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CUI BONO?

A CAPABILITIES APPROACH TO UNDERSTANDING HIV PREVENTION AND TREATMENT FOR PREGNANT WOMEN AND CHILDREN IN SOUTH AFRICA

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Abstract

The global health revolution of the last 50 years has generated significant health gains in terms of increased life expectancy and reduced maternal mortality. South Africa, an upper middle income country, has performed poorly along the same development indicators. Development gains for women and children won over two decades are now being reversed, largely due to HIV/AIDS. This is in spite of the evidence that lifesaving antiretroviral medication can prolong life and enhance quality of life. Using a joint *capabilities* and *health equity* lens, this thesis seeks to understand a critical development problem in South Africa – premature mortality in pregnant women and children attributed to HIV – an infectious disease that is both preventable and treatable.

The research identifies key barriers faced by pregnant and postnatal women with HIV who seek (freely available) access to PMTCT (prevention of mother to child HIV transmission) and ART (antiretroviral therapy) programmes in the public health sector. The study considers whether disparities in, and missed opportunities for, preventing and treating HIV in these population groups comprise avoidable, systematic and unfair health inequities. The implications for the capabilities of women and children with HIV in this country are also explored.

Qualitative research methods are employed to investigate the research concern. Semi-structured interviews with 83 women comprise the mainstay of the field research. Interviews with 37 caregivers of children with HIV, together with patient files and interviews with key informants, supplement the data collection. Research was undertaken in two sites in two provinces: Eastern Cape and Gauteng. Each site constitutes a bounded case study. A rural-urban perspective is put forward – with attention to equity considerations in access to maternal-child HIV services.

The study evinces a host of *avoidable factors* in the operational delivery of ART/PMTCT, along a range of intervention points in the continuum of care: including the antenatal, labour, postnatal and pediatric wards. While some of these factors are influenced by individual behaviour, the vast majority are directly linked to the health system – illuminating the ways in which the health system serves as a *social determinant of health* (SDH), and often restricting, constraining, and ironically, preventing people from obtaining the interventions and information they need to improve their health.

By connecting the empirical findings related to ART/PMTCT within the health system to the capabilities and health equity literatures, an understanding of disparities in access to, and delivery of, such services – and their importance in shaping health, development and health outcomes of these population groups – becomes clearer. As a consequence, strengthening the public health system is a necessary first step to ensuring at least some of the minimum conditions that allow people to be healthy. As an entry point, there is great scope for systems' interventions that would address the shortfall in health for black South Africans and deprivations in their health capability.

At the same time, the research reveals that – owing to the contribution of social determinants of health (e.g., factors that impact on health such as living and working conditions, but lie outside the realm of healthcare) to health status: good health is not achieved solely by access to and provision of good healthcare. This reality underscores the importance of health as a central capability; and good health as a normative social goal. In the capability view, the moral concern for state and society is the reduced capability of individuals due to health inequities that are socially-constructed, and in turn, changeable. Recommendations to address modifiable factors related to effective ART/PMTCT provision in these facilities are put forward, with a set of suggestions for future research in maternal, child and women's health in South Africa.

Acknowledgments

The seed of this study was, in many ways, planted years ago. When I was a post-graduate student at Boston University in the early 1990s, one of the course readings emphasised a central question of development, which stayed with me – informing both my practical work and research in development. Within the context of a rapidly globalising world, *cui bono?* Who benefits? It is this overarching question that both motivates and guides this research project: one that seeks to understand disparities in, and missed opportunities for, preventing and treating HIV in children and pregnant women in South Africa. This research would not have been possible without the assistance and support of a great many people – to whom I now offer thanks.

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The PhD is a lonely journey, requiring outstanding support from family and friends. I am blessed by enduring friendships: bonds that stretch across continents. I wish to thank one of my closest friends and co-author for his unmatched support of my work: Stu Woolman, a true mensch. As Stu would say, your friends are the people "who hold you in the world". In South Africa, those people are Caroline Kihato, Tashnee Padiaychee, Helen Nicholson, Lisa Ruch and Charisse Drobis, and I remain indebted.

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Johannesburg, South Africa

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Glossary of Terms

AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal care
ARV	Antiretroviral
ART	Antiretroviral therapy (single, dual and triple combination therapy)
AZT	Zidovudine
CA	Capabilities approach
CSDH	Commission on Social Determinants of Health
DoH	Department of Health
HCW	Healthcare worker
HIV	Human Immunodeficiency Virus
HRH	Human resources for health
MDGs	United Nations Millennium Development Goals
MSF	Médecins sans Frontières
MTCT	Mother to Child HIV Transmission
PMTCT	Preventing Mother to Child HIV Transmission
NSP	National Strategic Plan for HIV/AIDS and STIs (2007-2011)
NVP	Nevirapine
PCR	Polymerase chain reaction (infant test for HIV)
PHC	Primary healthcare
PNC	Postnatal care
RHRU	Reproductive Health and HIV Research Unit, University of the Witwatersrand
SdNVP	Single dose nevirapine
SDH	Social determinants of health
UNICEF	United Nations Children's Fund
UNAIDS	United Nations Joint Programme on HIV/AIDS
WHO	World Health Organization
Wits	University of the Witwatersrand

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Chapter 1

Premature Mortality Attributed to Pregnant Women and Children in South Africa: A Development Problem

Introduction

This chapter provides a brief introduction to the research concern, locates the problem in the South African context, and roots the remainder of the discussion within larger trends in health and development.

DIFFERENTIAL HEALTH OUTCOMES

The evidence base demonstrates that there have been remarkable health achievements globally in the last 50 years. In terms of life expectancy, the global health revolution has resulted in an additional four months added each calendar year over the last three decades for some countries – with significant reductions in maternal and infant mortality *WHO* (2000b; 2004); *Médecins sans Frontières (MSF)* (2001). These improvements have been attributed to public policies, socio-economic factors, and to some extent, improved medical care *Anand and Peter* (2004, p. 1); *Chen and Berlinguer* (2001); *Mann* (1997). But such gains have not been evenly distributed.

In parts of the developing world, there has been a marked decline among the same indicators and even a reversal in life expectancy for some countries in sub-Saharan Africa, including South Africa *Chen and Berlinguer* (2001); *Evans, Whitehead, Diderichsen, Bhuiya and Wirth* (2001); *MSF* (2001). For instance, a girl born today in Sierra Leone will expect to live 50 fewer years on average than a girl born in Japan *Ruger* (2006a; 2004a). In Southern Africa, life expectancy is getting shorter: "In stark contrast with children everywhere else in the world" *Dabis* and *Ekpini* state "children in southern Africa have a shorter life expectancy than their grandparents" (2002).

The majority of the world's population – 80% – reside in the developing world and suffer from a lack of drugs to combat diseases for which available treatment exists *MSF* (2001, pp. 10-11); *Chen and Berlinguer* (2001).[1] Preventable and treatable parasitic and infectious diseases account for 25% of the disease burden in the low and middle income countries while only 3% of the population in developed countries succumbs to the same diseases *MSF* (2001).

A Development Puzzle

While many countries have experienced significant health gains in terms of life expectancy and reduced maternal mortality, South Africa has performed poorly along the same development indicators. In spite of a high per capita expenditure on health ($748 in 2004 purchasing power parity terms – much greater than some of the middle income countries); its ranking by the OECD[2] as an upper middle income country; a high density of healthcare workers; good infrastructure; and, high levels of specialised knowledge and expertise in public health and medicine – the health of the majority of South Africans is appallingly poor. Health and development trends are dominated by premature morbidity and mortality linked to HIV infection; and they show no sign of reversing *Ntuli and Day* (2004); *Joint Learning Initiative* (2004); *Horsman and Sheeran* (1995); *Bradshaw and Nannan* (2006); *Bradshaw* (2008).[3]

The Research Question

Against that background, this research seeks to understand a critical development problem and dilemma in South Africa – premature mortality in pregnant women and children attributed to HIV – an infectious disease that is both preventable and treatable. Of a population of 48,5 million, an estimated 5,7 million South Africans have contracted HIV, the virus that causes AIDS *WHO/UNAIDS* (2008). This is the greatest number of individuals living with HIV within the borders of a single country.

While HIV is rolling back health gains for the population as a whole, its most pernicious effect has been on the health of children and pregnant women *Chopra et al* (2005); *South Africa Every Death Counts Writing Group* (2008a). In spite of the benefits of antiretroviral therapy (ART) and programmes to prevent mother to child HIV transmission (PMTCT), the *WHO* estimated in 2005 that only 10% of children and approximately 14.6% of pregnant women living with HIV who required treatment were gaining access to such interventions through the public health system in South Africa (2005b); *Joint Civil Society Monitoring Forum* (2007); *Ramkissoon, Coovadia, Hlazo, Coutsoudis, Mthembu and Smit* (2006). The two-fold question this thesis seeks to answer may be stated as follows: If free, life-saving treatment has such significant benefits for health and development – and is available for pregnant women and children with HIV/AIDS through the public health system – then why are the figures for treatment access so low; what are the primary barriers to antiretroviral treatment access and uptake for these population groups?

A larger question looms. Given the failure to deliver timely prevention and treatment, what are women and children with HIV in this country able to do and to be: what are the prospects for their development? The capabilities approach, developed by Amartya Sen, is employed to answer this broader question.

Unequal Distribution of HIV Infection across Population Groups in South Africa

HIV has now become the single leading cause of death in South Africa, regardless of age, sex or race *Bradshaw and Dorrington* (2005); *Pieterse et al* (2003); *Dorrington et al* (2004). However, it is important to note that the burden of HIV disease is not distributed evenly across population groups in the country. When the data are disaggregated by age, race and sex, they demonstrate that black women (South African women of African descent) of reproductive age, as well as black children under five, are bearing the brunt of morbidity and mortality in South Africa due to HIV-related opportunistic infections.[4] Black South African women who are pregnant have the highest HIV prevalence in the country, estimated at 30,2% *Government of South Africa* (2007a).

Significantly, *one in three* pregnant women in South Africa is HIV positive. In contrast, the HIV prevalence for the black South African population as a whole is considerably lower at 13,3% *Government of South Africa* (2005). An even greater contrast is the HIV prevalence between the most advantaged group in the country, the white population (South Africans of European descent), which is estimated at 0,6% and the most disadvantaged group, the black population, again estimated at 13,3% *Government of South Africa* (2005).

Even within the black population, women of reproductive age are disproportionately infected with HIV compared to men: South African women in the 25 to 29 age group have an estimated HIV prevalence of 33%. In contrast, men in the same age group have a prevalence of 12%. Among those 20 to 24 years of age, HIV prevalence is roughly 24% for women and 6% for men *Government of South Africa* (2007a).

The vast majority of South African children acquire HIV as a result of mother to child transmission (MTCT). Because there are such large numbers of pregnant women with HIV in this country, a significant epidemic in women of reproductive age translates into a significant epidemic in children *Coovadia* (2005); *WHO* (2006d); *UNAIDS* (1998). In sum, the published cause-of-death data demonstrate that black South African women and their infants are the population groups most severely affected by HIV infection in terms of morbidity and mortality *Abrahams* (2006); *Bradshaw et al* (2003b); *Bradshaw and Nannan* (2006); *Shung-King et al* (2006).[5]

Life Expectancy and Mortality

Life expectancy at birth increased from 1960 to 1990 by 3,5 years for the sub-Saharan African continent. It peaked in the 1990s but has since been on the decline. But nowhere has the decrease in life expectancy been "steeper and greater" than in Southern Africa, "where 40 years of increases in life expectancy were reversed in a period of 10 years" *Jamison, Feacham, Makgoba, Bos, Baingana, Hofman and Rogo* (2006, p. 13); *Cornia and Menchini* (2005). Recent health outcomes in South Africa – declining life expectancy and rising mortality rates – evince patterns of premature illness and death, largely attributed to HIV/AIDS *Groenewald, Bradshaw, Dorrington, Bourne, Laubscher and Nannan* (2005); *Dorrington, Bradshaw, Johnson, Budlender and Daniel* (2006).

In South Africa, the rate of life expectancy was 60 years of age in 1997. However, it dropped to 49 years by 2003 and continues to decline *WHO* (2004; 2000; 1998). The figures for South Africa are based on data from the ASSA 2000 model, and provide a visual depiction of these trends. (**Figure 1.1** illustrates declines in national life expectancy and **Figure 1.2** demonstrates losses in life expectancy by province.)

Figure 1.1 National Life Expectancy at Birth

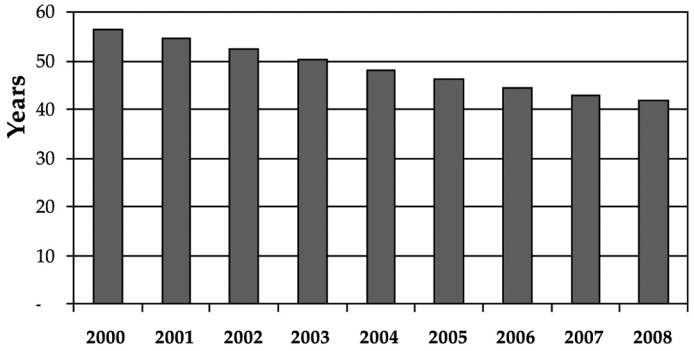
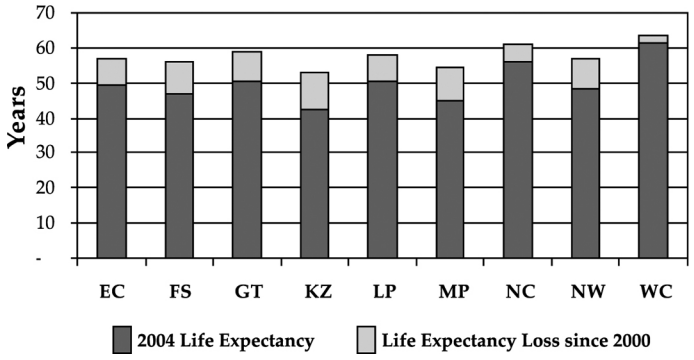


Figure 1.2 Life Expectancy Loss, 2000 to 2004



Note: EC= Eastern Cape; FS = Free State; GT = Gauteng; KZ = KwaZulu-Natal; LP = Limpopo; MP = Mpumalanga; NC = Northern Cape; NW = Northwest; WC = Western Cape.
Source: *Balasubramaniam and Sprague* (2005); original data sources used to construct Figures 1.1 and 1.2 are from the ASSA2000 model.

At the same time that life expectancy has declined, mortality rates have risen – primarily due to opportunistic infections associated with HIV/AIDS *UNDP* (2005); *Bradshaw, Bourne and Nannan* (2003b); *Groenewald, Bradshaw, Dorrington, Bourne* (2005).[6] *Jamison et al* document the direct impact of HIV/AIDS on child and adult mortality in the African sub-continent; and, on the epidemiology of almost the entire range of infectious diseases (2006). Although mortality figures in South Africa tend to be controversial, there is a great deal of unanimity in the trends *Bradshaw and Dorrington* (2005); *South Africa Every Death Counts Writing Group* (2008a-b); *Government of South Africa* (2006; 2001); *Pattinson* (2006); *Statistics South Africa* (2004; 2005).

Children

After national data are disaggregated to consider different groups in society, disparities in health outcomes become evident. In South Africa, infant mortality is five times higher among black children than white children *Evans et al* (2001, p. 3). High child mortality rates in children under age five in South Africa are one of the most visible manifestations of HIV/AIDS. Estimates reveal that each day 260 children are born infected with HIV in South Africa.[7] This is equivalent to 94 900 children newly-infected with HIV each year *UNICEF South Africa* (2006a-b). South African experts estimate that 75 000 children under five are dying each year, primarily of HIV and other common, treatable infections. Moreover, they also estimate that more than half of these deaths – 40 000 – are preventable *South Africa Every Death Counts Writing Group* (2008a). At this rate, more than 500 000 South African children will die over the next seven years unless considerable changes in policy and delivery are implemented.

Of the children infected with HIV each year in South Africa, only 10% will be tested for HIV. Most will die before they reach the age of two, unless they receive HIV testing and treatment in a timely manner *Every Death Counts Working Group* (2008a); *Joint Civil Society Monitoring Forum* (2007); *WHO* (2006); *Pattinson, Woods, Greenfield and Velaphi* (2005); *UNICEF* (2002); *WHO* (2000a; 2003a; 2006a-e); *MSF* (2006b).[8]

An estimated 90% to 95% of infants acquire HIV through the mother *Coovadia* (2005); *UNAIDS* (1998).[9] Paediatric HIV has been virtually eliminated in high-income countries. The availability of testing and treatment services has reduced transmission rates to less than 2% and dramatically increased the survival rates of HIV-infected infants *WHO* (2006e); *UNICEF* (2002); *Coovadia* (2005); *Médecins sans Frontières* (2006b).

Mother to child transmission rates in South Africa, however, remain unacceptably high, ranging from an estimated 11% to greater than 20% *Ashford, Black, Nyasulu and Pieters* (2007). The programme to prevent HIV transmission (PMTCT) from the mother

to the child was first introduced in South Africa in 2001 (before the national ART programme) in 18 pilot sites. The programme flowed from a landmark decision by the Constitutional Court in a case brought against the Government by the Treatment Action Campaign and other litigants *Heywood* (2005); *Bilchitz* (2003a); *Sprague and Woolman* (2006); *Leibenberg* (2003); *Bilchitz* (2001). The PMTCT programme has now been implemented country-wide in 3 300 public health facilities *Doherty et al* (2002; 2003); *Michaels et al* (2006). While PMTCT coverage is expanding, the quality and equity of existing PMTCT services have been questioned. Indeed, seven years on, much about the programme's effectiveness is unknown. The absence of reliable indicators regarding the success and the failure of the government's PMTCT programme constitutes part of the rationale for this research *Government of South Africa* (2008b, p. 42); *Chopra et al* (2005); *Jackson et al* (2007).

Pregnant Women

Despite problems with data collection and variation among an estimated six data sources, the trend in maternal deaths in South Africa is clearly an upward one *Government of South Africa* (2006); *Pattinson* (2006; 2008); *Bradshaw and Nannan* (2006); *Bradshaw and Dorrington* (2005). Since 1999, non-pregnancy-related infections have become the main cause of maternal mortality in South Africa (33,7%), with HIV/AIDS the single leading cause *Department of Health* (2006); *Jackson, Loveday, Doherty, Mbombo, Wigton and Matizirofa* (2006); *Shung-King, Mhlanga and De Pinho* (2006). In an astonishing report in the *Lancet*, maternal mortality in South Africa was estimated to be higher than that of Iraq *Kapp* (2007); *Lancet* (2008b-c).

Given current development indicators, South Africa will not achieve the international health-related Millennium Development Goals (MDGs). Goal three aims to promote gender equality and empower women, while Goal six seeks to halt and begin to reverse the spread of HIV by 2015. Goals four and five pertain to maternal and newborn health, child survival and reproductive health *Lancet* (2008a-b); *Bernstein and Juul-Hansen* (2006). Nor will it achieve national HIV/AIDS targets identified in the *HIV & AIDS and STI Strategic Plan for South Africa (2007-2011)* (NSP).

The goals of the NSP are to: a) reduce the rate of new HIV infections by 50% by 2011; and b) to reduce the impact of HIV/AIDS on individuals, families, communities and society by expanding access to appropriate treatment, care and support to 80% of all HIV positive people and their families by 2011 *Government of South Africa* (2007a); *Kapp* (2007). Preventing early morbidity and mortality for these groups – improving their prospects for development and for survival through access to life-extending essential

medicines and quality healthcare – can thus be seen as a government priority receiving insufficient attention *de Martino, Tovo, Balducci, Galli et a*l (2000); *Graham and Hussein* (2003); *Graham and Newell* (1999); *Palella, Delaney, Moorman, Loveless et al* (1998). Again, this research is motivated, in part, by the gap between robust on-paper policies, stated intentions (as well as legal obligation) and reality.

HEALTH, DEVELOPMENT AND SOCIAL JUSTICE

In South Africa today, health is a human right *Government of South Africa* (1996a). Access to healthcare is part of the basic law. It is clear that fundamental changes to the South African public health system since 1994 have centred on decreasing inequity across the country vis-à-vis access to heath services *Schneider, Barron and Fonn* (2007). Yet HIV/AIDS remains a critical development challenge. Importantly, for South Africans, the national HIV/AIDS treatment programme embodies the state's response to an entrenched public health epidemic, against a background of HIV/AIDS denial and claims that treatment was not affordable. Because it signifies whether or not HIV-infected South Africans will gain access to life-saving medications, the ART programme has become an important symbol of social justice and equity in healthcare *Nattrass* (2007; 2004); *Power* (2003).[10] The national fight for HIV/AIDS treatment, like the global one, has social justice at its core *Petchesky* (2003); *Jong-wook* (2003); *Farmer* (1999; 2005); *Mukherjee* (2004); *Gillies and t'Hoen* (2006); *Rosenberg* (2006; 2001); *MSF* (2001); *Schwartländer, Grubb and Perriëns* (2006).

Conceptual Framework

Development studies, a multi-disciplinary field, seeks to better understand the complex concatenation of factors that hinder and advance development. It is meant to do so through theory and by way of empirical studies set within the particular contexts in which development is meant to take root. If we are concerned with enhancing the development of individuals within our society, we need to ascertain the enabling conditions that are crucial for human development.[11] To that end, the conceptual framework employed in this study is discussed in detail in chapter three and extended in chapter six. However, a brief summary here is warranted.

The capabilities approach (CA), framework or view supports human beings in their development by marshalling and protecting a set of basic capabilities that allow for human development and flourishing. The CA is a normative framework: one useful for understanding the set of basic entitlements that, if afforded each person, would secure the needed preconditions to put human beings in society in a position to live a

life with dignity: a life they have reason to value. The CA also pays particular attention to the specific concerns of women vis-à-vis development. The CA is therefore relevant to a study that considers barriers to HIV services facing pregnant women, and the decisions they make as a result.

Poverty and inequality, often the subject of development studies, are empirical notions; they are viewed and measured as such. But health equity, like the CA, employs a normative approach. While *inequalities* in health describe differences in health "between groups independent of any assessment of their fairness" *inequities* in health refer to a subset of those inequalities that are deemed unfair *Evans et al* (2001, p. 4); *Whitehead* (1992, pp. 429-444; 1990). This important qualification of unfairness introduces questions concerning what fairness is; whether the inequalities are indeed avoidable; while also introducing questions about social justice *Evans et al* (2001); *Braveman and Gruskin* (2003); *Daniels, Kennedy and Kawachi* (2004) (to be discussed further in chapters three and six).

The *WHO* remarks: "Identifying a health difference as inequitable is not an objective description, but necessarily implies an appeal to ethical norms" (2007, p. 7). Accepted social ethics and social norms are thus critical. Social context, position and social policies provide a wide-ranging set of determinants that encompass economic, cultural, social and political factors. It is inevitable that individual health will vary due to biological variation and choice, e.g., whether or not to smoke, diet and exercise, as well as environmental health considerations. However, skews in the distribution of health by gender, race, income, or access to healthcare introduce questions about the nature of the skew relative to a particular group in society. Such questions about health equity ultimately raise questions that may warrant state action *Diderichsen et al* (2001).[12]

Diderichsen, Evans, and Whitehead observe that the burgeoning literature on the social determinants of health (SDH) demonstrates substantial differences in health outcomes between population groups, which "challenge our sense of justice and provoke our scientific curiosity" (2001, p. 13). The authors suggest that if we want to understand social health inequities, we must look upstream and downstream – upstream into social mechanisms and downstream to human biology (2001). *Wilkinson and Marmot* point out that not only are differences in health an important social injustice, they have attracted scientific attention to powerful determinants of health *standards* in societies. They have led to a growing understanding "of the remarkable sensitivity of health to the social environment and to what have become known as the social determinants of health" (2003, p. 7).

One of the key findings from this literature is that social gradients in health exist across all societies, regardless of how rich or poor. Authors, such as *Marmot* and *Daniels, Kennedy and Kawachi* note that although these gradients are present in all countries – they are not inevitable. Writes *Marmot:* "The slope of the ill-health gradient varies over time within countries and between countries. The fact that it is not a fixed property of society suggests that it is potentially changeable" (2000). He indicates that the evidence from the Whitehall Study suggests that place in the hierarchy determines risk of disease and death *Marmot* (2004, p. 51). Marmot calls this 'relative deprivation'. He suggests that the relationship between poverty and ill health is seen most clearly in developing countries like South Africa: "The high infant and middle-age mortality in South Africa… is an example" (2004, p. 50).

Any analysis of the phenomenon of premature mortality due to HIV/AIDS for pregnant women and children requires some normative 'teeth'. This combined framework – the CA and health equity – should provide the analytical heft that is required to understand this important development problem in our society.

RESEARCH OBJECTIVES

This research seeks to investigate the development problem of premature illness and death resulting from HIV infection for two groups in South Africa – pregnant women and children – by considering barriers to PMTCT and ART in the public health sector. To reflect its multi-layered complexity, this phenomenon is explored on both an empirical and a theoretical level, and has two inter-connected objectives.

The first objective is to deepen practical understanding of the barriers to ART and PMTCT for children and women with HIV; and hence to fill – in a small way – some of the gaps in the knowledge base. The second objective is to contribute to an enhanced understanding of premature mortality (attributed to HIV) and disparities in PMTCT/ART, as a social justice and development problem, by linking the capabilities and health equity literatures.

The significance of the answers that result from the research is this: a deeper empirical understanding of barriers to ART for pregnant women and children with HIV may shed light on missed opportunities for preventing mother to child HIV transmission in infants, and initiating antiretroviral therapy in pregnant women *de Martino, Tovo, Balducci, Galli et al* (2000); *Graham and Hussein* (2003); *Graham and Newell* (1999); *Palella, Delaney, Moorman, Loveless et al* (1998). At the same time, using the capabilities and health equity framework to consider disparities in PMTCT and ART provision for pregnant women and children and premature mortality may provide insight into avoidable health inequities. The larger aim is to understand and enhance human development for these population groups.

The following research agenda is put forward:

Agenda

1. Why are disparities in access to antiretroviral therapy for pregnant women and children – and the resulting premature mortality attributed to a preventable and treatable illness – a problem of social justice and development? Why is health a social justice concern? Why does health hold special importance for development and for capability? (chapter three)

2. What are the primary barriers to access and uptake of antiretroviral therapy and PMTCT for the two population groups? What does the published literature and the empirical research conducted during this study indicate? (chapters two, five and seven)

3. Do disparities in ART/PMTCT provision constitute 'health inequities' for black South African women and children with HIV/AIDS? In other words, are these disparities *unjust, avoidable and systematically associated with social disadvantage*? (chapter six)

4. What are the implications of this research for the capabilities of women and children with HIV/AIDS in this country? (chapter six) And, what alternatives are available? (chapter seven)

THE HEALTH SYSTEM

The research problem must also be placed within a systems context. With deep historical roots, five decades of structural, systematic inequalities in health, education, employment, and housing ultimately resulted in deprivation and exclusion for the majority population of black South Africans *May* (2000); *UNDP South Africa* (2006). In 2006, the richest 20% of the South African population had a human development index rank that was 101 places above the poorest 20%. Without delving into details, the result simply suggests high levels of inequality between segments of the population *UNDP South Africa* (2003).

The effectiveness of ART programmes of course depends on the effectiveness of the larger public health system. This system remains in a state of transformation, plagued with an array of challenges in the post-apartheid environment, including upgrading of infrastructure, putting data monitoring and information systems in

place, and retaining and increasing the number of health personnel *Schneider, Barron and Fonn (*2007). As *Altman* observed "AIDS has highlighted the difficulty of delivering antiretroviral drugs to patients in poor countries, thereby focusing world attention on the underlying cause: a lack of effective healthcare infrastructures" (2008).

In summary, South Africa's ART/PMTCT programmes' success rests on a functioning health system. That system is constituted by a number of discrete but interlocking parts: sufficient numbers of trained health personnel, proper health systems, medicine and related supplies, and the requisite physical infrastructure. But as other experts have shown, this initiative also depends on effective political will and commitment, strong leadership and management *Shetty* (2008); *Schwartländer, Grubb and Perriëns* (2006). Research demonstrates that this problem is not just a supply issue. It is well-documented that women in South Africa face a particular disadvantage when it comes to accessing information about HIV transmission, prevention and care, negotiating safer sex, and accessing treatment and support for HIV/AIDS *Birdsall, Nkosi, Hajiyiannis and Parker* (2004); *Smit, Beksinka, Ramkissoon, Kunene and Penn-Kekana* (2004); *Beksinka, Mullick and Kunene* (2006); *Ramkissoon, Coutsoudis, Coovadia, Mthembu, Hlazo and Smit* (2006). Thus far, South Africa's experience shows that even when countries are able to produce or to supply medicines at affordable prices and introduce treatment programmes, underlying structural drivers may inhibit access: e.g., disparities in access to health services, weak health systems and personnel, and gender-related determinants and social norms *Evans et al* (2001); *MSF* (2001; 2006d).

Much of the first generation of ART-based research investigated ART delivery and cost – the health system and its capacity to deliver (i.e., supply side issues) – without a great deal of attention to some of the structural drivers of transmission that might impact on prevention and treatment; or, the consideration of individual behaviour in relation to cultural and social norms that impact on behaviour, including psycho-social factors and health beliefs (i.e., the demand). These issues provide fertile ground for future research.

RESEARCH PROCESS AND METHODS

To attain the intended research objectives, the empirical research provides an investigation of the primary barriers to ART and PMTCT identified by women in two public health settings. Perceptions of patients and caregivers along their journey through the health system form the essential core of the field research. Interviews were undertaken with a range of key informants, including individuals affiliated with the public health facilities (e.g., nurses and doctors), together with academics and

practitioners with specialised knowledge and expertise in mortality, maternal health, child health, PMTCT and ART. Patient files and additional data sources were also utilised for the purposes of triangulation. A thick literature has recently emerged, although it remains less than comprehensive, which supports the use of case studies for controlled comparison and in-depth investigations of research questions *Yin* (2003); *Van Evera* (1997); *Cornwell* (1988). Four facilities in two differing geographical and socio-economic contexts, Gauteng and Eastern Cape, allowed for this case comparison. The intent was to achieve a sample composition that would include populations in urban and rural settings in South Africa – with a view to encompassing different types of impediments and experiences.

Study Limitations

One of the problems with a thesis – in circumscribing the domain of a specific research problem in the quest for depth and specificity – is the resulting focus. It is bound to leave out important concentric questions and considerations. In choosing to understand barriers facing pregnant women as a population group, I lost the opportunity to focus on HIV-infected women more broadly. Pregnant women with HIV are a group with particular health needs, and their challenges cannot necessarily be applied to women with HIV in general. This is a limitation when so many women in South Africa require access to the health system, to information on reproductive health and to ART.

Another important limitation is my choice to focus on pregnant women, their decisions, agency, anxiety, actions and experience as the mainstay of the field research. This choice came at the expense of interviewing caregivers of children (and the needs of children) more extensively. Within this mother-child dyad, the main unit of analysis is the mother (less so the child). However, the assumption being made is that the actions of mothers directly influence their children. I argue that the resulting analysis is useful for understanding barriers facing children. Nevertheless, those barriers are mediated (or not) by the mother. At one stage I was urged by a respected colleague (and paediatrician) to drop children completely. In my view, I would have been making the same mistake that has been made time and again: the usual approach is to look at child health or maternal health in isolation and not to consider their interdependence. In short, while there is evidence concerning both population groups in this study, the emphasis falls on the mother.

I chose to focus on the patient's journey through the health system in her quest for ART/PMTCT, and on specific points of service delivery in the care continuum. Because the interviews took place in a hospital setting, there was a selection bias of participants.

The participants were people who had made it to a clinic. I was not interviewing people in communities who chose not to secure health services at all (or simply could not due to economic or other constraints, regardless of their preference). One could argue that the more interesting – and sometimes more vulnerable – individuals are those who stay away from the health system completely.

The study sites were also highly context-specific. They present, in some ways, extreme best and worst case scenarios. The single facility studied in Johannesburg was relatively highly resourced (in human and financial terms). The facilities in the Eastern Cape Province, as a general rule, were not. The cases were not necessarily representative of all public hospitals: two facilities were research hospitals with the intellectual and financial resources that academic hospitals in South Africa attract. Analyses, interpretation and conclusions were also site-specific and may not be generalisable. However, the research did throw the rural-urban health divide – and attendant equity concerns – into stark relief.

STRUCTURE OF THE THESIS

Thus far I have articulated the research problem and question: setting the research concern against the backdrop of global achievements in health; while contrasting global achievements with increases in mortality and reductions in life expectancy in South Africa. Development gains for women and children won over two decades are now being soundly reversed – in spite of the evidence that lifesaving antiretroviral medication can prolong life and enhance quality of life.

In chapter two I discuss the knowledge regarding barriers to PMTCT and ART for pregnant women and children with HIV – the key literature and its limitations to date. I also highlight where further work is needed. Chapter three presents the conceptual framework employed in the study. I describe the combined theoretical framework that is used to investigate the research problem, spelling out the application to the thesis, including its strengths and weaknesses.

Chapter four summarises the methodology deployed in the study. I discuss the applicability of qualitative methods for the research; in particular, I touch on the importance of social context and the nature of 'internal experience' in studies such as this one where self-perceptions and beliefs about health and illness impact on health-seeking behaviour; and, ultimately, on health outcomes. I then review the research design, choice of case studies, techniques employed in the data collection, the ethics protocol, and methodological and ethical challenges faced.

In chapter five I present the empirical findings of the research as cross-cutting themes or issues across the sites. I explore rural-urban differences and highlight the implications of the findings for considerations of equity.

Chapter six considers the conceptual framework against the evidence. With reference to premature mortality and disparities in ART and PMTCT for the two population groups, I assess whether these are health inequalities or inequities (a subset of inequalities that are deemed unjust, avoidable and systematically associated with social advantage that is frequent, substantial and persistent, not random or occasional). I then reflect on the implications of these inequities for the capabilities of women and children with HIV in South Africa.

Chapter seven discusses the ways in which the health system serves as a social determinant of health. The chapter identifies factors that contribute to the current situation and offers targeted recommendations for addressing avoidable factors in HIV service delivery.

Chapter eight highlights the conclusions drawn, provides recommendations for future research, and puts forward a set of final observations.

I close this introductory chapter with a reflection on the field of development studies, its alleged irrelevance when it comes to affecting people's real lives, and the yawning chasm that often exists between understanding and action. The point of briskly unwrapping and laying bare a few larger weaknesses of this field at the outset is to be fully aware of pitfalls and opportunities that may lie in wait.

THE PROBLEM OF DEVELOPMENT (STUDIES)

Development as a field of research or practice seeks to advance the well-being of individuals in society. *Edwards* notes that the traditional province of the development practitioner is action, while that of the academic is understanding. Ideally, development studies seeks to connect the two along a trajectory: using robust research and attendant understanding to facilitate tangible change in the world *Edwards* (1996). *Sen*, speaking of equality, emphasised: "Equality, as an abstract idea, does not have much cutting power" (1992, p. 660). This statement is equally true of development. Practitioners of development want the knowledge gleaned from research to have the necessary muscle to translate into tangible improvements in the real lives of people *Owuso* (1975). Yet *Edwards* suggested two decades ago that the links between research and development are complex ones: "few would posit a simple, linear relationship

between the two" (1989, p. 116). In 1972, *Coleman* observed a similar challenge in translating research into policy in the social sciences: "Policy research involves two acts of translation: translation of the problem from the world of reality and policy into the world of scientific method, and then a translation of the research results back into the world of reality and policy" (1972). This two-fold challenge continues to vex academics and practitioners today.

Edwards also highlighted a primary weakness of development studies – that it has not had the measurable impact that was initially hoped: "This immense outpouring of information and advice is having demonstrably little effect on the problems it seeks to address [and] should at least give us cause for concern" (1996). He asked:

> "Why is it that our increasing knowledge of the Third World does not enable solutions to be found? Is this because practitioners refuse to listen? Is 'development' a matter to be left to practitioners anyway? Are there other, stronger forces that prevent the right action being taken? Or could it be, in Paul Devitt's words, that 'our kind of knowledge is simply not enough'?" (1996, p. 116).[13]

Edwards singled out one aspect of the relationship between research and development that helps to explain this predicament – the absence of strong links between understanding and action (1996, pp. 116-117). Along similar lines, *Farmer* contends that the "hypocrisies of development" are equally "morally flimsy" and "analytically shallow" (1999, p. 21). In the same vein, *Nabudere* declared development theory "dead but not yet buried" due to the mismatch between theory and practice, as well as development specialists' misconceptions regarding human behaviour (2006, p. 33).

Given current development indicators in South Africa – significant declines in life expectancy and sharp rises in mortality attributed to HIV/AIDS – we can no longer afford for development studies to be irrelevant, and for research to fail to inform understanding and accompanying action. South Africa's differences in health outcomes present an important case study for research on social inequalities in health because these differential health achievements among racial groups have largely been socially constructed. The significance of South Africa as a case study for inequity, and health inequity particularly, has been noted inside and outside the country *Seekings and Nattrass* (2005); *Gilbert and Walker* (2002); *Gilson and McIntyre* (2001; 2007); *Evans et al* (2001); *UNDP South Africa* (2003).

What happens here is in many ways a test case for other developing countries, and we cannot afford to fail. As Kevin De Cock, Director of HIV/AIDS at the WHO, declared: [South Africa is] also so different from the other African countries; it has such resources available – financial, human, and infrastructural". De Cock further observed: "What happens in South Africa is more important for the future of the HIV/AIDS epidemic than what happens anywhere else in the world". He concluded: "if they don't manage to get it right there, what is the likelihood of us doing it elsewhere in Africa?" *Shetty* (2008).

Early morbidity and mortality linked to HIV in children and pregnant women is one of the most important problems that South Africa has ever faced. Unlike other intractable issues, this problem has readily available solutions: many of the infections that lead to subsequent illness and death are entirely preventable and treatable. With these challenges and opportunities clearly in view as a touchstone and a departure point, we begin the journey.

Endnotes

1 For an in-depth discussion of the health inequities associated with globalisation, see *Chen and Berlinguer* (2001, pp. 34-44); see also *Gilbert and Gilbert* (2004).

2 Organisation for Economic Co-operation and Development.

3 Recall that the world's first heart transplant was performed by Dr Christiaan Bernard at Groote Schuur Hospital in Cape Town in 1967. South Africa was also a world leader in pioneering the primary healthcare approach until the 1980s. See *Kautzky and Tollman* (2008).

4 Opportunistic infections include bacterial infections (e.g., syphilis and tuberculosis), fungal infections (candidiasis, commonly known as thrush and cryptococcal meningitis), malignancies (such as lymphomas or kaposi's sarcoma), viral infections (cytomegalovirus, hepatitis, human papiloma virus, herpes zoster or shingles and herpes simplex or genital herpes), neurological infections (AIDS dementia complex, peripheral neuropathy), protozoal infections (toxoplasmosis, pneumocytis carinii pneumonia), and other infections and conditions. See 'AIDS-Related Opportunistic Infections' US National Library of Medicine, National Institutes of Health, available from http://sis.nlm.nih.gov/hiv/opportunisticinfections.html#a0.

5 Note that initially I had planned to investigate barriers to ART access in the adult population generally. It was because of the large burden of HIV morbidity and mortality concentrated in pregnant women and children that I chose to focus on these two population groups within my research. They are the worst affected and they are two of the groups most vulnerable to HIV transmission – biologically and socially.

6 See footnote four for more on opportunistic infections.

7 Child mortality rates are defined here as the probability of a child dying before they reach five years of age. As *Bradshaw and Dorrington* note, this is a "preferred indicator of child health as it includes a measure of the vulnerability of toddlers that includes the impact of maternal and environmental health". See *Bradshaw and Dorrington* (2005, pp. 419-429).

8 The *WHO/UNAIDS* estimated in 2007 that 32 000 children were accessing ART (2008).

9 Unsafe practices such as contaminated needles, unsafe blood and blood products account for a small percentage of cases; and an unknown proportion of children in South Africa become infected with HIV through rape. *Coovadia* (2005, see pp. 183-192); *UNAIDS* (1998).

10 The historical background surrounding access to ART was that of South African civil society battling the state for the provision of lifesaving ARV medicines – with this social justice campaign taken to the courts by the Treatment Action Campaign, together with the AIDS Law Project and other litigants and supporters *Petchesky* (2003); *Power* (2003); *Heywood* (2003 and 2005); *Nattrass* (2007); *Niekerk and Kopelman* (2005); *Lindsey* (2001).

11 One line of thinking is that empirical studies drive development theory. Not the other way around.

12 One example is healthcare financing and reform. In Mexico, for example, reforms aimed at increasing efficiency and equity were introduced in 1996, and decentralisation, in 1997. The empirical results ten years on reveal progress: *Lozano, Zurita, Franco, Ramírez, Hernández and Torres* state that "improvements in the quality of life and medical care have reduced the rate of selected cause of death and delayed the age of death" (2001, p. 290). They call for additional studies to assess whether or not healthcare coverage has reached "the most deprived" and to evaluate "what impact there has been on the health profiles of the target population". And, they stress that policies should be studied for their ability to promote health outcomes and to overcome existing inequalities (2001, p. 293); see *Evans et al* (2001).

13 *Edwards* suggests that chief among the factors contributing to the irrelevance of development studies are the 'professionalisation' of development studies; the devaluation of popular knowledge; the values and attitudes of researcher/practitioners that prevent them from working as equals; the control of knowledge by elites; and, a failure to unite understanding, action, relevance and participation. He concludes: "Taken together, these weaknesses make it very difficult for conventional development studies to have any significant effect on the problems they seek to address" (1989, p. 133).

Chapter 2

Context Setting: Maternal and Child Health, Health Systems, PMTCT and ART

This thesis considers the contemporary problem of ART and PMTCT access for women and children against the disease burden of HIV infection, the supply and demand for ART, existing healthcare and PMTCT policies, and within its historical and policy context. In this chapter my aim is to capture a set of key phenomena and salient debates that intersect with, and have a direct bearing on, the research problem – and ultimately on the development prospects for black South African women and children living with HIV. The research concern can be seen as part of a larger pattern – with the research question serving as the major thread, and extant factors and trends that influence the research problem serving as intersecting, complex strands woven into the larger tapestry of this complex phenomenon.[1]

I briefly outline the national public health response to the HIV/AIDS challenge in South Africa – the antiretroviral treatment (ART)[ᵏ] programme and the prevention of mother to child HIV transmission (PMTCT) programme; taking care to emphasise the context in which this response is grounded: that unequal access to quality healthcare is the norm in South Africa and that the health policy agenda of the African National Congress seeks to respond to such inequalities.

THE PUBLIC HEALTH RESPONSE TO HIV/AIDS

Disparities in Quality Healthcare in South Africa

The research concern must be set against a larger backdrop where inequalities in access to, and quality of, care and treatment generally, and for those who are HIV-infected particularly, remain the norm in South Africa: a legacy of 50 years of apartheid policies. Any research in this area must begin with this knowledge. In 2004, some 76% of specialists and 73% of general practitioners worked in private practice in

[ᵏ] Note that highly active antiretroviral therapy or 'HAART' refers to triple antiretroviral combination therapy, while ART can be used to refer to monotherapy (one drug, such as nevirapine, which is administered as a single dose to pregnant women), dual or triple combination therapy. I use ART to refer to all of these. When I am discussing problems with the administration of nevirapine (or NVP), I will refer specifically to NVP.

South Africa, although less than 20% of the population utilised the private health sector. The distribution of expenditures – personnel, beds, facilities – across the various categories – were all similarly skewed *Padarath, Ntuli and Berthiaume* (2004); *Government of South Africa* (2005). Indeed disparities in access to high quality healthcare are visible by race, class, and geographic location across the country *Wadee, Gilson, Thiede, Okorafor and McIntyre* (2003).

For those living with HIV/AIDS, only an estimated 460 000 South Africans who require antiretroviral therapy (ART) currently have access to such treatment in public clinics and hospitals. Yet it is estimated that 600 000 new patients will require immediate access to antiretrovirals *each year* for at least the coming decade *Barker and Venter* (2007).

A National Public Sector Antiretroviral Treatment (ART) Programme

In response to the HIV/AIDS[2] epidemic in South Africa, highly active antiretroviral therapy[3] (HAART) has become available in the public health sector based on the knowledge that it improves the health and survival of those living with HIV/AIDS who are indicated for treatment *Crum, Riffenburgh and Wegner, Agan et al (2006); Marins, Jamal, Chen, Sanny et al* (2003); *Walensky, Paltiel, Losina, Mercincavage et al* (2006); *WHO* (2006d). With the introduction of triple combination therapy (three drug combinations), patients have registered 50% to 80% improvement in survival and delayed progression to AIDS. Use of combination therapies globally has led to striking reductions in AIDS incidence (new infections), while dramatically reducing AIDS-related deaths.[4] In effect, countries that have introduced national ART programmes have stabilised their HIV epidemics as a result of triple combination therapy, enabling legislation and public health policies, and accompanying behavioural interventions *Palella, Delaney, Moorman, Loveless, et al* (1998); *Mocroft, Vella, Benfield, Chiesi et al* (1998); *Vittinghoff, Scheer, O'Malley, Colfax, Holmberg et al* (1999); *Detels, Munoz, McFarlane, Kingsley et al* (1998); *Hogg, Yip, Kully, Craib et al* (1999); *Parker* (2003); *Galvão* (2003; 2005); *de Ávila* (2003); *Rosenberg* (2001).[5] Based primarily on the efficacy of AIDS treatment and reductions in prices of ARV medicines, together with an extended civil society campaign, the DoH established a national AIDS public sector treatment programme in 2004 at the request of Cabinet *Government of South Africa* (2003b); *Lucchini et al* (2003); *MSF* (2006b); *De Cock* (2000); *de Mattos* (2003).

WHO and UNAIDS estimated that 1,7 million South Africans require immediate access to ART (2008). To date, this unmet need for treatment concentrated in one country is unprecedented. Four years after the South African Government's AIDS treatment programme was established, it was meeting only roughly 28% of total demand *WHO/UNAIDS* (2008); *Joint Civil Society Monitoring Forum* (2007). Existing research indicates

that many HIV-infected South Africans who make their way to public health clinics and hospitals for treatment and care throughout the country face significant barriers in antiretroviral therapy access and uptake *Ramkissoon, Coutsoudis, Coovadia, Mthembu, et al* (2006); *Smit, Beksinka, Ramkissoon, Kunene et al* (2004); *Beksinka, Mullick and Kunene* (2006); *Besser, Paruk and Dinat* (2002). However, there are large gaps in our understanding of the impediments to treatment for specific groups (e.g., women, children, men, youth and refugees) and the nature of these barriers – thus adding to the rationale for research in this area.

Prior to the introduction of ART in South Africa, mother to child transmission (MTCT) rates were estimated at 19% to 36%, depending on whether the mother elected to breastfeed or not *Coutsoudis, Pillay, Kuhn, Spooner et al* (2001); *Abdool Karim et al* (2003). Today, the transmission rate with a national PMTCT programme in place (for seven years) remains high – with an estimated transmission rate of greater than 20%. Controlled settings in highly resourced hospitals and clinics in South Africa have, however, documented transmission rates of lower than 5% *Moultrie* (2009); *Ashford, Black, Nyasulu, and Pieters* (2007); *Government of South Africa* (2007a).

MTCT: A Largely "Uncontrolled Epidemic" in Africa

Children living with HIV/AIDS in Africa and South Africa generally acquire HIV as a result of mother to child transmission (MTCT) *WHO* (2006d); *Coovadia* (2005); *UNAIDS* (1998). HIV infection can occur during pregnancy, labour, delivery and through breastfeeding *UNAIDS* (1998); *WHO* (2006d). In clinical trials of antiretroviral drugs for women and infants, low maternal CD4 cell counts (a measure of immunity), high maternal HIV viral load, vaginal birth (instead of a caesarean section) and breastfeeding were all significant risk factors for perinatal[6] HIV transmission *Stringer et al* (2008); *Coovadia* (2005).[7] In the USA and Europe, paediatric AIDS has been all but eradicated by ensuring high service coverage and systematically targeting each of those risk factors *Stringer et al* (2008); *European Collaborative Study* (1999); *US Public Health Task Force* (2005). While those countries have shown what is possible, *Stringer et* al emphasise that paediatric AIDS in Africa remains a "largely uncontrolled epidemic" (2008). The same is true in South Africa.

Scale of the Problem

The majority of global MTCT cases occur in sub-Saharan Africa (SSA), which captures 90% of the 800 000 cases worldwide *Stringer et al* (2008, p. 57). SSA bears 70% of worldwide HIV infections, and houses 90% of all HIV-infected children *Coovadia*

(2005, p. 184). In 2000, before the national ART rollout began, the South African Government estimated that 75 000 infants were born with HIV in that year alone. The South African HIV Clinicians' Society and other experts stressed that half of those infections could have been prevented if short course antiretroviral prophylaxis had been available *Abdool Karim et al* (2003). In 2002, 69 000 infants were estimated to have been infected with HIV at the time of birth, and 20 000 were infected through breastfeeding, bringing the total of HIV-infected infants to 89 000 for that year *Jackson, Chopra, Doherty, Colvin et al* (2007). UNICEF estimated by 2005 that 94 900 children were infected with HIV each year *UNICEF* (2006a). The *Joint Civil Society Monitoring Group* (2006; 2007) found that only 10% of children requiring ART gained access; *UNICEF South Africa's* estimates concurred (2006a).

Impact

The total number of children living with HIV in South Africa is unknown. Case finding of infants and children with HIV is particularly difficult. *Moultrie* points out that estimating the number of children with HIV is complex because the natural progression of the disease is altered by postnatal transmission. This 'denominator' has been estimated using various models but remains imprecise (2009); *Besser* (2009a). As a consequence, the total number of South African children with HIV requiring treatment is also largely unknown. Because of the difficulty of finding children who are already infected, the related costs to the state of treating and caring for children with HIV, and the importance of preventing new infections in infants in the first instance, the critical role of prevention – PMTCT – has been further emphasised.

For children who become infected with HIV, most will die before they reach the age of two unless access to ART is achieved *South Africa Every Death Counts Writing Group* (2008a); *Coovadia* (2005); *WHO* (2006d); *Pattinson et al* (2005). As will be discussed, much of the current data on morbidity and mortality in children with HIV is insufficient – with deaths in children widely agreed to be under-reported and undercounted *South Africa Every Death Counts Writing Group* (2008a, p. 1294); *Bradshaw and Dorrington* (2005); *Bradshaw and Nannan* (2006); *Bradshaw, Bourne and Nannan* (2003b); *Kashifa* (2006). In 2005, there were an estimated 1,5 million maternal orphans in South Africa, with 66% of children orphaned as a result of HIV/AIDS *Dorrington et al* (2006). As a consequence, *Chopra, Doherty, Jackson and Ashworth* emphasise that the HIV/AIDS epidemic is reversing gains in child survival in South Africa, making the achievement of national and international goals linked to child and maternal health much more challenging (2005); *Lancet* (2008b-c); *Bernstein and Juul-Hansen* (2006); *Campbell et al* (2006); *Dabis and Ekpini* (2002); *Graham and Hussein* (2003); *Government of South Africa* (2007a); *Kapp* (2007).[8]

Increasing Attention to PMTCT

The growing attention to PMTCT in Africa has also resulted from increasing understanding of its impact; from the knowledge that breastfeeding is a mode of HIV transmission; that simple, short course, cost-effective regimens could be implemented with good results; and that a large share – over 58% – of all HIV infections in sub-Saharan Africa were found in women of reproductive age (19 to 49 years) *UNAIDS/WHO* (2008). This accords with research on the increasing feminisation of the HIV/AIDS epidemic *Stevens* (2008a). Hence, research and practice demonstrated that mother to child transmission – the infection of infants with HIV – is wholly preventable using cost-effective uncomplicated regimens, while ensuring positive health outcomes for babies and mothers *Sweat, Gregorich, Sangiwa et al* (2000); *Wilkinson, Floyd, and Gilks* (2000); *Söderlund, Zwi, Kinghorn and Gray* (1999).

In the last several years there has been a dramatic response to HIV/AIDS globally, manifested by new funding opportunities, provided by sources such as the US President's Emergency Plan for AIDS Relief (PEPFAR), the Gates Foundation, the US Dept of Health and Human Services' National Institutes of Health (NIH), the US Centers for Disease Control and Prevention, the Elizabeth Glaser Pediatric AIDS Foundation, and other primarily European and US donors. These donors just cited have all funded PMTCT interventions and programmes in SSA. Nonetheless, *WHO* argues that "despite significant progress, they [these programmes] have not been implemented widely in resource-constrained settings" (2006d). Significantly, on the back of such initiatives, there has been a shift from pilot projects to national ART programmes. But this shift has come slowly.

By 2005, only 9% of all pregnant women with HIV, globally, were receiving antiretroviral drugs (single, dual or triple therapy) to prevent HIV transmission to their neonates *UN General Assembly* (2001). New national ART programmes in Africa have come into existence in the last several years, while new and renewed commitments have been made to take PMTCT and ART to scale for women and children in resource-limited settings.[9] These include the Abuja Declaration *WHO* (2003d), the Brazzaville Commitment *UNAIDS* (2006a-b), the 2001 *United Nations General Assembly's* Declaration of Commitment on HIV/AIDS (2001)[10] and the MDGs *UN Statistics Division* (2009); *UN* (2008); *WHO* (2006d); *Bernstein and Juul Hansen* (2006).

I now briefly draw attention to a larger discourse in the international health and social justice literature, which is impacting on (or possibly limiting) treatment provision and quality of care – the synergy or tension between strengthening health systems (and primary healthcare) and scaling up antiretroviral services.

UNIVERSAL TREATMENT AND HEALTH SYSTEMS' STRENGTHENING: CONFLICT OR SYNERGY?

This research can also be situated within a set of debates unfolding in the international health and social justice literature related to questions of access to and provision of ARV medicines for poorer populations in particular, and to basic services, healthcare (specifically *quality* primary healthcare) especially for populations in the developing countries *MSF* (2001); *Allotey* (2007); *de Ávila* (2003); *Department for International Development (UK)* (2004 a-d); *Desvarieux et al* (2005); *Galvão* (2003); *Garmaise* (2006); *Garrett* (2000); *Furber et al* (2004); *Farmer* (1999; 2005); *Chen and Berlinguer* (2001). In returning to historical social justice commitments, public health has most recently called for a return to Alma-Ata and its focus on primary healthcare *Lancet* (2008d); *WHO* (2008e).[11]

Revolutionary at the time, Alma-Ata and its 'Achieving Health for All by 2000' tag-line had at least four salient features. Firstly, health was explicitly agreed to be a human right and an important social goal, with governments holding primary responsibility for the health of their citizens. Secondly, the importance of active participation of citizens in the planning and implementation of their healthcare was recognised. Thirdly, primary healthcare was to be the unequivocal foundation of the healthcare systems of nations. Fourthly, Alma-Ata identified gross inequalities in the health status of populations in the industrialised and developing countries, and inter-group inequalities within countries, and deemed them unacceptable *Alma-Ata* (1978); *Lawn, Rohde, Rifkin, Were* (2008).

Significantly, it was Lee Jong-wook, former director general of the World Health Organization (2003-2006), who sought to connect the global 'Health for All' campaign with the international AIDS treatment agenda. Jong-wook was instrumental in introducing the 3 by 5 campaign to close the treatment gap between the 'haves' and 'have nots'.[12] The joint WHO-UNAIDS initiative aimed to make ART accessible to three million people, mainly in the poorest countries, by the end of 2005.[13] Before his death in 2006, *Jong-wook* wrote that the most urgent objectives for WHO included the health-related Millennium Development Goals and the 3 by 5 targets for HIV/AIDS treatment. The key to achieving these objectives, he noted, lies in "strengthening of health systems guided by the values of Health for All"(2003).

Why is this relevant? There is a major debate in the HIV/AIDS and public health community about the role and impact of HIV/AIDS – the focus on a single disease, called 'AIDS exceptionalism' – and its impact on health systems. The criticism of HIV, lodged by *England* and others, is that it dwarfs other diseases and concerns, and that this focus is unwarranted: indeed deleterious.

Unlike for *England* and other critics who claim that there are negative repercussions of AIDS treatment provision for health systems, for *Jong-wook* there was no conflict *Lancet* (2008a); *England* (2008a-b; 2007); *De Lay* (2008); *Gonsalves* (2008). In his eyes, the social justice goals of treating poor people and strengthening health systems were complementary. Tying these initiatives together requires a "comprehensive engagement with health systems" he stated *Jong-wook* (2003). Fundamentally, this meant a return to the resolutions made at Alma-Ata in 1978.

England makes the case against an AIDS focus, including AIDS funding, because this can divert resources from health systems and from other important diseases (2007; 2008a-b). But Research by *Yu, Souteyrand, Banda, Kaufman et al* found that major global HIV/AIDS programmes have in fact introduced considerable resources into countries (2008). In addition to rapid provision of HIV/AIDS services in some countries, infrastructure and primary healthcare (PHC) services have improved in some cases. However, they note that this has not been well-documented.[14] In South Africa, the question remains whether AIDS treatment can be expanded without attention to strengthening health systems, and investing in health personnel *Kautzky and Tollman* (2008). The relationship between primary healthcare and AIDS treatment also remains unclear. This debate thus has important implications for the research problem.[15]

Much of the first generation of ART-based research has investigated ART delivery and cost – the health system and its capacity to deliver (i.e., supply side issues) – without a great deal of attention to some of the structural drivers of transmission that might impact on prevention and treatment; or, the consideration of individual behaviour in relation to cultural and social norms that impact on behaviour, including psycho-social factors and health beliefs (i.e., the demand). (These provide fertile ground for future research.) Due to their significance, I briefly consider a set of factors that affect HIV transmission, prevention and treatment: women's social and biological vulnerability to HIV and socio-cultural norms in South Africa.

WOMEN'S BIOLOGICAL AND SOCIAL VULNERABILITY TO HIV TRANSMISSION AGAINST CULTURAL AND SOCIAL NORMS

In Southern and South Africa, women's greater vulnerability to, and risk of, HIV acquisition is both biological and social. Biologically, women are more susceptible than men to contracting sexually transmitted infections (STIs), including HIV, due to the greater area of mucous membrane exposed during sex (particularly young women whose genital tracts are not fully developed), the larger quantity of fluids that are transferred from men to women during sex, and the higher viral content in male

sexual fluids. Micro-tears can also easily occur in women's vaginal tissue as a result of sex. South Africa is thought to have a large number of untreated STIs. Individuals with untreated STIs are over six times more likely than other individuals to pass on or acquire HIV during sex, and a genital sore caused by an STI increases the risk of becoming infected with HIV from a single exposure by 10 to 300 times *UNAIDS* (2004b; 2004c).

Through increasing mortality, morbidity and related impacts, the global HIV pandemic is illustrating the myriad ways in which gender inequalities impact negatively on women's health. The evidence reveals that women's unequal status and position in society is often at the centre of such health inequalities in South Africa *Dunkle et al* (2004). Sexual risk behaviour is associated with interpersonal relationships, an inability to negotiate condom use, peer pressure to have sex, and 'coercive' male-dominated relationships *Matthews* (2005); *Jewkes* (2002a); *Klugman* (2000). Studies have demonstrated that social context and position in South Africa, as well as cultural factors and norms, have been significant in increasing HIV transmission among women *Government of South Africa* (2007a); *Varga* (2003); *Jewkes, Penn-Kekana and Rose-Junius* (2005); *Jewkes, Levin and Penn-Kekana* (2002a).

The position of women in South Africa means that they are often born into inequity; an inequity characterised by low socio-economic status, which predisposes women to poverty, to malnutrition and to lack of control over their own fertility.[16] This restricts the range of protections women have from contracting STIs, including HIV *Ackermann and de Klerk* (2002); *Bernstein and Juul Hansen* (2006); *Sprague* (2008). *Ackermann and de Klerk* and others observe that gender violence is widely understood to be a large problem in South Africa, though the exact levels are not known. Rape is one of the least notified crimes in the country (including child rape) (2002, p. 166); with only an estimated 2,8% of rapes reported *Ramsay* (1999). As the *WHO* states: "Gender-based violence is a major risk factor for the ill health and lack of wellbeing of girls and women around the world" (no date). A study conducted by researchers from the University of the Witwatersrand in 1995 showed that more than 60% of women were regularly battered by partners or spouses and 50%-60% of marriages were reported to involve physical and sexual violence *Wood, Jewkes and Maforah* (1998).

Dunkle et al state: "Gender-based violence and gender inequality are increasingly cited as important determinants of women's HIV risk; yet empirical research on possible connections remains limited" (2004). Given the burden of HIV infection and the associated social impacts, the connections between gender, health and HIV cannot be dismissed *Gender Medicine* (2006); *Grown, Gupta and Pande* (2005); *Klugman* (1999).[17]

Pregnant Women and Children with HIV/AIDS – A Rationale

Why focus on these particular population groups when few men are accessing treatment as well? While men are the most under-represented group accessing ART in the public health sector, men do not have the same biological and social vulnerability to contracting HIV that women do; and, men in South Africa, unlike women and children, generally make their own decisions about healthcare and whether or not to seek it *Joint Civil Society Monitoring Forum* (2007). In contrast, pregnant women constitute a significant target group since HIV prevalence in pregnant women remains over 30%. They are a population at risk of HIV infection, illness and death: HIV infection increases the risk of maternal death ten-fold *Pattinson* (2009). There is also the opportunity for preventing mother to child transmission. Because 92% of women have at least one visit to a hospital for antenatal care during their pregnancy, they therefore comprise a strategic group for targeted HIV services, with opportunities for HIV prevention, testing and treatment during antenatal care, delivery, postnatal care and follow up *Government of South Africa* (2007a); *WHO/UNAIDS* (2008).

