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# Maternal HIV-disclosure to uninfected primary school-aged children: motivations, fears and considerations in sub-Saharan Africa

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# MATERNAL HIV-DISCLOSURE TO UNINFECTED PRIMARY SCHOOL-AGED CHILDREN:

## Motivations, fears and considerations in sub-Saharan Africa

by

Ntombizodumo Brilliant Mkwanazi

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A THESIS

Submitted to the School of Public Health, Faculty of Health Sciences, University of Witwatersrand in fulfilment of the requirements for the degree

of

Doctor of Philosophy

JOHANNESBURG, SOUTH AFRICA

2017

## Declaration

I **Ntombizodumo Brilliant Mkwanazi**, declare that this research is my own work. I have duly acknowledged contribution from other people. The thesis is being submitted for the degree of Doctor of Philosophy in the field of Public Health at the University of Witwatersrand, Johannesburg, South Africa. The thesis has not been submitted before for any degree or examination at this or any other university.

**Signature:** 

**Student number: 566314**

**Name: Ntombizodumo Brilliant Mkwanazi** **Date: 14/ 06/ 2017**

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## Definitions

*a)* *ART*- antiretroviral treatment taken by HIV-infected patients

b) *ART access and adherence*- availability of HIV treatment and the ability to use it as directed by health care workers

c) *HIV-disclosure*- sharing of information about one's seropositive HIV status with others

d) *HIV-infected person*- a person infected with the human immunodeficiency virus (HIV)

e) *HIV-exposed but uninfected children*- children born to HIV-infected mothers who were exposed to the HIV in utero but are not HIV-infected themselves

f) *HIV-affected persons*- People, including, children who are affected by HIV through living with someone who is HIV-infected in their household

g) *Maternal HIV-disclosure*- an HIV-infected mother disclosing her seropositive status to her children

   i. *Full HIV-disclosure*- full information about HIV is provided by a mother, for example using the words HIV or AIDS

   ii. *Partial HIV-disclosure*- a mother sharing some information about an illness with a child. For example, a mother may tell a child that she is taking medication for an illness or a virus but not divulge that she has HIV

   iii. *No HIV-disclosure*- a mother telling a child nothing about her own illness

h) *Social exposure to HIV*- children being exposed to HIV in their household or community. This can also be extended to living in high HIV prevalence areas

*i)* *Social support*- the financial, practical, emotional, spiritual or emotional assistance that is provided to an individual especially after they have disclosed their HIV status

## Abbreviations

| | |
|---|---|
| AAP | American Academy of Paediatrics |
| ACDIS | Africa Centre Demographic Information System |
| AHRI | Africa Health Research Institute |
| AIDS | Acquired Immunodeficiency Syndrome |
| ART | Antiretroviral Therapy |
| ARVs | Antiretroviral drugs |
| CAB | Community Advisory Board |
| CEU | Community Engagement Unit |
| CHAMP | Collaborative HIV/AIDS and Adolescent Mental Health Programme |
| DDM | Disclosure Decision Model |
| DPM | Disclosure Process Model |
| DSA | Demographic Surveillance Area |
| DSS | Demographic Surveillance System |
| HAART | Highly Active Antiretroviral Therapy |
| HIV | Human Immunodeficiency Virus |
| IDUs | Injection Drug Users |
| MTCT | Mother-to-child Transmission |
| NDoH | National Department of Health |
| NM | Ntombizodumo Mkwanazi (Author) |
| NIMART | Nurse-initiated and Managed ART |
| PDI | Parental Disclosure Interview |
| PEPFAR | United States Presidents Emergency Plan for AIDS Relief |
| PLWH | People Living with HIV |
| PMTCT | Prevention of Mother-to-Child Transmission |
| TAC | Treatment Action Campaign |
| UKZN | University of KwaZulu-Natal |
| US | United States of America |
| VTS | Vertical Transmission Study |

| | |
|---|---|
| WHO | World Health Organization |

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## Preface

After completing a Master's degree in International Community Health in June 2009, I returned to South Africa to pursue a PhD. My PhD supervisors had projects within which I could integrate my PhD. I could either nest it within with an *HIV Treatment as Prevention* Trial or a *Maternal HIV-disclosure* (Amagugu) study. I chose the latter due to my passion for, and experience in, maternal and child health. Further, I had worked previously on the Vertical Transmission Study (VTS) from which mother and child pairs for the Amagugu Study were to be recruited. I had occupied various roles in the VTS at Somkhele, including as a breastfeeding counsellor, HIV counsellor, infant feeding counsellor and a junior manager, as well as being a study coordinator in the peri-urban site at KwaDabeka Clinic outside Durban.

While the VTS (2001-2006) enrolled both HIV-infected and HIV-uninfected women during the Prevention of Mother-to-Child Transmission programme, the Amagugu study intended to enrol only HIV-infected women with HIV-uninfected children with the aim of supporting them to disclose their own HIV status to their now 6-10 year old HIV-uninfected children. These women were last contacted more than six years ago, therefore they had to be traced and tracked before being offered enrolment into the maternal HIV-disclosure intervention (Amagugu study).

Clinic staff were identified as stakeholders who needed to be trained in maternal disclosure in order to support these women. All clinics where women were receiving anti-retroviral therapy (ART) treatment and care were provided with training in maternal HIV-disclosure and child-friendliness.

This PhD with publications comprises four first-authored papers attached as Appendix A. The first paper is a literature review on maternal HIV-disclosure. The second and third papers explore the women's experiences of living with HIV in an ART-era and their experiences of participating in a maternal HIV-disclosure intervention (Amagugu). Lastly, the fourth paper addresses the role of primary health care clinics in facilitating maternal HIV-disclosure and supporting HIV-affected families. This integrating narrative will discuss three main themes across all four papers.

## Original Papers

I. **Mkwanazi NB,** Rochat TJ, Imrie J & Bland RM. Disclosure of Maternal HIV Status to Children: Considerations for Research and Practice in sub-Saharan Africa. Future Virology (2012) 7 (12) pages 1159-1182

**Student's contribution to the paper**

Study conceptualisation. Literature searches and literature review. Writing the first draft, critical revision and finalisation of the manuscript.

II. **Mkwanazi NB**, Rochat TJ & Bland RM. Living with HIV, disclosure and partnerships a decade after the introduction of HIV programmes in rural South Africa. AIDS Care (2015) (27) **Suppl 1**: pages 65-72

**Student's contribution to the paper**

Study conceptualisation. Development of the research tools. Data collection, data management and data analysis including coding of the transcripts. Literature searches and literature review. Writing the first draft, critical revision and finalisation of the manuscript.

III. **Mkwanazi NB**, Rochat TJ & Bland RM. The Amagugu intervention: A qualitative investigation into maternal experiences and perspectives of a maternal HIV-disclosure support intervention in rural South Africa. (accepted in the journal, *Health Policy and Planning* on 26 April 2017)

**Student's contribution to the paper**

Study conceptualisation. Development of the research tools. Data collection, data management and data analysis including coding of the transcripts. Literature searches and literature review. Writing the first draft, critical revision and finalisation of the manuscript.

IV. **Mkwanazi NB,** Rochat TJ, Coetzee BJ & Bland R.M. (2013) Mothers and health workers' perceptions of participation in a child-friendly health initiative in rural South Africa. Health (2013) 5 (12) pages 2137-2145

**Student's contribution to the paper**

Study conceptualisation. Participation in the development of intervention materials. Training and oversight of the intervention staff. Literature searches and literature review.

Data collection, data management and data analysis including coding of the transcripts. Writing the first draft, critical revision and finalisation of the manuscript.

## Abstract

**Introduction:** As Prevention of Mother-to-Child Transmission and HIV treatment programmes have scaled-up, more women are being kept alive and fewer children are infected with HIV. One of the challenges that HIV-infected women face is how to disclose their own HIV status to their children. The disclosure literature suggests that the main reason for women's HIV-disclosure is to obtain social support, including financial, practical and emotional assistance, to help women to manage their HIV infection. HIV-related stigma, lack of knowledge of how to disclose, uncertainty about a child's reaction to disclosure, and a perception that a child lacks the developmental capacity to handle HIV-disclosure are factors that affect disclosure decisions. HIV-disclosure is considered a critical element in strengthening the capacity of families in the continuum of HIV care.

In 2011, the World Health Organization published guidelines for parental HIV-disclosure to children. These guidelines recommended full disclosure to primary school-aged children (from 6 years up to 12 years) and partial disclosure to younger children. Globally, but particularly in sub-Saharan Africa, HIV-disclosure interventions are lacking. The Amagugu maternal HIV-disclosure intervention was developed, piloted and evaluated between 2010 and 2012 to assist mothers to disclose their HIV status to their HIV-uninfected children. The intervention enrolled 281 mothers and their primary school-aged HIV-uninfected children, and aimed to increase maternal capacity to disclose their HIV status. This was implemented through six lay counsellor-led, home-based, sessions, including a health intervention at a primary health care clinic. The Amagugu intervention was acceptable and feasible in a high HIV prevalence, resource-poor, rural setting, and increased maternal HIV-disclosure to primary school-aged HIV-uninfected children.

**Methods:** This PhD study was nested within the Amagugu study and was conducted at the Africa Centre for Population Health, now the Africa Health Research Institute (AHRI), in the Hlabisa sub-district of Umkhanyakude, northern KwaZulu-Natal, South Africa. The aim of this PhD was to explore, in more depth, the experiences of women enrolled in the Amagugu intervention, including their experiences of the health intervention.

Both quantitative and qualitative methods were used. The sample for the PhD study comprised three groups: 1) all mothers from the Amagugu study (N=281); 2) a sub-sample of mothers from the Amagugu study (N=20) and 3) health care staff employed in the clinics where the Amagugu study took place (N=87). The quantitative data used in the PhD study

were collected at different time points from the 281 women, using questionnaires specifically designed for the Amagugu study, including baseline and post-disclosure questionnaires. Data on the clinic experiences were collected from the 281 mothers using semi-structured questionnaires administered after the health intervention. Semi-structured questionnaires, specifically designed for this PhD study, were administered to the clinic staff during the health intervention. Qualitative data were collected using semi-structured questionnaires with the clinic staff (N=87), nine focus groups with clinic staff after the health intervention, and in-depth and semi-structured interviews with the sub-sample of women (N=20) who were enrolled after the Amagugu intervention had been completed.

The University of KwaZulu-Natal Biomedical Research Ethics Committee (BREC Ref: BF 144/010) and the University of Witwatersrand Human Research Ethics Committee (Ref: R14/49) granted ethical approval for the PhD study.

**Results:** The results reported in this PhD are drawn from four papers written during the course of this PhD, (three published papers and one paper accepted for publication). The results have been integrated from the data collected from the women and health care staff that were used for the PhD, and a literature review that resulted in a publication.

The three main themes that emerged from the PhD are:

1. *HIV-related stigma and HIV-disclosure:* The literature review revealed that fear of HIV-related stigma was the most common reason for non-HIV-disclosure of HIV to both adults and children. In the sub-sample of 20 women, only two women had not disclosed to other adults due to fear of HIV-related stigma prior to the intervention. Those who had disclosed to only some, but not all other adults in their close social networks, reported HIV-related stigma at household (6/18), community (2/18) and clinic levels (1/18). Although HIV-related stigma was reported, there was also a normalisation of HIV and antiretroviral therapy (ART) in some communities due to the high social exposure to HIV in the study area. Qualitative data from the focus groups with clinic staff, and interviews with the sub-sample of 20 women, recognised that children's exposure to HIV education has played a role in the normalisation of HIV.

2. *HIV-disclosure and family strengthening:* The majority of women in the sub-sample had disclosed their HIV status to other adults including their partners, friends and

other relatives, prior to the Amagugu intervention. Most women reported living positively with HIV and receiving necessary support from those to whom they had disclosed. Of those women who had disclosed to partners, about half had disclosed to their partners first before disclosing to any other adults. Their partners had mixed reactions to disclosure but were overall supportive. Whilst women's original fear of disclosing their HIV status to their children had been that they would be stigmatised by their children, on the contrary, most children were supportive. The majority of women in the sub-sample expressed that they would advise other women in similar circumstances to disclose their HIV status to their children for social support, because disclosure increased family cohesion and improved antiretroviral therapy adherence. The health staff echoed the same sentiments regarding social support and family cohesion in the focus groups.

3. *HIV-disclosure and access and adherence to HIV treatment:* The interviews with the sub-sample of 20 women, and the semi-structured questionnaires and focus groups with 87 clinic staff, all revealed that participants agreed that whilst maternal HIV-disclosure was challenging, it was necessary for women to obtain social support from their children. Health care staff also agreed that maternal HIV-disclosure to their children was instrumental in supporting HIV-infected women to access and adhere to their HIV treatment. The clinic staff recognised the role they could play in health promotion and increasing opportunities for children to participate in activities at health facilities, but acknowledged that they needed support to address logistical constraints that hinder child-friendliness in health facilities, including heavy workloads, poor clinic infrastructure and staff shortages. The health intervention provided clinic staff with child-friendliness training and materials that were found to be acceptable and feasible, and yielded encouraging results.

**Discussion:** This study contributes to the literature about the experiences of African, HIV-infected, rural women with HIV-uninfected children living in an ART-era. In particular the experiences of women who have participated in a maternal HIV disclosure intervention in Africa have not been explored previously. The findings of this work indicate that a decade after being diagnosed with HIV, women in this resource-poor setting are generally living positively with HIV. However, HIV-disclosure to other adults does not necessarily translate

to disclosure to children, and parents require specific interventions to assist them with this, and to understand the development and level of understanding of their children.

**Conclusion:** Despite concerns raised by women prior to the intervention, including fear of HIV-related stigma and a perception that children lacked the developmental capacity to grasp knowledge about maternal HIV status, the women in this study reported no regrets in disclosing their status to children. They also reported receiving support from their children, which in turn, assisted them with adherence to their own HIV treatment. Future studies could test the same Amagugu intervention materials in a group of HIV-infected women with uninfected children not previously involved in research to explore whether similar results are found.

**Key words:** Maternal HIV-disclosure, sub-Saharan Africa, HIV-uninfected children, primary school-aged, interventions, resource-poor setting

# 1. Introduction

This PhD thesis explores the in-depth experiences of HIV-infected women who participated in a maternal HIV-disclosure intervention, the Amagugu study, conducted in a high HIV prevalence, resource-poor, and rural setting in South Africa. Three specific themes relating to maternal HIV-disclosure are explored:

i. HIV-related stigma and HIV-disclosure
ii. HIV-disclosure and family strengthening
iii. HIV-disclosure and access and adherence to HIV treatment

To answer my research question on where maternal HIV-disclosure studies have been conducted, with whom, and what lessons can be adapted to rural settings in sub-Saharan Africa, I reviewed the global literature on maternal/ parental HIV-disclosure. This led to an identification of the following main gaps in the literature:

a) Maternal HIV-disclosure research is mostly descriptive and was conducted in resource-rich settings.
b) Very few studies have been conducted with primary school-aged HIV-infected children.
c) No maternal HIV-disclosure interventions had been conducted in Africa
d) There is a lack of maternal HIV-disclosure interventions that consider the unique epidemiology of HIV and the socio-cultural factors such as HIV-related stigma, high social exposure to HIV, and the difficulty in discussing sex-related issues in the sub-Sahara African context.

Following the development and the implementation of the Amagugu intervention, I sought to answer the research question about the experiences of women living with HIV in an ART-era, ten years after their diagnosis. This was done by enrolling a sub-sample of women who had been part of the Amagugu study. These women were selected because they were diagnosed with HIV during pregnancy in a pre-ART-era but had been living with HIV for almost a decade and had survived and lived through the ART-era. I explain the women's

journey through an in-depth exploration of their perspectives around their HIV diagnosis. Through in-depth interviews I was able to explore various issues that surround their HIV infection, including, their reasons for participating in a maternal HIV-disclosure intervention and the maternal HIV-disclosure lessons they learnt.

A mixed methods approach has been used for this PhD study as it allowed for both descriptive data (including age, marital status, education, employment and health status) of the women and (age, profession, gender, and geographical areas) of the clinic staff to be collected. The interviews and the focus groups allowed for the qualitative exploration of women and health staff perspectives on various factors surrounding women's HIV infection, access and adherence to HIV treatment. The semi-structured questionnaires captured and described women's interactions with the clinic staff, the experiences of women and their children of a clinic intervention to support maternal HIV-disclosure, and examined how primary health care clinics can be supported to assist HIV-affected families with access and adherence to HIV treatment.

The three themes which emerged from this PhD are intertwined in the daily existence of HIV-infected women and shape their relationships with their significant others, children, families, communities, and their interactions with their health care facilities. At the centre of HIV infection lies disclosure decisions - what to disclose, to whom, how and when to disclose? The World Health Organization (WHO) Parental HIV-Disclosure to Children Guidelines of 2011 recommend full disclosure to primary school-aged children (from 6 years up to 12 years) and partial disclosure to younger children. However, disclosure decisions are complex and even more so when they involve children. It is well established in the literature that the main reason for HIV-disclosure is to obtain support from the disclosure targets (1-4). Whilst HIV-disclosure might have positive consequences - from family strengthening to greater access and adherence to HIV treatment and care- a number of factors affect disclosure decisions, including the fear of HIV-related stigma.

