whom you tell.

It is not surprising, then, that most women chose to tell only a few people, usually immediate family and a few of friends. Two women told only their sexual partners. Monica had disclosed to her sexual partners and two friends, whom she told because she “was in an emotional upheaval but now I don’t feel any need to disclose.” She had not told any members of her family because she did not “feel the need to and I also think it’s a bit difficult now because it’s been a long time.” Carol also had not told any members of her family “because it didn’t really become an issue for them to know.” She believed that she was “close” to her family but that “if it was a different diagnosis



... if it was cancer or if it was something else, would I say? And I don't really think I would." The common theme in the accounts of women who had not disclosed to their families was preventing unnecessary "worry". Women could also be understood to be protecting their families by avoiding disclosure. They were protecting them from the worry of knowing a loved one was living with a life-threatening illness and they were also protecting them from the possibility of stigma from their association with someone with HIV.

Clare had been diagnosed for two and a half years when she met with me. At that point she had told only her immediate family, her boyfriend and two work colleagues. She described this as "living two separate lives" because none of her friends knew. Clare's separate lives enabled her to maintain her previous identity that did not include HIV and where Clare could pass as "normal." Clare justified her decision, saying that she did not believe that she could be helped by her friends knowing, "because it doesn't really affect them; I want them to treat me the same as they always have. And they probably would, but I guess there is always that thing in the back of their minds." Clare did acknowledge that there may be a point in the future where she would be comfortable with her friends knowing, but she explained, "You've got to be right in your own head before you tell other people; figure it out." Until a woman is able to accept her new identity, and the part HIV is to play in her identity, disclosure to others is unlikely. Similarly, private narratives cannot become public until the protagonist has a clear sense of her identity.

Even when women were comfortable with their wider family and friends knowing their HIV status, some found it necessary to control information given to others by concealing certain details and constructing an account that was acceptable. The father of Miranda's first child was also HIV-positive, so there was no perceived need for them to be practising safe sex. However, the father of her second child, and current partner, was HIV-negative and when they announced their pregnancy, friends and family asked her, "How could you risk Allan's life like that?" Miranda believed others would find it more acceptable if she told them "it was just the once", explaining that "people can't deal with it and it's not like how can *he* risk his life, it's how can *you* risk his life?" Miranda went on to say that she had her "tubes done during the caesar" and "even now occasionally we will have unprotected sex":

And that's really hard; I am telling you because you're doing the research but I'd never tell anyone other than another positive women that we do that, because people can't understand that we don't wear a condom. But that's his choice. He knows what he's up against and I'm really worried about it.

By having a tubal ligation, Miranda has removed the risk to any potential child but, whilst she knew female-to-male transmission was a lower risk than male-to-female transmission, she still had to bear the burden of having to participate in an activity in which she was a danger to her partner; knowing that others would blame her if her partner did seroconvert. Others have also found that condom use within the relationships of HIV-positive women is often fraught (Gurevich et al., 2007; Lather & Smithies, 1997; Lawless et al., 1996) and that women's focus on protecting others can impede their own sexual fulfilment (Gurevich et al., 2007).

### **Private accounts and children**

Maintaining a private account ensures the protagonist protects herself as well as the ones she loves (Kirkman, 1997, 2001). This is particularly important for HIV-positive women who are mothers. Whilst few women had been recipients of enacted stigma, all of them had perceived implicit stigma. Many of the stories women told me revealed a great deal of energy consumed by worrying about their children and the impact that HIV would have on their children's lives. Potentially motherless children, a frail or ill mother unable to carry out duties that well mothers are able to, or discrimination directed at their children were scenarios that played out in the minds of many women. Denise explained how, in the early years of her diagnosis, she spent many hours worrying that someone might discover her HIV status. During this time she worked in her children's school canteen. Evident in her account is perceived stigma and worry:

I thought, oh God, what if someone finds out that I'm positive and I'm making lunches? I know that there is no risk but it's their reaction and then

what their kids will hear them say, and then they'll come to school and say something to my kids. Then I'll have to go up there and deal with it. All that emotional energy is just incredible. And it has to impact on your health.

### **Disclosure to children**

A handful of studies have examined HIV-positive mothers' disclosure to their children and all concluded that it was a difficult and complex decision (Draimin et al., 1999; Ingram & Hutchinson, 2000; Marcenko & Samost, 1999; Moneyham et al., 1996; Sandelowski, Lambe & Barroso, 2004; Schrimshaw & Siegel, 2002; Tompkins et al., 1999). Studies have found that up to 40% of mothers had disclosed to their uninfected children (Armistead et al., 1999; Ingram & Hutchinson, 2000; Tompkins et al., 1999), varying according to the mother's disease stage and ethnicity, and the child's age (Schrimshaw & Siegel, 2002; Thorne, Newell & Peckham, 2000). The child's age seemed to be the most important factor for the women in my study, but all found the decision to disclose to children extremely difficult to make.

Ten women had told at least one of their children that they were HIV-positive. Some women chose not to hide it so that their children had grown up with it, and others told their children when they were diagnosed. Joy said, "I told the kids straight away. How much they understood I don't know, but I thought this was easier than trying to keep something from them." With repeated bouts of illness, Joy thought that disclosing to her children was the only way to explain everything that was happening:

I think I had dropped down to 47 kilos and still had this chronic diarrhoea; I mean, I couldn't even do shopping. I would try to do the shopping with the kids and I would get the things to the cash register, that was it and I would poo my pants. I would say, 'Sorry kids, we are going to have to run.' And the anxiety through that was just unbearable. But the kids were really supportive and they would say, 'Come on Mum, you've done it again', but no embarrassment.

As well as telling their children, a few women told their children's school principals, usually when either they or their children's father was very unwell. The rationale for this decision was to ensure that others were watching how their children were coping with the news or an ill parent. As well as disclosing to their three children, Samantha and her husband told "their immediate teachers and the principal" when the children's father became "really sick". Samantha justified this decision as the best course of action for her children, because "we thought the kids needed support and so they knew if anything happened within the classroom, why it was actually happening."

Women who did disclose to school principals and teachers reported positive and supportive responses. Samantha's disclosure "went down really well and they were really good." However, there were occasions when peers were less supportive. When Samantha disclosed to the mother of her child's friend, whom she believed would be open-minded to this information, her daughter's friend was subsequently prevented from playing at their house, which Samantha remembered as "hard" for her daughter. Joy reported that her children had experienced a few tussles at school as a result of other children knowing her status. It is not surprising, then, that generally women decided against telling people who were involved in their children's school community in an effort to avoid ramifications for their children.

However, unwanted disclosure could also inadvertently come from one's children. To prevent ensuing discrimination, many women gave considerable thought to when their child would be able to understand the gravity of the information in relation to how others might react to this news. Goffman (1963: 72) noted that "intimates can come to play a special role in the discreditable person's management of social situations" and women in this study had to consider the role their children would play in managing their spoiled identity. Denise had disclosed her status to her son, but she and her partner were yet to tell their younger daughter. Part of the decision to keep the information from her was the fear that, when she was younger, "she would have gone to school and told the whole assembly."

I wish she could do that, but then what happens when the first time she has someone come and sleep? A couple of years ago my partner said, 'Oh, what

if those parents find out?’ I said, ‘Well is their kid in danger? No.’ I said, ‘Are we freaks? No.’ I said, ‘If they don’t like it then they’re not, not really her friends.’ That was what I said on the surface, but there’s always that wanting to protect your kids. You don’t want them to have to have other kids say mean stuff.

Even adult children did not always understand the risk of disclosure and how their mother expected them to refrain from telling others. Audrey’s son told one of his friends about his mother’s HIV status without her permission and when this friend revealed that she knew, Audrey was surprised and upset. She told her son “that he didn’t have the privilege of telling people my health status; that it was up to me.” Her son did not understand her reaction because this friend did not treat her any differently. However, Audrey explained that she felt it was her right to decide who knew and that knowing who knew about her status influenced the kind of conversations she might have. Having others know about their status without their permission or knowledge compromised women’s attempts at passing as “normal” and removed their sense of control of managing information about themselves. However, disclosure to a loved one can be burdensome for the person receiving the news and a few women recognised that unwanted disclosure could be avoided by encouraging loved one or friends to confide in one another rather than tell an additional person (see also, Persson & Richards, 2008). Laura told the people she disclosed to the names of other people who knew and told them to talk to each other:

When you give that sort of information to someone they have to do something with it because it is really overwhelming. ... They’re going to talk about it to someone, so you need to give them options of people that it doesn’t matter if they talk to them and that’s what I tried to do.

### ***Partial disclosure to children***

Most women with young children had not told their children because they judged their children to be too young, but women’s choices and approaches to disclosure were

varied. Some chose to allow HIV to be freely spoken around children in the belief that it would reduce the shock of sudden disclosure by allowing a gradual awareness. Other women who had decided against full disclosure preferred to explain HIV as “bad blood”, “bugs” or a “virus”, avoiding the use of the term HIV. This was done to avoid having their child naively repeat “HIV”, thereby bringing about unwanted disclosure and potential discrimination. Julia explained, “I was always worried that he’d go to kinder and say ‘HIV’. So I explained it as bug.”

A couple of women freely took their treatment in front of children but described it as vitamins or medication for the “bad blood” or unnamed virus. Adele explained that she wanted her daughter to have some knowledge of her status. So when she asked her why she took pills Adele told her she was “taking vitamins to keep me healthy.” Later when her daughter asked why she was not allowed to take the same vitamins as her mother, Adele told her she had “a virus in my body and without the drugs the virus will get out of control and I can get very sick.” Adele believed her daughter accepted this amount of information and explained that she was “waiting for her to probe more and to ask more.” Whilst she wanted to be “honest”, Adele’s priority was to protect her child, which for Adele meant limiting what she disclosed about her HIV status to her daughter.

### ***Deciding not to tell children***

Most women envisaged a time when they would tell their children, either when their children became sexually active or if they needed to explain illnesses that could occur in the future. However, a few women chose not to tell their children, believing there simply was no need to cause their children any anxiety, particularly if they were well. Monica said about her daughter, “I guess she will fall into that same family category. Like, why tell her, if there’s no need?”

Helen’s husband was adamant that their daughter never be told that both of her parents were HIV-positive, but Helen thought she would “find out at some point.” Helen had also considered that another family member might tell her or that “it will

slip out or she'll overhear or something." She then went on to add, "But I don't know; we might die in a car accident or something, so the need may never be there to even tell her."

Laura explained her daughter's age as one of the main reasons for deciding against disclosing her status when she and her husband were first diagnosed. She understood young children's sense of time to be very different and, because of the rapid progression of her husband's illness and death, Laura "didn't want her thinking that it was going to happen, like, tomorrow for Mum". She did not want her to be 'waking up every day thinking, is Mum going to get sick?' Laura went on to say, "I didn't want her to have a childhood that was filled with that sort of anxiety, because I was absolutely positive that she would be paying for it all of her life."

Laura had been diagnosed for 10 years when I met with her and she had still not told her daughter because "it became an irrelevancy in a lot of ways." Laura had stayed well and, because HIV had become a "very small part of my life", Laura had decided "she doesn't need to be concerned with that." Whilst Laura questioned her decision to not tell her daughter, the fear of disclosure negatively impacting on her daughter's life was her justification for keeping this information from her:

Motherhood brings up those wonderful things about: do you tell your kids? What do you tell your kids? When do you tell your kids? How do you tell your kids? Should you tell your kids? Shouldn't you tell your kids? ... I have come up with all these excuses over the years but the bottom line is I am just too chicken to do it.

Women's decisions about disclosure were very much driven by their desires to protect the people they loved. This was particularly so for women who were mothers, but also applied to family members and friends. Women were aware of the burden that disclosure placed on the recipient and they gave careful consideration to what that information might do to their relationships.

## Private accounts, peer support and isolation

Goffman (1963: 49) noted that one who becomes stigmatised later in life will need to learn “a second way of being”. For HIV-positive women this second way of being is often learned from other HIV-positive people, particularly women. Some of the things women told me that they learned from meeting other HIV-positive women included information about their disease, services available, information management, and disclosure. Women also learned about the plight of HIV-positive people, the stigma and the assumptions made about them. It is common in Australia for HIV-positive people to be categorised as “innocent” (Sandelowski, Lambe & Barroso, 2004)<sup>1</sup>. Many of the women in my study thought that the majority of services, information, and the categories of guilt and innocence: that is, those who were infected by blood products or their husbands (innocent) as opposed to those who were infected by drug use or sexual contact outside a regular or permanent relationship (guilty).

Among the women I spoke with there was a contrast between those women who felt part of a group and for whom meeting other HIV-positive women helped to reduce their perceived stigma, and those women for whom mixing with other HIV-positive women increased or heightened their perceived stigma. This seemed to be somewhat dependent on whether the woman was diagnosed before or after the availability of ARV treatments and the length of time since diagnosis. Almost all of the women in my study had met with another HIV-positive woman at some stage since their diagnosis. All of these women had appreciated meeting with other women; for some, it played a vital part in the acceptance of their disease and reduced their sense of isolation. For many, it provided hope for longevity and continuity of the life they had envisaged before their diagnosis. Audrey remembered her first meeting of “women who have survived 20 years” and described it as “awesome; it was just incredible.” Rachel was also keen to meet another positive woman, which she did, and found it “really good and she was really supportive.”