Women's health-seeking behaviour has an important bearing on the health of their infants. Children hold a special legal status as a vulnerable group in South Africa. The basic law in South Africa grants children unqualified and immediate rights to healthcare access (as opposed to the *progressive realisation* of those rights for adults) *Government of South Africa* (1996a). However, the special place that children have in South African law is at odds with the gritty truth of their socioeconomic status and development prospects in this country *University of Pretoria et al* (2005); *Tobin* (2005). This research also recognises the importance of safeguarding the health of pregnant women for their own sake, not just as bearers of children. The importance of a focus on the mother-child health dyad is critical, particularly when introducing health interventions, but its impact on access to medicines in this country is under-researched. Because of the inter-dependence of the two population groups and the reality that most interventions targeted to a pregnant woman or her child within a public health setting ultimately affect the health of both groups, there is a rationale for research that considers this dyad with greater scrutiny *Chersich* (2007); *Rosenfield and Figdor* (2001).

In chapter one I briefly mentioned some of the key limitations of the health system. Here I will discuss some of the chief factors that affect HIV service delivery for women and children, as well as the equity of access and provision. The intent is to situate the research problem within a health systems context, emphasising the high degree of change and stress within the system and on health personnel.

THE PUBLIC HEALTH SYSTEM AND EQUITY

The South African government's post-apartheid agenda reflects and responds to the reality of a highly unequal society. The major mandate of the African National Congress (ANC) in 1994 was to 'redress inequity' broadly. For the health sector, the ANC also articulated equity as a priority goal of its health policy agenda, situating "the achievement of health gains in broader equitable social and economic development" *Gilson and McIntyre* (2001, p. 191). This approach was not only a response to separate apartheid policies based on race and differential health outcomes but reflected South Africa's relatively poor health performance when compared to middle and even low income countries; and, notably, the "largely preventable burden of disease in the country" *Gilson and McIntyre* (2001, p. 191); *Wadee, Gilson, Thiede, Okorafor and McIntyre* (2003).

This is a system still in a state of reform, with a view to improving equity. The aims of restructuring the health sector as identified in the DoH 1997 White Paper were, principally: to unify the fragmented health services at all levels into a comprehensive and integrated national health system (NHS) through a district health system (DHS); to reduce disparities and inequities in health service delivery; and increase access to improved and integrated services, based on primary healthcare principles; to give *priority* to maternal, child and women's health (MCWH); and, to mobilise all partners, including the private sector, NGOs and communities in support of an integrated NHS *Government of South Africa* (1997a).[18]

In addition to the aims of the restructuring outlined, a set of seven objectives were put forward by Government in the White Paper for the Transformation of the Health System in South Africa *Government of South Africa* (1997a). The process by which the objectives outlined in the White Paper were to be met was intended as a participatory one between the government, private sector, NGOs and communities *Forman, Pillay and Sait* (2004).

The stated objectives of the DoH were:

a. To unify fragmented health services at all levels into a comprehensive and integrated NHS.
b. To promote equity, accessibility and utilisation of health services
c. To extend the availability and ensure the appropriateness of health services
d. To develop health promotion activities
e. To develop the human resources available to the health sector
f. To foster community participation across the health sector
g. To improve health sector planning and monitoring of health status and services *Government of South Africa* (1997a).

Schneider et al observe that any overview of the evolution in South Africa's health system is fraught with limitations. Efforts at transforming and restructuring the health system in South Africa have been quite vast in scope (2007). *Ntuli and Day* note positively that these reforms have included "significant equity-oriented policy measures" in an era when the international trend is towards user fees (2004, p. 2); see *Fonn, Xaba, Tint, Conco and Varkey* (1998). But *Schneider et al* remark: "Despite numerous initiatives to transform the South African health system, the reality is that – in WHO's summary terms of good health, equity and responsiveness – this system is as problematic as it was 12 years ago" (2007, p. 290). In a league table of health system performance (based on 2002 data), South Africa ranks 175th out of 191 countries included in the assessment *Schneider et al* (2007). *Harris* writes: "Despite the intentions, processes and policies dedicated to transforming South Africa's health sector from an inequitable and racially-skewed instrument of apartheid into a just and fair – equitable – sphere of democracy, South Africa still faces high levels of poverty and inequality". She observes that these translate into "disproportionately large cost burdens and patterns of ill-health amongst the poorest, most marginalized groups" (2007, p. 1).

MATERNAL AND CHILD HEALTH IN SOUTH AFRICA

Fewer Opportunities for Healthcare, ART and PMTCT for Women in Africa

Importantly, many women in sub-Saharan Africa have fewer opportunities to access antenatal services, to receive ART, to elect a caesarean delivery and to access safe and affordable alternatives to breastfeeding, compared to women in the developed world *Stringer et al* (2008). By implication, if they have fewer opportunities for healthcare, they have fewer opportunities for HIV testing and accompanying PMTCT and ART services.

Ultimately, there are more limited opportunities for preventing and treating HIV in women and children. *Stringer, Rouse, Sinkala, Marseille et al* highlight some of the issues:

> "It has been known since 1994 that MTCT is largely preventable, and interventions appropriate for use in the developing world have been available since 1999. Single-dose intrapartum and neonatal nevirapine – the simplest and perhaps most effective of the short-course antiretroviral regimens studied – has been available free of charge from the manufacturer since 2000. Nevertheless, few women have access to MTCT-prevention services. In the more than 3 years since its inception, the donation programme has shipped only 189 000 courses of the drug, a tiny fraction (<5%) of the estimate worldwide need… This inaction leads to the infection and ultimate death of about 800 000 children per year" (2003).

Because of the lack of health infrastructure, including health personnel, which characterises countries in the developing world to some extent, a multitude of clinical trials of simple, cost-effective PMTCT regimens have been undertaken that would address these limitations.

In Uganda, Cote d'Ivoire, Thailand, Cameroon and elsewhere, the results have shown that short course ARV regimens are effective but that taking the drugs for a longer duration is even more efficacious. Moreover, studies have demonstrated that breastfeeding remains an important route of transmission. PMTCT programmes have been established in Kenya, Malawi, Uganda, Rwanda, Botswana and South Africa. However, experts have noted that the outcomes have been disappointing to date. In a meta-analysis, for example, a median of 69% of mothers returned to collect their HIV test results. *Wilfert* observed that roughly 40% of those women identified as HIV positive actually completed full PMTCT treatment, with that low figure taking place in sites that were well-resourced, having been supported by the Elizabeth Glaser Paediatric AIDS Foundation *Wilfert* (2002); *Chopra et al* (2005).

In South Africa, compared with other African countries, a large percentage of women (92%) have at least one antenatal visit *Beksinka et al* (2006); *Government of South Africa* (2002; 2004). However, the quality of that care is very variable. *Mathai* points to some of the common problems:

> "The lack of relevant and quality antenatal care in developing countries is a major concern. A significant proportion of women in these countries do not attend antenatal clinics and the majority of those who seek routine antenatal care often do so only late in pregnancy and/or on few occasions" (2002).

Mathai suggests that (even in low risk pregnancies) all pregnant women, irrespective of risk "are advised to attend antenatal clinics regularly at specified intervals". This is in keeping with WHO guidelines. But large numbers of women are often seen over short periods of time. The result is that they often overwhelm "the few health workers available. This means less individual attention and care. The chances that problems are missed are high in such situations" (2002).

Policy Reforms to Improve Healthcare Access for Women and Children

Significant measures were introduced in 1994 to improve access to healthcare for pregnant women, women who were breastfeeding and children under six as part of Nelson Mandela's lead presidential projects. In 1994 a reproductive health steering committee was formed to conduct a national review of existing services in this area and to make recommendations for a new strategy. In the same year, the new National DoH, together with the WHO, conducted a rapid assessment of reproductive health services. A women's health conference hosted by the Women's Health Project (based at the University of the Witwatersrand) was held in Johannesburg in 1994 – bringing together women from across South African society to provide input into the policy process.[19] It was notable for its inclusion of grassroots organisations and for its success in policy formulation. *Klugman, Stevens and Arends*, formerly of that project, stated: "The Women's Health Conference in South Africa in December 1994 aimed to identify women's health needs and translate them into policy proposals. The process was inclusive, bottom up and cut across barriers of race, class and ideology. Prior to the conference, policy groups developed draft proposals on major areas of women's health, while provincial networking got input from the grassroots" (1995, p. 122). A number of the policy recommendations put forward there were incorporated into national reproductive health policies. Government officials from South Africa also participated in, and helped shape, the consensus achieved on sexual and reproductive health at the 1994 International Conference on Population and Development in Cairo and the 1995 Fourth World Conference on Women in Beijing, note *Cooper et al* (2004).

In 1995, a Mother, Child and Women's Health Directorate was established within the National Department of Health, with a view to increasing women's access to

appropriate health services, to ensure that approaches to health service delivery were consistent with the greater goal of gender equality; and, to provide reproductive and sexual health services to women and men. In so doing there was recognition that a disproportionate burden of reproductive health problems is faced by women and that gender and ill-health are linked *Doyal* (2000; 2001; 2006).

Free primary healthcare for all citizens followed in 1996. The primary healthcare approach became the cornerstone and organising principle of the healthcare system in the country. An enabling legislative and policy environment for reproductive health reforms (through the Bill of Rights and Constitution; see **Box 1** for a snapshot) was introduced and a Joint Monitoring Committee on the Improvement of the Quality of Life and Status of Women was formed to oversee and monitor government progress in promoting gender equity *Cooper et al* (2004); *Fonn et al* (1998); *Klugman* (1995; 2000).

Women's Reproductive Health in South Africa

There are a number of essential programmes and services to consider when discussing progress made in ensuring sexual and reproductive health for women in South Africa.

Definitions of SRH

Reproductive laws and policies in South Africa are among the most progressive in the world "in terms of the recognition that they give to human rights, including sexual and reproductive health rights" *Cooper et al* (2004, p. 70). However, while policy documents use the phrase sexual and reproductive health (SRH), there is ambiguity about the full content and scope of sexual health, reproductive health and women's health in South African policy, observe *Smit, Beksinka, Ramkissoon, Kunene and Penn-Kekana* (2004). The authors observe the propensity for SRH in South Africa to be stated in broad strokes and for various definitions to be cited, and hence, inconsistency to arise. In the National Contraception Policy Guidelines (NCPG), reproductive health is described as follows:

> "Reproductive health implies that people are able to have a responsible, satisfying and safe sex life; and have the capability to reproduce and the freedom to decide if, when and how often to do so. Implicit in this is the right of men and women to be informed of and to have access to safe, effective, affordable and acceptable methods of fertility regulation of their choice, and the right of access to appropriate health care services that will enable women to go through pregnancy and childbirth safely and provide couples with the best chance of having a healthy infant" (2004).

The definition above is not used consistently in other policy documents. Understanding what a concept entails is then made more difficult; as is the 'how' of translating the concept into services and rights that can be achieved. This task on the part of stakeholders such as government officials, advocates, and the public is not just challenging but a major stumbling block to policy implementation. **Box 1** summarises the chief changes in reproductive health legislation and policy up to 2004.

Box 1 Chief Legislative and Policy Advances Related to Reproductive Health in South Africa 1994-2004

1994
- Dept of Health reviews HIV/AIDS policy with a focus on preventing new HIV infections and treatment of HIV-related opportunistic infections
- Free public health services for pregnant women and children under six

1995
- UN Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) ratified by Government

1996
- Choice on Termination of Pregnancy Act

1997
- Maternal death made a notifiable condition
- Standing National Committee for Confidential Enquiries into Maternal Deaths established
- Patients' Rights Charter launched, giving patients the knowledge and rights to address quality in healthcare provision

1998
- New Population Policy
- South African National AIDS Council established
- Domestic Violence Act

1999
- Prevention of Mother to Child Transmission Programmes (PMTCT) introduced in the Western Cape Province by *Médecins sans Frontières*

2000
- National Guidelines for Cervical Screening Programme introduced

2001
- PMTCT Programme introduced in Gauteng Province

2002
- Treatment Action Campaign and Children's Rights Centre win Constitutional Court judgment instructing Dept of Health to rollout out a national PMTCT programme
- National Contraception Policy Guidelines launched
- Government approves provision of post-exposure prophylaxis in public health facilities for rape survivors

2003
- Government approves plan to provide national antiretroviral treatment programme through the public health sector at no charge

2004
- Sexual assault legislation under review to amend the definition of rape and enforce heavier sentences; National ART programme launched

Source: Adapted from *Cooper et al* (2004, p. 72).

Strengthening Maternal Health Services

Maternal health generally refers to the period of a woman's life that includes pregnancy, labour, delivery and postnatal care. The constituent parts of maternal healthcare and services begin prior to pregnancy and include contraceptive and abortion services, obstetric care – including routine and emergency care, antenatal care, perinatal services, delivery services and postnatal care *Shung-King, Mhlanga and de Pinho* (2006). Before 1994, maternal health services in South Africa were uniformly understaffed, overcrowded, lacking in privacy with frequent problems experienced by women seeking to gain access. Since then, *Beksinka, Mullick and Kunene* point out, along certain maternal health indicators, South Africa is performing well. For example, antenatal care attendance has remained over 90% since 1998; deliveries conducted by skilled health workers increased from 84% in 1998 to 92% in 2003; antenatal visits per patient appear to remain relatively high, as do the percentage of women who deliver in a healthcare facility (2006). Nonetheless, the quality of care across the board in terms of maternal health services and the attitudes of health providers have been identified as equally weak and poor. Experts also assert that postnatal care has not been adequately prioritised in maternal health services (2006). *Penn-Kekana and Blaauw* (2001); *Penn-Kekana et al* (2007); *Parkhurst et al* (2005); *Pattinson* (2005); *Blaauw et al* (2006). The table below indicates the latest available figures.

Table 1 Maternal Health Process[20] Indicators in South Africa (by percent)

	1998	2003
Antenatal care attendance	95.0	92.0
Antenatal visits per patient (median)	5.2	N/A
Deliveries conducted by skilled health personnel	84.4	92.0
Delivery in a healthcare facility	83.7	N/A
Rate of caesareans (ability to deal with obstetric complications)	15.8	N/A
Use of family planning	62.1	65.0

Note: N/A indicates data were unavailable.
Source: Adapted from *Beksinka, Mullick and Kunene* (2006, p. 299).

In 2000, a DoH White Paper identified Health Goals, Objective and Indicators (HGOI) for 2001-2005 with an accompanying strategy. Relevant objectives for maternal and child health included improving access to antiretroviral therapy for pregnant women, improving women's health, and reducing both maternal and neonatal mortality and morbidity. As a target, 50% of maternal service facilities were to have trained providers in PMTCT and ART programmes by 2005. The ultimate goal was to reduce

the maternal mortality ratio (MMR) by 25%: from 150 to 100 per 100 000 live births. The figure is now much higher, although the MMR cited by various sources varies *Beksinka et al* (2006).

Beksinka et al also highlight that staff shortages, training and staff motivation appear to be particular issues in maternal healthcare services. The introduction of PMTCT programmes, and the recommendation that women should be initiated into the antiretroviral programme during antenatal care, is placing additional burdens and challenges on maternal health services, including staff. The authors suggest that with the high maternal and perinatal mortality rates in the postnatal period, guidelines and systems need to be established to ensure that care of women and newborns continues well beyond labour and delivery (2006).

Added to this, ten years ago, *Ross* emphasised that in rural areas of South Africa many women do not take advantage of the services provided. The standard of care is low and many women attend antenatal care but deliver at home. He states: "In some cases this latter is at least 50%. Most women who attend, book late and miss some of the benefits of antenatal care; even when women do book the care is often sub-optimal with overcrowded clinics" (1998). While the figures of women who deliver at home have increased – experts claim that today only 15% of South African women deliver at home – many of the quality issues remain *South Africa Every Death Counts* (2008a).

Treatment with Respect and Dignity

In a range of studies, women have reported poor treatment at the hands of healthcare providers when what they want is respect. Women in the Western Cape Province using state maternity hospitals were found to be subjected to uncomfortable or degrading procedures *Fawcus et al* (2002). Studies conducted in Gauteng documented problems with lack of pain relief, not allowing women's partners to attend the birth and particularly harsh treatment of poor women and teenagers using services. A participant in *Fonn et al's* study stated: "I choose to give birth at home because at the hospital or clinic we teenagers they treat us very bad, they hit us and insult us, so it is better at home because my mother won't scold me" (1998); *Dunkle et al* (2004); *Blaauw et al* (2006); *Fawcus et al* (2002); *Jewkes et al (1998)*; *Jackson et al* (2006); see also *Parkhurst et al* (2005); *Penn-Kekana et al* (2007); *Penn-Kekana and Blaauw* (2001).

Quality

Pattinson reflects on the state of maternal care in South Africa: "The available information indicates that the standard of care during pregnancy has steadily deteriorated. The problems within the health services regarding maternal and

perinatal care have been clearly identified and recommendations to improve quality of care and reduce the relevant mortality rates are available but these have not yet been effectively implemented (2006). In the estimation of *Penn-Kekana, McPake and Parkhurst* – in spite of a considerable health infrastructure, availability of staff, free healthcare for pregnant women, legal termination of pregnancy and high utilisation of delivery services – "South Africa performs poorly for a middle-income country" in maternal health (2007). In their four-country study, they explore key factors contributing to maternal deaths. They note: "One factor that often contributes to the failure to deliver planned interventions effectively is the failure to invest sufficient resources". They stress: "The call for more resources is therefore appropriate" *Penn-Kekana et al* (2007). From the literature it becomes clear that in terms of *maternal health services*, financial resources and political will to push reforms have been lacking.

HRH

In the vein of sufficient human resources for health (HRH) – especially maternal health – a range of factors have impacted on the availability and supply of qualified nurses in South Africa. These have included a restructuring of educational institutions in South Africa, including the closure of some nursing colleges and the restructuring of educational curricula; widespread migration of public health nurses overseas or to the private sector in South Africa; poor working conditions and pay in the public sector; and, a poor understanding of supply and demand related to nurses in South Africa, as well as an improper distribution of skills and numbers within facilities and across provinces *Pick et al* (2000)[21]; *Mkhize and Nzimande* (2007); *Kortenbout* (1999). A recent strike by doctors in the public health sector, demanding better pay and working conditions, indicates that this is a continuing problem across the board *South African Press Association* (2009).[22]

A comprehensive report commissioned by the DoH, the *Pick Report*, provided a detailed set of HRH projections. The authors stated that the health professions were likely to face a significant shortfall of workers in some areas. In particular, the current level of doctors was likely to be able to continue to meet South Africa's needs, although the uneven geographic distribution should be addressed. According to the Health Professions Council of South Africa, however, 34 687 doctors were registered in South Africa in 2008. Of those, 10 653 were working in the public sector (quoted in *Naidu*) (2009). The level of nurses, according to projections by *Pick et al* was likely to become considerably worse as the production of nurses (net of the continued loss of nurses) from practice failed to meet South Africa's growing demand. While South Africa's HRH shortage was seen as 'not as acute' as some other developing countries at the

time, there was a documented need for additional nurses (2000). In addition, one of the major limitations of the report was that it did not sufficiently account for the added burden of HIV/AIDS into existing health personnel's workload (the report is dated 2000; the ART rollout only commenced in April 2004. A rollout was not even envisaged in 2000). The report stressed that the scope of practice of nurses could be improved. The distribution of staff across and within facilities was questioned. Similarly, the authors noted, other cadres of healthcare workers could be increased – particularly midlevel workers, i.e., those workers who have limited training and are not full professionals *Pick et al* (2000). However, this was not addressed with attention to the pipeline of skills required, future demand, training institutions and financial costs.

Key Message

From the *Pick Report* it was clear by the year 2000 that South Africa could no longer continue to assume a sufficient supply of appropriately trained and qualified healthcare workers – with the burden of HIV care and treatment not adequately known or factored into modelling projections. Even if the health sector were able to recruit and retain an adequate supply of relevant HCWs in South Africa to ensure 'better health for all', the distributional issues would still need to be overcome (2000).

Ensuring Child Health

In South Africa, "children" constitute all people under the age of 18, although the focus of this study is on the health and wellbeing of younger children. South Africa's commitment to maternal and child health accords with international treaties and initiatives, most recently the MDGs. In spite of South Africa's membership in collaborations such as the Partnership for Maternal, Newborn and Child Health and other international bodies and initiatives, child deaths are dominated by preventable and treatable diseases: "pregnant women and children of all ages still die at high rates from preventable conditions" state *Shung-King, Mhlanga and de Pinho* (2006).[23] Children appear to be "invisible and excluded" according to *UNICEF* (2006). *Werner, Sanders, Weston, Babb and Rodriguez* stake the claim that: "a persistent high death rate among children is widely considered to be one of the most telling indicators of unmet health needs in a population (1997).

The body of research and published documents on child health in South Africa can be called little else but anorexic. There is limited research into inequities in child health in South Africa, and in sub-Saharan Africa more generally *Solarsh and Goga* (2004). Much of the literature consists of policy statements, policy documents and grey literature. Despite data limitations, we do know that child health is declining

and that mortality is increasing *Shung-King* and *Zampoli* (2004); *Shung-King, Mhlanga and de Pinho* (2006); *Saloojee and Pettifor* (2005); *Bradshaw et al* (2003); *Daniels et al* (2006); *Norman et al* (2006); *Norman et al* (2007); *Solarsh and Goga* (2004).

It is important to note, though, that besides the dearth of child mortality statistics in South Africa and the fact that empirical data are not up to date, the methods used in data collection by Statistics South Africa (StatsSA) undercount child deaths by the organisation's own admission. Some sources claim that it is a 30% undercount of child deaths *StatsSA* (2005); *Shung-King et al* (2006, p. 121).

As noted, free primary healthcare for children under six has been part of South African policy since 1994. Embedded in national policies are guidelines for children. The government's *Strategic Plan for the National Health System (2004-2009)* cites the integrated management of childhood illnesses (IMCI) strategy, prevention of mother to child transmission of HIV and nutrition as priorities for child health in South Africa. Together, the documents are meant to be part of a comprehensive strategy to decrease mortality and morbidity rates. The IMCI strategy has three intervention points: improving the skills of healthcare personnel in deploying case-management guidelines when managing children; strengthening the health system (supplies, equipment, communication and referral systems) when dealing with children; and, improving household, family and community behaviours to promote child health and development *UNICEF South Africa* (2006a-b); *Solarsh and Goga* (2004).

In terms of development prospects for children, roughly 66% of South African children live in poverty, and one in four live in overcrowded household conditions. Almost half of South African children do not have access to clean, potable water. Proportionally, more children are living in poverty than adults – 22% of children as compared with 16% of adults. This reflects ongoing population movement and migration where adults flock to urban centres in search of work and children are left behind. The Child Support Grant was established by the Department of Social Development as a vehicle for providing funding to children living in poverty. *Shung-King, Mhlanga and de Pinho* note that primary school nutrition programmes have been implemented. However, the HIV epidemic is compounding existing challenges of poverty: "with thousands of children living with ill or dying caregivers. This has a direct impact on children's ability to access health services, especially young children who are not able to consent to their own medical treatment due to their age and the health services' reluctance to attend to unaccompanied minors" (2006, p. 121). Included in the IMCI is the care of children infected with HIV. The strategy caters for counselling and follow up as the main means of promoting child health vis-à-vis HIV/AIDS.

Some experts cite a lack of "systematic prioritization of child research funding" which then feeds into a "neglect of interest in research on how to implement cost-effective interventions" *Tomlinson, Chopra, Sanders, Bradshaw, Hendricks, Greenfield, Black El Arifeen and Rudan* (2007). *Tomlinson et al* assert: "Delivery of interventions is rarely considered a research priority; research on creating new interventions far exceeds that on delivering existing ones" (2007).

While a lack of research into child health issues is apparent, a lack of funding is not. *UNICEF South Africa* states: "The Government of South Africa oversees a budget that annually exceeds revenue expectations although in many areas key to children's survival, development and protection, these funds are not efficiently spent, leaving many children's programmes under-resourced" (2006a-b).[24] The following is a snapshot of the various successes and failures of government in relation to child health in South Africa over the ten year period 1994 to 2004.

Box 2 Successes and Failures in Child Health in SA, 1994-2004

Successes:

- Free healthcare for children under 6 years of age, children with disabilities and pregnant women
- Increased availability of primary healthcare services
- Expanded access to child social security grants
- Provision of water, sanitation and electricity to more families
- Roll-out of ART and PMTCT programmes
- Measles eradication imminent

Failures:

- Worsening infant and under-5 mortality due to HIV/AIDS
- Lack of progress in improving neonatal health
- Failure to reduce malnutrition rates
- High teenage HIV prevalence and pregnancy rates
- Suboptimal access to adequate secondary and tertiary care services
- Patchy availability of laboratory services and drugs

Source: Adapted from *Saloojee and Pettifor* (2005, p. 433).

Shung-King et al (2006) report that child health inequities are still found between urban and rural areas, between rich and poor areas by province; and, that preventative health programmes are not executed properly as a result of the impact of HIV/AIDS on the healthcare workforce. This includes PMTCT – with the true coverage of PMTCT unknown and coverage varying greatly by province. As a consequence, this is an area ripe for research, particularly applied research.

SOUTH AFRICA'S PMTCT PROGRAMME

The programme to prevent mother to child HIV transmission was first introduced in 18 pilot sites in 2001, following a landmark court case brought by the Treatment Action Campaign *Heywood* (2003); *Sprague and Woolman* (2006).[25] It has since been implemented country-wide in 3 300 public health facilities *Government of South Africa* (2008a). The principal aim of the programme is to "decrease the number of HIV-infected babies born to HIV positive mothers" *Government of South Africa* (2008a, p. 3). Note here the emphasis placed on the "C" in PMTCT, but not the "M" (this is corroborated by other researchers – to be discussed shortly). The programme has called for the delivery of a package of interventions, including: routine offering of voluntary, confidential counselling and testing for pregnant women during antenatal care; counselling on infant feeding practices; a single dose of nevirapine; and, the provision of free infant feeding formula for six months to HIV positive mothers *Government of South Africa* (2008a); *Buch et al* (2003). Nevirapine is meant to be provided free of charge in all public health facilities in South Africa to women who are HIV positive at 28 weeks gestation or later.[26] Women are given a single dose of nevirapine (in a tablet form) to take home with them, with instructions to take the pill at the onset of labour *Government of South Africa* (2008a).

Programme Evaluation

The National Department of Health states in a tender (seeking bidders to evaluate the PMTCT programme in 2008): "The effectiveness and impact of this programme is unknown" *Government of South Africa* (2008b, p. 42). This is surprising because in 2001 the DoH created a Comprehensive PMTCT Monitoring and Research Framework *Government of South Africa* (2001).

In a related inconsistency, the former minister of health, Dr Manto Tshabalala-Msimang – in a foreword to the revised PMTCT guidelines issued in 2008 – noted that the programme was evaluated in 2005 in three sites *Government of South Africa* (2008a). The evaluation echoed research by *Jackson et al*, which found that

"the impact of the programme depended on the degree of inequities in the health system as well as breastfeeding practices" (2007). Tshabalala-Msimang noted: "This means that just providing nevirapine was not sufficient to improve outcomes for both mothers and babies" *Government of South Africa* (2008a, p. 3); *McCoy et al* (2002); *Doherty et al* (2002).

Quality and Equity of PMTCT

While PMTCT coverage is improving, increasing both the quality and equity of services is essential to address premature morbidity and mortality in children and pregnant women *Chopra et al* (2005). *Doherty, Besser and Donohue* observe that the national averages for PMTCT programme uptake "mask the large differences in performance between provinces" (2004). In addition, the fact that PMTCT relies on a functioning public health infrastructure has been underscored by the former minister of health who wrote, "we realized that unless the health system as a whole was strengthened, the PMTCT programme will not succeed" *Government of South Africa* (2008a, p. 3).

Revised National Guidelines

In February 2008, new PMTCT guidelines were issued by the DoH in South Africa, in an effort to keep pace with the evolution in knowledge and clinical practice. The new guidelines were a response to a range of factors: clinical studies indicating that dual therapy was more effective than monotherapy; increasing cases of drug resistance[27] to nevirapine; revised WHO guidelines in response to clinical studies; the performance of the national PMTCT programme; postnatal transmission related to infant feeding practices; and considerable activism on the part of doctors and practitioners engaged in maternal-child health (who pressed the DoH to update the guidelines in line with international standards) *Government of South Africa* (2008a, p. 24); *Lancet* (2008c); *WHO* (2006d).[28-29] Key features of the revised guidelines included: a short course of zidovudine (AZT) from 28 weeks (in addition to the single dose of NVP) for the mother, with the infant receiving: a) a single dose of nevirapine after birth; and b) seven days of AZT. Alternatively, if the mother had received AZT for less than four weeks (or triple combination therapy for less than four weeks) during pregnancy, the mother would receive a bottle of AZT syrup to administer to her infant for 28 days *Government of South Africa* (2008a); *Baleta* (2008); *Government of South Africa* (2008c).

The table below indicates the risk of transmission without any intervention.

Table 2 No Intervention, Estimated Risk of HIV Transmission from Mother to Child

Risk of transmission from mother to child during labour and delivery	15% - 30%
No nevirapine	---
Exclusive breastfeeding	5% - 20%
Risk of transmission	**20% - 50% (ave of 45%)**

Sources: *WHO* (2006d); *de Cock* (2000).

As can be seen, the estimated risk of MTCT with no intervention ranges from 20% to 50%; *WHO* puts forward an average figure of 45% (2006d).

Studies have shown that triple drug combinations are most beneficial for individual health, as well as being the most effective in reducing MTCT. By improving maternal health, they also improve prospects for the child's survival *Chersich* (2007); *WHO* (2006 c-d). Based on studies in Africa, the table below indicates that rates of transmission in women on ART are remarkably lower, with MTCT rates reduced to less than 1% with the introduction of triple combination therapy for pregnant women.

Table 3 Observed Transmission Rates According to Each Intervention in Africa, 1995-2004

No intervention	**15% - 30%**
AZT monotherapy	13%
Single dose nevirapine (sdNVP)	12%
Short course AZT +3TC*	9.3%
Short course AZT + sdNVP	6.5%
Short course AZT +3TC+ sdNVP	4.7%
Triple ART	<1%

Note: *3TC is called Lamivudine in South Africa.
Source: *Smart and Sheriff* (2006).

Women who are living with HIV require a range of additional services during the antenatal, labour, delivery and postnatal period. A comprehensive package of interventions were developed and implemented in South Africa, as part of the revised PMTCT programme, including routinely offered voluntary counselling and testing

(VCT), counselling on infant feeding practices, safe non-invasive obstetric procedures, ARV prophylaxis and the provision of infant formula feeding, according to a set of criteria, called AFASS, i.e., is formula feeding for the mother 'Acceptable, Feasible, Affordable, Sustainable, Safe'? *Government of South Africa* (2008a; 2000a-b; 2002).

There is a host of programmatic aspects. These include outreach and awareness of the programme to women through public health campaigns, training of health personnel on HIV testing and counselling provision and education about infant feeding (exclusive formula feeding vs. exclusive breastfeeding), sufficient healthcare workers to provide the range of PMTCT-related services and evaluation, de-briefing, follow up and data management. These are outlined below.

Box 3 Specific Interventions of the PMTCT Programme in SA: Revised 2008 Guidelines

- Primary prevention of HIV especially among women of child-bearing age
- Integrating PMTCT interventions into routine maternal and child health as well as general HIV care, treatment and support services
- Providing an expanded package of PMTCT services, including:
  - o Promoting the acceptability of voluntary counselling and testing services in the context of PMTCT in facilities offering routine antenatal care
  - o Promoting routine offer of voluntary counselling and testing
  - o Involvement of the partner and the family in order to ensure a comprehensive approach
  - o Providing appropriate regimens to prevent mother-to-child transmission of HIV according to the risk profile based on the HIV test, CD4 cell count and clinical staging
- Providing other appropriate treatment, such as for opportunistic infections, nutritional support and antiretroviral therapy, depending on CD4 cell count, nutritional status and clinical stage
- Providing psychosocial support to HIV positive pregnant women
- Providing quality, objective and individualised counselling on safe infant feeding practices for HIV positive women in health facilities offering routine ANC services, through trained lay feeding counsellors and healthcare professionals using AFASS
- Strengthening obstetric practices which reduce PMTCT
- Improving follow-up care for HIV positive women and their infants
- Encouraging and supporting safe infant feeding
- Providing infant formula for at least six months for women who meet the AFASS criteria and who opt to exclusively formula feed
- Providing nutritional counselling and support for women who choose to exclusively breastfeed

Source: *Government of South Africa* (2008a, p. 14).

These interventions are meant to assist in achieving national HIV/AIDS goals. With regard to PMTCT goals identified in the National Strategic Plan (NSP), they are as follows: to reduce mother-to-child transmission of HIV by (a) broadening existing mother to child transmission services to include other related services and target groups; and (b) scaling up coverage and improve quality of PMTCT to reduce MTCT to less than 5% Government of South Africa (2007a, p. 11).

Lack of Clarity and Consensus on Monitoring and Measuring PMTCT Programme Effectiveness

Apart from data on clinical trials undertaken, *the operational effectiveness* of PMTCT in African countries has yielded little data thus far, note *Jackson, Chopra, Doherty, Colvin et al* (2007). They stress that studies of the complex aspects of PMTCT delivery in Africa have generally been hospital-based, with short follow up periods of six to 16 weeks, focusing on the initial pilot sites which have been running the longest (2007). The authors state: "While there is a substantial body of literature from clinical trials on the efficacy of short-course antiretroviral prophylaxis in reducing transmission from mother to child, data from Africa about the operational effectiveness of national programmes are sparse" (2007). *Stringer et al* contend that there is a lack of clarity and consensus about how best to monitor and measure the effectiveness of PMTCT programmes. And "without this clarity, it is difficult for policy-makers in developing countries to mount a coordinated response" (2008, p. 57).[30]

There is also very little social research on PMTCT for children and ART for pregnant women. This is a notable gap when access to the health system and acceptability of interventions depend on the users of the health system – their beliefs, behaviour, cultural and social norms and economic circumstances. In addition, it has become clear that very few high-prevalence countries have put in place ongoing country-level monitoring of PMTCT, another missing piece in understanding the effectiveness of PMTCT nationally, regionally and globally *Stringer et al* (2008, p. 58); *Connor, Sperling, Gleber, Kiselev et al* (1994).

The following are the identified barriers to PMTCT and ART access, delivery and uptake by women.

Barriers to Women's Access to and Provision of ART/PMTCT

Insufficient Numbers of Staff and Poor Quality of HIV Counselling and Counselling on Infant Feeding

An evaluation of PMTCT and infant feeding across seven provinces in South Africa noted that the five day PMTCT and infant feeding training course "is adequate to address the core competencies of providers working in maternal and child health services" but there are a number of "competing pressures on health care providers to attend a variety of training courses for priority health programmes". The evaluation observed that due to the "pervasive shortage of staff in most facilities" many of the potential trainers could not be released from work to allow them to become accredited trainers *Tint, Doherty, Nkonki, Witten and Chopra* (2003); *Stewart and Loveday* (2005); *Zungu-Dirwayi et al* (2004); *McCoy et al* (2002).

In 2006, *Ramkissoon et al* wrote that in some locations in KwaZulu-Natal (KZN), the PMTCT programme has been failing. Some of the reasons documented for this were pervasive stigma and discrimination; and, the inability of current health services to ensure that the prescribed nevirapine was taken (2006).

In some sites in KZN, PMTCT appeared to be hindered by shortages of counsellors, an insufficient supply of formula milk and a lack of district management. *Ramkissoon et al* observe: "Early and routine identification of HIV-infected pregnant women facilitates access to ART.... Although counselling and testing for pregnant women was introduced in 2002, uptake is limited and the majority of women attending antenatal care do not know their HIV status" (2006, p. 321).

Chopra et al stress that "women actually missed their nevirapine not because of stigma and ignorance but because of health systems failures". Counsellors, HIV test kits, and consent forms were not available (2005).

Feeding Options and Mixed Feeding

A range of reports have indicated that women struggle with feeding options. They are often provided with insufficient counselling or support. Healthcare workers often appear to 'steer' women towards their own preference – which results in women making inappropriate choices, given their available resources – in terms of money, time, and access to safe water for instance *Dlamini* (2008); *Doherty et al* (2000; 2003; 2004; 2006); *Coutsoudis* (2005).

Attitudes and Unwillingness of Healthcare Providers to Discuss Sexuality, Health, Fertility (contraception), and Childbearing Issues

Sexual and reproductive health services are essential for women to make effective choices regarding their health. Yet they are not being provided adequately in South Africa. Several studies indicate that HIV-infected women reported limited willingness on the part of healthcare providers to discuss sexuality and childbearing issues. One study reported: "This attitude causes many HIV-infected women to avoid discussing sexual activity with their health care providers for fear of reprisals as a result of engaging in sub-optimal safe sex practices…" This limits the provision of fertility options and attendant services for women who are HIV positive in South Africa, restricting the range of options women have to control and direct their fertility *Ramkissoon et al* (2006); *Shung-King et al* (2006); *Smit et al* (2004); *Cooper et al* (2007).

Lack of Integration of Services for Women who are Pregnant and HIV Positive

As noted, figures indicate that access to ART for pregnant women in South Africa and other developing countries still reaches fewer than 10% of people who need it" *Ijumba et al* (2004). The authors attribute this to a lack of integration of services within the public health system where HIV-infected women receive antenatal care, obstetric care and family planning services at primary healthcare facilities; whereas HIV services are provided mainly at hospitals and a few Community Health Centres *Stewart and Loveday* (2005); *Zungu-Dirwayi, Shisana, Udjo, Mosala and Seager* (2004); *McCoy, Besser, Visser and Doherty* (2002); and, *Ramkissoon, Coovadia, Hlazo, Coutsoudis, Mthembu and Smit* (2006).

Stigma and Lack of Confidentiality

Several studies have pointed to the presence of stigma and the lack of confidentiality at service points. *McCoy et al* note that barriers to uptake include: fear of learning one's status; fear of disclosing a possible positive status to husbands/partners; fear of stigma or discrimination; a sense of fatalism about the usefulness of knowing one's status; and, the perception of being at low risk for acquiring HIV (2002); *Rasmeni* (2007); *Dlamini* (2002); *Ramkissoon et al* (2006).

Focus on PMTCT as a Paediatric AIDS Issue

Some experts have observed that the focus on child health has obscured the rights of women and their own health needs. *McIntyre* states, "The prevailing view of PMTCT as a paediatric issue has hampered full implementation of these [maternal-child health] strategies: we have been too focused on an outcome measure of HIV-negative babies,

and too caught up in the difficulties of implementing even simple nevirapine-based strategies to see the bigger picture" (2005). This has been noted in other countries as well *Rosenfield et al* (2001; 2007).

Inadequate Communication for Pregnant Women

Recent research conducted by *Birdsall, Nkosi, Hajiyiannis and Parker* highlights the dearth of information in public health clinics and hospitals targeted towards HIV positive women in South Africa and couples who plan to have children. On the basis of a study analysing PMTCT calls made to the national AIDS helpline, the authors found a lack of communication and support for PMTCT interventions. Specific issues that required much clearer information provision and wider dissemination, according to the authors, included: whether an HIV positive woman can have a child; how pregnancy and delivery can be done safely; whether nevirapine can be taken during more than one pregnancy; and if an HIV negative woman can safely have a child with an HIV positive man (2004); *Stevens* (2008a-b); *Cooper et al* (2004). *Birdsall et al* called for additional research into the implementation of programmes that prevent mother to child transmission implementation and the uptake of such programmes by pregnant mothers (2004). The authors also suggested improving communications in the following targeted areas:

- Potential modes of HIV transmission between mothers and babies;
- Importance of testing for HIV when pregnant, or when intending to become pregnant;
- That HIV testing is not a mandatory part of antenatal care – it requires informed consent;
- The efficacy and safety of nevirapine;
- Infant feeding recommendations for HIV positive mothers;
- Timely HIV testing for infants (2004).

Barriers to PMTCT/ART for Children

In terms of timing, it is important to emphasise that ART access in sub-Saharan and South African public health settings is relatively new compared to the developed countries. In viewing barriers to PMTCT and ART for children, the majority of the literature on children's access to ARV drugs is still chiefly focused on children in sub-Saharan Africa (or elsewhere) and not in South Africa where differential conditions obtain.[31] Thus, there is a slim but growing literature. See, for example, *Michaels, Eley, Ndhlovu and Rutenberg* (2006); *Shung-King, Mhlanga and de Pinho* (2006); *Shung-King and Zampoli* (2004); *Meyers et al* (2006).[32]

The data on the benefits of ART for children's health are also relatively new, with recently published research on the effects of ARV medicines on children in South Africa serving to strengthen the existing evidence base *Violari et al* (2008); *Chersich* (2007).

According to the published literature, many of the barriers to ART access that have been identified to date for children can be viewed as "structural" barriers. There is not much attention to cultural and social impediments that may be preventing children's access. The identified barriers to ART access for children follow.

Limited Screening and Testing: Infant Diagnosis

According to MSF, significant hurdles to scaling up paediatric care remain, including limited screening for HIV in children, a lack of affordable, simple diagnostic testing technologies, a lack of human capacity, insufficient advocacy and poor understanding that 'ART is efficacious in children' *MSF* (2006b-c). As noted, infant diagnosis, especially early diagnosis, is critical but has proved very challenging *Violari et al* (2008); *Dlamini* (2002); *Moultrie* (2009). In South Africa, the early diagnosis of children has been improved by the use of polymerase chain reaction test (PCR) – a dried blood spot, usually taken by pricking the heel of a child to test for HIV.[33] *UNICEF South Africa* has been working to introduce blood testing widely in South Africa to ensure that younger children are diagnosed promptly but PCR tests are not widely available as yet in clinics (2006a-b).

Availability of Paediatric Formulations and PCR tests

MSF noted that in South Africa and elsewhere they aim to include more children in their treatment projects but their efforts have been hampered by a number of confounding factors: "The lack of paediatric ARV formulations makes determining and administering doses complex and burdensome. Doctors are forced to break tablets in two or crush and dissolve them. Care providers have to give small children foul-tasting syrups and large pills. Syrups and oral solutions are not suitable for older children because of the large amounts needed, but low-dosage tablets and capsules are not produced for most ARVs" *MSF* (2006c).

Expertise in Administering ART to Children

Limited experience with simplified standardised treatment guidelines has been described as an impediment. Further, nurses often express reservations (fear and

reluctance) to treat infants – in taking blood for instance. Consequently, far too few children have been started on ART in resource-limited settings. Moreover, as *WHO* suggests, "the need to treat an increasing number of HIV-infected children highlights the primary importance of preventing the transmission of the virus from mother to child in the first place" (2006c); *Meyers et al* (2006); *WHO* (2006c-d); *Chersich* (2007); *Gray* (2006); *Michaels et al* (2006).

Treatment Benchmarks for Children

Data and reporting coming out of the 2006 International AIDS Conference indicated that one of the problems was a lack of global and national treatment benchmarks to guide advocacy, planning and progress tracking for children, although this is changing. It was noted that access to care and treatment for paediatric AIDS patients remains inadequate. Globally few programmes were meeting the WHO target that 10% of people receiving ART be children. Participants called for the needs of children to be on national agendas and for government-defined targets to define treatment needs *XVI International AIDS Conference Website* (2006); *Médecins sans Frontières* (2006a-c).

Children as an Invisible Population

Many researchers in South Africa agree that children are often an invisible population *Shung-King et al* (2006). They are hard to find and hard to reach. Case finding of infants and children with HIV is therefore difficult, as mentioned *Moultrie* (2009). Much of the national ART rollout plans, execution, and subsequent studies have not focused on the needs of children *Shung-King and Zampoli* (2004); *Michaels et al* (2006).

Weak Data and Information Systems

DoH officials *Dlamini* (2008) and *Rasmeni* (2007) have acknowledged the inadequate capturing of data and information at facility, sub district and district level. As indicated, data on child morbidity and mortality are not sufficient; current data indicate a lack of knowledge and reporting related to HIV-linked illnesses and deaths *Shung-King et al* (2004; 2007); *Solarsh and Goga* (2004); *Bradshaw and Dorrington* (2005); *Bradshaw and Nannan* (2006); *Bradshaw, Bourne and Nannan* (2003b); *Kashifa* (2006); *Fox et al* (2002).

Conclusion

This chapter has sketched the evolution of the public health response to HIV/AIDS in South Africa: embodied by the national antiretroviral treatment programme and the prevention of mother to child HIV transmission programme. By drawing the context in which the AIDS response is rooted, I have taken care to stress that unequal access to quality healthcare among racial groups has been the historical norm in South Africa, while noting that the explicit health policy agenda of the African National Congress seeks to respond to such long-established inequalities. Access to and provision of HIV services for pregnant women and children must also be located against that background.

In this chapter I have foregrounded the international debate on the role and relationship between scaling ART, strengthening health systems and offering quality primary healthcare (in less resourced countries). In doing so I am drawing attention to a key question whose answer will fundamentally impact on access to and provision of HIV services for women and children in South Africa; and on the delivery of such services to the HIV-infected population more broadly (discussed in chapters five, seven and eight). I have emphasised women's biological and social vulnerability to HIV acquisition, together with social and cultural norms, as drivers of HIV transmission in this country. The aim has been to highlight the connections between gender, health and HIV, and their impact on women's health and development. The latter part of the chapter traced the evolution of equity and of maternal and child health policy within a transforming public health system. Particular attention is paid to policy reforms and related initiatives seeking to improve maternal health, child health and women's reproductive health. The trajectory of the PMTCT programme is discussed in detail, and a number of systematic weaknesses of the programme are singled out. The chapter concluded with the identification of barriers to women's and children's access to, and provision of, PMTCT and ART (from a review of the existing literature). In the next chapter I will describe and elaborate the joint conceptual framework employed to investigate the research question.

Endnotes

1 I identify these factors in chapter two and reflect on them in chapters five through eight.

2 Note that the United Nations Joint Programme on HIV/AIDS (UNAIDS) publishes an updated guide to preferred HIV/AIDS terminology each year. In 2008 they began to encourage the use of 'HIV and AIDS' rather than 'HIV/AIDS' because UNAIDS prefers writers to distinguish between the two. The intent is to highlight that there is no AIDS virus. HIV is the virus that causes AIDS – a syndrome. I have chosen not to use their preferred terminology in this thesis because, firstly, I find it to be unnecessarily clumsy to add 'and' each time; secondly, I do try to make the distinctions between the two where appropriate; and lastly, I find that after so many years of living with the epidemic, researchers do understand the distinction between the two.

3 Note that optimal health outcomes are not simply determined by access to medicines but depend on a range of psychological, social, behavioural and other factors.

4 Treatment reduces the viral load in the body. It renders individuals less infectious thus having a dampening effect on transmission.

5 Although studies of patients in poor resource settings have shown increased mortality rates in the first months on therapy compared to those in developed countries, the survival benefits are clear *Crum et al* [for the Antiretroviral Therapy in Lower Income Countries Collaboration and ART Cohort Collaboration Groups] (2006). In infants, the benefits of ARV medicines on their tiny immune systems are even more stark *Newell, Coovadia, Cortina-Borja, and Rollins* (2004); *Tindyebwa, Kayita, Musoke and Eley* (2004); *UNICEF* 2006a).

6 According to the *WHO*, the perinatal period encompasses the period from 22 completed weeks of gestation to seven completed days after birth (2001).

7 Obstetric factors, such as the premature rupture of membranes during delivery as well as infant factors, such as premature birth or mucosal lesions (abnormal tissues) can increase the risk of transmission. The viral load of the mother has a direct impact on transmission: the higher the viral load, the more likely the transmission. See *Coovadia* (2005, p. 183).

8 The UN General Assembly Session on HIV/AIDS, which pledged a 50% reduction in paediatric infections by 2010; see *United Nations General Assembly* (2001).

9 Wilfert notes that in August 2001, the United Nations-sponsored programme on prevention of mother-to-child transmission reported that the programme had reached a total of 137 575 women in antenatal care in nine African countries (Burundi, Botswana, Cote d'Ivoire, Kenya, Rwanda, Tanzania, Uganda, Zambia, and Zimbabwe). As part of the programme, 85 980 women were counselled (62% of the total) and 59 985 were tested: i.e, 70% of those tested were counselled but only 43% of those seen in antenatal care; 9 842 women were HIV+ or 16% of those tested. The intervention, either AZT or nevirapine, was given to 3 941 women, which is 40% of those found to be HIV+ by testing This is 18% of the estimated HIV positive women seen in those antenatal clinics. See *Wilfert* (2002, p. 863).

10 The UN General Assembly Session on HIV/AIDS, which pledged a 50% reduction in paediatric infections by 2010 *United Nations General Assembly* (2001).

11 The *Lancet* noted: "health for all" need not be a dream buried in the past. The right to the highest attainable standard of health can be a reality within our grasp" (2008d).

12 At the centre of Jong-wook's vision was the recognition that the lives of the poorest people were just as important as those of the rich. He understood that making (then-expensive) AIDS treatment available to the poorest people was a way of signalling that life-saving medicines were not the special preserve of the wealthy. See *Altman* (2006).

13 The goal of 3 by 5 was for WHO and partners to make the greatest possible contribution to prolonging the survival and restoring the quality of life of individuals with HIV/AIDS. See *Ijumba et al* (2004).

14 *Yu et al* call for the cessation of debates around horizontal versus vertical programmes, with a focus on the best ways of channelling large HIV/AIDS investments to benefit PHC (2008).

15 For the case against AIDS exceptionalism, see *England* (2007; 2008a-b). For the case *for* exceptionalism, see: *Gonsalves* (2008); *The Lancet* (2008); *de Lay* (2008); and, *Harrington* (2008).

16 On women's health and gender equality, see in particular, *Moss* (2002); *Doyal* (2000, 2001, and 2006); *Osmani and Sen* (2003); *Östlin, George and (Gita) Sen* (2001); *Patai* (1991); *Nussbaum* (2000).

17 In its review of human rights in South Africa, *Human Rights Watch* stated: "South Africa continues to be plagued by chronically high levels of gender violence… persistently high levels of violent crime, and gender inequality continue to inhibit the full enjoyment of human rights". They also noted that the Government has established 52 specialised sexual offenses courts (SOCs) throughout the country, which have had some success in improving rape conviction rates (2008). Accessed online from http://www.hrw.org/en/news/2008/04/06/universal-periodic-review-south-africa.

18 See *Government of the Republic of South Africa* (1997). White Paper for the Transformation of the Health System in South Africa. Available from http://www.doh.gov.za/docs/policy-f.html.

19 *Klugman, Stevens and Arends* of the Women's Health Project state: "Our concern centred around how to pull together women with different views, styles and discourses and from different class, cultural, language and geographic backgrounds. We wanted the Conference to go beyond listing demands" (1995). Sadly, the Project, which ran for roughly 15 years, appears now to be defunct.

20 Process indicators are meant to be more responsive to short-term changes, as opposed to indicators such as the maternal mortality ratio, which measures changes of a long-term nature. Many of the process indicators deployed internationally have not been used in South Africa according to *Penn-Kekana and Blaauw* (2001).

21 Analysis and reports have been conducted to understand and address the human resources for health (HRH) situation in South Africa. The most important and detailed report available is what is commonly known as the 'Pick Report' commissioned by the DoH and authored by *Pick, Nevhutala, Cornwall, Masuku and Fisher* (2000). There is a set of concrete proposals put forward in the individual chapters of the Pick report that could have formed the basis of human resources for health (HRH) interventions in the public health sector – but they were not taken up. The report is sound, robust and meets international norms and standards required of HR plans. The recommendations made in Chapter 4 related to staffing ratios, training of enrolled nurses, and scopes of practice, and suggested intakes of medical and nursing students, are extremely comprehensive. Critics of this plan claimed that consultations by the task team were not sufficiently broad and additional consultation with civil society organisations was necessary. There are entire categories within the assessment that are left completely blank. For instance, for Gauteng province, of the nine categories, only three have been completed. The same is true for the Eastern Cape and Western Cape. We review, discuss and analyse the Pick Report in detail in *Balasubramaniam and Sprague* (2005).

22 *Benatar*, a University of Cape Town-based physician, observes how the healthcare system reform has affected the morale of medical doctors: "The many changes in healthcare have resulted in widespread dissatisfaction and feelings of alienation on the part of physicians throughout the nation, and they led to an unprecedented protest march on Parliament by the medical profession last February 6 [2003]" (2004, p. 84).

23 A United Nations partnership with strong African participation that includes 80 member states and a number of international associations, agencies and non profits launched in 2005. This initiative is a merging of three previous ones: the Partnership for Safe Motherhood and Newborn Health; the Healthy Newborn Partnership; and, the Child Survival Partnership.

24 *UNICEF South Africa* notes that it is working on advocacy initiatives to boost birth registration levels for all children and for the development of a national policy on the protection of orphans and vulnerable children, as well as on the development of a national anti-rape and domestic violence strategy. See http://www.unicef.org.za.

25 In *Minister of Health v Treatment Action Campaign* (TAC), TAC took issue with the South African government's policy toward the provision of nevirapine (an ARV drug that reduces the likelihood of HIV transmission from mother to child by one-half to two-thirds). Despite the fact that the manufacturers of nevirapine had offered to make the drug available to the South African government free of charge for a period of five years in order to reduce the risk of the vertical transmission of HIV, only a fraction of the hundreds of thousands of pregnant women infected with HIV had access to nevirapine at an equally small number of research and training sites throughout the country. The Constitutional Court held that, in terms of section 27 of the Constitution, the government's decision to confine nevirapine to a limited number of research and training sites was 'manifestly not reasonable'. The Court found that a comprehensive and coordinated programme of nevirapine and breast milk substitutes could substantially reduce the risk of vertical transmission of HIV without placing a significant burden on the state. Accordingly, the Constitutional Court issued a legal order requiring the government to extend the provision of nevirapine beyond the current sites, while ordering the Department of Health to provide the requisite testing and counselling services needed to make nevirapine provision effective. See *Sprague and Woolman* (2006, in particular, pp. 356-357).

26 Gestation is the time period from conception to birth. The gestational age is the age of the foetus. Birth normally occurs at a gestational age of 37 to 42 weeks.

27 Resistance to ARV drugs may occur at any time. But drug resistance is found more commonly in mono and dual therapy regimens (as opposed to triple combination therapy). And it is of particular concern in women with short-term exposure to ARV medicines (to prevent HIV transmission to the child). The *WHO* notes: "Risk of resistance to HIV drugs is strongly associated with the mother's plasma viral load and CD4 cell count at the time of exposure. Thus, women at the highest risk of developing resistance to NVP with exposure to a single dose of it are those with more advanced HIV disease for whom ART is recommended" (2006d, p. 52, see pp. 51-54).

28 In 2007, a "Maternal and Child Survival Memorandum of Concern" was circulated by the *Concerned Paediatricians Group* (a group of paediatric HIV doctors and nurses around the country) and other organisations and associations involved in public health and maternal and child health. They sought endorsements of their memo, which they presented to the South African National AIDS Council (2007).

29 A *Lancet* 2008 editorial observed: "On Jan 25, South Africa's National Health Council finally adopted new guidelines for the prevention of mother-to-child transmission (MTCT) of HIV, following increasing pressure from AIDS activists and clinicians. This positive move is long overdue. In 2006, WHO recommended switching from a one-off single dose of nevirapine to more effective dual antiretroviral prophylaxis beginning in the third trimester of pregnancy. Botswana and South Africa's Western Cape Province have seen declines in paediatric HIV since rolling-out the new recommendations. But health workers in the rest of South Africa were left waiting for the health ministry to publish and disseminate the new guidelines. When the South African National AIDS Council last met on Nov 29, 2007, it said that the new protocol would be announced within two weeks. But nothing followed" (2008c, p. 360).

30 *Stringer et al* go on to develop a "validated consensus model for PMTCT effectiveness monitoring". And they develop the case for using population HIV-free child survival as a *gold standard metric.*

31 There remain gaps in specific knowledge areas related to paediatric AIDS in sub-Saharan Africa as well. *Tindyebwa et al* highlight the following knowledge gaps: "There are limited data on the natural history of paediatric HIV infection in Africa and other resource-constrained settings beyond the first 3 years of life. There are limited data on the biological markers of HIV disease among infants and children in sub-Saharan Africa – current assumptions that these are similar to infants and children in industrialized countries have not been validated" (2004).

32 Interview with key informant on 16 October 2006.

33 Because positive antibody results on their own do not establish infection in children younger than 18 months of age, assays to detect the virus are used for diagnosis in children.

Chapter 3

Health as a Social Justice Claim: A Conceptual Framework

The overall aim of this project is to achieve an enhanced understanding of a particular development problem in South Africa (discussed in chapter one). This research considers the primary barriers to timely antiretroviral treatment and prevention of mother to child transmission programmes in the public health system, without which premature morbidity and mortality attributed to HIV-related infections often result *Bradshaw* (2009); *Chopra et al* (2005); *Bradshaw and Nannan* (2006); *Marins, Jamal, Chen, Sanny et al* (2003); *Walensky, Paltiel, Losina, Mercincavage et al* (2006); *WHO* (2006d).[1]

The purpose of this chapter is to describe and discuss the theoretical framework used to investigate the research problem: the capabilities approach (CA), complemented by a health equity approach. As will be shown, the CA, together with a health equity approach, is well-suited to the complex considerations that radiate from the phenomenon of premature mortality and disparities in access to life-saving antiretroviral medicines for pregnant women and children in South Africa. To a social justice and development problem, the conceptual framework offers a social justice and development response, accordingly.

Ensuring Social Welfare

Most scholars and practitioners, together with citizens, agree that the state's role is to ensure the delivery of basic services, such as water, electricity, and healthcare. Moreover, nations view health as too important to be left entirely to chance *Titmuss* (1958); *Daniels* (1984); *Allotey* (2007); *DFID* (2004a-d); *Garmaise* (2006). This is why laws and codes regulate the health and safety of populations, and public institutions have been established to promote health. *Marmot, Friel, Bell, Houweling et al* observe that almost all high-income countries organise their healthcare systems around the principle of universal coverage – an approach requiring that everyone gain access to the same range of services, according to preferences and needs, regardless of social status, income or other demarcation (2008). The role and extent of state intervention in enhancing social welfare varies by country. The South African Government's responsibility in this sphere is large. "Indeed," *Hassim* writes: "South Africa is regularly described as the developing world's largest and most generous welfare state" (2007, p. 1).

That the state has a role in addressing social welfare is nothing new. This is the particular province of social policy. Social policy and its practitioners emphasise that states have responsibility for social security, improved welfare, and protection *Mkandawire* (2001); *Titmuss* (1974); *Tarantola, Byrnes, Johnson, Kemp et al* (2008); *Razavi and Hassim* (2006); *MacPherson and Midgley* (1987).[2] Social policy also recognises that promoting and protecting social welfare might not result from *laissez-faire* market economics, thus requiring particular interventions on the part of the state *Spicker* (1995); *Haagh and Helgo* (2002).[3] As *Dahl* notes: "without government intervention and regulation a market economy inevitably inflicts serious harm on some persons; and those who are harmed or expect to be harmed will demand government intervention" (1998, p. 174); *Karger, Midgely and Brown* (2003, see pp. 3-18).

Modern political philosophers have reflected on the ways in which social welfare could be enhanced by considering the normative relationship between state and society; and, the necessary prerequisites for citizens to shape a life with meaning. Many of the salient questions revolve around the conception of social justice held by the state, the basic rights afforded citizens, the content of government policies, and the ethics of society. As *Isaiah Berlin* wrote:

> "These beliefs about how life should be lived, what men and women should be and do, are objects of moral inquiry; and when applied to groups and nations, and indeed, mankind as a whole, are called political philosophy, which is but ethics applied to society" (1990, pp. 1-2).

One of the dominant responses concerning questions about the role of the state towards its citizens came in the form of social contract theory, derived from the writings of classical political theorists Thomas Hobbes, John Locke, and Jean-Jacques Rousseau, as well as contemporary theorists, notably John Rawls *Hobbes* (1962); *Locke* (1960); *Rousseau* (1997); *Rawls* (1971 and 1993). Because of its importance as a social justice framework in political philosophy, it was initially considered as a potential theoretical framework for this study. However, I will briefly explain why it was found wanting.

The Social Contract

While the theorists' interpretations of and their contributions to the explicit and implicit workings of the social contract differ, the thinkers just cited have employed this theory to advance the notion of what the purpose and particular obligations of government entail. In its most simple form, the social contract is a framework that establishes relationships between individuals and their state (and between individuals).

According to the basic design, citizens enter into a contract, a covenant, with their state, in exchange for the benefits of citizenship. In the ideal, individuals constitute themselves as a society for the welfare of the collective and of the individual because the sovereign state is committed to serving the "good" of the larger community. Significantly, this compact that binds citizens to their government is characterised by justice *Rawls* (1971). For *Rawls*, "society" is a cooperative venture "marked by conflict as well as by an identity of interests"; each society must grapple with a set of choices, including social justice principles for selecting social arrangements, distributing benefits and burdens (1993). Theoretically, the social contract model has been a persistent and prevailing feature of the political philosophy landscape. Practically, it has also had wide application: its underpinnings are embedded in constitutional arrangements and fit with many countries' notions of government *Skinner* (1978); *Ankerl* (1980); *Dworkin* (1986); *Nussbaum* (2008). But this theory has its limitations and detractors.

For example, critics question the supposed universality of the 'liberal individual' who is meant to be the agent of the contract. Among them, feminist and race-conscious philosophers have argued that the contract is not one characterised by freedom and justice. Rather, the contract is a vehicle by which women and non-whites have been manipulated and controlled: these groups are unseen; their views unheard *Pateman* (1988); *Mills* (1997). The objections to the social contract formulation come from other quarters as well. Of relevance to the research problem – the contract is conceived in the Lockean tradition as one of 'mutual advantage'. In *Gaultier's* critique of the contract tradition, he contends that people of "unusual need" such as the disabled and children are not included (quoted in *Nussbaum*) (2008, p. 25). This excludes people who are ill and vulnerable or marginalised (refugees or migrants for example). If independence is the *sine qua non* of membership in the contract, many people need not apply. *Nussbaum* observes: Rawls imagines the parties throughout as "competent contracting adults". She continues, "Rawls explicitly omits… the more extreme forms of need and dependency" (2008, p. 27).