When investigating such complex HIV-related issues, it is important to first consider the origin of the Human Immunodeficiency Virus (HIV) because how HIV was introduced into populations impacts on how different communities, including those in sub-Saharan Africa, can be assisted to respond effectively to the HIV epidemic. This includes addressing issues of stigma that are associated with HIV infection which make it difficult for HIV-infected

individuals to disclose their status to others and in turn shy away from accessing and adhering to HIV treatment.

# 2. Background

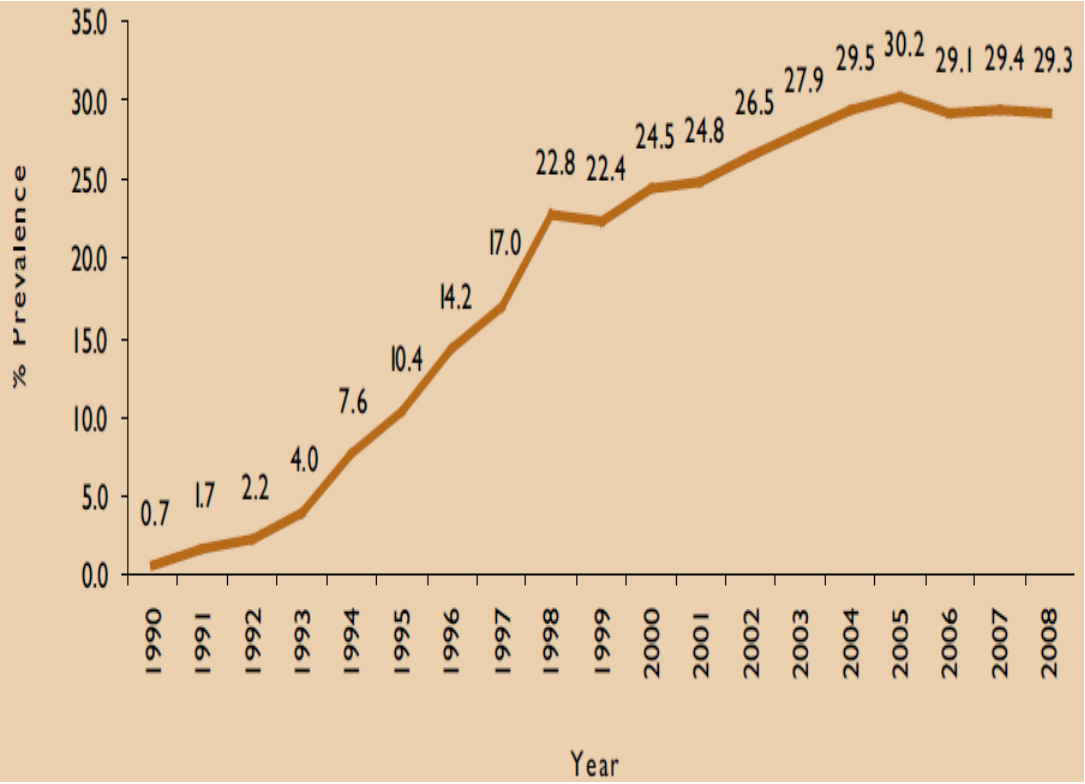
## 2.1 The origin of HIV and AIDS

In 1981, AIDS was identified as a new disease associated with homosexual men in the United States (US) (5, 6). Thereafter, similar cases were identified in other groups in the US and Europe, including injection drug users (IDUs) (7), haemophiliacs (8), recipients of blood transfusions (9), travellers from central Africa visiting Europe for medical attention (10) and new-born infants (11). In years to come it would be determined that heterosexual contact was the dominant mode of transmission of HIV and is the main cause of AIDS in Africa (12).

## 2.2 HIV infection in South Africa

In South Africa, the first case of HIV infection was reported in 1981 (13). Almost a decade later, in 1990, the first anonymous antenatal HIV prevalence survey was conducted to project the national HIV prevalence (14). Since then, anonymous antenatal HIV surveys have been used to estimate national prevalence in South Africa. HIV prevalence in the first antenatal survey was reported to be 0.76% (14). By 1995 antenatal HIV prevalence had increased to an estimated 10%, and by the year 2000 it had more than doubled to 25% (14) in a survey that tested 16,548 blood samples from 400 sites in all nine provinces of the country (14). Figure 1 illustrates the observed HIV epidemic curve among antenatal attendees in KwaZulu-Natal between 1990 and 2008.

**Figure 1: HIV prevalence epidemic curve among antenatal attendees from 1990 to 2008 in KwaZulu-Natal Province, South Africa**




**Source: 2008 National Antenatal Sentinel HIV and Syphilis Prevalence Survey (15).**

It is predicted that HIV prevalence in South Africa will continue to increase as more people initiate antiretroviral therapy (ART), but will eventually stabilise as a result of effective HIV prevention programmes (16). This means that people live longer and thus the population of people living with HIV increases as the virus causes a chronic rather than a fatal disease. In 2012, the HIV prevalence among 15-49 year olds was estimated to be 18%, an increase from the 15% reported in 2001 (17). Table 1 illustrates the prevalence and incidence estimates of HIV infection among antenatal clinic attendees, aged 15-49 years, in the Hlabisa health sub-district (study area) in the period between 1992-1999 (18).

**Table 1: Prevalence and incidence estimates of HIV infection among antenatal clinic attendees, aged 15-49 years, in the Hlabisa sub-district in the period between 1992-1999 (18)**

| Year | N | Prevalence of HIV (95% CI) | Incidence per 100 person-years |
|---|---|---|---|
| 1992 | 884 | 4.2% (3.0-5.7) | |
| 1993 | 709 | 7.9% (6.0-10.1) | 2.3 |
| 1995 | 314 | 14.0% (10.4-18.4) | 7.2 |
| 1997 | 4731 | 27.2% (25.9-28.5) | 8.2 |
| 1998 | 3166 | 29.9% (28.4-31.6) | 9.9 |
| 1999 | 3014 | 34.0% (32.3-35.7) | 15.0 |

### 2.3 HIV and women

South African women bear the brunt of HIV and are socially vulnerable to HIV infection due to marginalisation and persisting inequalities (19). These inequalities are perpetuated by poverty and unemployment and are made manifest through gender-based violence (20). The epidemiology of the HIV epidemic in South Africa is unique due to institutionalised inequalities stemming from the previous apartheid regime (13). Together, this regime and the migrant labour system served as catalysts of HIV transmission and other sexually transmitted infections (13).

### 2.4 The vertical transmission of HIV

The high HIV prevalence rates observed in the adult population are reflected in the rates of vertical transmission of HIV in South Africa. In sub-Sahara Africa, the vertical transmission rates for breastfeeding populations before the implementation of Prevention of Mother-to-Child Transmission (PMTCT) programmes were between 15-45% (21, 22). In 2001, the South African National Department of Health (NDoH) launched PMTCT programmes and, in keeping with policy at the time, single-dose Nevirapine was offered to HIV-infected women during labour and to their infants after delivery (23). Since then PMTCT regimens have evolved as illustrated in Table 2.

**Table 2: Evolution of South Africa's policy on the PMTCT of HIV, 2000–2011 (adapted from Barron 2013 in the Bulletin of the World Health Organization 91(1): 70-74) (16).**

| | |
|---|---|
| 2000 | Data presented at the 13th International AIDS Conference held in Durban, South Africa indicated that antiretroviral drug regimens were effective in reducing Mother-to-Child Transmission (MTCT) of HIV. |
| 2001 | The Ministry of Health endorsed the establishment of two research sites in all nine provinces for a period of two years to better understand the operational challenges of introducing antiretrovirals (ARVs) during pregnancy to reduce MTCT. |
| 2001 | In December, the government was ordered by the Constitutional Court to develop a fully capable and effective national programme to reduce MTCT of HIV by 2002. |
| 2002 | The government challenged the court order, but was unsuccessful. The PMTCT programme commenced. It included provision of free formula to infants for six months at any time during the first year of life. |
| 2003 | The government published a new operational plan for treating and caring for those who were HIV-infected. In addition, the plan included increased provision of Nevirapine, the extension of HIV treatment to all HIV-infected pregnant women and their infants and the expansion of related health-care services, such as voluntary counselling and testing. |
| 2004 | Introduction of comprehensive care management and treatment of HIV-infected individuals. Pregnant women with a CD4+ T-cell count < 200 cells/$mm^3$ became eligible for lifetime Highly Active Antiretroviral Therapy (HAART). |
| 2008 | The NDoH updated the PMTCT policy to include: (i) dual prophylaxis with Zidovudine and Nevirapine from 28 weeks' gestation; (ii) Nevirapine treatment for pregnant women during labour and for their babies within 72 hours of delivery; and (iii) HAART for pregnant women with a CD4+ T-cell count < 200 cells/$mm^3$<br><br>The Minister of Health launched the national PMTCT accelerated plan (A-plan) which aimed to reduce MTCT of HIV from 12% in 2008 to less than 5% by 2011, in accordance with the National Strategic Plan 2007–2011. |
| 2009 | President Zuma's speech on World AIDS Day outlined changes to be implemented in 2010, giving a clear indication that the political leadership required to address the scale of the problem was available. |
| 2010 | The NDoH revised the PMTCT policy again to include lifelong HAART for HIV-positive women with a CD4+ T-cell count ≤ 350 cells/mm3 and dual ART from 14 weeks onwards in the pregnancy for HIV-positive women with a CD4+ T-cell count >350 cells/$mm^3$, in line with Option A of World Health Organization guidelines. Nurse-initiated and managed ART (NIMART) was introduced by the NDoH in antenatal clinics (24).<br><br>Infant prophylaxis was daily Nevirapine for 6 weeks for all infants. Daily Nevirapine was continued for all breastfeeding infants whose mothers were not on HAART, to reduce postnatal transmission of HIV. |
| 2011 | Following a national conference on breastfeeding, the Minister of Health endorsed a policy that breastfeeding should be exclusively recommended at public health facilities and formula milk be reserved for medically indicated cases, and that the provision of free formula milk should be phased out. KwaZulu-Natal was the first province to phase out free formula milk in its PMTCT programme.<br><br>In line with a call from global agencies, the NDoH developed a national action framework for eliminating MTCT of HIV by 2015 (25). |

In 2010, when the effect of the South African PMTCT programmes was evaluated in a national population-based survey, the overall transmission rate was 3.5% and further decreased to 2.7% when the survey was repeated in 2011 (16, 26, 27). Furthermore, the percentage of HIV-infected women receiving ART to reduce MTCT of HIV increased from 83% in 2009 to 87% in 2011 (28).

**2.5 The progression of HIV treatment and care**

Providing free HIV treatment and care was rigorously debated by the national government in South Africa. In 2006, former South African President Thabo Mbeki was accused of being an AIDS denialist by the media when he was quoted as saying that there was no association between HIV and AIDS (http: //news.bbc. co.uk/2/hi/5265432.stm) (Page last accessed on 20 December 2016). His late national Minister of Health, Dr Mantombazane Tshabalala-Msimang was nicknamed "Dr Beetroot" when she 'prescribed' beetroot and garlic as alternative treatments for HIV, and escalated confusion in a population already bombarded by HIV/AIDS myths (http://www.nytimes.com/2009/12/02/world/africa/02safrica.html) (Page last accessed on 20 December 2016) (29, 30). The government's reasons for initial resistance to providing HIV treatment included concerns about the side effects of HIV drugs, poor infrastructure for rolling out treatment, lack of human resources and the unaffordability of HIV medication (31). It took the combined influence of civil society movements such as the Treatment Action Campaign (TAC) and pressure from the international community to change the government's stance and to ultimately provide free HIV treatment (29, 32). In 2004, HIV treatment and care was eventually rolled out in South African public health facilities, in a devolved programme that allowed patients to access HIV services at their nearest primary health care clinics (33-35).

**2.6 Children and HIV transmission**

As PMTCT and HIV treatment and care programmes were scaled up, more women were being kept alive and fewer children were being infected with HIV (36-38). Logistical constraints of initiating ART in pregnancy, such as a shortage of doctors in the public health care facilities, have been mitigated by the introduction of nurse-initiated and managed ART (NIMART) (39-41). Encouragingly, a substantial decline of 43% in the number of new HIV infections among children was reported in sub-Saharan Africa in 2013 (42). Globally in 2013, 3.2 million children under the age of 15 years were living with HIV, 91% of whom were in

sub-Saharan Africa (42). However, only 22% of these infected children were receiving ART in 2013 (42). In 2012, over 18 million children were reported as HIV orphans whilst millions of children under the age of 18 years were HIV-affected through living with HIV-infected parents (43).

### 2.7 Vulnerability of HIV-infected children

Despite dramatic decreases in the MTCT of HIV, efforts still need to be focussed towards the care and support of over 3 million HIV-infected children globally (19, 44). HIV-infected children have higher morbidity and mortality rates compared to their HIV-uninfected counterparts (45). These children also have the double burden of dealing with their own HIV status and that of their parents (45).

### 2.8 Disclosure to a child about their own HIV-infection

For HIV-infected children, being disclosed to about their own status is challenging (46), possibly leading to discrimination and stigmatization (47). Conversely, lack of HIV-disclosure to a child about their own HIV status may lead to poor ART adherence and possible drug resistance (48). The American Academy of Paediatrics (AAP) issued disclosure guidelines for HIV-infected children and adolescents in 1999 (47). The Academy strongly recommends disclosure to school-aged children, and suggested that disclosure decisions relating to an HIV diagnosis should be individualised to account for the child's cognitive ability, their developmental stage, clinical status, and social circumstances. There is consensus in the literature that it is best to disclose children's HIV status to them during the pre-adolescent years, before they become sexually active, and that the primary care-giver, usually the mother, is the best person to do this (49). Adherence to ART is one of the primary reasons for recommending disclosure to HIV-infected children (50). However, any efforts to increase HIV-disclosure must be cognisant of concerns regarding the negative impacts of disclosure such as psychological harm reported in some studies (50-53).

### 2.9 Vulnerability of HIV-exposed but uninfected children

Although HIV-uninfected themselves, children born to HIV-infected mothers face several risks including poverty, violence, ill health, inadequate medical care and other social problems (54). They are also at a higher risk of parental ill-health, hospitalisation and potential death (55). The existence of HIV in a home has the potential to seriously disrupt the

family system and child care (56, 57). Despite increasing numbers of these children who are themselves HIV-uninfected but living with HIV-infected parents, little research exists on the issue of disclosure within these families, particularly parental disclosure of their HIV status to their children (36, 37). Further, very few studies have specifically examined disclosure by fathers (58, 59), despite their involvement in a child's life from conception to grand parenting (60). In dealing with HIV-affected families, disclosure is considered an essential aspect in the continuum of HIV care (61) and family-based interventions are needed to guide caregivers in assessing whether to disclose, what to disclose (full or partial), how to disclose and when to disclose (appropriate age of a child) (62).

Most mothers struggle with disclosure decisions due to lack of knowledge about how to disclose their HIV infection to their HIV-uninfected children (52, 54, 55). Disclosure rates to school-aged and adolescent children vary; some studies have reported maternal HIV-disclosure rates as low as 30-40% (53, 63, 64), others have reported rates as high as 60-77% (65, 66). Mixed reactions to maternal HIV-disclosure have been reported by both children and mothers after the disclosure process (53, 65, 67).

### 2.10 Family-centred maternal HIV-disclosure interventions

Family-centred approaches to HIV prevention and care have been promoted as important for improving overall family health (68-71). Given that there is little research to guide interventions in South Africa, developing an understanding of the factors that are associated with disclosure is an essential step towards designing family-centred interventions that will assist families to respond to HIV. While disclosure of HIV status by a parent to a child is a complex, challenging, psychological and social process, it is also considered a critical element of strengthening the capacity of families with children to respond to HIV in high HIV prevalent communities (72-74). The feasibility of maternal interventions in sub-Saharan Africa depends on where the intervention happens (75) (home or health facility), who the unit of the intervention is (child or extended family household structure), what human resources are available, and whether these can be scaled up.

## 2.11 The Amagugu intervention

Amagugu is a home-based maternal HIV-disclosure intervention that was implemented in sub-Saharan Africa (73, 76, 77), and is explained in detail in the Methodology section (see page 36). The Amagugu intervention enrolled 281 HIV-infected women with their primary school-aged HIV-uninfected children. The current PhD study is nested within this larger Amagugu study. The Amagugu study explored whether a family-centred maternal HIV-disclosure intervention was feasible and acceptable and whether the intervention package would increase maternal disclosure rates in a poor-resourced setting with very high HIV prevalence (73, 76, 77).