Meeting with other women seemed particularly important for the few women who were diagnosed early in the epidemic. Some of these women spent several years without meeting another woman and they summed up this experience as very



isolating. For eight years, the only other person living with HIV that Denise knew was her partner. It was difficult for her,

... not knowing any other positive women or feeling like we're going through this by ourselves. There was no one to check information out with and there wasn't the information that you needed anyway. Besides, we were keeping silent out of fear: the stigma of not wanting to be judged.

It was very important for some women to meet with another HIV-positive woman soon after they were diagnosed. For others, the desire to do so could take years to emerge. Brooke did not meet with other women until four years after her diagnosis because "I wasn't ready." But once she did, she found that "it all started to get better – just listening to the experiences of other women." Adele also resisted meeting with other positive women "because I was just coping, struggling to cope with it." Although Adele did have a positive gay male friend who "who understood what I was going through", she still had not yet met with another positive woman, saying, "I don't feel like there is anything missing from my life. I mean they might help but I certainly don't feel that I need it now."

Meeting another woman with HIV could be a very powerful experience. However, some women found that having the same HIV status as another woman was not enough to form enduring friendships. Joy remembered when she was first diagnosed she formed a very close relationship with another HIV-positive woman over the phone, but when they actually met they lacked "that connection face-to-face." Eight years after her diagnosis, when Denise did finally meet with four or five other positive women, most of them had children. It soon became apparent to her that only she and one other woman had a history of injecting drug use and her first thoughts were, "Oh, I haven't got much in common with those women." But Denise found her meetings with these women to be beneficial, because, "Just seeing them and hearing them was giving me some support; some emotional support."

It was not uncommon for the women in this study to say that their partner, family or friends often avoided talking about HIV and pretended everything was as it used to be. Helen said that, after she and her husband told her family and their initial

questions were answered, “it hasn’t really been spoken about again.” Helen went on to say that, if she does bring it up with someone in her family, she or he will immediately change the subject. Helen interpreted this silence as distress, saying, “I don’t think they don’t want to talk about because they don’t care; I think it upsets them too much.” In this way, peer support could provide women with others with whom they could share the burden of their disease without having to worry about distressing their loved ones.

However, not all women benefited from meeting with peers, particularly before the health and longevity of PLWHA were improved with the introduction of HAART. Two women who were attending peer support groups prior to HAART stopped attending because they found it very confronting. Sophie remembered it as “so depressing. Everyone was talking about who was dying, who’s dead, which one’s dying and how this one’s shitting itself and this one needs to spew.” Miranda had a similar experience, finding these meetings “traumatic” because “they were still dying back then.” Seeing and hearing about the many illnesses and death experienced by other people living with HIV/AIDS could be more difficult to deal with than the sense of isolation experienced by not meeting with others living with HIV.

The fear of stigma or identification of being HIV-positive has been acknowledged as a factor contributing to the isolation of HIV-positive women (Ingram & Hutchinson, 1999) and sometimes self-exclusion from information, treatment and care (Malcolm et al., 1998). A couple of women in my study avoided other HIV-positive people because they believed it would confirm their status. Clare had met a few other HIV-positive people but she did not disclose her status to them. She interpreted her reluctance to disclose as her own discomfort with her status, saying she was in the “early stage of ‘I’m not 100% comfortable with everything yet’.” She feared that she might “freak out” and that it would reinforce her status: “Well, I really am and everyone knows I am now.” Polly believed that, by avoiding others living with HIV, she could escape the worry of possibly becoming ill in the future that was “always there in the pit of my stomach.” She went on to say, “I’d like to be free of that and sometimes I feel, if I keep away from others, which is hard because I have met some really nice women, but then I can deny it and be a lot happier.” Confirmation of one’s

status for these women would have compromised their ability to pass as “normal” women.

### **Public accounts**

Others have written about the decisions made by chronically ill people who decide to publicly declare their illness in an effort to educate the wider public or bring attention to their disease (Brophy, 2003; Hopkins Tanne, 2001). Such accounts are typically quest narratives (Frank, 1995), in which “illness becomes a motivator for social action or change” (Thomas-MacLean, 2004: 1649). Female celebrities in Australia who have made public their journeys with breast cancer include Olivia Newton-John, Jane McGrath, Kylie Minogue and Belinda Emmett. Susan Sontag (1978) argued that cancer was a highly stigmatised illness but noted in her book, *AIDS and its metaphors* (1990: 104), that “the onus of cancer has been lifted by the emergence of a disease whose charge of stigmatization, whose capacity to create spoiled identity, is far greater.” Sonia Lawless and her colleagues noted that HIV elicits “judgements of personal responsibility and blame to an extent unseen in other illness” (Lawless, Kippax & Crawford, 1996: 1371). In the past, society categorised HIV-positive women as “innocent” or “blameworthy”, depending on how they acquired their HIV infection. Universal blood-handling guidelines have almost eliminated the risk of acquiring HIV through medical procedures or blood products and therefore the category of “innocent” is rarely used now for women. Consequently most women are considered to blame for their HIV infection and some women in this study set about publicly challenging that notion.

### **Public accounts and the greater good**

Despite the risk of stigma, some HIV-positive women in Australia have declared their status publicly. They have usually done this in the hope of educating the wider public, reducing transmission rates, and reducing stigma for others living with HIV. Nine women in my study had constructed public accounts of their HIV status that they were

prepared to disclose to strangers in the hope that they would educate people about the transmission of HIV as well as help reduce the stereotypes and stigma surrounding HIV/AIDS. Some women were involved in their state-based Positive Speakers' Bureau, whilst others accepted speaking engagements to educate health-care professionals. Eight of these women gave public accounts to media, including television, radio and print interviews.

Most women felt they were “making a difference” by disclosing their status publicly. Some women also felt they were “making good out of bad” and that “things happened for a reason.” Layla’s experience having her first baby made her realise that “a lot of people need a lot of education.” When she accepted her first invitation to speak to midwives about her “experience as a positive mother”, she described her motivation as “knowing that hopefully the other women would benefit by these people having a better understanding about the needs of positive mothers.” Similarly, speaking with young people appealed to some of the women involved in the Speakers' Bureau. Audrey explained the public-speaking she did at schools as something she could do “to take the positive out of it and use it to the best of your ability.” Denise also envisaged benefiting her own children through the public-speaking she did with students: “I thought these young people that we’re impacting on are the kids in the generation that my kids are going to grow up with.” Denise also explained that she was contributing to the breaking-down of stereotypes when she disclosed her drug use in conjunction with her HIV status, because the students said things to her such as, “‘Oh, but you don’t look like you use drugs and you don’t look like someone that’s positive.’ So I was challenging that thinking.” Other women also thought that, by telling their story, they might help reduce the stigma attached to being an HIV-positive woman and the assumptions people made about them. This was particularly so for women who contracted HIV from their husbands or partners. Joy explained she was simply “a Mum at home looking after my kids, ... and I am not going to be ashamed of that and that is why I will talk and speak publicly and will do whatever I can.” Implicit in Joy’s account are the categories of guilt and innocence and, whilst Joy’s public narrative might avoid this dichotomy, her private narrative emphasises her innocence and her justification for refusing to feel shame.

It is important to note that, whilst only a handful of women had constructed a public account for sharing with strangers, all of the women who participated in my study shared their story with at least one stranger: me. Most did so in the hope that it would benefit other HIV-positive women. The advertisement for the study informed potential participants that “It is also hoped that a booklet discussing pregnancy and motherhood in HIV-positive women will arise from my study. The booklet will be distributed to participants and to organisations that support and care for HIV-positive women” (see Appendix F). I also asked each woman at the end of her interview why she agreed to participate. Almost all of them responded with altruistic reasons. Miranda’s reasoning was typical of many: “Oh, just for other women, really, who are making reproductive choices. Because I know how hard it was. They can make a better choice and it is not so scary.”

Goffman (1963: 37) argues that “‘speakers’ ... provide a living model of fully-normal achievement” and “proving that an individual of this kind can be a good person.” Most women in this study had benefited from hearing the narratives of other PLWHA because it helped to reduce stigma and isolation. Some of these women had reached a stage in their journey as a women living with HIV at which they were able to reflect on the benefits they had gained from hearing these stories and viewed public-speaking as an opportunity to benefit others in the same way they had. By participating in public-speaking, women were validating their own accounts that emphasised they were just normal women who, by chance, came to be living with this disease and that they were good citizens contributing to the education of others and possible prevention of HIV, as well as the reduction of stigma for PLWHA.

### **Public accounts and children**

Seven of the nine women who had constructed a public account of their HIV infection had children. Of the seven women with children who had constructed public accounts to share with strangers, four had told their children of their status, one had told one child but not her younger child, and two women had not told their children, although one of these children knew that her father had died of an AIDS-related illness.

What women were prepared to do with their public accounts was somewhat dependent on whether or not they had disclosed to their children and the age of their child. A few women were prepared to do public-speaking and media while their children were young and there was little chance of negative consequences or stigma for their child. Once their child started school, they stopped this work in the hope of “protecting” or “shielding” their child. Kate and her husband did media interviews about the birth of their daughter, which included print media with photos and radio interviews. Kate thought her daughter, who was a baby at the time, could “be protected from any hurtful ramifications that could possibly have come up. As she’s gotten older we made the conscious decision to shut that stuff down.”

Women with older children told of consulting their children about what kind of public work their children were comfortable with. Samantha said she sought her children’s “permission” before she did any public-speaking. In addition, she and her children had together constructed a public account should anyone question them about Samantha’s involvement: “They always say, ‘Well, Mum’s just a volunteer at the AIDS Council,’ so if they don’t want to say that I’m positive, they just say, ‘Mum’s a volunteer’, which is easy.” This allowed for Samantha to pass as a “normal” mother and thereby reduce the risk of enacted stigma. By including their children in the decision about the public accounts women gave, it enabled the women and their children to discuss how they would deal with any questions that might be asked and co-construct public versions that were acceptable to everyone. It also allowed the women to demonstrate to their children that they were sensitive to their children’s concerns.

All of the women attempted to protect their children from any potential ramifications related to the public-speaking they were involved with. Women who had disclosed to their children made a point of discussing the children’s concerns with them. Leanna was involved with the Positive Speakers’ Bureau and her son was “always very, very nervous in the beginning with me going to high schools in particular.” Leanna promised that she would never speak at his school and never mention his or his father’s name to prevent him from being identified. Leanna also spoke of her son’s concern about anything that mentioned HIV in their home, such as computer files or

pamphlets left around the house, in case a friend might see it. Leanna believed “he was very, very afraid that people would find out and he would be ostracised as a result. I think that was a very real fear for him and it was something that made him feel different to everybody else.”

Denise and Laura had teenage daughters to whom they had not disclosed. They both had experienced criticism from others about their decision not to disclose to their children, particularly in relation to the public work they did and the chance that their children might find out through the media. Consistent with women’s awareness of the need to protect their children, both women recognised the “emotional load” they would be imposing on them and had therefore decided to avoid giving their children this “burden”. Denise’s daughter was aware that both her parents had been drug-users and spent time in prison because of their addiction. Denise interpreted this information as “enough of an emotional load ... without the HIV”.<sup>11</sup>

Whilst Laura’s daughter did not know about her mother’s HIV infection, she did know that her father had died from an AIDS-related illness. Laura believed she was able to pass as an activist who, in her daughter’s eyes, was “fighting” against “discrimination that goes on with positive and gay people.” Laura attributed her daughter’s unquestioning acceptance of any public HIV-related work she had done to this belief. She had spoken publicly about her HIV status to media and had been on television. In an effort to protect her daughter from enacted stigma, Laura said she was “careful about who I speak to and what sort of things I allow to be released.” Both Denise and Laura conceded that they would disclose to their children if they were to get sick.

## **Public and private accounts of childlessness**

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<sup>11</sup> Denise wrote to me 18 months after we met, saying that her daughter now knew her mother and father were HIV-positive. She found out after she saw a newspaper interview that Denise and her partner had done. Denise believed that her daughter was “more upset about being the only one who didn’t know” than about the HIV. Denise also thought that her daughter had “handled it well” and that that could be attributed to her having access to “lots of accurate information” as a result of being around HIV all of her life.

Women without children in Australian society are often expected to explain their childlessness (Kirkman, 2001). When HIV-positive women confront this expectation they are also faced with the dilemma of disclosure. Several women recalled occasions at which they were requested to explain their childless lives and had devised ways of halting further inquisition from unaware outsiders. Yvette was childless because she was diagnosed with HIV in 1986 and then later discovered she was co-infected with hepatitis C. She had constructed a number of public responses to any questioning about her being childless such as: “Then I would have to have a man in my life!”, “I like to have them and then give them back!” or “It’s a long story.” Yvette gave humorous responses to questions that evoked pain and grief.