Today the policies that affect the development prospects of ordinary people are decided by public officials (e.g., rights to water, electricity and health and policies that regulate or control those services), the ostensible representatives of the people; they may be determined through public deliberation or result from court judgments. The question of 'how we are to live' in a just society requires some clarity about how social justice can be realised in South Africa – a society where large numbers of people require medicines purchased by the state – and unusual need is the norm rather than the exception.

But *Daniels, Kennedy and Kawachi* state: "Rawls did not talk about disease or health in his original account. To simplify the construction of his theory, he assumed that his contractors were fully functional over a normal life span – no one becomes ill or dies prematurely" (2000). Consequently, it is evident that Rawls excludes some conditions germane to our analysis, as the main thrust of the research concern is illness attributed to HIV-related infection and premature death for particular populations (pregnant women and children). Thus, the exclusive nature of the social contract makes this framework less responsive and hospitable to the questions under exploration. The research question can be fitted within a larger query about social justice and ethics, i.e., what are the prospects for development for children and pregnant women within South Africa (a developing nation)? That question begs the larger question of how social justice is conceived, and how it can be realised in South Africa – a context in which premature illness and death that could be prevented and treated – looms large. The long-standing social contract tradition can, then, give us a relational picture of citizen and state, a framing of rights and duties. However, it falls short for the reasons cited.

Ake claims that justice in society can be understood as a "complete equality of the overall level of benefits and burdens of each member of that society" not just a few (1975). If our covenant is truly to be characterised by justice and equality for all, we need a theory of social justice that includes all people, those who are dependent and disabled, especially those who are ill, and those who care for them; women and children, as well as men; one that looks at the development prospects of, and quality of life for, all people within our particular social context, their entitlements; and the content of those rights. We now turn to the capabilities approach.

THE HUMAN CAPABILITIES APPROACH (CA)

Nussbaum stresses that any useful theory of justice in the design of basic institutions needs to recognise and address the problem from the beginning. Consider those who are ill or dependent, she asks, "What, then, can be done to give the problem of care and dependency sufficient prominence in a theory of justice?" (2008). Yoked to that question, we must also inquire: what can be done to ensure that women are given equal standing in such a theory? *Nussbaum* notes that the idea that all citizens are equally entitled to a substantial set of preconditions for a dignified human life has held an enduring appeal throughout the centuries in Western legal and political thought "less because intellectuals have favoured it than because it has great resonance" in the lives of ordinary people (2008, p. 1).

It is precisely a set of fundamental preconditions for development that form the basis of the capabilities approach. First introduced by Amartya *Sen*, the notion of 'capability':

> "…represents the various combinations of functionings (beings and doings) that the person can achieve. Capability is, thus, a set of vectors of functionings, reflecting the person's freedom to lead one type of life or another...to choose from possible livings" (1992, p. 40).

The notion of social and economic development (or socio-economic development, social development or simply development) that is employed here (and throughout this project) is akin to Amartya Sen's conception of development as freedom: *Sen* has advanced an expanded notion of holistic development that can be seen as "a process of expanding the real freedoms that people enjoy" (1999, p. 3). Development signifies improving the quality of life of individuals, with their agency and freedom to choose serving as essential aspects to a life of dignity and flourishing. Development is thus viewed as both a process and an end in itself, rather than a means to an end. As *Sen* has articulated, it consists in advancing substantive freedoms and removing that which impedes those freedoms: "Development requires the removal of major sources of unfreedom: poverty as well as tyranny, poor economic opportunities as well as systematic social deprivation, neglect of public facilities as well as intolerance or overactivity of repressive states" (1999, pp. 3-4).

Having reviewed alternative frameworks, *Sen* asserts in *Development as Freedom* that capabilities offer the best basis for thinking about development goals because the CA inquires: what are people actually able *to do and to be*? For many years, critics of economic development (and of development economics) in contemporary discourse took aim at the dearth of "social dimensions" among its core concerns *Mkandawire* (2001, pp. 21-22); *Pierson* (1998); *Le Grand, Propper and Robinson* (1992); *Myrdal* (1975); *Galbraith* (1958). Against the backdrop of development analyses traditionally preoccupied with income, Sen's capabilities approach has been path breaking. His view on wealth accords with Aristotle's. *Aristotle* wrote: "wealth is evidently not the good we are seeking; for it is merely useful and for the sake of something else" (1998). Low income may impact on hunger, undernourishment and literacy. Better education and health may improve one's income. However, there are other influences in these interconnections.

These factors may thus correlate but there may be other variables that tell us much more. If we concentrate on income-poverty alone we will miss other aspects of development that may tell us whether a person is free to do the things he or she values; whether this person's choice and agency allows her to create a life, to participate in the world on her own terms. *Sen* highlights: "the departures are often much more important from a policy point of view than the limited concurrence of the two sets of variables" he stresses, "the role of income and wealth – important as it is along with other influences – has to be integrated into a broader and fuller picture of success and deprivation" (1999, p. 20).

In sum, against the background of dominant economic approaches that compare utility or income, or even commodities (such as primary goods) the more recent preoccupation with choice, agency and freedom – that characterises the CA – is a welcome one. *Nussbaum* notes: "Prior to the shift in thinking that is associated with the work of Amartya Sen… the most prevalent approach to measuring quality of life in a nation used to be simply to ask about GNP per capita". She adds: "Thus South Africa always did very well among developing nations despite its enormous inequalities and violations of basic justice" (2002, pp. 125-126). *Sen* found that the income and utilitarian-driven approaches failed to capture many dimensions of actual or possible development, thus ignoring if, how, and whether, those resources are actually converted into 'functionings'. In response, *Sen* introduced the capability approach (1999, p. 74).

If capability is a kind of freedom, in assessing social justice in society we can view individual advantage in terms of the *substantive freedoms* (their capabilities). We can then understand poverty and illness as capability deprivation *Sen* (1999, pp. 96-104).[4] *Sen* suggests that any assessment of progress in human development must be done with reference to whether the real freedom of individuals has been expanded. He emphasises the centrality of freedom in the development process; and, the ability to choose. He asserts that "free and sustainable agency" is not just a constitutive part of development – it is an *engine* of human development (1999, p. 4). As the *Human Development Report* states:

> "[T]he basic purpose of development is to enlarge human freedoms. The process of development can expand human capabilities by expanding the choices that people have to live full and creative lives. And people are both the beneficiaries of such development and the agents of the progress and change that bring it about (2004, p. 127)".

Women and Development

Notably, the CA, unlike many other theories, considers the role and needs of women in relation to their development. Martha Nussbaum, who collaborated closely with Sen, took up and extended the CA in relation to the particular needs of and application for women. In her defence of the choice of capabilities as a robust framework for advancing the human development of women, *Nussbaum* states:

> "I… argue that international political and economic thought should be…attentive…to the special problems women face because of sex in more or less every nation in the world, problems without an understanding of which general issues of poverty and development cannot be well confronted" (2000a, p. 4).

Of the CA, *Nussbaum* writes of her own vision and interpretation: "I shall defend one such an approach, one that seems to me to do better in this area than other prominent alternatives" (2000a, pp. 4-5). Nussbaum's list of those central ten capabilities appears below.

In *Nussbaum's* interpretation, which I endorse, the list creates an account of the indivisible elements that are essential for human functioning. In Nussbaum's words, "All are of central importance and all are distinct in quality" (2002, p. 131).

The larger purpose and project of the CA is to look at the list as "combined capabilities" and to pursue each capability for each and every person, treating each person as an end. With these (enumerated) as threshold levels of capability, the social goal is getting every person above the threshold. In the *Nussbaum* conception – through the process of "overlapping consensus" – nations can discuss capabilities in comparison with their notions of "the good" (2000a, p. 132; 2000c, p. 5).[5]

Box 1 The Central Human Capabilities (Nussbaum 2007)

1. *Life.* Being able to live to the end of a human life of normal length; not dying prematurely, or before one's life is so reduced as to be not worth living.
2. *Bodily Health.* Being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter.
3. *Bodily Integrity.* Being able to move freely from place to place; to be secure against violent assault, including sexual assault and domestic violence; having opportunities for sexual satisfaction and for choice in matters of reproduction.

4. *Senses, Imagination, and Thought.* Being able to use the senses, to imagine, think, and to reason – and to do these things in a "truly human" way, a way informed and cultivated by an adequate education, including, but by no means limited to, literacy and basic mathematical and scientific training. Being able to use imagination and thought in connection with experiencing and producing works and events of one's own choice, religious, literary, musical, and so forth. Being able to use one's mind in ways protected by guarantees of freedom of expression with respect to both political and artistic speech, and freedom of religious exercise. Being able to have pleasurable experiences and to avoid non-beneficial pain.

5. *Emotions.* Being able to have attachments to things and people outside ourselves; to love those who love and care for us, to grieve at their absence; in general, to love, to grieve, to experience longing, gratitude, and justified anger. Not having one's emotional development blighted by fear and anxiety. (Supporting this capability means supporting forms of human association that can be shown to be crucial in their development.)

6. *Practical Reason.* Being able to form a conception of the good and to engage in critical reflection about the planning of one's life. (This entails protection for the liberty of conscience and religious observance.)

7a. *Affiliation.* Being able to live with and towards others, to recognize and show concern for other human beings, to engage in various forms of social interaction; to be able to imagine the situation of another. (Protecting this capability means protecting institutions that constitute and nourish such forms of affiliation, and also protecting the freedom of assembly and political speech.)

7b. Having the social bases of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of others. This entails provisions of non-discrimination on the basis of race, sex, sexual orientation, ethnicity, caste, religion, national origin.

8. *Other Species.* Being able to live with concern for and in relation to animals, plants, and the world of nature.

9. *Play.* Being able to laugh, to play, to enjoy recreational activities.

10a. *Control over One's Environment. Political.* Being able to participate effectively in political choices that govern one's life; having the right of political participation and protections of free speech and association.

10b. *Control over One's Environment. Material.* Being able to hold property (both land and movable goods), and having property rights on an equal basis with others; having the right to seek employment on an equal basis with others; having the freedom from unwarranted search and seizure. In work, being able to work as a human being, exercising practical reason and entering into meaningful relationships of mutual recognition with other workers.

Source: *Nussbaum* (2007, pp. 22-24). (Shown verbatim and in its entirety.)

Differences between Sen and Nussbaum

There are several other important differences between Sen and Nussbaum's conceptions of the CA, and they merit a brief mention. Firstly, Sen was never comfortable articulating and publishing a concrete list of capabilities, as Nussbaum has done. Secondly, Nussbaum explicitly reflects and relies on previous writings by Aristotle and Marx in her approach whereas Sen does not *Nussbaum* (1999; 2000a; and 2002). Much (though not all) of Sen's analyses, in developing the CA, are underpinned by economic and socio-economic arguments; his arguments are largely (but not always) based on empirics and real-world examples (this is most visible in *Development as Freedom*).[6] *Nussbaum*, in addition to publishing and endorsing a specific list of capabilities, generally marshals political theory and ethics (rather than economics) to buttress her arguments. Whilst Sen and Nussbaum have both addressed women's development and the status of women in their work, Nussbaum makes cross-cultural claims, especially for women: Sen does not. *Sen* (1990; 1992; 2001b); *Nussbaum and Sen* (1993); *Sen* (1999 Chapter 8); *Osmani and Sen* (2003).[7] Indeed, *Nussbaum* challenges arguments that the diverse nature of the world and its people disallow an explicit, universal set of preconditions and capabilities that would improve quality of life and enable human development, including those for women in the developing world (2000a, p. 7); *Kamtekar* (2002). As one reviewer noted, Nussbaum's *Women and Human Development* is an ambitious work of political philosophy which seeks to guide both constitutional design and social policy, while arguing for the *universal status* of the Capabilities Approach and its application for women *Kamtekar* (2002, p. 262).

Relevance of Approach to the Research Problem

For *Nussbaum*, the capabilities approach argues that "a key task of a nation's constitution, and the legal tradition that interprets it, is to secure for all citizens the prerequisites of a life worthy of human dignity – a core group of 'capabilities' in areas of central importance to human life" (2008).

When considering social justice goals from a development perspective, ensuring good health and freedom from premature death is central to the enterprise. The CA acknowledges, and indeed emphasises, the crucial role and importance of life, bodily health and integrity – including freedom from premature death. This approach therefore has the advantage of allowing us to map onto citizens a set of basic and concrete entitlements, with a view to ensuring the kind of human development discussed; at the same time, protecting human health and ensuring reproductive health and freedom. In the capabilities' conception of development, people are free

from premature death due to preventable and treatable diseases; they have the freedom to make choices (including but not limited to bodily health and reproductive choices); to become who they want to be; and, ultimately, to flourish. The CA also has important conceptual linkages and practical synergies with health and human rights.

Health and Human Rights

For *Nussbaum*, the CA has always been a "species of a human rights approach". She observes that unlike Sen: "I myself have attempted to defend the use, for political purposes, and as a basis for constitutional thought… a list of ten 'Central Human Capabilities'" (2007, p. 21). Human rights comprise a set of normative standards and principles, the origins of which can be traced to antiquity. However they have taken modern shape through the works of political philosophers and a series of international treaties and conventions, such as the Universal Declaration of Human Rights (UDHR) in 1948, a response to the atrocities of World War II. Subsequently, the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights, both take 1976 as their starting date. Human rights are often described as claims that individuals have on governments by virtue of being human *Tarantola, Byrnes, Johnson, Kemp et al* (2008).

Even though the UDHR is not binding, states that are signatories agree to be held to certain procedures, responsibilities and reporting on compliance *Mann, Gostin, Gruskin, Brennan et al* (1999, p. 10). These are embodied in states' legal instruments and institutions *Tarantola et al* (2008). *Sieghart* argued that non-discrimination is the "master key" to understanding human rights. When human rights have been violated, the violation has normally entailed some kind of discrimination. Articles 1(3) and 55 of the UN Charter, and both Covenants (cited above), use identical words extracted from the UDHR that emphasise non-discrimination as the central aspect of all of these agreements: "…without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status". Non-discrimination, then, can be seen as the life-blood of human rights theory and practice (1988, p. 9; see 1985).

Health, Human Rights and Development

The CA can be viewed as a human rights approach, and the causal links between health policies, human rights and development are increasingly recognised *Gruskin and Tarantola* (2000). The philosophical origins of rights and their justification are diverse, spanning from natural law, positive law, theories of human need, and capabilities.

In spite of the diversity of theories, there is a general consensus that a central core of human rights claims can be made. Thus human rights play a key role in shaping programmes, policies and practices that seek to improve social and individual welfare *Tarantola et al* (2008, p. 2): *Bilchitz* (2003a-b). The CA successfully links human rights with development and health – with health holding a prominent place.

HEALTH AS A SOCIAL JUSTICE CLAIM

Why is health a social justice concern and why does health hold special importance for development and for capability? Why does health constitute a social justice claim in the capability view?

Many experts argue that not only do nation states hold the primary responsibility for ensuring basic service delivery, it is the state's duty to address the disparity between potential and actual health outcomes or achievements *Ruger* (2006a); *Sen* (1999).[8] In the capability view, this is because health holds special moral importance (2004).[9] The capability framework gives special moral importance to health capability: "an individual's opportunity to achieve good health and thus to be free from escapable morbidity and preventable mortality" *Ruger* (2004a, p. 1076); *Sen* (2004). In the CA, health can be seen as a form of freedom, and ill health can be understood as its opposite *Peter* (2000). As *Canguilhem* observed, "health is a feeling of assurance in life to which no limit is fixed" (1989, p. 201). Health affects an individual's well-being and it is a pre-requisite to functioning as an agent. Good health is, then, necessary for development and for flourishing *Sen* (2004); *Pellegrino* (1999); *Sen* (1992). As *Sen* points out: "we are not able to do much if we are disabled or ceaselessly bothered by illness, and we can do very little indeed if we are not alive" (2004, p. 28). Thus health is regarded as critical for its own sake and because it allows for other things *Anand* (2004); *Ruger* (2004b); *Sen* (2004).

What does it mean to be healthy? While health is inevitably bound up with biology, it can never be a value-free notion *Canguilhem* (1991); *Peter and Evans* (2001). As *Peter and Evans* note, "value judgments are required in order to make distinctions between normal and abnormal, healthy and pathological, and even medical disease versus deviation from some other non-medical social norm" (2001, p. 26). Health is therefore seen as a product of complex biological and social valuations. A focus on biomedical factors alone can obfuscate the distributional issues that impact on the social basis of health. At the same time, a pure concentration on social factors may obscure biological ones. As a state of being, only partial control can be obtained over our own health. At birth we take on a specific biological and social heritage that casts an imprint on our health projection over the course of our lifetimes. Prior to adulthood, we are exposed

to a spectrum of physical and social environments over which we have little control *Evans et al* (2001). The World Health Organization's definition is often employed as an all-encompassing definition of health.

> **WHO Definition of Health** – Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.[10]

Why can health be seen as a 'special' good or condition and a priority for development? Indeed, one could argue that the health of our two target population groups might improve with improved food security, potable water or electricity.

The Special Nature of Health

Anand claims that health has been recognised as a special good, and the foundation of other goods, throughout the ages. He points to the writings of a series of philosophers to substantiate his assertion. For example, he notes that *Democritus* in his book *On Diet* wrote the following in the fifth century BC:

> "[W]ithout health nothing is of any use, not money nor anything else" (quoted in *Anand*) (2004, pp. 16-17).

> *"Descartes*, in 1637, declared that health is the highest good: [T]he preservation of health is…without doubt the *first good and the foundation of all other goods* of this life" (*Discours de la Methode*, quoted in *Anand*) (2004, p. 17).

Anand finds that the reason health is so important is based on two intertwined rationales: firstly, "[health] is directly constitutive of a person's well being"; and secondly, "it enables a person to function as an agent – that is, to pursue the various goals and projects in life that she has reason to value". *Anand* stresses: this is "an agency-centred view of a person, for whom ill-health reduces the full scope of human agency. If we see health in this way, then inequalities in health constitute inequalities in capability to function" (2004, pp. 17-18).

The *WHO's Commission on Social Determinants of Health* also supports the view that health is a special good (2007). *Sen* too agrees. He states: "The fact that health is central to our well-being needs emphasis, as does the equally basic recognition that the

freedoms and capabilities that we are able to exercise are dependent on our health achievements" (2004, p. 28). *Nagel* puts it this way:

> "What we find desirable in life are certain states, conditions, or types of activity. It is *being* alive, *doing* certain things, having certain experiences that we consider good.[11] But… it is the loss of life, rather than the state of being dead…that is objectionable" (1979, p. 3).

Nagel comments further on the significance of a life cut short: "The death of Keats at 24 is generally regarded as tragic; that of Tolstoy at 82 is not…Keats' death deprived him of many years of life which were allowed to Tolstoy; so in a clear sense Keats' loss was greater" (1979, p. 9). *Nagel* concludes, "[D]eath, no matter how inevitable, is an abrupt cancellation of indefinitely extensive possible goods" (1979, p. 10).

It is this conception of "indefinitely extensive possible goods" that begins to hint at the rather nebulous view of what good health comprises – and its implications for one's capability, for functionality and, indeed, flourishing. With good health, anything is possible. With ill health, the range of indefinite possibilities becomes narrowly circumscribed. *Ruger* notes the social ethics attached to capability and flourishing: the "ethical principle of human flourishing underlies society's obligation to maintain and improve health. This principle holds that society should enable human beings to live flourishing lives. Flourishing and health are inherent to the human condition" (2006b, pp. 406-407).[12]

Hence, in the capability view, the state's obligation "rests on the ethical principle of human flourishing" *Aristotle*, quoted in *Ruger* (2006, p. 999); see also *Ruger* (2004a p. 1075); *Sen* (1999; 1992; 2002). *Nussbaum* emphasises that the "basic intuition" from which the capability approach springs in the political arena is "that certain human abilities exert a moral claim that they should be developed" (2000a, p. 83). *Ruger* suggests that expanding human capabilities – the real freedoms that people have – is the *ultimate end* of public policy (2004b, p. 1094).

Sen argues that if we view human health as central to human development, then *deprivations* in the functioning of health can be seen as unjust because they reduce the capacity for individuals to develop and to flourish.[13] *Nussbaum* observes that some specific functions are central to human life and we need to make judgments about them: "We judge frequently enough that a life has been so impoverished that it is not worthy of the dignity of the human being" (1999, p. 72). In this way, good health can be seen to exert a moral claim on society *Pellegrino* (1999, p. 247); *Sen* (2002); *Sen* (1999).

Just Health or Just Healthcare?

That good health should be part of a conception of a just society is not in dispute in political philosophy: the debate turns on the nature and reach of such a social justice claim. I now briefly review some of the key arguments surrounding this debate.

Peter and Evans point out that theories of social justice are quiet on health broadly, and health inequalities specifically. The authors write: "Turning to the literature on moral and political philosophy, one finds few direct efforts to deal with health equity. Theories of social justice are generally silent on the topic of health" (2001, p. 3). Similarly, *Daniels, Kennedy and Kawachi* assert: "The philosophical literature has produced theories aimed at evaluating socio-economic inequalities but has tended to ignore health inequalities and their causes" (1994, p. 72).

As noted by *Anand, Peter and Sen*, and in separate publications by *Ruger* (2006a-b), *Peter and Evans* (2001); *Daniels, Kennedy and Kawachi* (20004), philosophers and applied ethicists who address health or health inequality tend to limit the focus to health*care*. *Ruger* argues that philosophers have been slow to give health (as opposed to healthcare) any special moral significance because philosophers, such as *Rawls* and *Daniels*, make the assumption that health is not an appropriate focal point for evaluating social justice claims (2006a-b). Implicit in this discussion is the complexity of measuring good or ill health. *Peter and Evans* note that, at first blush, health (and greater equity in health) as a social goal would seem obvious. Nevertheless, underneath this seemingly simple proposition is a labyrinth of intricate issues related to the meaning of health and how it is measured, what good health constitutes, its socio-biological constitution, and the factors that affect the distribution of health status across and within populations as a consequence (2001, p. 25). The authors stress that turning to bioethics and medical ethics, the focus is on the rationalisation of greater equality in healthcare and the rights of individual patients (2001).

Combing the public health literature turns up very little in the way of ethics, although there is now a growing link between public health and human rights *Mann* (1995; 1999); *Gruskin and Tarantola* (2000) *Galvão* (2005); *Roseman et al* (2005) *Gruskin et al* (2005); *Hassim, Heywood and Berger* (2007). *Mann* argued that traditional public health began as a social movement, but "at least in its contemporary form, [it] is struggling to define and articulate its core values" (1997, p. 8). In a theory-building article, which seeks to overcome divisions between medicine and ethics on the one hand, and public health and human rights on the other, *Mann* remarked on a: "long-standing absence of an ethics of public health" and called for the building of bridges that would connect these

disciplines, with a view to strengthening coherence and identity, and identifying professional roles and responsibilities (1997).[14]

While egalitarian theories tend to focus on the distribution of certain goods such as healthcare, utilitarian theories focus on the utilities of satisfaction, desire and preference. Whereas liberal theories of justice, notably that of *Rawls*, have viewed health as a natural good: "health and vigor, intelligence and imagination, are natural goods; although their possession is influenced by the basic structure, they are not so directly under its control" (quoted in *Ruger*) (2004a, p. 1075). In contrast to these natural goods, *Rawls* developed a list of primary goods society is meant to safeguard to some extent. These include: "rights, liberties, and opportunities; income and wealth; and the social bases of self-respect" (1993). *Nussbaum* writes: "Rawls' evident concern is that no society can guarantee health to its individuals". She asserts that the capabilities approach is very close to Rawls' notion of primary (not natural) goods (2000a, p. 88). *Nussbaum* states:

> "My response to this is that, with these other items as with self respect, society can hope to guarantee the social basis of these natural goods, and that putting them on the list as a set of political goals should therefore be useful as a benchmark for aspiration and comparison" (2000a, p. 89).

But even if *Rawls* had placed health on his list of primary goods, *Sen* is unlikely to agree that the CA is close to *Rawls'* conception of primary goods.[15] *Sen's* criticism of *Rawls* is that we should attend not only to the distribution of primary goods, but also to how effectively people are able to use those goods to pursue their ends. *Sen* stated that the primary goods focus is insufficient, as it does not take into account individual health (and functioning) and environmental health, among other issues.[16]

Daniels and others suggest that the demand for equality of *access* or entitlement to *health services* – as opposed to good *health* – is the proper claim that should be lodged. *Daniels* attests that "health is an inappropriate object, but health *care*, action which promotes health, is appropriate". He continues, "a right claim to equal health is best construed as a demand for equality of access or entitlement to health services… " He emphasises: "a right to health embodies a confusion about the kind of thing which can be the object of a right claim" (quoted in *Ruger*) (2004a, p. 1075). Again, health capability encompasses more than just healthcare. *Ruger* disagrees with Daniels. She stresses that one must not assume that more and better healthcare is all that is needed to improve health. The main effect of healthcare may depend on the type of care and often on other factors (2004a, p. 1076).[17]

In response to the bias in ethical theory against health (as opposed to healthcare) as the focal variable of social justice, *Ruger* suggests that "we lack a moral framework" for viewing health, and that a capability view of health provides us with just such a moral underpinning (2006, p. 1002). However, the CA does not tell us what to do about the shortfalls.

Strengths and Limitations of the CA

With regard to strengths, given that the research problem is concerned with premature illness and death for HIV-infected women and children, the first major advantage of the CA – unlike social contract theory, utilitarian, income or poverty-based development frameworks – is that it pays due attention to illness and premature death. The CA specifically states the central capabilities (1-3) as "being able to have good health, including reproductive health," "not dying prematurely" and freedom from "violent assault, including sexual assault" while having opportunities for choice in "matters of reproduction". Capabilities 1-3 seem to articulate and address important considerations that flow from the research problem, which is not just a theoretical problem but a major development challenge for South Africa. Secondly, if we turn to the basic problem of women's exclusion from theories of social justice, the CA also gives us proper traction in moving towards enhanced human development for women, as well as for other marginalised populations, including children. As *Nussbaum* notes, too often women are not treated as ends in themselves – "persons with a dignity that deserves respect from laws and institutions. Instead, they are treated as mere instruments of the ends of others – reproducers, caregivers, sexual outlets, agents of a family's general prosperity" (2000a, p. 2).

Thirdly, the CA is both a human rights and development framework where rights can be understood as social and material preconditions for development, and as constitutional guarantees, which require government action, legal protection and enforcement. This approach fits with health as a human right – enshrined in South Africa's Bill of Rights, and its conception of socio-economic rights within the Constitution *Government of South Africa* (1996a); *Bilchitz* (2003a-b); *Leibenberg* (2003). Fourthly, this approach is relevant to the South African country context where GNP is comparatively high in the region, yet human development is low, and inequality is high, rendering this approach more attractive than other more utilitarian or income-based approaches that fail to attend to the nuances embedded in such a complex reality *Seekings and Nattrass* (2005); *Wadee, Gilson, Thiede, Okorafor, and McIntyre* (2003). Fifthly, as mentioned, this normative approach assists in articulating, at a minimum, what basic justice does require vis-à-vis development and flourishing.

There are several limitations. A concrete list of essential preconditions also leaves itself open to criticism and interpretation. Not everyone will agree on what is 'essential' and whether the current list fits the bill. There are concerns about pluralism and diversity lodged by feminists. As *Quillen* notes, "feminist scholars want first to acknowledge the complexities of a female subjectivity constituted amid shifting and irreconcilable discourses, without as a result denying female agency" (2001, p. 87); see also *Charlesworth* (2000).

Other critics contend that *Nussbaum's* conception of social justice "relies upon an untheorized and an ahistorical liberal state". These same critics assert that *Nussbaum* ignores the specific historical place of states within a changing global political economy; and "accounting for the positioning of states within such a global context reveals the importance of states' differing relations to other states, transnational institutions, and their citizenry" *Feldman and Gellert* (2003).

Lastly, any framework inevitably leaves things out that may be as important as what remains. The CA makes certain claims about what individuals require. However, the structures and systems that underpin those conditions are not taken into account, such as social and economic institutions and hierarchies; social position and social and cultural mores *Quillen* (2001). The CA also fails to mention the contexts in which special claims could be lodged. (If such claims are meant to be left to the law, this is not obvious.) Whether capabilities can be realised or not may depend in whole or in part on these structures. How these structures perpetuate what is seen as a social norm, and how these structures and norms might be changed goes beyond what the CA offers. Last, but definitely not least, the CA does not offer a remedy for, or guidance to take action on, deprivations or disparities in capabilities. Owing to this latter deficiency in the CA, I am including a significant addition to the theoretical framework. I elaborate and provide the rationale for this in the next section.

LINKING CAPABILITY TO HEALTH EQUITY (AND DEVELOPMENT THEORY TO ACTION)

In this section, I discuss enlarging the conceptual framework to include health equity as an approach that will link theory to action. As I have articulated above, the CA makes specific claims about what individuals require for development but it does so without reference to an historical context, by necessity (again, *Nussbaum* emphasises that each country should discuss its application, tailoring it to the needs of the particular environment).

Rooting understanding and responses in context is critical. To that end, I believe the CA offers an important framework for development in South Africa but it misses South Africa's unique context, while also missing some of the important conceptual linkages between health and inequality. In my view, the health equity literature, which includes literature on the social determinants of health, is well-poised to plug these gaps.

I contend that health equity approaches will shed additional light on the research problem and what to do about it – by way of appropriate social policies for instance. A defining feature of South Africa is its legacy of inequality, as discussed in chapter one. *Seekings and Nattrass* assert: "no other capitalist state (in either the North or the South) has sought to structure income inequalities as systematically and brutally as did South Africa under apartheid" (2006, p. 2). There is not a single society without inequalities in health. However, as noted in chapter one, the scale of inequalities in South Africa poses a particularly dramatic case *Gwatkin* (2000); *McIntyre and Gilson* (2001); *Wadee, Gilson, Thiede, Okorafor and McIntyre* (2003); *Sen* (1999).

Thus, what is called for, in addition to the CA, is a combined development approach that can encompass a large and complex terrain which moves us from health as a social justice claim to action on avoidable health inequities: thus moving us from development in theory to practice; from research to action.

Health Equity

Braveman and Gruskin emphasise that equity essentially means social justice or fairness: "it is an ethical concept grounded in principles of distributive justice" (2003, p. 254). To constitute a health inequity, a disparity in health must be consistently associated with social advantage that is frequent, substantial and persistent, not occasional or random *Whitehead* (1992); *Evans, Whitehead, Diderichsen, Bhuiya and Wirth* (2001). This research investigates disparities in access to antiretroviral therapy for pregnant women and children – and premature mortality due to preventable and treatable illness. These trends, as presented, are troubling. But do they constitute health inequities or inequalities? And, what, if anything, should be done? These questions will be tackled in chapters six and seven. *Daniels, Kennedy and Kawachi*, drawing on the health equity literature, assert that "an account of justice" should aid us in determining which health inequalities are unjust and which acceptable (2000; 2004). But any account of justice must be informed by the values that we cherish as a society; as a community. *Lee Jong-wook* observed that "effective public health action needs an ethical position as well as technical skills. To shape a healthier future, we need to be clear about our values, as well as our science" (2003).

Evans et al note that "deep-seated imbalances generated by discrimination and power differences often underlie disparities in health" (2001, p. 4).

> "When we assess inequalities across the world in being able to avoid preventable morbidity, or escapable hunger, or premature mortality, we are not merely examining differences in well-being, but also in the basic freedoms that we value and cherish" *Sen* (1992, p. 69).

Sen is one scholar who has successfully linked the CA with health equity. His own conception of the CA relies heavily on the social determinants of health, including the integration of public policies into a comprehensive set of health improvement strategies (2000); *Sen* (1985). There is a growing literature on the social basis of disparities in health. As noted, SDH include living conditions in households, conditions in communities and workplaces, access to healthcare, including its allocation, quality, as well as the financing and utilisation of healthcare resources, together with programmes and policies that affect those factors *Braveman and Gruskin* (2003). The literature on SDH and health equity are closely linked (often difficult to distinguish), and there has been a recent resurgence of research and policy on health equity and SDH *WHO* (2007; 2008a); *Marmot et al* (1999; 2004; 2006; 2008); *Anand, Peter and Sen* (2004); *Evans et al* (2001); *Shaw et al* (1999); *Whitehead* (1990; 1992; 1998); *Wilkinson* (1997; 2003; 2006).

To advance the global health equity agenda, the WHO created the Commission on Social Determinants of Health (CSDH) in 2005.[18] The Commission's mandate was to seek answers to the following questions: "What pathways lead from root cause to stark differences in the health status of a population?"; and, "where and how should we intervene to reduce health inequities?" *WHO* (2007). The CSDH launched its final report in August 2008 with this bold declaration: "Health inequities are killing people on a grand scale" *WHO* (2008a).

The lack of attention to equity and equal opportunities, including in health, as a core constituent of development had previously been a lacuna throughout the development literature. As *Cling, Cogneau, Loup, Naudet, Razafindrakoto* and *Roubad* stress: Even while philosophers, sociologists and economists such as *Rawls, Dworkin, Roemer* and *Sen* have studied equity extensively, and equal opportunities as a key component of equity, "the issue has remained marginal in terms of…development" (2005, p. 2). An attention to equity is beginning to reveal itself in the development policy literature. For the first time in 28 years of publication, the World Bank's annual *World Development Report 2006* addressed "equity and development" in a report by the same title. *Cling et al* analysed the content of the *World Development Report* and found important shortcomings.

Despite this, they concluded that the report's main contribution was to place equity firmly on the development agenda (2005, pp. 34-35). *Petchesky* has cautioned, however, that although the links between health and economic development policies are now acknowledged by the major international agencies responsible for health funding (such as the World Bank and DFID), "there is little recognition that dominant macroeconomic models and entities 'are bearers of social relations and are imbued with social values, and power relations are not immutable'" (2003, pp. 13-15).

Gwatkin, Director of the International Health Policy Program at the World Bank, expresses confidence that we are now seeing a renewal of concern and commitment vis-à-vis health inequalities but he claims that we have no strategies yet for addressing these intractable challenges. He suggests that the World Bank and International Monetary Fund are cognisant of health and other inequalities, citing the introduction of the *Poverty Strategy Reduction Papers* that accompany debt forgiveness plans to support his view. Reflecting on a health equity series (five articles published in the *Bulletin of the World Health Organization* in 2000), Gwatkin suggests that a new generation of research on health inequalities has been produced (2000, p. 3). He states:

> "Renewed concern for health inequalities and the health of the poor has begun to produce important findings…. What the research undertaken so far has not yet produced is a strategy for moving beyond understanding and applying this knowledge to the challenges and problems that have been identified" *Gwatkin* (2000, p. 3).

In terms of research and policy activity on health equity, there have been significant strides taken. Mexico, the UK, the Netherlands, Sweden, Chile, China, Japan, Tanzania, Russia, South Africa, Kenya, Bangladesh and Vietnam all pose different case studies that have been documented to some extent *Whitehead* (1998); *Evans et al* (2001).[19] Trends in Europe, for example, have impacted particularly on disadvantaged populations. With worsening health trends, many countries began to sit up and take notice as that continent has traditionally been host to some of the healthiest nations in the world. Now most European nations are reporting a widening gap in health outcomes. Such evidence has been provided from Spain, Sweden, the Netherlands, and the UK *Whitehead* (1998, pp. 472-476); *Navarro and Benach* (1997); *Shkolnikov* (1996); *Kunst and Mackenbach* (1995); *WHO* (1985). In response, the WHO European office established a programme to focus on health inequalities, which led to a common health policy for the region of Europe, titled "European Health for All"; the European Union now presents a report on health implications of EU policies annually. The effect has been to demonstrate to members that policies in social security, employment or social action can influence the health of groups within the population. Thus by the mid-1990s, the countries of the

European Union had identified research on inequalities in health as a priority for its public health programme, spearheading research and policy development on health equity, internationally *Whitehead* (1998, p. 472).

For the purposes of this research, there are a number of findings regarding social determinants of health that have so far been substantiated. These generalisations serve as a basis to ground future work and are thus important to briefly review. Four main findings are highlighted.

1. Social gradients exist in all societies regardless of how rich or how poor (discussed in chapter one).

Daniels, Kennedy and Kawachi observe that social gradients are influenced by policy choices – not the result of fixed laws of economic development (2004, p. 65). *Marmot* notes that the income/health gradients are not just a reflection of the deprivation of the poorest groups. A gradient in health operates across all societies. But the slope or steepness of the gradient is affected by the degree of inequality in a given society, although it does not appear to be explained solely by access to healthcare (2004, pp. 65-66). Hence, income (or relative income) or socio-economic status is just as important – if not more – than absolute income in determining health status (2004, pp. 65-66, 68).

Also significant, *MacIntyre* notes, is the "ubiquity, both over time and space, of the observed pattern of systematically poorer health and a shorter life span is associated with each successively lower position in any given system of social stratification" (1998). *Diderichsen, Evans and Whitehead* point out that this finding challenges earlier thinking that societies living in extreme poverty would suffer poor health and that there would be little differentiation among groups, also challenging the assumption that absolute poverty was the primary determinant of inequities in health (2001, pp. 13-14).

2. There is a relationship between income and life expectancy up to a point.

Daniels et al note that this levels off after $8 000-$10 000 GDP per capita "with virtually no further gains in life expectancy" (2004, p. 66). The levelling is most visible for the rich countries. Data on the wealth of countries and the life expectancy of residents in those nations reveals that some of the richest countries do not perform well in terms of life expectancy. This includes the US, Qatar, Brunei and Luxembourg, all high income earners but with lower life expectancy than countries with less wealth,

such as Cuba, Georgia and Costa Rica (according to 1995 data produced by the UN Human Development Report's statistics). *Daniels et al* conclude that the evidence indicates that the relationship between income and health is not fixed, and that it is mediated by other processes, such as social organisation, culture, and government policies (2004, p. 67). *Daniels et al* inquire: "If we are right that the health of nations does not reflect some inevitable natural order, but that it reflects policy choices – or features of society that are amenable to change via policies" then we must ask about the justice or injustice of alternate policies (2004, p. 68).

3. There are identifiable causes/pathways by which inequality produces effects on health.

The evidence that *Kawachi and Kennedy* (1997) and *Daniels et al* (2004) present for this is striking. One of the strongest predictors of life expectancy is adult literacy, while gender disparities related to access to basic education also have a relationship with the level of health achievement in societies. Across different US states, for example, differences in women's status (measured as political participation and economic autonomy) were strongly correlated with mortality rates *Daniels, Kennedy and Kawachi* (2004, p. 72).

These authors suggest that societal pathways are linked to political processes. They state that one way income inequality undermines health is through its role in undermining civil society. Income inequalities "erode social cohesion" (measured by higher levels of mistrust and diminished participation in civic organisations). Such lower participation in the political process undermines the responsiveness of government to address the needs of the worst-off groups in society (2004, p. 72).

4. Social policies can serve to prevent unequal consequences of ill health.

The role of education, in particular, as a determinant of health has been well-captured by the literature. *Grown, Rao Gupta, and Pande* note, "For a long time, researchers have recognised that educating girls is important for improving health, reducing gender inequality, and empowering women" (2005, p. 541). *Marmot* states, "Education, as a marker of socio-economic status has been shown in a large variety of studies to be related to morbidity and mortality" (2004, p. 55). *Gilson and McIntyre* (among others) demonstrate the correlations between literacy and decreased rates of infant mortality in South Africa (2001, pp. 191-209). *Diderichsen, Evans, and Whitehead* note that the effects of education on health have been hypothesised as resulting from at

least one of the following three pathways: (i) Labour market, economy and household conditions allow individuals with more education to obtain higher paying jobs, and to reduce their risk of taking up employment that requires hazardous conditions that may impair their health (mining in South Africa is an appropriate example in this country); (ii) More educated people are more likely to avoid health risks like smoking and to take part in preventive behaviour such as medical checkups and prenatal care, whereas unskilled workers have less control over their work and fewer opportunities to choose healthy lifestyles; and (iii) More education may lead to "more resilient social psychological status – a sense of control or self-efficiency" (2001, p. 18).

A second example of an appropriate social policy is that of employment. *Evans et al* observe that an effective link between health and employment depends on whether individuals can generate an income that will ensure well-being. In contrast, in many countries, job security correlates with life expectancy in adults. Russia is a good example of this: the poorest often have the highest-risk occupations in unsafe mines or in commercial sex work. Appropriate social policies thus become critical.

Limitations of the Literature

The relationship linking social and economic factors with health outcomes is now well-established *Marmot and Wilkinson* (1999); *Solar and Irwin* (2007). While it is evident at the individual and population level that poor health and economic and social disadvantage are linked, in causal terms the relationship is not well understood. As mentioned in chapter one, clearer understandings of the causal pathways – the interaction of biological and social causes and their effects – are called for by scholars *Shaw, Darling, Gordon and Davey Smith* (1999); *Bonnefoy, Morgan, Kelly, Butt and Bergman* (2007). Another limitation of SDH knowledge and literature rests with the normative aspect of health equity. *Anand, Peter* and others caution that the extensive empirical research on SDH has yet "to be matched by an appreciation of the normative underpinnings" of health equity (2004); *Evans et al* (2001). This gap is a crucial one *Gwatkin* (2000).

Added to this, as the CSDH stresses, models of SDH that seek to explain functioning and impact have not made explicit the role of the health system as a social determinant. Although differences in access to healthcare do not fully account for patterns in health achievement among population groups, they do have great relevance for exposure and vulnerability to illness *WHO* (2007).

Despite the fact that the causal pathway linking SDH to biological processes is not fully understood, the general view is that sufficient evidence exists to take action in those areas that can be remedied: where knowledge points to action *Whitehead* (1990); *Evans et al* (2001). The *WHO* emphasises that the role of governments and of policy in addressing such social inequalities in health is crucial (2007; 2008a). In any society, protection of the public's health from preventable illness and death is part of the state's role. Human capabilities and health equity as a combined framework should be well-placed to frame and consider the research question against a larger background of social justice and development challenges, while seeking to address the range of concerns to be investigated along the journey. This combined approach, then, effectively links development with freedom, with health as a social justice concern, and with health as a basic human right *Sen* (1999); and *Ruger* (2004a-b).

Conclusion

This chapter has explicated the joint conceptual framework used to understand and explore the research problem. It briefly considered why the social contract was found wanting as an acceptable theoretical framework for this project. It outlined the Capabilities Approach, while discussing its relevance for and applicability to research concerned with women's health and development. Within the frame of women and human development, Nussbaum's vision and interpretation of the CA is described, and her list of 10 central human capabilities is put forward. I note that I endorse Nussbaum's list and its explicit emphasis on the social goal of moving every individual above the threshold. I move on to acknowledge key differences between Sen and Nussbaum, including that Sen does not articulate a set of criteria by which social policy (and development progress) can be measured. In contrast, the value of Nussbaum's approach (and why it is favoured in this project) is that it clearly identifies and maps onto citizens a set of concrete entitlements that allows for human development, protects human health, while ensuring reproductive health and freedom. Nussbaum also pays due consideration to women's development within her list.

The second half of the chapter engages in a discussion of health as a social justice claim. It considers why health holds special and primary importance to development, also exploring the complex considerations surrounding what it means to be healthy. In capturing the debate on whether health or health*care* should be the focal point of a social justice claim, a number of tightly-held assumptions begin to unfold, including what good health is (the concatenation of social and biological factors), measurability, and the multiple factors that impact on health distribution across and within populations - as well as the lack of engagement of theories of justice with health as a social justice

claim. Through the discussion in this chapter, the divide between good health on the one hand, and good healthcare on the other, becomes more explicit.

Following a summary of the strengths and weaknesses of the CA, health equity is introduced as a literature that will complement the capabilities approach. I emphasise that a health equity approach allows for conceptual linkages to be made between health, inequality and social determinants of health – which is appropriately matched to the South African context. I explain how the global health equity policy agenda has resurged. And I articulate four findings from the literature that are particularly relevant to the research problem, and serve to ground future work. After enunciating the limitations of the health equity literature, including the gaps in the knowledge base, I close by pointing to the particular merits of a joint capabilities-health equity approach for this research. The health equity literature, combined with a secondary analysis of mortality data on pregnant women and children with HIV, is used to complement and deepen discussions of capability in relation to the research problem. In the next chapter I describe in detail the methodology used to investigate the research question.

Endnotes

1 See also *Niekerk, Knies, Rabie, Zeier, van Rensburg, Frans, Schaaf, Fatti, Little and Cotton* (2005); *Michaels, Eley, Ndhlovu and Rutenberg* (2006).

2 *Mkandawire* defines social policy as follows: "Collective interventions directly affecting transformation in social welfare, social institutions and social relations. Social welfare encompasses access to adequate and secure livelihoods and income. Social relations range from the micro to the global levels, encompassing intra-household relations of class, community, ethnicity, gender, etc". (2001, p. 1); *North* (1990).

3 Even for *Adam Smith*, some things could not be left to the workings of the marketplace and could only be assured by government intervention *Pellegrino* (1999, p. 245); *Smith* (1817); *Smith* (1909).

4 See *Sen* (1999, pp. 87-110).

5 Overlapping consensus is a term used by Rawls in *Political Liberalism*. See *Rawls* (1993).

6 He did, after all, win the Nobel Prize in Economic Sciences in 1998.

7 *Sen* devised the concept of missing women to reveal the enormity of the phenomenon of, as he puts it: "women's adversity in mortality by focussing on the women who are simply not there, due to unusually high mortality compared with male mortality rates" see (1990).

8 Scholars and practitioners in public health, medicine, development and other fields may agree on action, however the philosophical or ideological foundation may differ. This is true in public health as well but the foundation or basis for action is not necessarily a moral one. It may also result from maximising utility – saving the greatest number of lives. And, for public health, the focal point of action is healthcare – not a set of indivisible capabilities – that includes health among others *Ruger* (2006a); *Mann et al* (1999).

9 *Nussbaum* writes in her introduction to *Women and Human Development*, "My own version of the [capabilities] approach derives from a period of collaboration with Sen at the World Institute for Development Economics Research in 1986 when we recognized that ideas I had been pursuing in the context of Aristotle scholarship had a striking resemblance to ideas that he had for some years been pursuing in economics" (2000a, p. 11).

10 Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19 June - 22 July 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100); and entered into force on 7 April 1948. (The definition has not been amended since 1948). Available from http://www.who.int/suggestions/faq/en/print.html.

11 Emphasis in the original.

12 See *Ruger* (2006a-d).

13 Deprivation (e.g., in health or poverty) can be absolute or relative. See *Marmot, Smith, Stansfeld* (1991); *Wilkinson* (1997).

14 Mann and Annas have suggested in separate publications that medicine and public health are complementary; and that medicine has claimed ethics while public health uses the language of human rights *Mann* (1997); *Annas* (2004).

15 *Nussbaum* writes that Rawls does suggest putting health on the primary goods list in his "Priority of the Right" see *Nussbaum* (2000, p. 89); *Rawls* (1988).

16 Sen has also identified a separate limitation of Rawls. In Sen's view, the focus of John Rawls and other political theorists in social justice theory has been on 'just institutions' rather than on 'just treatment of people'. Professor Amartya Sen, Lecture on Social Justice, University of the Witwatersrand, 21 April 2007.

17 *Daniels et al* and *Anand and Peter* have considered the application of Rawls' theories to health, despite the fact that, as *Daniels, Kennedy and Kawachi* acknowledge: "Rawls did not talk about disease or health in his original account" *Daniels, Kennedy and Kawachi* (2000; 2004); see also *Anand and Peter* (2000) (a response to *Daniels et al* (2000)).

18 In 2003, the new Director General of the WHO, Dr Lee Jong-wook on assuming office, pledged to help the world's poor, stating: “Questions of health equity and the empowerment of the poor have a personal relevance for me. As a Korean born in 1945, I grew up in a country impoverished and torn by war…” *Jong-wook* (2003); *Altman* (2006). Jong-wook was also responsible for introducing the global campaign to treat three million people in the poorest countries with ARVs by 2005 *WHO* (2004).

19 *Evans et al* published a series of country case studies in an excellent book (see 2001). For the chapter on South Africa, see *Gilson and McIntyre* (2001).

Chapter 4

Methodology

The aim of the empirical research was to understand the primary set of barriers to HIV-infected children and pregnant women's access to and delivery of PMTCT and ART – by employing, chiefly, qualitative research methodology and related data and information gathering techniques.

In this next section, my aim is to justify the choice of qualitative methodology as the appropriate one for investigating the research question by pointing to specific strengths of qualitative research, and the applicability of qualitative methods for this particular study. I briefly touch on the importance of social context and the nature of 'experience' in studies such as this one, where self-perceptions of and beliefs about health and illness impact on health-seeking behaviour and health outcomes. I discuss the phenomenon of the researcher becoming part of the research process, and the importance of reflexivity to address this challenge. I then highlight the debates over what it means to do 'valid' research using qualitative methods, with the major issue hinging on credibility.

Within South Africa, the more dominant influence of quantitative methods in studies of disease management and medicine reflects an international trend. This debate warrants mention because the current bias towards quantitative methods has a bearing on the acceptability of studies of a more qualitative nature such as this one. It matters particularly when studies seek to shape or evaluate clinical practice and health policy in South Africa.[1]

PART I. QUALITATIVE RESEARCH

While qualitative research is used across disciplines, the divergence between quantitative and qualitative methods has its origins in the historical emergence of disciplines such as sociology and social anthropology – essentially, studies rooted in the 'social' *Strauss* (1987, p. 2). There are strengths to both quantitative and qualitative approaches and they often work synergistically. *Kuhn*, in describing the history of scientific progress, emphasises the interaction of qualitative and quantitative approaches: "large amounts of qualitative work have usually been prerequisite to fruitful quantification in the physical sciences" (1996, p. 162). Qualitative research

refers to research methods that use interpretive description rather than statistics to explore and analyse underlying meanings and patterns of social relations *Neumann* (2007). Qualitative research methods are generally agreed to be the most appropriate for gaining in-depth understanding of social and behavioural phenomena *Robson* (1993); *Strauss* (1987). This is because the dominant concern of qualitative research is with understanding and analysing meaning within particular social contexts. As *Baxter and Eyles* note: "We set out to learn to view the world of individuals or groups as they themselves see it" (1997, p. 506).

Qualitative research also allows for investigation of relational aspects between individuals and systems; persons and culture; and behaviour and social norms – making it particularly appropriate for a study like this, which explores the inter-dependence of health systems (including health personnel), with individual, behavioural, and psycho-social factors, as well as cultural norms *Robson* (1993); *Bailey* (1997).

Internal and External in Studies of Illness and Health

It is often the nature of one's experience within particular contexts that is so important to social scientists. For example, *Kleinman* suggests that "experience" is the flow of "everyday actions in a local world". The participants in a local world, he observes, "are absorbed in certain things that…matter greatly". Notes *Kleinman*: "At the level of social experience, the moral is defined by local processes concerning lived values that are at stake". But local worlds are not bounded entities, he emphasises. Local worlds are open to influences that include global social forces. And no matter how permeable, local worlds are the "grounds of human lives" (2004, pp. 269-270).

Similarly, in studies of health and illness, *Giacomini and Cook* assert that qualitative research offers "empirically based insights about social or personal experiences, which necessarily have a strongly subjective – but not less real – nature than biomedical phenomena" (2000, p. 358). Further complexity arises when a person's medical condition (as diagnosed), may not accord with her view of her own health. Anthropologists have investigated illness and health as an 'internal' perspective that is constructed by the person and not by the physician or 'external'. Such studies have introduced new insights into the connections between mind, body, and conceptions of illness and wellness. There is now a body of literature from medical anthropology critiquing biomedical approaches. It emphasises the weaknesses of the "natural science model of illness and healing" *Ware* (1992, p. 356). The ubiquitous *Sen*, speaking of the merits of an anthropological perspective on illness, puts his finger on the interconnection of the internal and external:

> "in getting a grip on what counts as illness, how it arises and how healing can be done, any kind of exclusive reliance on externally observed clinical symptoms and remedial connections cannot but be at least partly deceptive. If 'illness and pain are rooted in the person' then the kind of detached statistic on which economists and medical statisticians frequently rely may have to be very seriously supplemented by more involved scrutiny of how people comprehend and appreciate what is happening to them…and also the social influences that affect these realisations" (2004a, p. 265).

Sen points to the limitations of methods that fail to engage the views of participants who are the objects of study. There is, then, a "disciplinary contrast between the methodological inclinations of observation-oriented subjects (economics is a prime example of this) and perception-oriented studies (often favoured by anthropologists)" stresses *Sen*. He writes that the "choice is often determined somewhat arbitrarily but the relative simplicity of easily measurable statistics, which in this case take the form of data emerging from external observations. But that is not a good enough reason to opt in the direction" (2004a, pp. 263-264). *Sen* puts us right at the heart of the debate between quantitative and qualitative methods and the implications therein:

> "There are ways of 'getting at' perceptual information – questionnaires have been a mainstay of the social sciences for a long time – and the enterprise of information-gathering can certainly be redirected if the 'internal' view were to be established as being epistemically superior to external observations. The conceptual debate, thus, has major policy implications" (2004a, pp. 263-264).

Reflecting on this particular study, if I had relied solely on quantitative approaches, e.g., the number of people accessing PMTCT services, the number of people agreeing to test for HIV, the number of people who received PMTCT and ART, without considering factors that facilitate or impede access, provision and uptake – social, individual, systems and their interaction – the insights would have been far less rich. I should state that some of the early and major evaluations of PMTCT and barriers to children's access to ART nationally (and in sub-Saharan Africa more broadly) found in the literature review did take this approach. In hindsight, it was the perceptions of participants, the 'internal' and the 'local worlds' together with other information and insights into the health system gleaned from key informants, and the recorded medical history located in the patients' files, the 'external' – which when combined – allowed for a more textured, multi-layered understanding of the participants' experience of HIV, accessing treatment, and the health system as an enabler or inhibitor of good health.

The Role of the Researcher

In such studies where face to face interviews are conducted with participants, it is important to note that the researcher herself is a "positioned subject" *Rosaldo* (1989). With in-depth interviewing techniques that create an evolving dialogue with the interviewees, the researcher inevitably affects the interaction, note *Baxter and Eyles*. Because she is a participant in the conversation, reflexivity must continually be taking place: with the researcher reflecting on how and what she is doing, consciously considering how she is relating to the subject (1997, p. 506). The observer thus becomes part of the research process. While this has its own set of challenges, the strength of qualitative research is that it explicitly acknowledges and seeks to manage this dynamic.[2] Because of this tension, *Serrant-Green* emphasises that, again, researchers must constantly place themselves within the research, consider their role in the research process, and any effects their socialisation and life experience may have; this can include gender, race, class and language (2002, p. 33).[3]

Debates over Validity and Credibility in Qualitative Research

Importantly, *Angen* observes that there is still a great deal of debate over what it means to do "valid" research using qualitative methods. She points out that for a long time qualitative methods were accepted in certain fields only as preliminary results to be subjected to quantitative verification (2000, p. 378). Thus, qualitative approaches to inquiry were seen as exploratory ones that would undergo further validation through quantitative methods. *Baxter and Eyles* attest that 'rigour' in qualitative studies still means the satisfaction of the conventional criteria of "validity, reliability and objectivity within quantitative research" (1997, p. 506). *Cook and Campbell* define validity as the "best available approximation to the truth or falsity of a given inference, proposition or conclusion" (1979). For qualitative research, *Lincoln and Guba* employ the phrase "dependability" in qualitative research which closely corresponds to the notion of "reliability" in quantitative research (1985, p. 300). But *Golafshani* argues: "reliability, validity and triangulation, if they are relevant research concepts, particularly from a qualitative point of view, have to be redefined in order to reflect the multiple ways of establishing truth" (2003).

Angen is one of the most vocal critics of methodological approaches that force social scientists to adopt measures of validity that are accepted by quantitative methodologists. She states that, ultimately as researchers, what we want is to be sure that "we have done the right thing". We want to claim that because we have "made all the right moves" we have procured "*the truth"* (emphasis hers). However, she cautions that the

reality of life as we live it is characterised by fluidity and context and is relational. We must continually return to the essential question of what it means to do good qualitative research (2000, p. 380).

The locus of debate appears now to have shifted to how validity or credibility can be ensured and to the criteria for evaluating qualitative research. A number of authors have considered and written extensively about this question, some with a view to evaluating qualitative methods, ensuring validity, and identifying strategies for ensuring rigor in qualitative methods and analysis *Altheide and Johnson* (1994); *Guba and Lincoln* (1989; 1994); *Georgio* (1992); *Bernstein* (1985); *Gadamer* (1994); *Alcoff* (1994); *Creswell* (1988). *Baxter and Eyles* stress the importance of academic rigour: "we must not forget the general context of rigour around the principles of academic integrity, including responsibility and honesty. In their view, rigour concerns the extent to which a piece of research is "believable and hence worthy of attention" with a set of evaluative criteria serving as base principles to guide judgments about the integrity of a study (1997, p. 506).

Giacomini and Cook attest that there are four key aspects of qualitative analysis: participant selection must be justified and their inclusion must be relevant to the research question; data collection methods must be appropriate to the research goals and setting; the data collection process must be sufficiently comprehensive to support robust and thick descriptions of observed events; and, the data must be appropriately analysed with multiple sources of information, and member checking of findings for verification (2000, p. 357).[4] Indeed, across studies of qualitative research, there is agreement and convergence on the use of multiple sources of data and information to substantiate and verify claims and statements made. In line with questions concerning validity (or credibility), this research took due cognisance of and sought to address the key aspects of qualitative analysis identified: ensuring appropriate participant selection; rigour in data collection methods (using multiple sources of data with a view to generating thick and rich data); while ensuring robust data analysis; and member checking (by colleagues) for verification of results.

This section has traced some of the salient debates taking place among methodologists, particularly in studies of illness, health and health policy. My main objectives in this section have been: a) to recall the strengths of qualitative research and their application for the study; b) to observe that studies of health and illness have the dual dimensions and tensions of the external and the internal (and, to note that both are relevant for this particular study); c) to briefly highlight the challenges that need to be addressed when employing qualitative techniques, such as the researcher's role in the research;

and d) to point out that the South African debate intersects with international debates, no longer about the superiority of quantitative methods, but about the 'gold standard' for ensuring reliability in qualitative methods; and, this evolution in confidence over qualitative methods is occurring against a backdrop where quantitative methods in medicine and public health have had prominence.

In the next section I describe the methodological approach, design and techniques applied during the study. I explain the choice of target population and key informants; the type of sampling approach that I have employed and why it was been selected; I briefly explain the choice of research sites and highlight the procedures followed in conducting interviews and collecting data. Lastly, I review some of the main methodological and ethical problems that arose during the study and how I sought to resolve them appropriately, i.e., taking due cognisance of the sensitivity and confidentiality required in each instance.

PART II. THE STUDY

The empirical research sought to understand the primary set of barriers to HIV-infected children and pregnant women's access to healthcare; to uptake of antiretroviral medicines, particularly for women in the antenatal, delivery and postnatal period; to the enrolment of women in and uptake of the prevention of mother to child transmission programme; and, access to and provision of ARV prophylaxis (during PMTCT) and ART thereafter for children in the South African public health system. To refer to this whole system of health, I employ the phrase the 'continuum of care'.[5]

Design

To attain the study objective, it was agreed that the research would provide a snapshot of primary barriers identified in the two larger public health sites under investigation, with perceptions of women (patients and caregivers) forming the essential core of the field research.

Ethics Protocol

Conducting research and interviews with patients in a public health facility in South Africa requires ethics approval from a range of stakeholders, including the university with which the research is affiliated, the health facility involved, and the provincial government. The medical ethics application and protocol (including the

semi-structured questionnaires, e.g., the instrument, informed consent forms and doctoral study procedures) were constructed, reviewed and revised over a period of nine months in close consultation with Loveday Penn-Kekana, Peter Cleaton-Jones (head of the medical ethics committee) and colleagues from the Wits Centre for Health Policy.[6] Medical ethics approval and clearance by the University of the Witwatersrand Human Research Ethics Committee (medical) (required for any interviews conducted in hospital) was received on 8 February 2008 protocol number **M080119**. All interviews were conducted over the period March 2008 to February 2009.

Triangulation

The richness intrinsic to including context as a main part of the study signifies that one cannot rely on a single data collection method. It is triangulation or corroboration that results in an in-depth understanding and coherent picture of the research concern *Yin* (2003, p.4). Using mixed methods also enables the researcher to draw on different sources to validate the data – with a view to relying on alternate sources to test its reliability *Denzin and Lincoln* (1998). With this in mind, multiple methods and sources were used to investigate the research question. At the same time, compatibilities and discrepancies were documented and explored as they arose. These will be discussed further within the research findings (**Table 1** summarises the various data gathering techniques employed).

Case Studies

With the case study approach, I sought to understand one phenomenon in greater depth *McMillan and Schumacher* (2001). The use of bounded case studies can lend itself to rich data and in-depth analysis, allowing for the unearthing of detailed records of a few cases, rather than generating a thinner analysis of a larger sample *Yin* (2003) *Van Evera* (1997); *Cornwell* (1988). This is particularly important in development studies, where the social and economic context and location, which provide the complex concatenation of conditions in which development is rooted, is so critical. Two different geographic locations and socio-economic contexts, Gauteng and the Eastern Cape, allowed for this comparison to take place. My working assumption was that inhabitants in the more poorly-resourced Eastern Cape Province might face different barriers from urban dwellers within the city of Johannesburg in Gauteng Province; that perceptions of HIV/AIDS and treatment between the two groups might vary, as might the quality of PMTCT and ART service provision.[7] The sites thus became the locus of the study.