## 2.12 Current PhD study

The current study was conducted at the Africa Centre for Population Health (www.africacentre.ac.za), now the Africa Health Research Institute (AHRI) (www.ahri.org) in the Hlabisa sub-district of Umkhanyakude District in rural northern KwaZulu-Natal, South Africa. Using a mixed methods approach, this study explored in more depth the experiences of women involved in the Amagugu intervention. This includes their interaction with the clinic staff in their primary health care clinics where they access HIV treatment and care during the health intervention with their children described below (4.3.6.2 on page 43). The PhD study used:

i. Quantitative data collected through semi-structured questionnaires from the 281 women enrolled in the Amagugu study
ii. Qualitative data collected through in-depth and semi-structured interviews from a sub-sample of 20 women enrolled specifically for this PhD
iii. Quantitative and qualitative data collected through semi-structured questionnaires and focus groups from 87 clinic staff from the Amagugu women's primary health care clinics specifically enrolled for the PhD

# 3. Literature Review

## 3.1 HIV-disclosure

For the purpose of this thesis, HIV-disclosure is defined as sharing of information about one's seropositive HIV status with others (78). Maternal HIV-disclosure refers to an HIV-infected mother disclosing her seropositive status to her children. Maternal HIV-disclosure can be categorised into no disclosure, partial disclosure and full disclosure of HIV status (79). No disclosure refers to a mother telling a child nothing about her or the child's HIV infection. During partial disclosure some information about an illness is shared with a child, for example a mother may tell her child that she is taking medication for an illness or a virus but not divulge the name of the virus. Full disclosure is when full information about the illness is provided, for example, a mother telling her child that she (the mother) is HIV-infected (77). HIV-infected women may decide to disclose their status to others, including their children, for various reasons including a need to obtain social support (80).

## 3.2 Social support

Social support refers to the financial, practical, emotional, spiritual or emotional assistance that is provided to an individual especially after they have disclosed their vulnerability in a particular aspect of their life, for example disclosure of an HIV infection (59). This could include money for transport in order to access health care and food to take with medication, reminders to take medication, and assistance in caring for children in case of hospitalisation or illness (81-84). Social support has the potential to be an important family strengthening activity in areas of high HIV prevalence, however, it is challenging for people living with HIV to receive the necessary support without disclosing their HIV status. (68). Social support is particularly important for HIV-infected individuals to access and adhere to HIV treatment (4, 85). Health care workers often encourage people infected with HIV to disclose to at least one person for social support (4, 86).

## 3.3 Parental HIV-disclosure

Three literature reviews (55, 87, 88) and a systematic review (89) demonstrate the lack of maternal HIV-disclosure intervention studies for primary school-aged children in sub-Saharan Africa. Most studies on maternal HIV-disclosure have been conducted in the United States with low-income African-American families, and include adolescents (67, 90, 91)

rather than primary school-aged or younger children, as is now recommended by the World Health Organization Guidelines (46). In contrast there are numerous studies on HIV-infected women's disclosures to partners and other adults in their lives (92-94). There is a dearth of literature providing guidance for interventions to support maternal HIV-disclosure (77, 88, 95, 96), particularly in sub-Saharan Africa, where the number of HIV-affected children is increasing rapidly (36, 37). Limited literature suggests that disclosure of parental HIV status may potentially cause psychological harm as children may not be equipped to handle the implications of disclosure (52, 53).

Murphy's review (55) examined factors affecting maternal HIV-disclosure, including maternal health status, questions asked by children, child age and gender, fears regarding disclosure outcomes, maternal disclosure regrets and disclosure advice received by mothers. Other factors examined by Murphy included characteristics of children who were aware, and unaware of maternal HIV status, what influenced children's reactions to disclosure, and child-coping and problem-solving skills and perceived HIV-related stigma.

A review by Hawk (87) examined rates and predictors of disclosure, reasons for non-disclosure, how mothers executed their disclosure plans and adjustment of families following disclosure. The author suggested further development of structured interventions to assist mothers and their families with the disclosure process. A comprehensive literature review conducted for the current study revealed that available research on maternal HIV-disclosure is mostly descriptive and from resource-rich settings (88). It further concluded that the key role played by the family should be considered when designing parental disclosure models for sub-Saharan Africa.

Qiao and colleagues (89) examined disclosure rates, the disclosure process, and reasons for and impacts of disclosure and non-disclosure in their systematic review. Their review emphasized the importance of building evidence-based, developmentally and culturally appropriate, interventions to assist HIV-infected parents to disclose to their children, particularly in resource-poor settings.

### 3.4 The World Health Organization HIV-disclosure Guidelines for Children

In 2011, the World Health Organization (WHO) issued HIV-disclosure Guidelines recommending disclosure to children, including those below 12 years of age, of their own HIV status and that of their parents and caregivers (46). The purpose of the guidelines is to

assist health care workers to support children and their caregivers with complex disclosure issues. The guidelines were intended to be part of a comprehensive approach towards the holistic wellbeing of a developing child and as a part of the continuum of HIV care in HIV-affected families. The guidelines were informed by evidence from a comprehensive literature review (72) and acknowledge that how disclosure takes place may vary from culture to culture and can be adapted to different geographical areas. The guidelines recommend that disclosure initiatives should be accompanied by efforts to increase availability and accessibility of HIV treatment and management of stigma associated with being infected or affected by HIV (72).

Despite the WHO recommendations, both health workers and caregivers continue to express a lack of knowledge and skills with regards to disclosure to children (97-100). The guidelines recommend full disclosure to children of school age (from age 6 up to 12 years) and partial disclosure to younger pre-school children. The findings of the WHO review revealed that caregivers who disclosed had better outcomes in terms of their own ART adherence than those who did not disclose (64, 101, 102). In an American study where disclosure to children was forced due to maternal ill-health, negative outcomes following disclosure including changes in the child's behaviour were reported (67). The WHO review, however, reported greater understanding of HIV amongst children who were disclosed to, compared to children who were not disclosed to (72, 103). However, it is important to note that all data were based on maternal reports; future studies could usefully explore children's perspectives on this issue. The WHO review also acknowledged that their findings were limited by the small number of eligible studies.

### 3.5 Maternal HIV-disclosure

Maternal and child benefits as a result of disclosure have been reported (55, 87-89) and can be categorised into psychological, physical and social outcomes. Mothers' disclosure has been linked to improved maternal mental health as a result of being relieved from the burden of keeping their HIV status a secret, and decreased depression, stress and anxiety (58, 63, 66, 104, 105). Social and physical benefits include increased social support and improved physical health due to improved ART adherence (64, 106, 107). The psychological benefits for children include decreased depression over time as a result of custody planning (108, 109), increased HIV knowledge and a positive association between disclosure and active planning for the future (83, 103, 108, 110). Higher family cohesion and improved mother-

child relationships are some of the benefits for both mothers and children (66, 67, 83, 111) despite the initial negative emotional reactions of children reported in some studies (55, 67). An improvement in the quality of the mother-child relationship is related to psychosocial adjustment and higher perceived social support (105, 106). Furthermore, negotiating lifestyle changes that HIV treatment requires may promote family communication and cohesion (107). Many mothers do perceive better relations with children following disclosure, citing greater closeness, expressed affection, and children's supportive behaviors (66, 107, 112).

### 3.6 Motivations for disclosure and non-disclosure

Whilst the benefits of disclosure are known, issues of stigma still prevail both globally (108, 113, 114) and locally in African settings (53, 84, 115, 116). Disclosing to children is a daunting task for a number of reasons, including the perceived immaturity of children to handle maternal HIV-disclosure (52, 117), HIV-related stigma (96, 113, 114, 118), uncertainty about the child's reaction (77), and a perception by mothers that they lack the skills to undertake HIV-disclosure (52, 55, 64, 77, 84, 87, 89, 116, 119). Most studies have found that reasons for non-disclosure to children usually fall into three main categories: practical (84, 113, 116), emotional (59, 65, 84, 113, 116) and HIV-related stigma (67, 96, 118, 120). These reasons are shown in Box 1 (88). Lack of emotional maturity in children was cited by mothers as their reason for non-disclosure in studies in Burkina Faso (121), South Africa (53) and the United States (90). Similarly, reasons for disclosure to children were based on practicality in the American studies (66, 79, 83), including that it was better for the children to hear about the maternal diagnosis from the mothers themselves than from someone else.

**Box 1: Reasons given by mothers for disclosure or non-disclosure of their own HIV status to their children**

**Reasons for disclosure**

***Practical***

- Wanted children to hear their HIV status from them and not from other people (65, 66, 105)
- Wanted to respond to their children's questions about HIV/AIDS after hearing about HIV from others or observing parents taking medication (105, 122)
- Wanted to educate their children about HIV and protect them from HIV (59, 66)
- Concerned that their own health was deteriorating (63, 67, 123)
- Felt children were developmentally ready for disclosure (67)
- Wanted to make custody plans for their children (83)
- Wished to have support from their children (81, 84)

***Moral***

- Felt that disclosure was the right thing to do (83)

***Emotional***

- Could not bear to keep a secret any longer from their children (83)

**Reasons for non-disclosure**

***Practical***

- Did not know how to disclose (52, 64, 84, 116)
- Lacked perception of the benefits of disclosure for children (84)
- Concerned that children might ask how their mothers became HIV-infected (83)
- Perceived inability of children to keep secrets (52, 53, 64, 81, 83)

***Emotional***

- Felt their children deserved a worry and carefree childhood (59, 65, 83)
- Concerned about children's internalizing problems (52, 53, 64, 66, 119, 122)
- Felt children were too young (64, 66, 116, 119, 122, 124)

***HIV-related stigma***

- Wanted to protect children from stigma (67, 81, 108, 113, 116, 119, 122, 124)

### 3.7 HIV-related stigma

Stigma was used by Goffman in his seminal analysis of the term to refer to "an attribute that is deeply discrediting" (125). In the case of HIV-related stigma, it would be the HIV-infection that is a discrediting attribute (126). HIV was initially associated with marginalised groups such as sex workers, homosexuals and injection drug users (127), but it has remained a stigmatising disease even in other mainstream populations (126, 128-131). It is argued that stigma is largely a social construct and defined contextually; what may be viewed as stigmatising in one context may not be viewed as such in another context (132). HIV-infected

children may also be victims of what Goffman referred to as *courtesy stigma* or *stigma by association* (125, 133), due to sharing the same residence as HIV-infected family members including their parents. As such, interventions to mitigate HIV-related stigma need to adopt family-centred approaches rather than individualised approaches (68, 69). When addressing HIV-related issues including stigma, some have argued that individualised approaches to HIV are not pragmatic because HIV is a family disease (68, 69, 134).

### 3.8 Theoretical models/ frameworks of disclosure

Over the years scholars have developed theoretical models in an attempt to inform the designs of disclosure studies and interventions (135). In their critical review of theoretical models of disclosure, Qiao and colleagues found few models or frameworks in the HIV field as a whole, but identified three major theoretical models of disclosure (135). The Four-Phase Model, the Disclosure Decision Model and, the Disclosure Process Model.

#### *3.8.1 The Four-Phase Model*

The Four-Phase Model is based on the work of Elizabeth Kubler-Ross (1969) who proposed a framework for understanding the feelings experienced by terminally ill patients (136). The Four-Phase Model itself was developed by Tasker (1992) in an attempt to provide guidance to HIV-infected parents on how to disclose their own status and that of their HIV-infected children to the children themselves (137). The model does not only focus on the role played by caregivers in executing disclosure to children, but also highlights the role of health professionals in guiding parents with disclosure of their own seropositive status and that of their children (135). Though the model has been supported by a few qualitative studies indicating that parents require disclosure assistance and guidance from health professionals, it needs to be applied with caution in collectivist cultural settings where children might have multiple caregivers with conflicting opinions regarding disclosure to a child, as opposed to individualistic cultures (135). Another critique of the Four-Phase Model is that parents may not want health professionals to be directly involved in their disclosure to children (59, 66).

Tasker explains disclosure as a process with four phases: 1) secrecy phase; 2) exploratory phase; 3) readiness phase, and 4) disclosure phase (137). It is important to note that this model was developed before the introduction of ART, when HIV was still effectively a terminal illness (137). The Four-Phase Model should therefore be applied with caution in the current context where HIV is regarded as a chronic rather than a terminal illness. Since the

model does not identify other factors, such as full or partial disclosure, that are involved in the disclosure decision making process, Qiao and colleagues argue that applying it to predict disclosure or non-disclosure is a challenge (135). Table 3 shows a description of the Four-Phase Model.

**Table 3: The Four-Phase Model adapted from Qiao 2012 (135)**

| **Behavioural patterns or needs of HIV-infected parents and health professionals** | | |
|---|---|---|
| **Phases** | **HIV-infected parent** | **Professional** |
| Secrecy | • Feels shock, loneliness and isolation<br>• Identifies trusted adults to disclose to<br>• Professionals may be the only people available to share feelings with | • Respects the parents' need for confidentiality<br>• Creates a trusting and a safe environment for parents to discuss disclosure issues |
| Exploratory | • Searches for parental support groups to explore disclosure to children<br>• Considers talking to children about medication and clinic visits | • Recognises that the ultimate decision to disclose lies with parents<br>• Expresses honest opinions to provide different perspectives. |
| Readiness | • Moves closer to disclosure to children<br>• Makes disclosure plans and discusses strategies with other trusted adults | • Collaborates with parents in planning disclosure<br>• Mutual respect for knowledge and skills of both parents and professionals |
| Disclosure | • Executes a disclosure plan with or without presence of professionals | |

### *3.8.2 The Disclosure Decision Model (DDM)*

According to Julia Omarzu who designed the Disclosure Decision Model (DDM), the disclosure event has four critical components (138). These critical components are the depth (how intimate or private is the information shared), the breadth (the number of topics covered during the disclosure), the duration (time spent disclosing), and the emotional content (emotions expressed during disclosure including love or guilt); each of which impact on how the disclosure target will respond to disclosure (138). The DDM is influenced by different theoretical perspectives listed below:

- **The Social Influence Theory** as developed by Paul Lazarsfers and colleagues in the 1940s and 1950s within the social communication theory (139, 140). The theory proposes that a person's behaviour, attitudes or feelings are influenced by their interactions with others (139, 140).
- **The Disease Progression Theory** suggests that disclosure occurs as a result of declining health, when an individual can no longer conceal the symptoms of a disease

(80). With the advancements in HIV care and treatment, the Disease Progression Theory is becoming less applicable as HIV-infected individuals are living longer and healthier lives (80).

- **The Consequence Theory** suggests that the relationship between disease progression and disclosure is moderated by what an individual may anticipate to be the consequences of disclosure after weighing risks and benefits (80). As the disease progresses there is a need to evaluate consequences of disclosure; if benefits and rewards of disclosure outweigh the risks, people opt for what would offer them personal satisfaction (80). This theory is aligned with Thibault and Kelly's social exchange theory asserting that individuals avoid costly interactions and seek to maximize personal gains (141).

The DDM explains disclosure through decision making stages resulting in different types and levels of disclosure (135). During the first stage there is an assumption that there are goals to be realised through disclosure. At least one of these goals needs to be deemed important and accessible for disclosure to be considered a social strategy. In the second stage, a particular goal is identified and initiated, then, an individual strategizes on how to execute that goal. During the third and final stage, an individual evaluates relative risks and benefits of executing their identified goal and determines the depth, breadth and duration of disclosure (135). The DDM further suggests that both the discloser and the disclosure target may influence the disclosure process; how the disclosure target reacts to disclosure can determine whether disclosures to others will occur in future (135). The model acknowledges that disclosure is a complex phenomenon influenced by various factors including perceived benefits and risks, and thus emphasizes a thoughtful process of weighing those benefits and risks (135, 142).

### *3.8.3 The Disclosure Process Model (DPM)*

The Disclosure Process Model (DPM) was first designed by Chaudoir and Fisher to provide a framework for studying stigmatising conditions but was later modified for HIV-disclosure (78). It is aimed at assisting researchers to answer two important questions; when and why interpersonal disclosure may be beneficial in stigmatising circumstances. It has four main components: 1) the antecedent goals; 2) the disclosure event; 3) mediating processes, and 4) outcomes and the feedback loop (143). These are discussed in detail below.

The DPM is based on the principle that people will disclose if they believe disclosure will assist them towards their intended goals, or antecedent goals (138, 143). For example, if a discloser perceives that they will obtain social support after disclosing, they are more likely to disclose (138, 143). It also proposes that people's behaviours are regulated by two separate motivational systems; the approach and avoidance dimensions. Approach goals-oriented individuals are focussed on the prospect of a positive outcome in pursuit of their desired goal. They narrow the gap between themselves and their goals. Conversely, the avoidance goals-oriented people are focussed on the possibility of a negative outcome in pursuit of their desired goal. They extend the gap between themselves and their goals. Chaudoir and Fisher argue that avoidance and approach goals are what ultimately shape how individuals perceive and respond to the environment (143). Those with avoidance goals are at a physical health risk if, for example, they cannot access and adhere to ART as a consequence of non-disclosure (144-147).

Disclosure impacts on every domain of a discloser's life (78). Multiple types of mediating processes may influence a person's disclosure outcome at individual, dyadic and social contextual levels (110, 123). At an individual level a person may benefit by improved mental health (65, 66). The dyadic context suggests that disclosure has implications for both the discloser and the disclosure target (142). As a social outcome, disclosure may create HIV social awareness, helping in the reduction of HIV-related stigma (148). Receiving favourable feedback from a disclosure target following disclosure increases the likelihood that the discloser will disclose to others in future; conversely, if the feedback received is negative, it would decrease the likelihood of disclosure being repeated in the future (143).

There is consensus amongst the three theoretical frameworks that before embarking on disclosure, the discloser weighs risks and benefits (135). The need for social support seems to be the biggest motivator for disclosing in all three frameworks. It would benefit future disclosure interventions to consider how individuals make disclosure decisions and what their biggest motivators for disclosing are.