Layla spent the first three years of her diagnosis believing she would be unable to have children, so when people inquired about when she and her husband would be starting their family, she told them, “We can’t have children”, saying “that would shut them up.” This explanation backfired when she became pregnant and people remembered what she had told them. She then had to construct a new account, telling people:

“Oh, it’s just a miracle! It’s really meant to be, we couldn’t believe it.” So I felt like a bit of a fool but some people expect your life to take a certain course; you get married, you have kids, that sort of stuff and if it doesn’t go according to plan you’ve got to have some sort of excuse for that. It’s crazy.

Louise was the only woman in my study for whom a child-free life was preferred and not influenced by her HIV status. She was an only child and her partner was from a “traditional” family. Louise said, “There was so much pressure it was unbelievable”, from both of their families to have children. This issue was further complicated because they had not told either family about her HIV status. Louise’s choice not to have children had contributed to a considerable rift between herself and her mother, which resulted in them not talking for seven years. Louise believed her age (38) and the fact that her partner’s parents had since become grandparents had helped reduce some of the pressure she felt.



However, Louise said that she thought that some people saw her as a pariah because she did not have any children and did not want to have any. She likened society's attitude to women without children to that of HIV-positive women and thought education was required on both fronts; explaining, "Just because we don't want kids it doesn't mean that we're axe murderers; because we are seen as freaks, basically. It's like, how can you?"

## Summary

HIV-positive women are vulnerable to exacerbated stigma because of their child-bearing capabilities and their roles as mothers. Even though many of the women in my study had not experienced enacted stigma, they all had perceived stigma. This was often intensified for women who were mothers. Being HIV-positive not only presented these women with a personal risk and fear of stigma but also posed a threat to the well-being and safety of their children.

The risk of stigma resulted in most women constructing at least two accounts of their HIV status. Generally, women's accounts were private, with different versions constructed for different audiences. Most women with young children had not yet disclosed their status to them, although most envisaged a time when they would. A few had decided it was too great a burden for their children and considered disclosure only in the context of illness. Those women who did construct public accounts did so in the hope they would educate others and help reduce stigma for other positive women and their families. These women gave careful consideration to their public accounts in a concerted effort to protect their children.

The stigmatised nature of HIV meant that ultimately many women did not tell work colleagues and even friends or family members. The consequence of this non-disclosure was that some women were isolated within their disease which, in turn, left them unsupported in their anxiety and concerns.

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## Chapter 7

### *Living with uncertainty*

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Living with uncertainty has been identified by others as a major part of living with chronic or life-threatening illness (Cohen, 1993; Kostbade-Hughes, 1993; Wiener & Dodd, 1993; Wray, 2004), including HIV/AIDS (Brauhn, 1998; Brown & Powell-Cope, 1991; Crossley, 1998a; Katz, 1996; Siegel & Krauss, 1991; Weitz, 1989), even after the introduction of HAART (Anderson & Weatherburn, 1998; Davis, Frankis & Flowers, 2006; Rier & Indyk, 2006; Sowell, Phillips & Grier, 1998; Trainor & Ezer, 2000). An HIV diagnosis disrupts not only one's sense of identity but also disrupts one's ability to plan for the future (D'Cruz, 2003; Katz, 1996).

Van den Burg (1972: 4) argued that the onset of serious illness results in the end of normal life: "One suddenly becomes uncertain about things most taken for granted: faith and integrity of the body, of one's role in other people's lives and their role in one's own life, and faith in the future." Others have explored the temporal orientations of HIV-positive people utilising narrative theory (see, for example, Berger, 2004; Cameron, 2001; Crossley, 1998a; Ezzy, 2000; Stevens, 1996; Stevens & Doerr, 1997; Viney & Bousfield, 1991). Crossley (née Davies) (2000; Davies, 1997) identified that an HIV-positive diagnosis condemned the individual to the present and prevented the projection of the future, particularly in the early years of the epidemic. However, as time passed, so too did the initial belief that death was imminent and inevitable. Crossley (2000: 142; Davies, 1997) went on to say that PLWHA must live with the confusion of two "ways of being". The first involves a closing-off of the future as one prepares for death. The second involves an opening of the future and "battling against the obstacles blocking one's path." This dilemma is compounded by the advances in antiretroviral treatment.

The future orientations of PLWHA have also been explored in relation to work and financial needs (Ezzy, de Visser, Grubb et al., 1998; McReynolds, 2001) as well as how parents with HIV/AIDS plan for the care of their children after their death (Barnes, Taylor-Brown & Wiener, 1997; Heath & Rodway, 1999; Simoni et al., 2000; Thorne, Newell & Peckham, 2000; Van Devanter et al., 1999). However, little has been written about how HIV-positive mothers envisage their own futures or how HIV-positive women experience longevity while living with uncertainty, particularly within the context of potential stigmatisation. In this chapter I explore the use of narrative forms to examine how PLWHA envisage their future. I then explore how the women in my study accounted for the future and the ways in which that may have changed over time. I also examine how women's experiences and understandings of illness influenced these accounts. Finally, I explore the role of HAART and whether this provided women with hope.

### **Narrative forms and PLWHA**

Narrative forms have been utilised to explore the illness or disease stories of PLWHA, building on Arthur Frank's (1995) three narrative forms: restitution, chaos and quest. Briefly, the plot of the restitution narrative is built on the premise: I was healthy yesterday, today I am ill, and tomorrow I will be healthy again. The emphasis is on health and therefore restitution narratives are inadequate when the illness is terminal or chronic. The plot of the chaos narrative suggests life will never get better. The stories are chaotic in the sense that they lack coherent sequence or narrative order. The quest narrative involves meeting the illness head on, based on the premise that there is something to be gained by the experience of becoming ill. Douglas Ezzy (2000) developed this idea and proposed two narrative forms, "linear" and "polyphonic", to examine time and hope in the lives of PLWHA with a particular interest in spirituality and religious beliefs. Michele Crossley (2000) also used these three forms, reworking them for people who were long-term survivors of HIV/AIDS. She referred to them as "living with a philosophy of the present/conversion growth story" (quest), "living in the future/normalising story" (restitution), and "living in the empty present/story of loss" (chaos). Whilst both of these researchers' contributions

are important to understanding the experience of time for PLWHA, their participants were predominantly gay men and I argue that the experience for women, particularly mothers, is different and needs to be reconsidered.

The chaos or “living in the empty present” narrative form can be discerned in many of the accounts of people explaining their lives after they were diagnosed with HIV. When the diagnosis is completely unexpected and therefore shocking, many people, including the women in my study, have described this time as chaotic. Additionally, in the absence of treatment, when there was little hope or expectation of longevity, some people found themselves unable to move beyond this chaos. Others were able to do so and adopted a narrative of “living with the philosophy of the present” or quest. Also referred to as conversion/growth stories (Crossley, 2000), this narrative form enables one to seek meaning from living with a life-threatening and highly stigmatised disease. Some people, even prior to the availability of HAART, have always refused to allow HIV to interfere with the way they envisaged the future and, as a result, these people adopt a restitution or “living in the future” narrative form that enables them to continue to imagine a future and make plans accordingly. As Ezzy (2000: 616) pointed out, narratives “are always in-process and somewhat inconsistent and unfinished.” In short, as time passes and one survives, she or he can transition to another narrative form to make meaning and sense of her/his life.

Prior to HAART, the narrative form of living with a philosophy of the present was the narrative form most discernable in the accounts of PLWHA once they moved beyond the chaos of their diagnosis, as demonstrated by the research of Ezzy (2000) and Crossley (1998a; 2000; Davies, 1997). As noted by Davies (1997: 567), this narrative form provided a sense of “liberation from the shackles of everyday existence in which one is always fighting toward the future.” This freedom allowed one to enjoy the present rather than focusing on the possibilities for the future. One could imagine this would be preferable when the future is likely to include illness and death. The philosophy of the present also meant that women who had children could focus on making the most of the time they had and enjoy each day of mothering their child. However, many mothers living with HIV found it difficult to mother without thinking about the future, because part of being a good mother includes being present for all of their children’s milestones. As demonstrated by the women in this study, the future is

implicit in motherhood – they did not want to be free from the shackles of planning for theirs and their children’s futures. Even though many who were diagnosed prior to HAART found it difficult to plan for long periods of time, they instead set short-term goals, which they revised as each milestone was met. HAART offered the prospect of considering even longer periods of time and most women, particularly those diagnosed post-HAART, preferred to envisage the future, as normal mothers do, and imagine a life of normal longevity in which they would live to see their children grow up.

In the short term, after diagnosis, the women in this study put a lot of effort into retaining their identity as “normal” women. For many who had not yet had the children they planned, this entailed spending a considerable amount of time focusing on their quest to become mothers. This usually included assessing and managing their own health and then taking all the steps they deemed necessary to avoid vertical transmission. In a sense, these were practical tasks with a short-term focus. Similarly, women who were diagnosed and already mothers also often focused on practical tasks including the daily care of their children. This sometimes included thinking about who would care for their children after they died. All of the mothers in this study presented a narrative of “good mothering”, which included protecting their children from the risk of HIV transmission as well as the stigma that could ensue. Integral to the narrative of good mothering was living to see their children into adulthood and bearing witness to their children’s milestones.

In the end, like other “normal” women in Australian society, the women in this study wanted to be “good” mothers. However, an uncertain future often meant motherhood was fraught with anxiety that could not be resolved for all women. There is no conclusion to HIV other than death. Even after treatment, HIV does not go away and biomedicine is still unable to provide any real idea of what the long-term future looks like for people living with HIV.

The women who told me their stories were at different stages of their journey with HIV. The length of time since diagnosis varied from 12 months to 16 years; a few women had been extremely ill but most were asymptomatic. However, how they constructed their future depended on several factors, including whether they were

diagnosed before or after HAART, whether they had been ill, and whether they had witnessed the illness and death of others.

I asked women how HIV influenced their thoughts about the future and whether HAART was a factor in this. The way in which most women envisaged their future changed over time from being a day-to-day prospect when they were first diagnosed, to setting short-term goals (such as one year), to longer-term goal-setting (such as five or more years). Women's ability to revise their accounts of the future was significantly influenced by whether they were diagnosed before or after the availability of HAART.

### **Day-to-day**

Nearly all women recounted the period after their diagnosis as a day-to-day proposition. Most assumed impending death and experienced a disruption to their plans. During this time, women can be understood as "getting their head around the virus" and "reframing their sense of their self" (McDonald, 2002: 129). Even when women moved beyond the initial shock and devastation of their diagnosis, some were never able to envisage the same future they had once imagined. Of course, for the women who were diagnosed prior to HAART, there was little prospect of longevity and these women were often unable to imagine any future at all. Some women changed their plans, thinking their life would soon be over. Miranda had been living overseas for six years when she was diagnosed. She decided to return to Australia because she thought she "was going to die within a year."

Some of these women spent years believing that illness would suddenly descend on them. Living day-to-day was described as a way of coping; the only certain thing about the future was illness and death. Denise explained the apparent futility in thinking about the future, saying:

I've just lived one day at a time for so long. I don't think, 'Oh next Christmas I'm going to do this or that.' I think for so long it was always, 'Oh in the future I'll get sicker,' and I don't know when that will be.

By only thinking about one day at a time, Denise and women like her were able to impose some control over their lives by managing issues as they arose. This enabled them to cope with vulnerability and uncertainty.

### **Beyond day-to-day**

Both the availability of HAART and the experience of survival led to the revision of day-to-day living for many women. Most women found themselves with the prospect of a future, albeit very uncertain. At this point, women moved into the subjunctive mode as they began to imagine a future in which multiple pathways were possible. The possibilities could include: a long life in which they may be lucky enough to be a so-called long-term non-progressor (when PLWHA lived for more than 10 years without any symptoms and minimal immune system damage); ten or so years of being asymptomatic before requiring treatments or; the improvement of treatments so that side-effects were minimal and HIV was truly a chronic manageable illness. As women began to consider these possibilities they gradually revised their accounts of the future to include longer periods of time. Kate explained that "in the early years" she felt she had to live long enough to see her daughter start school. At the time of the interview her daughter was eight and Kate had revised that goal, not only to include seeing her daughter start high school, but also staying well, "until she can be an independent functioning person; an adult." Layla told of revising her goals beyond hoping to see her first daughter start school, to starting high school and then, later, hoping to be present at her 21st birthday:

I don't need to do a few years ahead because that few years ahead comes by so quickly anyway. I suppose also that in these 10 years I am still as well as I was, and I can't see that changing in the foreseeable future. So there's no need to reach for a certain number of years. It's a bit of a change.



Layla went on to explain, “I think before I was giving myself little goals for the future, but now I just get on with it, really. I don’t feel like I need to do that any more.” Remaining asymptomatic for so many years and reaching many of her short-term goals removed some of the urgency Layla felt about the present and gave her the hope that she could continue to stay well and fulfil her role as a mother. Tara explained it succinctly, telling me that, once the initial phase of shock had passed, she realised that “Everything that was there before is still there and everything that is to come is still to come.”