Table 1 Techniques Employed in Data Collection

Techniques	Actor or focus area	Number
Case Study Approach	Public health sites Number of facilities Primary healthcare clinic Public hospitals	2 4 1 3
Interviews		
With Patients based on semi-structured questionnaire	Pregnant or postnatal women: Johannesburg site Eastern Cape site	 60 23
With Primary Caregivers of HIV-infected Children	Johannesburg site Eastern Cape site	20 17
With Key Informants	Doctors, nurses, health professionals National department of health Provincial departments of health: Eastern Cape Gauteng	12 3 2 2
Tailored to knowledge of each group	Legal and advocacy organisations (AIDS Law Project) International-local NGOs, e.g., Gender and children's organisations University-based academics/doctors (Health and social policy/legal/medical with links to teaching hospitals): research agencies (Medical Research Council)	2 2 2 13
Total number of interviews conducted (actual)		**158**
Supplementary data-capturing tools		
Notes	Major and minor statements and aspects	
Audio recorder	Full record of interview	
Record of Interview (ROI)	Key issues, quotations, major statements and observations; Significant barriers identified to healthcare; PMTCT; ARVs (self-identified and observed)	
Coding	Identifying key themes/core categories as they emerge (through comparing notes with ROIs and memos	
Memoing	Notes to self done in parallel during data collection as ideas occur across interviews	
Medical records	Patients	
Other sources		
Review of literature	Journals, books, grey literature[8]	
Analysis of primary sources (key policy documents)	Dept of Health and Wits RHRU pamphlets and posters, legislation, white papers, policy or discussion papers, guidelines (PMTCT, infant feeding), yearly budgets and statistics	
Historical, social, economic context or other (strategy, policy) specific to each site	Case studies of a Johannesburg hospital	

The selection of sites was based on their differing peri-rural and urban locations and socio-economic contexts but similar HIV prevalence. The Eastern Cape is primarily a rural province: of a population of 6, 4 million, 70% are classified as poor and 30% of residents are unemployed; 93,6% of the population depends on the public healthcare system. In terms of racial composition, 87,5% of the Eastern Cape population is black (of African descent); 7,4% is coloured (of mixed race descent); 4,8% is white (European descent); and 0,3% is Indian (Asian descent). The HIV prevalence in the Eastern Cape is estimated at just over 30%. The population in Gauteng is estimated at 9,8 million; it is a highly urban and densely-populated province, capturing 20% of the total South African population, with an estimated 22,6% unemployment rate. It is also the richest province in South Africa. The HIV prevalence in Gauteng is estimated at 29,6%. *Eastern Cape Department of Health* (2008); *Health Systems Trust* (2008); *Statistics South Africa* (2000).

In terms of geographic location, the Eastern Cape site is located 400km from Durban on the southeast coast of South Africa, and approximately 230km from the city of East London. Roughly 20km west of the Eastern Cape research site is Qunu (very near the birthplace of former president Nelson Mandela). Johannesburg is the provincial capital of Gauteng Province; it is located in the northern part of South Africa: quite close to Botswana to the west and Swaziland to the east.

The rationale for not selecting rural-urban sites within the same province (e.g., looking at a similar demographics but with a rural-urban mix) is that the whole province of Gauteng is primarily urban (while the Eastern Cape is mainly rural). Essentially, one must compare inhabitants in different provinces to achieve this rural-urban perspective.

One *public hospital* was studied in central Johannesburg, which provided the whole array of HIV services at a single site: antenatal care including HIV testing, maternal delivery, postnatal care, paediatric care (including infant HIV testing), and ARV initiation for the mother and child – although points in the continuum of care were located in different wards (antenatal, postnatal, labour and paediatric wards). In contrast, in the Eastern Cape interviews were conducted at one *public health clinic* which provided antenatal care (ANC) and postnatal care (PNC) and the following HIV related services: HIV testing, counselling, treatment and provision of nevirapine as part of ANC (but did not deliver babies, test or treat infants). Interviews were also conducted at two *public hospitals* that performed maternal deliveries, conducted HIV testing and provided ART. Only one of the two hospitals performed HIV testing and provided paediatric HIV treatment and care. The two hospitals were linked, were on

the same grounds adjacent to one another, shared resources (such as a photocopier), and were managed by one CEO. The clinic was located roughly four kilometres from the two hospitals.

Qualitative Interviews

In the first part of this chapter, I explained the value of interviewing individuals to gauge their perceptions and experience, and linking the internal with the external. The choice of qualitative interviews with participants was also a response to a long-standing criticism that development studies often fails to create links between understanding and action. A partial reason for this, *Edwards* posits, is that researchers often divorce themselves from context by remaining in the realm of theory (1996). Face to face interviews were a way of seeking first hand knowledge. I conducted semi-structured in-depth interviews with HIV-infected women and caregivers of children living with HIV, and with two types of key informants. The interview schedule was adapted to each population group or type of key informant, accordingly (interview schedules are attached). Recruitment or inclusion criteria for interviews was developed at the outset and used primarily by HIV counsellors or nurses working in the clinic/ hospital who recruited the patients for the study (attached in appendices).

Population

The *unit of analysis* for the study was women (pregnant or postnatal) and children, while the *unit of observation* was the mother or primary caregiver (as the provider of care). Based on the literature, the assumption being made was that the particular symbiotic relationship between the mother and the child could increase understanding of the research problem, shedding fresh light on low treatment uptake and provision for HIV-infected women and children. To gauge the perceptions of participants vis-à-vis the continuum of care, there were two main populations groups studied.

Population Group 1 HIV-Infected Women Requiring Access to ART/PMTCT

Group 1A	A Public Hospital in Johannesburg: Pregnant or Postnatal
Group 1B	Two Eastern Cape Public Hospitals (one academic) and one Public Clinic: Pregnant or Postnatal

All of the women in groups 1A and 1B were HIV positive and either pregnant or postnatal. Most were indicated for antiretroviral treatment (but not all): the CD4 count (a measure

of immunity) of a small minority of women fell above the level indicated for treatment (a CD4 cell count of <200 cells/mm^3 is the qualifying number in most public health settings in South Africa). However, since they were HIV-infected, all women required access to the prevention of mother to child HIV transmission programme. All women, regardless of CD4 cell count, would have thus been indicated for ARV prophylaxis to prevent or reduce the risk of transmission of the human immunodeficiency virus to the child, and possibly triple combination antiretroviral therapy (I describe the components of this programme in great detail in chapters two and five).

Focus of Interviews

The emphasis was on primary barriers to accessing the continuum of care – the heath system/hospital/clinic, care, prevention, treatment and support. All interviews with participants took place in a hospital or clinic setting – either at the hospital site in Johannesburg (antenatal, postnatal or paediatric ward) or the two public hospitals (maternity wards) and one clinic in the Eastern Cape (a primary healthcare clinic accredited for ART provision).

Of the women who came to deliver at hospital, many had not previously been to the hospital for PMTCT or ANC. These women were generally 'unbooked' patients who show up to deliver. They are thus meant to receive an HIV test in labour or after labour, as well as receiving (or missing) the PMTCT interventions of nevirapine or AZT for herself and her child in the labour ward. Here the emphasis was on understanding the factors that prevented or delayed the women from accessing the health system, ARVs and PMTCT before delivery. Women were interviewed in the Eastern Cape postnatally (still in hospital, prior to discharge). The guiding questions for both groups were: *Why is access to and uptake of PMTCT for pregnant women who require treatment through the South African public health system so low? What are the primary barriers to access and uptake?*

Population Group 2 HIV-Infected Children Requiring Access to ART

Group 1A	Johannesburg Cohort: Children Requiring ARVs
Group 1B	Eastern Cape Hospitals Cohort: Children Requiring ARVs

The group studied comprised children from birth to 10 years of age living with HIV for whom treatment was indicated. Children were not interviewed due to ethical and other difficulties. Instead, a mother or primary caregiver (e.g., father, grandmother, aunt or foster parent) was interviewed.

The emphasis was on understanding the delay in HIV testing and treatment access, any problems accessing ARVs, and why PMTCT was missed entirely.

The guiding questions for this group were: *Why is access to and uptake of antiretroviral therapy for children who require treatment through the South African public health system so low? What are the primary barriers to access and uptake?*

In summary, the population groups were thus disaggregated into the following four groups.

Group 1A **One Hospital in JHB** Women: ANC or PNC Age range: 20-40 Sample size: 60	**Group 1B** **Two Hospitals/One Clinic in E Cape** Women: ANC or PNC Age range: 20-40 Sample size: 23
Group 2A **One Hospital in JHB** Children requiring ARVs Age range: 0-10 Sample size: 17	**Group 2B** **One Hospital in E Cape*** Children requiring ARVs Age range: 0-10 Sample size: 20

*Note: Only one hospital of the three facilities studied in the Eastern Cape offered HIV services for children.

Sampling - Participants

I worked with HIV counsellors to identify women and children who fit the recruitment profiles. Once the recruitment criteria were met, however, a random sampling technique was employed to minimise any biases involved in selecting participants. The process and procedures for informed consent were used in each instance. Semi-structured interviews were conducted with the target population groups in the facilities. In terms of the sample size, I had initially targeted at least 30 respondents in each category. However, due to the in-depth, intensive, and detailed nature of the responses, added to the fact that I was looking at the case history of each person interviewed, I revised that target, based on reaching a saturation point or convergence.[9]

Sampling - Key Informants

I selected purposive (or purposeful) sampling as the preferred strategy for selecting an appropriate sample of key informants, seeking answers to the research question from their perspective. Purposive sampling is said to be a useful method to increase the utility of information obtained from smaller samples. With this type of sampling, the researcher searches for information-rich key informants and research sites *McMillan and Schumacher* (2001, pp. 400-401). Purposive sampling was particularly useful in identifying and selecting those key informants with specialised expertise from people with varied views, disciplinary backgrounds and experiences.

Key informants were of two types: those who worked in or were attached to the sites under study; and those who worked in the fields of maternal and child health and HIV/AIDS treatment.

Key Informants Linked to Sites

Conversations with this group of interviewees focused on systems; structures and policies used in the hospital; procedures; the specific tasks of the interviewee (responsibilities and duties); their perception of their job; morale and motivation; training opportunities; key challenges; relationships with patients; views of patients; perceptions of barriers faced by women/caregivers in accessing ARVs and PMTCT; views of patients' health-seeking behaviour; views on stigma, support, disclosure vis-à-vis participants.

Key Informants with Specialised Knowledge

The focus was on looking at key indicators, i.e., changes in maternal and child mortality; the health system, staffing, expertise, data systems and management; policies and procedures; the objectives of policy documents and their execution, e.g., the revised PMTCT guidelines and the NSP; challenges to PMTCT and ART uptake by the population groups; and possible explanatory factors: individual barriers; social and cultural norms; health systems, policies and structures.

The following information was gathered in the interviews with participants.

Table 2 Perceptions by Pregnant Women or Primary Caregivers vis-à-vis Selected Indicators

Psychological	- Fear - Lack of trust in doctor/healthcare worker - Stigma - Shame - Anxiety - Depression
Social/Community	- Lack of acceptability - Stigma
Norms/Culture/Religion/ Beliefs/Values	- Conflict with Personal Beliefs - Conflict with Religious Beliefs - Conflict with Political Beliefs - Conflict with Cultural Practices - Conflict with Family Advice
Economic	- Transport unaffordable - Taking time off from work - Other
Political	- Foreigner/refugee status - Other
Legal	- Lacking identity documents - Other
Structural	*Institutional* - Availability of HIV Testing at Facility - Availability (Stocking and Supply) of ARV drugs for Pregnant Women - Availability (Stocking and Supply) of ARVs for Children - Availability of Health Professionals - Availability of HIV Counselling Staff - Concern over Protection of Patient Confidentiality - Quality of Services Rendered - Quality of HIV Counselling - Quality of Infant Feeding Counselling - Fairness of Health Staff - Training of Staff in PMTCT - Training of Staff in Paediatric AIDS Management

Outline of Procedures and Interview Practices: Johannesburg

Interviews with Patients

At the Johannesburg facility, interviews with women receiving antenatal and postnatal care took place from March through September 2008 (antenatal and postnatal clinics), which were staffed by the DoH, with the Wits Reproductive Health and HIV Research Unit (RHRU) providing staff to support to the clinics. Caregivers of HIV-infected children were interviewed in the paediatric ward in the same facility from September 2008 to February 2009.

A separate room was made available for the interviews. Two lay HIV counsellors recruited patients according to the recruitment profiles in the antenatal and postnatal clinics; one lay HIV counsellor assisted in the paediatric ward. I had a translator available the majority of the time in case the interviewee could not speak English well.[10] To each potential participant, my colleagues (who translated) and I explained the purpose of the study and asked for her consent to participate. If the interviewee appeared at all uncomfortable or doubtful we told her that it was okay not to speak with us (essentially giving them permission to leave). It was the case sometimes that the interview would begin in English and we would quickly ascertain that the communication was not optimal. We would then revert to Xhosa or Zulu (the two languages most commonly spoken by patients at the Johannesburg facility), depending on the preference of the interviewee.

Outline of Procedures and Interview Practices: Eastern Cape

Interviews were conducted over the month of October 2008. The same procedures were followed in the Eastern Cape with the following exceptions. There were three facilities involved in the study: Two public hospitals and a primary healthcare clinic. The rationale for having three facilities was as follows. Unlike Johannesburg hospitals, in the Eastern Cape, women would go to hospital solely to deliver their babies. They would not generally receive ANC or postnatal care in hospital. PMTCT would generally take place in the labour wards of hospitals. Thus, to learn whether women had been initiated onto ARVs and received a single dose tablet of nevirapine, the best place to interview women was in the hospitals. However, to understand if women had been tested, counselled and initiated onto ARVs during antenatal care, it was necessary to look further downstream, to the clinics.

In the two Eastern Cape hospitals, the paediatric and maternal wards were the sites for interviewing patients. We interviewed caregivers while they were waiting to be seen by a doctor: these were individuals who were coming to hospital for routine management of HIV for their children; almost all of whom were on ART. We interviewed pregnant and postnatal women in the maternity wards (pre and post labour), and sometimes in a separate room if they had not yet delivered (in the office of the ward nurse responsible for HIV/AIDS). (We declined to interview women when their privacy could not be assured.) In each of the two hospitals there was one dedicated nurse for HIV and PMTCT services: these two nurses were the only individuals who provided HIV testing and counselling to all patients at this facility; and they took responsibility for the PMTCT programme at each hospital. These individuals also recruited patients for us.

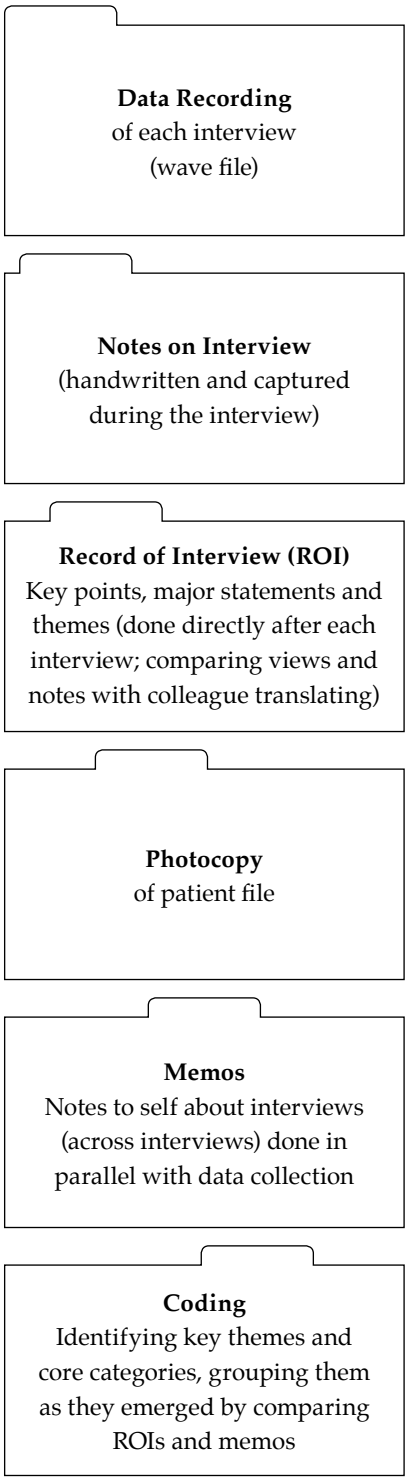
As a way of thanking all participants for their time and insights, each person received either a muffin or a sandwich at the end of the interview. They were not offered anything upfront so the food did not serve as an incentive to participate and there were no other direct benefits. The length of the interview ranged from 20 minutes to one hour and 25 minutes.

All interviews were taped, as long as consent was received (the consent form had separate approval sheets to be interviewed; taped; and to access the patient's file). In a number of instances, participants agreed to be interviewed but did not want to be taped. This was obviously respected. Interviews were recorded using an audio recorder device; and the files were transferred onto my laptop as sound (wave) files that could be stored and listened to again. At the same time, detailed notes were made by the translators and me. As previously noted, I received most of the translating assistance from a colleague employed by a fieldworker agency, Pumla; with additional translation assistance from Siphamandla in Johannesburg and Lwash in the Eastern Cape.

After each interview, the translator and I sat with our respective notes and I typed up the 'record of the interview' (ROI). This was a summary snapshot of information gathered. Putting this together based on our immediate memory and notes directly after the interview assisted in retaining key information. We also recorded information and compared our own views of the honesty and candour of each participant, i.e., was the interviewee being frank? Did we think the information was truthful? We noted the content of what was said, highlighting particular aspects, such as key barriers that were self-identified, and those we were able to identify, as well as central aspects such as stigma, disclosure, support, access to ARVs, access to PMTCT and quality of HIV counselling. In addition, I made notes of contradictory statements.

Alongside the interviews, the files of patients were photocopied and key data were recorded, such as socioeconomic and demographic data (income, access to electricity, piped water and flush toilet), using the patient's journey from the starting point through the points in the continuum of care, to track barriers as they occurred (elaborated in chapter five).

Table 3 Data Capturing and Organisation



Across the interviews, drawing on grounded theory, I coded key themes and core categories, recording them as they emerged – comparing my notes with the ROIs and memos. The memos were notes that I wrote in parallel during the data collection. (These were ideas and questions that would occur to me across interviews.) I also made memos about any relationships or links across categories. Data captured and gathered from each participant included the voice recording of the interview, handwritten notes on the interview, the typed ROI based on my notes, memory and my colleagues' – after each interview. Patient files were photocopied and a typed summary of the important aspects of the individual's health, history, treatment and care in hospital and related information was recorded. The methods for capturing, organizing, grouping of data and information were informed by a range of primarily qualitative sources *Strauss and Corbin* (1990; 1997); *Baxter and Eyles* (1997); *Charmaz* (1999); *Strauss* (1987); *Denzin and Lincoln* (1998); *Altheide and Johnson* (1994); *Hammersley* (1995).[11]

Study Limitations

There is a range of limitations in the study design and execution. The study took place in two provinces. Thus, the perceptions and information

gathered reflect issues that were specific to these facilities at the time of the study, and to participants in either the Eastern Cape or Gauteng seeking prevention, care and treatment at those facilities. The social-demographics thus reflected the populations living in those areas (and not, for example, deep rural communities).

Another limitation was my possible distance (women of a different race, nationality, language and class) from respondents. At the same time, the in-hospital nature of many of the interviews may have leant a bias to responses – e.g., women or caregivers might have been fearful of poor treatment from the hospital or might downplay negative experiences (even though the information sheet explicitly stated that I was not affiliated with the hospital and their care and treatment would not be affected). Another consideration of in-hospital interviews is what *Penn-Kekana* calls the 'halo effect' – women who have recently delivered are so joyful about the recent birth that they minimise negative issues or experiences. In my interviews, however, I found little or no halo effect. This might be attributed to the very real circumstances women faced: their HIV status, poverty, other health risks, fear for the health of their baby, and the accompanying effects of such anxiety on their psychological state.

While I chose to study two population groups, in the main, women's perceptions and experiences are the dominant emphasis – rather than those of children. This was a deliberate decision made to circumscribe the scope of the study, while giving some insight into barriers to PMTCT/ART for children. Barriers facing children and their caregivers could have occupied the sole focus of this study. They did not. This poses a limitation when there is so little social research on children with HIV.

In the end, I was able to gain knowledge of barriers facing children – an essential aspect of barriers to preventing and treating children with HIV – because I interviewed women and caregivers with HIV-infected children in the postnatal and paediatric wards; identifying those missed opportunities for PMTCT/ART services for children. Yet it was only by interviewing women in the ANC and labour wards that I came to grips with the barriers to PMTCT/ART facing women. These population groups are entirely linked. The focus on the mother-child dyad and journey through the continuum of care thus proved to be the appropriate lens: for it generated genuine insight and clarity into the choices and constraints of mothers, which inevitably impact on their infants. The urban/rural comparison also proved useful, allowing for exploration of questions of equity. But the mother-child dyad and rural/urban approaches resulted in a complex study – with a large number of interviews undertaken in four facilities (in different wards) at two sites (in different parts of the country). Staying true to the research design was ambitious – perhaps too ambitious for a doctoral study.

What I gained in widening the lens – viewing the trajectory of the patient's journey through the care continuum – I lost in probing the depth of individual experience.

Methodological Challenges

The deployment of a rigorous methodological approach depends in part on gaining access to research sites and key informants. It is often assumed that the researcher will be able to obtain access to patients – many of whom who are ill. And, there is an assumption that the researcher will achieve the ideal sample composition and size. However, this is sometimes equivalent to leaping over the moon.

A main impediment involved getting access to the proposed clinics, and gaining provincial DoH approval for the study in Gauteng, and in the Eastern Cape. At one stage, I had no site (let alone two) and no prospect of a site in the near future. This was a reflection of the overwhelming demands on health personnel in the public sector: their time and energy is overtaxed. Health personnel and officials are not usually keen to spend time with a researcher who is submitting their facility to the scrutiny of research. With assistance by Loveday Penn-Kekana and others,[12] and through multiple communications with stakeholders in the health sector, this hurdle was eventually overcome and sites were secured. In the Eastern Cape I struggled to gain interviews with doctors and nurses where the facilities were extremely short-staffed and existing staff overloaded.

Gaining access to interviews with key informants from the departments of provincial and national health was also challenging. Another problem, which is not unique to this study, was language. I employed the translation skills and acumen of primarily one, but at times three, fieldworkers who spoke multiple South African languages. This helped to obviate some problems posed by language. At the same time, any discussion taking place in another language not known to the researcher (even if present) may preclude the ability of that researcher to hear and understand comments made directly; to ask the follow up questions at the moment they should be asked; and to probe, as necessary. Early on, this came out in the summary ROI, where I found that key information was not solicited from the interviewee. For instance, Pumla (the translator) would say, "and then she said I am eligible for ARVs but not on treatment yet". And I would say to Pumla, "So, did you probe and ask her why she is not yet on treatment?" Pumla would say (sheepishly) "No. I forgot to ask why". Due to this, I began insisting on immediate translation into English so that I could participate in the interview. At times, there was simply so much complexity around the woman's status, the steps she had taken, and confusion around the timeline and visits to three or so clinics, that we spent a great deal of time trying to piece together what had happened.

Following lengthy conversations, we would go to the patient file to try and fill in the missing pieces where the information was absent. Indeed, finding files and collecting standard information from the files proved to be difficult at times. In the Eastern Cape we battled to photocopy patient files; and files were extremely thin at those facilities because patients often move between facilities (e.g., hospitals and clinics) and tend to carry their own records. In Johannesburg, in contrast, even if patients are referred out, they retain their ANC or 'road to health' card, and a sizeable patient file remains in the hospital (in the Western Cape, for example, patients do not hold onto their own files).

Sometimes there was no file for the patient. At times crucial information was missing – e.g., whether HIV counselling had been provided; whether the patient had received PMTCT; whether the patient had been initiated onto ARVs; last CD4 cell count; HIV status of the baby well after six weeks post-delivery (when the baby should have been tested for HIV, and the information recorded).

Added to this, the photocopier was out of order in the two Eastern Cape hospitals during our entire visit except for the first day. The clinic in the Eastern Cape had no photocopier. (It is illegal to take patient files off-site to record information or copy them elsewhere.) As a consequence, in the Eastern Cape I was left with very large gaps in information regarding the patient's health history. While this provides insight into health systems, from a research perspective it was very frustrating when the aim was to try and understand their experience against what was recorded in the file – and to pinpoint what seemed to have gone wrong when PMTCT/ART interventions were missed at multiple points.

At the Johannesburg facility a common problem arose in the beginning leading to my discarding about 10 patients and conducting an additional 10 interviews there. Patients would tell me their "English" name and they would write it on the consent form. This was perhaps because I spoke with them in English (and I am a white woman). But when I went to the files, I found that their names were recorded using their "African" name. I thus only had their surname to go on, and there were people with very common surnames and I wasn't able to identify the person I had interviewed with total certainty. After that, I made adjustments accordingly.

In addition, as *Mouton* observes, a distinctive feature attached to social science research is that participants are aware that they are "objects" of investigation and tend to react to this accordingly; a phenomenon commonly known as reactivity. Individuals may become resistant, apathetic or may deliberately misinform the researcher. They may embellish or hide the truth based on what they think the interviewer wants to hear.

Reactivity can become the single greatest threat to the validity of the research findings – if human behaviour and interaction are central to the research, as they were here (1996, pp. 146-147). I was aware of these problems and sought to resolve them through the reflexivity discussed earlier – and by discussing with the colleague translating about the veracity of the person's statements; how honest and forthcoming was the person? Having a translator and colleague participate in the interviews may also have helped reduce a strong one to one relationship with the interviewee, which could also have assisted in reducing the phenomenon of social desirability or reactivity.

At the same time, the translators also introduced another dynamic, as they had her own personality, race (black), dominant language (Xhosa and Zulu speakers), class (middle and lower), gender (two females and one male)[13] and his or her own interpretation of the interviewee's responses.[14] One of the most important aspects of the study was the range of ethical questions and dilemmas that inevitably arose and had to be carefully managed.

Ethical Considerations

Whenever human subjects are the objects of study, there are numerous ethical concerns to be addressed. This is a common dilemma in social research. Most research methodology experts note that the possible risk of participants feeling like a means to an end is balanced by the benefits associated with understanding the needs of the target population group more broadly. Some researchers note that open discussion and negotiation can promote fairness to the individuals involved in the research. And, that this knowledge can empower participants in the interview setting *McMillan and Schumacher* (2001, pp. 421-422).

All individuals interviewed were informed of the study and its purpose, and asked for their written consent. Only those who felt comfortable and consented to be interviewed were interviewed. Beyond those clearances, ethical questions arose. They revolved mainly around the axis of access to care and treatment; and the exchange between the individual and health personnel – exactly the point of the study.

The interviews were based on the explicit understanding that all that passed between us was confidential. During the interviews it became clear that several participants had not received sufficient HIV counselling, if any. Some women appeared to be depressed; while a few others had not received crucial information that would allow them to take particular steps to improve their health, for example, having a CD4 cell count taken to determine eligibility for ART.

A few women had received the results of their HIV tests (usually at a different public health facility) but had received no counselling, information or support, or counselling on infant feeding. My agreement with the facility was that if I came across patients in need of treatment or counselling/support who had not received it, I would engage the services of an HIV counsellor or doctor, depending on the needs of the patient. In each instance – as agreed – I asked the participant if she would like to speak with a HIV counsellor or social worker; and, if so, whether I could introduce them. I then found the social worker or HIV counsellor at each site directly, and asked them to speak to the patient. But, unfortunately, this was not always easy or straightforward (as discussed later here and in chapter five).

Another ethical complication arose in the Eastern Cape because in many locations in South Africa, due to the chronic shortage of hospital beds, a woman who delivers in a public hospital is only kept in the ward for six hours on average post-delivery unless there is a major complication. Effectively, to interview postnatal women in hospital (before discharge at 10am the next morning), we had to conduct interviews quite soon after they had delivered. We were thus interviewing women in their hospital gowns at their bedside prior to their departure to go home. Not only were these women vulnerable (having just delivered), they might have thought they needed to acquiesce to an interview as a condition of their departure – an assumption we worked very hard to dispel at the beginning of the interview. The nurses in the Eastern Cape hospitals were selecting and advising us on which women had delivered and whom we could interview. In about three instances, a nurse wanted us to interview women who were in visible pain. We delicately but firmly refused (one woman had a sizable pool of blood next to her bed). In another instance, we were told to interview a woman but there was a patient in the bed right next to her and we could not guarantee her confidentiality during the interview, so we declined to interview her. We interviewed a smaller sample as a result, selecting women who appeared strong in body and mind, not in visible pain, coherent, and willing to speak with us.

In another instance in Johannesburg (one of the more confusing situations), a woman had received a negative HIV test roughly one month before she delivered her baby. While in labour she was told she was HIV positive and given ARV prophylaxis at regular intervals, in keeping with PMTCT guidelines. The baby was also given ARV prophylaxis, and the woman was encouraged to formula, as opposed to breast, feed. However, because the woman received a negative HIV test so close to her delivery date, and she seemed not to recall any details of taking a second HIV test in the labour ward, she was convinced that she was actually HIV negative.

The woman also revealed in the interview that she had elected to formula feed but that she was mixing breastfeeding with formula feeding – thereby increasing the risk of transmitting HIV to the child (if she were indeed HIV positive). There was nothing in the file to indicate when and where she had tested positive for HIV. Thus – either this information was missing in the file and the patient had seroconverted and not received any counselling – or health personnel had mistakenly given her and her child ARV prophylaxis when she was really HIV negative.

Based on this confusing situation and the woman's poor mental state, after gaining her verbal consent, we connected her to resources within the hospital: testing, treatment and support. After speaking with the doctor and reviewing her story against the file, I told the woman that she would need another test to determine her status and that she would need to speak to the doctor and undergo counselling. I also mentioned that mixed feeding was not advisable – that mixing formula feed with breastfeeding would undermine some of the benefits of breastfeeding, and would increase the risk of HIV transmission to the child. I asked her if she would speak to the HIV counsellor, and the doctor and social worker on-site. She agreed. The course of action was to seek consent to test the woman, using rapid HIV testing to determine her status (which was positive in the end); to provide her with counselling, information and support around her HIV status; and, to discuss and assess her ability to formula feed. This particular case raised questions around proper capturing of information in the file; denial of HIV status; and the very real possibilities of seroconversion in pregnancy; and effective communication with the patient.

Linking patients to HIV counsellors became much harder in the Eastern Cape as there was an acute shortage of health staff. We could only indicate patients who required additional psycho-social and mental health support (often, the little counselling they had received was not enough), suggest, plead, wait, and hope for the best. There was one instance in the Eastern Cape where we interviewed a 19 year old woman in the maternity ward who had delivered the day before. She told us that she had only learned of her HIV positive status because the words "reactive" were written on her antenatal card. (Part of the HIV coding system where "non-reactive" indicated HIV negative; reactive indicated HIV positive.)

Someone had taken blood from her while she was pregnant but they had never informed her of her HIV test result, nor had they given her pre or post test counselling. Pumla and I stood there wordlessly for a moment, absorbing the information. We then queried this several times to be certain. We asked if we could organise HIV counselling for her (Pumla is trained as a psychologist and an HIV counsellor – and

could have provided some counselling there and then). The woman refused. We asked in a different way, e.g., can we give you some information on treatment and support? Again she refused. She told us in the interview that her mother made the decisions about her health, and we encouraged her to tell her mother that HIV counselling would provide her (the mother) with information that might be beneficial to her (the daughter) and to the baby. And, would she perhaps consider sharing this information with her mother? If so, could she consider returning to her local clinic with her mother to ask for counselling? To this, she agreed. Whether she would act on it was another question altogether. This experience was eye-opening. By this time I had conducted over 80 interviews with women living with HIV who were either pregnant or postnatal. This was the first time I had come across such fierce denial. It revealed that individuals sometimes use denial as a shield of perceived protection to hide behind while they continue to grapple with the reality of their status. Ultimately, it was the woman's choice to accept her status and seek support. We could offer her information outlets but it was up to her to take them. Frustrating as it was to us, we had to stand down (while offering possible resources should she choose to use them).

In sum, in these cases, in addition to the use of ethical guidelines and personal awareness and sensitivity to possible ethical dilemmas, I – on certain occasions – felt an ethical obligation to ensure the woman or caregiver who needed counselling, treatment or testing, would gain access without delay. Normally I consulted colleagues (doctors or staff members) in the clinics who had the needed experience in the area of concern – working closely with the translators to separate opinion and fact. In some cases, Pumla and I made decisions according to our own conscience when we felt the nurses were asking us to compromise our own ethics (interestingly, there were never doctors around during these key dilemmas in the Eastern Cape). Even though I generally felt that we had fulfilled our ethical obligation to these women and to the health facility that was hosting us – it was not much consolation – especially in the Eastern Cape. I felt that the female patients in the maternity and labour wards were often treated by health staff as objects and not people. These women – their faces and stories – stayed with me. In Johannesburg I was usually able to check the files and learn the outcome of HIV tests or queries about ART access. In the Eastern Cape, however, women were released rapidly and referred to their nearest local clinic. Thus it was not possible to trace them.

In closing this methodology chapter, on reflection, speaking with pregnant or postnatal women with HIV/AIDS is social research at its most intimate and complex. The reality of this kind of investigation is that, as researchers, we often move into a

sphere that we may not ourselves inhabit. This project took me into the public health system and into confidential conversations with black South African women: all of whom were HIV positive; most were poor. For better or worse, I was not an insider-researcher with deep knowledge of the black South African community – this was not my community. In these situations where we are perceived as an 'other', we draw on our common humanity to construct a bridge that will transport us past differences in language, culture and experience to a safe place – where time, place, urgency, the hurly burly of life are almost suspended. My colleagues (who translated) and I worked to create this space for the women we interviewed to speak freely. While they spoke, we wanted these women to feel that time was standing still. That nothing was more important than their story in that moment.

HIV is becoming a chronic condition in this country and there are glimmers of that reality. But for many it remains a stigmatised illness. Thus, sharing one's health status and personal experiences with strangers on the other side of a table in a hospital or clinic remains an untold act of trust. This compact creates an awesome responsibility on the part of researchers, as we are forced to make sense of seemingly incomprehensible realities.

Interviewing became an invitation, a dance to be executed with care, with deft skill. It was a process of empathic listening, probing, clarifying, and speaking when necessary, while holding that person's story (her journey) gingerly in your hand. Much like the way you would hold a butterfly that alights on your open palm. As a result, as researchers were not inert objects sitting on chairs like slabs of stone. As *Paul Klee* said: "One eye sees, the other feels" (1986).

At times, I felt like the only thing I could do – we could do – was to remain present: to bear witness. You cannot do this kind of research and not be changed by it – after speaking with a woman who tells you that this is her fourth child. She had three other children who died (stillbirths and a drowning), and she is hoping, as she pats her pregnant tummy, that this one will 'make it'. You see the indomitable strength of the woman who is holding up her tiny baby with HIV, lavishing affection on him as she tells you that he has survived four hospital admissions for TB, pneumonia and three blood transfusions – all before he was nine months of age. Or the pregnant woman who shares with you, her voice low and issuing from a place of sorrow, that she has already had two miscarriages at the age of 23. Her parents told her, she says with her voice trembling, this time – if the baby dies – she must bury the child with her own hands.

A question – "how are you dealing with your positive HIV status now" often prompted genuine reflection and pouring forth of emotion. At these moments, we could not help but shed tears in solidarity. (As a rule, we made sure to bring tissues with us to each interview.) The participants were often very willing to reflect on their experiences. In many cases they had not disclosed their status to another soul. The conversation became an opportunity to communicate what they were thinking and feeling; their worries and coping strategies. We were able to share the good news: when the participant's baby was given a PCR test and determined to be HIV negative, for instance, the mother would generally beam. We could not keep ourselves from saying "Congratulations!" as we heaved a huge sigh of relief: another HIV infection averted. In terms of the lows, there were too many to recount.

I have never felt more honoured by the trust the participants placed in me when they unburdened themselves on complex and highly sensitive issues surrounding their health and HIV status. The courage of these women in addressing an array of challenges injected new inspiration and hope into the study. That the majority of women unfolded themselves in front of our eyes and ears was a testament to their faith in us, or to the research project. Whatever the case, we, like health professionals, were allowed behind a curtain that is normally drawn. I cannot stress enough how profound a privilege it was.

Conclusion

The first half of this chapter identified a number of central debates taking place among methodologists in relation to studies of illness, health and health policy. I took care to note the evolution in qualitative techniques and the growing confidence in qualitative methodology by researchers. I underscored the dominance of quantitative methods in studies of public health and medicine in South Africa, observing that the South African debate vis-à-vis qualitative research, like the international one, revolves around the 'gold standard' for ensuring reliability in qualitative methods. I articulated the particular strengths of qualitative research and its applicability for a study such as this one. And I discussed the challenges to be addressed in employing qualitative techniques. In the second half of the chapter I presented the methodological approach, design and techniques utilised in the study. I reviewed the choice of target population and key informants; sampling approach elected and the rationale for its selection; and explained the choice of research sites. I also outlined the procedures followed in conducting interviews and collecting data. Lastly, I discussed the range of methodological and ethical challenges arising during the study, while explaining my actions to resolve them. The next chapter presents the findings of the empirical research.

Endnotes

1 For example, improvements to the prevention of mother to child transmission programme (PMTCT), i.e., the introduction of dual therapy to replace single dose nevirapine and changes in recommendations surrounding infant feeding practices were based on clinical studies, without considering the acceptability of formula feeding, for example. In the revised PMTCT guidelines, the exact studies reviewed by officials within the South African Department of Health are noted (see Section H: 'Some Cited Evidence' Annex to *Government of South Africa* (2008a, see pp. 77-80)).

2 On this challenge, an honest and thoughtful reflection comes from *C Wright Mills*: "It is best to begin, I think, by reminding you, the beginning student, that the most admirable thinkers within the scholarly community you have chosen to join do not split their work from their lives. They seem to take both too seriously to allow such dissociation, and they want to use each for the enrichment of the other. Scholarship is a choice of how to live as well as a choice of career; whether aware of it or not, the intellectual worker forms his or her own self in working toward the perfection of craft; to realize personal potentialities, and any opportunities that come his or her way, such a person constructs a character which has as its core the qualities of the good workman. What this means is that you must learn to use your life experience in your intellectual work: continually to examine and interpret it. In this sense craftsmanship is the center of yourself and you are personally involved in every intellectual product upon which you may work. To say that you can 'have experience' means, for one thing, that your past plays into and affects your present, and that it defines your capacity for future experience. As a social scientist, you have to control this rather elaborate interplay, to capture what you experience and sort it out; only in this way can you hope to use it to guide and test your reflection, and in the process shape yourself as an intellectual craftsman" (1959).

3 See *Serrant-Green* for a discussion on the debate, benefits and drawbacks of having insider status as a researcher researching one's own community (2002).

4 For *Baxter and Eyles*, assessing qualitative research methods also necessitates the formulation of criteria such as credibility; transferability; dependability; and confirmability (1997, p. 512).

5 It also refers to a comprehensive, integrated approach to healthcare whereby the patient is able to access different types and points of care in a seamless way *Stevens* (2008a-b). This is discussed in greater detail in chapter five.

6 This included Bronwyn Harris, a fellow doctoral student at the Centre for Health Policy (CHP) (Wits), who was also putting forward a large ethics application for CHP researchers at the same time, and was extremely helpful. I also thank Prof Johann Mouton for his insightful and comprehensive comments on this chapter; and, I thank Dr Glenda Gray and James McIntyre (Perinatal HIV Research Unit, Wits) for their insights related to the design of the study.

7 I address differences between rural and urban populations in chapter five.

8 For example, evaluation of PMTCT sites and programmes in South Africa; and, assessments of ART and VCT uptake.

9 The actual number of interviews conducted in the end was large: too large. I suffered from data and information overload. One could argue that this is part of the learning process, and the only way to learn (how many interviews are too many) is by doing.

10 There were occasions when the translator was unavailable to join me and I would conduct interviews only with strong English-speakers.

11 And by a qualitative research methodology course I took from 25 to 28 March at the Wits Medical School, given by Prof John Eyles, McMaster University, Canada and Honorary Professor, University of the Witwatersrand.

12 Loveday Penn-Kekana was a co-supervisor on this thesis, who had to drop out due to ill health. Penn-Kekana's work in South Africa is well known, and she is published widely in the fields of maternal health, HIV/AIDS, intimate partner violence and rape. I owe her a debt of gratitude for her support, interest and expertise, particularly on developing the ethics protocol.

13 One of the translators, Siphamandla, was male. We asked the patients if they were uncomfortable speaking with him, and no one was. This individual had the personal sensitivity and care that seemed to put female patients at ease. He also held a Bachelor of Science degree in medicine, coupled with a great curiosity, which assisted in understanding patients' clinical symptoms and their experience of the health system.

14 When I first arrived in the Eastern Cape I was told a disturbing anecdote by a researcher and a registered nurse. She had provided translation for an American researcher during the course of interviews. When the researcher (from the Eastern Cape) interviewed the participants in Xhosa, they would explain their experience with the health system and they would say "But don't tell the white woman that!" After hearing this, I was very worried I might face the same difficulty. I told the translators to be aware of this but thankfully it did not happen.

Chapter 5

The Patient's Journey: Identifying Missed Opportunities for Preventing HIV in Children and Treating HIV in Pregnant Women in South Africa

All of the 83 women interviewed in this study had in common their HIV positive status, their current or recent pregnancy, and an experience of the health system and continuum of care. Not only did they have to manage their own HIV status but they had to make decisions in pregnancy (or thereafter) that would impact on the child's health and HIV status. During the conversations, each woman shared her response to her HIV positive status and her efforts to accommodate that reality: including whether she chose to deny, keep secret, or disclose her status to a partner, family or friend. Each woman had her own reaction and response; she chose how to address her new reality by taking certain steps to manage her health and the health of her foetus or infant; choosing not to take action; or, choosing to delay action. Although easy generalisations could not be made, there were recurring themes expressed by women in the interviews. Below I present two experiences of these women's journeys through the health system, constructed from common conversations, held at both research sites. These accounts are fictional though representative of each of the sites, with descriptions taken from patients' stories and central themes (heard throughout the interviews) woven through each story.

PART I. THE PATIENT'S JOURNEY THROUGH THE CONTINUUM OF CARE: THE INTERNAL

Patient A. An Academic Public Hospital in Urban Johannesburg, Gauteng Province

Thembi rises at 5am to get ready for the journey to hospital. She washes, eats, tidies the small shack that she shares with her partner and his family, and walks the 300 metres to the taxi rank. She prepares to squeeze herself into the perpetually overcrowded Volkswagen mini-bus taxi. Thembi leaves early because she lives about 20 km from town and gridlock begins just after 7am in Johannesburg. She knows that the other pregnant ladies will begin queuing in the antenatal care (ANC) ward of the hospital at around 7am. First in, first out. She has gone for ANC previously, and she usually waits several hours to see the doctor. She is anxious because, although this is her second baby (her first baby stays with her mother in KwaZulu-Natal Province),

she has tested positive for HIV. So far, she has told no one about her HIV status. Only the HIV counsellor and the doctor know that she is living with a virus. Her partner, Siyabonga (his name means 'thank you'), does not know. To dip her toe in the water, she asked him recently if he has had an HIV test and he shook his head no, saying: "Too much of judging".

Thembi's brow is furrowed with worry. She is afraid her baby will contract this HIV and she is worried that if Siyabonga finds out about her HIV positive status he will leave her. She has no job and a standard four (sixth grade) education. She is fully financially dependent on Siyabonga and his brother. She is not sure where she and her baby would live. Before she fell pregnant she earned some income making and selling beads but now that she is almost eight months pregnant she has stopped working. During her first appointment (at seven months), she received the HIV test and some counselling but it was hard to keep all of the information straight. They said something about feeding the baby with formula but her head was pounding with the idea that she is now one of those people that other people talk about. Suddenly there was not enough air in the room and she felt like her heart was going to explode in her chest. The HIV counsellor told her to relax and take slow breaths. The counsellor made her feel that it was going to be okay. Thembi kept thinking of a TV programme where the main character reacted to her HIV positive status. Watching the programme, Thembi was so grateful that she was not that actress. But this time it was her on the receiving end of the news. On the soapie they talked about HIV and treatment – about living positively with HIV. She knows that today one does not have to become a thin stick and vanish into dust – that one can live with this disease. But her heart is still sore and she is frightened about what the future holds. She received a nevirapine pill from the hospital with instructions to take it when she goes into labour. She understands that this nevirapine is supposed to help protect the baby from HIV. She carries it with her everywhere. What Thembi wants most is for her baby to be HIV free and healthy. In dark moments she prays that if it is too late for her, so be it, but don't let her baby suffer.

She is wondering if she will be taking that *umuthi* (medicine) that everyone says is like magic. They call the pills 'sweets' at hospital. "Did you get your sweets?" she overheard a counsellor ask. Her cousin who used to look like a frail silhouette has taken those ARVs and now she is strong, healthy. Thembi has no problem taking those pills. She wants to save her baby and stay alive. At hospital Thembi had a test taken during her first visit. They called it her 'CD4' test. That test, the counsellor told her, will determine whether she is eligible to go on treatment. She will find out the results today. She was booked for an appointment two weeks ago but because of the expensive taxi fare from Soweto she didn't have the money and had to make another appointment.

(That woman at the hospital was so cross she had missed her appointment: she had given her an earful.) The taxi rocks up to the hospital entrance and Thembi crawls past the other passengers to get out. She takes out her blue antenatal card, walking noiselessly past the mean-looking security guard to the antenatal ward.

Thembi will not get the results of her CD4 cell test back today. There appears to be a shortage of lay HIV counsellors at the hospital. After waiting two hours, she receives an examination by a kind, white lady doctor who tells her that they must continue to monitor her hypertension. And the results of her CD4 cell count test are not available ("where are they?" Thembi thinks). She admires the doctor's care in explaining things. The doctor looks right in Thembi's eyes when she talks. (Thembi was startled by this the first time it happened.) Thembi wants to ask more questions about HIV but there are loads of patients waiting, and she feels shy. She thinks that her English is not very good and, in truth, she prefers to speak to someone who speaks Zulu, like the HIV counsellors. The doctor stresses that Thembi must return again within a week for her test results; that they will initiate ART if she qualifies. The doctor says, again looking her full in the face, "this is very important". Thembi leaves the small examination room and looks around but she cannot find an HIV counsellor. She asks a sister (nurse) about counselling but the sister tells her, gently but firmly, that it is the counsellors with whom she must speak; that she must rush off now to locate a blood pressure cuff.

Thembi makes a booking to return in 10 days' time. She leaves the hospital feeling slightly dejected. She did have a nice conversation with another patient while waiting in the queue (everyone waits patiently for their turn. There is an unspoken faith in this hospital's services). Her new friend is also HIV positive and pregnant. They exchanged cellphone numbers. (A connection!) Thembi fingers the piece of paper with her new friend's number on it. This cheers her a bit.

It will turn out that Thembi does qualify for ART: her CD4 cell count is 184 with a CD4 cell count of <200 cells/mm^3 being the qualifying number in many public health settings in South Africa. This hospital, an academic one, will initiate patients onto antiretroviral therapy at levels of 250 cells/mm^3 or less depending on the symptoms of the patient. But in the next week before Thembi can return to the hospital to collect her results and her medication, her water will break. Thembi will find the nearest taxi and head to the hospital.

Alone in the labour ward at the hospital, she feels okay. As a Zulu, Thembi knows that Siyabonga's culture does not allow him to come into the hospital.[1] It is very hectic in

the ward, with lots of babies being born. The labour becomes stressful. The sisters do not shout but they speak sternly, and her requests for water and pain relief are ignored. The doctor examines her and instructs the ward nurse to prepare her for a caesarean section. Thembi has never had one but she trusts the doctor and she is thankful that now she will get some pain relief. She remembered to take her nevirapine pill when she first arrived at hospital but she vomited shortly after taking it. She prays that it will work. After the baby is born (an *umfana* – a boy!) and before she is discharged, the sister in the labour ward tells her to give 'a syrup' to the baby for 28 days, explaining that it is because Thembi is 'positive'. It comes in a little dark bottle, which Thembi tucks into her handbag. The sister whispers a few questions to Thembi, being careful that other patients cannot hear: 'where does Thembi live? Is there clean water there?' The sister tells her that she must not breastfeed. As long as clean water is available, she must feed the baby with formula milk. But Thembi is not told why. The nurse has disappeared and Thembi is told she is being discharged. Thembi thinks that she will be able to manage the syrup but breastfeeding is what she is accustomed to. Her in-laws and Siyabonga would suspect something is strange if she is feeding the baby with a cup! She tells herself she will ask the nice counsellor about this when she comes back in another month for her postnatal check-up.

Eventually (a few months later), Thembi, who had been mixing breast milk and formula, will learn that 'mixed feeding' increases the risk of transmitting the virus to the child.[2] She will have her baby tested for HIV at two and a half months (instead of the suggested six weeks) and her little boy will turn out to be HIV free. It will take much longer for Thembi to get onto triple combination therapy for her own health. Thembi will disclose her HIV status to Siyabonga and he will express his support for Thembi and the baby. He will, however, still refuse HIV testing and treatment for himself.

Patient B. A Public Hospital in Oliver Tambo District, Eastern Cape Province

Mpho has been attending antenatal care at her local clinic near her home in Coffee Bay in the Eastern Cape. She has been to the clinic three times. She was told that she has diabetes. This, together with a previous miscarriage, creates a high-risk pregnancy. The *umongikzi* (nurse) told Mpho that she must watch her symptoms at home. If she experienced things like dizziness and bleeding she must go to the hospital straightaway. Mpho is also HIV positive but she has not disclosed this information to anyone. When she woke up this morning the mud walls and thatched roof of the *rondawel* were spinning.[3] When she saw the blood running down her leg, fear seized her heart like a quick bolt of lightning. Her little sister, Nozizwe, who sleeps next to

her, stares wide eyed and open mouthed at the blood. Mpho raises herself, ordering her sister to fetch water from the stream. But clever Nozizwe locates the bucket – water still in it – being careful not to spill the precious resource inside. Mpho throws on her clothes, steadies herself and rushes outside. Shielding her eyes from the blaring sun, Mpho calls to her mum urgently "*umama!*". Looking across the expanse of low grass, she sees that her mother is deep in conversation with their neighbour. "*Molo. Kunjani sisi?*"[4] Mpho calls to the neighbour, issuing the morning greeting breathlessly. Mpho motions to her mum.

After much inspection and clicking of her tongue, her mother whips her mobile phone out of the pocket of her cotton skirt, scrolling through the list of contacts. In this vast, rural place with only the sound of the occasional bird punctuating the silence, Mpho and her mother wait with their heads bowed together against the broad expanse of blue sky, listening for the dial tone that will connect them to the ambulance service. After they place the call, Nozizwe rushes to put together a bag with Mpho's clothes. Mpho washes herself, wrapping a clean turban around her head. Before she has had time to think, she is swept away by two men in an ambulance. As they traverse the 22 km to hospital, Mpho watches as the red dust on the road curls up in large clouds behind the vehicle.

This is her first time delivering a baby, and at this hospital. She feels afraid but remembers the famous pride (*uphondo*) of Xhosa women – Mpho's lineage – which has been instilled in her for the last 24 years. She will betray no fear. She makes her face impassive, like a mask. The sister who shows her to her room is kind; she gives her a fluffy blue dressing gown to wear. Mpho likes the way the walls are painted pink. The sister says she will come back and take her blood pressure. Mpho is told that she will stay in the hospital ward until she delivers and they will monitor her health. Two days pass. Mpho mainly sleeps but she has a nightmare. In the dream the baby is born with open sores all over its body and no one will touch the child. She wakes up and thinks that this is what it is to be HIV positive, an *isiqalekiso* (curse) on her first-born. She wants to ask if she will get the *iyeza* (nevirapine pill). (A friend Mpho met at the clinic told her that the sisters will issue the pill in the hospital.) But Mpho is too shy and too proud to ask. She thinks that the sister will tell her what she needs to know. Although she is anxious, she mustn't succumb to her emotions: and she mustn't ask. Today the sister checks her file and asks her about her health history. But she doesn't say anything about the nevirapine. Mpho first learned of her HIV status when she looked at her ANC card. It said 'reactive' and she knew that meant HIV positive. She was shocked. She had heard that people are supposed to receive counselling but she has not received any counselling or information about HIV.

She has so many questions but she doesn't feel comfortable asking a stranger. She has told no one about her status: not even her sister or mother. Sometimes Mpho thinks that maybe it is not true; that they confused her with someone else. Mpho slips further behind the invisible mask she uses as a shield, and wills herself not to think about it.

Two days later Mpho delivers her baby. At the onset of labour a sister named Nomonde gives her a pill and tells her to take it. Mpho wonders if it is the NVP but she doesn't ask. She heard on the radio that this NVP is supposed to protect the baby from the virus. When it is all over, they put her baby girl (she has named her Andisiwe) on her chest. The child seems healthy (Mpho looks the child over, slowly, to make sure she has no sores). Mpho begins to breastfeed Andisiwe. After that Mpho sleeps a long time. When she wakes, a different sister comes by, asks her how she is feeling, and gives her 'a syrup' to give to her baby. Mpho is not told what the syrup is or what it is for – just that she should give it to the baby for the next 28 days. Mpho wonders if the baby will also have this HIV. She thinks that she must tell her mother and maybe, together, they can figure out what to do.

FINDINGS: NAVIGATING THE CONTINUUM OF CARE

Patients A and B - Placing these stories in the context of interviews

With Thembi and Mpho's stories, I have embedded aspects of their particular experience that mirror those 'internal experiences' shared by many patients in the interviews conducted.

Cost of public transport

Women often came from townships outside the city of Johannesburg, using public transport to travel into the city for healthcare. However, some patients might stay in areas closer to the city centre, such as Hillbrow, which would reduce the cost of transport; and, might even allow them to walk to the hospital. Like Thembi, the majority of women interviewed were travelling from townships outside the central business district (CBD). The cost of transport was expressed as a major barrier to healthcare access and timely treatment among the 60 pregnant or postnatal women interviewed at the Johannesburg site – often delaying their visits to the hospital. Thembi mentions that she misses an appointment because she did not have the fare, a common occurrence: with other women saying that they will walk if need be or will borrow the money so that they don't miss an appointment.

The implication is that delayed visits result in a delay in HIV testing, counselling, and HIV staging. All of these delays may result in an attendant delay in treatment access for the woman, which affects her health and that of her child. In the worst case scenario, ART for the mother and PMTCT for the child are missed completely. Delayed visits also delay the time necessary for women to begin to process the knowledge of their HIV status and the accompanying psychological impact. The goal is for women to initiate ART for their own health, ideally through triple combination therapy, thus improving health outcomes for the woman, and reducing the risk of HIV transmission to the child, while improving child survival *Chersich* (2007); *WHO* (2006c-d) (**see Exhibit 1** for a visual indication of how the revised guidelines for PMTCT are implemented in practice – from the first antenatal visit through the postnatal period) (see **Exhibit 2** for the routine services provided in each facility).

As is the case for many peri-rural residents, Mpho takes an ambulance (a patient transporter) to hospital to deliver her baby (a free service), which eases the cost of transport. Normally, of the 23 women interviewed in the Eastern Cape, the majority attended ANC at a local clinic (usually) within walking distance. However, ART services in local clinics are limited in the Eastern Cape (few sites are ART-accredited). Thus, while maternal delivery may be free, the cost of transport to an accredited clinic may be expensive. It is also time-consuming to travel between different service points to access different services in the trajectory of care. (I discuss the fragmentation of services and implications later in this chapter.) Patients stated:

> "It is difficult to manage costs. The clinic visits, they impact the budget. The price of food is making it more difficult. It is difficult because no one is working" (Interview with postnatal patient, 7 August 2008).

> "I have enough money to buy food but transport is a problem" (Interview with postnatal patient, 30 July 2008).

> "It is expensive to manage my health" (Interview with postnatal patient, 11 June 2008).

> "Money is a barrier" (Interview with postnatal patient, 12 August 2008).

> "Being unemployed is a problem. I am stressed about money" (Interview with ANC patient, 28 March 2008).

Poverty and unemployment

As was the case with Mpho, in the Eastern Cape women were more likely to be living with their parents; although sometimes they co-habitated with a partner or husband. The women interviewed in the Eastern Cape tended to be slightly younger, mid to late 20s, while the women from Johannesburg ranged in age from early 20s to late 30s (the sample pool of women interviewed in Johannesburg was also larger: 60 compared with 23 in the Eastern Cape). The women in the Eastern Cape who lived with their parents were more likely to be economically dependent on them. Often, they stated that their mothers made decisions about their health. The women from Eastern Cape also tended to be fully unemployed (The unemployment rate in Oliver Tambo District, the location of the Eastern Cape site was 77%.) *Eastern Cape Provincial Dept of Health* (2008). Johannesburg inhabitants were unemployed as well but many were engaging in piece-work and informal trading. The majority of women interviewed in the Eastern Cape were receiving some kind of social grant (child support or HIV/AIDS), which assisted with expenses each month. It was less common for an interviewee from Johannesburg to receive a social grant. My sense was that the information channels and processing of social grants was better in the Eastern Cape than in Gauteng.

Fear, stigma and economic dependence

Mpho's story reveals the fear and denial that can accompany an HIV positive test result, which is compounded when counselling is not provided at the time of testing. She spoke to no one; a healthcare worker (HCW) did not discuss the implications of her HIV status for her health and her foetus, providing no information and support. To put it baldly, this patient has been failed by the health system. There were multiple opportunities for HCWs to provide counselling: in ANC, during her admission to hospital, her wait in hospital, in labour, or postnatally (either while still in hospital or when the patient returns for postnatal care). And this did not occur. A significant number of women mentioned the omission of counselling at these points along the care continuum. (Staffing will be discussed in this chapter and in chapter seven.) Mpho mentions that her pride restricts her from showing emotion and from asking questions. She looks to the nurse to initiate the conversation about HIV and treatment. This stoicism and failure to ask questions is a social norm, which may have cultural roots.

Thembi touches on the stigma of HIV when she mentions her partner's fear of testing (or reluctance) and 'judgment'. She also mentions that she has not disclosed. Disclosure to a family member or friend often takes time. Fear of how a person living with HIV will be perceived by others is a common finding of these interviews; fear of a partner's reaction in this study was very common, and was usually linked to a

woman's economic dependence on her partner; and, her anxiety that once her HIV status was known, her partner might leave (having been left behind or abandoned was an experience described by 5% of participants). Again, fear of disclosure, due in particular, to economic dependence (on partners, husbands or the partner's family) was a commonality shared by women attending the Johannesburg facility.[5]

While patients, healthcare workers and researchers agree that stigma is abating, it is ever-present. *Human Rights Watch* noted:

> "People living with HIV and AIDS in South Africa continue to fear discrimination and victimisation. Few people choose to publicly disclose an HIV-positive status, fearing that this will cause stigmatisation in their community and loss of their jobs" (2008).

Thembi and Mpho mention their anxiety. These women were HIV positive, pregnant (or recently pregnant), and poor. The amount of emotional stress they were experiencing needs emphasis. More than 90% of all women interviewed fell below the poverty line and were unemployed. In an estimated half of all 83 interviews conducted with women, they had not disclosed or discussed their HIV status with another soul. These women only spoke about their HIV status with the lay counsellor and doctor; and with us in the interview. This meant that they were not seeking or gaining emotional support outside the health system, thus placing even greater importance on support structures within (counsellors, social workers, support groups). Again, women are often reliant on that system to instruct and guide them. While much research takes place on ART coverage and operational structures, conversations with these 83 women shed light on the labyrinth of psycho-social issues faced by women and the importance of mental health support.

As indicated in Thembi's narrative, it was frequently mentioned that women would strike up conversations with other women in the hospital. Sometimes they would become friends, and this served as an informal networking opportunity for women to find support in managing their own HIV status, in deciding whether and when to disclose, and in related matters. Most of the women who had received or gained support from another woman in a public health setting seemed to be aware that they were supporting each other. In coping with their HIV status, women mentioned that they gained strength primarily from family (a child or children, a husband, mother or sister), friends, and from other sources (for example, their own strength or internal resources, an HIV positive role model, their minister, or their faith in God). There seemed to be a correlation between disclosure to a family member or friend and a resulting, positive mental state.[6]

Negotiating HIV status and disclosure

The most common response, when asked about her reaction to HIV, was for women to say: "HIV is not a death sentence". Regarding the disclosure of their status, women frequently shared their worries and fears.

One woman, 24 years of age and living with her partner, noted:

> "Yes. I disclosed to my boyfriend. He was angry but ended up being supportive. He wants to control the way I talk about HIV [though] and when I talk about it… so I don't feel that I can talk [about my status] openly" (interview with postnatal patient, 7 August 2008).

A woman, 36 years old and married said:

> "I haven't disclosed to him [her husband]. He drinks and I am afraid of what he might say because he is HIV negative and I am positive. I don't know how he will react".

She also said:

> "people are scared of themselves" "stigma prevents people from testing" (interview with postnatal patient, 12 August 2008).

A third woman said:

> "There is stigma attached to HIV. I cope by not telling people because people will criticize. I gain support from one of the counsellors at the hospital when I feel low" (interview with postnatal patient, 5 June 2008).

One patient stated:

> "Being HIV positive was difficult at first. There is a negative association attached to HIV. But since I have had HIV counselling here – I feel strong because of the counselling" (interview with ANC patient on 4 April 2008).

One woman said:

> "I was afraid in the beginning. I thought they were going to tell me that I was going to die. But they explained and I realised HIV is not a death sentence. It is sometimes difficult. I feel embarrassed. I feel like other people might know. Being with other HIV positive [people] when I come here [to the hospital] makes me feel strong. And, support from my husband" (interview with ANC patient, 9 April 2008).