### 3.9 Predictors of disclosure

#### *3.9.1 HIV-disclosure to other adults*

Whilst there is a dearth of literature on maternal HIV-disclosure to HIV-uninfected primary school-aged children, numerous studies have investigated HIV-infected women's disclosure to other adults including partners, family and friends (149-155).

It is assumed that increased social support would lead to decreased stigma (2). Women infected with HIV in particular, disclose their status to their partners in order to practise safe sex as part of living positively with HIV infection (75, 156-158). Disclosure to partners poses its own challenges, including fear of HIV-related stigma (78, 82, 126, 152, 154, 158-165), blame for the HIV transmission, possible abandonment and violence from the partners (82, 150, 155-158) but many studies report support from partners, family and friends following disclosure (153-155, 166-170).

The benefits of disclosure to partners include social support, safe sex, and access and adherence to HIV treatment (2, 155, 157, 171). In American studies disclosure to live-in partner and children was associated with ART and medical appointment adherence; conversely, less disclosure to children was associated with poor medical appointment adherence (85, 172).

Studies of disclosure to other adults have identified various predictors of HIV-disclosure: longer duration of HIV diagnosis; (92, 152, 155, 173), higher educational status (159, 166, 174), older age (155, 175), being married or living together (82, 175-177), being on ART (178), and knowledge of partner's status (92, 167, 176) increased likelihood of disclosure.

#### *3.9.2 Developmental stage of a child*

Early literature on children and illness has demonstrated that as children grow, so does their understanding of illness (105, 179-181). In their research, Christ and Christ, wrote about children's understanding of a parent's terminal illnesses such as cancer (180). They recommended that children be provided with age-specific information. The same recommendation can be applied to parental disclosure of HIV infection. The WHO Parental Disclosure Guidelines suggest that disclosure to children should be tailored to their cognitive-

developmental ability to understand the information (46). A recent Kenyan study of parental HIV-disclosure suggested that HIV-infected parents with both HIV-infected and HIV-uninfected children preferred partial disclosure from the age of five years and full disclosure from ten years onwards (182).

### *3.9.3 Maternal health status*

Mothers are advised to consider their health status before they disclose their HIV status to a child in order to avoid distressing the child (73). Contrasting evidence has been reported on maternal health status and disclosure with some mothers preferring to disclose whilst they are still healthy (66). Mothers with lower CD4 cell counts reported to have disclosed more frequently than those with higher CD4 cell counts in one study (52), while in another study the severity of a mother's illness was not significantly related to disclosure (103). In a further study, there were no significant differences in medical variables such as CD4 cell count between mothers who had disclosed to their children and those who had not (106).

Most studies have relied on maternal reports, however, in one of a few studies conducted with children in Kenya, children expressed a desire for parents to disclose when they are feeling well (183). The reasoning behind this statement was that having observed their mothers when they were very ill at was too traumatising for the children concerned (183). However, mothers expressed that there may be a case to disclose fully to children in exceptional cases, for example if the mother was too weak to do anything for herself so that children would be able to offer practical help including taking her to hospital or collecting her medication (183). The Kenyan study did not, however, interview parent-child dyads but separately interviewed parents, and both HIV-infected and uninfected children who were not from the same families.

### *3.9.4 Access to HIV treatment and care*

In a situation where the mother has not accessed HIV treatment and care services, delaying disclosure to a child is recommended until the mother is able to access such services (73). It is beneficial for a child's mental health to see their mother physically well and living positively with HIV (74, 184, 185). In a study from the US, even adults who planned to disclose to other adults delayed disclosure when they were ill and waited until they were on ART and looking well (178). Numerous studies suggest that when children are aware of their mothers' HIV status and that their mothers are taking ART, they become actively involved in

monitoring and reminding them to take their HIV treatment (85, 101, 102, 113, 186, 187), thereby improving their mothers' ART adherence.

### *3.9.5 Child-friendly health facilities*

Ensuring that children have adequate social support following disclosure of maternal HIV status is critical (46). Increasing children's access to health care support networks has the potential to improve health outcomes in families (188, 189). The challenge is that most health care facilities do not prioritize health promotion and are not child-friendly (190, 191). Health care facilities are not designed to meet the needs of children, therefore children find health care facilities frightening spaces (192, 193). Moreover, the medical terminology used in health facilities is not child-friendly (192-196). In resource-poor settings, health promotion is a low priority due to staff shortages (197-199) and health care facilities being over-burdened (35, 200). Resource-rich settings also struggle with health promotion among children in primary health care (190, 201). Other barriers to child-friendliness include a lack of infrastructure and staff fatigue (197, 202). A multi-site study in Kosovo, Uganda and Pakistan found that children, health care staff and parents expressed frustrations about poor health systems in terms of disseminating health information (190). Providing training and simple tools for child-friendliness and health promotion in a resource-poor, high HIV prevalence area, was well accepted by health care workers and HIV-infected mothers (97).

### *3.9.6 Duration of maternal HIV diagnosis and disclosure patterns*

Most studies suggest an association between the duration of time since an HIV diagnosis and disclosure. A multinational study conducted in Tanzania, Kenya and Namibia found that those who had known their status for more than three years were more likely to disclose than those who had known it for less than a year (173). Similar findings have been observed in South African studies (148, 155), an Ethiopian study (92) and a Thai study (203). However, in a Ugandan study, 83% of the participants disclosed to someone on the day they received their HIV-positive results (156), while in a South African study of PMTCT attendees 72% disclosed their HIV status to their partners within a week of being diagnosed with HIV (75). The high disclosure rates in Uganda could be attributed to the participants being members of The AIDS Support Organization (TASO) (156). In the South African study the motivation for disclosure could have been the social support which the mothers received, especially with their infant feeding option as they were also enrolled in an infant diagnostic study (75).

### *3.9.7 Social exposure to HIV*

Due to high HIV prevalence and roll-out of treatment and care in local health services, many households in sub-Saharan Africa are now socially exposed to HIV. Research conducted in rural South Africa indicated that 40% of the population shared a household or living arrangements with people who were either initiated on ART or were enrolled in pre-ART care (204). Similar findings were observed in a study of HIV-infected pregnant women who were attending an antenatal clinic in an urban setting in South Africa: 36% of women reported knowing someone who was HIV-infected, of whom 72% were their family members (162). Knowing someone who is also HIV-infected increased the likelihood of disclosure in studies from Ethiopia and Tanzania (92, 205).

### *3.9.8 Custody planning*

An association between disclosure and custody planning has been documented in the literature (83). In the US study, where 50% of mothers had disclosed their HIV status to their children, over 50% of the mothers had also made formal custody plans (110), with the majority nominating female relatives as guardians. In another US study, mothers who had disclosed wanted to open communication regarding custody of their children (186). Two Thai studies indicated that mothers made use of extended family networks as part of Thai culture when making custody plans (203, 206). Most Thai mothers made custody plans with aunts and uncles (54%), whilst 27% chose grandparents (203). For HIV-infected parents who were African immigrants in Sweden, custody planning was particularly difficult as they were separated from their extended families (207). There has been an increase in interventions to assist with making custody arrangements over recent years (73, 76, 185, 208, 209).

### *3.9.9 Socio-cultural factors affecting disclosure in sub-Saharan Africa*

#### *3.9.9.1 Intergenerational communication gap*

Discussions around HIV invariably include discussions about sex. In the African context, it is particularly difficult for parents to engage in discussions about sexual topics – including HIV – with children, when these issues are considered taboo (84, 116, 210). For example, amongst Batswana people, living in Botswana, it is considered inappropriate for children to discuss sexual matters with their parents (116). Similar observations were made in Asia, where a qualitative study from Thailand revealed that parents' HIV status and their HIV-related

deaths are very sensitive topics with adults creating a "wall of silence" around children regarding these matters (120). An American study of Asians immigrants (East, Southeast and South Asian) reported similar findings that sexual behaviour, illness and death were taboo subjects in Asian cultures, hindering HIV discussions and disclosure processes with children (211). There have been interventions to narrow the intergenerational gap. One such intervention is the Collaborative HIV/AIDS and Adolescent Mental Health Programme (CHAMP), conducted in South Africa (212). This intervention was adapted from an American programme with the same name and sought to facilitate communication between pre-adolescents and their families as an HIV prevention strategy through promoting resiliency (212).

#### *3.9.1.2 Faith and religion*

People's faith plays an integral part in their understanding of the illness and the type of treatment they will access. In sub-Saharan Africa, the issue of faith cannot be underestimated when designing interventions to assist HIV-affected families (151, 164). A multinational HIV-disclosure study in South Africa, Swaziland, Malawi, Lesotho and Tanzania, found that HIV-infected people found strength in their faith to help them disclose their status (164). In a Nigerian study, almost 30% of participants disclosed to their pastors which was three times the number that disclosed to siblings and friends (82). In a Kenyan study, pastors were at the top of the list that people living with HIV (PLWH) disclosed to, indicating an important role played by religion when dealing with life changing experiences.

### 3.10 Thesis themes

This thesis focused on three main themes, tabled next.

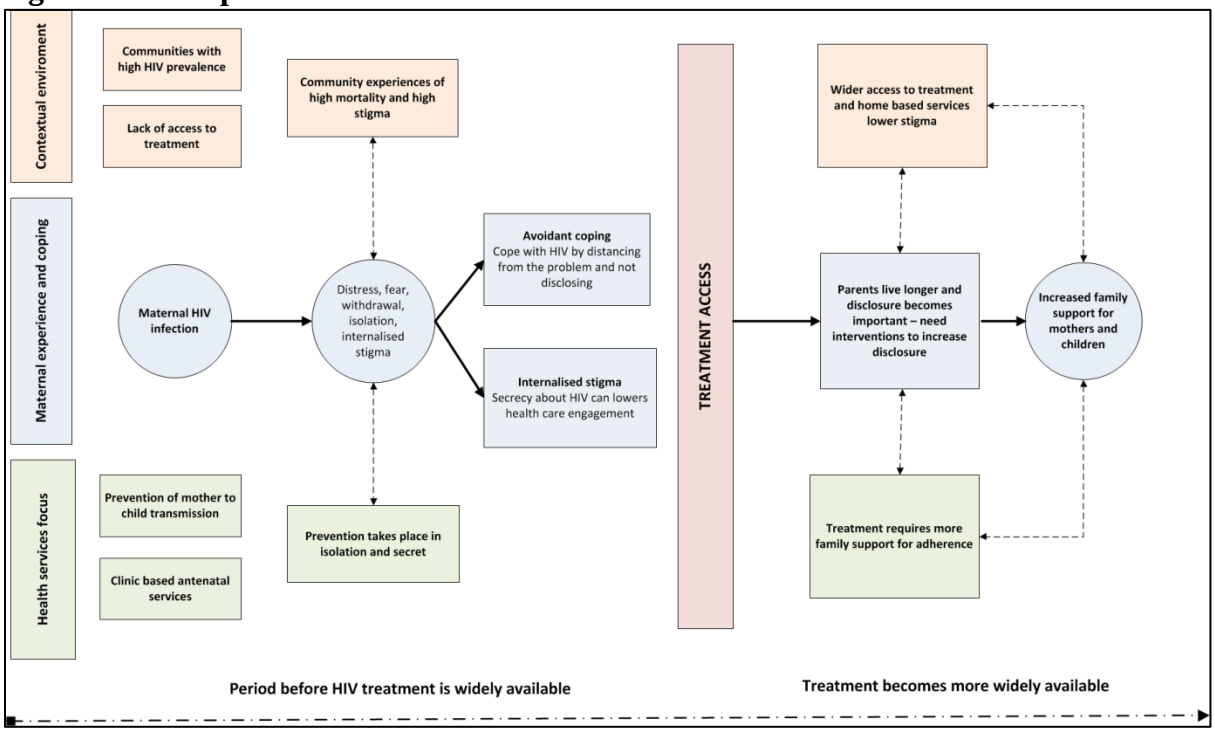
**Table 4: Thesis themes**

| | **Themes** | | |
|---|---|---|---|
| | **1. HIV-disclosure and stigma** | **2. HIV-disclosure and family strengthening** | **3. HIV-disclosure and access and adherence to HIV treatment care** |
| **Key messages** | Stigma and lack of family disclosure may limit HIV prevention and treatment efforts. | Family disclosure interventions may increase disclosure and family communication. | Stigma impacts most directly at a family level, rather than at a community level, so interventions targeting communities may not change mothers' health behaviours as much as home-based, family-centred disclosure change strategies. |
| **Paper I Maternal HIV-disclosure literature** | Reasons for maternal disclosure and non-disclosure to children show that disclosure can increase family communication and reduce stigma. | There is a relationship between maternal HIV-disclosure and ART adherence. Disclosure of maternal HIV to children is not common, or even considered by mothers to be necessary for children's well-being. Family HIV-disclosure interventions increase the number of people to support HIV treatment adherence in the home. | Maternal disclosure has health and relationship advantages for both the mother and the child. |
| **Paper II Living with HIV in an ART-era** | Implications of stigma on maternal access to HIV treatment and care. Increased access reduces stigma but stigma can still remain a barrier, especially in close relationships and families. | Access to HIV treatment changes community level perceptions of stigma, but not necessarily the individual behaviour of mothers. Disclosure to other adults takes time, even to partners, but often happens on its own over time in stable relationships. | Social support, relationships, and living arrangements are important and intertwined with disclosure. |

| | | | |
|---|---|---|---|
| **Paper III Maternal HIV-disclosure experience** | Consequences of family disclosure on reducing family stigma and increasing support for maternal HIV treatment. | Capacity of children to be an important part of their mother's ART adherence or adjustment to living with HIV. | Mothers need support to develop skills to disclose their HIV status to their children and these skills also support adherence to their own HIV treatment. |
| **Paper IV Improving the capacity of families and clinics for maternal HIV-disclosure** | Health service-centred interventions can reduce clinic level stigma and help health care staff, including nurses, recognise the strength of mothers and the role that children can play in supporting adherence in their mothers. | Family disclosure interventions had a positive impact on mothers' confidence to take their children with them to their treatment clinic. | Maternal-centred interventions can reduce perceived stigma and increase maternal engagement with health services. |

The study was informed by a conceptual framework after a comprehensive literature review (88). The conceptual framework is discussed below.

**Figure 2: Conceptual framework**




The conceptual framework in Figure 2 above, illustrates how the presence or the absence of HIV treatment impacts on how HIV-infected mothers cope with their infection, including how family support increases disclosure, and access and adherence to HIV treatment. After being diagnosed with HIV, a woman may adopt either one of two coping strategies - active or avoidance coping (74). Active coping is an ideal strategy as it allows an HIV-infected mother to embrace rather than avoid her HIV status. Thus she addresses the situation positively by employing mechanisms to assist her, including disclosure to others for social support. Through maternal HIV-disclosure, communication channels between a mother and her child are opened, allowing for HIV education and prevention to her child and improved family cohesion. Those who opt for avoidance coping prefer to keep their diagnosis a secret. The secrecy causes mothers distress and results in poor mental health and poorer parent-child communication. The child is at a disadvantage as they are not provided with HIV education to protect themselves from HIV infection. Children are also unable to engage in custody planning in case of a mother's hospitalisation or death. When treatment is not available it might be easier to opt for avoidance coping and have no hope for the future, but as HIV treatment has become more widely available and HIV-infected mothers are surviving longer

to care for their children, then disclosure becomes increasingly necessary for social support and improving access and adherence to ART.

### 3.11 Conclusion

In this literature review I have defined HIV-disclosure in general and specifically reviewed the global literature on parental/ maternal HIV-disclosure. The review indicated a lack of maternal HIV-disclosure interventions for uninfected primary school-aged children in sub-Saharan Africa (88) (See Figure 1 in Paper 1). Although there are theoretical frameworks and models to assist in the understanding of HIV-disclosure, some of their components are no longer applicable, as HIV has evolved from being regarded as a terminal illness to being a chronic illness.

However, common reasons for disclosure and non-disclosure are reported across all maternal HIV-disclosure studies, particularly the need for social support and the fear of HIV-related stigma. Maternal and child variables, including duration of HIV diagnosis, access to HIV treatment and care, custody planning for mothers, and developmental age and social exposure to HIV for children, may predict disclosure. Socio-cultural contexts including faith or religion and cultural practices, such as how parents discuss HIV and sex-related topics with their children, need to be considered when designing family-based disclosure interventions including maternal HIV-disclosure interventions. These factors may impact on the failure or success of these interventions.

The next chapter describes the methodology, both qualitative and quantitative, used in the current study to explore the experiences of HIV-infected women enrolled in a maternal disclosure intervention. The maternal HIV-disclosure views of the health care workers where these women and their families receive HIV treatment, care and support were also investigated to understand how HIV-affected families can be further supported by health care facilities to manage HIV in the sub-Saharan African context.