However, a few women acknowledged that, although their future no longer felt dire or urgent, as Layla explained, “it still feels slightly uncertain.” Although Stephanie hoped that she would live long enough to see her toddler son become independent, she, too, conceded uncertainty, because her husband was 20 years older than she and so, “if it is not me then it will be him. ... Even though I am fine now, no one can really predict what will happen in the future. ... So I am not sure when I start to think of the longer-term future.”

### ***Longer-term planning***

Most women had not incorporated HAART as the key to a long life in their accounts of their futures. However, HAART clearly did provide new hope. The women who were diagnosed post-HAART gave accounts of believing they could live well into the future. These women did not usually construct their future journey based on milestones in the same way as women who had less faith in HAART. A couple of women believed they could live to become grandmothers. Adele based her account of the future on the success of HAART, saying, “I am so healthy and the drugs are working and everything is going fine, I am looking at being a grandmother.” She went on to add, “I probably won’t be 96 like my grandmother and still going strong, but I am looking at being up that way.”

A few mothers who were diagnosed post-HAART claimed that HIV had not led them to revise their future; they intended to continue being the mother they were before HIV and live to see their children grow up. Helen said, “HIV hasn’t changed motherhood for me ... I’m going to be here forever and I’m not going to miss out on seeing her finish high school. I’m going to be here for her. So nothing’s really changed.” These women were more willing to embrace the “long-term manageable chronic illness” narrative that the availability of HAART had allowed and they tended to minimise HIV to medical appointments and pills.

However, in general, women were less optimistic about a life of “normal” longevity. Sarah found it difficult to look too far into the future explaining that she took, “each day as it comes”:

I try not to think that I am going tomorrow but I also don’t kid myself. I know I haven’t got as much time as everybody, so I figure it’s just make the most of the time with my little girl that I have got.

## **Illness**

Most of the women in this study were asymptomatic, did not require antiretroviral therapy and had never had an AIDS-defining illness. However, the threat of illness was present and many women had given considerable thought to this possibility and what it would mean for their families, particularly their children. Five women had also experienced the death of their partner or husband. Most of these women had considered contingency plans for their children. In contrast, several women actively tried not to think about the possibility of illness or death, finding it too painful or upsetting to think about leaving their children without a mother.

## Women who have had AIDS

Only two women in this study, Joy and Georgia, had been diagnosed with an AIDS-defining illness. Georgia spent 18 months extremely unwell, undergoing all sorts of tests before she was finally diagnosed with AIDS. She changed doctors several times during this period, trying to find an answer for her ill-health. After hardly being able to eat for three months, she was diagnosed with oesophageal candidiasis, a “telltale sign of AIDS.” At that point her T-cell count was 50 copies/mL and her viral load was over one million copies/mL. Georgia started treatment immediately and described her road to recovery as “slowly, slowly” but felt that, four years on, she was still “getting better and better.”

Georgia thought she had unknowingly lived with HIV for up to 14 years before she was diagnosed with AIDS. Being diagnosed brought her motherhood identity to the fore and she was actively pursuing her quest of motherhood at the time of interview. Georgia’s experience with treatments was positive and she was hopeful they would provide her with longevity. She had considered that she might not live to see her child grow up but it was,

... a matter of ... being positive and not letting it affect your life and saying, “What is the difference? What does it really affect? My boyfriend has to wear a condom. I may not have kids. I have to look after my health far better but apart from that I could still lead a normal life; especially with the treatment now.

Whilst Georgia was concerned that she may not live to see her prospective child grow up, she did not think this was likely. Rather, she had considerable faith that treatment would provide her with a “normal” life that included relatively normal longevity and therefore, unlike Joy, she did not consider the virus as threatening to her sense of future.

Joy was diagnosed in 1994 because, like Georgia, she had experienced unexplained ill-health. Joy also had three miscarriages in one year which she attributed, at the time, to anaemia. Five years after her diagnosis she felt her life was “just slipping away.”

She was losing weight, experienced chronic diarrhoea and said, “My head wasn’t where it should have been because of all the stress.” Shortly after, she was diagnosed with CMV (Cytomegalovirus) and admitted to hospital. Joy was losing sight in one of her eyes. She had a shunt inserted into her chest and spent the next 18 months having chemotherapy and Ganciclovir. Joy described this time as “reality time”, saying she “hit the wall.” That was when she thought, “This isn’t going to go away. ... I had nothing worked out for the kids, no wills. That was always my biggest fear; what was going to happen when I died? Where were they going to go?” Joy found peace of mind from organising custodial arrangements for her children in the event of her death.

Joy also experienced significant lipoatrophy from HIV treatment and she described “trying to get my head around going from a size 12 down to a size 8 with everything falling off me; basically being skin and bone.” Joy found these physical changes a difficult part of living with HIV, saying “even though these medications are making us live longer, which is great”, that it was a painful reminder every day when she looked in the mirror. Consequently Joy said she was unable to consider the longer-term future and could not move beyond living her life day-to-day. Joy attributed this unwillingness to her sudden decline into ill health to saying, “I saw myself go down too quick so I don’t like to dwell on that [future]. I can see how it can get you just like that if your guard is down. But as far as holidays go we will make plans for the following year but that is it and then we get back on to today.” By focusing on the day-to-day aspects of life, Joy could remain in control of her stress and remain vigilant against the effects HIV was having on her health.

Despite both women experiencing extreme ill-health and believing they were close to death, they were at very different stages of their journey with HIV and motherhood. Both women were relying on treatments for their health, but their experiences with treatments were quite different and thus so were their accounts of the imagined future. The most likely explanation for this was the environment in which the women were diagnosed. Joy was diagnosed prior to HAART, when diagnosis equated with death and, when HAART did become available, her interaction with treatment had been difficult, with strict treatment regimes that required planning meals around her

treatment times and side-effects that diminished her quality of life. Although she was now on a “good” combination, Joy believed she had few treatments options left:

So I only have got a few combinations, two to be exact, up my sleeve, if these ones fail. So at this stage I am staying one step ahead of what the pharmaceutical companies can come out with but how long that will last I don't know. It is just the luck of it.

Joy felt she had little, if any, control over her journey with HIV. In contrast, Georgia, who was diagnosed after HAART, started treatment immediately and it had improved her health, with few side-effects. She believed that HIV had altered the course of her journey but that she remained in control. Although both women had probably been HIV-positive for a similar amount of time, their experience of HIV was very different. Joy had not only witnessed the ravaging effects of HIV and treatments but had also experienced them herself, whereas Georgia had not known about her HIV status for very long, treatment was successful, and she had not been an active participant in the PLWHA community prior to HAART.

### **Death of a partner**

Five women had lost a partner to AIDS. All of these women were tested and diagnosed as a result of their husband's illness. In addition to finding out that they and their husband were HIV-positive, Laura, Eliza and Samantha all had to cope with the illness and subsequent death of their husband, within 12 months of this shocking news. Not surprisingly, these women saw their future potential for illness reflected in the experience of their husbands. Eliza remembered feeling “very, very sad” when caring for her husband because, in the future, she too would “get sick like my husband.” Samantha also recalled watching the illness and death of her husband who, towards the end of his life, was unable to walk and no longer remembered her or their children. He died from lymphoma within one year of diagnosis:

At the time, I thought my life was going to be ending too, because watching him die I thought I was going to die as well because I still really didn't have a proper understanding of the whole thing. It was a very short time. There was a lot of anger and a lot of everything. We told parents, we told close friends. I had to work out wills and what was going to happen with our house and what was going to happen with the children: who were they going to go to? What Anthony wanted when he went, how he wanted to be buried, the funeral, the whole bit. The kids organised that as well. We had a pretty traumatic 11 months.

Kate's and Leanna's partners lived nine and 11 years respectively after diagnosis before they died of AIDS-related illnesses. Kate's husband had died only 12 months before we met and it was something she did not wish to dwell on because it was still very painful. However, Kate did say that, since they had been diagnosed, she had focused on her husband rather than herself, because he had been unwell for many years. As a result, until his death, she had not really reflected on how HIV might also make her unwell. Being a sole parent also increased her sense of fragility:

I suppose I was detached from it at some level and really, since Shaun died, it is almost like the realisation that, 'Wow, it's not just him; it's me as well'. ... That you are on your own with this and it is not buffered by someone else and so there is a great deal of pressure on you to stay well for your child.

Leanna's main focus on her future after her partner died was living long enough to get her son to an age at which he could be independent. Leanna recalled going to her doctor around one year after her partner's death and asking him if he thought she could live another four years because her "benchmark was always when he turned 18. Because I felt like at least if he was 18 and he had lost both of his parents that he may have been able to cope far better than if he had been 12 or 14." Leanna said her doctor told her that he was confident that she could live that long, although he was unsure how well she would be. At this time, Leanna was focusing on the quantity of her life rather than the quality. She had reached her goal by the time I met with her but, by this time, her health had significantly declined. Leanna had by then redirected her focus to the quality of her life with a complex treatment plan that addressed both her

HIV and hepatitis C infection. She was hopeful that within 18 months her health and quality of life would improve.

The deaths of partners emphasised the likelihood of a future of illness and death but, at the same time, made women all the more determined to survive for as long as they possibly could to avoid orphaning their children. Four of these women had re-partnered and they all found consolation knowing that their children had someone else they could rely on in the event of their mother's death. This was particularly so when their new partner was HIV-negative, which was the case for three women. Samantha found comfort knowing her partner would care for her children "if anything happened to her" and that they would "actually all stay together."

Five other women had also lost their ex-husbands or ex-partners to AIDS. It was notable that none of these women reflected on what the death of the ex-partner meant to them. Janice remembered it was "sad" because her ex-partner had dementia at the end of his life, and Miranda and Adele spoke about their children and the effect that the death of their father had had on them. Stephanie and Celia mentioned that their ex-partners had both died within two years of their diagnosis but these deaths were recounted to explain how they were infected with HIV. It is likely that these women did not dwell on the deaths of their ex-partners so they could avoid thinking about a possible parallel fate for themselves. It is also possible they still blamed their ex-partners for their infection and, that by disassociating themselves from their ex-partner's death, they could minimise the impact HIV had on their everyday lives. But it is also important to acknowledge that the emphasis in the interview was mothering and this influenced the joint construction of the accounts women gave me.

### **The possibility of illness**

I asked the women who had not been ill with HIV or an AIDS-related illness if they had thought about illness as a possibility and how this affected their sense of self and motherhood. Almost all women had given some thought to the possibility of illness in the future, but to a varied extent. Once women moved beyond assuming the

inevitability of illness when they were first diagnosed, most reconstructed their accounts of the future (often with children), and the thought of getting sick in the future remained distant for some women. However, many women preferred to avoid thinking about it altogether.

As a strategy for maintaining normalcy, many women tried to forget that they were HIV-positive and continued with their life as planned. Celia said, “I try not to think about it. ... I know it will happen but I don’t like to think about it.” Stephanie explained that it is a painful thought, particularly in relation to leaving behind a child. “It is upsetting to think about and sometimes I just try to put these thoughts aside. I try to forget it.” Women who had been diagnosed after HAART (in the five years prior to the interview) tended to explain HIV as something that would not have a significant impact on their life until they became unwell. Nicola explained that she considered having HIV as similar to another family member who had cancer, and whilst “it suddenly becomes your whole life, ... you have got to put it back in perspective. ... It doesn’t affect your everyday living unless you are ill.” By making this comparison, Nicola was able to construct an identity that is similar to someone who was in remission from cancer: illness was a possibility but not an inevitability.

Some women who had been diagnosed post-HAART and who had not been unwell saw no reason for their health status to change. Brooke said, “Because I’ve been fine, I just assume I am going to be fine. ... I don’t really think about the possibility of becoming ill much at all.” A couple of women took this a step further and said they did not allow such thoughts. Adele, for example, said “I don’t think about getting ill”, and Olivia asserted, “I don’t have any intentions of getting sick.” For these women, denying the possibility of illness or death from AIDS equated with living a “normal” life; normal mothers in Australian society do not have to think about illness and death and managing a highly stigmatised illness.

Women who had been diagnosed for more than five years (before the availability of HAART) were more likely to construct an account of the future in which illness was probable. This was also true of the women who diagnosed in the two years prior to the interview. Polly, who had been diagnosed for only two years, said “The thought of



being sick in the future is always there in the pit of my stomach somewhere”, and Sarah said, “I know I haven’t got as much time as everybody.” It was also something Clare thought about frequently, although she believed it was, “going to be a long way off.”

Like other women who were not yet taking treatments, Clare saw her journey with HIV and possible illness in stages, the first being asymptomatic, not requiring treatment; the second stage requiring treatment to help the body control HIV; and then a further stage in which HIV would no longer be managed by treatment and in which illness would prevail. She explained, “If I were on treatments I guess I’d think about it; that I was through the next stage and then the next stage is getting sick. But it’s still a few stages away.” In thinking about it in this way, women were segmenting their journey into manageable bits. Women who were asymptomatic and not on treatments could position themselves in the “first stage”, where the other stages were in the distant future. Implicit in these thoughts is the potential for treatment to continue to improve, making the next stage less difficult and traumatic and enabling them to further defer the final stage.