ANTENATAL CARE

Delays in seeking ANC

Thembi's decision to wait until she was seven months along before her first antenatal visit was also very common in the women attending the antenatal clinic in Johannesburg. This was a frustration expressed by doctors and health personnel within the clinic. Again, the danger is that ART and PMTCT are delayed or missed because the required time to test women for HIV and to initiate ART is short. However, Mpho's case illustrates that even if ANC occurs earlier, key services can still lie out of reach, particularly when there is a lack of information imparted to the patient; and, the patient-provider relationship is poor.

Health status and referral criteria

Because the Johannesburg facility offered tertiary care, patients would have to meet the referral criteria before obtaining an appointment, i.e., have another underlying condition that increases the risk of the pregnancy, such as diabetes, a previous caesarean or hypertension (as was the case for Thembi). HIV does put patients at greater risk for death in pregnancy but this alone is normally insufficient to access tertiary care. This hospital was primarily treating level III patients, but also treating level IV patients, while the two Eastern Cape hospitals were delivering care from Levels I to III at one site and Levels I to IV at the academic hospital.[7] A larger point is that the health of these women was vulnerable due to the combination of: their HIV status, the fact of their pregnancy, combined with at least one other condition or illness (possibly more than one). One woman said:

> "I was turned away at Jeppe Street Clinic and Hillbrow. I was already on ARVs. Maybe they turned me away because I was HIV positive?" (interview with antenatal patient, 11 June 2008).

A few other women at the Johannesburg site mentioned they were turned away by the clerk. The patient described above was turned away at three Johannesburg clinics, despite having a letter from a doctor. This might have been because she, and other women, did not meet the referral criteria. This, in turn, might be perceived by the patient as poor treatment or discrimination (sometimes it might be). At a tertiary facility, the clerk might also be discharging her normal responsibilities, i.e., to refer patients to clinics for ongoing, nonspecialist treatment. Alternatively, this phenomenon could be a response from overloaded health personnel who instruct clerks to send patients away as a coping strategy. If this was occurring on the basis of discrimination due to foreigner status,

HIV or other, it should be explored in future research (there are anecdotal reports of this discrimination taking place in the city of Johannesburg). Whatever the case, it was clear that clerks were not able to clearly communicate to a patient why she was being turned away or referred. Subsequently, patients can lose faith in health services. They may also feel stigmatised by their HIV status. And, missed opportunities for timely HIV services may also result.

Delays in CD4 cell count test results, HIV staging and ART initiation

Thembi's doctor's insistence on her return within 10 days to receive the test results and be staged for HIV was common practice within that site, with patients being told by doctors and nurses that they must get their test results and be staged before initiation onto combination therapy (if indicated; if the patient did not qualify for ART, or could not be staged or initiated onto ART before labour, she would receive NVP to self-administer in Johannesburg. Health personnel would administer 600 mg of AZT in labour, and 300 mg every three hours until delivery). According to the national protocol, women whose gestation is greater than or equal to 28 weeks are meant to be initiated onto AZT and are given a NVP tablet. Johannesburg was following these guidelines. For Thembi, she missed HIV staging and AZT or ART initiation because her CD4 cell test results were not available during her visit and she delivered prematurely. (In the rural sites, uptake of dual therapy was trailing urban ones.)

This underscores that there is a short and fragile time window for a woman to be tested for HIV; have her CD4 cell count taken; return for the results; be staged for HIV; and be initiated onto ART while still pregnant. Thembi's example is illustrative of the patients' experiences in Johannesburg. This study indicated that sometimes patients whose CD4 cell count test results indicate eligibility for ART are still missed in the clinic system. The test results have somehow not made it back into the patients' files. Women who are HIV positive with a gestation period of less than 28 weeks are meant to return to the hospital within one week for the CD4 cell count test result and HIV staging. Problems with timely initiation for Johannesburg women, then, clustered around CD4 cell test results, staging, and initiation.

This delay can be traced to the health system and individual behaviour. Generally women benefit most from ART if they have begun taking the drugs at least one month before delivery. However, the tendency is to present late for ANC (at seven months), and any delay by the patient (missing or delaying her appointment), clinic system or health personnel can result in delaying or missing ART or PMTCT for the patient and infant. In short, delay of HIV services often means denial.

Role of the lay HIV counsellors viz. nurses in HIV/AIDS service provision

Thembi's failure to find a lay counsellor from whom to seek advice was an unfortunate reality. In the Johannesburg site lay HIV counsellors were responsible for providing all HIV counselling and related services. They were trusted by women because they spoke Zulu and Sotho, and they had a similar class, cultural and educational background to the patients. Thembi did not ask questions of the doctor, citing her shyness and her poor English (another reality). A counsellor, for whatever reason, was not available on the day that Thembi sought counselling. A shortage of counsellors has been documented in most provinces. By the nurse's response, it becomes clear that there was a division of labour at the site – with HIV lay counsellors responsible for HIV positive patients, and nurses' duties comprising other areas. The primary duties of lay counsellors in this site included: providing pre and post HIV test counselling to patients or caregivers of patients; assessing and preparing patients for treatment readiness; adherence counselling for PMTCT regimens; and for antiretroviral therapy; provision of counselling for pregnant women regarding infant feeding choices; and, the identification of women who qualify for antiretroviral treatment in the clinics but who have been missed previously in the hospital or clinic system.

In the Eastern Cape, in contrast, the nurses provided all counselling and related HIV services at both hospitals. One dedicated nurse was selected to run the PMTCT programme and to provide HIV counselling at each hospital. She did this from roughly 8 to 1pm Monday through Friday. One sister (the dedicated nurse) said:

> "I provide five counselling sessions per day, and then I stop. I have other work to do" (interview with key informant on 14 October 2008).

This was exactly the case at the sister hospital. What's more, if this individual is ill and does not report to work, or is undergoing training elsewhere, HIV services are not provided. Infrequently, an HIV counsellor would assist in providing some counselling; or a doctor would perform an HIV test. It was recognised that doctors were too busy to provide sufficient counselling – thus any counselling they provided might not be optimal. Counselling provision was not perceived as the routine role of a doctor (although some doctors did so); and there is often a higher power distance between doctors and patients, which might impair patients' ability to ask questions, as seen in Thembi's story. The nurses acknowledged that there was generally, then, no HIV testing and counselling provided for patients admitted in the afternoons, weekends, or on public holidays. One nurse said:

> "I was trained in PMTCT but not in VCT" (interview with key informant on 17 October 2008).

It was not clear why this blatant shortage of staff dedicated to HIV service delivery remained unaddressed. However, a shortage of nursing staff is evident across the country (*Besser*, citing Health Systems Trust data, reports a staffing gap of 36% across the country, with some provincial deficits registering upwards of 50%) (6 June 2009). It was unclear why more lay counsellors were not deployed to assist in filling this gap. One nurse said:

> "We used to have them [lay counsellors] but they disappeared" (interview with key informant on 22 October 2008).

Other nurses interviewed spoke of the challenge of attracting and retaining health personnel in certain towns in the Eastern Cape. The nurses were leaving for jobs in the private sector and overseas (interviews with key informants on 15, 16, 17, 20, 22 October 2008). At one of the Eastern Cape hospitals, three nurses were leaving at the end of the month (October 2008).

Accessing information on HIV and ART from the media

Despite the fact that the majority of women were poor, like Thembi and Mpho, most women used television or radio programmes to gain additional information about HIV. Sometimes the first exposure to HIV or ART was through such media. Some women listened fastidiously to one particular radio or TV show or host. In my roughly 12 months of conducting field research in these four facilities, across the two provinces, I never saw free pamphlets containing public health information that women could take away with them to gain information on HIV in pregnancy. There were educational posters on the walls (and condoms were distributed free of charge). While most of these women were not well-educated, they were literate. Many were hungry for more information. When asked whether they would take advantage of educational brochures or pamphlets almost all said yes.

Knowing someone with HIV, on treatment, or seeing someone die

All women knew someone living positively with HIV with many women claiming that this role model gave them hope and sometimes paved the way for women to see themselves as HIV positive and living a healthy life. Most often, like Thembi's cousin, women knew someone who, having initiated antiretroviral therapy, had their physical health improve – made manifest to the naked eye. Often, the person mentioned was a brother or sister. This is in keeping with research on ART initiation in clinics and hospitals in the immediate aftermath to the ARV rollout. The research illustrates that patients were getting onto treatment late, already exhibiting AIDS-defining illnesses, which made treatment less beneficial. A significant number of women and caregivers interviewed saw the dramatic improvement of their children on ART, which convinced them of the benefits for their own health. This appeared to underscore a trend in South Africa, which seems a logical extension of a generalised HIV epidemic: almost everyone seemed to know someone who was/is living with HIV/AIDS and taking treatment. Or they knew at least one person (if not more) who had died of HIV-related diseases. The key point is that the information and awareness of women, and their perceptions of HIV/AIDS, were influenced by someone else's experience of HIV, and often of treatment. These influences were mainly positive ones that educated women about living with HIV.

Beliefs about and knowledge of PMTCT/ART and willingness to take ART

The majority of patients I interviewed (across the sites) had some knowledge of antiretroviral drugs. Some had not yet initiated ART but many were willing to do so: possibly after overcoming an initial fear and sometimes surprise, denial, horror or shock; and, often the stark realisation they would be taking these pills for the rest of their lives. One key informant from the Eastern Cape emphasised:

> "The information has reached the rural areas. Anyone who has a radio or TV knows about HIV" (16 October 2008).

In the Eastern Cape, however, women generally had low levels of knowledge of the workings of antiretroviral drugs (compared to women in Johannesburg) – with a few having no knowledge of ART. Many of the Eastern Cape women interviewed had no knowledge (at all) of PMTCT: they didn't know that drugs were available to reduce the risk of HIV transmission from mother to child or for their own health. Even in the postnatal period (where women had delivered the day before and had

not yet been discharged), no one had told them what PMTCT was. This matched an earlier anecdote I had heard. One key informant (a researcher from the Eastern Cape) stated that in 2003, after the public health clinics in that province began dispensing nevirapine, the DoH introduced public health messages on PMTCT services (on billboards for instance). Researchers found that the patients didn't understand the connection between the pill they were taking and preventing HIV transmission to the child in pregnancy (interview with key informant on 14 October 2008). The researchers informed the DoH of this finding, and the department supposedly made changes to their public health campaign as a result.

This appears to be a continuing problem, however. In interviews women did not know there was a relationship between their HIV status, the drug they were taking (NVP and sometimes triple combination therapy), and prevention of MTCT. In several instances, when asked if they were taking medication, women would whip out their bottle of drugs and show me what they were taking. But they didn't know that the medication was for HIV and they couldn't identify the names of the drugs they were taking, thus revealing a lack of knowledge of what is termed 'treatment literacy'.[8] One key informant noted the disconnections:

> "[There is a] frequent disconnect between healthcare providers' perceptions that they are 'educating' and a client's understanding (knowledge transfer) and then [there is] a second disconnect between knowledge transfer and successful action on it (behaviour change). We need to bridge both gaps" (6 June 2009).

It turned out that when I looked at the patient's file, some of these women were given ARV prophylaxis in labour but didn't know they had received it. Mpho's story is indicative. She is given AZT syrup for her infant but she has no idea what it is. She suspects that NVP is administered to her in labour but she is unsure; and she doesn't ask. This was the norm in the Eastern Cape.

When asked whether women believed that HIV transmission from mother to child could be prevented through ARV prophylaxis in pregnancy, many women genuinely wanted to believe this but found it hard to fathom. They thought it was "quite a miracle". Some women said they did not believe it, in both the Eastern Cape and Johannesburg. In Johannesburg, however, women were more likely to have heard of PMTCT and think it effective. In the Eastern Cape, again, many women were not told about PMTCT in ANC in labour or after.

In Johannesburg, patients generally had much more knowledge about PMTCT and about ART. One patient said:

> "I went onto ARVs because I was very sick. I was afraid about taking the drugs. I was not sure what the drugs would do. But I felt confident because I started taking them in hospital and there were doctors around" (interview with postnatal patient on 30 July 2008).

At the Johannesburg site, when asked how the drugs functioned, the majority of women gave a simple but true explanation such as "ARVs help reduce the viral load. They do not cure" (ANC Patient 28 March 2008). In the Eastern Cape, women struggled to come up with a reasonable explanation. In viewing the education levels of women across the two sites, there is not much difference. It seems that better knowledge on the part of Johannesburg patients could be attributed to more frequent visits at the same site; possibly the lay counsellors' availability and ability to speak patients' own language (allowing women to build relationships of trust with the lay counsellors); greater access to information in urban areas; and the greater tendency of patients in Johannesburg to ask questions. One key informant emphasised that this enhanced knowledge constitutes a stage of empowerment (6 June 2009).

Trust in health personnel and the critical role of counselling

The women's statements shed light on the particular individual-systems nexus that begins with the patient's first ANC visit. The individual and health personnel were engaged in what can be seen as a kind of ritual dance – where the individual is seeking information and support; and aiming to establish trust and faith in the health system. Mpho was looking to the nurse to initiate a conversation about HIV and to provide the necessary information. But it was not forthcoming. Thembi was searching for a lay counsellor whom she could trust. If the health system fails a woman (if she receives insufficient information, counselling, support), she may withdraw or begin to lose trust in the hospital's services and staff.

Against a background where women have economic obstacles to transport, they were also managing psycho-social aspects of their HIV status, including whether or not to disclose. In Mpho's case, there was no counselling at all. She was left to absorb her status alone. The role of counselling in allowing women to ask questions, to normalise their status, to feel that they are not alone and providing information on how to disclose, treatment and infant feeding options cannot be over-emphasised. As was seen in Thembi's case, when she sought counselling at a critical juncture (her last visit

before she delivered prematurely), there were no HIV counsellors available and she was too shy to ask questions of the doctor. Often counsellors share strategies on how to deal with in-laws (taking pills or preparing formula feed in secret or related issues), or they simply listen and express support. Recall that patients may not have shared this information with a single other person. The nurse or lay counsellor is in a position of authority, of respect, of power. HCWs *are* the link between the health system and the patient. They often determine whether or not the patient will gain access to health services or information. As such, they serve as a social determinant of health. But sometimes health personnel play a more confrontational and controversial role. One patient stated:

> "I was in denial about going onto ARVs and refused at first. It was only when I went back to a second HIV counsellor when I was five months pregnant that the HIV counsellor said 'you are killing your child by not taking the medication'".

The patient then "became very worried about the baby's health and she was frightened into action". However, when she told her husband that she was taking the pills: "He reacted in a violent manner and threw the pills away". When she went back again for counselling the third time, the counsellor helped her to figure out a way to put "the pills in a different place and to take the pills in secret". And she has done that ever since. This same patient also missed a few doses of her medication. The lay counsellor and doctor explained to her that she could develop resistance if she did not adhere properly to the medication (interview with ANC patient on 29 July 2008). Patients had varied experiences with HCWs. For every patient that had a negative experience with health personnel, two more had positive things to say:

> "I delivered three babies here. I've had a good experience" (interview with postnatal patient on 5 June 2008).

One patient remarked:

> "There is discrimination in the labour wards especially at night against people who are HIV positive by the sisters. The sisters decide on and restrict the supply of pain medication. They shout and are rude… But one sister was helpful. Sister X. I cried on her shoulder. Sister X encouraged me to take my ARV pills" (interview with postnatal patient on 29 July 2008).

Thembi discusses the mountain of information that is given to someone testing positive for HIV who is pregnant. One session is insufficient to retain this information; and, because she delivers prematurely, she is unable to have a follow up counselling session. The efficacy of ARV drugs taken in pregnancy and during labour is reduced over time in breastfeeding populations, owing to post-partum HIV transmission in breastmilk *Jackson, Musoke, Fleming, Guay et al (*2003*); Leroy, Karon, Alioum and Ekpini* (2002). Hence, feeding options should be clearly explained and women should be counselled so that they understand the implications of breastfeeding, and mixed feeding (which increases the risk of HIV transmission to the child), with women also understanding if and how formula feeding is feasible and can be achieved, in line with the AFASS assessment (discussed in chapter 2).

Patient's role in health decision-making

The comments made by patients interviewed in the Eastern Cape and the statements made by key informants there all point to a passivity on the part of women there. Shyness also played a role in Johannesburg, as seen with Thembi. But women there tended to ask more questions about their health. I don't know whether this was a function of a more rural upbringing, with less exposure to the health system – or if it was cultural. The Eastern Cape is part of the former Transkei. Oliver Tambo District is considered a mainly rural district with this particular town (where research was carried out) as the main centre. Most of the women who delivered in the hospitals were often coming from more rural locations in the district: only 9% of households in this district have potable water *Eastern Cape Provincial Government* (2009). It is possible that women who delivered in hospital felt intimidated. What became evident was that this passivity and shyness impairs women's ability to promote their own health and to seek information that will allow them to make health decisions. The HCWs seemed to accept this passivity as 'the way of things'. A foreign doctor in the Eastern Cape clinic observed with some incredulity:

> "The patients are passive. They just wait patiently and don't motivate for themselves" (interview with key informant, 20 October 2008).[9]

Timely HIV testing and PMTCT interventions during labour and against cultural/social norms

Although Thembi was not staged for HIV and she missed ART/AZT initiation, she received the nevirapine (NVP) pill and took it correctly. However, the fact that she

vomited indicates the efficacy of the medication may have been reduced. However, she did receive a caesarean section, which – if performed before the onset of labour – reduces the risk of MTCT (because there is less fluid and blood exchange and less trauma to the baby through a caesarean section, unlike a vaginal delivery).[10] She also received the ARV prophylaxis for her newborn (AZT syrup), which she planned to administer. However, due to poor counselling in the antenatal and labour wards, she did not understand the benefits of formula feeding or the risks of breastfeeding, coupled with the fact that in her culture and family breastfeeding is the norm, she chose to breastfeed at home. (Mpho is not even given this choice.) When Thembi goes to the hospital (because the counsellor and sister told her not to breastfeed), she will formula feed, thus she will mix formula and breastfeeding.

Mpho and Thembi's stories show the complex interplay of factors that impact on individual behaviour. Mixed feeding was being practiced by a number of women interviewed, throwing into relief the poor and infrequent counselling received by women in ANC and labour, indicating a lack of understanding of feeding options; and, the complexities of changing standard behaviour against social norms. The sheer volume of information given to women during HIV counselling is massive. When given to a woman newly-diagnosed with HIV, this can be even more overwhelming.

One patient said that while the counsellor "was helpful":

> "I was in a daze – I couldn't really concentrate on what was said. I felt so stressed" (interview with postnatal patient on 5 August 2008).

Another patient explained:

> "I was given an HIV test when I was pregnant. I learned that I was positive and I was traumatised… The counsellor was keen to give me information but I wasn't able to hear it. I was in shock. I had to sit for two hours at hospital before I could get myself together to go home. I sat on a bench and I saw another pregnant woman crying. I thought 'we are in the same boat'. We exchanged numbers and have supported each other ever since" (interview with postnatal patient on 29 July 2008).

Once this patient learned of her status, she did not disclose immediately. She wanted to see how her husband would respond and so she talked more generally about HIV to him:

> "It took a long time but I did disclose to him… my partner was very supportive" (interview with postnatal patient on 29 July 2008).

Another woman said:

> "When I found out I was HIV positive, I was not sure if I should have an abortion or not" (interview with postnatal patient, 12 August 2008).

One woman explained:

> "The information on getting pregnant if you are HIV positive is confusing. There's an emphasis on telling people that they shouldn't get pregnant. Then they are afraid if they are pregnant and HIV positive" (interview with postnatal patient, 5 June 2008).

The ideal scenario would be to offer a number of routine counselling and follow up sessions to ensure retention of information, answer questions, and allow for psychological support. However, due to the compressed time period between a first visit at seven months, and delivery at nine months (or earlier), with an average of three ANC visits[11] – there is often insufficient time to provide adequate counselling. Again, this speaks to the importance of getting women into ANC earlier, accordingly, with an emphasis on frequent and robust counselling.

LABOUR WARD

The labour ward as a key site for HIV interventions

Labour and delivery is a compressed period where there is a major opportunity to offer HIV-related services. Thembi's experience in the labour ward shows that a number of things can go right or wrong, including the woman taking the NVP pill (or not), receiving ARV prophylaxis for the child (a single dose after labour), and ARV medication to administer to the child at home, with instructions to bring the child back to hospital for HIV testing at six weeks.

The nurse is meant to look at the patient's chart, determine if she is HIV positive, and ask the woman if she has taken her NVP pill (if she is not on triple combination therapy, which obviates the need for a single drug intervention). If she has not, the nurse should administer the pill (thereafter, she receives AZT every three hours throughout labour until the neonate is delivered). If the woman's HIV status is unknown, the woman should be tested and counselled – with the whole range of counselling including the role of ART, adherence, support, disclosure, encouraging partner testing, nutrition, feeding choices. Mistakes and oversights can often take place.

One key informant (a nurse) emphasised:

> "We do dispense the syrup [for infants upon discharge from hospital] but the administration of nevirapine is meant to occur every few hours [throughout labour]. This is sometimes missed in the labour ward if things get busy" (interview with key informant on 17 October 2008).

The same individual said:

> "We don't always mark down infant feeding options [selected by the mother] either" (interview with key informant on 17 October 2008).

Because of the shortage of hospital beds in South Africa, a brief stay in hospital is the norm. In the Eastern Cape and in Gauteng, women are routinely discharged six to 24 hours after a normal, vaginal delivery, on average. (Women who are admitted the previous day or afternoon will normally be discharged by 10am the next morning.) A woman who has had a caesarean section would be discharged within three days. The WHO guidelines indicate that patient discharge can occur six hours after a normal maternal delivery, i.e., no complications, provided there is a home-based visit within the first three days. In South Africa the practice of discharge is in line with the WHO guidelines: but home based visits rarely occur, however. One key informant noted that this was indicative of the public health system: "we follow one part of the international guidelines but not the other" (2 June 2009). As a result, while this point in the care continuum constitutes a huge opportunity for intervention, there is also great pressure in the labour ward and on staff. Because of the brief period of time in hospital, the labour ward, then, remains both a choke point and a gateway for prevention, treatment, counselling and information provision.

POSTNATAL CARE (POST-DISCHARGE)

Missing PMTCT/delaying ART and weak referral systems within facilities

Postnatal care, sought after the woman has delivered, been discharged from the hospital and returns, is the gateway to future care and HIV service provision. The women I interviewed in the postnatal ward in Johannesburg, as well as caregivers interviewed in the paediatric ward, were more likely to have had some fear of antiretroviral drugs, with many of these patients missing or delaying ART for themselves, and some missing PMTCT for their infants. The delayed access to treatment (i.e., only initiating ART after missing PMTCT and ART in pregnancy) for women highlights missed opportunities for treatment in the postnatal and paediatric points in the continuum of care.

It also underscores the strong links between mental health and behaviour – the patient's decision to withdraw or refrain from initiating prevention or treatment. It again highlights the vital role of counselling in influencing behaviour, and appears to point to psycho-social issues about HIV, including fear or denial; and, fear or reluctance about ART. The key message is that communication amongst providers is critical; as is communication between providers and patients. What is essential is "the right provider with the right message delivered in the right way" notes *Besser* (email communication on 6 June 2009). And, that communication across all points in the continuum of care should be maximised for prevention, care, treatment and support for maternal and child health.

In the end, antenatal care provides the optimal point of intervention. It offers a routine, safe entry way into prevention, treatment, care and support. ANC also serves as a gateway to the other points in the care continuum (for mother and infant) – the major opportunity for HIV interventions, together with other sexual and reproductive health information: TB and cervical cancer screening, family planning, preventing pregnancy and preventing infections in HIV negative women, and related counselling across that spectrum. Women who missed or withdrew from antenatal care were more likely to have missed ART for themselves and PMTCT for their infants. It seems that follow up in communities might be a possible intervention to address this (I discuss this in chapters seven and eight). At the same time, if ANC is missed, the postnatal and paediatric wards in the care continuum also serve as key points of intervention, for example, in counselling on feeding options (highlighted in **Table 4**).

The choice and challenge of formula feeding

Clearly, managing formula feeding against social norms was difficult.[12] Patients stated:

> "Bottle feeding is stressful. People ask me why are you not breastfeeding? I lie and tell them I feed my child in the morning and at night" (interview with postnatal patient on 5 August 2008).

Another woman who admitted that she was mixing formula feeding with breastfeeding said, with regard to feeding options:

> "I wasn't really given a choice". [She said that, in order to cope with formula feeding, when people ask why she is not breastfeeding, she says] "I have no milk in the breast" (interview with postnatal patient on 26 August 2008).

A key informant (a former nurse who had become an HIV/AIDS researcher) in the Eastern Cape noted that the "tins" used for formula feeding were associated with stigma (14 October 2008). This was confirmed by other key informants, and has been identified in studies on infant feeding. The title of one article on the subject is telling: "When they see me coming with the tins they laugh at me" see *Doherty et al* (2006).

One woman noted:

> "I hide it [the truth]. I say the baby doesn't like breast milk to anyone who asks why I am not breastfeeding" (interview with postnatal patient, 7 August 2008).

Another patient said:

> "The nurse told me that formula feed was the only safe option – she did not give me a choice" (interview with postnatal patient on 5 June 2008).

One woman observed:

> "I wasn't given feeding options – I was simply told to formula feed" (7 May 2008).

A fourth patient, when asked how she manages formula feeding, said:

> "I put the formula in a canister without a label (e.g., a can for instant coffee). I worry about what people think so I cannot tell anyone about my status outside my family. I keep it to myself" (interview with postnatal patient on 7 August 2008).

Women were engaging in a harmful trend – mixed feeding – with women failing to be informed of, and thus not understanding, the risks and dangers involved. One key informant, a nurse, said:

> "In the [PMTCT] training course we took, they emphasised the importance of breastfeeding and the promotion of breastfeeding – and that you must assess each woman individually" (interview on 17 October 2008).

The challenge of infant feeding among the diverse rural and urban settings for women in South Africa requires further investigation.

Experience with health personnel

One patient, describing her experience, said:

> "Counselling was poor to non-existent". [In terms of talking to health personnel, she noted] "When I first came [to hospital] I was not free [to speak]. I was feeling like they would tell others that I was HIV positive". [But over time, she began to feel more comfortable and later she felt that the staff were supportive] "I also realised that there were other women who were HIV positive" (interview with postnatal patient on 7 May 2008).

One patient, who was referred from another clinic, and gave birth at the Johannesburg site said:

> "The nurses were rude". [They made comments about her] "being on ARVs and 40 years old and what business did she have to give birth?" [She said she wanted to lodge a complaint but she didn't] (interview with postnatal patient on 5 June 2008).

A third patient said that she:

> "enjoyed coming to the hospital and talking to the women, especially counsellor X. She is a source of great support to me … The staff are great. They make you feel at home. They should keep up the good work" (interview with postnatal patient on 7 August 2008).

PAEDIATRIC WARD

Some of these women were getting onto treatment only after their child tested positive for HIV (the child's poor health might have required admission to the paediatric ward of the hospital), and after the child was initiated onto ART. This late initiation only became apparent in interviews in the postnatal or paediatric ward. Women (including caregivers) saw how positively the child responded to the drugs and this convinced them that they could do the same for their own health. Sometimes women mentioned that they would deal with their child's health first, and then worry about themselves. One key informant noted:

> "In our experience, mothers will do almost anything for their child and next to nothing for themselves. To us, this explains uptake of HIV testing, PMTCT treatment and immunizations which are all

> perceived to be child-centered; and poor uptake of family planning and on-going treatment for the mother, which are mother-centered" (email from key informant on 6 June 2009).

This emphasises the mother-child dyad, the way mother and child operate as a unit from pregnancy through the early postnatal period, and the overlapping opportunities for protecting the health of both at different points in the continuum of care.

In sum, it must be emphasised that in the interviews with caregivers of children, unexploited opportunities for HIV testing, counselling and treatment for women often came to light in the paediatric ward. Health personnel in the paediatric ward failed to refer the mother to the postnatal clinic or adult ARV clinic for HIV testing and counselling for her own health. Yet these services were available in the same facility: again pointing to the weak referral systems between wards and between facilities. When asked if these wards de-briefed or consulted regularly on patients across the units, the doctors in the antenatal, postnatal and paediatric wards said they did so rarely if at all.

Early HIV testing and diagnosis of infants

This was a yawning gap in counselling and communication. Counsellors or sisters were not getting the message across to these women that they needed to return to the hospital to have their infant tested for HIV. In Thembi's case, despite mixing breast and formula feeding, she was lucky and HIV transmission was avoided. However, she had her child tested at two and a half months instead of six weeks (While a test at six weeks is optimal, it often takes between two weeks and six weeks for the results. Results can take as long as six months for the results to return) *Besser* (email communication on 6 June 2009). If her child had acquired HIV, early testing and early treatment initiation would have been key to achieving a better health outcome. The guidelines in South Africa have not yet been change to reflect study results indicating the clear benefits of children on early treatment; but they will be. (New guidelines are anticipated at the end of 2009.) *Violari et al* (2008); *Besser* (2009b). *Besser* points out that most clinics do not have the capacity to start ART in infants. Children, overall, are under-treated for HIV (2009b).

Primary focus on the child's health - neglect of woman's health

Thembi – despite being willing to initiate ART – had yet to do so for her own health. Again, the individual-health systems dynamic comes into view. Often the women mentioned that they needed to tend to their child's health first (and sometimes

their husband or partner who was sick) before they could tend to their own. The avoidance of HIV transmission to the child is but one measure of PMTCT success. As *Chersich* observes:

> "Ultimately, an HIV-uninfected child, with an infected mother who has an unmet need for care, is a poor outcome for prevention of mother-to-child transmission programmes" (2007, p. 3).

At the Johannesburg site, health personnel from the Wits Reproductive Health and HIV Research Unit (RHRU) in facilities (in interviews) actually emphasised the importance of the health of the mother for her own sake (and for the child) but this was not the norm.[13]

Drug and formula supply

In Johannesburg, across all interviews with women and caregivers, there was no single instance of a stock out of antiretroviral medicines, including NVP (and this question was asked during each interview). Women said there was no shortage of or delay in accessing their ARV medicines. However, in the Eastern Cape, women did experience a shortage of NVP. The pill was not available at the clinic because there was a stock out. (Apparently, this situation was reported in the press but I was not able to find mention of it. Other provinces have reported shortages of formula.)

Having shared glimpses of the internal experience of patients in this study, I now turn to observations made by key informants. These comments provide additional insight into some of the systems and procedures that underpin service delivery.

PART II. THEMES IDENTIFIED IN INTERVIEWS WITH KEY INFORMANTS - THE EXTERNAL

Introduction of dual therapy

The Johannesburg site began the provision of dual therapy early in 2008, coinciding with the release of the revised PMTCT guidelines. They were using dual therapy when I began research in March of 2008. When I visited the Eastern Cape in October 2008, they had not yet begun to administer dual therapy in line with the revised PMTCT guidelines. They had begun, as Mpho mentions, to halt the administration of NVP in clinics. Instead, they were issuing NVP in labour wards. One nurse said this was because women often lost or forgot their pill (interview with key informant on 14 October 2008). In terms of benefits, this approach may be a way to ensure less

drug wastage and greater consistency in NVP administration. It also offsets the risk of nevirapine resistance induced when women receive two doses of NVP: one taken early erroneously and a second dose properly administered in the labour ward *Besser* (email communication on 6 June 2009). This approach would benefit those women who failed to take the drug or lost their pill. The implication with this approach is that NVP administration – formerly the responsibility of the mother – now falls entirely to the health system. The limitations of this decision are as follows: it puts even more pressure on health staff who are already overburdened; it exacerbates existing weaknesses in the system, such as the failure to identify women's HIV positive status; it disadvantages women in South Africa who deliver at home; while also assuming that all women do deliver in a health facility (which is not the case); and it fails to offer prevention for women whose early onset of labour (prior to arriving at hospital) is at home.

HIV coding system unduly complex

Through interviews across sites, it became clear that the HIV coding system, which was meant to protect the patient's confidentiality, was unnecessarily complex and sometimes incorrect. The HIV status of patients was missed as a result, and PMTCT was not administered. A sister and head of her ward said that women would be asked their HIV status when they were in various stages of labour. The women were often "disorientated and confused". She said the sisters would look at the recorded information and find:

> "It was impossible to decode the [HIV] code" (interview with key informant on 14 October 2008).

Ensuring HIV confidentiality restricts communication

Nurses explained that confidentiality around HIV impeded their ability to talk openly about patients with HIV and to patients with HIV, restricting knowledge, communication and action. There was concern expressed that the hospitals would be subject to lawsuits by patients whose status was inadvertently disclosed. The burden of confidentiality was mentioned a number of times, with health personnel believing that this was an onerous aspect of HIV that constrained HCWs in discharging their duties.

Staff shortages to conduct HIV tests/provide counselling

At the two public hospitals in the Eastern Cape, there was one sister responsible for all HIV testing. As noted, if health personnel are only available to test women

during the hours of 8 am to 1pm (and no one is available in the afternoons, nights or weekends), this creates obvious gaps in HIV service delivery. In Gauteng, because of the use of a cadre of HIV lay counsellors tasked with managing HIV services, the opportunities for women to test were simply greater. There were more health personnel available to test at every point: during ANC, during labour, postnatally, in the paediatric virology ward, and thereafter. However, because of a situation where the lay counsellors were paid through NGOs (by the DoH), and those payments were often delayed by several months, this affected the motivation and morale of the counsellors and restricted the HIV testing available in the facility.

Defaulters, lack of ARV adherence, and patients lost to follow up

There was frequent mention by key informants of patients defaulting on ART, of patients who become 'lost to follow up' meaning that they stopped adhering to their medication, fell out of the health system, and they needed to be 'traced'. At the time of the study, facilities were employing different methods to close this gap: through phone calls to patients. They were also beginning to look at deploying community healthcare workers to visit patients at their homes (this was based on informed consent of patients at the outset).

Financing and funding of ART treatment sites and sustainability

The Johannesburg facility provided more and better quality services than the three facilities studied in the Eastern Cape. This is attributed, in part, to the greater resources available to the Johannesburg site, including the support provided by RHRU staff. However, this is also true of many sites across the country that are funded by the US President's Emergency Plan for AIDS Relief (PEPFAR). It is worth noting that there are hundreds of treatment sites supported and funded by PEPFAR; and sometimes in concert with other local and international NGOs and academic institutions, such as the following: RHRU and PHRU, the Perinatal HIV Research Unit (both are attached to the University of the Witwatersrand), together with Enhancing Child HIV Outcomes (Echo), Elizabeth Glaser Pediatric AIDS Foundation, Columbia University, Broadreach, Absolute Return for Kids, Right to Care and other private organisations or providers). Should PEPFAR funding be withdrawn, this would be a major blow to many of these treatment programmes. Long term sustainability is therefore a concern.

Inadequacy of data and information systems and monitoring

Comparing the available data from other sources (shown below) with findings from this study allowed me to look for any discrepancies or alignment between my observations and the publicly available data on PMTCT.

During the research I spoke to health personnel, health officials and data managers about the type of data they collected at each facility and what it was used for. At the Johannesburg facility, there was a dedicated data manager who came on board while I was conducting the research. The wards in Johannesburg kept regular statistics, which were computerised. However, in the Eastern Cape facilities studied, there were no computers at two facilities. Information was recorded by hand. During the period of study there was one photocopier available (shared by the two hospitals) and no computer systems at the clinic. (As I mentioned in chapter four, the photocopier broke down on the first day. It was not repaired during the remainder of my visit).

The sister at one site in the Eastern Cape who managed the PMTCT programme shared figures recorded for the two months of August and September. I was able to note down each category and figure as she had recorded it. (She had written them by hand on a piece of paper and I typed up what she had written). These figures, together with PMTCT data from OR Tambo District in the Eastern Cape, provide some insight into the lack of quality data collected, data systems and the missed opportunities for HIV testing, prevention and treatment.

In terms of HIV testing, the numbers of women who tested for HIV were 24 in August and 25 in September. Yet there was a total of 107 live births to HIV positive women who delivered in August; and 92 in September. It is not known how many total deliveries (including HIV negative women) took place during these months, as the figures are not recorded. My guess is that there were significant numbers of missed opportunities for HIV testing: of the women who tested, 11 women (of 24) tested positive for HIV in August (almost 50%), and 9 (of 25) tested positive in September (over 26%). Over the two months, 38% of those tested were HIV positive: only 13% of women in August and 14% in September were issued NVP.

There must have been a carry over of CD4 cell testing of women from one month to the next (who had tested in the previous months) because the number of women who received a CD4 cell count test was 24 (but only 11 tested HIV positive and this group would have required a CD4 cell count test). The number of women referred to other clinics for ART was 6% and 4%, which indicates – of the women testing positive for

HIV – less than half were referred for PMTCT/ART, illustrating missed opportunities for such interventions. Only 2% of women in August and 9% of women in September were initiated onto ART. Also see that, in August, the number of women choosing to exclusively breastfeed plus formula feed equals 109 but the total sample of HIV positive women giving birth during August is 107 (two more than the total).

Another puzzling aspect is the high percentage of women electing to formula feed when 91% of households in this region of the Eastern Cape lacked potable water, and the majority of women I interviewed there failed to receive any information or counselling on infant feeding (according to the AFASS criteria, these women should have been electing to breastfeed due to the dearth of available, clean water).

Table 1 PMTCT Figures Recorded for August and September 2008 at One Hospital in the Eastern Cape

	AUGUST Number and (%)	SEPTEMBER Number and (%)
Live births to HIV positive women	107 (100%)	92 (100%)
Babies given NVP	107 (100%)	92 (100%)
Women issued NVP	13 (12%)	14 (15%)
Women who received pre-test counselling	24 (22%)	25 (27%)
Women tested for HIV	24 (22%)	25 (27%)
Women who tested positive for HIV	11 (50%)	9 (26%)
Women who received a CD4 cell test	24 (22%)	6 (6%)
Women referred for ARVs	7 (6%)	4 (4%)
Women put on ARVs	2 (2%)	8 (9%)
Women opting for exclusive formula feeding	107 (100%)	89 (97%)
Women opting for exclusive breastfeeding	2 (2%)	3 (3%)
HIV exposed babies followed up at 12 months and tested	Not done at this site	

Note: Numbers have been rounded.

Note that babies were not tested at this facility. If the goal was simply to track numbers of MTCT by recording HIV positive children at 12 months, this fails to engage or address early HIV testing, diagnosis and management of infants with HIV *Tindyebwa et al* (2004); *Meyers et al* (2006); *Shung-king and Zampoli* (2004).

In short, the type of indicators the facility elected to record – and the actual figures recorded – show the small portion of total PMTCT activity documented, and the attendant poor quality of information. Some of the inconsistencies could be attributed

to human error as well. No qualitative information was recorded. Moreover, no figures were recorded concerning the number of women who received HIV counselling and HIV related information: such as treatment, adherence, nutrition, PMTCT, infant testing and infant feeding options (even with a tick box approach). Of equal importance, according to health staff at the site, what little information was collected was not being used to improve current practices and systems: "There are no feedback loops for quality improvement" as one key informant noted (6 June 2009). The figures indicate that NVP administration to the child is good. Whether PMTCT administration to the mother was appropriate to the numbers requiring it is difficult to ascertain from these figures alone. Note that there is no way to validate the quality of data collected – especially when the data indicate that 100% of babies are given NVP, against a background where administration of NVP to the mother is poor, as corroborated in the interviews.

The facilities should be recording the total number of women who took NVP in labour (NVP uptake) – whether self-administered or administered by health staff – against all HIV-exposed births (children with an HIV positive mother and therefore exposed to HIV during labour and delivery). The figures also point to potential gaps in providing HIV testing to pregnant women and initiating women onto ART, as this site would be one of the few offering it (especially because primary healthcare clinics were not offering NVP); and one facility that would refer women to clinics for ARV initiation (even though clinics providing ANC stopped providing nevirapine, the accredited clinics would provide ART to patients). There appears to be double-counting in this facility and in others. There is no attention to NSP targets or to aligning facility indicators to NSP goals at any of the facilities in the Eastern Cape – even though there is a General Manager for District Health Services indicated on the Eastern Cape Provincial DoH Website, whose role is to "develop, monitor and evaluate the rendering of district health services, including maternal and child health" *Eastern Cape Provincial DoH Website* (2009).

In contrast, at the Johannesburg facility there was variation in what type of data was recorded and what the information was used for. There was a perception that data captured in the paediatric ward, however, were used primarily by donors to monitor and justify their funding. Although a doctor and a sister said that the information was given to the DoH for national and provincial reporting, the sister in the paediatric HIV ward could not tell me what the indicators for the NSP were with regard to HIV transmission in children. There seemed to be no goal-setting, monitoring of progress, mid-course corrections, feedback amongst staff, etcetera. In the antenatal and postnatal wards, in sharp contrast, staff from RHRU were very clear on national goals, the transmission rates to infants, the number of women testing each month, etcetera. As indicated, RHRU staff are exceptional.

Below are consolidated data from Oliver Tambo District (which comprises 40 sub districts) in the Eastern Cape.[14] Indicators are provided for each quarter, over four quarters (equivalent to one year). I downloaded the figures directly from the Eastern Cape Provincial Dept of Health Website. They are thus publicly available.

From these figures, the data show that the testing rates in ANC for women move from 63% to 80%, which is quite high. However, the test rate for babies hovers around 55% to 58%. This is too low, indicating that they are failing to test over 40% of babies for HIV. Transmission rates to the child are also unacceptably high, over 20% across the four quarters, with over 25% of babies testing positive (higher than the national average and much higher than the national target of 5%). The administration of NVP to newborns is high: up to 100% by the final quarter. What is disturbing is the percentage shown for pre-test counselling (and this is the only figure provided for counselling): from a high of just over 9% declining to almost 6% in the final quarter shown.

Table 2 PMTCT Data from Oliver Tambo District, Eastern Cape (over four quarters)

District	HIV Services	Indicator	Type	2005/06 Q4	2006/07 Q1	2006/07 Q2	2006/07 Q3
O Tambo DM	PMTCT	HIV test ANC rate	%	63.0	79.1	80.9	100.0
		HIV test rate baby	%	55.0	50.4	58.1	100.0
		HIV transm baby 1 yr	%	24.8	21.7	22.6	21.7
		HIV+ test rate	%	23.5	24.4	24.7	23.1
		NVP newborns	%	80.8	84.0	100.0	100.0
		NVP uptake	%	13.7	16.6	25.1	28.0
	VCT	Pre-test couns inc	% x 12	8.6	9.2	7.9	5.8
		VCT HIV pos rate	%	38.0	28.5	30.3	28.6
		VCT male rate	%	28.4	24.2	24.2	25.9
		VCT testing rate	%	63.6	66.2	72.5	74.6

Source: *Eastern Cape Provincial Dept of Health Website*, see 'Statistics on HIV and AIDS" available from, http://www.ecdoh.gov.za/uploads/files/240207133326.pdf (accessed on 16 April 2009).

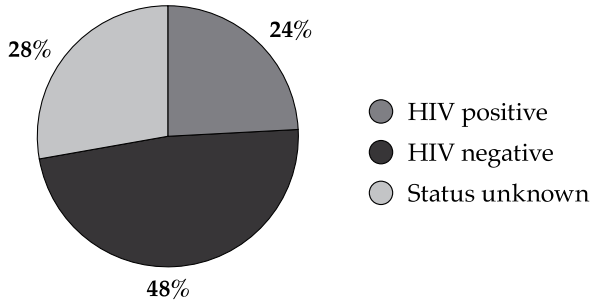
In terms of the accuracy of the data, several key informants involved in data management indicated that the figures should not be trusted; that there were discrepancies in how indicators were defined, counted and reported: one data capturer said that 70% of the data were simply not recorded at all (interviews with key informants in the Eastern Cape on 15 and 17 October 2008). One of the key informants observed: "Data quality is very poor across the [Eastern Cape] province". "Statistics in the nevirapine register are accurate" but "some statistics are double-counted" and "they carry over figures from the previous month". Health personnel are filling in information but they are not working from a common definition of an indicator (17 October 2008).

If these data are correct, and that is a big assumption, the weakest aspects highlighted by these data are as follows: HIV testing, counselling, provision of NVP and ART to women, infant HIV testing and follow up with children. These aspects correspond with my findings. Note how limited the quantitative information is in understanding how improved PMTCT and ART delivery for women and children can be achieved.

Significant percentage of women have unknown HIV status at delivery

Considering that the woman's HIV status was unknown in 28% of births at the hospital in Johannesburg where resources and testing opportunities are greater (as indicated by this research, it is safe to assume that a significant percentage of women were not receiving HIV testing in the Eastern Cape either). In Johannesburg the research shows that women refuse testing; repeat testing for women who refuse is not routinely offered; HIV test results may be incorrect (attributed to poor sensitivity of rapid HIV tests) (see *Black et al* (2009)); women may undergo sero-conversion of their HIV status during pregnancy; and, HIV testing is not always available at the time women seek testing due to a shortage of staff or test kits. To illustrate the significant number of women whose HIV status is unknown at the time of delivery, I employ figures from the Johannesburg site over the one year period of March 2007 through February 2008.

Figure 1 HIV Status at Time of Delivery - Johannesburg (March 2007 - Feb 2008)



Source: Data and figure from Dr Vivian Black, RHRU, University of the Witwatersrand. Reprinted with permission.

From the birth register, 10 111 deliveries occurred at the Johannesburg facility during this period. Among the women who delivered, 2 436 (24,1%) were HIV positive, 4 839 (47,9%) were HIV negative and 2 835 (28%) were of unknown HIV status (**see Figure 1**). The 2 835 women of unknown HIV status missed HIV testing completely. Those who would have tested positive missed life-saving interventions and opportunities to reduce the risk of HIV transmission to the child. The number of women who were HIV positive at the time of delivery was 24%; 28% of women's HIV status was unknown; and the remaining 48% were HIV negative.

The key message from the pie chart is that a significant number of women deliver without having an HIV test. The chart also indicates that roughly one quarter of women (at the Johannesburg site) require ART and PMTCT. Of that 24%, how many are receiving prevention and treatment interventions?

TASK SHIFTING IN JOHANNESBURG CLINICS

During my doctoral research, a particular phenomenon began to come to light in the Johannesburg (JHB) site. I, together with my colleague Dr Vivian Black, decided to study it in greater detail. As noted, the HIV lay counsellors were responsible for HIV-service delivery at the JHB site. That practice is in line with 'task shifting' presented and approved in the NSP.

> "Task shifting: This involves the delegation of activities to less qualified cadres and includes, for example…lay counsellors (rather than nurses) 'pricking' patients for rapid HIV tests; lay counsellors (instead of social workers) for orphan support activities. The NSP recommends that regulatory and policy barriers to task shifting be identified" *Government of South Africa* (2007a).

While the counsellors work in public hospitals and clinics, they are employed by intermediary non-governmental organisations (NGOs) in these three clinics and others in South Africa. The Department of Health makes payments to the NGOs and the NGOs, in turn, administer a monthly stipend at the rate of R1,000, which is below the minimum wage in South Africa (The minimum wage is R1,663.20 per month for those who work full-time.).[15] It is important to note that the lay counsellors are not volunteers. They expect to be paid like any other employed professionals and they rely on monthly payments to fund basic costs of living, including transport to work.

What became increasingly clear was that the HIV counsellors' monthly payments were consistently delayed, sometimes for months at a time. Yet they were seen as, and acted as, the main stewards of HIV service delivery in the clinics – indeed the pillars of the HIV programme. We wondered whether delayed payment might be having an impact on the performance of counsellors and on the type and quality of services received by patients. Hence, we decided to explore this further.

Focus

Dr Black and I investigated whether late payment of HIV lay counsellors had an impact on VCT service delivery in three antenatal clinics in inner-city Johannesburg, including the facility were I was conducting research.[16]

Methods

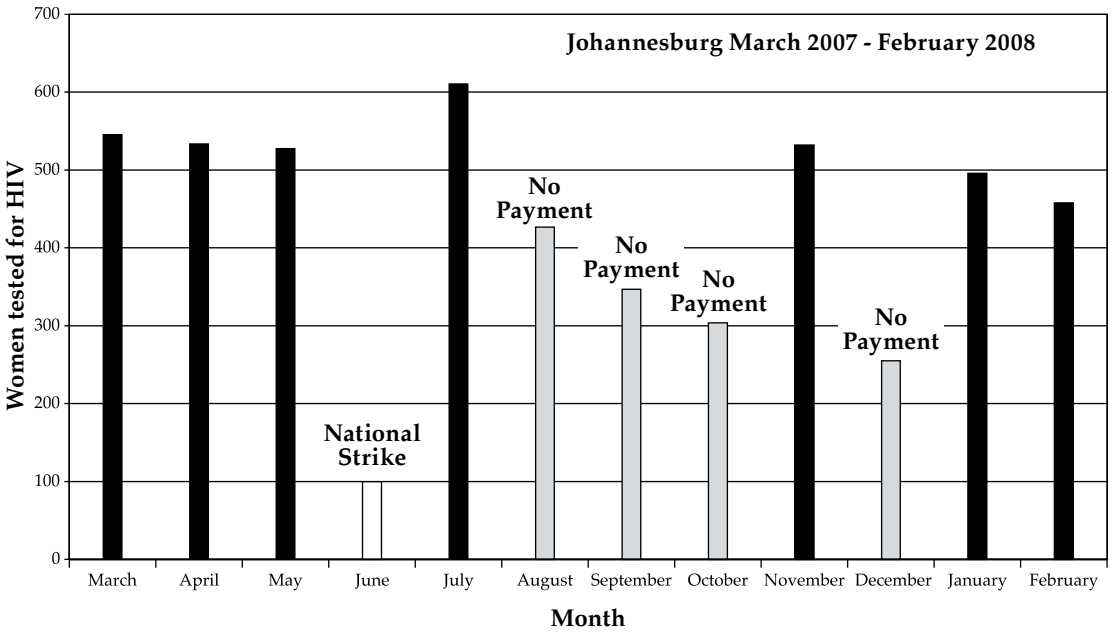
We had administrative staff record the number of pregnant women attending these antenatal clinics for the first time. The numbers of women who had an HIV test were recorded by midwives (who conducted the rapid HIV tests in the clinics). We calculated the voluntary counselling and testing uptake (women who consent to be tested) for each month over the period 1 March 2007 to 28 February 2008 (one year) from three antenatal clinics in Johannesburg. This was calculated by dividing the number of women who completed voluntary HIV counselling and testing by the total number of pregnant women seeking antenatal care (and HIV testing and counselling) for the first time. Using the figures, we recorded the number and percentage of HIV tests performed each month. We recorded which months lay counsellors had received their remuneration (or not) over the same time period. The proportion of women completing HIV testing was compared for the months when lay counsellors were and were not paid using the Fisher's exact test – a test of statistical significance. The mean number of women completing HIV tests in the months where counsellors were and were not paid was compared using an unpaired t-test. Data from June 2007 was excluded from the analysis (due to a national public workers' strike that included nurses and lay counsellors). Comparisons were calculated, including and excluding December (a month which frequently has a different pattern of clinic attendance owing to women returning to their, often distant, homes for the holidays). Data were entered into a Microsoft Excel 2003 database and analysed using Graph Pad Calculator (2002 – 2005 Graph Pad Software Inc).

Results

We found that lay counsellors did not receive their monthly salaries at the end of July, August, September and November 2007. They received remuneration for July through September only at the end of October 2007. They received their November 2007 pay at the end of December 2007. Following each of the seven months when remuneration was received (March, April, May, October and December 2007; January and February 2008), of the 4 722 women who attended an antenatal clinic, **78.5**% had an HIV test. Following the four months of non-payment, among 2 502 women who attended the clinic, **53.3**% had an HIV test. If we exclude December from the analysis, this difference is still significant (with a p value of < 0.0001). Following these three months when counsellors were not paid, of 2 069 women who attended antenatal clinics, **52**% had an HIV test (**Figure 1)**. Again, the **52**% when counsellors were not paid contrasts with **78.5**% for the other months when they were.

In **Figure 2,** the number of pregnant women tested per month was usually above 500. However, each month following nonpayment of the counsellors, there was a substantial decline in the number of women who test for HIV – which would be lower if these counsellors were not supported financially by individual staff on-site (in response to their dire financial situation). Following nonpayment, the counsellors often did not report to work. In June 2007, there was a national public sector strike that included healthcare workers. Lay counsellors were not paid at the end of July, August and September 2007. They received their remuneration for these months at the end of October, but were not paid at the end of November 2007. As counselling and testing is the entry point into HIV prevention and treatment services, this had a number of consequences.

Figure 2 Voluntary Counselling and Testing Provided in Three Antenatal Clinics in Johannesburg over a One-Year Period



Source: Bar chart prepared by Dr Vivian Black. Reprinted with permission.

Implications

The data demonstrate that late payment of lay HIV counsellors was having a significant impact on HIV testing in these three clinics, particularly in the months following non-payment. This trend is illustrated by the declining figures following non-payment of the counsellors. In terms of alternative explanations for the drop in testing uptake, there were no specific variables that would affect the rate of HIV testing, such as changes in the total number of counsellors, or to counsellors' responsibilities.

There were no changes to management policy or delivery; no new interventions were employed to improve HIV testing during this period (which might have had the opposite effect).

The data suggest that while the total number of staff did not change, absenteeism increased (possibly due to counsellors' inability to pay for transport), and the motivation and morale of the lay counsellors was likely to have declined – affecting their on-the-job performance. We did not interview staff regarding their motivation or morale during this period, as our main objective was to determine whether late payment impacted on the delivery of services. However, it was clear that lay counsellors were anxious about non-payment (they made repeated verbal inquiries about late payment to clinic staff). The findings also indicate that pay may be a marker for overall HCW performance. Health personnel, if improperly paid, may thus be seen to hinder VCT delivery: the opposite may also hold true. If lay counsellors continue to provide these services without reliable pay, service provision and outcomes may thus continue to be negatively affected.

In our investigation of these clinics, the new NSP brief for lay counsellors has not been accompanied by legally-commensurate employment conditions that govern their scope of work, provision of adequate training for PMTCT delivery, health benefits and other employment benefits, career development and trajectory, psychological support, protection against infection and ill-treatment, and other forms of statutory and constitutional protections afforded employees under South African labour law.[17] From the data, lay counsellor performance, morale and absenteeism directly impacts on the service delivery – quantity (the numbers of pregnant women who are served in the clinics) and the quality of those services. Secondly, their performance impacts directly on the health of pregnant women, determining whether women are able to initiate antiretrovirals and thus improve their health and survival. Thirdly, their actions impact on the efficacy of the programme to reduce mother to child HIV transmission. As noted, under the new PMTCT guidelines, pregnant women are initiated onto AZT from 28 weeks gestation with a single dose of nevirapine at the onset of delivery. Lay counsellors are integral to the successful implementation of this new programme. Without them, these services are not provided to patients in the Johannesburg clinics. Of concern, is the high percentage of women giving birth in public hospitals whose HIV status is unknown, as discussed.[18]

PART III. PRIMARY BARRIERS TO TIMELY PMTCT (FOR CHILDREN) AND ART (FOR WOMEN) AT THESE SITES

Based on the interviews with patients, key informants, a review of patient files, against the policies and procedures for ART/PMTCT, the following is a consolidated summary of barriers, barrier type, and potential consequence issuing from the barrier or delay.

1. **No money for public transport** (individual economic)

Money was viewed as a primary obstacle to healthcare and HIV services for patients in this study.

2. **Fear of a positive HIV test result/stigma** (individual psycho-social)

Delays in seeking ANC and HIV testing stemmed from psycho-social factors: mainly fear and anxiety.

3. **Anxiety or denial of HIV positive status after testing** (individual psycho-social)

Women expressed their shock upon hearing of their HIV positive result, although some women had some indication that they were positive due to failing health. Some women who had not initiated ART until after their child was born withdrew from the health system, indicating that they had delayed or missed PMTCT/ART for psychological reasons.

4. **Patient refuses to test (fear of result, fear of consequences)** (individual psycho-social)

I wasn't able to speak to any women who had refused to test because one recruitment criterion for the study was an HIV positive test result. However, from the existing data on the number of women whose status was unknown at Johannesburg (and other facilities) (**Figure 1**), and from interviews with health personnel, women do refuse to test. The assumption, based on this research, is that this is owing to fear, stigma or other psychological factors. Repeat testing to patients who have refused then becomes essential.

5. **Clerk turns patient away at first booking** (health personnel)

This came out in patient interviews only at the Johannesburg site (providing specific levels of care amid high demand). In viewing the referral criteria and procedures in Johannesburg, it became evident that the hospital does send women away – whether this is legitimate or not was difficult to ascertain.

6. **No HIV testing available because no health personnel available to test (or health personnel busy with other responsibilities) or no HIV test kit available** (health personnel/health systems)

In all facilities patients told of not receiving counselling. Putting this together with interviews from health personnel in the sites, this could be attributed to a lack of HIV test kits (Eastern Cape), and a shortage of health personnel to test women.

Whether there was an absolute shortage of health staff at these sites was not something I can fully answer. But it was evident that there was a shortage of staff *dedicated to HIV service delivery* at every hospital and clinic in this study and/or a lack of integration of HIV into routine services, owing to insufficient numbers of staff – or the absence of staff – on the days when women presented for ANC.

7. **Poor or no HIV counselling received at time of HIV test** (health personnel)

Poor (or no) counselling led to attendant psychological impacts on the woman, which affected both her knowledge and behaviour.

8. **Patient does not return for CD4 cell count test results in timely fashion** (individual economic and/or psycho-social)

Again, possibly due to her psychological state or economic circumstances, the patient withdraws from the health system and does not return for HIV staging and initiation.

9. **Patient's file does not have CD4 cell count test results recorded** (health system)

ART can only be offered if the patient qualifies. Thus a CD4 cell count is a requirement for timely ART. Here the procedures in hospital were leading to inefficiency and ineffectiveness in this area.

10. **In labour and postnatal wards, unbooked patient does not receive HIV test** (health personnel)

If a woman missed ANC completely (she is called an 'unbooked patient' because she shows up to a hospital for the first time to deliver her baby – having received no ANC), she should receive an HIV test in the labour ward, thus still allowing for post exposure prophylaxis to the child. This is an optimal point for HIV education and counselling, including treatment (for the mother), adherence, nutrition, infant testing, and infant feeding options. This opportunity, however, was consistently missed.

11. **In labour ward, woman's coded HIV status incorrect, misread, impossible to decipher, or not recorded (woman and child not given ARV prophylaxis)** (health system/health personnel)

Here the complex coding system was expressed by health staff as a barrier to deploying HIV-related interventions in the labour ward. If the woman's status was unclear, she would need to be re-tested (this research showed that repeat testing was not always occurring).

12. **In labour and postnatal wards, poor or no counselling given on infant feeding choices** (health personnel)

In some instances, women were tested for HIV but they were not provided with counselling in the labour or postnatal wards, often leading to a ripple effect of a lack of information, coupled with a poorer psychological state and an attendant lack of information to make choices with regard to infant feeding and managing the infant's HIV status.

13. **In labour ward, clearly HIV positive woman given no ARV prophylaxis (for woman or child)** (health personnel)

A woman with HIV is given no NVP or AZT in the labour ward. This was taking place across all facilities but more frequently in the Eastern Cape.

14. **Patient tests negative and sero-converts** (becoming HIV positive in pregnancy) **but repeat testing was not provided (so status shows negative and no interventions are provided)** (health personnel)

Research has shown that a number of women sero-convert during pregnancy (and initial HIV test results are sometimes incorrect). This is why policies and procedures for repeat testing are put into place. But if testing is not repeated, there are women whose sero-status will change from negative to positive and they will miss all HIV-related services as a result *Black et al* (2009).

15. **In postnatal ward, patient not tested for HIV and not initiated onto ART in timely fashion** (health personnel)

At times, testing was not provided to women of unknown HIV status. To women who test HIV positive, staging, ART initiation, family planning; and follow up care and support was not provided.

16. **In paediatric ward, women not given HIV test, counselled on ART availability** (health personnel)

A woman with an HIV-infected child is not screened for HIV, or informed of ART for herself. She is not counselled on family planning, or provided follow up care and support (as above).

Potential consequences of these barriers are withdrawal from the health system; missing PMTCT for the child; missing or delaying ART for mother; delaying HIV testing and treatment for the child (if HIV positive). The result may be that prevention is missed for the child; and, treatment is missed for the mother. Missed opportunities to counsel the woman on HIV, treatment, adherence, nutrition and prevention of transmission in a future pregnancy also result. The larger implication is that poorer health outcomes for the child and the mother result.

Of the barriers identified on the previous pages, some were higher for women, and some were more frequent. Across the facilities studied, the weakest aspects of the PMTCT programme undermined the patient's journey through the care continuum, making access to information and services challenging. These were as follows.

Summary of Key Findings: The Weakest Links in the PMTCT Programme

Poor (or mal) distribution of health personnel dedicated to HIV testing, counselling and related PMTCT and ART interventions (counsellors/HCWs were not available to test, poor follow up for patients who refused testing, repeat testing in pregnancy should occur to address patients who sero-convert) leading to inadequate testing coverage and inadequate PMTCT/ART service provision in these facilities. Another way of looking at this is the poor integration of HIV services into routine healthcare.

Inadequate knowledge of PMTCT on the part of HCWs and lay counsellors leading to inadequate information for the patient to promote and address her health.

Poor HIV counselling on adherence, disclosure, support, and nutrition – leading to confusion or misinformation and lack of support. Highlighted within poor counselling is the *very poor or no counselling on infant feeding* in particular, increasing risks of HIV transmission postnatally.

Poor referral networks between feeder clinics and hospitals and between units (paediatric and postnatal) within hospitals leading to missed opportunities for PMTCT/ART.

Poor systems and practices for data capturing and dissemination to track clinic/hospital progress against NSP indicators in the Eastern Cape, paper based systems used to capture indicators and the indicators themselves were both inadequate. The data capturers did not have training, did not have common definitions of indicators, double counting was occurring, etcetera.