# 4. Methodology

This chapter first describes the Amagugu maternal HIV-disclosure intervention within which the current PhD is nested. Data from the Amagugu study were used to describe the demographic characteristics of the sample, to investigate HIV-disclosure by the enrolled women to other adults and children prior to the intervention, and their experiences of participating into a health intervention. I enrolled 20 of these women into a further sub-study specifically for my PhD to explore qualitatively the women's experiences of living with HIV in an ART-era and their experiences of being part of a maternal HIV-disclosure intervention. As part of Amagugu intervention, I led a health intervention and trained health care staff on maternal HIV-disclosure and child-friendliness in preparation for maternal HIV-disclosure. This was implemented to improve mothers' health care and custody planning and to increase children's access to a health care and social support network. For the current study I used qualitative data from focus groups and semi-structured questionnaires. I administered questionnaires and conducted focus groups with 87 clinic staff from the nine clinics where mothers in the Amagugu study were receiving their HIV treatment and care. I will describe my roles in both the Amagugu study and the PhD study. Women who enrolled in the Amagugu study were previously part of the Vertical Transmission Study (VTS). Both the VTS and the Amagugu study, including the Amagugu intervention package, are explained below.

## 4.1 The Vertical Transmission Study (VTS)

The current study enrolled women and their primary school-aged children who had previously participated in the Vertical Transmission Study (VTS, 2001-2006). The VTS assessed HIV transmission risks and survival associated with exclusive breastfeeding and other types of infant feeding (38, 213). The VTS was conducted at the Africa Health Research Institute between 2001 and 2006 and was funded by the Wellcome Trust (Grant Number: 097410/Z/11/Z). In the VTS women were tested for HIV, for the first time, as part of a PMTCT programme which was implemented in the Umkhanyakude District from 2001 (214). The VTS enrolled approximately 3,000 HIV-infected and HIV-uninfected women from eight antenatal clinics in the Hlabisa sub-district and one clinic outside Durban. Women were enrolled during pregnancy and subsequently followed-up with their infants for two years after delivery to assess vertical HIV transmission, morbidity, mortality and growth of infants associated with exclusive breastfeeding and other types of infant feeding (38, 215,

216). The morbidity and mortality of women was documented, in addition to any breast health problems they encountered (213, 217, 218). Women choosing to breastfeed were supported to exclusively breastfeed by breastfeeding counsellors who visited them at their homes during the first six months after delivery (213). The breastfeeding counselling visits were strongly associated with adherence to cumulative exclusive breastfeeding (213, 219).

Four years after the completion of the VTS, in 2010, when the participant children were between 6 and 10 years of age, we tracked and sought informed consent from only the HIV-infected mothers who had given birth to HIV-uninfected children to enrol into a new study called "Amagugu" - a family-centred maternal HIV-disclosure intervention (73, 76, 77) funded by the Canadian International Development Agency (CIDA).

One of the challenges of identifying and locating the previous VTS participants in the study setting was the extreme mobility of the population (220). The majority of the mobile phone numbers used during the VTS were no longer working, therefore most of the re-tracing of potential participants was carried out by individual home visits. During a dissemination workshop to share the VTS results with participants in 2006, most of the mothers had indicated that they wished to be contacted for future studies. If we could not find one of the VTS mothers at her homestead during the physical tracking, we left a message to ask her to send a free text message to the study mobile phone if they wished to be contacted about the Amagugu study. This strategy was useful in re-establishing contact with some potential participants.

### 4.2 The family-centred maternal HIV-disclosure study (Amagugu)

The Amagugu study aimed to assist HIV-infected mothers to disclose their HIV status to their HIV-uninfected primary school-aged children using culturally- and age-appropriate disclosure materials specifically designed for the study. The VTS had been a very well received and highly acceptable research study that had made a positive impact in the community. Consequently, when the Amagugu study was presented as a 'continuation of VTS' it was easy to rebuild rapport with previous VTS participants and to ask them to consider enrolling in the Amagugu study.

**My roles in the VTS, Amagugu study and current study**

I was involved in various stages of the VTS including:

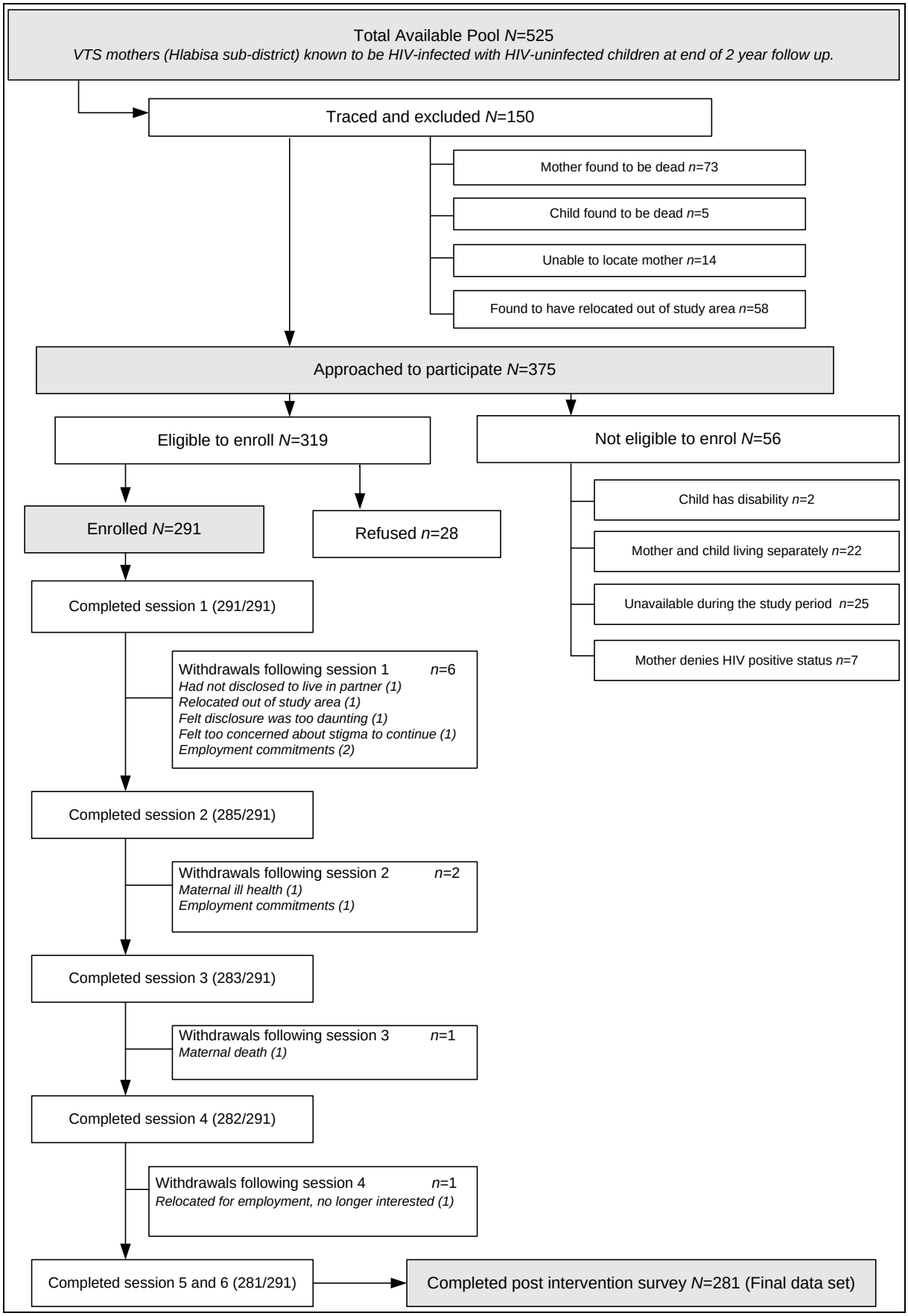
- Raising awareness about the study before it commenced, conducting talks at the clinics, and presenting the study at community meetings;
- Recruitment of participants;
- Data collection;
- Data cleaning;
- Data analysis that resulted in a publication (214);
- Dissemination of VTS results.

As a Project Coordinator for the Amagugu study, my roles in the Amagugu and current study included, but were not limited to the following:

- Communicating with stakeholders about the study including local tribal authority, local community, the Africa Centre's Community Engagement Unit (CEU) and the Community Advisory Board (CAB);
- Development of study tools;
- Data collection;
- Data quality control and assurance;
- Data analysis resulting in various publications for the Amagugu study (73, 74, 76) and for the PhD study (88, 97, 184), including one paper in accepted in the journal *Health Policy and Planning* on 26 April 2017
- Dissemination of Amagugu study results.

A consort diagram (in 4.2.1 Figure 3) illustrates how the 525 HIV-infected women who had an HIV-uninfected child and were still under "follow-up" at the end of the VTS in the Hlabisa sub-district (and not the Durban cohort) were tracked for invitation to join the Amagugu study.

### *4.2.1 Figure 3: Consort diagram representing women enrolled into the Amagugu study*

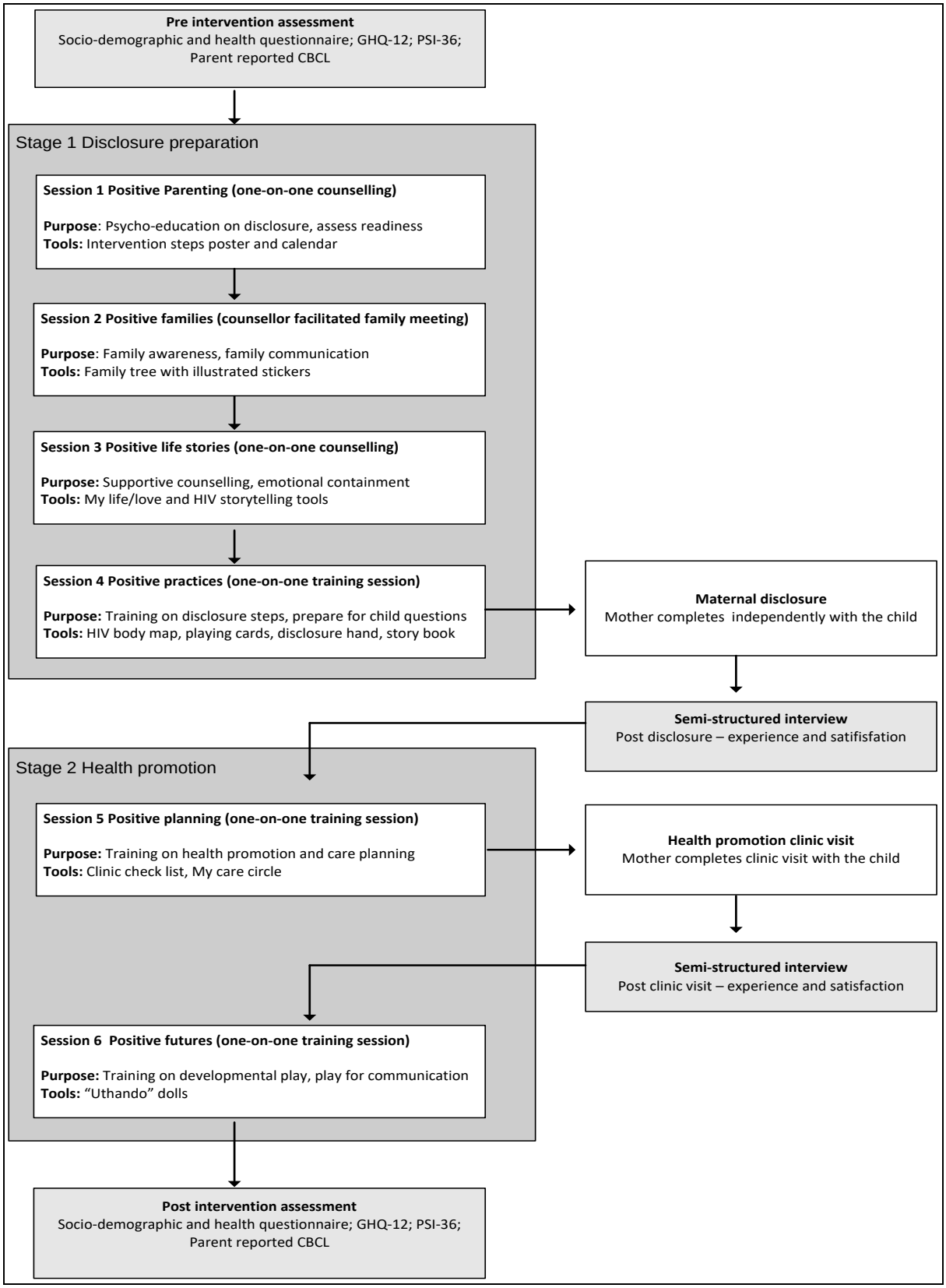


Following tracking of the 525 HIV-infected women, 375 women were approached to participate in the Amagugu study. Although the homes of the other 150 women were found, they were excluded from invitation to participate for various reasons including maternal or child death, mother was living outside the study area or the mother could not be located. Of the 375 women that were approached, 319 were eligible for enrolment but 28 refused to participate, and 56 were not eligible for enrolment for various reasons including child disability, mother and child living separately, mother unavailable during the study period and mother denying her HIV infection. Of the 291 mothers that were eventually enrolled, there was recognition that maternal HIV-disclosure was difficult as children were perceived to be young and unable to maintain confidentiality. However, the women welcomed the assistance that they were going to be provided during the Amagugu study. Ten mothers withdrew before completing all the Amagugu sessions, leaving a final sample of 281 mother-child pairs enrolled in the Amagugu study. Following informed consent, women that had been part of the VTS were enrolled to the Amagugu study if:

- They acknowledged their seropositive HIV status
- They had a 6-10 year old HIV-uninfected child that had been part of the VTS when the child was between 0-2 years
- The mother was living with the child in the study area or the mother had regular access to the child at least two nights per week to ensure adequate support during the disclosure period

The Amagugu study had two main stages. Stage 1 entailed preparation for disclosure through provision of disclosure tools to participating mothers, and one activity-driven family session involving other family members. Stage 2 was a health promotion visit which comprised of training the mother to undertake a health promotion visit with the child to the health facility following disclosure as an extension of the child's support. 4.2.2. Figure 4 illustrates these home-based sessions and the data collection points of the Amagugu intervention. The study materials are described after this.

### *4.2.2 Figure 4: The Amagugu intervention data collection points*



### *4.2.3 The Amagugu study intervention package*

The Amagugu intervention was home-based and delivered by trained intervention counsellors. The counsellors did not directly intervene with the participants' children, but rather provided mothers with printed materials and child-friendly activities to support age-appropriate disclosure. The counsellors trained and supported mothers to communicate with their children independently and to disclose on their own, thereby transferring skills and empowering women. The Amagugu disclosure materials are outlined in 4.2.4 Table 5 below.

### *4.2.4 Table 5: Amagugu Intervention maternal HIV-disclosure tools and materials*

| **Tools/ Materials** | **Description** | **Purpose** |
|---|---|---|
| Talk and Play Reminder | A5 illustrated colour card | Offers specific guidance on planning of disclosure |
| Family Life Line | A4 card artwork and stickers | Teaches a 5-step process and what each step offers the child |
| HIV Body Map | A4 HIV Body Map with stickers | Demonstrates a 5-step intervention and teaches age-appropriate activities and games |
| Playing Cards | A7 ten matching pairs playing card set | Through practice ensures that a mother is skilled and confident and feels enabled to undertake disclosure using intervention tools and materials |
| Safety Hand | A4 card and pens for artwork | Helps a mother to develop her own child and family personalised materials |
| Family Treasures Story Book | A5 illustrated 14 page English-Zulu Story Book | Allows for role-playing practice and development of personal talking points |

## 4.3. The current PhD study

### *4.3.1 Study aim*

To explore in more depth the experiences of women involved in the Amagugu intervention. This includes their interaction with the clinic staff in their primary health care clinics, where they access HIV treatment and care during the health intervention with their children.

### *4.3.2 Research questions*

1. Where have maternal HIV-disclosure studies been conducted, with whom and what lessons can be adapted to rural settings in sub-Saharan Africa?
2. What are the experiences of women living with HIV in an ART-era, ten years after their diagnosis?
3. What motivates HIV-infected mothers to enrol in a maternal HIV-disclosure intervention and what do they report post intervention?
4. What were the experiences of women and their children of a clinic intervention to support maternal HIV-disclosure? How can primary health care clinics be supported to assist HIV-affected families to access and adhere to HIV treatment and care?

### *4.3.3 Study objectives*

1. To explore HIV-infected women's experiences of living with an HIV diagnosis in an ART-era using qualitative enquiry methods.
2. To qualitatively explore HIV-infected women's motivation for, and their experiences of, participating in a maternal HIV-disclosure intervention.
3. To determine which factors within primary health care clinics facilitate or obstruct implementation of a family-centred HIV-disclosure intervention using mixed methods.