### **Mind over matter**

Managing one’s thoughts about illness and death was one way women could control the impact of HIV on their lives. Many women spoke of “positive thinking” and of maximising their health by reducing stress, adopting good diets and using complementary medicines. Stephanie believed herself to “have always been in very good health”. She did not smoke or use any drugs, only ever drank modestly and had an active lifestyle; her diagnosis prompted her to be even more prudent about her health. Sarah said, “I think living positively is the key”, and Celia had a similar view that being positive was important and allowed her to “just keep going.” Janice also attributed her wellness to “mind over matter”, saying, “I think that’s why I’ve gone almost 11 years and I’ve never had to have the treatment.” As well as having “the attitude that it is not going to make me sick”, Janice said it was important to “look

after yourself.” This kind of thinking allowed women to feel that they had some control over the impact HIV was having on their body.

Two women who were diagnosed before HAART credited motherhood with their unwillingness to give up. Leanna said “I just had to survive” and Denise, who had never been able to envisage a future said, “Sometimes I really believe that being a mother and surviving is because it’s like you know you can’t give up because you’ve got to keep going for your kids and your family.” However, many women, such as Janice and Yvette, also claimed that “luck” had played a role in their longevity. Yvette, for example, said, “I know I am so lucky to still be here.” She went on to say that she did not think it was entirely about having a positive attitude because she had known “a lot of people who have had positive attitudes and thought this was never going to beat them and they died anyway.” Yvette could not be sure whether it was due to her genes or her immune system that she had survived when so many others had not, but she was “certainly very grateful.”

Rachel was the only woman who talked about finding solace in spirituality, saying, “I just try and think the day I die is the perfect time for me. I do believe that the soul doesn’t die.” This was a belief Rachel held before her diagnosis and she attributed to her ability to remain in a positive frame of mind and not dwell on the “what if” scenarios.

### **Children and the possibility of death**

Most women found it very difficult to think about someone else raising their children if they were to die, although some were able to find a little comfort in knowing that there was someone whom they could trust to raise their child should they succumb to AIDS. Joy found peace once she had organised custody arrangements for her children, saying, “So with that it was quite a big relief, actually. I had done all those things I needed to do.” Similarly, Samantha “needed to know where my children were going to be” and sought the assistance of a solicitor to formalise her wishes. Stephanie had a close and loving relationship with her sister who had also come from overseas to live

in Australia, as well as older stepchildren who she believed would help care for her son should she be unable to. “So I feel 100% confident about that if anything happened to me, because of the HIV, Samuel’s well-being would be assured.”

The women who did not want to incorporate illness in their future also did not want to acknowledge the possibility of death. Brooke said, “I don’t really think about the possibility of dying and leaving my daughter without a mother.” Monica also felt this way: “In relation to parenting and HIV, it doesn’t really come into it. ... Because I don’t think I’m going to die. I mean eventually, but I don’t think I’m going to die necessarily from HIV at a young age.” These women had not given much thought to who might care for their child should they die prematurely, and had not discussed possible future custody arrangements with family or friends. These women remained optimistic about the future, although this optimism was not always strongly associated with reliance on treatments. Optimism seemed to be associated with having young children, remaining asymptomatic for 10 years or more and being diagnosed post-HAART.

### **Leaving something behind**

Donna Barnes and her colleagues (1997) studied the videotaped testimonials made by HIV-positive mothers for their children. They argued that this medium created a forum for “eternal mothering” in which mothering continued after the woman had died. The women in their study had videotaped family histories or stories, as well as explanations and information for their children about their likely premature death. It is important to note that the videotaping project was carried out from 1991–1993, when there were no effective treatments for AIDS.

The concept of leaving something behind for their children was also important for five women in my study. However, this notion differed for these women. Two women had spent time creating mementos for their children. Denise had a “memory box” which contained “wishes” she wrote for her children. “Pink ones for my daughter – I’m not sexist but I had to work out a way – blue for my son, and green are memories for them

both to share.” Denise said she wrote down things like when they first walked and talked, thoughts she had about her life, and how HIV had affected their family, and included lots of photos of them all. Although her children were not interested in a lot of the “wishes” now, Denise anticipated a time when they would be and she would not be alive to pass on that information. Adele started a diary for her daughter, “writing things down, thinking that when Briana is older she can read this and know me because I wouldn’t be around when she grew up.” Unlike Denise, Adele gained confidence in the treatments she was taking and believed they would provide her with the longevity she needed to see her daughter grow up; she no longer wrote in the diary.

Sarah had started a financial “nest egg” for her daughter “for when, and if, her Dad and I are both gone.” Sarah said she was not concerned about her own material wealth but it was important to her that they be able to leave some financial security behind for their daughter. Sarah was not confident about longevity but, by providing financial stability, she could continue to “mother” her daughter after her death.

Two women saw immortality in having a child. Laura, whose husband died within 12 months of his diagnosis, found comfort in knowing that they had had a child together. She remembered thinking, when she was diagnosed, that she “was really lucky because I had a child who was negative” and that she, “would have something of him” after he died. Laura went on to explain that “she looks so much like her father that it does help in that continuation stuff. It’s true that immortality comes through your children.” Georgia, who had not yet had a child, also felt this way, saying, “Tim will be a great father and I’d like to, if I do go earlier, leave something for him.”

## **Treatments**

I asked women what role they thought treatments would play in their future and whether treatments provided them with hope or the ability to think about the future. As I described in Chapter 5, the women in this study were generally wary of treatments, both in relation to their use during pregnancy and for general health maintenance. They were particularly concerned about long-term safety and sceptical

about what was known about women's physiology in relation to HAART. Laura thought that the clinical knowledge about treatments had improved but that this did not extend to women, saying, "Now I think the doctors have a better idea of what they can and can't do with treatments. I don't think they know what they are doing with them with women still, but that is changing." Louise also felt this way, saying that in the past she had always believed she would "never go on treatments because they do more harm than good. Also at that time they didn't know enough about the effects on women." Louise had since changed her mind and "would definitely consider" treatments if they were recommended, but was still "wary of the side-effects." Rachel had similar thoughts, saying that although the treatments were "life-saving ... people have to be really careful with them. Not be too swayed by doctors!"

At the time of interview, 11 women were taking treatment on the recommendations of their doctors because their CD4/T-cell counts and/or viral loads indicated immune system damage. One woman, Samantha, was "having a break, ... a little holiday! I haven't had one for a few years so I just needed a bit of time." Most women told of being reluctant to commence treatments, believing treatment to be something they would prefer to have in reserve for when their body could no longer fight HIV on its own. When treatment was recommended, these women found the decision difficult to make because it was seen as a transition to "the next stage". Denise explained how, after 12 years of not requiring treatment and slow decreases in her CD4/T-cell count, she stopped going for regular three-monthly testing because she "felt the same the whole time." However, the previous year a woman she knew, who had also not undertaken regular clinical monitoring, suddenly died. This was a "wake-up call" for Denise, who then went for tests. She discovered her CD4/T-cell count had dropped to 50 copies m/L and her viral load was 750,000 copies m/L, which resulted in her doctor recommending treatment. Although Denise had only just commenced treatment when I spoke with her, she said "if that hadn't happened to that woman, I probably wouldn't be here."

## Treatments and control

A few other women had taken treatment in the past but stopped without agreement from their doctors when they decided they were well enough or could no longer be compliant. Brooke was very reluctant to commence treatments but eventually agreed when her viral load rose above 100,000 copies m/L and she had a cold sore that would not heal. She then took antiretrovirals for 18 months and “they worked really well”, but then she “got sick of taking them” and stopped without consulting her doctor. Avoiding consultation with her doctor about her decision to cease treatments allowed Brooke to construct an account in which she was in control of her decisions and her life. This example illustrates the complex nature of women’s decisions concerning their health, treatment and planning. Whilst women acknowledge that treatment will probably play a role in their longer-term future, they struggle with the tension between wanting a normal life and accepting an identity as a woman who requires treatment and medical intervention for the rest of her life.

Some women experienced the transition to taking treatments as a loss of control. This was particularly so for women who were diagnosed when there was no effective treatment for HIV/AIDS. Crossley (1998b: 511) explained that “in the absence of a course of treatment or cure the physician’s role may become largely redundant , with a related decrease in the patient dependency”. Denise was diagnosed in 1987 and had only just commenced HAART weeks before we met for the interview. She experienced this transition as losing control: “I’ve lost total control of my life. Someone else has control of my life.” Denise explained that she also had an interaction between her methadone and antiretroviral treatments and as a result she felt “unbalanced.”

I want to get normality back and being on the treatments I just felt like I’d totally lost control. So then I rang my doctor and luckily didn’t get her but got the reception and said, ‘This is how it’s going to be from now on,’ and I laid back down the ground rules and I sort of felt like I took control back.

When Denise perceived other people to be in control of her life, she said it was “really threatening” and remembered telling another person, “If I was to die it would be

because of all the stress caused by going on treatments.” As a result of living for more than a decade without treatment, Denise felt that, by conceding to treatment, she was relinquishing control of her life to biomedicine and that her life would be governed by other people’s decisions about what was best for her with little, if any, input from her. The accounts of losing control also bear traces of what Michelle Crossley (2000: 155) referred to as “personal and cultural fight for patients to be treated as something more than a biological entity infected by disease.”

After 14 years of good health without taking any treatment, Leanna experienced rapid weight loss and significant changes to her CD4/T-cell count and viral load, which led to her doctor recommending treatment. Leanna described starting treatment as relinquishing “control of my surviving to somebody else. Whereas before I depended on my own resources to survive and I felt like it was a lot to do with my inner strength and my resilience, and I found it very difficult to make the decision to go on treatments.” Despite having a number of very unpleasant and sometimes debilitating side-effects, Leanna felt her “hands were tied” because, without the treatment, she believed she “would have had only 18 months to two years before I was really, really looking at the end of things.” Despite finding it a very hard decision, Leanna accepted that taking treatments was the only way she could defer reaching the last stage of her journey with HIV.

Being diagnosed with HIV left many women feeling out of control and the start of treatment often further compounded this feeling. Taking treatment was a daily reminder of having HIV and diminished women’s sense of normalcy. Commencing treatment signified a new stage of the disease for women who had survived long periods without it, perhaps even the final stage before illness and death. Treatment offered the possibility of controlling the virus but, at the same time, it made these women feel out of control and different from other women.

### **Hit hard, hit early**

Highly Active Antiretroviral Therapy was announced at the XI International AIDS Conference in Vancouver in 1996 (Wood & Montaner, 2007). Many HIV specialists

then thought HIV would best be controlled if treatment were taken as soon as possible after sero-conversion, to minimise immune system damage. Some women in this study said they were advised to commence treatment when HAART first became available. Kate recalled feeling “a lot of pressure just to embark on combination therapy” as a result of the information presented at this conference, but she experienced “awful side-effects” and stopped taking it. She justified this decision by saying, “I was well; I didn’t need to.”

A few women who started treatment in 1997 gave accounts of “levels that went haywire” or CD4/T-cell counts that “seemed to be going down and down.” Stephanie was the only woman who was diagnosed in late 1997 and commenced treatment with a relatively low viral load (20,000 copies/ $\mu$ L). She recalled that her doctor suggested she “start immediately on triple therapy”, and within two months her viral load was undetectable and remained so.

Denise recalled being “offered treatments” when HAART first became available. She refused and, with hindsight, interprets this decision as beneficial. Denise believed that her doctors thought she was “irresponsible” in her decision, but Denise believed she had made the right decision, saying, “I am so glad now I didn’t go on treatments too early.” Isabelle remembered just prior to HAART that her “consultant tried to talk to me about drugs and I thought, well? Because at that time there was only AZT, ddc, ddI and I thought, look, I’d rather keep drugs in reserve.” After Vancouver she agreed to take the treatments, mainly because she was working overseas and did not have access to regular monitoring. Isabelle thought that, “if I’d been home, I would’ve said, ‘I’ll just sit and wait.’”

### **Saving treatment for the next stage**

Most women who were not yet taking treatments believed they would probably do so at some point in the future. They told of preferring to let their body use its own “natural” mechanisms to fight HIV and save treatment for a time when it could no longer contain the virus. Layla elucidated this, saying, “I like to know I’ve got



something there for the future. I am not one that would use up lots of drugs now and leave myself nothing. I'd just like to wait as long as possible."

Women who had been diagnosed for a decade or more said that they found the very idea of having to take treatments emotionally distressing. Yvette described it as "like being diagnosed again" and Denise said she "felt as vulnerable then as I did 13 years ago when we were first diagnosed." She also reflected that the decision to take treatments was "harder than making the decision about the termination" (which she had had when she was first diagnosed), although she did acknowledge that it was possible that she felt this way because she had "forgotten how much energy went into that."