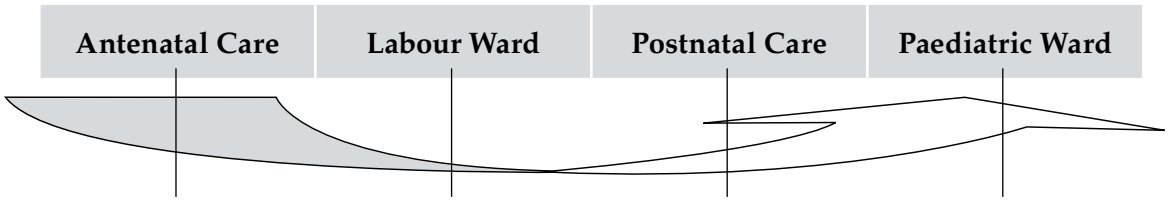
Lack of clarity and consensus on monitoring and measuring PMTCT programme effectiveness nationally, provincially, and in each facility. This was resulting in poor understanding of what is occurring in facilities; how performance should be managed; and, poor sharing and dissemination of information on what PMTCT programmes were doing well and which were failing.

Inequity of coverage in the Eastern Cape province is lagging well behind Gauteng in the implementation of dual therapy, raising issues around the equity of coverage. The implication is that health outcomes improve with dual therapy, which has been delayed, impacting negatively on health outcomes.[19]

The quality of current PMTCT service provision is highly variable within and across the facilities studied: HIV testing, ART and PMTCT service delivery can be 'hit or miss'.

Moving from the findings to points of intervention to plug the gaps in missed PMTCT/ART delivery, there are presently four critical points of entry for HIV testing and counselling, for prevention of HIV infection in children, and initiating women onto ART. These are as follows.

Table 3 Mother-Child Dyad: Key Points for PMTCT/ART in the Care Continuum



Antenatal Care	Labour Ward	Postnatal Care	Paediatric Ward
ANC provides best opportunity for HIV counselling and testing (early ANC entry is recommended). ANC provides best opportunity for preventing HIV in children and initiating ART in women. Testing, PMTCT, ART in ANC allow for better health outcomes for mother and child.	If HIV testing is missed in ANC, there are still opportunities for testing/counselling and for information provision. There is ample opportunity to provide PMTCT. Mother should be counselled on infant testing at six weeks and on infant feeding options.	If PMTCT/ART is missed in labour ward, postnatal care (PNC) provides opportunity for HIV testing and ART initiation for mother, especially counselling. First PNC visit is opportunity for additional info on HIV testing for child, and info on infant feeding.	If PMTCT/ART is missed at all previous points, the paediatric ward is an opportunity to test the child and to offer testing and/or to refer the mother for testing at another facility if needed.

→ Key opportunities for counselling, support, information provision on reproductive health options, partner testing, family planning, etc. ←

PART IV. *CUI BONO?*[20] PMTCT, ART AND EQUITY

Research from this study indicates that if you are pregnant and living in the OR Tambo District of the Eastern Cape, you are less likely to access timely HIV testing, counselling and PMTCT/ART interventions than your urban counterparts in Johannesburg. Again, the Eastern Cape is primarily a rural province with 70% of residents poor, 30% unemployed, and roughly 94% of the population reliant on the public health system *Eastern Cape Provincial Government* (2009). In contrast, Gauteng is highly urban

and densely populated, capturing 20% of the South African population (and that figure does not account for migrants or refugees). Gauteng has an estimated 22.6% unemployment rate, and is the richest province in the country *Health Systems Trust* (2009); *Statistics South Africa* (2000). Access to specific types of healthcare, including ART and PMTCT, was more difficult for populations from the Eastern Cape. There were fewer sites accredited for ART, fewer places to access PMTCT, fewer locations offering infant testing for HIV and diagnosis, follow up, and paediatric HIV care and treatment. Factors that compounded this problem included the following.

Patient-Provider Dynamic in Eastern Cape

Many women were timid about asking questions. This may be a function of personality, socialisation, culture, or a mix of these or other factors. Whatever the case, the observed passivity on the part of the patients and the treatment of patients by health staff, particularly in rural areas – when mixed together – created a dangerous cocktail. Women who did not ask questions or make requests were more likely to be failed by the health system in this study. The tendency of patients to be passive in the Eastern Cape is real, and health personnel feed that passivity, to the detriment of patients' health. To be frank, women were often treated more like furniture than participants in their own health decision-making. Communication and engagement with the patients, where the patient makes decisions about her health in conversation with the provider, needs to be re-introduced. This dynamic is not perfect anywhere in the world. But it is happening in Johannesburg. Urban environments appear to make for more competitive environments. Patients become more vocal about placing demands on healthcare providers (relatively speaking), asking questions, and exhibiting persistence – to the benefit of their health and that of the child.

Fragmentation of Service Delivery and Expense of Transport

A central problem for rural women was the organisation and location of services (and distance between points of service delivery). In the Eastern Cape, antenatal care would be provided in clinics, which were geographically close to women's homes. Ideally, a woman would receive an HIV test and counselling at a clinic, and would initiate ART there. Because there were few sites accredited for ART, however, it was most likely that women would have had to travel a greater distance for HIV services. They would thus deliver at a hospital, accessing ARV prophylaxis (syrup) for the child there. If they had not yet received an HIV test and treatment, it was meant to be provided in the labour ward in hospital. But because of the limited availability of infant PCR testing, women would need to return to the hospital for infant testing. If the woman had not

initiated treatment, she would need to visit her local clinic for her own ART initiation, monitoring and collection; and to collect formula if she had elected to formula feed. But many clinics were not yet geared up to provide paediatric HIV care and treatment (although they were making progress in this area). Nonetheless, she might be able to access immunization services for the child at her local clinic. The mother would thus need to return to the hospital for the child's HIV care, treatment and monitoring and to an ART accredited site for her own. Below is an attempt to map this visually.

Table 4 Points of Access in the Continuum of Care - Eastern Cape

1. ANC	2. Delivery	3. Postnatal	4. Paediatric HIV	5. ART Mgt/Routine Services
Clinic A* →	Hospital →	Clinic A →	Hospital ↔	Clinic A
HIV testing and counselling (mother)	PMTCT	ART initiation (mother) Formula collection	PCR test (child) ART initiation (child) HIV management (child)	ART management (mother) Regular collection of formula Child immunization

*Note: This is assuming that clinic A offers both HIV testing and ART initiation for the mother. It is possible that the mother might receive ANC and HIV testing at one clinic but have to travel to an accredited ART clinic for ART initiation, which would introduce an additional step (travel to Clinic B). The number of ART-accredited clinics located in the OR Tambo District is very small.

Note that the mother is likely to receive ANC and postnatal care in the same clinic – and possibly ART management (depending on the ART accreditation of the clinic closest to her home). However, delivery would normally occur in a hospital. At this stage, she is likely to seek paediatric HIV management at a hospital. She may also need to seek immunization for her child at a separate facility. *Health Systems Trust* data from 2003 indicate that 86% of clinics in the Eastern Cape would have immunization (EPI) services. However, it is unclear whether the same clinic would have ART services for mother and child, which might introduce travel between two clinics and the hospital.

An HIV-infected mother with an HIV-infected child would thus move through points 1 through 3 during ANC, labour, and postnatal care. Thereafter, she will need to move regularly between points 4 and 5 on the continuum to receive regular check-ups, immunization for the child, ART monitoring and collection for herself (at the clinic) and for her child (at the hospital). One can see the required movement between points of care. Distances between the clinic and hospital would vary but they are likely to be significant (and possibly unaffordable) – with the hospital often being quite far from women's homes and the clinic being quite close in the Eastern Cape.

HIV service delivery for a mother and child essentially forces a woman to access care in a fragmented way. This type of structure is burdensome in terms of time, money and energy, and appears to set people up to fail. It is unlikely to be clear to women which services are available at which point. It takes some time to understand how and where to access services on the continuum. Mistakes or delays could result in neglect of health and foregone opportunities for health information, and interventions, with potentially harmful health consequences. This emphasises the importance of integrating services into a single facility.

The converse, for Johannesburg patients accessing a public hospital, is shown below.

Table 5 Points of Access in the Maternal/Child Continuum of Care - Johannesburg

1. ANC	2. Delivery	3. Postnatal	4. Paediatric HIV	5. ART Management
Hospital →	Hospital →	Hospital →	Hospital →	Hospital with down referral to local clinic →
HIV testing and counselling (mother)	PMTCT	ART (mother) Formula	PCR test (child) ART initiation (child) Continuous ART management (child)	Regular ART management (mother) Collection of formula Immunization (child)

As can be seen, in the Johannesburg facility, every point of access (1-5) from ANC through postnatal care is potentially available at the hospital, although in practice, not all women would have accessed each point in the continuum of care at this hospital. Recall that few women would benefit from this one-stop shop, as the hospital requires patients to meet the referral criteria – and they may only go to this hospital for emergency care. The key implication here is the possibility of integration and service provision of maternal and child health services at a single site. In the aftermath of pregnancy, postnatal care and PCR testing might be received in hospital – or the patient could be successfully down-referred to a local clinic where she is meant to continue ART access for herself, her child, and to access related health services, including immunization. This is possible but the problem is that normally the paediatric HIV care (both perceived and actual) in clinics is not yet as good for children as that received in tertiary facilities in many provinces, and women often return to the hospital for their child's HIV management as a result (this is certainly the case in Eastern Cape – with a mixed picture in Gauteng). Some women are able to obtain ART in the adult ART clinic at the hospital, thus keeping their HIV management and the child's at one site. And, some women are able to access all services at the primary healthcare level in Gauteng. However, not all women are able to do this.

Failing to Deliver ART through Primary Healthcare Clinics (PHCs)

The answer to this particular problem would be to strengthen primary healthcare services, integrate HIV services with other routine health services, and to offer all possible maternal/child health services (including HIV) at a single point that is close to where people live. This was the initial objective of the primary healthcare system. However, with the introduction of ART, the South African Government took a number of actions that led to the current situation. First, they introduced an accreditation process for offering ART based on the assumption that ART management would be highly complex, and that PHC clinics would not be equipped to provide adequate care. The accreditation process also favoured urban areas with good infrastructure to speed ART access. However, this, as foreseen by other researchers, has exacerbated an existing rural/urban healthcare divide *Ijumba et al* (2004). Now, the accredited ART sites tend to be located in urban areas, which are at a distance from the homes of rural populations. *Human Rights Watch* stated: "Health care facilities are frequently physically and economically inaccessible to the poor, to rural populations and to other vulnerable groups in poorly serviced areas" (2008). Returning to the initial debate begun in chapter two on the relationship between expanded AIDS treatment and strengthening primary healthcare (PHC), based on these research findings it would seem that strengthened PHC services, which are able to offer maternal and child HIV services, together with routine health services (especially immunization for children and reproductive health services for women), would enable people to seek treatment close to home, to do so more rapidly, with more frequent visits, at less expense, while also allowing tertiary facilities to focus on specialised care, as intended – with a view to improving health outcomes while providing comprehensive, *integrated* care *MSF* (2006b); *Lutge et al* (2006) *Bateman* (2008).[21]

PMTCT Exacerbates Underlying Inequities in Healthcare

This study is not the first to make the point that underlying inequities in healthcare in South Africa exist but few studies have looked specifically at the relationship between existing inequities and the impact on PMTCT service delivery. In a recent study, Jackson *et al's* findings dovetail with findings from this research. They observe: "underlying inequities in healthcare quality within South Africa are predictors of PMTCT programme performance and will need to be addressed to optimise PMTCT effectiveness *Jackson et al* (2007, p. 509). The cornerstone of PMTCT is effective counselling and testing. The execution of PMTCT programming is occurring within a context where infrastructure is not optimal, coupled with an under-staffed, under-trained cadre of healthcare workers in resource-poor areas of South Africa.

The population is poor and their socio-economic conditions play an important role in determining whether they will be able to access antenatal care and the continuum of care thereafter. As *Ijumba, Poole, George and Gray* noted at the outset of ART accreditation: "access to ARVs is anticipated to be very uneven across the country, worsening existing health system inequities" (2003). The PMTCT programme seems to intensify extant health system inequities as well. This makes it more difficult and more onerous for rural populations to access HIV services.

Insufficient Knowledge of PMTCT

Based on comments by women, caregivers and health personnel interviewed, HCWs had insufficient knowledge of preventing HIV mother to child transmission, including the risks of infant feeding, the role of dual therapy and other factors. While both sites had an inadequate emphasis on the knowledge base of HCWs (and how to monitor and improve it), with regard to PMTCT/ART for women and children, this problem had a more negative effect in the Eastern Cape because it was compounded by insufficient staff. Inadequate numbers of staff with insufficient knowledge is a recipe for disaster, leading to missed opportunities in HIV testing, prevention and treatment.

Conclusion

This chapter has captured and elaborated the main findings of the empirical research. It began by offering two patient stories that would illustrate the nature and type of barriers women face in their journey through the continuum of care, and in the access and provision of ART/PMTCT in two public health sites: Eastern Cape and Gauteng. The initial stories (the internal) were then placed in the context of interviews undertaken with 83 women living with HIV, and cross cutting themes were identified and explored. Where possible, delays in access to care and HIV services were pinpointed in relation to their location in the continuum of care: antenatal, labour, postnatal or paediatric wards. Part II of the chapter set forth a set of recurring themes identified in interviews with key informants (the external). A set of findings regarding insufficient data and information systems as structural weaknesses within the PMTCT/ART programmes was located within that discussion. In Johannesburg, the phenomenon of task shifting was explored to consider whether and to what extent health personnel (as a social determinant of health) impact on HIV service delivery. The impact was found to be significant – revealing much about the role of health care workers in timely service provision. In part III, primary barriers to women's timely access to and provision of PMTCT and ART were put forward, and key findings summarised. In part IV, I discuss factors that impact negatively on the equity of prevention, care and treatment. In the next chapter I use secondary analysis on mortality to make conceptual linkages and explore connections between premature mortality linked to HIV in pregnant women and children; assessments of health equity; disparities in PMTCT/ART provision; and the implications for the capabilities of women.

Exhibit 1 PMTCT Revised Guidelines

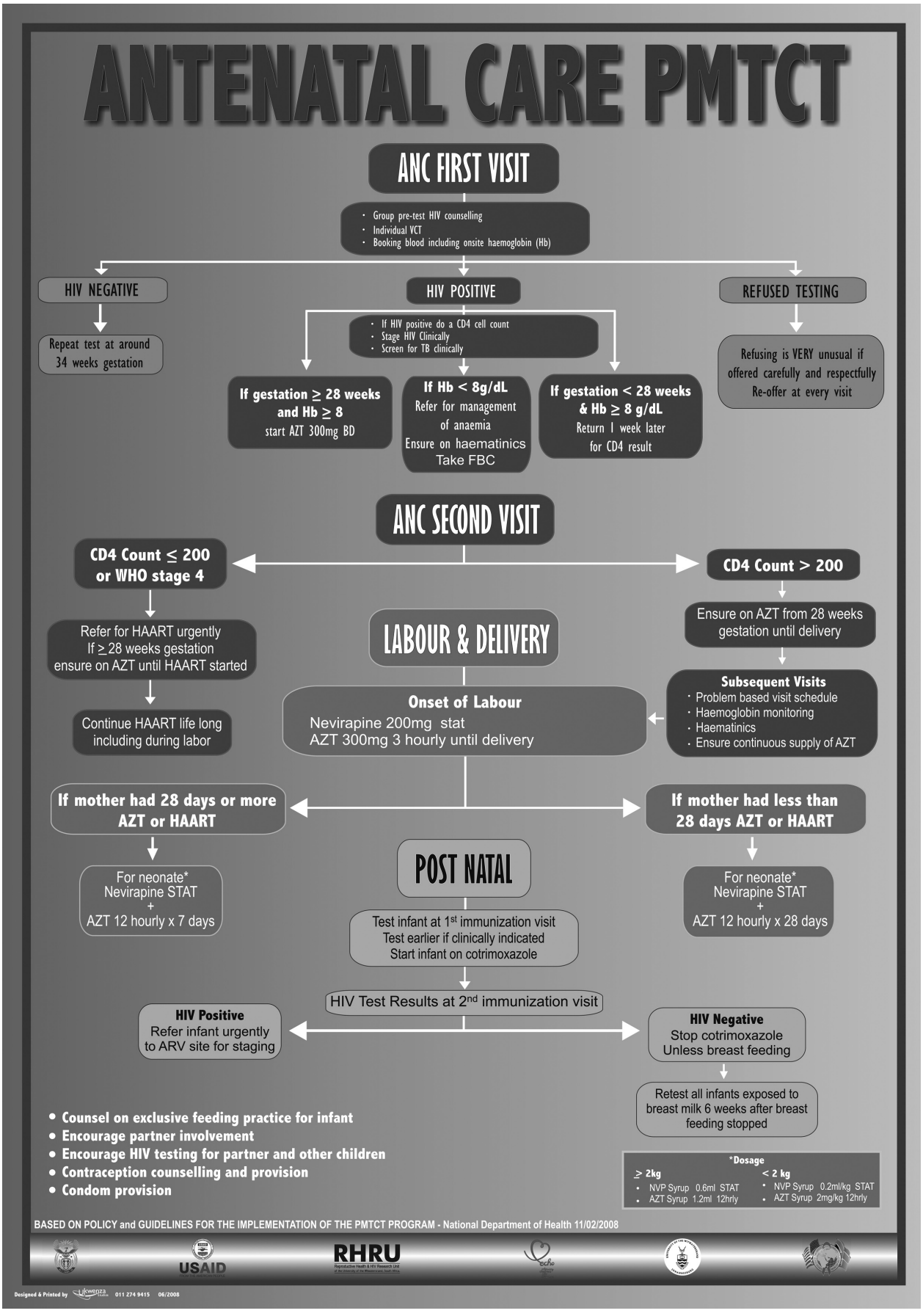


Exhibit 2 Routine Health Services Provided in Each Facility

	JHB* Site	EC* Hospital	EC Hospital	EC Clinic
Antenatal Care (ANC)	√	√	√	√
Labour and Delivery	√	√	√	No
Postnatal Care	√	No	No	√
Voluntary HIV Testing and Counselling (main provider)	√ (counsellor)	√ (nurse)	√ (nurse)	√ (counsellor)
CD4 Testing and Staging	√	√	√	√
Provision of ART to women (triple combination therapy)	√	√	√	√
Provision of Dual Therapy for PMTCT	√	No (NVP only)	No (NVP only)	No (NVP only)
HIV Support Group during ANC	√	No	No	No
HIV support group for women during Postnatal period or after	No	No	No	No
HIV support group for kids/youths	√	No	No	No
Observed quality of counselling on infant feeding	Variable	Poor or None	Poor or None	Poor or None
Provision of formula feed	√	No	√	√
Family counselling	No	No	No	No
Information on social grants	√	No	No	No
Data manager on site	√	No	No	No
Computer systems for data management	√	No (paper based)	No	No
Photocopier on-site	√	No	√	No
Pharmacy on-site	√	No	√	No
Paediatric HIV clinic	√	No	√	No
PCR testing	√	No	√	No
Social workers available	√	No	No	No
De-briefing among all levels of staff	No	No	No	No
Sufficient supply of equipment	√	√	√	No
Sufficient supply of medicines	√	√	√	√
Sufficient nursing/counselling staff to provide HIV testing (observed)	√	No	No	No
Sufficient doctors (observed)	√	√	√	No
Used private room for HIV counselling	√	√	√	No
Clinic infrastructure in visible state of deterioration	No	No	No	√
Reported shortage of HIV test kits in the past 12 months	No	√	No	√
Printer fliers/info on health available	No	No	No	No
Condoms available including female	√	√	√	√
Patients were seen on the day (i.e., did not have to return due to shortage of staff	√	√	√	No

* JHB is Johannesburg; EC is Eastern Cape.

Endnotes

1 This is changing in Zulu culture, and it is more commonly accepted that in urban areas women go to hospital to give birth and men are accepted in labour wards. However, it is a cultural norm that women (who used to be cared for by midwives in a hut in a rural area) take care of childbirth, and it is not a "man's place" to be in the hospital. Again, this is changing.

2 Thembi was feeding the baby with formula when she went back to hospital because the sister told her to do so – but she was breastfeeding at home.

3 Circular mud hut.

4 Xhosa phrase meaning 'Good day or hello'; 'how are you sister?'

5 Dr Mitch *Besser* who co-founded the mothers2mothers programme in South Africa, observes that – from M2M's experience, once the man sees the baby and 'assumes ownership', he is much less likely to 'run away' (email communication on 6 June 2009).

6 I am not a psychologist so I did not explore whether this finding is in keeping with the psychological literature but I suspect it is. The reverse was also true: women we assessed as being depressed or fragile had generally not disclosed to anyone. As indicated in chapter four, in these instances, we linked women who appeared depressed, confused or upset to HIV counsellors for attention.

7 Level I and Level II patients can also be treated at a tertiary hospital. Level III patients require the expertise and care associated with the sub-specialities and less common specialities (such as cardiology, endocrinology, oncology, organ transplantation, plastic and trauma surgery, neonatology, sophisticated paediatrics and specialised imaging), or access to scarce, expensive and specialised therapeutic and diagnostic equipment found only at a central or tertiary hospital (the third level referral). Patients with uncommon ambulatory conditions who attend the hospital for highly specialised outpatient services are also classified as receiving care at this level. Level IV patients may be served at a tertiary hospital. These patients require care by sub-specialists which is currently very costly or requires significant expertise *Lutge et al* (2006).

8 In response, the Treatment Action Campaign launched a campaign on treatment literacy. See TAC booklet. Available from http://www.tac.org.za/Documents/Literacy/Literacy.htm.

9 The doctor said that this would not be the case in her home country of Sri Lanka.

10 *Besser* notes that the benefits of emergency caesarean section are less clear (email communication on 6 June 2009).

11 The WHO standard is four ANC visits. The average varies by province. In a study conducted of the mothers2mothers programme, they found that two visits were sufficient to achieve improved outcomes when mothers were enrolled in the programme. See *Baek, Mathambo, Mkhize, Friedman, Apicella and Rutenberg* (2007).

12 It was also called 'cup feeding'; health personnel emphasise feeding the infant with a sterile spoon and cup. This is because the risk of bacterial infection and diarrhoea is increased when using the nipple on a plastic bottle which is difficult to keep sterile (based on discussion with Dr Vivian Black, 5 June 2009).

13 RHRU staff are more likely to be researchers, clinicians or midwives with specialised knowledge and interest in reproductive health and HIV in women.

14 The name of the district where the research took place.

15 *Government of South Africa* (1997b).

16 A system of monitoring and evaluation has been established within the three antenatal clinics where the Reproductive Health and HIV Research Unit, University of the Witwatersrand Dept of Obstetrics and Gynaecology work in close partnership with the Provincial DoH.

17 See *Cooper* (2003).

18 See *Ramkissoon et al* (2006); *Nkonki et al* (2007); *Doherty et al* (2005).

19 As mentioned, Gauteng introduced dual therapy in February 2008 whereas the Eastern Cape was just beginning in October 2008.

20 Who benefits?

21 This strategy is discussed in each of the remaining chapters of the thesis.

Chapter 6

Capability and Health Equity: Making the Connections

This chapter is an exploratory one. Its aim is to investigate and construct conceptual links between the capabilities' approach; empirical findings from the research; and, health equity. This chapter is also a 'findings chapter'. It makes use of existing data (secondary analysis) to bring together the theory on health equity and capabilities on the one hand, with the practice of health equity assessment and the study findings on the other.

With reference to disparities in PMTCT and ART provision for women and children and premature mortality attributed to HIV/AIDS, in part I of this chapter, I assess whether these are health inequalities or inequities (a subset of inequalities that are deemed unjust and avoidable). The research will show that, for children, these health inequalities constitute inequities. For pregnant women, the situation is not as clear cut. I also consider – in a subsequent chapter on explanatory factors and recommendations (chapter seven) – if these are indeed health inequities, what action might be taken? Based on the results from this chapter (the secondary analysis) and those of chapter five (primary research), In part II, I discuss the implications for the capabilities of women and children in this study.

As noted, the field of development studies seeks to employ research and attendant understanding to effect real change in people's lives, allowing them to develop freely and to flourish. Often times this entails removing unfreedoms that constrain people's choices *Sen* (1992; 1999). When we ask who or what is responsible for patterns of disease and inequities in health, we begin to wrestle with complex factors surrounding society, agency and accountability, as well as biology. *Krieger* points out that it is because of this sheer complexity that we need good theory to guide us (2001a).

Theory allows us to structure our ideas – enabling us to further explain causal connections "between specified phenomena within and across specified domains by using interrelated sets of ideas whose plausibility can be tested by human action and thought" *Krieger* (2001a). But theory alone is insufficient in development. Let us recall the criticism of development studies in chapter one – its alleged inability to transform people's life chances. To respond to this charge, we also need frameworks for action:

for translating theory into practice. An evidence base is, then, essential. To act, we need an appropriate conceptual understanding of why and how we can intervene – together with an empirical basis to tell us where.

PART I. ASSESSING DISPARITIES IN PMTCT/ART FOR WOMEN AND CHILDREN: HEALTH INEQUALITIES OR INEQUITIES?

We began this inquiry from an ethical position that views disparities in access to HIV prevention in children (PMTCT) and treatment (ART) for pregnant women as problematic. But do they constitute health inequities?

Recall that equity is an ethical and a normative concept – not value-free but value-laden *Peter and Evans* (2001); *Evans et al* (2001); *Anand and Peter* (2001); *Braveman and Gruskin* (2003). Indeed, value judgments are important in making assessments between the normal and abnormal *Anand and Peter* (2001, p. 26); *Canguilhem* (1989). Social values underpin the policy choices of nations. We know that equity is an important social value and goal within health policy in South Africa (as discussed in chapters one and two). With roughly 49% of South Africans living below the poverty line, social needs in terms of adequate housing, nutrition, electricity, water services and employment are putting immense pressure on the state *UNDP South Africa* (2003). With so many competing claims, urgency and priority are critical. Not every inequality is unjust and avoidable *Anand and Peter* (2004). The question is: are these?

At this juncture, I offer an operational definition of health inequity based on the literature. Clarity is crucial, as the definition will guide the accompanying analysis.

Health Equity Defined

To constitute a health inequity, a disparity in health must be unjust and avoidable; and, systematically associated with social disadvantage that is frequent, substantial and persistent, not random or occasional. A health disparity is an inequity when it is systematically associated with social disadvantage in a way that places an already disadvantaged group at further disadvantage (by virtue of being poor or located in a remote rural region for example), and at increased risk of ill health, thus compounding the social and economic consequences of ill health *Braveman and Gruskin* (2003); *Sen* (2004); *Whitehead* (1998).[1]

Based on this definition, how do we make a determination?

In any health equity assessment – the literature notes that the social disadvantage must be reasonably evident. In other words, scientific evidence must be used to illustrate that social determinants are playing a role in the causal pathway such that the disparity is strongly associated with unjust social structures; and, those socially-created structures are then systematically putting disadvantaged groups at greater disadvantage *Braveman and Gruskin* (2003, p. 256); *Evans et al* (2001); *Anand and Peter* (2001). There is thus, a burden of 'proof'.

To investigate whether the research problem constitutes a health inequity, the following question is considered.

- Does a lack of ART/PMTCT provision for pregnant women and children with HIV/AIDS constitute a health inequity?

This next section is exploratory. My aim is to apply the health equity literature to the research concern to see what new insights, if any, can be gleaned. The rationale is that, in trying to build linkages between the conceptual and the empirical, we may advance understanding of the research problem, and potentially, how it could be addressed.

To conduct a proper assessment, we need to rely on an acceptable standard or test, one that fits the current context and flows from the definition. Investigating health inequalities requires a comparison of groups in society, against some form of reasonable health achievement *Braveman and Gruskin* (2003); *Evans et al* (2001). To define an appropriate comparative space, I am drawing on work by *Barry* (1990); *Sen* (2001); *Kubzansky et al* (2001); *Gilson and McIntyre* (2001); *Lozano et al* (2001); and, *Östlin et al* (2001).

Selecting a Standard of Comparison Between Groups in Society

There are two ways of distinguishing health inequities from health inequalities, according to Barry: a) to identify existing standards of health distribution (or health outcome) – defining ways in which people should be treated as equals and then analysing whether or not the standard is applied consistently; or, b) to develop a reasonable standard of health achievement where none exists. For instance, an existing standard of equity may be the development of a reasonable or basic level of national health attainment: life expectancy at birth of 60 years of age perhaps. Or, it could be ensuring universal immunization. Equity would be achieved if all regions of a country obtained the minimum life expectancy or ensured immunization coverage for all. If they failed, the focus would be on understanding the shortfall, and achieving the minimum threshold *Barry* (1990); *Peter and Evans* (2001).

1. **Standard for Children: Freedom from Premature HIV-Linked Death through Universal Prevention of Mother to Child Transmission Services Provision in South Africa**

Using the second option (b) presented by Barry, I am suggesting the employment of a standard where none currently exists.[2] For children, I am selecting freedom from HIV-linked deaths (premature deaths) – through universal provision of PMTCT services – as the standard. As we know, mother to child transmission is the overwhelming source of HIV in infants (2005); *Coovadia* (2005); *Chopra et al* (2005). I am thus linking the standard to the research concern to explore whether there are any correlations.

2. **Standard for Women: Freedom from Premature HIV-Related Maternal Mortality through Universal Provision of ART in Public Health Facilities in South Africa**

For women, the standard I am employing is freedom from maternal mortality attributed to HIV, through the universal provision of ART. In both instances, I am suggesting a reliance on universal provision of ART/PMTCT as the best intervention we have to avert unnecessary deaths. This assumption has its limitations, which I will discuss later in the text. These standards are very robust in the South African context. I am assuming some causality between lack of ARV intervention (through PMTCT for the child and ART for the mother) and death. It is possible that this intervention can be made and death still results. And, you reader, may be saying, we know this standard is not achievable so why go into an elaborate discussion? Because the research findings (from the primary research) outlined in chapter five told us something about the experience of black South African women (pregnant or postnatal) accessing particular HIV services through the public health system. But it did not allow us to explore morbidity, mortality or treatment of women and children by race or sex. Placing the research concern under the microscope in a comparative way (i.e., across categories such as race, wealth, and sex) may generate more insights than what we could achieve solely by looking at the experience of one population group: hence allowing more insight into equity – and health equity – considerations.

To assess whether the standard is being achieved, I consider the situation for black South African infants compared to white infants. According to the health equity literature, we should consider the health achievement of the most socially advantaged group (the white population) against that of the most disadvantaged group (the black population).

The rationale is that the health of the wealthiest, most privileged groups in a given society, reflects the levels that are biologically achievable and serves as a standard for what should be attainable for everyone: this is the highest level of capability and freedom in this comparative space. The argument is, given the proper resources or arrangements, the highest attainable standard of health could be reachable for greater numbers of individuals than what is currently taking place amongst more disadvantaged groups in society *Braveman and Gruskin* (2003); *Barry* (1990).

Freedom from Premature Mortality due to HIV in Children and Pregnant Women

To make a comparison of health achievements across black and white population groups, we are essentially looking at significant, key trends in health status and disease – and the burden and role of HIV infection in these trends. One way of doing this is to consider premature mortality attributed to HIV both in infants and pregnant women; if this is a significant phenomenon; and, whether it occurs across race. The distribution of disease and mortality should be occurring randomly regardless of race and other factors. When disparities in health intersect with the fault lines of racial, ethnic or other social groups, or by geographic area, this is cause for concern, and may warrant action, note *Evans et al* (2001). Evidence of skews in health amongst groups in a society that are associated with education, income, race, or access to healthcare raises questions about social justice and health equity *Evans et al* (2001). In **Annex 1**, I have included a discussion of the data used for this analysis, and their limitations.

Mortality Rates in Infants and Children in South Africa

To apply the standard, I am exploring age-specific and cause-specific mortality for infants and children, comparing data from racial groups in the country (where data are available). While I am not considering whether these infants and children received ARV prophylaxis (universal provision of PMTCT), the assumption is that if infants and children had received such services to prevent HIV transmission from mother to child, these children would not be: a) HIV-infected; and, b) dead prematurely due to HIV. I acknowledge the possibility of children receiving PMTCT but acquiring HIV postnatally; however, even if the child had contracted HIV at a later stage, mortality would most likely be averted through ART. The data on ART in children indicates the efficacy of treatment (as discussed in previous chapters). I present numerical statistics, and match this with some qualitative analysis later in the discussion.

The infant mortality rate (IMR) refers to the probability that an infant born in a specific year (of a defined period) dies before reaching the age of one *WHO Statistical*

Information System (2008). I am viewing both IMR and child mortality to see what the data yield. The IMR is a key indicator of health and a measure of the health of the larger population; it is also an indicator for the millennium development goals (MDGs) *Bradshaw and Dorrington* (2005).

Below is a breakdown of the infant mortality rate by race group (the traditional four racial categories in South Africa). The IMR for the poorest versus the richest quintiles in South Africa is presented. The highest IMR in the country is indicated (by province and rural/urban) as a percentage.

Table 1 Infant Mortality Rate (IMR) per 1 000 Live Births (Internal Disparities within South Africa)

By Racial Group (Gilson and McIntyre 2001) (1993 data)*	
White (of European descent)	13 / 1 000
Indian (of Asian descent)	32 / 1 000
Coloured (mixed race)	22 / 1 000
Black (African descent)	72 / 1 000
By Racial Group (DoH 2002) (1998 and 2006 data)	
White	15 / 1 000
Black	63 / 1 000
Black-white ratio	4,1
Poorest/Richest Quintile (UNFPA 2005)	
61,6 (black) / 17,0 (white)	
Poorest/Richest Quintile (DoH 2002) (1998 and 2006 data)	
87,4 (black) / 21,9 (white)	
Provincial (Highest/Lowest) (UNFPA 2005)	
61,2 (Eastern Cape) / 8,4 (Western Cape) 74,5 (Eastern Cape) / 39,0 (Western Cape)	
Rural/Urban (UNFPA 2005)*	
52,2 / 32,6	
Rural/Urban (DoH 2002) (1998 and 2006 data)	
71,2 / 43,2	

Sources: **Gilson and McIntyre* (2001) (using 1993 data); *UNFPA* (2005); *Government of South Africa* (2002) (1998 data).

Note: I could not find comparable quantitative data across racial groups for children – only for infants.

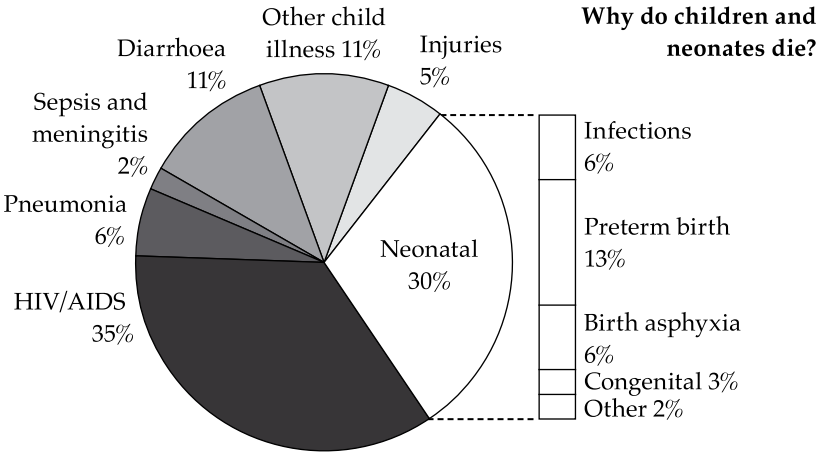
Implications

From the data, the highest IMR (72 per 1 000 live births) is recorded among black South African infants (infants of African descent). This contrasts quite significantly with the lowest IMR among white children (children of European descent) in the same data set (13 per 1 000). The black/white ratio presented is also significant. The poorest quintile of infants dying is also black, whereas the richest is white. And, viewing the IMR by province, the radically higher IMR in the poorer Eastern Cape Province contrasts with the significantly lower IMR in the richer Western Cape (WC) (where a much lower HIV prevalence than many of the other nine provinces prevails. The population demographics in WC are also different).[3] We can see that the IMR for infants in rural regions of South Africa is significantly higher than for infants in urban areas. A 2000 burden of disease study conducted by MRC researchers also highlighted considerable variation in infant mortality by province. *Bradshaw and Dorrington* stress that the IMR is a sensitive marker of the prevalence of HIV among pregnant women in areas of high prevalence. This is because, in the absence of highly active antiretroviral therapy and/or prevention of mother to child transmission programmes, high mortality rates in young children result (2005, pp. 419-420).

Causes of Death in Infants and Children

Using data (from three national audits), the *South Africa Every Death Counts Writing Group* mapped the causes of deaths in children and neonates (shown below) (2008a).

Figure 1 Causes of Death in Children and Neonates



Source: *South African Every Death Counts Writing Group* (2008a, p. 1298). Reprinted with permission from the authors.

Contribution of HIV/AIDS to Mortality

From the pie chart, HIV/AIDS has captured a 35% share of total deaths in neonates and children. The course of HIV infection in infants and children is much more rapid than in adults. *Coovadia* notes, without ARVs, the upper end of mortality in HIV-infected children is in the region of 55% by two years of age; 90% by three years, and 98% by five years (2005, p. 184). Thus the majority of children with HIV who lack access to ARVs are dead within five years. Note that the data are sourced from public health clinics and hospitals, the main users of those facilities are black, and thus the data are drawn almost exclusively from black South African children. To provide a different source (using MRC data from Bradshaw and Nannan), the top 15 causes of child mortality are identified below.

Table 2 Top 10 Causes of Death for Children under Five in South Africa (2000)

Rank	Cause	Number of deaths	Percentage of total
1	HIV/AIDS	42 749	40,3
2	Low birth weight	11 876	11,2
3	Diarrhoeal diseases	10 786	10,2
4	Lower respiratory infections	6 110	5,8
5	Protein-energy malnutrition	4 564	4,3
6	Neonatal infections	2 920	2,8
7	Birth asphyxia and trauma	2 584	2,4
8	Congenital heart disease	1 238	1,2
9	Road traffic accidents	1 219	1,1
10	Bacterial meningitis	1 141	1,1

Source: Adapted from *Bradshaw, Bourne and Nannan* (2003b) (using 2000 data).

The Burden of Disease: How Many South African Children are Dying?

In terms of the scale of HIV infection in children, the MRC-National Burden of Disease Study for the year 2000 estimated that more than 100 000 South African children die every year, and childhood deaths are likely to continue to rise due to HIV/AIDS and diseases of poverty *Bradshaw, Bourne and Nannan* (2003b). A different source, the *South Africa Every Death Counts Writing Group* estimates that 75 000 children under five are dying each year, primarily of HIV and other common, treatable infections. They also estimate that 40 000 of those deaths are preventable (2008a).

In terms of total numbers, according to sowewhat dated research by *Moosa*, black children under age five made up 16% of the total population but accounted for 55% of all deaths. Whereas, white children made up 11% of the population and accounted for only 7% of all deaths (1984). The key message from this and earlier data presented is that white infants and children are dying in smaller numbers compared to their black counterparts.

Are white children and women dying of HIV?

We can answer this question, in part, by looking at HIV prevalence data, and the number of white children under five living with HIV. Data on HIV infection by race is not widely published. However, HIV data are collected by the National Blood Transfusion Services in South Africa *Abdool Karim et al* (2005). In addition, researchers from the Nelson Mandela Foundation, in conjunction with the Human Sciences Research Council (HSRC) (South Africa) conducted a national population-based survey (2002). They found that while HIV infection spans all race groups in the country, it is significantly higher in the black population *Shisana* (2002).

Table 3 South African Race Group and HIV Prevalence in Two Surveys

Race Group and HIV Prevalence	(HSRC 2002) (%)	(National 2005) (%)
Black	12,9	13,3
White	6,2	0,6
Coloured	6,1	1,9
Indian	1,6	1,6

Note: Ages covered in these surveys are age two and up.
Sources: *Shisana* (for the HSRC) (2002); *Government of South Africa* (2005).

One can see from **Table 3** that the highest burden of prevalence is borne by the black population, followed by white or coloured (depending on the survey), and Indian.

Table 4 HIV Infection Rate by Age, Sex, Race and Locality (1995, 2001)

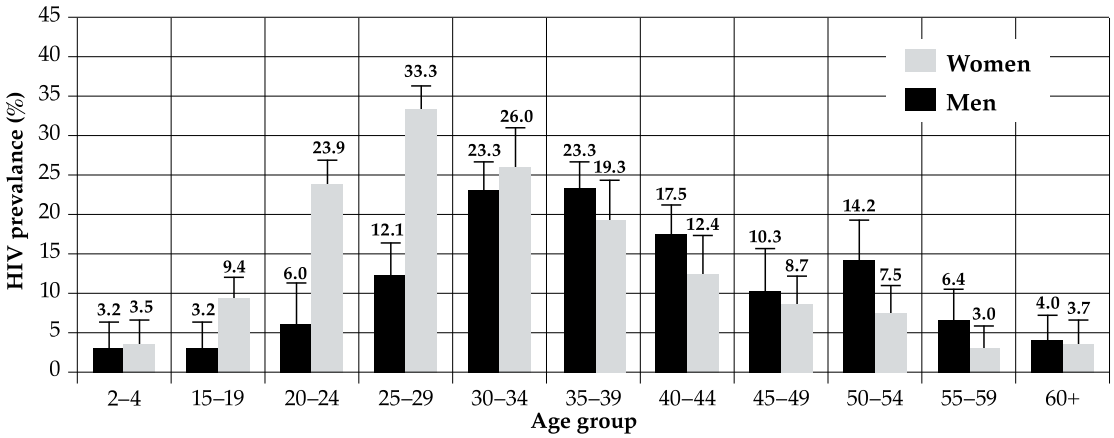
Table 2.10		TOTAL	Sex		TYPE OF AREA		POPULATION GROUP			
			Male	Female	Urban	Non-urban	African	Coloured	Indian	White
All ages										
	1995	1 098 262	490 223	605 665	578 913	511 643	1 070 324	21 490	2 124	7 786
	2001	5 574 763	2 538 526	3 029 386	3 264 685	2 280 155	5 222 039	149 950	27 691	76 966
0–19										
	1995	82 454	11 929	70 189	33 046	49 898	82 112	719	36	114
	2001	478 661	106 877	369 205	219 688	262 837	473 011	8 013	661	1 534
20–29										
	1995	468 741	150 742	316 036	236 436	229 455	458 226	8 597	735	2 478
	2001	2 020 233	720 679	1 309 126	1 112 216	902 979	1 941 412	47 366	7 604	17 084
30–39										
	1995	405 169	218 671	186 294	230 157	170 858	392 261	9 532	1 068	3 726
	2001	1 952 484	962 664	986 248	1 226 322	708 167	1 791 679	63 145	13 352	37 351
40–49										
	1995	120 726	88 500	32 160	67 875	116 564	2 527	265	1 310	--------
	2001	908 581	559 312	342 399	580 109	319 055	819 465	28 435	5 269	17 980
50–59										
	1995	20 073	19 268	986	10 860	9 053	20 019	114	20	154
	2001	196 244	172 870	22 393	116 208	78 761	178 402	2 927	779	2 893
60–69										
	1995	1 099	1 112	0	539	555	1 141	1	0	4
	2001	18 559	16 125	14	10 142	8 356	18 071	66	26	125

Source: *Actuarial Society of South Africa* (2002).

From the table above, HIV infection in the black population (5,2 million by 2001) is exponentially greater than in the white population (76,988 by 2001). Note also the large gender differences.

HIV prevalence in young children and in women can be seen in the following graph.

Table 5 HIV Prevalence in South Africa by Sex and Age Group



Source: *HSRC Fact Sheet* (2005). Available from http://www.hsrc.ac.za/Factsheet-40.phtml.

From the HSRC data, South African children aged two to 14 have a high HIV prevalence. In that age group, the *HSRC* observes:

> "4.9% of boys and 5.3% of girls are HIV positive, translating into an estimated 129 621 children. In the slightly older age group of 5-9, 4.2% of boys and 4.8% of girls have HIV – an estimated 214 102 children... Most children in this group are likely to have been HIV positive from birth" (2005).

From the available data and research, HIV prevalence in white children is likely to be very small, with adult males – particularly gay men and men in heterosexual relationships who also have sex with men (MSM) – representing the largest share of the white population living with HIV, followed by adult white females. The first wave of HIV infections in South Africa were found in 1982 in gay men, coupled with a group of haemophilia patients. This might account for the larger share of HIV prevalence in the white population shown in 2002.[4] Very few white South African children, then, are dying of HIV. (Over the course of 12 months of field research in public health clinics in urban and rural sites, I never once saw a white woman or child being tested or treated for HIV. When I queried doctors about this, they confirmed that this was typical.) Historically, as mentioned, the white population would be less likely to use public sector services due to their higher income, greater socio-economic status, and access to private medical insurance.

Key Message

In short, the data suggest differences in health outcomes for infants, in terms of rich/poor, rural/urban populations, and advantaged (white) and disadvantaged (black). MRC researchers corroborate these internal disparities shown in the UNFPA data: "The infant mortality rates in the Eastern Cape and KwaZulu-Natal are each more than double the rate in the Western Cape" *Bradshaw and Dorrington* (2005, p. 498); *Bradshaw et al* (2003a-b).

From the data, HIV is responsible for roughly 40% of deaths in children. Again, despite variations in the total number, there is much uniformity in the trends. From a review of the various data sources, Abrahams suggests it is evident that infant mortality and morbidity rates are rising in South Africa; and that a significant number of current child deaths are preventable *Abrahams* (2006); *Shung-King et al* (2007). The authors of *South Africa Every Death Counts Writing Group* state that South Africa is one of 12 countries in the world that, since 1990, has been falling behind in child mortality, rather than moving ahead. They observe that some of the countries that ranked with South Africa on child mortality in 1990 (Mexico, Egypt and Brazil) have halved their

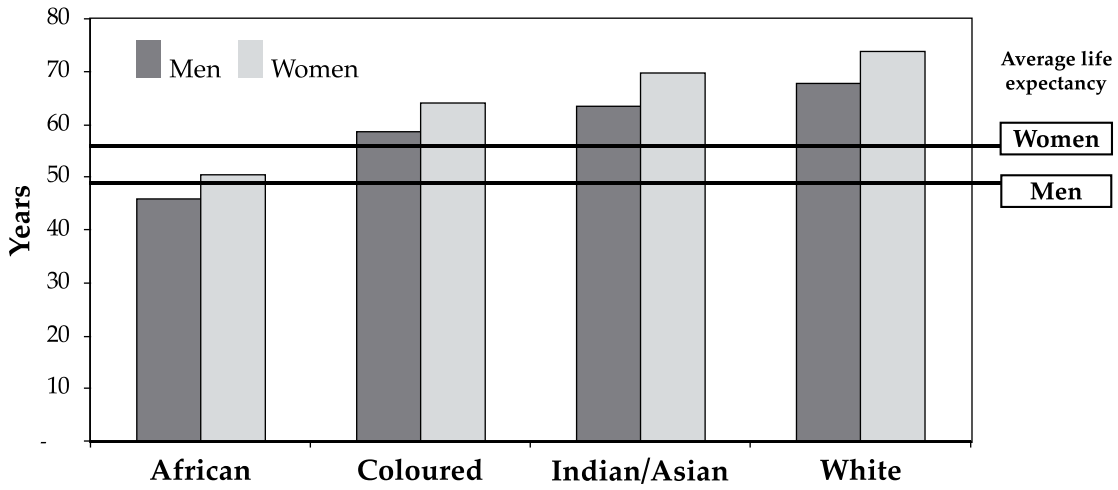
mortality rates for children younger than 5 years, while South Africa has fallen further behind (2008a); *UNICEF* (2007).

Applying the Standard for Pregnant Women: Freedom from Premature Maternal Mortality

I have already touched on some aspects and data which pertain to women's health, including HIV prevalence. Women with HIV should be able to access ART for their own health. For most women, this is a pre-requisite to good health for herself and her infant. Although this is not a perfect or precise indicator, one way of looking at the provision of ART in pregnant women is by considering premature mortality attributed to HIV in pregnant women; if this is a significant phenomenon; and, whether it occurs across race. Again, the distribution of disease and mortality should be occurring randomly.

From **Figure 2** and **Figure 4** below, it becomes clear that deaths in women cluster in the reproductive age range, from 20 to 24 years of age through to the 40 to 44 age group, before they begin to level off. We can also see that, over a relatively short period of time, there has been a steep increase in deaths among women from 1999 to 2005. The norm is that women have a survival advantage over men. Greater longevity for females and higher mortality for males is an established phenomenon in the developed countries. Yet this advantage for females is relatively new. *Östlin et al* observe that "where social discrimination is less pervasive, women tend to increase their life expectancy beyond that of men" (2001, p. 177); *Waldron* (1983) (Note that South Africa's profile is not defined by female excess mortality, and thus matches a developing country one.) *Hunt and Annandale* (1999); *Östlin, George and Sen* (2001) (see **Figure 2**).

Figure 2 Life Expectancy at Birth by Sex and Race Group in South Africa



Source: *Balasubramaniam and Sprague* (2005).

Commenting on maternal mortality trends, *Bradshaw and Nannan* observe that the 1990s in South Africa, witnessed "an extremely rapid change in the cause of death profile resulting from the HIV/AIDS epidemic" *Bradshaw and Nannan* (2006).[5] In 2003, the figure for maternal deaths per 100, 000 live births was 165, an increase from 135.6 per 100, 000 in 2002 *Pattinson* (2006); *Government of South Africa* (2006). According to the Saving Mothers Report, since 1999, non-pregnancy related infections have become the main cause of maternal mortality in South Africa (33,7%), with HIV/AIDS the main cause *Jackson, Loveday, Doherty, Mbombo, Wigton and Matizirofa* (2006).[6] By 2004, non-pregnancy related infections were the "most common cause at all levels of care" *Department of Health* (2006, p. 8).

By 2004, deaths attributed to HIV/AIDS had risen to 662 deaths – constituting 20% of non-pregnancy related infections *Government of South Africa* (2006, p. 8).[7] The increase in deaths in this category is striking and is corroborated by other research on rising adult mortality *Jamison et al* (2006); *Dorrington et al* (2004); *Groenwald et al* (2005).[8] For our purposes, what is significant is, as *Bradshaw and Nannan* report, "The causes [of maternal deaths] have shifted from hypertension and haemorrhage as the leading causes to non-pregnancy related infections resulting from HIV-related diseases" (2006, p. 139).

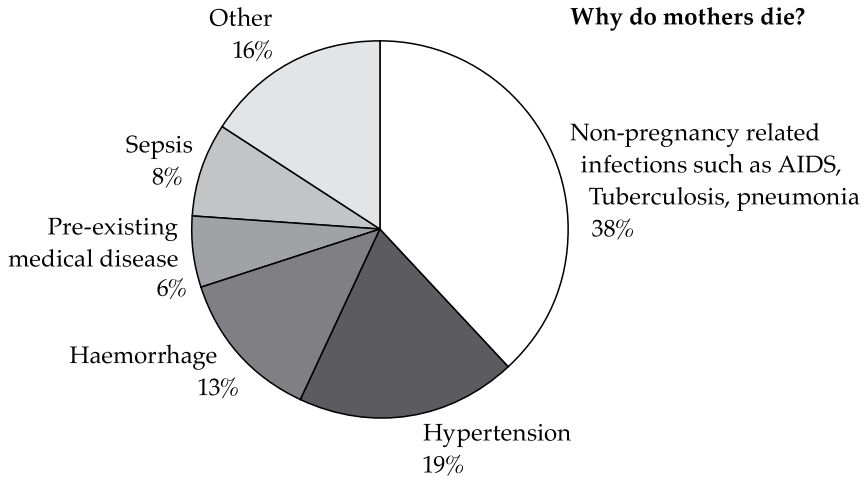
Table 6 Top Five Causes of Maternal Death (87,2% of maternal deaths) in SA

Cause	% of Deaths
1 Non-pregnancy related infections (primarily HIV/AIDS)	29,7%
2 Complications of hypertension in pregnancy	22,7%
3 Obstetric haemorrhage	13,5%
4 Pregnancy related sepsis (includes septic abortions & puerperal sepsis)	12,4%
5 Pre-existing maternal disease	0,9%

Source: *Government of South Africa* (2001).

Cause of death data from a later source – the *Saving Mothers* 2002-2004 report – is used in the pie chart (**Figure 3**). HIV/AIDS and related diseases contributed to 38% of maternal deaths. This shows an increase over the 2001 data just presented. The *South Africa Every Death Counts Writing Group* cautions: "this finding [38%] is probably an underestimate since only 46% of women were tested for HIV, and 78% of those who were tested were HIV-positive" (2008a, p. 1298).

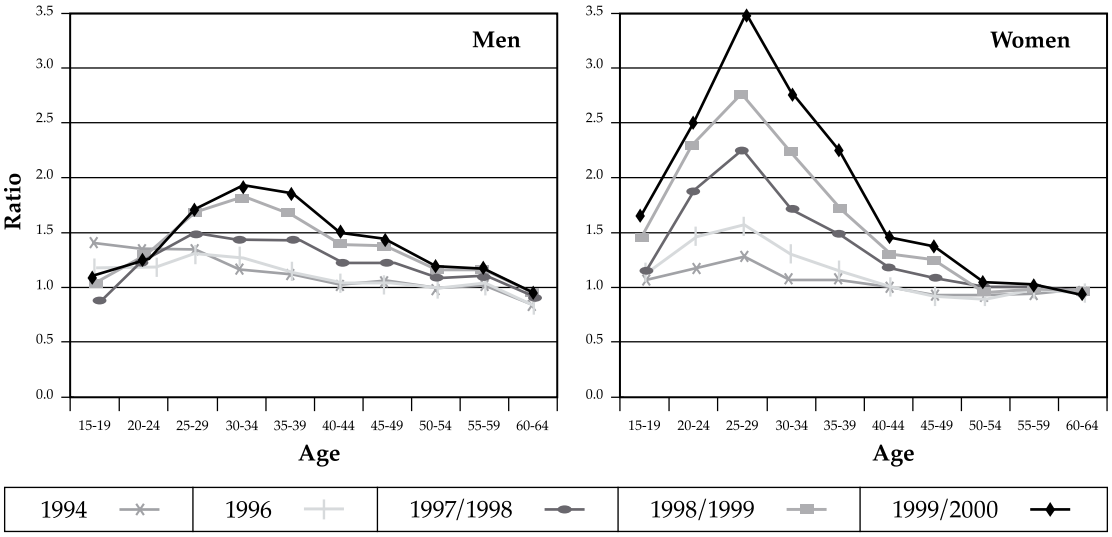
Figure 3 Causes of Death in Pregnant Women in South Africa



Source: *South Africa Every Death Counts Writing Group* (2008a p. 1298). Reprinted with permission from the authors.

This next graph provides an illustration of the impact of HIV/AIDS on mortality by sex and age.

Figure 4 HIV/AIDS and Mortality in South Africa by Age and Sex



Source: *Bradshaw and Dorrington* (2005, p. 422).

One can see that the majority of deaths are concentrated in women of reproductive age, with HIV deaths in women far exceeding those of men.

Figure 2 (p. 175) demonstrates that white women have the greatest life expectancy of all groups in society, also suggesting that, in the main, they are; a) not affected by the same burden of HIV infection as black women; and b) not experiencing the same phenomenon of premature mortality attributed to HIV-related infections.

What do white children and pregnant women die of?

Since we are considering freedom from premature death as an indicator of health outcomes for black women and children compared with those of whites, the question can be asked: are white children and pregnant women dying prematurely? And, are they dying of HIV-related diseases?

Differing Disease Profiles

It is very difficult to find research on cause of death data specifically in white South African pregnant women or children. The norm is to present data across racial groups. However, *Burgard and Treiman* emphasise that during the apartheid era, institutionalised racial inequality in life chances resulted in the coexistence of distinct child mortality profiles, with white children dying from less preventable causes, such as congenital and other non-communicable disorders and their black and coloured counterparts dying from preventable diseases, such as infections or other acquired diseases and accidents (2006).

Bradshaw, in a recent review of national health status, confirms the differing disease profiles are a continuing feature of society. Like some other developing countries, South Africa has an overlapping health transition where diseases of poverty co-exist with diseases affecting wealthy populations in the same country. She points out that South Africa has a quadruple disease burden. This includes diseases attributed to under-development and poverty, such as malnutrition and diarrhoea (classified as Type I), chronic diseases such as stroke and diabetes (Type II), together with a high burden of injuries and accidents (Type III), and a large burden of HIV-related diseases (Type IV) *Bradshaw* (2008)*; Bradshaw and Nannan* (2006).

Commenting on cause of death data from 1997 to 2001, *StatsSA* reports: "An analysis of sample data by population group reveals striking differentials in mortality patterns by population group. While the main causes of death among Africans and coloureds were TB, HIV, influenza and pneumonia, and unspecified unnatural causes, whites and Indians tend to die of diabetes, ischaemic heart disease and cerebrovascular diseases" (2004).

Premature Mortality and Years of Life Lost for Black Women

Kubzansky et al note that one of the most commonly used health outcomes in research on social inequality and health is age-adjusted and age-specific mortality rates. But, they stress, in the context of increasing global life expectancy, of greater relevance "is premature mortality". They state: "We all eventually die, but the relevant question is, at what age?"(2001, p. 107);[9-10] *Bradshaw et al* (2003a, p. 17).[11] The following charts indicate years of life lost (YLLs) for women and men in South Africa.

Figure 5.1 YLL - South African Males

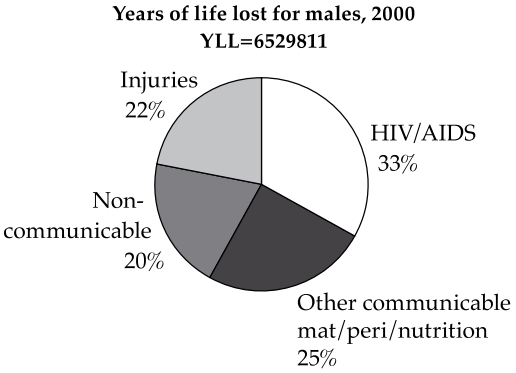
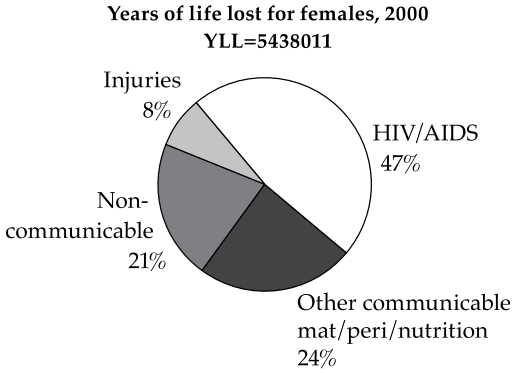


Figure 5.2 YLL - South African Females



Source: *Bradshaw et al* (2003a, p. vi).

Note the contribution of HIV/AIDS to years of life lost: 47% for females compared with 33% for men. Not all of the females dying prematurely are pregnant women. However, coupled with the graph indicating the impact of HIV on mortality by sex and age presented earlier, we know that a significant share of women with years of life lost would be pregnant women.

The Medical Research Council (MRC) released a report concluding that the increased mortality rates reflected rising HIV-related deaths. The report stated: "HIV/AIDS is the leading cause of premature mortality in 2000 in all provinces, but ranges from 14% of the total in the Western Cape to 51% of the total in KwaZulu-Natal" *Bradshaw, Nannan, Groenewald, Joubert et al* (2005).[12] *Dorrington et al* wrote:

> "The consistency between the [ASSA] model and the data together with observations from other data sources lead to the conclusion that HIV/AIDS must largely account for the observed increase. The change in pattern of deaths is clear in the raw data before adjustment for extent of underreporting of deaths, as has been confirmed by official South African mortality statistics for 1997–2000" (2002).[13]

Key Message

As with children, despite slight differences in the total numbers, HIV is the leading cause of death in pregnant women. *Ronsmans et al* emphasise the impact of HIV on maternal mortality: "In countries most severely affected by HIV, such as Malawi, Zimbabwe, and South Africa, the AIDS epidemic is thought to have reversed previous gains in maternal mortality" (2006).

The data suggest a huge burden of HIV infection in black South African women of reproductive age. The mortality statistics indicate that maternal mortality is increasing, and that HIV is one of the leading causes (a significant change from pre-1998 causes of death).

Health Inequality or Health Inequity: Applying the Criteria

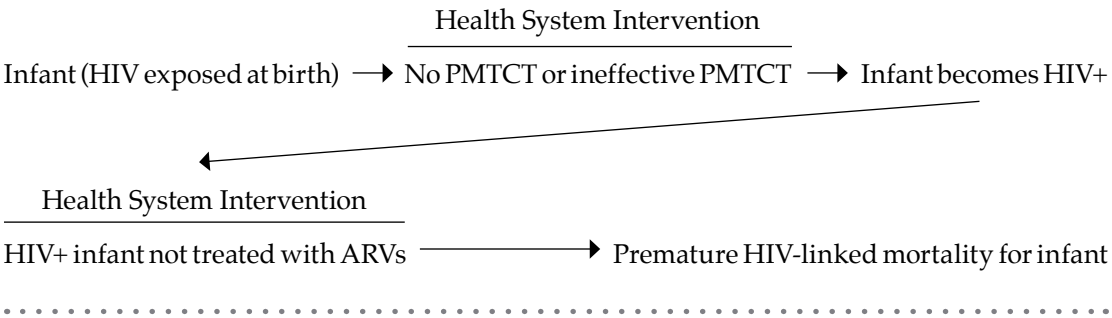
For Children

In comparing health achievements of the white versus black infants and children in South Africa, the following becomes evident.