### *4.3.4 The study setting*

The current study was conducted at the Africa Centre for Population Health (www.africacentre.ac.za), now Africa Health Research Institute, AHRI (www.ahri.org) in the Hlabisa sub-district of Umkhanyakude District, northern KwaZulu-Natal, South Africa. The setting is rural, resource-poor, and predominantly isiZulu speaking (221, 222). In 2012, the HIV prevalence amongst women attending antenatal clinics in KwaZulu-Natal was 37%, and

the local district of Umkhanyakude was among the ten health districts with the highest HIV prevalence in KwaZulu-Natal, estimated at 41% in 2011 and 35% in 2012 (223). Between 2004 and 2012, health care in the study area was provided through 17 primary health care clinics with a comprehensive, decentralised, HIV Treatment and Care Programme through a partnership between the Africa Centre and the KwaZulu-Natal Department of Health, with support from the United States Presidents Emergency Plan for AIDS Relief (PEPFAR) (34, 35, 224). The Department of Health has exclusively managed this programme since 2012. When the PMTCT programme was introduced in the local district in 2001, the Africa Centre worked in partnership with the provincial Department of Health to implement it, and at the same time the Africa Centre invited PMTCT attendees to enrol in the Vertical Transmission Study. How the PMTCT programme has evolved since then is illustrated in Table 2 on page 7.

#### *4.3.4.1 The PMTCT of HIV Programme*

The PMTCT of HIV Programme is part of a global strategy towards an AIDS free generation (225, 226). In 2001, the South African government introduced a comprehensive package for a PMTCT Programme. This was initially introduced as a pilot programme and was later brought as a full-scale national programme, in response to a Constitutional Court ruling (225, 226). In line with the International standards for a comprehensive strategy, the PMTCT policy recognised that in order to prevent HIV among women and children, four elements of PMTCT were essential (226). These included:

- Primary prevention of HIV especially among women of childbearing age;
- Preventing unintended pregnancies among women living with HIV;
- Preventing HIV transmission from a woman living with HIV to her infant; and
- Providing appropriate treatment, care and support to women living with HIV and their children and families

#### *4.3.4.2. The Africa Centre Demographic Information System (ACDIS)*

The Africa Centre was set up in 1998 when the University of KwaZulu-Natal (UKZN) and the South African Medical Research Council were responding to a rapidly growing HIV epidemic in the Hlabisa sub-district of Umkhanyakude District, in KwaZulu-Natal (222). A Demographic Surveillance System (DSS) was established in 2000. The DSS has collected demographic and socio-economic data twice yearly from eligible individuals (women aged

between 15-49 years and men aged between 15-54 years) in approximately 11,000 households within the Africa Centre's Demographic Surveillance Area (DSA), which makes up about 40% of the land area and population of the Hlabisa sub-district (34, 227, 228). The HIV surveillance programme has been nested within the DSS since 2003 and data collected in the HIV surveillance can be linked anonymously to longitudinal data collected in the households (229). From 2007, eligibility to participate in the HIV Surveillance programme was extended to all residents aged 15 years and older, and since January 2012 these biennial visits have been extended to three times a year. The HIV burden in the DSA is immense with 24% HIV prevalence in adults 15 years and older as reported in 2011 (171, 204, 221, 222, 228, 230, 231). Linkage of the Amagugu data with the DSS data provides an opportunity to obtain additional evidence on factors such as family composition, household structure, social HIV exposure within households and other information that impact on the mother and child HIV-disclosure outcomes.

### *4.3.5 Study design*

The current study used both quantitative and qualitative methods of enquiry. The sample for the current study comprised three groups: 1) all mothers from the Amagugu study (N=281); 2) a sub-sample of mothers from the Amagugu study purposely selected from five of the nine geographic catchment areas representing both peri-urban and rural settings (N=20), and 3) health care staff employed in the clinics where the Amagugu study operated (N=87).

Quantitative data were collected at different time points from the women in the Amagugu study including baseline, after the health intervention, and post disclosure, using semi-structured questionnaires specifically designed for the Amagugu study. A different battery of semi-structured questionnaires were also administered to the clinic staff during the health intervention, and were used to obtain demographic characteristics prior to the health intervention. Qualitative data were collected through a combination of in-depth and semi-structured interviews with the sub-sample of 20 women after the disclosure intervention, and nine focus groups with clinic staff which were conducted after the health intervention. Table 6 illustrates the participants, methods of enquiry and measures used in the current study.

**Table 6: Participants, methods of enquiry and measures for the current study**

| Participants | Research question | Method of enquiry | Measures |
|---|---|---|---|
| Sub-sample of mothers from the Amagugu cohort: N=20 mothers | What are the experiences of women living with HIV in an ART-era, ten years after their diagnosis? | Qualitative | In-depth interviews |
| Sub-sample of mothers from the Amagugu cohort: N=20 mothers | What motivates HIV-infected mothers to enrol into a maternal HIV-disclosure intervention and what do they report post intervention? | Qualitative | Semi-structured interviews |
| Cohort of mothers from the Amagugu study: N=281 mothers | What were the experiences of women and their children of a clinic intervention to support maternal HIV-disclosure? | Quantitative | Semi-structured questionnaires |
| Employees from the 9 local primary health care clinics where Amagugu mothers received their HIV treatment and care: N=87 clinic staff | How can primary health care clinics be supported to assist HIV-affected families to access and adhere to HIV treatment and care? | Qualitative | Focus groups |

The data used for analysis in this study were collected at different time points during the Amagugu intervention, as illustrated in Table 7.

**Table 7: Sample and data collection points for the current study**

| Participants | Number | Inclusion criteria | Measures | Data collection points and place |
|---|---|---|---|---|
| HIV-infected women and their HIV-uninfected 6-10 year old children from the Amagugu study | N=281 | • Being enrolled in the Amagugu study | • Semi-structured questionnaires | • Baseline and post Amagugu intervention at home before and after clinic visit following disclosure at home |
| Clinic staff | N=87 | • Being over 18 years old<br>• Working at one of the clinics where Amagugu operated<br>• Willingness to consent to enrol | • Semi-structured pre-clinic and post-clinic training questionnaires<br>• Focus groups | • Before and after mothers undertook a health promotion visit with the child at her HIV treatment and care clinic |
| A sub-sample of HIV-infected women from the Amagugu study | N=20 | • Willingness to consent to enrol | • In-depth and semi-structured interviews | • Three months post-intervention at home |

### *4.3.6 Sample selection and measures*

The data used for the current study included data collected during the Amagugu intervention, data collected from health staff as part of the clinic intervention and data collected with a sub-sample of women post Amagugu intervention. These samples and data collection tools are detailed in Table 8 below and explained further thereafter.

**Table 8 Data collection tools**

| *Amagugu study sample* | *Clinic intervention sample* | |
|---|---|---|
| • Baseline Information Form<br>• Parental Disclosure Interview<br>• Health Update Form | • Clinic visit Follow-up and Child Experience Form<br>• Pre- and post- clinic training questionnaire<br>• Focus groups | • In-depth interviews<br>• Semi-structured interviews |

#### *4.3.6.1 Amagugu study sample*

The data from the Amagugu study analysed for the PhD study included:

##### *4.3.6.1.1 The Baseline Information Form (N=20)*

The Baseline Information Form is a structured questionnaire that was used to collect socio-demographics data from all the women participating in the Amagugu study. The form included additional data on the mother's living arrangements and whether the mother was still in a relationship with the father of the child or not. I analysed the Baseline Information Form data of the sub-sample of 20 women. The analysis included assessment of maternal physical health, including whether or not the mother was on ART, her duration on ART and CD4 cell counts at baseline in the Amagugu study. The physical health status assisted in determining whether or not maternal illness was a motivation for a mother to disclose her status to a child.

##### *4.3.6.1.2 The Parental Disclosure Interview (N=20)*

The Parental Disclosure Interview (PDI) was developed by Daniel Pilowsky (1999) (232). It is a semi-structured questionnaire with some open-ended questions. It was specifically designed for HIV-infected women. The interview covers six domains and enquires about levels of disclosure and related information including:

1. Personal and family information;
2. HIV history;
3. Disclosure to partner and other adults about HIV infection;
4. Disclosure to children (younger than 18 years old) about HIV infection;
5. Custody planning;
6. Disclosure to older children (18 years old and above) about HIV infection.

Women were asked to whom they had or had not disclosed their HIV status prior to the Amagugu intervention and their reasons for disclosing or not disclosing. This was done to determine whether disclosure to other adults would facilitate disclosure to children. I analysed the PDI data of the sub-sample of 20 of the 281 HIV-infected women enrolled in the Amagugu study.

##### *4.3.6.1.3 The Health Update Form (N=281)*

Post-intervention, the Health Update Form was used to collect data on maternal physical health status including ART information and the most recent CD4 cell count results. With

regards to the sub-sample of 20 women, the Health Update Form assisted in observing if there had been changes since the enrolment into the intervention, with regards to accessing HIV treatment and care services, particularly if a mother had reported not accessing such services at Amagugu baseline.

#### *4.3.6.2 Clinic intervention sample*

##### *4.3.6.2.1 The Amagugu Study Health Promotion Clinic Visit*

Between one to two weeks after disclosure, the Amagugu counsellors trained mothers on the health promotion visit and provided them with the materials and activities to use with their children during the clinic visit. Each mother was encouraged to engage in a health promotion activity by taking her child for a clinic visit. I also conducted training on child-friendliness and maternal HIV-disclosure for the clinic staff, and provided health information posters and health promotional play materials.

##### *4.3.6.2.2 Clinic visit Follow-up and Child Experience Form (N=281)*

Semi-structured questionnaires were administered to the mothers on the content of the health promotion training and the experiences during the clinic visit. The aim of the health promotion clinic visit was to improve HIV-infected mothers' health care and custody planning. It also aimed to increase their children's access to a health care social support network, at their nearest primary health care clinic where their mothers were accessing HIV treatment and care. The clinic visit was also used as a health promotion exercise to orientate children to the clinics, and to encourage the perception that clinics are friendly, informative, spaces where children can come for help for illness or health advice (200, 233-235). I analysed data collected from (N=281) mothers and their children before and after the clinic visit.

**Box 2: Amagugu materials provided for the clinic visit**

The Amagugu Name Tag: Each child was provided with a name tag to assist the child to have a sense of identity and pride, and serve as a visual reminder to the health care staff of their commitment to ensuring that children were welcomed in the clinic.

The Clinic Checklist: The clinic checklist was designed as an "I spy" activity, to encourage the child to explore the clinic. It is a 'learn by doing' tool which helped the child become familiar with the clinic processes (including patient registration and medical procedures); the infrastructure (including the waiting area and toilet); and to meet and engage with health care providers (including the clerk, other patients and the HIV nurse).

The Uthando Doll: The larger intervention included a play-for-communication component where children were provided with ethnically-appropriate dolls. Children were encouraged to take their doll to the clinic and participate in 'pretend play' of medical procedures such as checking temperatures and giving injections. Including the doll in the clinic activities encouraged the child to learn about medical procedures in a fun and non-threatening way.

Clinic Visit Reminder Card: This A5 illustration card was a reminder tool for mothers, to help them organise, plan and execute the health care visit. The card also served as an advocacy tool in the clinic where the mother could use it as a reminder for busy health staff of the commitments to provide a child-friendly clinic visit.

**Materials provided for the clinic facilities**

Health promotion posters: An A3 poster titled "Let's Make Clinics Child-friendly!" was designed. The poster provided key health promotion messages and reminders about child-friendliness, including: children should be welcomed at clinics even when they are not ill, health care environments are spaces for information and advice, a health care support network is important for children whose parents have chronic illnesses, play is important for children in reducing anxieties and allowing for health promotion learning.

A Medical Play Kit: A commercially sourced medical play kit and an Uthando doll were provided to each HIV nurse to engage the child in health demonstrations. The play kit included a stethoscope, thermometer, syringe and otoscope.

Amagugu intervention materials: As part of the intervention mothers were provided with an HIV Body Map with stickers, to demonstrate to children how the HIV and other viruses attack the human body and how they can be managed with medication such as ARVs; health promotion playing cards- a set of 20 specifically designed playing cards with health promotion messages.

These tools were also available in the nurses' examination room during the child's visit, so that the nurses could reinforce the messages mothers had taught their children during disclosure

#### *4.3.6.2.3 Clinic staff (N=87)*

As part of Amagugu study, an intervention to support child-friendliness at the participating primary health care facilities was developed and implemented. The training was first piloted by myself at four of the nine implementation clinics, selected to include both rural and peri-urban settings. During piloting, dialogue and feedback were elicited from staff to finalise the

training programme and clinic resources for a child-friendliness component (see Box 2). The training was then implemented at the five remaining primary health clinics. I developed and gave each clinic staff member a two-page training manual that illustrated all of the steps to be followed when attending to the Amagugu mother-child pairs that came for a health promotion visit in the clinic (See Appendix B). The nine participating clinics were provided with materials to use during the health promotion visit.

The clinic staff training targeted a diversity of staff including nurses, HIV counsellors and clerks to maximise opportunities for improving the quality of interactions with children during clinic visits. All clinic staff that were available in the clinics where the Amagugu study operated during the recruitment period were invited for participation. Only two male security guards in two rural clinics refused participation as they could not leave their work stations unattended for safety and security reasons.

#### *4.3.6.2.4 The Pre- and Post- clinic Training Questionnaire (N=87)*

Before requesting mothers to take their children for a clinic visit, the clinic staff were assessed and then trained in maternal HIV-disclosure and child-friendliness (N=87). The clinic staff's knowledge and attitudes to maternal HIV-disclosure and child-friendliness were assessed through semi-structured questionnaires. The semi-structured questionnaires were used to collect socio-demographic data and also contained open ended questions on child-friendliness and maternal HIV-disclosure. The pre-clinic training questionnaires were administered to the clinic staff during training on maternal HIV-disclosure and child-friendliness training conducted for the clinic staff members in all nine facilities before Amagugu mothers and children undertook their clinic visit. The post-clinic training questionnaire was administered to the clinic staff after mothers and children had completed their clinic visit post disclosure. The questionnaire aimed to assess clinic staff knowledge and attitudes on maternal HIV-disclosure to 6-10 year olds and child-friendliness in the clinics. Both the pre and post clinic training questionnaires had the same set of questions. An example of questions in the pre-clinic training questionnaire is provided in Box 3**.** The full questionnaires are attached as Appendix C.

**Box 3: Sample of questions in the Pre-clinic Training Questionnaire**

**Child-friendliness**

Below is the Amagugu Project definition of child-friendliness. Please read before you answer questions that follow.

***Child-friendliness of clinics***

*Clinics can be made a fun place for children as opposed to scary. Friendly and welcoming staff is what children need in order to feel free to approach clinics whether they are sick or are just seeking health information. In the clinics healthy living information can be presented in a fun way that children can easily understand.*

When you read the above definition, would you say this clinic is able to achieve this?

If Yes, why and if No, why not?

***Disclosure of mother's HIV infection to children***

*Many HIV-infected mothers are giving birth to HIV-uninfected children due to access to ARVs. One of many challenges faced by HIV-infected mothers from this community is whether to disclose their HIV infection to their children?*

Do you think it is important for HIV-infected mothers to disclose their HIV status to their children?

If yes, why, if no, why not?

#### *4.3.6.2.5 The Focus Groups*

One focus group discussion was conducted in each of the nine clinics where the Amagugu study operated. From nine focus groups, a total of 87 clinic staff members participated. The average number of participants in each clinic was 12 members. Focus groups were chosen for their unique capacity to capture opinions, experiences and perspectives of a group of people in order to gain knowledge about a particular topic while observing the interactions of participants (236). In order to make the environment as natural as possible and to make participants comfortable the focus groups were conducted in rooms in the clinics that were identified by either the sister-in-charge of the clinic or other personnel who were the contact persons for the clinics. Focus groups were deemed appropriate for the clinic staff because maternal HIV-disclosure and child-friendly clinics were perceived to be less sensitive topics for this group of participants, and they suited the time constraints and patient load in all participating clinics.

Focus groups were conducted to triangulate data from the pre and post-clinic training questionnaires administered to the clinic staff, and the Clinic Visit Follow-Up Forms which captured the maternal and child experiences of the health intervention. I conducted the focus

groups very early in the day, immediately after morning prayers, or late in the afternoon when all the patients had been attended to, because it was challenging to get all staff together once they had started reviewing patients. These times were suggested by the clinic management in their respective clinics after we had held preliminary meetings with them to discuss the study. For example, some clinics are near schools and are frequented by learners after school; whilst some are busiest in the mornings as some patients come from very far and struggle to get transport if they do not arrive early at the clinics. All focus groups were conducted in isiZulu and with the participants' permission they were audio recorded.

The focus group discussions focused on maternal HIV-disclosure, child-friendliness and the clinic staff's experiences in interacting with the Amagugu children that came for a clinic visit. The plan was to include as many clinic staff as possible during the administration of questionnaires and in the focus groups. A focus group guide was developed and used to facilitate the discussions (see Appendix D). Focus groups lasted approximately 60 minutes. I transcribed the audio-recordings verbatim, and then I translated the transcripts from isiZulu to English. The transcripts were then imported to ATLAS.ti for data management and coding. All data sources and data collection tools for the current study are shown in Table 7 on page 41.

*Group dynamics*

I anticipated that power dynamics in terms of mixing senior and junior clinic staff members might be a challenge, with a possibility of junior staff members feeling intimidated to express their views in front of their supervisors and managers. I took extra care to emphasize upfront that participation was completely voluntary, and I requested all members to speak freely because all views were equally important. The content of the focus group discussions helped in facilitating the discussions because the questions in the guide were not biased towards any particular grouping but addressed everyone's interaction with children that came to the clinic. Conducting the focus groups in isiZulu assisted in making all participants comfortable to express themselves openly in their own language.