Those who had watched their partners or husbands die also preferred to leave treatment until the "final stage" when their bodies could no longer contain the virus. Leanna had refused any offers of treatment from her doctors because she had "seen the effects of mono-therapy in the early nineties on Tom [partner] and other friends of mine, where I actually think it made their health deteriorate." Laura remembered that, when the first lot of treatments became available, "they were going to save the world!" Laura was "cynical" because she had witnessed the effects of the early treatments on her husband:

He was on AZT in the early days when they were giving them far too much and he was on the ddI trial and the amount of dramas that he had with that and he was taking prophylaxis for this and prophylaxis for that and a whole lot of tablets. He was on Ganciclovir when it first came in and he was one of the first people on it. So I guess I had seen what treatments didn't do, because they failed him quite badly. And we were all very anti-treatments in the mid-90s. I think most positive people were very sceptical about these wonder cures because we had seen wonder cures for quite a while. We'd also seen our friends get very sick on them, and so that was kind of like, oh yeah.

Most women equated taking treatment with being sick rather than as health maintenance. Yvette had not had any AIDS-related illnesses in the 15 years since

diagnosis. She said that the thought of having to commence treatment really frightened her because she equated taking treatments with moving to the next stage, disease progression, “because you usually take tablets or medicine when you are sick. So if I can put off taking all those tablets for as long as possible – psychologically I am not sick. I can almost convince myself – not that I don’t have it, but that I am not sick.” The idea of committing to a lifetime of treatment was difficult for most women, like Audrey, who had “never taken any medication in my life for anything.” Similarly, Denise said, “If I have a headache I don’t even take a pill.”

It appeared to be more difficult for women who were diagnosed before HAART to accept the thought of taking treatment. This was in part because, when they were first diagnosed, there was no treatment available and they had survived a number of years without it. Furthermore, women associated treatment in the early years of the epidemic with high levels of toxicity, seeing it as experimental and something that was saved for people who were stricken with an AIDS-related illness. Despite the availability of much safer and more efficacious treatment, these women were unable to move past their understanding of what it meant to be on treatment: that one is at the final stage, and illness and death were looming. For those who were well, treatment posed as something that could threaten their current quality of life.

### **Treatments not part of the future**

Only Carol said she thought she would probably never take treatments. This was a change in her thinking after her experience of having a court order against her decision to not give her daughter the recommended prophylaxis. Carol explained that she “used to think, oh yeah, if they recommended it, then I would, but that was quite early on when I didn’t feel like I knew much.” Carol did not believe that treatments would improve her health. Instead, it would be “clearing up one problem but giving me another, so I would look more at other methods of just getting overall good health rather than just having the HIV under control.” Carol did not believe her longer-term health and future were dependent on treatment. However, it is feasible to interpret this change of heart as coming about because she felt she had lost control over her

decision not to treat her daughter, and refusing treatments for herself was one way she could reclaim control of her decisions related to HIV.

## **Treatments and hope**

Other researchers have written about hope in the lives of people living with HIV/AIDS, particularly since the availability of HAART (see, for example, Ezzy, 2000; Hall, 1994; Klymä, 2005; Trainor & Ezer, 2000). Kelly (2007) argued that within the HIV epidemic, hope is temporally structured according to pre- and post-HAART, which makes it difficult to construe with regard to health and illness. The introduction of HAART and the subsequent marked reduction in AIDS-related deaths has meant that PLWHA who were diagnosed before HAART have had to reconsider and reconstruct their futures and their sense of health, whilst others have had to contend with fluctuating periods of wellness and illness. This is further problematised by the fact that HIV health and treatment success (undetectable viral load) have often been accompanied by debilitating side-effects (Persson, Race & Wakefield, 2003). By comparison, those diagnosed after HAART are often more willing to embrace HAART as offering the prospect of HIV becoming a chronic, manageable illness. This was also mostly true for the women in my study.

Women who were diagnosed prior to HAART were less likely to be hopeful about the role treatments would play in their wellness and longevity. When it came time for Denise to commence treatment, she told her mother that she was considering this and reported her mother saying to her, “Well you’re not going to die on me are you?” Denise said she told her, “No, of course not”, but really thinking “Well I hope not. But I wasn’t sort of sure.” Denise had spent a decade thinking that she would die from AIDS and had seen treatments fail other PLWHA. This experience was a barrier to her hoping that treatments could have a better outcome for her.

Some women who were diagnosed pre-HAART were able to construct an account of the future that tenuously balanced hope and caution. Despite believing the treatments

still to be largely “experimental” and that people taking the treatments (including herself) were “human guinea pigs”, Laura felt that HAART did provide new hope:

What it gives now, I think, is an enormous amount of hope that we didn't have. People who have been on treatment and are doing well on treatment, shown to newly diagnosed, particularly to newly diagnosed women, gives them hope. They can see other women who are doing okay and there are options. We didn't have any options for a long time.

Not surprisingly, the women who had lived with HIV for many years found it difficult to make the transition from living with a terminal illness to a “chronic manageable illness.” Some of these women maintained hope that the journey they had first embarked on would now be vastly different and allowed them to imagine a future. Yvette explained how her outlook had drastically altered:

Now I am starting to think that AIDS is actually going to become a manageable disease and that people are going to live for 30 to 40 years with it. ... So I am starting to wonder if I should be making plans for being 60 or 70 years old. You know, this wasn't in the plan.

In contrast, women who were diagnosed after the introduction of HAART were more likely to be hopeful that the treatments would provide them with almost “normal” longevity and that antiretroviral therapy would continue to improve. These women talked about aiming for a decade or so free from treatment, then, if necessary, using treatments for (what they hoped would be) a chronic, manageable illness that would not necessary shorten their natural lifespan, or if so, only by a small amount. Women also found hope in meeting others who had survived for long periods of time. Audrey had met people who had “survived 20 years”, which she said, “kind of gives me hope.” Similarly, Sarah had met women who had survived 10 or more years and extrapolated their experience to her own, saying, “I always think to myself ‘oh, well that's 10 years I've got.’” Sarah, like others, was also hopeful that, within those 10 years, advances in treatments would provide her with additional time to mother her child.

Mary was both confident and hopeful, believing she would live a long time: “I know I’m going to live for another 20, maybe 30, 40 years; that’s what I’m hoping.” Women like Mary, who were less involved with other PLWHA, seemed more willing to embrace hope and the idea that HIV could really become a long-term manageable disease.

### **Treatments, motherhood and future**

While most of the women in this study took treatments during their pregnancy, almost all of them ceased the treatment immediately or soon after the birth of their baby. It is important to note that most women did not clinically require treatment, although one woman, Nicola, did wonder whether she was feeling more energised as a result of taking treatment. Nicola had commenced treatment 18 weeks into her pregnancy but had not decided if she would continue once her baby was born. She said, “I haven’t decided yet because I feel quite good and it’s not until you start feeling good that you realise how bad you were. Not that I was feeling really, really bad, but I just have so much more energy now so there is obviously something that’s happening there.” Some women recounted finding it very difficult to continue treatments with a new baby, usually because the regimen was so strict and they were focused on the day-to-day tasks of caring for a new baby. Brooke, who did not “really want to be taking them anyway”, found taking the treatment with a new baby an additional chore. “Some mornings I can’t even plan to have a shower, even getting dressed! I mean, if I don’t have time for that, then how am I going to take pills on time? And you have to have food as well. If you just had to take them, without food, maybe it would be easier. I was taking them at 8.00 a.m. and 8:00 p.m. but often I don’t get to have breakfast until 10.00 a.m.”

Most of these women framed treatments in their accounts of the future as something they would take if “necessary”, but preferred to “wait and see”. Some women maintained hope that their body could resist the virus on its own, whilst others hoped for new treatment options that would make the transition to treatment less distressing. The few women who had commenced treatment because of clinical markers

indicating immune system damage found that treatment was strongly intertwined with their roles as mothers and their hope of seeing their child grow up. Kate said:

I suppose my life and my view of wellness and stuff is very much driven by her position in the world. I guess, having a child, being a positive parent – I mean I can't stand doing it, but I do it for her, I suppose, I don't really do it for myself. Because I think I shouldn't rob her of having a mother. It's good motivation. It's worked for me. She's the reason I take this treatment. I'm not just playing with my life here; I'm playing with two lives.

As Kate illustrates, a woman's desire to be the best mother she can, which includes living long enough to see her child an independent adult, can influence her attitudes and concerns about commencing or adhering to treatment. Yet commencing treatments created a new worry: how much time would these treatments provide?

So it's in the back of my head that what happens when these ones fail? How many options are there left? How many years can I get? I've just got to get her to a certain age, you know, but obviously, when she hits that age and I'm still alive, it's still not good enough. Then I'll have to get to, you know, being a grandmother or, or whatever. I can't say it motivates me actually to change my life that much, in terms of seeking out new and whacky and wonderful possible life-saving things, but it's just constantly in my consciousness that I have to reach this level. So I suppose maybe spiritually it is a driving force.

Like Kate, most women viewed treatments as the final stage of their journey with HIV and something that would only buy them an additional 10 years or so of life. Therefore, most women considered that remaining treatment-naïve (never taken treatment) for as long as possible would ensure they would have additional time once their body was no longer able to ward off HIV on its own. Framing treatments this way provides a different perspective from which to reflect on how women view treatments in their lives. Layla's account was typical: taking treatment during pregnancy and then stopping once her baby was born so she could leave treatment for

the future when it became absolutely necessary. “So I thought, I am not going to go back on them until I really need to.”

Women who were not on treatments found the concept of committing to taking pills for the rest of their lives very confronting. It reminded them of their HIV infection, the circumstances that led to their infection, and the pain and grief associated with being HIV-positive. As most women strived for “normality”, which included motherhood, working, and their various roles as wives, partners and so on, treatment was viewed as something that would interfere in, and probably detract from, their busy lives. Even living with a partner who was taking antiretrovirals did not make this scenario any easier to imagine, Sarah said:

Cameron is on treatments but I am not. ... I don't think I have got my head around it. If my CD4 count did drop really low and my viral load suddenly shot up? I don't think I have really got my head around it mentally, to be ready to take pills for the rest of my life. With a child and I work part-time and things are pretty hectic with a two and a half-year-old. But I also know there will come a point and a time in my life when I will probably end up on treatments.

Taking treatment did in fact pose an enormous hurdle for Sarah when the time came. Sarah wrote to me in early 2004 updating her story, explaining that at the end of 2003, she had begun to get “sick all the time” and had to commence treatment. Sarah wrote, “I wasn't happy about this as I felt it was the beginning of the end for me. I had counselling for about six months prior to starting to get my head around it.” Sarah had a difficult time once she started treatment, with two allergic reactions, insomnia and persistent nightmares for three months. She then had a car accident in which she was not injured but which she attributed to the fatigue caused by the side-effects of treatment:

I spiralled into deep depression and my nerves were shot. I was fighting with Cameron all the time. I was angry all the time or I would cry for days and hide in bed. Along with constant vomiting and diarrhoea: pretty much a

major mess. Not good for Lila. I even spoke of driving myself into a tree, as the world would be better off without me! Then I spoke to the counsellor at the hospital in tears and we convinced my doctor it wasn't really agreeing with me.

At the time Sarah wrote this she was on a two-week break from treatment and due to recommence the following week.<sup>12</sup> At this time Sarah had been diagnosed for about five years and had not reached her goal of remaining treatment-free for up to 10 years. By commencing treatments, Sarah felt she had begun the final stage of her journey with HIV and that there might only be a few options left for her now.

### ***Cure***

Although I did not specifically ask women if they had thought about the possibility of a cure for HIV; eight women mentioned “cure” or “magic pill” during the course of their interviews. Laura spoke cynically of the early days of treatment and “wonder cures”. Yvette joked that chocolate was her cure. She went on to say she believed treatments would make HIV a manageable chronic illness but she thought it unlikely that a cure would be found. Lily was extremely cynical, saying that, “a cure is out there”, but the profits being made by pharmaceutical companies from antiretrovirals, and potentially from immunisations, meant “they” would not want to cure HIV.

Brooke and Nicola gave accounts of looking for claims of cures when they were first diagnosed. Brooke interpreted her attitude as “naïve” and Nicola, who initially thought she would “quit my job and go and sit in the study and learn how to cure myself,” then decided she wanted to live as “normally” as possible, which meant getting on with life as it was planned before. Searching for a cure would have become her quest and Nicola was resistant to HIV becoming a major feature of her life, because she would not have been able to maintain her identity and pass as a “normal” woman if she had pursued this path.

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<sup>12</sup> Sarah rang in February 2007 to congratulate me on the launch of *Common Threads* and tell me of her new contact details. At that point she and Cameron were well.



Newly diagnosed women tended to be more optimistic about the real likelihood of a cure; this was based on the belief that the treatments were continuing to be improved and more were becoming available, therefore a cure was inevitable. Sarah believed treatments to still be largely experimental, but she interpreted this as necessary, because “one day they might find the magic pill!” Clare and Polly, who had both been diagnosed within two years or so of the interview, believed a cure was possible and even likely. Clare thought this would happen within “ten years” and Polly thought “the cure could come about ... by Western medicine even.” By believing a cure was possible, these women were able to consider a life of normal longevity and actively plan for their futures as women and mothers.