Firstly, stark differences in life chances for black versus white infants are visible (**Table 1**). There are greater numbers of black infants dying prematurely than white infants. Secondly, black South African infants and children tend to be much poorer than their white counterparts, and to be affected by so-called diseases of poverty. Thirdly, the greatest contributor to deaths in infants and children is HIV/AIDS – roughly 35 to 40% of deaths – (and we know that deaths attributed to HIV/AIDS in children are under-reported, so this figure could be higher, and possibly significantly higher). We can also see that infants in rural areas are dying in greater numbers than urban infants. We know that the majority of children in rural areas are black – not white. For example, the highest and lowest figures are excerpted from the Eastern Cape. In terms of racial composition, 87,5% of the Eastern Cape population is black; 7,4% is coloured; 4,8% is white; and 0,3% is Indian (of Asian descent).

With the dominant source of HIV infection in children being MTCT, this underscores the reality that new HIV infections are *not* being prevented in children through PMTCT interventions, suggesting a causal connection between the following.

Infants born to HIV positive mothers are not receiving PMTCT (or PMTCT is failing to be effective):



Is this Avoidable? **Absolutely.**

Avoidability

Based on the three audits (see **Annex 1**), the authors identified modifiable factors and the distribution of those factors across: a) families and communities; b) administrators and policy makers; and c) healthcare providers *South Africa Every Death Counts Writing Group* (2008a).

The greatest number of avoidable factors was located at the healthcare provider point (health systems and health personnel), where 53% of all avoidable factors related to child deaths was linked to actions on the part of healthcare providers (such as poor assessment and management of patients in facilities). The authors state that 35% of early neonatal deaths and stillbirths were associated with an avoidable factor related to health personnel (e.g., fetal distress in labour which went unrecognised). The authors emphasise: the data "suggests that intrapartum stillbirths and antepartum haemorrhage together account for 29% of all stillbirths. These intrapartum stillbirths are eminently preventable with appropriate care during childbirth" *South Africa Every Death Counts Writing Group* (2008a).

There are also modifiable factors in family and community settings – mainly delays in recognising warning signs and seeking healthcare. An additional 22% to 32% of deaths were related to administrative modifiable factors, such as transport failure. These factors (lying outside the reach of health facilities) underscore that the healthcare system alone is not to blame, other factors are also responsible. I believe this is a causal connection. Leaving aside the possibility that some infants could die even though they are on ARVs, and some infants might have contracted HIV postnatally, the majority of infants are contracting HIV through MTCT, which emphasises the lack of PMTCT intervention for these children. The consequences of this lack of intervention are highlighted in the preceding figures, charts and graphs on mortality and causes of death attributed to HIV: 35-40% of deaths in infants and children. With researchers again indicating that at least half these deaths are preventable *South Africa Every Death Counts Writing Group* (2008a).

Does a lack of PMTCT provision for children with HIV/AIDS constitute a health inequity? Yes.

For children, from the analysis, is there a shortfall in health achievements for black infants and children compared with white infants and children? **Yes.**

Is the shortfall in children:

a) Frequent, substantial and persistent (not random or occasional)? **Yes.**
b) Systematically associated with social disadvantage? i.e., ill health is influenced by or linked to social factors and/or social arrangements: such as race, socio-economic status; systems or other social structures? **Yes.**
c) Is there sufficient evidence to show that social determinants, such as the health system, are playing a role in ill health, e.g., a causal connection? **Yes. It appears to be a causal connection.**
d) Avoidable? **Yes. There are many factors that result from direct actions by health personnel that are changeable.**

What we see is a substantial and persistent health inequality (premature mortality) that is systematically associated with social disadvantage for black South African children – ill health is influenced by social disadvantage, race, sex, socio-economic status (poverty), and geographic location. These factors interact to put individuals at increased risk for ill health.

From the data, black South African infants, children and pregnant women are dying in significant numbers, and their lives are cut short due to preventable and treatable diseases, mainly due to HIV-related infections.

While there are limitations in the data, we know that there are large numbers of infants and children dying in public health facilities and clinics across South Africa; that deaths are under-counted and under-reported, and these are almost all black children. White children and pregnant women tend not to be affected by diseases of poverty, including HIV, and the numbers of white children and mothers dying prematurely are small. Thus, if we look at the two ends of the social hierarchy spectrum for our population groups (black and white), there is a shortfall in health achievements for blacks compared to whites.

Based on all of the available evidence and against this 'burden of proof' the answer to the question is yes. The extent of premature mortality in children is, as documented

across the data and studies, consistent across studies; it is pervasive; and it is significant in limiting health outcomes and health capability. It is not random or infrequent.

White South African infants and children are generally free from premature mortality attributed to HIV. However, black children are not. The data on premature black infant and child deaths attributed to HIV are fairly overwhelming and consistent across different sources and over time. The data on avoidable factors are also very reliable.

For Pregnant Women

In terms of maternal mortality, maternal deaths have increased, and deaths attributed to HIV/AIDS are highest in women of reproductive age. Again, these are primarily black women. We know that HIV prevalence in pregnant women is estimated at 30%, the highest in the country; that the HIV prevalence figures derive from antenatal attendees in public health settings, who are primarily black and all of whom are pregnant *Government of South Africa* (2005). However, the causal link between lack of ART and maternal mortality is more tenuous. There are other factors that come into the mix: complications, underlying conditions, and a range of individual factors that may not be avoidable.

Health System and Individual Intervention

HIV+ pregnant woman → Lack of ART before labour/delivery → Maternal death linked to HIV

Avoidable? **Possibly. In some instances, yes**.

Unlike children, there is not the same direct, clear and causal chain for maternal deaths. There is a large burden of HIV infection in pregnant women; and there are significant numbers of maternal deaths attributed to HIV. While the intervention of ART before labour may safeguard health and survival, other factors may also play a role, including other underlying conditions and obstetric complications.

Avoidability

According to analysis by the *South Africa Every Death Counts Writing Group*, 44% of maternal deaths had a modifiable factor related to family/community action—e.g., inadequate or no antenatal care, while 32% of maternal deaths had a modifiable factor related to administrator action—e.g., absence of blood for transfusion, and no transport

between health institutions. And, 54% of maternal deaths had a modifiable factor related to health-care provider action at the primary facility level; 48% at secondary level; and 37% at tertiary level—e.g., non-adherence to standard protocols (2008a, p. 1299).

> "South Africa has three important gaps in care. First, the coverage gap between present coverage and universal coverage—e.g., the gap between skilled attendance at 84% and full coverage at 100%. Second, the quality gap between the coverage of a package or contact opportunity and an effective intervention that can be provided through that package—e.g., the gap between the percentage of pregnant women attending at least one antenatal care visit (94%) and first antenatal visit before 20 weeks (27%). Third, the equity gap between coverage for the poorest quintile and the richest quintile—e.g., the gap between women from the richest and poorest families receiving skilled attendance is 30% (98% and 68%, respectively)" (2008, p. 1301).

Does a lack of ART provision for pregnant women with HIV/AIDS constitute a health inequity? Not necessarily.

Is the shortfall in pregnant women:

a) Frequent, substantial and persistent (not random or occasional)? **Yes**.
b) Systematically associated with social disadvantage? i.e., ill health is influenced by or linked to social factors and/or social arrangements: such as race, socio-economic status; systems or other social structures? **Yes**.
c) Is there sufficient evidence to show that social determinants, such as the health system, are playing a role in ill health, e.g., a causal connection? **There is some evidence – and a correlation – but there is insufficient evidence to show an explicit causal connection**.
d) Avoidable? **The situation is avoidable to an extent. There are many factors that result from direct actions by health personnel that are changeable. At the same time, there are other factors, individual ones that lie outside the control of the health system**.

We know that women are dying prematurely in large numbers due to HIV but is it because of a lack of timely ART access? Possibly. But who or what is responsible; and is it fully avoidable? I am suggesting that for pregnant women there is not the same causal link between HIV infection, ART access, and premature death as there is for

children. While this may not meet the rather stiff criteria, this significant problem is still cause for concern. And, avoidable factors need to be addressed. The women and children who are experiencing the shortfall share common characteristics: race, socio-economic status, and social disadvantage; and for some, being located in a rural region. All of this places them at increased risk for HIV acquisition, and makes them less likely to obtain quality treatment and prevention. Prevention and treatment for HIV/AIDS and other diseases is available. There is a shortfall in health achievements between the most disadvantaged women in South Africa, compared with their advantaged counterparts. Given the contribution of HIV to mortality in pregnant women, there is a crucial role for expanded HIV services for women of reproductive age.

Why Should We be Concerned with Differential Health Achievements in South Africa?

As *Anand* observes, there are at least two reasons for examining inter-group inequalities in health among populations within the same country. Firstly, it allows us to identify particular groups that are at high risk or who suffer from especially poor health. The working assumption is that social policy and public health would target the worst off or high risk groups directly, with a view to improving their health and prospects for development. Secondly, it allows us to identify inequalities in health that are *unjust and potentially preventable*, thus targeting health inequities that might be successfully addressed through policy. Indeed, the focus is on the role that social policy can play in ensuring that the social environment and social factors improve (rather than impede) health (2004). This accords with a capability view of health as a social justice concern *Ruger* (2004a-b; 2006a-b) (discussed in chapter three).

What is particularly injurious, *Sen* stresses, is the lack of opportunity that some members of society may have to achieve good health and development due to inadequate social arrangements (2002). He emphasises: "An illness that is unprevented and untreated for social reasons (because of, say, poverty…), rather than out of personal choice (such as smoking…) has a particularly negative relevance to social justice" (2002). *Evans et al* (and others) note that we should be less tolerant of specific inter-group inequalities in health, such as racial or gender inequalities. This is because such inequalities give rise to the suspicion that they are socially created (as opposed to being genetic for example). *Peter and Evans* state: "Vast disparities in health status, whether between global regions, nations, social groups, or genders, are an affront to basic intuitions of fairness" (2001, p. 25).

PART II. IMPLICATIONS FOR THE HEALTH AND CAPABILITIES OF WOMEN WITH HIV IN SOUTH AFRICA

What do the findings from chapters five and six suggest for the capabilities of pregnant women and children with HIV (the population groups studied)?[14] Having charted this terrain, what can be said with regard to these women and their potential for development as freedom; what are these women and children able to do and to be?

Nussbaum asks:

> "Are they [individuals] really able to do and to be these things, or are there impediments, evident or hidden, to their real and substantial freedom? Are they able to unfold themselves or are their lives, in significant respects, pinched and starved?" (2008, p. 1).

I cannot speak *for* all black South African women and children with HIV and do not claim to do so *Alcoff* (1994). But I can and will speak *to* the experiences they conveyed in our conversations, and my observations throughout the study – both in the Eastern Cape and Gauteng. I will draw out regional differences where required.

The Central Human Capabilities - Nussbaum's List

1-3. *Life, Bodily Health, Bodily Integrity*

I have grouped the first three capabilities together as they seem to comprise a family associated with health that can be considered jointly. Such an exploration requires a return to the complex reality of black South African women with HIV/AIDS. We know that Nussbaum conceived of the ten central capabilities as integrated and indivisible. Even though they are numbered, she does not order them or place extra weight on a higher or lower number in the sequence of ten. Since much of the previous discussion has been concerned with death, it seems appropriate to begin with life. Do these women possess the ability to live to the end of their normal human lifespan without dying prematurely or being robbed of good health?

To answer that question, perhaps it is helpful to recall the discussions from part I of this chapter indicating years of life lost for black South African women. The evidence points to strong linkages between gender and ill health – with HIV playing a leading role. In chapter two I discussed women's greater biological and social vulnerability to HIV transmission. HIV and ill health for women can be seen as a

bi-directional, mutually reinforcing relationship. By virtue of biology and social norms, women are more vulnerable to HIV acquisition. HIV infection places them at greater risk of ill health.

Are black South African women able to have good reproductive health? Reproductive health refers to reproductive processes across all stages of life. Good reproductive health suggests that women are able to have a "responsible, satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so" *WHO* (2009). The *WHO* emphasises:

> "Implicit in this are the right of men and women to be informed of and to have access to safe, effective, affordable and acceptable methods of fertility regulation of their choice, and the right of access to appropriate health care services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant" (2009).

The special reproductive health needs of HIV positive women also need to be considered within the gamut of reproductive health services. *Ramkissoon et al* recommend that the provision of comprehensive, holistic care for women who are HIV-infected requires "promotion of optimal therapeutic care and well-being through strengthening sexual and reproductive health services" (2006).

This is currently not taking place. If it were, it would expand women's knowledge, choices, and freedom vis-à-vis reproductive health. *Ramkissoon et al* note that this requires the integration of HIV services with reproductive health services with the necessary guidelines for implementation (2006); see *Cooper et al* (2007).

Are South African women able to access healthcare in a way that allows them a safe pregnancy, labour, delivery, with a view to having a healthy baby? The findings from this study suggest that the access to and quality of care is very variable. This finding is reinforced by research by *Penn-Kekana and Blaauw* who found that 83% of women were given no pain relief; 18% were shouted at; and over 4% were "beaten or slapped" (2001). This research is indicative of the kind of care women receive in public health settings and the treatment they are afforded.

Staying on the theme of bodily health, are women able to obtain adequate nutrition and shelter? Women in this study expressed great difficulty in buying sufficient food for themselves, primarily due to high food prices and the fact that they were not working. They were economically dependent on male partners or spouses for food and shelter

as a result. Food security was expressed as an issue of deep concern and struggle. Consequently, if women suffer from hunger, they are not able to attend to other concerns. Pregnant women require additional, healthy food. Pregnant women who are taking ARVs also require food with a high nutritional content; as do children with HIV.

On the whole, women seemed to have access to adequate housing – although a few women described insecure living situations. Many women in the Eastern Cape lacked potable water and had to collect it from the nearest riverbed or other water source. Lack of access to clean water constrains a woman's options in terms of choosing formula feed, which in turn reduces the risk of transmitting HIV to the child.

In terms of bodily integrity, are women able to move freely from place to place; to be free from violent assault, including sexual assault and domestic violence; having opportunities for sexual satisfaction and for choice in matters of reproduction? While this study was not focused on sexual assault and intimate partner violence, the research shows that this is a particularly intractable problem in South Africa. It is under-documented and under-reported *Ramsay* (1999). One study found that South African girls' first sexual experience was often forced – and this pattern was repeated, in that men continued to exert control over young women. The same young women continued to have sex with the men because they were beaten if they refused *Wood, Maforah and Jewkes* (1998). Thus, the onset of the pattern of abuse begins with girls' very first sexual experience. *Jewkes, Penn-Kekana and Rose-Junius* assert: "Patriarchal ideas render girls vulnerable to abuse through legitimising on some level displays of male power… which serve to manufacture gender hierarchy and communicate about gender power relations" (2005, p. 1809); see also *Jewkes* (2002c); *Jewkes, Levin and Penn-Kekana* (2002a).

The research suggests that women are often not free to choose when it comes to matters of fertility, contraception, and reproduction. *Klugman* observes:

> "We see in southern African countries a 'traditional' cultural practice in which men have the right to make all decisions regarding sexual relations. If a husband initiates sex, his wife may not refuse him; the same applies in relationships outside marriage. This makes it impossible for women to protect themselves from HIV/AIDS by initiating non-penetrative sex…or insisting on fidelity or condom use…." (2000, p. 2).

Women in South Africa can thus not sufficiently protect and ensure their bodily health and integrity, indicating a significant shortfall in this capability.

4. *Senses, Imagination and Thought*

Are women able to use their senses – are they able to think and reason in an unfettered way? Women's constrained and straitened circumstances seem to dampen and circumscribe their powers of imagination and creativity. This is not to say that they are not able to think and dream. It is simply made more difficult when pressing concerns, as seen with Thembi and Mpho, crowd out artistic impulses and creative potential. Much of their time was taken up with material concerns: access to sufficient food and transport. Because most of the women were living in grinding poverty, this can impair artistic freedom but also restrict access to literary and musical events, including access to books or musical instruments.[15] In terms of adequate education, most women had low levels of schooling. The stigma of illness and their lack of full economic freedom also impaired their ability to express themselves. Thus, while women are able to exercise this particular capability to some extent, reaching their full potential would be difficult.

Research conducted in the south-western townships (Soweto), South Africa, illustrated that gender was linked to lower levels of education and income, "placing women in disadvantaged social positions and rendering them more vulnerable to disease" *Gilbert and Soskolne* (2003a, p. 202); *Veenstra* (2000); *Gilbert and Walker* (2002).

5. *Emotions*

Exercising this capability "to love, to grieve"; to experience emotions means not having one's emotional development blighted by fear and anxiety. On the one hand this is an area where some women seemed to exercise the greatest freedom. At the same time, for other women, this was not the case. In terms of free expression, women explained that they were afraid of disclosing their HIV status to their partners and to others. Some women held their emotions in – to the detriment of their mental health. For younger women (especially), restricted opportunities for emotional expression and processing might be detrimental to their emotional development. In short, this capability and the degree to which it could be exercised differed among the women – with a significant number having some capability deprivation in terms of emotional expression.

6. *Practical Reason*

Were women able to exercise their practical reason, reflecting on and planning their lives in an uninhibited way? Again, because of their often dire economic conditions, the majority of women were not able to plan and reflect – in accordance with their conception of 'the good'. They were, frankly, thinking about how to organise their next meal; their next taxi ride. This particular capability was quite limited for most women.

7. *Affiliation a-b*

In part (a), this entails living with and showing concern for others; practicing compassion but also protecting institutions that nurture those forms of affiliation while protecting freedom of assembly and speech. Women were able to live with and show concern and compassion for others – in keeping with cultural and social norms. The difficulty was in (b), ensuring the social bases of non-humiliation, respect and non-discrimination on the basis of race or other (HIV). Many of these women suffered a litany of humiliations. They had to wedge themselves into unsafe and unregulated taxis (driven by drivers with incredibly poor driving skills and often a keen willingness to endanger their passengers). Women's poverty meant that they often had to ask for financial support from others, which can be humiliating and degrading.

Women also suffered indignities in accessing the health system: "What women said they wanted from the maternity services was to feel attended [to], to deliver in a safe, clean environment, and the assurance that complications could be dealt with. But most of all, they wanted to be treated with dignity and respect," write *Fonn et al* (1998). The study by *Jewkes et al* uncovered an environment replete with physical abuse and humiliation of patients (2007).

Furthermore, the healthcare workers described themselves as being insensitive, "rude, uncaring" to female patients. They acknowledged that they treated clients selectively, showing more respect for men and discriminating against poor and non-literate women. They attributed these attitudes to their socialisation in a society stratified by class, race and gender" *Fonn et al* (1998, p. 24). This results in poor quality of care. *Penn-Kekana and Blaauw* emphasise: "Although there are institutions in South Africa, both within the public and private sector, which are providing excellent technical quality of care, there is also evidence that at many institutions the technical quality of care is extremely poor" (2001, p. 21). This capability is thus not generally met.

8. *Other Species*

In terms of being able to live in relation to plants, animals and the world of nature, women's experiences would vary by region. In Gauteng, the deeply-urbanised nature of the province would make it more difficult to be around and amid nature. Not everyone would have access to a private or public garden or park. Having pets would be unlikely since they are costly to feed. In the rural Eastern Cape, women might be living in mud huts with nature outside their doorstep. Having said that, most women would not have the choice and the ability to decide whether to have a garden or pet or not.

9. *Play*

In terms of enjoying recreational activities, laughing and playing, my research and observations in this area were limited. Laughter and play were in short supply in our interviews, although there was the occasional joke or remark. In my estimation, there would be some laughter and play but again their financial and health concerns and conditions would restrict this capability.

10. *Control over one's Environment*

Only a small minority had direct control over their material environment. While political participation is assured by law, whether they would have the economic resources to pay for a taxi to vote is another question. Their political participation could be infringed as a result of their restricted economic freedom. Most of the women relied on their male counterparts or parents for housing – thus they did not own their own property. Deprivations in this capability were quite clear across the spectrum of women interviewed.

In summary, on the one hand these women were beset with innumerable obstacles. Their social status in South African society tended to be low and most of these women were living in impoverished circumstances. For these South African women, their capabilities are undermined: the difficulty of dealing with their own HIV status, anxiety about their child's HIV status, food security, lack of employment and economic dependence on their partner or another family member places enormous stress on the lives of these women. All of this requires indomitable strength.

There is often a cloak of invisibility that surrounds black women with HIV making their way noiselessly through the health system. For those women who have received poor care and treatment, it can be the final insult. Like Mpho, when they turned to the health system for assistance, that system failed them. The words of Charlotte Brontë are relevant here: "I wanted to speak, to rise – it was impossible" (quoted in *Gordon*) (2008, p. 3).

In response to the conditions faced by black women in South African society, various strategies are used to negotiate, navigate and overturn those conditions. As the stigma of HIV is decreasing, it is offering new possibilities to women. Improved health has a ripple effect on psychological health. Women are realising that they have control and agency over their lives. Amid great difficulty, many women are navigating their way through the labyrinth of complex choices that face them. In many ways, these are women who are rising above their present circumstances – engaging in ways of constructing value for themselves.

Despite this, the challenges faced by many of these women in addressing their health, together with the burden of an overwhelmed healthcare system (including staff), is often extracting too much from South African women. In the end, the deprivations discussed are affecting women in vast ways, across the spectrum of capabilities articulated here. The negative implications of 'systems failures' for the health of women and their children are incalculable. The links between gender inequality, HIV and ill health become further magnified, casting a web of harmful effects on women, children and their society. Other researchers have emphasised the interconnections between maternal deprivation and gender inequality on the one hand, and the health of children (of both sexes) and subsequently of adults on the other *Osmani and Sen* (2002, p. 106); *Siegrist and Marmot* (2004).

Within this framework that encompasses literacy, education, employment (including opportunities to take up work that allows for breastfeeding), access to immunization – these factors on their own and when they interact with one another become crucial in ensuring the health and wellbeing of the child: and the health (mental and physical) of the mother is an essential piece of the equation. Gender inequalities in opportunities for education and employment have significant repercussions for women and for society as a whole. The so-called *hidden penalties* of gender, then, manifest as increasing mortality rates for women and children, contributing to higher fertility for women, "limiting economic progress and advances, and impairing political participation for women" *Osmani and Sen* (2002, p. 119). This is currently the case for most black women in South Africa.

Conclusion

Through the analysis in chapters five and six, the dominant aim has been to unravel and understand the links between missed opportunities for PMTCT in children and ART in pregnant women, action or inaction on the part of the health system, premature morbidity and mortality for pregnant women and children, and the implications for the capabilities of women. If chapter five sought to capture and explore women's experience of the continuum of care, chapter six aimed to consider the connections between race, sex, inequality, HIV, premature death and the resulting capabilities of women, with additional scrutiny. What becomes evident when viewing larger health trends at a national level, against what is taking place at facility level, is an overlapping set of inequalities and disadvantage, coupled with a cascade of missed opportunities for ART/PMTCT that impact on the health status of these groups, combining to put these women and children at further risk of ill health and premature mortality, while undermining their prospects for development as freedom.

Annex 1 Data Used in the Analysis and Limitations

Cause of Death Data (Kasturi) Sen and Bonita observe that the most useful standard for measuring health status is the cause of death recorded on the death certificate, called vital registration systems.[16] This was a national system developed by William Farr and introduced in the UK from 1837. It is still the basis of the International Classification of Diseases, used today by the WHO. However, less than one-third of the global population has national vital registration systems in place, with less than 5% of the Africa regions of the WHO covered *Sen and Bonita* (2000, p. 577).[17]

South Africa's vital registration systems' coverage is fairly high compared to other African countries.[18] Coverage for birth registration in South Africa was recently estimated at 78% (using a combination of national data and UN estimates). However, death registration is lower than that of birth registration. For example, data from a rural demographic surveillance site covered less than 30% of all child deaths registered. In addition, cause of death certificates "can systematically miss some of the causes" *South Africa Every Death Counts Writing Group* (2008a). *Gilson and McIntyre* state that in South Africa "routine health data are largely unavailable and what exists are both limited and weak" (2001).[19]

Statistics South Africa (StatsSA) compiles routine mortality statistics based on the cause of death indicated on the medical certificate for registered deaths. And improvements in death registration since 1994 have been made. However, according to experts, "vital registration data do not provide reliable national tracking of the numbers or causes of death, especially death in children and babies" *South Africa Every Death Counts Writing Group* (2008a, p. 1294). For example, *Bradshaw et al* observe that children are often not registered at death (2003b). *Bradshaw and Dorrington* emphasise: "the statistics are problematic, as death registration is known to be incomplete and to suffer from misclassification of cause of death" with a particular problem of under-registration of deaths in rural regions and misclassification of deaths.[20] To overcome this limitation, national facility-based audits on maternal, perinatal and child deaths have been established (2005). They are an important source of data and accompanying action *South Africa Every Death Counts Writing Group* (2008a, p. 1294).

There are three such national audits relevant to pregnant women and children. They are: the *National Committee on Confidential Enquiries into Maternal Deaths*; the *Perinatal Problem Identification Programme*; and *Child Healthcare Problem Identification Programme*. The three audits have four responsibilities: 1) to record every death and the direct and

underlying medical cause; and discuss the modifiable factors within the health system and beyond; 2) to synthesis data for every site and across the sites and identify local and national priorities for action to reduce deaths; 3) to make recommendations for action and implement these actions; and, 4) to assess whether the recommendations have been executed. In short, the audits are significant and they serve to identify modifiable factors surrounding death and to implement recommendations, accordingly *South Africa Every Death Counts Writing Group* (2008a).

In terms of limitations, data only concentrate on deaths in public health facilities but 15% of deliveries take place outside of the health system. Thus, the strengthening of vital registration and capturing information about non-facility deaths, alongside these audits, is important. One central database to collate information on child deaths in South Africa is lacking. At present, formal national structures to review child deaths, such as the National Council for the Confidential Enquiry into Maternal Deaths, which is overseen by the Department of Health, does not exist for children. Thus a range of data on child deaths is available, but the statistics are drawn from different data sources, for instance, the Medical Research Council, the Department of Health; StatsSA; the WHO and the three committees just described. The criteria for defining and collecting the data also vary between agencies *South Africa Every Death Counts Writing Group* (2008a).

With regard to data classified by race group in South Africa, I could find no national health data with a detailed racial breakdown across age and sex after 1998. The usual source is the South African Demographic Health Survey (DHS) – a population-based survey. However, the DHS no longer group data by race. The data on race that I did find were from UN sources with some data from StatsSA (this has trends but not a disaggregated presentation). There are some older data on trends in mortality, such as Gilson and McIntyre (who use data from 1993) that I have employed. However, as most researchers are quick to note, data from 1999 and 2000 only begin to capture the impact of HIV infection on mortality *Burgard and Treiman* (2006); *Bradshaw et al* (2003a).

Another limitation of the data is that the assessment of HIV in a patient is done through testing and staging (CD4 count and/or viral load). However, the authors note that this was missing in half of the maternal and child deaths reported in the National Committee on Confidential Enquiries into Maternal Deaths audit and the Child Healthcare Problem Identification Programme. Hence, in addition to child deaths being under-reported and under-counted, information on HIV as the cause of death is under-reported and under-counted among women and children.[21] In short, data collection and reporting is

improving.[22] However, current information on child deaths is particularly poor, with high levels of underreporting. Nevertheless, experts agree that amongst the various data sources there is sufficient evidence to map trends and related developments *Bradshaw and Nannan* (2006); *Bradshaw and Dorrington* (2005); *South Africa Every Death Counts Writing Group* (2008a).

Endnotes

1 *Inequalities in health* describe the differences in health "between groups independent of any assessment of their fairness". Whereas, *inequities in health* refer to a subset of those inequalities that are deemed unfair and avoidable *Evans et al* (2001, p. 4).

2 There is no health equity gauge linked to ART in women or PMTCT in children. While PMTCT policies exist, these do not explore equity implications. I discuss some of the other limitations of equity related to PMTCT in chapters five and seven.

3 The Western Cape has a large white population and a large coloured population (larger than the black population, again, South Africans of African descent), which is not the case in the other eight provinces. In the 2001 census, an estimated 18.4% of the population was white; 26.7% were black; 53.9% were coloured; and 1% were Indian.

4 While the primary route of HIV transmission in South Africa remains heterosexual sex, transmission between men who have sex with men (MSM) is significant, but it is highly stigmatised.

5 Maternal death is defined by WHO as the death of a woman while pregnant or within 42 days after termination of pregnancy, irrespective of the duration and site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes *WHO* (2001).

6 The second Confidential Enquiry into Maternal Deaths covered deaths occurring over the period 1999-2001; and, the third report covered the period 2002-2004, and was published in 2006 *Beksinka et al* (2006). *Ronsmans et al* are quick to emphasise that capturing maternal deaths is not straightforward, even in countries with advanced statistical systems. They note that much has been written about these measurement constraints and some of these difficulties relate to the very nature of maternal death—an outcome prone to under-reporting owing to: "misclassification of causes, sensitivity in the case of certain complications such as induced abortion, and to absence of a diagnosis or declaration of pregnancy". Other measurement difficulties can be attributed to weak routine reporting systems, as well as to the large sample sizes needed to produce current estimates (2006).

7 See *Government of the Republic of South Africa* (2006; 2001).

8 See *Dorrington, Bradshaw, Johnson and Budlender* (2004); see also *Bradshaw, Laubscher, Dorrington, Bourne, and Timaeus* (2004); *Groenewald, Bradshaw, Dorrington, and Bourne* (2005).

9 Measures of premature mortality include years of productive life lost (YPLL) and YLL. Age-specific and age-adjusted mortality have been used to compare health status across populations, historically. These are measures that offer descriptions of death rates in a population but do not account for the burden of premature mortality: "since most deaths occur among persons in older age groups, crude and age adjusted mortality data are dominated by the underlying disease processes of the elderly". To address this problem, measures were introduced and employed, accordingly. YPLL indicates the years of potential life lost in a population in a given time period. YPLL is used to distinguish the burden of premature death in populations, and can be seen as a measure of unfulfilled life expectancy. (There are debates about how "premature" death is defined. Often it is defined as death before a specific age, such as 65). *Dranger et al* (2004). A range of estimates are now available that include Years of Life Lost (YLL), Years lost due to Disability (YLD) and Disability-Adjusted Life Years (DALYs) by age, sex and cause *Barss, Smith, Baker and Mohan* (1998).

10 YLLs highlight and accent premature mortality. The analysis makes it possible to pinpoint diseases resulting in many early deaths. At the same time, very premature deaths can be identified and targeted for prevention to reduce the burden of disease. *Bradshaw et al* note that the use of years of life lost (YLLs) as a measure of mortality in South Africa provides a different ranking of causes from the ranking based on the number of deaths, apart from HIV/AIDS, as it takes age into account. For instance, cardiovascular diseases contribute relatively less to the disease burden in SA, whereas homicide and violence contribute more to the YLL. It is thus significant for public health planning.

11 Please note that this section relies solely on Bradshaw (from the MRC) and Dorrington (from the ASSA and University of Cape Town) for such figures and statistics because this kind of data gathering and analysis is done by very few individuals in the country and I could not find any other sources.

12 Because of criticism lodged by government (linking AIDS to deaths was seen as controversial under the Mbeki Administration), the authors of the study, and others producing mortality statistics, were asked to justify their estimates.

13 The MRC report warned that without interventions, the impact of HIV/AIDS can be seen to more than double the burden of premature mortality by the year 2010. In accordance with the political climate at the time, discussions of HIV/AIDS were dominated by whether HIV was the causal agent of AIDS and whether a treatment programme would be affordable. They also called for better data to inform knowledge and accompanying interventions *Bradshaw, Nannan, Groenewald, Joubert et al* (2005).

14 Throughout this discussion, I am referring to Nussbaum's List of Ten Central Capabilities presented in chapter three.

15 The state of South African public libraries is rather dreadful and books are expensive to purchase. Musical instruments and opportunities for learning to play them are generally scarce.

16 It remains a critical source of information today (see *Whitehead* (2000)). Farr penned a letter in 1839 (appended to the first annual report of the Registrar General in the UK), noting: "Diseases are more easily prevented than cured, and the first step to their prevention is the discovery of their exciting causes!" With similar enthusiasm, he goes on to explain the fundamental importance of the registry for preventing and managing disease. (He would append a letter to every subsequent annual report from the General Register Office.) (Quoted in *Whitehead*) (2000, p. 86). In sub-Saharan Africa only two countries have complete cause of death data through vital registration systems: Mauritius and the Seychelles.

17 This is because, in developing countries, physicians are often not present at the time of death to record the cause.

18 This quote from the *IDRC's* Website throws the impact of the dearth of data for the developing countries into sharp relief: "For the one billion people living in the world's poorest countries, where the burden of disease is highest, those who are born or who die are still not counted. The health profile of these populations is akin to an iceberg: the bulk of reliable data remains hidden. This great information void is a major, long-standing constraint to the articulation of effective policies and programs aimed at improving the health of the world's poor. As such, it perpetuates profound health inequities in the developing nations of the South. Available from http://www.idrc.ca/en/ev-9435-201-1-DO_TOPIC.html"

19 *Barnett and Whiteside* note that up to the year 2000, data on mortality in South Africa were collected but not publicly released (2002). National debates over the extent of the problem of HIV/AIDS resulted in the release of these data in 2000. Now the Medical Research Council and the Actuarial Society of South Africa (ASSA) collect and analyse data from the Department of Home Affairs' Population Register and there is much greater public information about mortality trends as a result (2002).

20 Cause of death is often not specified or is incorrect owing to payouts on medical or insurance policies. Some deaths are recorded simply as natural or unnatural. In addition, in rural areas, traditional leaders charged with the task are often unqualified to determine the actual cause of death *Bradshaw and Dorrington* (2005, pp. 421-422); *Bradshaw et al* (2003a, p. 13). *Bradshaw et al* suggest that due to the requirements of the Home Affairs Inquest Act, unnatural causes of death require investigation, which results in a bias toward better documentation and knowledge of unnatural causes (2003, p. 13).

21 *The South Africa Every Death Counts Writing Group* states that "this is a proxy for poor quality of care received" (2008a, p. 1297).

22 In February 2005, StatsSA released an official report on deaths in the country over the period 1997 and 2003. The report suggested significant improvements in reporting of adult deaths but under-reporting of child deaths was continuing, although the extent of this under-reporting was unclear *Abrahams* (2006); *Shung-King et al* (2006).

Chapter 7

Addressing Disparities in PMTCT and ART Delivery

As discussed at the outset of this thesis, a range of factors have a bearing on the research problem. They serve as intersecting strands in the larger pattern of this phenomenon – and they often have a push or pull effect on ART/PMTCT delivery. The current problem of ART and PMTCT access and provision for women and children with HIV must be seen in context: considering the burden of HIV infection for these population groups; policies governing equitable healthcare in South Africa; evolving practice concerning ART and PMTCT in public health settings; limitations in human resources for health (HRH); and, against a historical legacy of unequal access to health services.

By connecting the empirical findings related to ART/PMTCT within the health system with literature on health equity and capabilities, a greater understanding of the role of PMTCT/ART in development is achieved. Essentially, the effective provision of PMTCT (for the child) and ART (for the woman) can serve simultaneously as an intervention and a vehicle for better human health and development. The converse also holds: denial of, or missed opportunities for, timely PMTCT and ART normally have a resulting negative impact on mental and physical health and development. An understanding of disparities in access and delivery of such services, and their importance in shaping the health – and the implications for the health outcomes – of these population groups, then, becomes clearer.

Nonetheless, as *Krieger* notes, shared observations of disparities in health outcomes do not necessarily result in common understandings of cause – or agreement on approaches to address those disparities (2001a). There are four main uses for assessments of health equity, according to *Evans et al*: 1) describing the difference; 2) calculating the public health impact; 3) attributing causality; and, 4) assessing interventions (2001). The previous chapter was concerned, in the main, with describing the difference. The purpose of this chapter is, firstly, to highlight and reflect on factors that have contributed to the current situation – disparities in, and missed opportunities for, timely PMTCT for children and ART for pregnant women; and, secondly, to identify avoidable factors and targeted interventions: where changes could be made in response to some of the specific problems raised. The spotlight is trained on the public health system, illuminating ways in which the health system serves as a social determinant of health (SDH) in South Africa.

EXPLANATORY FACTORS AND RECOMMENDATIONS

The following factors assist in explaining the current situation. In order to determine how such realities can serve as a springboard for change, I have placed recommendations next to each contributing factor. Again, the focal point of recommendations is the enhanced delivery of quality HIV services for women and children – PMTCT and ART – at the time individuals seek prevention, treatment, care and support.

The Health System as a Social Determinant of Health

As the Commission on Social Determinants of Health asserts, models of social determinants of health that seek to explain their impact have not made explicit the role of the health system itself as an SDH. While differences in access to healthcare do not fully account for patterns in health outcomes among population groups, they do have great importance for exposure to illness and vulnerability to disease *WHO* (2007). Indeed for many countries, including South Africa (as this research confirms), access to healthcare and treatment remains a major stumbling block to good health, to human development and flourishing. At the same time, the role and effect of social determinants of health (beyond healthcare) on health outcomes also become more visible.

This study reveals a range of avoidable factors in HIV/ART/PMTCT service delivery (see **Table 2**). While some of these are influenced by individual behaviour, the majority are directly linked to the health system. Indeed, the lion's share of missed opportunities for PMTCT in children and ART for women can be attributed to health personnel. One of the key messages from the research (across the four facilities in the Eastern Cape and Gauteng where research was undertaken) is that the health system often restricts, constrains, and ironically, prevents people from obtaining the interventions and information they need to improve their health. Even the individual factors that often appear intractable, such as stigma, fear and denial, may potentially be alleviated through additional counselling and psychological support. Improving PMTCT and ART delivery would thus need to go some way towards addressing both individual and systems' factors – many of which are entirely modifiable.

In terms of relevant social policy to address some of these limitations, there is a major role for strengthening human resources for health (distribution, function, knowledge, skills and scopes of practice), and improving the relationship between healthcare workers (HCWs) and patients. This is in line with the Department of Health's own vision of the patient-provider relationship and the principle of *Batho Pele*.

Batho Pele, a Sesotho phrase that means 'people first' was selected as the slogan for the transformation of service delivery in the public health sector in 1997, according to one minister: "because it reminds us that the sole purpose of the public service is to serve the people of South Africa. Every thing that public servants do is after all done for and on behalf of the citizens of this country" *Skweyiya* (1997).

Table 1 Contributing Factors and Recommendations by Category

Human and Financial Resources

- Ensure proper human resources for health (HRH) *distribution* (numbers) of staff, *function* (skills and scopes of practice), *qualifications* and *knowledge* needed for quality healthcare, with particular attention to correcting imbalances and deficiencies in PMTCT/ART/HIV service delivery:
  - Review infrastructure and resource requirements for facilities
  - Review financial investments in HRH
  - Improve knowledge of health personnel through training, monitoring, on-site feedback and supervision
    - Quality, rigorous training at national level must keep pace with improvements and advances in PMTCT/ART care and treatment (scientific knowledge, government policy and clinical practice)
  - Review organisation, management, and deployment of additional cadres of health personnel through 'task shifting' based on workload against existing staffing needs and skills – with attention to ensuring sufficient staff (distribution, numbers and skills) to deliver quality HIV services
  - Review organisation and management of service delivery through partnerships and collaborations
    - Partnerships with service providers, including academic institutions, and NGOs (local and international) need attention to planning, deployment and *integration* of staff and services with regular review and monitoring to ensure quality service delivery; avoid duplication; and maximise staff and resources
  - Provide, fair, lawful, secure employment, payment and working conditions to all staff who deliver public health, particularly HIV lay counsellors who perform critical HIV service delivery but are paid through intermediary NGOs
    - Pay continuous attention to attitudes and conditions of health personnel, including conditions of work, morale, physical health, and remuneration, through financial and non financial benefits
- Ensure better mental health support for patients and health personnel (review resources dedicated to and available for psychological support)
- Provide sufficient technological support (computers, internet, email, databases and photocopying)

Organisation and Delivery of Health Services and Flow of Information

- Review the use of primary healthcare clinics as the basis for delivering HIV services to greater numbers of people at lower cost and greater convenience to populations (saving transport and time) with the requisite attention to ensuring quality of management and services
- Review delivery strategies in facilities for timely ART/PMTCT interventions to ensure best possible quality care for women and children
    - Regular reviews of quality of care should be conducted
- Understand the individual-systems nexus, improve patient-provider relationship and communication, in line with *Batho Pele* principles
- Engage in improved communication and information sharing between wards in facilities (ANC, PNC, paediatrics, ART clinics), and between facilities, with attention to improved referral networks
- Ensure community design, deployment and ownership of HIV-related interventions (e.g., tracing ART defaulters)
- Improve public health information and messaging in facilities (targeted to particular population groups: e.g., women, men, caregivers of children, youth)

Leadership, Management and Information Systems

- Engage in priority-setting for maternal and child health at the national and provincial levels, re-committing to NSP targets and MDGs
- Review allocation of facility managers to take responsibility for ensuring proper leadership, management, and oversight of quality care and staff performance in facilities and for the PMTCT programme in particular
- Ensure sufficient administrative support in facilities to support both managers and health personnel
- Engage in target-setting, monitoring and evaluation, definitions and indicators at facility level, particularly qualitative indicators and outputs, re-commit to district, provincial, national target setting and monitoring and evaluation
- Managers should host regular facility de-briefing on performance of facility in key indicators such as VCT provision (numbers and quality); PMTCT; ART; PCR (infant) testing and results, and against facility, district, provincial and national targets
- Managers need to pay regular attention to needs, stresses and morale of health personnel through dialogue, support groups, rotation, counselling, performance-based incentives, and offering tea and a dedicated 'break' room[1]

Equity in Health

- Consistent and routine monitoring and reporting should occur with attention to:
    - Disaggregating results of each site by province, wealth, urban/rural location, and
    - Other relevant indicators, including the development of guidelines, methods, indicators and targets relevant to NSP goals and provincial strategic plans
- Provide capacity building in equity measurement and monitoring
- Prioritise equity measurement for women and children at all levels of the health system
- Conduct regular reporting and review of equity indicators (qualitative and quantitative)

HUMAN AND FINANCIAL RESOURCES

In this study, a key barrier to healthcare access generally, and ART/PMTCT services specifically, was the ability of the health system and health personnel within public health settings to deliver those services at the time patients sought care. In the Eastern Cape, due to inadequate numbers of staff to perform HIV testing – the essential first step in the continuum of HIV services – women missed opportunities for preventing MTCT and initiating ART for their own health. If health personnel are only available to test women during the hours of 8 am and 1 pm, and no one is available in the afternoons, evenings or during weekends, it is obvious that this presents a yawning gap in service provision. This was the case at the two public hospitals where there were an estimated 30 deliveries taking place at each site on weekends.

In Gauteng, because of the use of a cadre of HIV lay counsellors tasked with managing HIV services, the opportunities for women to test were simply greater. There were more health personnel available to test at every point in the continuum: during ANC, during labour, postnatally, in the paediatric virology ward and thereafter in the adult ART clinic. While there may be sufficient staff in these facilities in Gauteng, key personnel issues, such as the delayed payment to the lay counsellors, impacts negatively on performance; on the numbers of women who are tested; and the provision of ART and PMTCT. In terms of individual factors, such as economic barriers and psycho-social factors, a greater investment in counselling (particularly by trained mental health specialists, social workers and dedicated counsellors to provide support) to address HIV/AIDS would enable better returns on the existing financial investments made by the DoH.

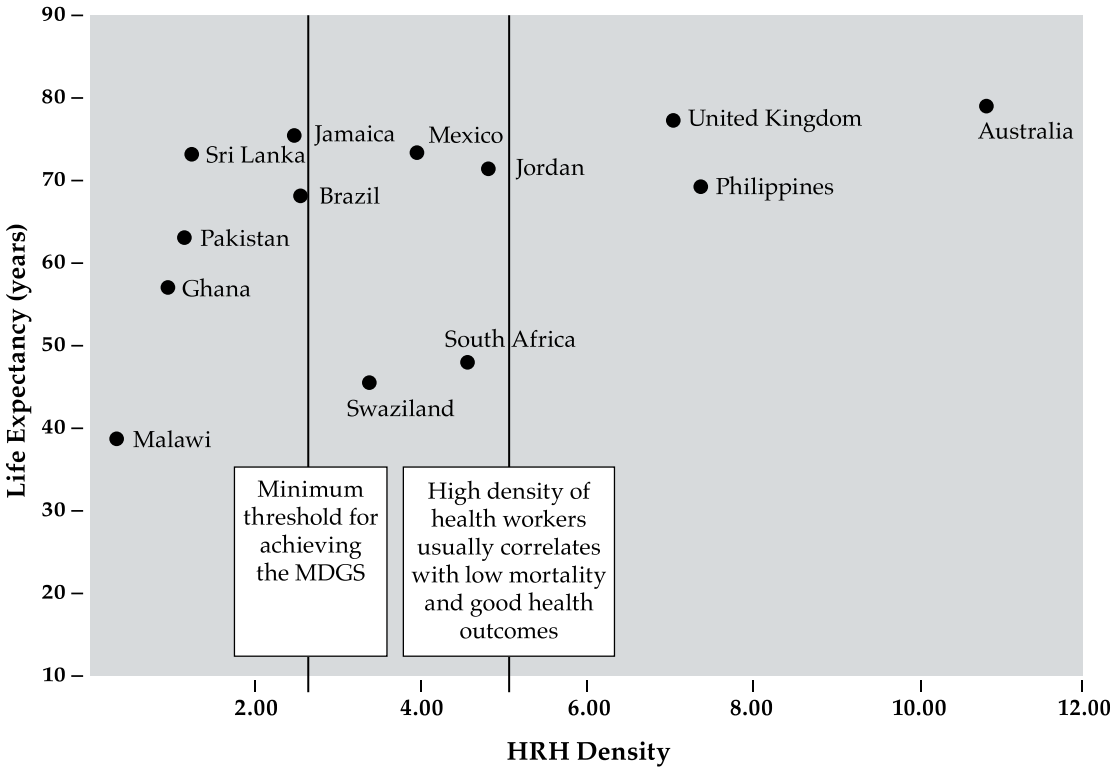
The staggering dimensions of the HIV/AIDS epidemic have thrown the inadequacy of the country's health system into sharp relief, presenting health personnel in particular with steep new challenges. HIV/AIDS has had a threefold impact on health workers. Firstly, it has increased demand, stress and mental fatigue, by inducing loss of morale, depression and reduced productivity. Secondly, struggling with an excessive burden of work due to staff shortages, unsafe working environments and low levels of pay and recognition, the morale and motivation of health workers are at an all time low. With such working conditions in the public sector, productivity is often (but not always) stifled. Thirdly, with the increased ease of labour movement and growing job opportunities in the private sector and overseas, the rate of public health worker migration has risen substantially *Ntuli and Day* (2004); *Joint Learning Initiative* (2004); *Horsman and Sheeran* (1995). Unsurprisingly, many health workers seek better qualities of life elsewhere, as evidenced by the massive outflow of health

professionals which the health sector has experienced, numbering 250 000 from 1989 to 1997. However, as health workers flee, the stress on the cadres of HCWs that remain is amplified, and the likelihood of burnout increased *Joint Learning Initiative* (2004); *Besser, Paruk, Dinat* (2002). In addition to the burden of HIV, there has been a resurgence of tuberculosis (TB), including multi-drug resistant TB, which has exacerbated the stress and workload of healthcare workers (see, in particular, *MSF* (2005)).

Human Resources for Health (Distribution and Function)

Health inequities often derive from an unequal distribution of resources among groups in society. The effects of the mal-distribution of HRH across the provinces can be seen in the figure that follows. Care must be taken when interpreting these data: a variety of factors affect the way in which HRH are able to achieve health outcomes, and life expectancy is only one measure of health. While I do not have disaggregated data on health personnel dedicated to HIV service delivery, the distribution of HCWs at-large demonstrates some trends which are likely to be impacting on the performance of PMTCT/ART programmes, and healthcare delivery more generally.

Figure 1 International Comparison of Life Expectancy and HCW Density



Source: *Balasubramanium and Sprague* (2005); data sources are from *Joint Learning Initiative* (2004).

Note that the three countries that have the lowest relative life expectancy viz. HRH density – Malawi, Swaziland and South Africa – also have the highest HIV prevalence, globally. According to the data, these distributional issues *are* significantly impacting on the health status of the underserved communities who comprise the majority of the South African population and consequently, national health outcomes. On the one hand, as can be seen in **Figure 1**, South Africa's HCWs appear to have significantly under-performed in comparison to countries such as Mexico and Jordan, which have similar levels of health personnel. When compared to countries such as Ghana, Sri Lanka and Jamaica, which have lower health worker densities than South Africa, the effectiveness (and efficiency) of South Africa's HCWs and health system is further highlighted. However, while this provides an important illustration of the links between inputs and outcomes, these figures need to put into context. The data sources are from 2000. They do not take into account a generalised and concentrated HIV epidemic in South Africa, and the accompanying impact on demand for health services by users, once a national ART/PMTCT programme was introduced, as well as the additional burden placed on HCWs. It is thus unfair to compare across countries' performance without taking the extra burden on HRH and health services into account.

The takeaway here is that studies, including this one undertaken almost a decade later, indicate and corroborate that South Africa's health personnel have been unable to meet the needs of the country largely because they were not appropriately geographically distributed, and their skills and scopes of practice were not well matched with local needs and conditions. What was clear in the year 2000 has been exacerbated with the burden of HIV/AIDS *Pick et al* (2000).

Of significance, this situation also prevails in other countries where "overall availability and balance of different types of personnel and skills… are often inadequate and inappropriate" *Lancet* (2004, p. 999). In South Africa, distributional issues and the inadequate number of healthcare workers attending to HIV/AIDS care, treatment and prevention are no doubt having an impact on the health status of users of the public health system *Besser, Paruk, Dinat* (2002); *Padarath, Ntuli and Berthiaume* (2004).

In addition, personnel management systems are weak. Human resource planning and management within the public health system have not been robust historically, and are not generally undertaken in consultation with all health stakeholders, while they also lack adequate implementation. DoH personnel face high staff turnover rates for reasons that include limited career and development opportunities, over-work, sickness and death – sometimes related to HIV *Padarath, Ntuli and Berthiaume* (2004).

Gilson and McIntyre observe that an increase in staff salaries in 1995 failed to retain public sector health workers because the higher salaries were not maintained over the next several years, not even keeping pace with inflation (2007).

HCWs, it must be said, face institutional hurdles that compromise their work, their health, and the overall functionality of the public healthcare system. Investments in current and future health workers must be made, and the incentives, development, training, remuneration and support mechanisms must be provided to enable health workers to perform effectively and efficiently throughout the country. Supportive systems, including basic technology, such as computers and photocopiers, are essential. This requires a mix of national leadership, policy and regulatory changes, cooperation and collaboration with all stakeholders in health, investment in health facilities and personnel, and a focus on improving the effectiveness and efficiency of health services.

An urgent limiting factor to care, treatment and support in the South African public health system is thus its health personnel. An accessible, caring and high quality health system – the principal aim of the Department of Health (DoH) – is not possible without the strategic and effective deployment of appropriately trained and skilled health workers of all types working in tandem with each other and with the communities they serve. However, whilst long term planning is essential, steps must be taken to address the immediate concerns of health workers currently in practice, particularly HIV lay counsellors. Note that with the requisite commitment and planning, this situation is changeable but it would need to be addressed at the highest levels of government.[2]

Payment and Secure Employment for HIV Lay Counsellors

I have discussed the problematic introduction of task shifting within the context of a chronic shortage of health personnel in the public health system. In terms of basic social arrangements in South Africa, a laudable policy is underpinned by an untenable employment situation for the providers of key HIV/AIDS services in the country (see *Woolman, Sprague and Black* (2009)).

To remedy the situation of lay counsellors, they should be employed by the government and have the same remuneration and benefits as government employees. Like other health personnel, they should receive appropriate debriefing, training and mentoring to ensure that the service they provide is of an appropriate standard which would allow them to discharge their duties with confidence. Clearly-defined job descriptions and roles would allow them to be integrated into the health team with resultant better care of the patient and the economic and moral empowerment of lay counsellors themselves.

Human resources – people who deliver care to patients – also require sufficient infrastructure to perform well, this includes equipment, supplies and physical space.

Knowledge of HCWs and Attention to the Quality of HIV Service Delivery

Such quality service delivery has implications on a national level. Rigorous, ongoing training of all HCWs who provide ART/PMTCT services is not occurring. (Current training is woefully weak.) What is needed is robust and frequent training as a requirement for all HCWs, regardless of their current qualifications. HCWs across the board need training in multiple areas but particularly in HIV management of pregnant women and children (the special needs of both population groups). Training in effective communication and in customer service should be provided to all health personnel. Existing service delivery must continue while staff are in training, thus requiring rotation of staff and planning such that not all knowledge and skills reside with a single person within a facility.

Attention to the Needs of Women with HIV (including comprehensive information on sexual and reproductive health options)

Women's whole range of reproductive health needs should be explained, and information provided. Continual, regular training is required on existing and new developments, such as female microbicides and male circumcision; information on HIV and STIs; prevention of pregnancy, such as through condoms (and female condoms); terminating a pregnancy; problems with fertility; management of HIV in pregnancy; safe ART regimens for women who are already on combination therapy and have become pregnant. Information and counselling on the full range of reproductive health options for women (including also sterilisation of partner and woman, STI treatment, screening and treatment for other diseases, such as cervical cancer) is essential. All of this requires continual updating of HCW knowledge and skills.

Attention to the Special Needs of Children

Specific areas where healthcare workers need training is in communicating the importance of early testing of children for HIV (indicated in **Table 4**). This requires that the mother or caregiver brings the child for testing. HCWs express fears of treating young children and babies, and they need training and support to gain confidence. They also require on-site supervision and feedback. HIV management in children requires up to date knowledge of healthcare, nutrition support, managing clinical symptoms and complications. Also, working with children and babies with HIV can be psychologically upsetting. Health staff often require proper counselling

and support themselves. Special, focused and targeted training sessions on the management of children with HIV are recommended *Government of South Africa* (2005); *Michaels et al* (2006); *Tindyebwa et al* (2004).

Attention to and Investments in Mental Health in HIV Service Delivery

It becomes obvious after speaking with women and caregivers that there is a strong connection between mental health (and psychological support) and physical health. Often women lacked the emotional support to take the next step that was required in managing their health (ANC, returning for CD4 cell test results and ART initiation, returning for PNC and PCR infant testing in a timely fashion). Given the psycho-social impacts of HIV, coupled with individual behaviour and the multiple decisions a woman has to make, together with the actions that must accompany those decisions, it becomes obvious that routine, frequent counselling is essential. Organisations in South Africa, such as "mothers2mothers" have been established to address these challenges.[3] The research from this study stresses the role of counselling and psychological support for women in the management of HIV and the implementation of ART and PMTCT. The current number of trained social workers in the country is insufficient to meet national needs. Indeed, current investments in health personnel to address the mental health of patients are insufficient. Yet such investments (in quality and frequent counselling, support groups in clinics, sufficient numbers of counsellors, and social workers) would have a positive effect on patients' physical health, while allowing them to make informed decisions about their health, potentially leading to better health outcomes.

ORGANISATION AND DELIVERY OF HEALTH SERVICES

The Individual-Systems Nexus

Colvin, Chopra, Doherty and Jackson stress that in order to optimise PMTCT effectiveness, several "critical steps" are essential: the woman must present at an antenatal clinic; there must be continuity of care to ensure that counselling and HIV testing are both accepted and offered; she must return for her test results (if they are not available on the same day); she must be staged (CD4 cell count and viral load testing); and, if appropriate, initiated onto antiretroviral drugs; the woman must be screened and offered treatment for *other* possible risk factors; safe obstetric practices must be used; appropriate counselling on infant feeding must be offered; and there must be postnatal follow up. The child must be tested for HIV and diagnosed, with proper counselling on nutrition, support and other factors given to the mother or caregiver

(2007). Proper follow up related to the child's health includes early HIV testing for HIV exposed infants, diagnosis, management, immunization, and nutrition-related interventions *FAO/WHO* (2008); *Michaels et al* (2006, pp. 10-11). The achievement of these critical steps requires a health system and personnel that can discharge these functions as outlined, and an individual who takes an active part in managing these steps. This, again, highlights the important interplay between the health system and the individual's behaviour, response and reaction to events and to individuals (health personnel) within that system. Improving PMTCT and ART delivery would need to go some way towards addressing both individual and systems' factors.

It would also be beneficial if staff (doctors, nurses, midwives, lay counsellors) understand and attend to the interplay between the individual and the health system. By taking cognisance of the particular choke points in the system (such as delayed initiation of ART) and how they could be overcome, HCWs could better facilitate access, and retention, while improving the experience of the patient.

Investment in improved patient-provider communication would be valuable, especially in rural areas. 'Customer service' requires knowledge and skill, and health providers should be trained in this area. The ability of HCWs to provide high quality services should not be assumed. There should be mechanisms in place to reward exceptional performance and to manage poor performance.

Below is a presentation of the barriers discussed, where they occur in the care continuum, with an identification of barrier type, but also whether it is avoidable, and the targeted intervention that could be employed to address each specific barrier.

Table 2 Breakdown of Primary Barriers to ART/PMTCT by Type and Primary Location in Continuum of Care

KEY TO TABLE:
P = potentially; **Y = yes (definitely)**; **U = unlikely**; **U/P = it is *unlikely* that the barrier could be avoided altogether but it could *potentially* be reduced**

Antenatal Care

Individual Barriers to HIV Testing		**Avoidable?**	**Targeted Intervention**
Transport	Economic	P	Possible govt transport subsidy
HIV stigma	Psycho-social	U*/P	Counselling and support group
Fear of post test result	Psycho-social	U/P	Counselling and support group
Denial of post test result	Psycho-social	P	Counselling and support group
Refuses testing**	Psycho-social	P	Social worker counselling/support

* With individual barriers, under the category 'avoidable' I believe this to be open for debate. Making an assessment in an area that is highly dependent on an individual's mental health is difficult. Each individual would have different perceptions of HIV stigma, fear, denial, and related factors, for example. Based on the research, my view is that HIV stigma or fear may not be a barrier that is entirely avoidable but it could be potentially reduced or addressed through appropriate mental health interventions and support within the health system. Again, the *individual* barriers and the analysis of 'avoidability' are not hard and fast but would depend on each person.

** Refuses testing: the individual, acting on her own behalf, may refuse testing but sometimes a patient's family (mother, husband or partner) encourages the individual not to test.

Individual Barriers to ART/PMTCT		**Avoidable?**	**Targeted Intervention**
Fear of taking the drugs	Psycho-social	P	Counselling/Support group
Denial of HIV status	Psycho-social	P	Counselling/Support group
Stigma of HIV	Psycho-social	U/P	Counselling/Support group
Patient does not return for CD4 cell test results	Psycho-social/ Economic	P	Patient follow up: phone call/SMS/ visit by community healthcare worker
Woman (not on triple combo) fails to take NVP pill***	Psycho-social	P	Counselling on purpose/role of NVP in preventing MTCT

*** This was reported by sisters/lay counsellors but it was unclear why: i.e., if they simply forgot or deliberately chose not to take it. I never spoke with a woman who said she had forgotten to take it or refused to take it.

NB: Counselling should be frequent and regular, with partner/family counselling available to allow for partners (men) to be tested and counselled by professional counsellors. Counselling should include the role of treatment, adherence, disclosure, nutrition, PMTCT, infant feeding options with information on infant testing. It should also include information on reproductive health, contraception and fertility options for women.

Antenatal Care

Health Personnel as Barrier to HIV Testing	Avoidable?	Targeted Intervention
Repeat HIV testing not offered to patient who had earlier refused	Y	Re-train HCWs; allocate sufficient staff for this purpose; establish indicators and monitor this. Allocate senior staff member to manage/oversee this function
HIV counsellor not available to test patient*	Y	Allocate sufficient staff for this purpose; allocate supervisor to monitor/be responsible for this task; incorporate into performance review
Clerk turns patient away at first ANC booking**	Y	Re-train clerks on access policy/procedures for all patients, including foreigners, and communication skills (to explain to patients that they do not meet the referral criteria)

* This could be due to a shortage in staff or text kits on the day; or, health personnel need to attend to other things.
** Reasons cited for this include: patient did not meet referral criteria; patient was a foreigner without proper identification; clerk acts as gatekeeper on behalf of over-loaded clinic staff (health personnel), i.e., to manage or reduce patient numbers.