#### *4.3.6.3 Sub-sample of women*

***The 20 women from the Amagugu study***

It had been two months since the completion of the Amagugu study; I no longer had the 'security' provided by fellow colleagues when they were still conducting research in the same

areas. For safety and security reasons I selected only five of the nine catchment areas that were within the Africa Centre's Demographic Surveillance Area because the visibility of other researchers in the areas provided 'security' for myself and the participants. Purposive sampling which involves choosing participants from whom the researcher can learn about the experience was used (237). Polinghorne refers to such a sample as 'fertile exemplars' of the experience (237). Before the in-depth interview was conducted, I explained the study verbally, provided written information in isiZulu and obtained written consent from the participants. I had anticipated that up to 20 women would be required before reaching saturation. As this is a PhD with publications, after completion of 15 interviews, I shared the transcripts with the two co-authors of the manuscripts (Tamsen Rochat and Ruth Bland), after which we had an analysis meeting. A preliminary round of data analysis with the co-authors indicated that saturation had been reached as no new themes were emerging from the data (238). Given resources available I conducted five more interviews, resulting in 20 interviews, to ensure a balance of perspectives from different geographical areas.

The details of how the researcher attributes such as being a female and a Zulu, from the study area could have impacted on the current study, are noted in the Qualitative data Analysis and the Discussion sections.

#### *4.3.6.1.1. The in-depth and semi-structured interviews (N=20)*

In-depth interviews were chosen for their ability to explore issues where little is known and where it is important to obtain an in-depth understanding of an issue (239, 240). Interviews cater for a more personal, private and comfortable environment that is suitable for each individual participant's needs, thus allowing greater autonomy than is easily achieved through other qualitative methods such as focus groups (239).

Scientific literature, including the literature reviewed as part of the current study, indicate that HIV-related stigma often prevents HIV-infected women from disclosing their status to their children and significant others (88, 96, 108, 118, 123, 129, 130, 161, 162, 164) resulting in them not accessing HIV care and not adhering to ART (101, 130, 148, 187). The sample was selected to obtain an in-depth understanding of the experiences of women living with HIV in the ART-era and their experiences of participating in the Amagugu intervention. Socio-demographic and disclosure data from the baseline survey of the Amagugu intervention were analysed for this sub-sample.

As HIV-related stigma may be associated with HIV-disclosure research, in-depth interviews offered a suitable tool for handling very sensitive issues including sexual relationships which are part of HIV research with women (239). In-depth interviews are particularly useful for engaging previously marginalized groups including HIV-infected mothers who are often not granted an opportunity to narrate their own stories (239).

Rich information regarding the maternal experience of living with HIV in the ART-era could be missed if data are only captured through semi-structured questionnaires; therefore, a two-part qualitative interview guide was developed for in-depth, semi-structured interviews to be conducted with this sub-sample from the Amagugu study.

The first part of the interview guide was an in-depth exploration of the women's experiences of HIV since diagnosis in pregnancy with the study child. The second part of the guide addressed specific questions regarding their participation in the Amagugu intervention and their experiences of the disclosure materials. The semi-structured nature of the guide provided sufficient structure to the interview, while the open-ended nature of the questions enabled participants to express themselves more candidly (240). I conducted the interviews two months after the data collection for the Amagugu study had concluded. Each interview lasted approximately 60 minutes. They were all conducted in women's homes and in the women's own language, isiZulu. All twenty women were interviewed once. All participants granted permission for the interviews to be audio recorded and the recordings were uploaded as MP3 files onto a password protected computer as the Africa Centre data protection protocol dictated.

I am a bilingual, with isiZulu as my first language, and was also a member of the Africa Centre Translation Panel. I transcribed the audio recordings verbatim and translated the transcripts from isiZulu to English. Where I was not sure of the most accurate translation I discussed the transcripts with another bilingual isiZulu first language speaker, a PhD candidate who was also a member of the Africa Centre Translation Panel. During the transcription process I also documented other expressions such as laughter, pauses, discomfort or hesitation in responding to some questions and tone of voice to assist in the interpretation of data and contextualisation of the responses. In addition, I kept a journal and took extensive field notes of non-verbal cues including gestures and personal reactions, and incorporated reflections on the interview content and information that might inform interpretation of results to avoid researcher bias which is the extent to which I as a researcher

might influence the research process (241). The in-depth interviews transcripts were imported to ATLAS.ti version 7 Qualitative Analysis Software (www.atlasti.com) for data management and coding (242, 243). Once the qualitative data were imported to ATLAS.ti it was easier to organise and apply codes as necessary. This part of the analysis process was more deductive than inductive in nature. I coded the transcripts and compared codes across interviews to determine dominant thematic areas. Codes were reviewed for redundancy and similar codes were grouped under a single higher order category called 'family' in ATLAS.ti. Higher order categories which resulted from collapsing codes with similar ideas together reflected the important thematic areas linked to interview guide categories. An interview guide is shown in Box 4.

**Box 4: Interview Guide**

**Interview guide**

**Part 1:**

**Reasons for enrolling in a maternal HIV-disclosure intervention**

- What made you decide to join Amagugu study?

**Living with HIV**

- Please tell me about how it has been living with HIV since your diagnosis. Probe on:
  - **i.** Who has been disclosed to?
  - **ii.** Access to HIV treatment and care

**Part 2**

**Partial or full disclosure**

- Please describe how you disclosed your status to your child? Probe on whether the words HIV were used
- Reasons for full or partial disclosure

**Amagugu disclosure materials**

- Did you use the materials that you were provided with to disclose?
- Please share your thoughts on the disclosure materials that you were provided with to help you during disclosure process
- How did the disclosure materials inform your decision to either fully or partially disclose?
- How did your child react after you disclosed your HIV status?

**Advice to other mothers**

- What do you think are the important lessons that you learned during the disclosure intervention?
- If you were to give advice to another HIV-infected mother who has not disclosed to her child, about disclosure, what would your advice be

## 4.4 Data management plan

The Africa Centre has a well-established Data Centre with document management and data capture sections that have been in operation since 2000. For the 281 Amagugu study participants and the 87 clinic staff, confidentiality was maintained in line with Africa Centre policies. All Amagugu participants were allocated study numbers and were only identified by names in the tracking forms for practical reasons. The tracking of participants was conducted by the Amagugu study counsellors and myself. In line with Africa Centre policies, all the Amagugu staff including counsellors, data capturers and the administrator had signed the Confidentiality Oath. All Amagugu study tracking forms were returned and locked in filing cabinets in the Data Centre for safe keeping, including forms for those who could not be

located. Amagugu data collection forms were transported daily by study vehicles to the Africa Centre where they were stored in locked cabinets in the Data Centre. Data were entered into a specifically designed Amagugu Access database by designated data capturers, using unique study IDs to identify participating individuals.

All qualitative data audio recordings from interviews with women and focus groups with clinic staff were stored on a password protected computer which was kept in the Amagugu study office. The consent forms were kept in a locked cabinet in the in the Data Centre.

### *4.4.1 Quality control and quality assurance*

Once the data were collected, all the Amagugu study forms were submitted to the project administrator who checked them for completeness, consistency and accuracy. If there were any discrepancies the administrator returned the forms to the relevant counsellors for correction before submitting them into the data capturers who also checked them before entering them onto the Amagugu Access database.

I transcribed the audio recordings of the interviews myself after listening to them several times. I checked the transcripts and compared them with my field notes for the correct contextualisation of qualitative data for this study. The translations of the consent forms, and five interview and three focus group transcripts were checked by a bilingual, isiZulu first language speaker who was part of the Africa Centre Translation Panel and a fellow PhD candidate.

### *4.4.2 Debriefing sessions*

While conducting research in the participants' homes, the counsellors and I observed that over and above HIV, participants and their families were also confronted by other socio-economic challenges, as the study area has very high unemployment rates and levels of poverty. To relieve counsellors of the stresses of working in an HIV and poverty stricken community, I conducted one-hour weekly debriefing sessions with each counsellor, discussing each family and deciding on relevant action points to resolve specific issues. As I was also involved in the data collection, I also had monthly debriefing sessions with the Amagugu study manager, a research psychologist, to manage the emotional content of some data from the field and deliberate on the action points.

### *4.4.3 Reimbursement of participants*

There was no reimbursement for participating in the Amagugu study. However, due to the long duration of some sessions including the baseline assessment, family visit and the maternal disclosure training visit, participants were offered refreshments for these sessions. The sub-sample that participated in the interviews was also offered refreshments because the interviews took approximately one hour.

## 4.5 Data analysis

### *4.5.1 Quantitative data analysis*

All quantitative data were entered into an Access database by the study data capturers and then imported into STATA 11 for data management and analysis. Descriptive statistics were used to summarise and tabulate demographic characteristics including the mean child and maternal age, IQR, employment, income, education, HIV treatment status of the participants and child gender. Factors potentially associated with full disclosure of HIV were examined using univariate logistic regressions findings, and a multivariate model was investigated with maternal sociodemographic factors (mother education), and maternal health (mother CD4 cell counts and mother hospitalization).

### *4.5.2 Qualitative data analysis*

From the formulation of the research questions to the interpretation of findings, thematic content analysis was employed for this study (244-246). This method was adapted from the grounded theory approach developed by Glaser and Strauss (247). The grounded theory is led by an inductive approach which claims that patterns, themes and categories of analysis emerge from the data (247). However, this study used both inductive and deductive approaches. The analysis process was guided by a conceptual framework that was adapted from the Amagugu Intervention Conceptual Framework (74), research questions, focus group and interview guides. Common themes and categories were extracted from the interview and focus group transcripts. During the analysis process I followed the 5 steps which are the basic elements of qualitative data analysis (245, 247-249). It is important to note that qualitative data analysis is a fluid and iterative process of going back and forth through these steps.

*Steps 1 and 2- Getting to know the data and the focus of the analysis*

I made notes after each interview and focus group, documented anything that could inform the interpretation of results during the initial phases of analysis. I listened to the audio recordings, read and re-read the transcripts several times to familiarize myself with the data (245, 248). While listening to the audio recording and reading the transcripts, I was mindful of my research questions and attentive of the participants' responses that addressed the research questions directly. I immersed myself in the data while identifying emergent themes.

*Step 3- Categorising data or developing a coding scheme*

I re-read the transcripts and created as many codes as possible. I excluded data that were unrelated to my study topic. I reviewed my code list, and removed redundant codes until I produced a final code list.

*Step 4- Coding data; identifying patterns within and between categories*

I imported nine focus group transcripts and 20 interview transcripts to ATLAS ti. for ease of data management and coding. I conducted separate analyses for the focus groups and interviews. I manually coded data from the 20 semi-structured interview transcripts and conducted content analysis to the participants' responses to the specific questions from the interview guide. Once I completed coding, I reduced the codes by grouping together similar codes under higher-order categories. I collapsed codes with the same underlying idea under a single higher order category, called 'family' in ATLAS ti. The families generated from collapsing codes with similar ideas together formed the themes that emerged from the data.

*Step 5- Interpretation of data*

As part of the validation process, and because this is a PhD with publications, I had analysis meetings with my two co-authors of the manuscripts who independently read all the transcripts and generated their own code lists. We explored aspects of researcher bias as both co-authors are first language English speakers and do not share some aspects of the Zulu culture such as the participant's language as I do. We deliberated on how my language and culture could bias my analysis process. We then discussed the three lists and reviewed codes to reach consensus and adjust the final list accordingly. The transcripts were read in accordance with the final code list to determine the degree to which the codes cover all aspects of the interviews and focus groups.

After importing all the transcripts to Atlas ti., I coded each transcript according to the codes that were adopted by the three contributing authors on the final list. I then exported the coded

sections of the transcripts from Atas ti. to a word document with all the headings according to main themes and began the write up process until I had accounted for all the codes and coded material.

*Triangulation*

Triangulation refers to comparing results from different data collection methods or data sources (250). The results from the clinic staff data collected through the focus groups and the semi-structured questionnaires, and the interviews from the sub-sample of 20 women and semi-structured questionnaires from the 281 women were compared in terms of:

*i.* the experiences of the health promotion visit
*ii.* views on maternal HIV-disclosure to uninfected primary school-aged children
*iii.* child-friendliness of the health facilities

Additional socio-demographic data collected at Amagugu baseline on all 281 women, including the sub-sample of 20 women, were available, extracted (with participant consent) and analysed.

#### *4.5.2.1 Reflexivity*

A researcher may influence all the processes of the research from formulation of a research question, data collection, and data analysis to the interpretation of the results (241). Reflexivity refers to acknowledging that as a researcher you may influence all these processes (241). To minimise biases that may occur it is important for the researcher to be sensitive to their own background, race, culture, beliefs, personality and values as these may all impact their research positively or negatively (236). The influences that I as a researcher might have imposed on the research process could serve as either strengths or limitations as detailed in the Discussion section.

### 4.6 Ethical considerations

Ethical approval for this study was obtained from the University of KwaZulu-Natal Biomedical Research Ethics Committee (BREC Ref: BF 144/010) and the University of Witwatersrand Human Research Ethics Committee (Ref: R14/49). (See Appendix E). Further, the study was presented to the Africa Centre Community Advisory Board and the Hlabisa District Hospital Management which both granted approval. (See Appendix F). The consent forms for the three groups of participants are attached as Appendix G.

### *4.6.1 Minimisation of risks for study participants*

HIV stigma is a recognized and serious problem in the study area. Extra care was taken to minimize the risks associated with discrimination of and within, the families involved in the project. Since the Amagugu study was going to approach the same participants who were previously enrolled in the VTS, we followed the same community entry strategies that we had used in the VTS. The VTS had been well received in the community. Before we started recruitment in the participants' homes for the Amagugu study, I requested time slots in the community meetings through *izinduna* (local tribal authority representatives) and councillors. In the meetings I explained that we were going to be visiting some families who had been visited during the VTS and would be assisting mothers with some aspects of parenting their children. This served as protection for the participants as both HIV-uninfected and infected mothers were visited in the VTS and the community would not be able to identify them as HIV-infected when the Amagugu home-visits were conducted. Mothers were able to keep in contact with their counsellors via mobile phones, provided by the project, if they needed help or support between sessions. Psychological support was offered, where needed, by Dr Rochat, one of Amagugu investigators, a clinical psychologist with expertise in family counselling.

With regards to any adverse events that could emerge with mothers during qualitative interviews, I have several years' experience in counselling. Furthermore, before the start of the Amagugu project all staff members received training around a risk response protocol that included how to respond to psychological and social issues such as depression and suicidal ideation. At the time of the study being conducted there was a well-established emergency referral response team within the Africa Centre. The response team included a specialist paediatrician (principal investigator of the Amagugu study), a clinical psychologist (co-investigator of the Amagugu study), and social workers who were available 24 hours a day and were able to refer participants within the existing health facilities. This response team was trained and able to respond to all crisis situations including medical emergencies, domestic violence, sexual assault, abuse and psychological crisis. Given the close relationship between the Africa Centre and Hlabisa Hospital, the clinical psychologist had rights of admission to the hospital in cases of emergency, for example if a mother, child or family member were observed to be actively suicidal. The specialist paediatrician, Dr Bland, who was also the Amagugu study principal investigator, conducted weekly teaching ward rounds

in the children's department at Hlabisa Hospital and also had rights of admission for emergency paediatric cases.

We kept all participants' information confidential and allocated study numbers instead of using actual names of the participants in the forms and transcripts. All participants were given study information sheets which were written in isiZulu and the study was explained to them in isiZulu. I translated the study information sheet and the informed consent forms. The back translation of the study information sheet and consent forms was done and verified by a member of the Africa Centre Translation Panel. All participants signed an isiZulu informed consent form before they were enrolled into the study.

### 4.7 Conclusion

In this Methodology chapter I firstly discussed the Vertical Transmission Study, the study in which the Amagugu participants first participated. Then I briefly discussed the Amagugu study in which this current PhD is nested and how the three sets of participants - the 281 women from Amagugu, the sub-sample of 20 women, and the 87 clinic staff members were recruited, and how both quantitative and qualitative methods were employed to answer the research questions. Both quantitative and qualitative analyses approaches were described. The next chapter will discuss the findings of the current study.

# 5. Results

In this section I present the results from the analysis of both the quantitative and qualitative data collected in the current study. This includes results from the questionnaires, focus groups and qualitative interviews.

The characteristics of women and children (N=281) that undertook the health promotion clinic visit are shown in Table 9 below. Women's ages ranged from 23-54 years and their children's ages ranged from ages 6-10 years. More than half of the women (53%) had completed secondary school, but only about one third were employed. There was almost an equal number of girl (49.8%) and boy (50.2%) children enrolled with their mothers in the study.