However, most women did not hold hope for a cure and this is likely because of the high level of scepticism these women had about the efficacy and long-term safety of HAART, as well as the “trial-and-error” nature of treatments early in the epidemic.

## Summary

Most women were cautiously optimistic about their future, particularly those who were diagnosed after the introduction of HAART. Time and wellness were vital to women's accounts as they envisaged a future that was as "normal" as it could possibly be. Women held hope that they would see their children into adulthood, and being in control of the future was an important feature of this goal. In an effort to control the uncertainty of one's future, women often constructed accounts that were goal-oriented, some preferring short-term goals whilst others were more comfortable with long-term ones. Narrative forms can be useful to consider the accounts about the future of women living with HIV/AIDS, but it is important to recognise that their narratives are unfinished and subject to constant revision. Women who were mothers gave accounts of the future that were child-centred.

Experiences of illness or death of a loved one heightened the experience of living with uncertainty. Whilst treatments offered hope for the future and were key to HIV being a manageable chronic illness, many were wary of the long-term effectiveness and safety, and most women gave accounts in which treatments were preferably saved, for the next stage of disease progression, when the body could no longer contain HIV on its own; some women viewed this as the final stage of their journey with HIV. The availability and accessibility of treatment seemed to create a paradox for some women. On the one hand treatment made a life of "normal" longevity possible, but at the same time the strict adherence and life-time commitment required to commence treatment made women feel abnormal or out of control.



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## Chapter 8

### *The journey continues*

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Motherhood came into my mind straight away. That was the first thing I thought of when I was diagnosed. I think everybody goes through the same thing. You think that it, that's the end. What about these things you haven't experienced in life? And motherhood was one of them. So it was pretty much an instant thought, and that was one of my first questions when I came into the centre, "What about motherhood?"  
[Nicola]

Nicola and many other women who participated in my study revealed that an HIV diagnosis raises the question of motherhood. For some, this is immediate; for others, it may occur as they assimilate their diagnosis. Women who were diagnosed without children were devastated by the apparent loss of motherhood, whilst women who were already mothers thought they would not be able to complete the journey they had commenced with their children.

Much has been written about HIV-positive women and vertical transmission, but little is known about what an HIV diagnosis means to women who intended to become mothers or who are mothers of existing children. I conducted this research because I wanted to fill this gap in our knowledge of HIV-positive women living in Australia and the place of motherhood in their lives. Previous research I had been involved in had addressed other aspects of their social lives, such as sexual practice and career interruptions, but when I spoke with these women about these issues they nearly always steered the interview in a direction that allowed them to talk about how HIV had affected their roles as mothers or their desires and decisions to become mothers. The 076 protocol and the availability of HAART were influencing their decision-

making and contributing to their constructions of accounts of the future. As Mathieson and Stam (1995: 284) noted, disease and self are not spoken about “in the bustle of daily life but rather [in] conversations about those aspects of life that still matter the most.” Therefore it seemed timely to examine the role of motherhood in the lives of HIV-positive women in Australia. I was particularly interested in examining the significance of motherhood for HIV-positive women in the face of a potentially life-threatening disease and within a society that was often resistant to them becoming mothers.

This research is the first of its kind in Australia and has found that motherhood remains foremost in the women’s identities even when they believe it to be unobtainable. Women seek to find ways to fulfil this identity. They resist discourses that position them as uncaring, undeserving and immoral, instead constructing accounts in which they present themselves as careful and thoughtful women who make informed choices and who want the best for their children. Women go to great efforts to minimise HIV in their lives and to live as “normal” women and mothers. Most live in relative secrecy to achieve this and to protect their children. Some women struggled to accept the protocols known to reduce vertical transmission because they conflict with what “normal” mothers do: protect their children from harmful side-effects and potential toxicity. They resisted the use of their children as medical “guinea pigs”. It is within this context that information targeted at HIV-positive women must be developed, taking into account the women’s perspective, particularly their concerns for their babies’ health and safety, as well as their own well-being. Examining the construction of HIV-positive women’s identities within the Australian context is also important because, as this research has demonstrated, women position themselves outside “mainstream” HIV discourses. Information, education and services targeted at PLWHA are likely to miss many of these women.

My use of the journey metaphor in this thesis seemed the most appropriate way to examine the stories that the women constructed in conversation with me. When I asked women to tell me their story of how being diagnosed with HIV had influenced their thoughts and feelings about motherhood, almost all of them told a chronological story, starting with their diagnosis and then describing various aspects of their lives pertinent to motherhood. Essentially they were describing a journey that began at

diagnosis, demonstrating how HIV had altered the course of their intended life. As a metaphor, journey accommodates the complexity, similarities and nuances of women's accounts, from the chaos and devastation of their diagnosis (which for many included the belief that they would not be able to pursue their desires to become mothers, or see their children into adulthood) to the reclamation or reconstruction of their accounts of the future.

But as a journey, the HIV narratives women told were in progress, subject to revision, and therefore unfinished (Ezzy, 2000); constantly evolving and taking shape. By using "journey" I was able to consider the women's accounts as the stories they told themselves and others of how HIV had influenced their life and, for most, changed its course. The effects encompassed the life already lived as well as the one that was still to come. Like others (see, for example, Garro, 1992; Mathieson & Barrie, 1998), I, too, found as I interviewed women that what emerged was not simply the story of illness, but a story altered by illness. Many women when first diagnosed believed they would be unable to have children or continue mothering their existing children. However, over time, most women were able to reconstruct their accounts to include motherhood. They usually wanted to continue with the life they had planned. The women constructed their identities of motherhood as natural and rightful. Irrespective of the revisions women made to their lives and their identities after an HIV-positive diagnosis, motherhood remained an integral part of their identity.

The accounts constructed by HIV-positive women are likely to differ in several important ways from those of women with other chronic illnesses. Since the availability of highly active antiretroviral therapy (HAART), many have claimed that HIV can be managed in much the same way as other chronic illnesses such as diabetes. But there are some notable differences between HIV and many other chronic illnesses. For example, women with HIV are often diagnosed without any symptoms, which can make their diagnosis harder to assimilate. Most of the women in this study were asymptomatic when diagnosed; these women were not ill and, with the exception of regular blood tests, were not patients. HIV is also both stereotyped and absent from mainstream Australian society, resulting in further marginalisation for women living with this disease. What is perhaps most important is that the stigma associated with HIV is unrivalled by any other illness and women are doubly

vulnerable to this stigma because of their child-bearing capabilities. The risk of vertical transmission and the “type” of women they are assumed to be make them unsuitable for motherhood in the eyes of many.

Although the women in this study could not be understood as homogeneous in the context of their lives as a whole, the majority of them were Anglo-Saxon, Australian-born, of middle-class socio-economic status with at least high school education. The findings from this study have limitations. Whilst the women’s accounts are insightful, generalisation is not possible. This study was not designed to be representative; it was intended to explore the uncharted experience of how women construct meaning and negotiate their identities when diagnosed with HIV during their child bearing years. Specifically I wanted to explore the impact of an HIV diagnosis had on women’s thoughts and feelings about motherhood. There are, of course, other important areas of HIV-positive women’s lives that would justify future research, including sexuality and sexual desire, social and familial networks, work and career choices and ageing, and the impact of long-term HIV sero-positivity in families in which either or both parents are HIV-positive. Future research could also consider the meaning of HIV in the lives of women who do not desire motherhood or the experiences of living with an HIV-positive child or children. This research only captured the experience of one woman who did not desire motherhood and one woman who was a mother of an HIV-positive child. The experience of fatherhood and HIV has also received scant attention.

This thesis has been a longer journey than I anticipated. Becoming a mother twice during its course undoubtedly delayed its completion. I have had to think reflexively about my experience of motherhood and its impact on this research. Whilst it has deepened my understanding of the stories the women shared with me about their journeys as mothers, and I have been able to apply this insight as I have interpreted their accounts, I have also questioned “what I know” and “how I know it” (Hertz, 1997: viii). The women’s experience of uncertainty has heightened my own sense of uncertainty and vulnerability. I keenly understand the imperative to survive that most mothers described. There are risks I no longer take – I have even altered the way I drive since I have become a mother. I understand now how motherhood permeates all aspects of one’s life.

I have reflected on how the interviews may have been different had I have already been a mother when I met with the women. It is likely that the accounts would have been different, perhaps with a greater emphasis on the performative aspects of motherhood: the women may have told a different story to a different listener. I think that by not being a mother when I conducted the interviews, the women who were mothers were able to be “authoritative” about motherhood. It is also possible that the women who did not yet have children, or for whom HIV had been a barrier to motherhood, felt more comfortable talking to another woman who was not a mother. Had I not become a mother, it is possible that I would have written a different thesis. I might have focussed on the more medicalised aspects of living with HIV and Chapter 7 *Living with uncertainty* might not have been written. My own heightened sense of vulnerability and the love I now had for my own children probably influenced my awareness of the themes that emerged from the women’s accounts that I presented in this chapter. Working for such a long time with the women’s accounts has meant that their stories have become “‘voices in the head’ that are hard to forget” (Warr, 2004: 586). As suggested by Warr, I have had to work hard to find the right balance in keeping the stories close and honouring their integrity, whilst generating powerful and meaningful analysis and interpretation.

Of course, I cannot know what effect, if any, I had on the lives of the women who participated in this research. I do know that, for many, recounting some of the events of their diagnosis and life since that time was often painful and sometimes distressing, but most did so for altruistic reasons. In recognition of this, the co-production of *Common Threads* (McDonald, 2006a) was my tangible contribution from the research to the benefit of HIV-positive women, standing as evidence of collaboration in translating research into practice. It was also my way of recognising the value of women’s experiences as a source of knowledge (Bell, 1999).

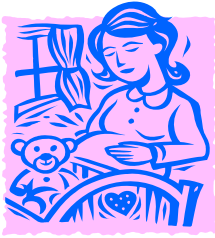
Most women had overcome the initial obstacles that HIV had placed in their paths to motherhood. However, HIV will continue to interfere in their lives in numerous ways as their journey continues, with the ever-present possibility of illness and death, treatments and their potential side-effects, decisions about disclosure (particularly as their children get older), and the threat of stigma. These women had worked hard to



create “normal” lives; negotiating HIV within their lives and making sense of how HIV has altered the course of their lives. But, with no likely reprieve from HIV, this will be a lifelong journey.

## **Appendix A: Notice calling for volunteers**





## Notice calling for volunteers

### A research study about motherhood and HIV-positive women

**Australian Research Centre in Sex, Health & Society  
215 Franklin Street, Melbourne, Victoria, Australia.**

This study will examine the issues faced by HIV-positive women concerning pregnancy and motherhood. These will include the decision to have (or not to have) a baby and whom to consult for medical and emotional support. I would like to speak to women who have had an HIV diagnosis during their childbearing years. This will **include** women who **have** had children, women **thinking of** having children, women who have **decided not to** have children and women who may have **been advised not to** have children.

If you are a woman living with HIV and are willing to talk to me, please contact me to arrange a time and a place that is suitable to you. I would like to hear about your experience, whether your diagnosis is a recent discovery or something that you have lived with for years. Of course, everything you say will be treated in the strictest confidence.

If you agree to participate in this study, your interview will be edited to retain a focus on your account of HIV and motherhood and returned to you to allow you to expand or clarify your story. The version of the interview that both you and I agree on will be the one used in the study. It is also hoped that a booklet discussing pregnancy and motherhood in HIV-positive women will arise from this study. The booklet will be distributed to participants and to organisations that support and care for HIV-positive women. If quotations from your story are included in this booklet your anonymity will be maintained; changes will be made to any identifying details.

I have experience in talking about these issues and in handling this information appropriately. For the past four years I have worked as a researcher on The Living with HIV program at the Australian Research Centre in Sex, Health and Society. In that time I have been the principal author on two reports, *Standing on shifting sand: Women living with HIV/AIDS in Australia* (1998) and *A complex uncertainty: Women on health, hope and living with HIV in Australia* (2000). I have also interviewed over 30 women living with HIV around Australia.

I am a PhD researcher who wants to find out from women themselves **what a diagnosis of HIV means to their plans or experience of being a mother**. I am happy to answer any questions before you agree to participate in this research. Having agreed, you can change your mind about participation. Please phone me on (03) 9285 5108, mobile 0427 989 676 or write to me at the above address or at [K.McDonald@latrobe.edu.au](mailto:K.McDonald@latrobe.edu.au).

I look forward to speaking with you,  
Karalyn McDonald.





## **Appendix B: Consent forms**



## STATEMENT OF INFORMED CONSENT (1)

**PROJECT TITLE:** HIV-positive women, pregnancy and motherhood

**RESEARCHER:** Ms Karalyn McDonald, a PhD researcher at the Australian Research Centre in Sex, Health and Society.

**PROJECT DESCRIPTION:** The purpose of this study is to learn from women who are diagnosed as HIV-positive and the impact this has on women's plans or experiences of being a mother. This study will examine the issues faced by HIV-positive women concerning pregnancy and motherhood. These will include the decision to have (or not to have) a baby and whom to consult for medical and emotional support. The study will include women who have had children, women who are thinking of having children and women who have decided not to have children.