Health Personnel as Barrier to ART/PMTCT	Avoidable?	Targeted Intervention
No counselling received at time of HIV test	Y	Dedicate sufficient staff to task. Establish indicators and monitor this. Institute supervisory oversight to take responsibility/accountability. Re-train staff regularly on counselling. Institute performance review, including monitoring and support of staff. Include reward/incentive scheme if possible
Poor counselling received at time of HIV test	Y	Same as above
Woman not given single or dual therapy (health personnel misses ART eligibility in the file)	Y	Re-train staff to identify eligibility from patient file; establish indicators and monitor for this. Institute performance review of staff taking this into account

Antenatal Care

Health System Barriers to HIV Testing and ART Initiation	Avoidable?	Targeted Intervention
No HIV test kit	Y	Review ordering, stocking, supply issues. Ensure accountability for failure with proper oversight
Patient's file does not have CD4 cell test results to indicate patients' eligibility for ART at time of appointment	Y	Review procedures from personnel to lab to file to pinpoint problems and make adjustments. Re-train staff to emphasise speed from lab to file to patient, supervise, monitor and review performance

Labour Ward

Health System as Barrier to HIV Testing	Avoidable?	Targeted Intervention
Patient's coded HIV status impossible to ascertain from the file	Y	Change HIV coding system (as planned)
Patient's HIV status not recorded Patient with unknown HIV status not tested	Y	Re-train staff, supervise, monitor, and review performance, ensuring accountability

Health Personnel as Barrier to ART/PMTCT	Avoidable?	Targeted Intervention
No counselling received at time of HIV test (no info given to patient PMTCT and ART)	Y	Dedicate sufficient staff to task. Institute supervisory oversight to take responsibility/ ensure accountability. Re-train staff regularly on counselling. Institute performance review, including monitoring and support of staff. Include reward/incentive scheme if possible
Poor counselling received at time of HIV test (no info given on: adherence, infant feeding choices, infant testing for HIV)	Y	Same as above
Patient with HIV not given PMTCT (single or dual therapy)	Y	Re-train staff, supervise, monitor, and review performance, ensuring accountability
Infant not given ARV prophylaxis		Same as above

Postnatal Care (after patient is discharged and returns for follow up care)

Health Personnel as Barrier to HIV Testing	Avoidable?	Intervention
Woman with unknown HIV status does not receive HIV testing	Y	Re-train staff, supervise, monitor, and review performance, ensuring accountability

Postnatal Care

Health Personnel as Barrier to ART/ Paediatric HIV Testing ART for Infant	Avoidable?	Intervention
Woman with known HIV status does not receive information on infant testing; ART for her self and infant; cotrimoxazole; counselling on infant feeding practices; immunization; nutrition; family planning, safer sex, partner testing, or disclosure	Y	As indicated above
Woman with HIV does not have CD4 cell count taken to determine her eligibility for ART	Y	As indicated
Woman with HIV does not receive any counselling at time of HIV testing	Y	As indicated

Paediatric Unit

Health Personnel as Barrier to HIV Testing/ART	Avoidable?	Intervention
Child admitted to hospital for illness (e.g., TB) but not tested for HIV	Y	Re-train staff, supervise, monitor, and review performance, ensuring accountability
Mother of child with positive PCR not tested for HIV	Y	Same as above
Mother of child with HIV Not counselled on ART for her health	Y	As indicated
Father of child with HIV not tested for HIV/not counselled on ART		Target men through public health messaging

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Using Primary Healthcare Clinics for Improved HIV Service Delivery

In 2006, MSF published a report on its interventions in Lusikisiki, Eastern Cape using a primary healthcare approach to provide ART, including PMTCT for children and ART for pregnant women. Their assessment indicated that the retention of users is superior in clinics – with only 2% of patients lost to follow up.[4] In terms of improvements in CD4 cell count and viral load reduction, clinics also outperformed hospitals. Note, in terms of weaknesses, deaths were higher in clinics. These results have not only accrued to MSF's sites; down referral from hospitals to primary healthcare clinics is also taking place in Gauteng and Western Cape, with primarily good results.[5] However, *MSF's* results must be seen with caution.[6] There are questions about the sustainability of quality services and outcomes once a donor-funded, pilot project is transferred to the DoH. The key message is that changes in practice may generate important benefits but they must be appropriately designed, managed, supported and sustained over the long-term (2006d).

Ensuring Community Design and Ownership of HIV Interventions: Involvement in Clinic and District Hospital Boards

In accordance with the NSP, communities should design and participate in public health and HIV awareness campaigns. Ideally, they should be involved in public health interventions within communities, such as treatment literacy. To that end, there should be broad representation of communities on various local level structures, especially people living with HIV/AIDS so that members are involved in design and deployment of related activities, in line with NSP goals *Government of South Africa* (2007a). This is not taking place widely at present.

Tracing Patients Lost to Follow up and Defaulters

In the postnatal and paediatric wards there was a repeated phenomenon of patients defaulting on their drug regimens, and often, becoming entirely 'lost to follow up'. This meant that patients were falling out of the health system as a consequence. Research from this study suggests that the underlying reason for this was that patients received little or no counselling, particularly on adherence but also more generally. Much of this could be attributed to psychological issues and lack of support in managing one's HIV status – which impacts on disclosure and adherence (the testimony of women shows that it is very difficult to adhere to medication if a woman is hiding her status, fearful that others will find out, and unsupported by family or friends). Again there was frequent mention of this problem across facilities.

Besser points out that a patient's return to the health system for appointments is wholly voluntary (2009b). Addressing this problem would, then, require health system agreement on a set of interventions and follow up activities to plug these gaps. The DoH would need to decide on points of intervention within the care continuum, where clients could be tracked: e.g., in ANC, at the threshold of ART initiation (after CD4 cell counts are available); PMTCT initiation; infant testing, etcetera. Key questions raised revolve around ethical ways of tracing patients – and the available human and financial resources to carry out tactics and strategies. It should be noted that an additional investment in mental health support may alleviate problems with defaulters and adherence since many of problems that appear to drive patients away from the health system are psycho-social.

Follow up to trace patients who default or become lost using community healthcare workers is being tested in some facilities. Since 2001, a range of policies has been mooted with regard to the official management of community health workers (CHWs), home healthcare and community based care in South Africa.[7] However, the frameworks formulated to govern community healthcare workers have never been finalised. This is a great opportunity for addressing limitations in health system performance. CHWs should be encouraged with the necessary human and financial investments made. Again, this means the dedication of resources to ensure that the existing investment in HIV/AIDS treatment is not lost, also ensuring better patient services and care, while addressing possible drug resistance *Government of South Africa* (2000c).

LEADERSHIP, MANAGEMENT AND INFORMATION SYSTEMS

Under former health minister Barbara Hogan, rumours of a prioritised emphasis on PMTCT have circulated, but no action has yet been forthcoming. Mention of a social mobilisation plan for PMTCT has also been made by civil society, with draft documents sent to researchers and activists within the health sector for comment. However, nothing has been publicly launched or announced; the anticipated deadline for such an announcement was February 2009 – a deadline that has come and gone.

Maternal and Child Health as a National Priority

In a public meeting in 2009 with the Deputy Minister of Health and the Minister of the Executive Council (MEC) for Health in Gauteng, I asked if they were aware that the quality of PMTCT delivery was wanting and HRH was a limiting factor to PMTCT performance. In reply, health officials said they were aware of some "reports". When asked if there would be an "acceleration of PMTCT quality in the province" the MEC said simply that PMTCT had been "rolled out across the [Gauteng] Province" – as if, in a tick box fashion, this could be checked off the list.[8] He did, however, mention that management and leadership were weak, acknowledging that those factors were contributing to the poor performance of the public health system (quoted in *HIP Meeting*) (26 March 2009). A new health minister, Aaron Motsoaledi, was appointed in May 2009 (the third over the course of this study). There is anticipation, discussion (on various health listservs) and some anecdotal reports that he may launch a plan to prioritise PMTCT.

Management and Leadership in Health Facilities: Oversight of Effective Clinic Procedures

There has been inattention to planning, management and oversight in order to create the greatest possible opportunities for HIV testing, PMTCT and ART provision. For example, no one seems to be asking the most basic questions such as: do we have sufficient staff to provide HIV testing to pregnant women; are we collecting the right data to monitor clinic services; and how are the data used? Supplies of drugs and sufficient equipment also need to be addressed in such planning exercises.

At the root of some of the many problems and missed opportunities is the sheer lack of proper management and accountability. A dearth of supervision, reporting structures, opportunities to debrief staff on their performance – or to provide guidance on ways of improving practice – characterises these sites. A manager could ensure oversight

of the facility's services, monitoring the quality of those services, while making sure that proper data collection and reporting were done against provincial and national goals. Administrative support is also needed. Managers cannot perform well without proper assistance. Dedicated clinic (or ward) managers could be required to meet with managers at other neighbouring sites and within the same facility to feed back on their own procedures, look for gaps in clinic procedures and ways of addressing them, including improved referral networks and case management. This is such an obvious way to improve clinic services yet it is being employed in very few settings.

Ensuring the Use of Quality Indicators and M & E Frameworks

Growing attention, by researchers, is being paid to increasing coverage and scale of PMTCT, i.e., quantitative indicators. However, the *quality* of PMTCT and ART services and interventions, and effective ways of improving quality and equity (e.g., with VCT offered effectively), is receiving insufficient attention. Hence a focus on the delivery of quality services – and ways of monitoring and evaluating those services – would make a lasting contribution in these facilities.

Having said that, at a national level, there is no consensus on how PMTCT service delivery should be evaluated. There is a glaring lack of consensus on monitoring and measuring PMTCT programme effectiveness nationally, provincially, and in each facility. Such criteria seem essential to improving service delivery and expanding quality service provision across the country.

Greater Provision of Public Health Information to Patients in Facilities (e.g., pamphlets and brochures)

There is a role for printed information in public health settings to assist women in negotiating their HIV positive status, options in pregnancy, and future steps to address their mental and physical health, while also providing information on HIV testing in infants and paediatric care for children with HIV. At the moment, this is a completely under-utilised resource. I am aware that facilities and departments have budget constraints. However, it is inexpensive to type, print and photocopy a one page handout on reproductive health for women (although I have noted that some facilities in the Eastern Cape have no computers or photocopiers, which would first need to be addressed, as I suggest in the recommendations). Expanded public health campaigns for partner testing support groups for men, and targeted messaging to particular population groups, would also be beneficial.[9]

EQUITY IN HEALTH

Routine, consistent monitoring and reporting should be occurring across public health facilities in South Africa but this is not the case. Capacity building in measurement and monitoring; and, the development of guidelines, methods, indicators and targets relevant to NSP goals and provincial strategic plans should be prioritised**.** This requires a political commitment to researching and documenting equity in health and disparities related to access and provision in healthcare and HIV services. There should be attention to building capacity to measure equity, and data should be gathered at facilities, with information on wealth, urban/rural location, and other relevant indicators. Regular review of results and reporting (qualitative and quantitative) should occur with dedicated managers to take responsibility for facilities' performance.

I have looked more closely at factors that appear to explain or contribute to the current situation, and possible interventions for addressing those factors.

Conclusion

Throughout this chapter my aim has been to identify factors that explain the existing state of service delivery. Any plan to address those in a systematic way would require consensus on key structural drivers: the way in which health services are organised and delivered, including the distribution and roles of health personnel (task shifting); and a prioritisation of recommendations according to available financial (and human) resources. I have not prioritised interventions, as recommendations follow from the ways in which the organisation and delivery are decided. As I have indicated, there are different models: e.g., the use of primary healthcare clinics for HIV service delivery is one way. There is not yet agreement on the appropriate model. And, there is presently no agreement on 'task shifting'. As *Besser* emphasises, we need to think of task shifting beyond a task assumed by nurses and doctors – and even the provision of HIV services – and to consider quality service provision in a more holistic way.

Moreover, if we are to come to grips with PMTCT, we must think of this programme as a comprehensive, multidimensional programme and approach that enhances the health of mothers and children. It must attend to the reproductive health needs of women – with information on preventing unwanted pregnancies, and managing HIV in future pregnancies. An enhanced PMTCT programme must prevent new infections in infants by reducing MTCT at every available opportunity in the continuum of care. HIV free survival is the appropriate goal for the health of the infant.

This requires timely ART delivery to the mother and proper infant feeding counselling and support. For infants who acquire HIV, enhancing their health and survival through timely testing, provision of timely cotrimoxazole, and promoting immunization is critical. A family-centred approach to care and treatment is key to success. This must include family counselling, partner testing and the testing of other children in the family. Families need mental health support in managing HIV. Of course, any implementation of these recommendations would require political will and engagement on the part of stakeholders within the health sector – and a renewed commitment to preventing, treating and managing HIV in women and children.

Endnotes

1 Recall that in the Eastern Cape in some facilities there was no tea for staff (and no soap): a reflection of existing financial resources or a lack of attention to providing essential supplies. Whatever the reason, this has an attendant impact on staff attitudes and morale.

2 I thank Dr Mitchell Besser for his comprehensive comments on this chapter.

3 The vision of mothers2mothers (m2m) is to create an effective, sustainable model of care that provides education and support for pregnant women and new mothers living with HIV/AIDS. They employ a model at the community level that trains and employs HIV positive mothers who have benefited from these services previously. These 'Mentor Mothers' comprise a team of caregivers and educators, working directly with mothers living with HIV, to become an integral element of clinical PMTCT care. Based in antenatal clinics, maternity wards, post-delivery clinics and hospitals offering ART to women living with HIV, m2m works "alongside" established PMTCT and ART programmes. They thus seek to provide a comprehensive service to foster a supportive environment – one which promotes empowerment and companionship, assists women in combating stigma within their families and communities, supports a mother's adherence to medical treatment, and reduces the likelihood that her children will become AIDS orphans. Founded by Dr Mitchell Besser in 2001 in Cape Town, in one of few success stories in this area, the organisation has since become a multinational NGO. For more information, see http://www.m2m.org/.

4 *MSF* observes: "This higher drop-out rate at hospital can be due to sicker people starting treatment (higher early mortality), having to travel further, less preparation of ARV users, and less effective follow up of defaulters by adherence counsellors" (2006d, p. 8).

5 Based on discussions with Dr Vivian Black and research from Cape Town presented by *Moultrie* (2009).

6 I have not seen an assessment of services/outcomes after MSF withdrew and the DoH took over. However, anecdotal reports suggest that the programme has declined. A new assessment of the programme requires proper study and analysis.

7 On community healthcare workers, see *Government of South Africa* (2000c).

8 As if it was 'done and dusted' as South Africans like to say.

9 The Johannesburg facility has tried to encourage partner testing (of men) in the postnatal ward and in the paediatric ward with little success.

Chapter 8

Beyond Healthcare: Addressing the Social Determinants of Health and Ensuring Good Health as a Central Capability

The last century bore witness to great improvements in the health of people globally. *Siegrist and Marmot* observe that the social inequalities in health facing us today are an important public health problem even in advanced societies where the mean difference in life expectancy between those at the top of the social hierarchy and those at the bottom is from four to ten years (2004, pp. 1463-1464).[1] While socio-economic inequalities in health have been observed persistently over the course of human history, "Recent analyses suggest that for the most part they have increased over the past century and even in the past few decades" write *Robert and House* (2000). There is no society without inequalities in health. Yet, as discussed in previous chapters, the extent of health inequalities – which constitute inequities – pose a particular problem for development and flourishing for many South Africans *Gilson and McIntyre* (2001); *Wadee et al* (2003). The research concern of inadequate prevention and treatment interventions for pregnant women and children with HIV is located within a larger context in which premature mortality attributed to HIV/AIDS, an abnormal situation, is becoming the norm.

Two of the larger conclusions gleaned from the analyses (conducted in chapters five and six) warrant additional emphasis in this final chapter. The first primary insight or contribution that flows from this study is that the health system itself serves as a social determinant of health (SDH). This research captures the ways in which the health system can play a crucial role in reducing morbidity and mortality – in improving the health status of South Africans – with health personnel at the forefront. At the same time, the many interlocking spheres of inequality in social status, in income, in access to basic services (particularly for black South Africans), illustrate the importance of factors that also impact on health but remain outside the reach of the health sector. Safe water, electricity, adequate living and working conditions comprise many of the other social determinants of health. The fruits of this analysis point to the second conclusion: achieving good health and development in this country will only be achieved when we have a shared consensus that health is advanced but not limited to good healthcare; and that good health (and not healthcare or the progressive realisation of access to healthcare services) is the appropriate social goal. This conclusion introduces a number of policy implications.

The study has thus revealed two findings that may at first glance seem contradictory. First, the way in which the health system serves as a SDH in the South African context has become more transparent, more accessible. Subsequently, reforms and interventions aimed at strengthening health systems would bear fruit in South Africa. *Ruger* rightly notes that "one must not assume that more and better health care is all that is needed to improve health" (2004a, p. 1076). Nonetheless, in the South African context, strengthening the public health system is a necessary first step to ensuring at least some of the minimum conditions that allow people to be healthy. As a point of departure, there is great scope for systems' interventions that would address the shortfall in health for black South Africans and deprivations in health capability (discussed in detail in chapters five, six and seven). These interventions (identified in chapter seven), if adopted, would also address inequities – although smaller – for 'coloured', rural, poor, and other disadvantaged groups as well. The health system has thus far not fulfilled its obligation to deliver a people's health system for all South Africans with *Batho Pele* (people first) – in accordance with the social contract forged between the Government and the South African people in the post-apartheid era.

Second, while the health equity literature on assessment has allowed for further understanding of the problem, the capabilities approach suggests that societal efforts be made to bring each individual's health functioning "as close as possible to (or above) a certain level of minimal normal functioning (in so far as an individual's circumstances permit)" observes *Ruger*. She stresses that this also includes the ability to avoid premature mortality: "Premature mortality implies placing special emphasis on efforts to avert deaths from preventable causes that do not allow individuals to live a life of normal length (e.g., a child dying of AIDS)" (2004a, p. 1077).

In any society, protection of the public's health from preventable illness and death is part of the state's role. If we are going to take health seriously in this country we must begin to elevate health as a normative national goal that is achievable. It is because of the contribution of social determinants of health (that impact on health but lie outside the realm of healthcare to health status), that good health is not achieved solely by access to and provision of good healthcare. This reality underscores the importance of health as a central capability. In the capability view, the moral concern for state and society is the reduced capability of individuals due to avoidable health inequities. As the *WHO's Commission on Social Determinants of Health* states, "When such inequalities arise systematically as a consequence of individuals' social position, governance has failed in one of its prime responsibilities, i.e., ensuring fair access to basic goods and opportunities that condition people's freedom to choose among

life-plans they have reason to value" *WHO* (2007, p. 8). Such shortfalls in health capability have incalculable negative implications (as discussed in chapter six) for both individuals and society.

Importantly, the health status of black South African women and children with HIV will not improve without additional high-level recognition of this problem and much greater political will. Ultimately, national responses must be rooted in ethical values about health because ethical claims often have the power to "motivate, to delineate principles and responsibilities within broader society" *Ruger* (2004a, p. 1075).

Moving forward from understanding and recognition to comprehensive, coordinated policy action requires a consensus about the problem and how to proceed. So far these pieces appear to be missing in South Africa. This is in spite of mounting evidence of premature mortality linked to HIV in the population groups studied here, which has been brought to the attention of the national DoH by various stakeholders in different forums and publications *South Africa Every Death Counts Writing Group* (2008a-b); *Bradshaw and Dorrington* (2005); *Bradshaw et al* (2003 a-b; 2004); *Groenewald et al* (2005); *Wines* (2005); *Statistics South Africa* (2004; 2005); *Dorrington et al* (2004).

If the job of the state is to take care of the nation, public servants of modern nations must ask – what Nussbaum calls – the obvious question, constantly: 'what can be done?' But the state's public officials also confront, what *Nussbaum* terms, 'the tragic question'. She explains:

> "In all situations of choice, we face a question that I call 'the obvious question': what shall we do? But sometimes we also face, or should face, a different question, which I call 'the tragic question': is any of the alternatives open to free us from serious moral wrongdoing?" (2000b, p. 1005).

The tragic question demands those who serve as stewards of public health to reflect on the moral implications of action or inaction: it urges us to consider constitutional and other commitments that protect and enhance social well-being, and to ask whether alternatives are available. Each public servant is a moral agent. *Nussbaum* writes:

> "[I]t is valuable to face the tragic question…because facing it helps us think how we might design a society where such unpalatable choices do not confront people "(2000b, p. 1005; 1990).

Contemporary societies commit themselves to a set of protections and social goals. South Africa has made the commitment to ensuring healthcare and greater equity in the health status of the population. Constitutional commitments in the basic law have been put in place in response. But this has been inadequate. Thus far the phenomenon of premature mortality attributed to black South Africans with HIV, and the shortfall in their health achievements, comprise a development and social justice problem that remains largely unchecked. Such tragic dilemmas call for a reckoning because the decisions that are being made result in greater illness and death. In this situation of preventable mortality due to HIV/AIDS, I am suggesting that South African public servants should face 'the tragic question'. Such a tragic question begs for a response commensurate with the depth and scale of the problem: HIV infection in children is preventable; HIV infection in pregnant women is treatable. Again, the modifiable and changeable factors identified in chapter seven could enhance PMTCT/ART provision, with an attendant beneficial impact on health outcomes.

CONTRIBUTIONS AND LIMITATIONS OF THE RESEARCH[2]

The aim of this research has been to shed light on the research concern, in particular, missed opportunities for preventing HIV in children and treating HIV in women, and the implications thereof. Much of the value of the research lies, first, in its effort to highlight the internal experiences of women – their perceptions and challenges (in accessing HIV services through the public health system), using primarily qualitative methods. Strangely, I could find no other PMTCT studies where patients were interviewed, with their own views documented. Studies employing qualitative social research methods have thus been lacking in this area. This research and others will, I hope, begin to fill the gap.

Second, while imperfect and a great challenge to execute, I believe the mother-child approach – the dyad – was very useful in determining missed opportunities for both the woman and child in accessing HIV testing, prevention and treatment services. During pregnancy, and even in the immediate postnatal period, the woman and child operate as a unit. The norm, as indicated, is to focus on one population group. That approach misses the linkages and fragmentation between service points that need to be accessed by the mother for her own health and her child's health. Such fragmentation often defines these patients' experiences, while presenting key points of opportunity for timely interventions. As a limitation, I have focused on the mother's experience, with less attention to the child's, or other aspects of child health, such as nutrition and immunization.

As a third contribution to the literature, I have not seen another study conducted in the public health system in South Africa that investigates the continuum of care for maternal-child services in such detail – the patient's journey through that system – drilling down to the details of which interventions take place at what point. Nor have I seen one that looked so long and hard within the facilities studied, across the rural-urban divide in South Africa, using a case study lens and an equity perspective. This study, however, struggled to capture the array of complexities presented. Even as the rural-urban comparison was a strength, it was also a drawback. The choice of two sites (rather than one) also restricted a more penetrating analysis of a single facility.

Fourth, I have not seen another attempt to frame premature mortality linked to HIV as a development and social justice problem; to apply the capabilities and health equity literature to the research concern; or, an effort to determine whether such health inequalities comprise inequities. Nonetheless, this exercise has great limitations, made worse by the lack of available data. The landscape to be covered is too vast for one doctoral study. In the end, I did not make the headway on operationalising health as a social justice claim that I had hoped.

I have identified contributing factors that help to explain the current situation and attendant recommendations in chapter seven. In the next section I put forward a set of suggestions for additional research.

SUGGESTIONS FOR FUTURE RESEARCH[3]

The following areas warrant further investigation, with an emphasis on applied social research.

Maternal and Child Health

Early Diagnosis, Treatment and Management of HIV in Children and Women

The base of social research on HIV in children is very thin in South Africa. There is much research on clinical outcomes in infants with HIV. However, this is not matched by qualitative studies, especially longitudinal studies that track children as they grow older. There is limited understanding of the mechanisms through which children with HIV could be identified more swiftly (e.g., case finding of infants with HIV). For example, what are the pathways in communities, in family or social networks or early warning systems, for alerting women, men and caregivers to early HIV testing, diagnosis and treatment? This could include HIV-exposed infants who initially test negative and sero-convert postnatally.

Additional social research on how families manage HIV in children – coping skills and strategies for adherence and disclosure – would be useful (particularly as children get older, attend school and begin to become aware of their status, often before they are told by someone else). *Ramkissoon et al* suggest that "disclosure to children is probably one of the most difficult tasks faced by HIV-positive women and requires considerable courage, preparation and time" (2006, p. 325); *Mtshizana* (2004). There is already a sizeable cohort of children living with HIV on ART in South Africa. But this growing group of children is not well-documented or understood. Unlike the corps of doctors specialising in paediatric HIV, there does not seem to be a similar grouping of social scientists in South Africa who focus specifically on HIV in children. The strategies by which families support children with HIV – and teach those children coping skills, including stigma negotiation, nutrition and living a healthy life – would be a useful starting point for research. As this cohort of children becomes older (the oldest child living with HIV I observed in the public health system was 12), they could be interviewed on their own, subject to the necessary ethical considerations and protocols.

The holistic health and development of children is under-studied and under-documented in South Africa. If researchers, activists, paediatricians and officials are going to understand and improve children's health there will need to be a movement away from traditional disciplinary silos, such as law and medicine. For new infections to be prevented, paediatricians will need to focus much more on the linkages between maternal, women's and child health. Because so many of the problems associated with HIV diagnosis, case finding, ART initiation and adherence are psycho-social, researchers and advocates of children's health (including international and local NGOs) should work across disciplines: with psychologists, anthropologists, public health and development specialists working in collaborative research groups with clinicians and midwives. Each group can use the speciality of their discipline to report findings to their own academic, research and policy communities. Academics and practitioners need to reshape their disciplines, curriculum, theory and practice, accordingly. To address the problem of children with HIV in this country – prevention and treatment – a movement for children's health is needed.

HIV Testing

In terms of maternal health, this study has touched on the many women whose HIV status is unknown at delivery – pointing to failures in the provision and acceptability of HIV testing; missed opportunities for repeat testing when women refuse; testing for women for whom a test kit or healthcare worker was unavailable at the time of their visit; testing for women who seroconvert; or women who received an inaccurate HIV

test result; and poor referral systems and networks between wards in the same facility and between facilities. This is an area requiring much further understanding because it presents a basket of missed opportunities for PMTCT and ART – and for health promotion more generally. These inter-linked problems require more knowledge of the psycho-social, economic and other considerations that determine or influence women's behaviour. Added to this is the role that health personnel and health systems play in assisting or hindering HIV testing, diagnosis, treatment, care and support. The delays by women in seeking ANC and in retrieving CD4 cell counts for ART initiation have been noted. Such delays often translate into denial of timely ART and PMTCT altogether – with both mother and child failing to benefit. As this research has indicated, many joint problem-opportunities for intervention cluster in the labour ward. Due to ethical considerations, it is generally not possible to interview women in active labour; or to observe what takes place. However, research should target the labour ward as a choke and entry point – a critical opportunity for maternal and child health interventions, information and support – possibly by interviewing health personnel responsible for maternal deliveries, as well as other key informants.

Infant Feeding Options and Acceptability for HIV Positive Women

This study and others have shown that one of the weakest aspects of interventions to prevent new MTCT of HIV infections in children is in guiding mothers on infant feeding *Latham (*1999; 2000). Other studies have demonstrated that formula feeding in South Africa is having poor health outcomes for children *Coutsoudis et al* (1999); *Nudati et al* (2000). Indeed, *Doherty et al* observed that postnatal mother to child HIV transmission was occurring in 50% of the cases studied (2006); see also *Preble and Piwoz* (1998); *De Cock et al* (2000); *WHO* (2003e).

Blame is largely laid on the poor counselling on infant feeding received by mothers and the lack of related support *Chopra et al* (2005). In such a diverse country, different regions may call for different strategies in terms of formula versus breastfeeding. To address the problem of mixed feeding and poor counselling on infant feeding, it has been suggested by some researchers that we should 'treat our way out of the problem'. The argument made is – rather than dealing with the complexities of socio-cultural norms, stigma, assessments of safe water supplies and feasibility (in diverse resource settings in the same country) – all women with HIV (regardless of CD4 cell count) should be initiated on short-term ARV prophylaxis and instructed to breastfeed exclusively *Ashford* (2008).[4] However, the existing research suggests that a comprehensive, robust effort has yet to be made in South Africa to provide women with sufficient information and support about safe infant feeding options (see *Coustoudis* (2005); *Doherty and Chopra* (*2006*); *Coovadia* (2005)).

To address the very real problems highlighted, I am suggesting social research to consider women's perspectives across rural, urban, peri-urban and peri-rural settings: their views on breast versus formula feeding, complaints, failures, successes and strategies, with a view to understanding how this problem could be surmounted in such a way as to protect a woman's role as primary custodian of her own reproductive health, while leading to better health outcomes for the child *Chersich* (2007); *WHO* (1997). It is also critical that the South African policy on infant feeding reflects the challenges and on-the-ground realities faced by South African women across the country; hence research should inform policy.

Women's Health

As I have documented elsewhere, there is not yet a strong foundation of public health policy and practice that conceives of and supports women's health on its own – without conceiving of women as bearers of children or as caregivers. Academic discourse and policy discussions have focused on ways of addressing this problem in South Africa and beyond *Sprague* (2008); *Stevens* (2008a-b); *Klugman* (1995; 1999; 2000); *Lancet* (2007); *Moss* (2002); *Cooper et al* (2004); *Petchesky* (2003); *Shaw* (2006); *Annandale and Clark* (2000).

Mental Health

Mental health is a neglected area in South Africa generally, and particularly for women. South African women face conditions of poverty, gender inequality and social disadvantage. They may be living with HIV; suffer from intimate partner violence; or, other forms of abuse Jewkes *et al* (1989; 2002a-b; 2005). *Moultrie and Kleintjes* state: "In SA, the lives of most women have been characterized by chronic social adversity and race/class and gender oppression" together with inequality in access to resources (2006). Evidence-based reviews have reported significant correlations between women's HIV positive status and a range of psychopathology disorders and psychological distress *Moultrie and Kleintjes* (2006); see *Dunkle et al* (2004); *Olley et al* (2003; 2004; 2005); *Stein et al* (2005); *Morrison et al* (2002).

Additional research is necessary to understand and address women's mental health vis-à-vis HIV in both rural and urban contexts, which introduce different norms and stresses *Kehler* (2001). Research could include both maternal and postnatal depression and other types of anxiety and stress-related disorders. This study reveals that women often look to health providers for information, answers, comfort, counselling and support – not only for physical ailments but for psychological distress

Cooper et al (1998; 1999). Research on coping strategies and the role of support networks, particularly within public health settings in South Africa, would be useful in learning how women's mental health could be better supported within the structures of the health system and in HIV service delivery.

Understanding the Links between Gender and Ill Health and Enlarging the Evidence Base

In South Africa, research on the pathways by which inequality produces ill effects on health in women would be helpful in documenting and substantiating the connections between gender and poor health. There is evidence that women are treated more poorly by doctors, nurses and other hospital staff than men internationally *Doyal* (2001). In South Africa, in studies of maternal health services provided in the public health sector, healthcare workers described themselves as being insensitive, "rude, uncaring" to women because they are women (quoted in *Fonn et al*) (1998); see *Jewkes, Abrahams and Mvo* (1998). These and other studies indicate that black South African women are treated more poorly, not only because they are women but also because they are poor *Dunkle et al* (2004); *Blaauw et al* (2006); *Fawcus et al* (2002); *Jewkes et al (1998)*; *Jackson et al* (2006); see also *Parkhurst et al* (2005); *Penn-Kekana et al* (2007); *Penn-Kekana and Blaauw* (2001). Exploring the physiological effects of ill treatment on women's health is critical. Identifying the contribution of social determinants of health (especially health personnel) to the ill health of women would assist in understanding these links and in building a body of evidence in this area. *Goldman and Hatch* state: "What seems essential is to look at women's health separately from that of men – not simply combining the data or adjusting for sex in the analysis – and to use a gender-specific approach" (quoted in *Panelli and Gallagher*) (2003, p. 96); *Colomer-Revuelta et al* (2007). This would enable greater understanding of those conceptual links; also providing the empirical evidence to support changes in health policy that ensure women are treated with the requisite dignity and respect.

Reconstructing Gender

This research has been unable to grapple with the full extent of gender inequality and gender inequity that underlies the experiences of women with HIV/AIDS in South Africa (on gender and inequality related to health, see *Sen* (2001a); *Osmani and Sen* (2003); *Moss* (2002); *Doyal* (1979; 2000; 2001; 2006); *Östlin, Piroska, George and Sen* (2001)). Unlike sex, gender is a social construction that includes the different behaviours, roles, expectations and responsibilities that women and men learn within the context of their culture or society *Östlin, George and Sen* (2001). As a social category, gender – and

the power relations that attach to it – has the potential to confer upon men and women different societal, family, peer and even personal norms and expectations with regard to accepted conduct *Bates, Fenton, Gruber, Lalloo, Medina Lara, Squire et al* (2004). *Moynihan* suggests that while society views these categories as 'fixed' they vary tremendously across cultures and between individuals. They are mutable (1998). *Lorber* confirms that, like culture, gender is a human invention. It is thus dependent on individuals and social systems to perpetuate or rebuild these notions (2004).

In this study, black South African women generally held a low social status and were economically dependent on men (partners, spouses, fathers). Because of this, men's views about women's HIV positive status were perceived as very important. This economic dependence, coupled with a marginalised social status, increased women's vulnerability to illness, while limiting the range and scope of options HIV positive women had (whether perceived or actual). There is some research on the links between HIV, economic empowerment and microfinance; and, on turning socioeconomic rights into tangible provision of services or entitlements (such as welfare) *Hassim* (2005). Indeed, studies conducted in rural South Africa have shed light on the interplay between some of these factors *RADAR* (2002); *Pronyck et al* (2006); *Epstein and Kim* (2007). But much of the research investigates economic interventions (or changes in economic status) as a lever for changing behaviour and reducing HIV transmission. And most of it falls outside of formal structures or sectors, including health. Future research could study these connections, considering whether gender norms (male and female), identities and related behaviours are changeable in the absence of economic incentives or changes in income; and, the drivers of such change. Can the gender and social norms (such as men's perceived entitlement to sex) that negatively impact on women's social vulnerability to HIV transmission be changed? And, since the health system plays such a key role as a SDH, what part do health personnel play in reshaping such gender norms?

Public Health and Health Systems Research

The Patient-Provider Relationship

Additional exploration of the patient-provider relationship is needed. Key questions revolve around the nature and extent of this relationship, and how it could be improved to better empower the patient. This is especially true given cultural or social norms that may enforce stoicism or failure to express pain by individuals (to the detriment of patients' health). There is also great scope for research focused on the needs of rural patients; their health-seeking behaviour and perceptions; their impediments to healthcare access more generally. What are the factors that enable or inhibit healthcare

access? How do rural populations view health personnel? What is the role of providers (community healthcare workers, for instance) in linking patients to the health system? What are the innovative approaches being employed?

Models for Integrating and Enhancing HIV/AIDS Service Delivery

Exploring the strengthening of primary healthcare clinics for HIV service provision in South Africa would be one approach that could dramatically improve and address the needs of patients with HIV, especially more rural populations – obviating problems with time, economic costs of travel and fragmentation of services. Other studies and accounts also support this finding (see in particular *MSF* (2006d); *Steinberg* (2008); *IRIN* (2008)). A recent review of the World Bank's health, nutrition and population projects uncovered a need to "ensure that health-system strengthening is explicitly linked with improvements in specific health outcomes for the poor" *Lancet* (2004). The report noted that tensions between programmes for health-system strengthening and specific diseases, such as HIV, could be overcome to improve the performance of larger programmes and health outcomes through the *integration* of service delivery. In this vein, there is anecdotal evidence that what may be hindering the national Department of Health from adopting a PHC approach to scale up and integrate HIV service delivery with other health services is the cost, if demand for HIV services were further increased *Moultrie* (2009). However, most experts agree that there is much 'fat' in the health sector budget that could be cut. The use of primary healthcare clinics for HIV service delivery entails a critically different approach – a massive shift in policy. What or where is the evidence base to reject or support such a change in policy direction?

I now close this thesis with two reflections.

FINAL REFLECTIONS

1. On Frameworks for Development Studies

A curious observation can be made on the utility of existing frameworks for development studies. In chapter one I recalled the criticisms levelled at the field of development studies, its irrelevance and failure to make the kind of impact that was once hoped. One of the weaknesses of development studies came to light for me in this research, sparking a range of related questions and insights.

I have focused on a development problem and dilemma that is relevant, timely and indeed urgent. HIV/AIDS is one of the most critical development challenges in

the Southern African region. It robs many individuals of their health, productivity and their very life (as demonstrated by the analysis in chapter six). Without proper intervention, HIV does not generally allow individuals to flourish. To frame and address the research concern, I employed the capabilities approach as a conceptual framework that conceives of development as freedom and which locates health (and particularly health capability) integrally within this larger notion of development. The capabilities approach (CA), by Sen's admission, has its derivation in the work of Aristotle. Thus, the conceptual framework is rooted in political philosophy with health as a social justice claim: one that seems to have some 'teeth'. I linked the CA with the health equity literature to ensure its relevance to the inequality that characterises South Africa. This also enabled the use of a lens that captured equity concerns in a robust manner, while providing analytical tools for measuring and investigating the social basis of disparities in health. And, it provided a literature with established links between ill health of an individual, social position, exposure to disease, vulnerability, social consequences of ill health and potential policy interventions.

With capabilities and health equity as a combined framework, I carried out empirical research to determine the primary barriers preventing women and children from receiving timely HIV prevention and treatment in the public health system. I then linked health as a social justice claim to the health equity literature to consider whether disparities in PMTCT/ART constituted health inequities, using the findings to underpin and enlarge the analysis. Once this determination was made, I considered the implications for the capabilities of these population groups. I also used the social determinants of health literature, together with the empirical findings, as a lens to consider what action could be taken to address the modifiable factors arising from the research (with the health system at the centre of the analysis). I found little in the way of frameworks (relevant to this study) that would nimbly link theory to action along a trajectory, however. At times, I felt like I was borrowing pieces from different fields, sawing off what was not relevant, gluing it together and hoping it would hold. In the end, I felt that I was able to demonstrate, through the evidence, that the disparities in PMTCT provision for black South African children were avoidable health inequities; and disparities in ART provision for black South African women with HIV were, if not inequities, a dire situation that could be vastly improved. Once the inequities are documented, what then? How does one mobilise political will to adopt the requisite remedies?

By definition, development studies is inter-disciplinary. Development problems are so complex and multi-faceted, they beg for multi-disciplinary approaches. At times, what should be a herculean strength – a cross-disciplinary field – becomes an Achilles'

heel, a hodge-podge of approaches glued together. I often felt like a cartoonish Alice in Wonderland who had fallen into the catacombs of the public hospital's 'rabbit hole'. On her journey, Alice comes to yet another locked door that may be a way through. She looks at her friend, the Rabbit, for guidance. Rabbit reaches into his bottomless top hat looking for the magic key that will open the door. Each time they reach another locked door, it has become smaller, and the right key, harder and harder to find; equivalent to performing a dozen impossible magic tricks. Rather than a straightforward journey that leads to the 'fruit' (good public health) for the patient, she is sent on a zany trip that often defies all logic. All prompting one to wonder – is this the best we can offer? Is there a better way? With limited tools I often felt that the people at the centre of this research, on this journey through the health system, deserve more from us as researchers concerned with advancing health and development for our society.

Similarly, public health lacks a 'soup to nuts' approach with a conceptual basis that both grounds theory and allows for movement from theory to practice. Public health is strong on policy and interventions but the philosophical basis for action – ethics and social justice – is weak. With no compelling theory or rationale, movement along a theory-intervention axis is often undermined. *Mann* describes the problem for public health, which I believe is equally applicable to development studies. He wrote:

> "Lacking a coherent conceptual framework, a consistent vocabulary, and consensus about societal change, public health assembles and then tries valiantly to assimilate a wide variety of disciplinary perspectives, from economists, political scientists, social and behavioral scientists, health systems analysts, and a range of medical practitioners. Yet while each of these perspectives provides some useful insight, public health becomes thereby a little bit of everything and thus not enough of anything" (1997, p. 8).

For all its advantages, the health equity literature suffers from the same problem. (The same is true of the capabilities approach.) As mentioned, the health equity literature takes health and social justice for granted as a departure point without explicating the moral foundation used to underpin health and social justice as a normative goal. Theorists either focus on the moral aspect of health or on the measurement of health disparities. There are few scholars who can make the leap between health and justice, measuring inequities in health, and taking accompanying action: thus traversing the terrain of theory and practice in a meaningful way. Amartya Sen is one. But he does not provide policy recommendations that spring from his empirical analysis (it is not that he cannot; it is not his *modus operandi*). Perhaps this demonstrates the bias of

scholars; to stay in the land of theory. And of practitioners: to remain in the realm of results. Again, even when strategies and policy options exist, the lack of consensus about social change on the part of public officials (and sometimes researchers), and the accompanying lack of political will, often derails intended policy change.

HIV/AIDS Reshapes and Redefines the Boundaries of Traditional Disciplines

What this research also reveals is the way in which HIV/AIDS as a robust and rich field of study is demanding new and interdisciplinary approaches and lines of inquiry from researchers, particularly as the social norms, issues and aspects of this disease are better understood. HIV/AIDS is reshaping the skill set of researchers, forcing us to become knowledgeable about psychology, public health, medicine and sociology *Gilbert* (1995).

What is needed is the strengthening of conceptual frameworks that underpin these disciplines, while making linkages between disciplines more explicit. Strengthening movement from theory to practice is also needed both to bolster the moral basis for action in areas such as health equity, while teaching us how to better measure health inequities, to establish consensus and take appropriate action on the social determinants of health. This would assist in addressing weaknesses in the development field, in my view. I am not dissuaded. I think it must be done. Given the important connections between health and development, I believe there is great scope for establishing stronger linkages between relevant disciplines (such as health and development for example); and for bridging the aforementioned gaps between theory and action. *Krieger* observes: "Ultimately, it is theory which inspires our questions, which enables us to envision a far healthier world than the one in which we live, and which gives us the insight, responsibility, and accountability to translate this vision to a reality. Who shall create this theory? The task is ours" (2001a, p. 674).

2. On the Transformative Aspects of HIV/AIDS

Over time, as this research has indicated, highly active antiretroviral therapy is shifting the landscape for patients with HIV. It is allowing for the disease to be managed as a chronic illness in some of the poorest parts of the world. South Africa is no exception *Wilson and Halperin* (2008). An editorial in the *Lancet* noted: "Antiretroviral treatment has transformed AIDS from an inevitably fatal condition to a chronic, manageable disease in some settings". However "this transformation has yet to be realised in those parts of the world that continue to bear a disproportionate burden of new HIV-1 infections and are most affected by increasing morbidity and mortality" (2006a).

In South Africa, this public health intervention – a drug prescription that has symbolised new hope for a nation – still remains out of reach for far too many.

The change in our collective perspective vis-à-vis HIV has been a slow manifestation: matched by an equally belated government response to the monumental challenge of HIV/AIDS in South Africa. But the winds of change are sweeping through our country: changes in patients on a clinical level have run parallel with an even larger social transformation. To put this in context, it is helpful to recall the initial conceptions surrounding the HIV/AIDS epidemic and the foundation of the early response.

Owing to the distinctive features of the disease – the lack of a cure, HIV transmission primarily through sex, its initial concentration among marginalised populations (gay men, sex workers, drug users, poor people) – there was an unspoken consensus among researchers and physicians that this disease was something new, indefinable, special *Mann* (1999). The response and attention to HIV/AIDS patients on the ground first came (mainly) from the younger, less-established mavericks within the medical field who were attending to radically ill patients. Originally called Gay-Related Immunodeficiency Disease (GRID) in the United States, gay men activists – at first the most visible "victims" – used their organising power. They pressed for increasing awareness, funding for research, humane treatment of people living with HIV, and attention to human rights. The depth and scale of what has become a global pandemic eventually drew the conventional health establishment into the fold *Mann* (1999); see *Shilts* (1988); *Bayer and Oppenheimer* (2000).

This was always an epidemic characterised by fear and prejudice against those who were diagnosed. The great concern was that a dreaded sexually transmitted disease affecting high risk groups would spill over into the so-called 'general' population.[5] Those living with HIV were thus viewed as a threat to the established order. Stigma and intolerance were revealed on a massive scale. "It is clear that in a depressingly predictable manner, AIDS accentuated already existing patterns of prejudice, marginalization and discrimination" *Mann* observed "whether expressed towards gay men, or injecting drug users, or people (usually women) with multiple sex partners, the common pattern was to use AIDS as yet another justification for stigma" *Mann* (1999, p. 168). One of the most prominent South Africans openly living with HIV, Judge *Edwin Cameron* wrote that AIDS is "stigma disgrace discrimination hatred hardship abandonment isolation exclusion…" a "rampaging murderer. It is made moral. It is condemnation…" (2005, p. 42).

Like Cameron's, the language used to describe the HIV/AIDS challenge was unusual in public health and medical terms that generally focused on disease 'control' and

'eradication'. *Mann* stated, "AIDS was called a challenge to the moral capacity of our societies; officials stated that, ultimately, how we responded to HIV/AIDS would be the standard by which we would be judged by history" (1999, p. 165).

HIV/AIDS is still a challenge to the moral foundations of this nation, to its leadership. Against a history of denial of the effects of HIV and AIDS, and a fundamental questioning of the causal link between the two, the early response in South Africa foundered. One study estimated that 330 000 lives were lost while the government dithered on a treatment programme *Chigwedere et al* (2008).[6]

Over the last five years since treatment became freely available, there has been a social transformation sweeping across South Africa, from the most isolated outposts to hopping urban centres. It has been led by activists from the Treatment Action Campaign, such as Zackie Achmat, Nkosi Johnson and others – especially ordinary South Africans. Individuals spoke out against the accepted wisdom of the African National Congress to claim that affordable treatment was not the special preserve of people in wealthy countries. African lives, too, were priceless. Civil society campaigns broadcast that 'yes, you *can* live positively with HIV'.

This social mobilisation has been underpinned by a health system offering new life to people who are ill. It has been catalysed by community leaders who have 'outed' themselves in church pulpits, in community centres, on radio programmes, while having tea with their neighbour. These folks made their HIV status known in order to make it safe for others to live positively with the virus. Treatment literacy, provided by NGOs, has not only exposed people to antiretroviral drugs, shattering myths about witchcraft, but empowered people to take their health – their very lives – into their own hands. Healthcare workers and doctors, frustrated by their inability to treat their patients, instead of sending patients home to die suddenly found themselves able to provide hope in a bottle.

For those of us in Southern Africa, we live and work at the epicentre of the HIV/AIDS epidemic. That an epidemic could have 'transformative capacities' is not surprising *Mann* (1999). In fact, HIV has shaken the foundations of our world, pulling "back the curtain to remind us, at our always young even though advancing age, of the terrible injustice of early death" wrote *Mann* (1999, p. 171).

Focusing on a disease that affects so many of us – 5,7 million – brings us back to the mirror. Before his own early death, *Mann* noted that as researchers in this field, we are "forced by the AIDS pandemic to confront many unexamined beliefs, prejudices and other ways of oversimplifying the world and life" (1999, p. 171).

Instead of closing ourselves off, the HIV epidemic is teaching us to expand our minds – to revisit old thought patterns. It is revealing the potential that exists for knowledge to stimulate change at an individual, a social and a country level. Research in this field requires us to fight the impulse to turn away. It begs us not to create distance and dissonance; not to shield ourselves from what we see. We must, instead, witness and document – translating what we see into something that our different (academic, policy and other) communities can understand. Perhaps this has always been our most important task.

The epidemic has offered us the possibility of breaking down the walls – physical and psychological – that separate us from each other. It evinces the conditions in which people live and die; how they hope; how they dream; how *we* adapt to the changing aspects of their lives. It is by deeply looking that we are able to see – not only the humiliations and indignities – but the joys, the triumphs. It is only by binding ourselves to our neighbour and seeing ourselves as one body, one community, that we realise how we are all part of the same society, the same fabric, the same beauty and ugliness – the same journey. It is by not divorcing our selves from our work, as *C Wright Mills* instructed his students in 1959, that we, as researchers, may truly understand.

By remembering our own common, shared humanity, perhaps we can find the transformative potential in others and in ourselves, and thus be more capable "of being citizens of the world, more able to see injustice, more willing" to see what ties us together. The HIV/AIDS epidemic seems to have brought us "closer to understanding the nature and direction of a deeper transformation in our individual and collective lives – which is to say, in human history" *Mann* (1999, p. 171).

Endnotes

1 For example, Finland, the UK, Sweden, Denmark, France, the Netherlands, the US, Hungary and Switzerland all fit this pattern. See *Evans et al* (2001).

2 One under-explored area was the failure of this research to engage issues concerning financing. When I began this study, the DoH was flush. Financial issues were not then at the forefront. My concern was the identification of barriers identified by women. In 2009 it seems that financing is becoming a significant impediment to initiating patients onto ART.

3 This section has benefited from discussions with Dr Vivian Black (Obstetrics and Gynaecology, Wits), Jo Vearey (Forced Migration and Public Health, Wits), Bronwyn Harris (Centre for Health Policy, Wits), Dr Tammy Meyers and Mike Schoenke (Enhancing Child HIV Outcomes, Echo, Wits), and presentations and work by Dr Harry Moultrie (Echo), and Marion Stevens (Health Systems Trust).

4 I disagree with this approach because the long term implications for the health of women are unknown; there are questions about resistance and adherence; ethical issues are introduced when women are not given a choice of feeding options (and breast milk is a mode of HIV transmission); and, in my view, this approach takes women's agency and choice away from them.

5 On the US epidemic, see *Shilts* (1988, pp. 220-226); *Bayer and Oppenheimer* (2000).

6 "More than 330 000 lives were lost to HIV/AIDS in South Africa from 2000 and 2005 because a feasible and timely antiretroviral (ARV) treatment program was not implemented" *Chigwedere et al* (2008).

Appendices

APPENDIX 1a

Information for Recruiting Participants: Checklist for HIV-Infected Pregnant or Postnatal Women with ART and PMTCT Indicated

The site supervisor (doctor) explains the initial purpose of the study and *invites* the individual to participate in the study. He/she makes it clear that the healthcare or treatment of participants who decide not to participate will not be affected in any way if they elect not to participate. The site supervisor reviews and ticks off the following checklist before allowing each participant to meet Courtenay Sprague and Pumla. Participants who have initially agreed to meet with us will again be invited to participate in the study: they will be given the background and purpose of the study, any questions they have will be answered, and informed consent will be sought in all instances. Forty women will be invited to participate in the study (the sample size is 30).

***Checklist for HIV-Infected Pregnant Women with Treatment Indicated Who are Accessing PMTCT**

1. Willing to participate in the study (Y or N) _____

2. Age (20 to 40) (Y and indicate age) _____

3. Gender (Female, Y or N) _____

4. Pregnant or recent birth (Y or N) _____

5. HIV-infected with treatment indicated (Y or N) _____

6. PMTCT indicated (Y or N) _____

NB: All answers to questions 1-6 above should be 'yes'. If a participant answers no to any of these questions she does not qualify for recruitment and selection.

APPENDIX 1b

Information for Recruiting Participants: Checklist for HIV-Infected Children with Treatment Indicated



The site supervisor, HIV counselor or doctor explains the initial purpose of the study and *invites* the individual to participate in the study. He/she makes it clear that the healthcare or treatment of participants who decide not to participate will not be affected in any way if they elect not to participate. The site supervisor reviews and ticks off the following checklist before allowing each participant to meet Courtenay Sprague and Pumla. Participants who have initially agreed to meet with us will again be invited to participate in the study: they will be given the background and purpose of the study, any questions they have will be answered, and informed consent will be sought in all instances. Forty primary caregivers will be invited; the sample size is 30.

Checklist for HIV-Infected Children with Treatment Indicated Who are Accessing ARVs

1. Willing to participate in the study (Y or N) _____

2. Primary caregiver of the child (Y or N) _____

3. Age (0 to 10 years) _____

4. HIV-infected with treatment indicated (Y or N) _____

5. Accessing ARVs (Y or N) _____

NB: All answers to questions **1-4** should be **yes**. The answer to **5** can be **yes** or **no**. If a participant answers **no** to any of questions **1-4**, she/he does not qualify for recruitment and selection.

APPENDIX 2

Sample Information Sheet and Consent Form for Participants (Women)



General information

Good day. How are you? My name is Courtenay Sprague and I am a doctoral student at the University of the Witwatersrand in Johannesburg. This is my colleague Pumla. We are inviting you to be a participant in the study. If you prefer to speak in Xhosa/other language, we are happy to continue this conversation in your preferred language. [Switch to Xhosa/other language here if preferred.]

Background to the Study

There are a number of reasons why people may not go for treatment or receive good care when they are ill. Our study will seek to gain a better understanding of the health system; we will be focusing on barriers to treatment and services for pregnant or postnatal women and children who are infected with HIV and require antiretroviral therapy: anti-AIDS medication. We would like to invite you to participate in this study, and to be interviewed to discuss your experience and the decisions you have made about seeking and receiving care for yourself and your child.

Informed Consent

It is entirely up to you whether or not you are interviewed. It is your right to refuse to be interviewed and that will not affect the treatment or care that you receive in any way. We do not work at any hospital/clinic and cannot influence the care that you receive in any way. No benefits or harm will come to you by participating in the study.

If you do agree to be interviewed, you can stop the interview at any time. You don't have to tell us why. If you don't want to answer any of the questions that you are asked you can just tell us, and that will not be a problem in any way.

We would also like permission to look at your hospital records. This will assist us in understanding the services and care you have received at the clinic/hospital.

To make the interview easier for us, we will also ask if we can tape the interview. This is to help us remember what you have said. If you do not want the interview to be taped that is your right, and it will not influence the interview or the research in any way.

Confidentiality

The information that you provide in the interview will be kept confidential. Neither of us are staff members at any hospital/clinic. We will not report what you said to anyone who works at the hospital/clinic.

At the end of the research project we will write up a report. This report will include information that you have given us, but your name will not be used. No one involved will know that it was you who gave us the information that you did. If you give us permission to tape the interview we will listen to the tape and write down every thing that you say but not use your name. We will then destroy the tape.

About the interview process

Firstly, we would like to interview you for about 60 minutes. The interview can be done in English, or if you would prefer in your home language. After the interview, we will look at our notes/listen to the recording and think about what you have told us.

If you have any further questions or complaints

You can contact the Principal Investigator of the project:

Ms Courtenay Sprague
Doctoral Candidate (Development Studies)
University of the Witwatersrand
2 St David's Place
Wits, 2193
South Africa
Tel: +27 11 717 3603
Email: Courtenay.sprague@wits.ac.za

You can also contact the Human Research Ethics Committee (Medical) which oversees the ethical aspects of this study. Members of this committee can be contacted through **Ms Anisa Keshav** on **011 717 1234**.

Participant Consent Form for Study

(C Sprague doctoral study, University of the Witwatersrand)

I have read the information sheet or it has been properly explained to me (in the case of illiterate participants), and I understand that I am being asked to give my consent to be interviewed for the study. I understand that I am free to stop the interview at any time and this will have no impact on my care or treatment. I also understand that no benefits or harm will come to me as a result of my participation in the study.

I agree to be interviewed for the study.

CONSENT TO BE INTERVIEWED FOR THE STUDY BY PARTICIPANT

Yes, I give my permission to be interviewed for the study.

_____

Name Signature Date

_____ _____

Interviewer's name and signature:

Date: _____

Witness consent (in case the interviewee is illiterate):

I _____ (witness name) hereby confirm that this information sheet has been read and explained to _____ (interviewee name) and that the interviewee hereby gives their consent, willingly and freely, for the interview to take place.

_____ _____

Witness name and signature:

PARTICIPANT CONSENT TO CONSULT AND CAPTURE PATIENT RECORD INFORMATION ANONYMOUSLY

(C Sprague doctoral study, University of the Witwatersrand)

I have read the project information sheet or it has been properly explained to me (in the case of illiterate participants), and I understand that it is up to me whether or not my records are reviewed and recorded. It will not affect in any way how the interviewer treats me if I do not want my records to be reviewed. I understand that the records will assist researchers to understand the services and care I have received at the clinic/hospital. I understand that the information that I give will be treated in the strictest confidence. My patient information will be anonymized and my name will not be used, printed or published in any form. I understand that if my records are captured on a data spreadsheet, the document will be password protected and will be destroyed after the study is published.

Yes, I give my permission for my patient information to be reviewed and anonymously recorded.

_____

Name Signature Date

_____ _____

Interviewer's name and signature:

Date: _____

Witness consent (in case the interviewee is illiterate):

I _____ (witness name) hereby confirm that this information sheet has been read and explained to _____ (interviewee name) and that the interviewee hereby gives their consent, willingly and freely, for the interview to take place.

_____ _____

Witness name and signature:

PARTICIPANT CONSENT TO TAPE INTERVIEW FOR THE STUDY

(C Sprague doctoral study, University of the Witwatersrand)

I have read the project information sheet or the purpose of the study has been properly explained to me (in the case of illiterate participants), and I understand that it is up to me whether or not the interview is tape-recorded. It will not affect in any way how the interviewer treats me if I do not want the interview to be tape-recorded. I also understand that it will not affect my care or treatment if I choose not to have the interview tape-recorded.

I understand that if the interview is tape-recorded that the tape will be kept in a locked box and destroyed after the study has been published. I understand that the information that I give will be treated in the strictest confidence and that my name will not be used in any form when the interviews are typed up and the study is published.

Yes, I give my permission for the interview to be tape recorded.

_____

Name Signature Date

_____ _____

Interviewer's name and signature:

Date: _____

Witness consent (in case the interviewee is illiterate):

I _____ (witness name) hereby confirm that this information on taping the interview has been read and explained to _____ (interviewee name) and that the interviewee hereby gives their consent, willingly and freely, for the interview to be taped.

_____ _____

Witness name and signature:

APPENDIX 3

Sample Interview Schedule - Participants

Question Guide - Participants (Women - Postnatal, Rev 29 July 2008)

Note: This is an interview guide only. If the interviewee provides a great deal of information, some of these questions will not be asked. The questions will serve as a platform for eliciting information if it is not easily forthcoming from the interviewee.

Part 1. Self-perceptions, Health & Support

1. Once you delivered your baby, how did you end up coming to the clinic for postnatal care? How old is your baby?

2. Did you come here for ANC/Delivery?

3. How did you feel about coming to the clinic for postnatal care?

4. Did anyone accompany you to the clinic?

5. How is your health now?

6. How is the health of your baby?

- **a.** How old is your baby?
- **b.** Has your baby been tested for HIV?

7. Who makes the decisions about your health?

8. Who makes the decisions about the health of your baby?

9. Do you feel supported or unsupported by friends/family?

- **a.** Could you give some examples (of support or lack of support)

10. Do you have someone to share child care with who will help you take care of your child?

Next we will record socio-demographic information and discuss any economic aspects that may impact on healthcare and treatment.

Part 2. Socio-Demographic and Economic Aspects

1. What is your age?

2. What is your level of education?

3. What is your marital status? Married, unmarried, living with someone, widow?

4. Are you employed? If so, what is your monthly income (rands per month)?

5. What is your household income (rands per month)?

6. Are you receiving any state support – e.g., a grant

- Do you have electricity, gas or other fuel for cooking, lighting or heating?
- Do you have piped water?
- A flush toilet?
- Mobile phone?
- A car?
- A television?
- A radio?

7. What are the costs that you have to bear when you come to the clinic?

8. Are those costs manageable or not manageable right now? Have you had problems managing these costs in the past?

9. Did you take time off from work? How does your employer feel about your leaving work?

10. Do you have enough money or not enough money to buy food?

Please could you elaborate/give examples?

11. Do clinic visits impact on your ability to manage your costs? Please explain.

12. Do you think it is expensive or affordable to manage your health?

13. Does anyone help you with your expenses? Please explain.

14. Do you know the HIV status of your partner?

15. Do you feel comfortable negotiating the use of a condom with him?

Part 3. Next, You Will Be Asked About Your Experience with the Health System and with HIV Testing, Counselling and Follow Up

Where and when did you have your HIV test taken?

Can you tell me about that experience?

[Prompt – what was your reaction?)

Do you recall if there was a counselor there to give you **pre and post test** counselling?

- What kind of information did the counselor give you?
  - **o** Did they discuss options with you for you and your baby?
  - **o** Did you receive a **nevirapine** tablet to take?
- If so, did you take it?
- Did they recommend follow up tests or treatment?
  Did you have your **CD4 count** taken?
  Did they give you the results?
  Did they initiate you on ARVs?
  Are you taking ARVs? (if so, since when?)
- What did you think of the counselling and support they provided?
- Were you able to go for the recommended treatment?
- Did they counsel you about infant feeding?
  What options did they give you?
  Did the healthcare provider recommend a particular option for feeding your baby? Please describe.

Which option did you choose and why?

- What did you decide to do (breast feed, formula feed, or mix?)
  How are you coping with the option you selected?

Are there any challenges?

Part 4. Experience Discussing Health with Personnel

1. Tell me about your experience talking to the doctor/nurse about your health.

If haven't mentioned, prompt: did you feel about asking questions about your own health/the health of your baby? Did you feel that you could discuss freely or did you feel constrained? (probe for their level of comfort in asking questions)

2. When you were at the clinic, did you feel like you were treated fairly or unfairly by health personnel?

3. Was the information they gave you clear or confusing?

- When you leave your appointments, do you understand what you must do for your health?

4. Did you feel that the quality of your care was good or poor or somewhere in between?

Part 5. The Next Set of Questions is Around HIV

a. How do you feel about your HIV positive status now?
b. Do you think that there is stigma or a negative association attached to HIV
c. Do you think that stigma is a problem for you?
  o If so, how do you cope with stigma?

Have you disclosed your status?
  Why or why not?

Now you will be asked about your understanding and beliefs about a particular type of medicine.

Part 6. Psycho-Social - Knowledge and Beliefs about ART

- Could you tell me about your knowledge of antiretroviral therapy – anti-AIDS drugs?
  - **o** What can the drugs do and what can't they do?
  - **o** [If they don't mention – ask] did you know the drugs are available to people free of charge at the clinic?
  - **o** If yes, who told you about this medicine? Was it a doctor, a nurse or someone else?
  - **o** How do you feel about taking this medicine?
- Before you had your baby, did you know that medicine was available to pregnant women to prevent HIV from being passed from the mother to the child? And to treat a child who is diagnosed with HIV?
- Have you ever felt like you had to make difficult choices related to your health and the health of your child?
- Did your doctor/nurse tell you about the importance of special medications for children who are diagnosed with HIV?
- Can you tell me if you are you taking the medicines?
- If not, why not – what are your concerns?

If taking the drugs carry on with the following:

- If taking the medicine, how did you feel in your body and in your mind – <u>before</u> you took the medicine?
  - **o** Could you tell me about your experience taking the drugs?
- How did you feel in your body <u>after</u> you started taking the medicine?
- How did you feel in your mind?

The next question will deal with how difficult or easy it was to access the medication.

Part 7. Availability and Access to ARVs for Women or Children

- If you are taking medicine, could you tell me about your experience getting the pills:
- Were the drugs available (for you or your child) when you needed them?
  - Was there a problem or delay?
- Did you feel any side effects such as pain, numbness or other side effect? Did your doctor/nurse tell you to expect these?
- How are you feeling now?
- Are you able to follow the guidelines of the doctor/nurse in terms of nutrition?

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