This study involves a conversational long interview of one to two hours. To ensure accuracy the interviews will be audio-taped and full transcriptions will be made. Your interview will be summarised and returned to you. You will then be offered the opportunity to make comments on Karalyn's overall interpretation of your interview. You may wish to have another meeting with Karalyn, either in person or over the phone to discuss the interview summary. This second conversation should take place between six and 12 months after the first interview, and will probably take less than one hour. The version of the interview that both you and Karalyn agree on will be the one that she uses for her study.

Once transcription has occurred the tape will be erased. Any names used during the interview will be replaced by pseudonyms and any individually identifying remarks will be changed. Your contact details will be kept separately from the transcribed interview in a locked cabinet. Your details will be kept only for contact between you and Karalyn for this project and then destroyed. Data will be stored in locked files at the Australian Research Centre in Sex, Health and Society. Computer files will be kept on a secure file server and accessible only to Karalyn via password. It is possible that you may find participation in this project distressing. Karalyn will provide you with details about counselling and referral services that you may wish to use. You are free to withdraw consent and discontinue participation in the research for a period of up to one month after your interview.

The results of this study should bring greater understanding to organisations that provide support and information for women living with HIV in Australia as well as to the medical profession and to the general community of the experience of an HIV diagnosis and the experience and decisions of mothering as an HIV-positive woman. It is also hoped that a booklet containing information and aspects or parts of women's stories around the issue of pregnancy will arise from this study to provide to organisations that



support and care for HIV-positive women. If quotations or aspects of your story are included in this booklet it will be altered to ensure your confidentiality.

**CONSENT FOR PARTICIPATION IN THE STUDY:**

I, \_\_\_\_\_, have read (or, where appropriate, have had read to me) and understood the information above and any questions I have asked have been answered to my satisfaction. I agree to participate in this activity, realising that I may withdraw from the study for a period of up to one month after my interview. I agree that the research data collected for the study may be published in reports, academic journals and books which may include quotations from the agreed text of my interview in a way that will not identify me.

Any questions regarding the project entitled *HIV-positive women, pregnancy and motherhood* can be directed to Ms Karalyn McDonald, (03) 9285 5108 or to her supervisors, Professor Doreen Rosenthal (03) 9479 3572 or Dr Maggie Kirkman (03) 8344 4333.

If you have any complaints or queries that the researchers have not been able to answer to your satisfaction, you may contact Ethics Liaison Officer, Human Ethics Committee, La Trobe University, Bundoora, 3083. Telephone (03) 9479-1443.

Participant's Name: ..... Signature: .....  
(to be printed)

Researcher's Name: Karalyn McDonald .... Signature: .....  
(to be printed)

Date .....

## STATEMENT OF INFORMED CONSENT (2)

**PROJECT TITLE:** HIV-positive women, pregnancy and motherhood

**RESEARCHER:** Ms Karalyn McDonald, a PhD researcher at the Australian Research Centre in Sex, Health and Society.

**PROJECT DESCRIPTION:** As you would be aware, the purpose of this study is to learn from women who are diagnosed as HIV-positive about the impact this has had on their plans or experiences of being a mother. This study examines the issues faced by HIV-positive women concerning pregnancy and motherhood. These will include the decision to have (or not to have) a baby and whom to consult for medical and emotional support. The study will include women who have had children, women who are thinking of having children and women who have decided not to have children.

After editing and analysing these stories it has become apparent how powerful and vivid these stories are. At a minimum, the stories exemplify the challenges and problems that positive women everywhere face in their day-to-day lives. For example decisions about when to start treatment, treatments in pregnancy and treatment for newborns can be very difficult. We believe it would be useful for not only other positive women to read these stories but for medical practitioners, policy-makers, law-makers, service-providers and probably women everywhere to better understand these experiences, and the context in which decisions are undertaken.

The purpose of this additional consent form is to ask for your permission to print the story that both you and Karalyn have agreed upon. Karalyn is proposing three possible forums for the printing of your story:

- A booklet for all of the women who participated in this research (only women who agree to include their story will receive a copy and recipients would be asked not to pass this information on or to reproduce it in any way).
- To include the stories in an appendix of Karalyn's thesis. The thesis will be read by her supervisors and examiners and will be available to users of the La Trobe University Library.
- A book contract for this research may be sought after the thesis is completed. If such a contract was obtained, your story, or part thereof, could be included in this book.

Over the page a number of options are presented for each proposal. These options are:

- Yes, giving permission to print the story as it is.
- Yes, giving permission to print the story but with further editing and/or modifications.
- No, refusing permission for your story to be printed in its entirety.

The final request, to print the story if a book contract was obtained, offers a fourth option. This is to fictionalise the story which would mean parts of your story might be mixed with another woman's story to create a fictional character but from real experiences.

Before you decide about your story being printed in full in any of the above forms, we want you to think about the potential risks associated with your story becoming more public. We think there are three main things to think about. First, the possibility of identification. If somebody who knows you reads the story, s/he may recognise the story and identify you from the story. Second, if you are recognised, there is a possibility that you could be discriminated against as a positive person or treated in a way that is less than you deserve. Third, some of the choices that positive women make in their lives include decisions that may be construed as unlawful or potentially damaging to others, including partners and children. If you were identified from your story in this study, then your story could be used as evidence of such actions and decisions. If there are any issues that you feel would make you vulnerable to legal sanction please let us know. However, you must decide what information is removed or printed and we cannot guarantee your confidentiality.

Bearing these risks in mind, we understand and support whatever decision you make about your story including your decision to change or leave out details in the version you authorise for publication. Regardless of what you decide, your name will never be published and a pseudonym of your choice will always be used. It is also possible for us to change additional details to further de-identify your story. For example we can change the age, sex and birth order of your children or even the number of children you have or any other details that may be unique to your story.

Whatever you decide, your participation in this research is greatly appreciated and you have made a very valuable contribution to this research project.

**CONSENT FOR MY STORY TO BE INCLUDED IN A BOOKLET FOR PARTICIPANTS:**

I, ....., understand that only women who agree to have their story in the booklet will receive a copy. The recipients of this booklet will be reminded that the copy is not for distribution and cannot be reproduced in any way (including photocopying). However, I understand this cannot be guaranteed.

- Yes, I would like to include my story in this booklet as it is
- Yes, I would like to include my story in this booklet but with further editing/modification
- No, I do not want my story included in the booklet.

**CONSENT FOR MY STORY TO BE INCLUDED IN THE APPENDIX OF KARALYN MCDONALD'S THESIS**

I, ....., understand that the thesis will be read by Karalyn McDonald's supervisors and three examiners. The thesis will then be stored in the library at La Trobe University where it will be available for students and other academic researchers to read.

- Yes, I would like to include my story in Karalyn's thesis as it is
- Yes, I would like to include my story in Karalyn's thesis but with further editing/modification
- No, I do not want my story included in Karalyn's thesis.

**CONSENT FOR MY STORY TO BE INCLUDED IN A BOOK IF A CONTRACT WAS OBTAINED:**

I, ....., understand that Karalyn may seek a book contract after the completion of the thesis. If a contract was obtained I

- Yes I would like to include my story in this book as it is
- Yes I would like to include my story in this book, but with further editing/modification
- Yes, I would like to include my story in this book but I would prefer you to fictionalise the story.
- No, I do not want my story included in this book.

Please see over – your signature is required on the next page.

Any questions regarding the project entitled *HIV-positive women, pregnancy and motherhood* can be directed to Ms Karalyn McDonald, (03) 9285 5108 or to her supervisors Dr Jon Willis (03) 9285 5382, Professor Doreen Rosenthal (03) 8344 4333 or Dr Maggie Kirkman (03) 8344 4333

If you have any complaints or queries that the investigator has not been able to answer to your satisfaction, you may contact the Secretary, Faculty Human Ethics Committee, Faculty of Health Sciences, La Trobe University, Victoria, 3086. (ph: 9479 1443), email: m.junge@latrobe.edu.au.

Participant's Name: ..... Signature: .....  
(to be printed)

Researcher's Name: Karalyn McDonald .... Signature: .....  
(to be printed)

Date .....

## **Appendix C: Interview schedule**



### **1. Diagnosis of HIV:**

Your experience of being diagnosed HIV-positive?

What your diagnosis meant to you/in relation to motherhood?

What your diagnosis meant to those who are close to you?

Support from those around you in relation to HIV?

### **2. Motherhood**

The meaning of motherhood to you personally?

The meaning of motherhood (and HIV) to those around you?

Achieving motherhood as a positive woman?

Insemination, pregnancy, birthing, breastfeeding, treatment, support.

The possibilities of substitutes for biological motherhood – other people's children.

### **3. Identity**

Can you tell me about yourself?

What are the words you use to describe yourself?

How central is HIV in your sense of your self as a whole?

Has your sense of being HIV+ changed over time?

How much has HIV had an effect on your life: friends, history?

Does antiviral therapy have an effect on the way you see yourself?

Does the possibility/experience of being sick affect your sense of yourself – your sense of motherhood?

Did your thoughts about the future change when you first heard about treatments being possibly effective?



#### **4. Partners (past or present)**

Attitude of partner to HIV?

Attitude of partner to parenthood?

Your partner's support of you in relation to HIV and motherhood?

#### **5. Disclosure**

Who knows about your HIV status?

What have been good/bad experiences in telling people?

Disclosure in relation to the medical profession?

Disclosure in relation to children, telling them and telling others?

#### **6. Power and control**

In relation to the medical profession/doctor(s)

In relation to your partner?

Over your own body/over the HIV virus?

#### **7. Passage of time**

Changes in the role of HIV in your life

Changes in the feelings of wanting/not wanting children or for those who are mothers

what children has meant to your life?

## **Appendix D: Demographic information sheet**



## Demographic Information Form (Confidential)

I may have already covered some of this information, but I need to ask a few questions to be clear about the different experiences of women that I am talking with. If there is anything here that you would prefer not to answer, that is fine.

Date of interview: \_\_\_\_\_

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone number(s): \_\_\_\_\_

Age: \_\_\_\_\_

Education (what is your highest level of education?): \_\_\_\_\_

\_\_\_\_\_

Employment (Current – paid/voluntary; Overview of history of employment):

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Where were you born? \_\_\_\_\_

Where were your parents born? \_\_\_\_\_

Where was your partner born? \_\_\_\_\_

If your partner is employed what does s/he do? \_\_\_\_\_

What is your partner's HIV serostatus? \_\_\_\_\_

How do you identify sexually? \_\_\_\_\_

When were you diagnosed/infected? \_\_\_\_\_

Current viral load/CD4 count? \_\_\_\_\_

Do you know your hepatitis C status? \_\_\_\_\_

Are you using antiretrovirals (how long for)? \_\_\_\_\_

Children (how many?) \_\_\_\_\_

Age of children? \_\_\_\_\_

<b>Demographic characteristics of participants</b>	<b>N</b>	<b>%</b>
<b><i>State</i></b>		
Queensland	10	29.4
New South Wales	8	23.5
Western Australia	6	17.6
Victoria	5	14.7
South Australia	4	11.8
Northern Territory	1	3.0
<b><i>Country of birth</i></b>		
Australia	29	85.3
Overseas	5	14.7
<b><i>Age of women</i></b>		
25-39	4	11.8
30-34	13	38.2
35-40	9	26.5
40+	8	23.5
<b><i>Time since diagnosis</i></b>		
1 year	2	6.1
2-5 years	9	27.3
6-10 years	17	51.5
11+ years	5	15.1
<b><i>Using antiretroviral therapy</i></b>		
Yes	12	35.3
No	22	64.7
<b><i>Co-infected with Hepatitis C</i></b>		
Yes	6	17.6
No	28	82.4
<b><i>Mode of HIV transmission</i></b>		
Heterosexual sex	28	82.4
Heterosexual sex &/or injecting drug use	6	17.6
<b><i>Education</i></b>		
Tertiary	14	41.2
Completed secondary school	6	17.6
Year 9 or above	14	41.2
<b><i>Relationship status</i></b>		
Married or de-facto	22	64.7
Single	12	35.3
<b><i>Number of children</i></b>		
None	6	17.6
One	16	47.1
Two	7	20.6
Three or more	5	14.7
<b><i>Child born before diagnosis</i></b>		
Yes	16	59.2
No	11	40.8
<b><i>Child born before 076 protocol</i></b>		
Yes	14	87.5
No	2	12.5

## Appendix E: Newsletters

Due to copyright this material has been removed.































## Appendix F: *Common Threads* cover page

A copy of *Common Threads* can be obtained from:

The Australian Research Centre in Sex, Health and Society  
La Trobe University  
1/215 Franklin Street  
Melbourne 3000  
Victoria, Australia.  
Phone +61 3 9285 5382

OR

The National Association of People Living with HIV/AIDS  
PO Box 917,  
Newtown 2042  
New South Wales, Australia  
Phone: +61 (2) 8568 0300 or Freecall\* 1800 259 666

\* free from most fixed phones in Australia. Charges may apply when calling from mobile and pay phones.

<http://napwa.org.au/women>















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