**Table 9: Maternal and child characteristics (N=281 mothers and children)**

| **Maternal Characteristics** | **N=281** | |
|---|---|---|
| ***Age (years)*** | | |
| Median | 35 | |
| Range | 23-54 | |
| | **N** | **%** |
| ***Education*** | | |
| No education | 17 | 6.0 |
| Completed some or all primary | 108 | 38.4 |
| Completed some or all secondary | 148 | 52.7 |
| Post school education | 5 | 1.8 |
| Missing | 3 | 1.1 |
| ***Employment*** | | |
| Employed | 90 | 32.0 |
| Unemployed | 188 | 66.9 |
| Missing | 3 | 1.1 |
| ***Regular Income*** | | |
| Receives regular income | 73 | 26.0 |
| Does not receive regular income | 208 | 74.0 |
| ***Hospitalisation (<12 months)*** | | |
| Yes | 30 | 10.6 |
| No | 250 | 89.0 |
| Missing | 1 | 0.4 |
| ***CD4 Count (most recent)*** | | |
| ≥501 | 77 | 27.4 |
| 351-500 | 53 | 18.9 |
| ≤350 | 71 | 25.3 |
| Missing | 80 | 28.5 |
| ***HIV treatment status*** | | |
| On ART | 118 | 42.0 |
| Not on ART | 155 | 55.2 |
| Missing | 8 | 2.8 |
| **Child Characteristics** | **N=281** | |
| ***Age (years)*** | | |
| Median | 7 | |
| Range | 6-10 | |
| | **N** | **%** |
| ***Gender*** | | |
| Female | 140 | 49.8 |
| Male | 141 | 50.2 |
| ***Hospitalization (since birth)*** | | |
| Yes | 43 | 15.3 |
| No | 221 | 78.6 |
| Missing | 17 | 6.0 |

The clinic staff comprised of 41 (47%) nurses, 23 (26.5%) HIV counsellors and 23 (26.5%) clinic clerks. Their median age was 39 years (IQR 31-49); only six were male. Sixty two

(71%) worked in rural clinics, while 25 (29%) worked in peri-urban clinics. During the clinic visit mothers rated 65% of clerks and 70% of nurses as "very friendly".

Table 10 shows the socio-demographic characteristics of the sub-sample of 20 mothers and their children. The median age of the women was 32 years (IQR 29-37) and the children's median age was seven years (IQR 6.5-7.5). There were substantially more girl children in this sample (girls 13: boys 7), and the mothers had predominantly undertaken full disclosure to the child as part of the intervention (full 16: partial 4). Almost all women (18/20) reported being in stable partnerships, half were living with their partners (9/18), and disclosure to partners was high (13/18). Most women were unemployed (14/20) and had attended at least some secondary school. The majority of mothers were on ART. When comparing these characteristics to those of the larger sample of Amagugu mothers, there were no noticeable differences, apart from the over-representation of girl children, and the finding that more of the mothers had undertaken full disclosure (80% vs 61%).

**Table 10: Maternal and child characteristics of the sub-sample (N=20)**

| Study ID | Maternal Age (Years) | Child Age (Years) | Child Sex | Marital Status | Employment Status | Length of time on ART in Years | Last CD4 Cell Count Results cells/ml | Type of Disclosure To Child | Disclosed to Current Partner | Lives with Current Partner |
|---|---|---|---|---|---|---|---|---|---|---|
| 1 | 26 | 7 | F | No current partner | Unemployed | 4 | 105 | Partial | No | No |
| 2 | 32 | 6 | M | Current partner | Unemployed | 1 | 568 | Full | Yes | No |
| 3 | 32 | 7 | F | Current partner | Employed | Not on ART* | 379 | Full | No | Yes |
| 4 | 44 | 8 | M | Current partner | Employed | 7 | 800 | Full | Yes | Yes |
| 5 | 46 | 7 | M | Current partner | Unemployed | 6 | 700 | Full | Yes | Yes |
| 6 | 36 | 6 | F | Current partner | Employed | 1 | 297 | Full | Yes | Yes |
| 7 | 37 | 7 | M | Current partner | Unemployed | 5 | 487 | Full | Yes | Yes |
| 8 | 49 | 8 | F | Current partner | Unemployed | 6 | 219 | Full | Yes | No |
| 9 | 28 | 6 | F | Current partner | Unemployed | 1 | 212 | Partial | Yes | No |
| 10 | 39 | 8 | F | Current partner | Employed | 2 | 467 | Full | Yes | Yes |
| 11 | 28 | 7 | F | Current partner | Unemployed | Not on ART | 629 | Full | Yes | No |
| 12 | 32 | 7 | M | Current partner | Unemployed | 2 | 518 | Full | Yes | Yes |
| 13 | 37 | 7 | M | Current partner | Unemployed | 1 | 400 | Partial | No | No |
| 14 | 38 | 6 | F | Current partner | Employed | Less than 1 year | 350 | Full | Yes | No |
| 15 | 31 | 8 | F | Current partner | Unemployed | Not on ART | 709 | Full | No | No |
| 16 | 36 | 7 | F | Current partner | Employed | Not on ART* | 459 | Full | Yes | Yes |
| 17 | 28 | 6 | F | Current partner | Unemployed | Less than 1 year | 300 | Full | No | No |
| 18 | 29 | 8 | M | Current partner | Employed | Not on ART* | 370 | Full | No | No |
| 19 | 32 | 7 | F | No current partner | Unemployed | Not on ART | 540 | Partial | No | No |
| 20 | 29 | 7 | F | Current partner | Unemployed | 3 | 394 | Full | Yes | Yes |

*At the time of the study the cut-off for ART initiation was CD4+ T-cell count $\leq 350$ cells/$mm^3$

## 5.1 Themes

The three main themes that emerged from the qualitative data analysis in current study are:

1 HIV-related stigma
2 HIV-disclosure and family strengthening
3 HIV and access and adherence to HIV treatment

### *5.1.1 HIV-related stigma*

#### *5.1.1.1. Household and community level stigma*

A comprehensive review of global literature undertaken for this study indicated that the fear of HIV-related stigma is rife and instrumental in preventing HIV-infected individuals from disclosing to others (88). HIV-related stigma was found to be the most common reason for non-disclosure of HIV status irrespective of whether disclosure target was a partner, a family member or a child (53, 96, 108).

In the qualitative study, the majority of women reported living positively with HIV and receiving necessary support from those that they had disclosed to prior to the Amagugu intervention (184).The minority of women reported not having disclosed to anyone due to the fear of HIV-related stigma. This finding is illustrated in the quotation below:

*"Mncfff! I have not disclosed to anyone because I know my family members. If you say something as problematic as this [HIV infection], the person would just dwell on that picture and then not regard you as their family. I don't know under what circumstances will I ever tell them? For now, I'm sorry I don't feel like telling them about my HIV infection."*
(32 year-old mother of a 7 year-old girl)

Another woman justified her reason for not disclosing to her partner as follows:

*"I have never told the man of the house. How can I even start? The problem is that he said he was going to go somewhere for work and he went to test at the clinic. He then showed me his negative results. Then I thought to myself: "How can I then show him my positive results?" I then just kept my mouth shut."*
(37 year-old mother of a 7 year-old boy)

Two other women reported experiencing HIV-related stigma prior to the intervention.

*"I disclosed my HIV status to my sister-in-law; she did not know her own status then. The family mocked me and did not even want to use the same utensils as me. I lost weight, I wore size 32 but now I have regained my weight and I wear size 38. After my sister-in-law discovered her own positive status they stopped discriminating against me."*
(26 year-old mother of a 7 year-old girl)

*"I told my boyfriend because people were talking about me and telling him that he was with someone has AIDS and on ARVs. I told him that's the reason I'm using condoms with him. I wondered where on earth was he going to get someone without HIV if he left me?"*
(32 year-old mother of a 6 year-old boy)

The study area has high social exposure to HIV with the majority of women in the qualitative study reporting being aware of another HIV-infected adult in their household. Some children were inadvertently aware of someone who was HIV-infected or was on ART either in their homes or in the community.

*"I did not tell my children about my status at the same time. I told the eldest one first, and then I told the middle one that was born in 2002. He seems to have an understanding because he even likes reading AIDS pamphlets from the clinic. He said to me: "Mom don't stop taking pills." They had a play at school about a girl who stopped taking pills and died. These days he is also sad because he just lost his paternal aunt through HIV during the Easter holidays. I told him that his aunt died because she did not want to accept her positive status."*
(32 year-old mother of a 7 year-old boy)

ARVs were openly shared in some communities and even normalised like 'teabags' as expressed by the woman in the quotation below:

*"Most of my neighbours are now open about their HIV status; we even lend one another pills [ARVs]. They [my neighbours] come to my house to borrow pills and say: "We have come to borrow our teabags."*
(46 year-old mother of a 7 year-old boy)

High HIV prevalence in the study area at the time of diagnosis resulted in confusion and disbelief regarding sero-positive results in the women themselves and their family members:

*"The day I tested for HIV, everyone who came out of that [HIV] testing room was HIV-infected. I thought to myself, it means we are all sick. Even those who were testing us must be sick. I also have a cousin who was fit and not looking sick in anyway, but one day she had a severe headache and went to the clinic and then discovered that she was HIV-infected. It was then that she started losing weight because this was eating her inside but she started treatment immediately because of her low CD4 cell count results. She still was not even thin. She looks fine; you can never tell that she is infected. I then realised that this HIV thing is real."*
(29 year-old mother of an 8 year-old boy)

*NM: "Are you the only one who is HIV-infected in your family?"*

*"My brother is also HIV-infected. He disclosed to us [the family]."*
(36 year-old mother of a 7 year-old girl)

The health care staff also shared the same sentiments as the mothers regarding the high social exposure to HIV in the study area. They emphasized the importance of maternal HIV disclosure to children so that children can openly assist their mothers with the collection of ARVs.

*"I can see maternal HIV-disclosure is important. Children should know about our state of health as parents if we are infected. As we are working with pills, sometimes it is difficult for us [health workers]; you will find that a child comes here [to the clinic] after school and has been sent by their mother to fetch mother's pills. And you would ask the child: "What pills have you come for?" She would say: "They are pills for TB." When you check the mother's card you realise that it is not TB pills they are fetching. Personally, it is difficult for me to take out that person's file because the child has said it is TB pills to the child. I usually say: "Please tell mom to come to the clinic so that she can be weighed." It is because I know these are not TB pills. What if the child knows of someone who is taking similar pills maybe they know that their friend's mother is taking similar pills for HIV? They might get disturbed that way. That is why I think it is important for children to know because if you have not told children the truth, they can have resentment later."*

(39 year-old female nurse)

#### *5.1.1.2 Clinic level HIV-related stigma*

HIV-related stigma was also reported at a clinic level; one of the two women that had not disclosed to anyone prior to the Amagugu intervention, had also neglected to check her CD4 cell count due to fear of being stigmatised when seen attending an HIV clinic. She perceived the physical structure of the HIV clinic to be a source of HIV-related stigma."

*"I'm laughing at those caravans up there. It's just that it's frightening to walk up there [to the HIV clinic].*
(32 year-old mother of a 7 year-old girl)

Some HIV-infected women reported experiencing discrimination by the clinic staff sometimes when attending to their sexual and reproductive health matters. For example, a woman who went to the clinic to report that her condom burst, but reported not receiving necessary support from the clinic staff:

*"I had this child [last born] because the condom burst. I went to the clinic but they could not help me, then I went to the hospital."*

*NM: "Why are you saying they did not help you?"*

*"I went there and they said: "We know people like you who say condoms burst meanwhile they did not use them." The following day they did not help me either. I then went to the hospital, and I discovered that I was pregnant. They asked me what I wanted to do and I told them nothing since the baby was already there. I attended all my antenatal classes there [at the hospital] and the child was born HIV-negative."*
(32 year-old mother of a 7 year-old boy)

### *5.1.2 HIV-disclosure and family strengthening*

#### *5.1.2.1 HIV-disclosure to partners*

The qualitative study reported very high HIV-disclosure rates to other adults; the majority of women had disclosed their status to their partners, friends and other relatives prior to the Amagugu intervention. Of those who had disclosed to their partners; about half had disclosed

to their partner first, before disclosing to other adults. The partners had mixed reactions following disclosure but were overall supportive, even if they themselves were not HIV-infected:

*NM: "Does your boyfriend know about your [HIV] status?"*

*"That was the first thing I told him. He accepted it and said that HIV is a very common thing now, there is no need to be scared. He said what matters is how we look after ourselves, our lifestyle and the way we do things. He said he also checks himself every three months and he was still fine. He said that my [HIV] status is not a problem."*
(37 year-old mother of a 7 year-old boy)

*"When I first tested I disclosed my status to my partner and he said to me: "I wonder how you got it." I said: "Maybe I have had too many children. There are many ways, maybe I was I was helping someone. He did not fight with me. He said he was also going to go to the clinic to check and he did. He goes every six months. Maybe he has strong soldiers [immune system] because they cannot detect it."*

*NM: "What is his [HIV] status?"*

*"He is [HIV] negative."*

*NM: "Did you see his results?"*

*"I always go with him. His clinic card is almost full now."*
(32 year-old mother of a 7 year-old boy)

Some of the women's partners questioned the source of HIV infection:

*"I went to check and found out that I was HIV-infected and I told him. He then asked me where I had gotten such news from."*
(44 year-old mother of an 8 year-old boy)

*"I disclosed my [HIV] status to him. He did not want to accept and then we had our second child. After that I tried to break up with him. I think he already had it [HIV] by then, he was able to listen to me and we followed the procedures we were told at the clinic. He ended up*

*going for an HIV test. He asked where I got the virus from and I said: "My brother I don't know."*
(38 year-old mother of a 6 year-old girl)

Some of the women's partners kept their sero-positive status a secret and only revealed it after the woman's own disclosure:

*"He [my fiancé] had no problem at all when I disclosed my status to him. He said: "We have to accept it as it is. All I can say to you is that I am sorry because this is all my fault. I fooled around a lot." Oh yes he really fooled around. He said: "I know you were still young and innocent, I'm the one who brought this disease. I knew long time ago that things were like this, it's just that I did not know how to start telling you, what would I say? Now that it has come out please forgive me." I told him there is nothing I can be angry or shout about."*
(36 year-old mother of a 6 year-old girl)

*"Yes I discovered that I was infected when I was pregnant with Andile*. My husband did not have a problem when I told him. I discovered that he was also infected; you know the males have that thing... they are not forthcoming with information. When I really followed-up on the story I found that he already knew his [HIV] status. [Laughter]. It's just that they [men] first have denial if they have not seen any changes in their bodies."*
(49 year-old mother of an 8 year-old girl)

*NM: "How did your husband react when you disclosed your HIV status to him?"*

*"He was shocked but he said I must not say anything to anyone. He was the one to declare it to the family. He also tested positive and he is also on ARVs. We support each other because we even fetch each other's ARVs from the clinic."*
(39 year-old mother of an 8 year-old girl)

*NM: "Does your boyfriend know your [HIV] status?"*

*"I disclosed my status to him but he was hiding his status from me. In fact he is the one who made me reach the stage of taking pills. He hid from me that he was taking ARVs. Sometimes we would use condoms and sometimes we would not. I ended up getting sick."*

*NM: "How did you find out that he was taking pills?"*

*"People were telling me about his [HIV] status and I did not believe them. He did not tell me. After a long time I started taking my ARVs. I asked him about them because he would hide that he was taking ARVs and he would stop taking them when he visited me until he stopped taking them completely. I told him that he should take them because I was also taking them. When I got sick I told him that maybe I was getting sick because we were not having safe sex. I stayed healthy for a long time after discovering my HIV status and my CD 4 cell count was fine when I went to check. After I got involved with him I got sick. Now he is openly taking ARVs."*
(28 year-old mother of a 6 year-old girl)

#### *5.1.2.2 HIV-disclosure and improved family cohesion*

The maternal HIV-disclosure literature revealed positive outcomes for both mothers and their children including improved family cohesion if women disclosed (185, 187, 251). Family-centred interventions as opposed to individualised care are perceived to be advantageous for HIV-infected women and their families in high HIV prevalence areas (68, 69). In this study women raised concerns about family-centred care such as being able to attend HIV treatment and care with their partners. One woman also articulated that she found that, although she had not yet started ART, she was already gaining a lot from her partner's transference of knowledge to her after he had attended his ART classes.

*"My partner is the one who attended [ART] classes first and he is already taking treatment. I learn most of the things from him. Even when I get taught something, I tell him that he knows more than me. [Laughter]. I would say there is no problem because even the CD4 cell count I that I recently checked was high, it was 580. And since I first tested in 2003, I had never checked it before."*
(26 year-old mother of a 6 year-old girl)

All women that had disclosed to their children stated that the most beneficial aspect of disclosure was the social support they received from their children. While their original fears had been that they would be stigmatised by their children after disclosure, on the contrary, children were supportive. They were reported to assist their mothers with ART adherence by reminding them to take their HIV treatment on time:

*"Sometimes when I am upset I go to bed early, she would come and wake me up and say: "It's 8 o'clock." I would say: "I'm sleeping". She would insist: "Mama it's 8 o'clock you have to take pills."*
(36 year-old mother of a 6 year-old girl)

*NM: "How is your relationship since you have opened up about your HIV status to your children?"*

*"What makes me happy is that they are now my alarm clock. Before I disclosed my HIV status, they were not my alarm clock. They were just looking at their mother taking pills and they could not even ask what the pills were for? Now, even when I have gone to sleep and if they did not see me taking pills, they would wake me up and ask: "Did you take the pills"? Sometimes I would say, leave me alone, I'm tired of this, just wanting them to give me attention. "Mom, drink your pills, you will die if you don't."*
(46 year-old mother of a 7 year-old boy)

*"The young one that I stay with, if my alarm goes off, he fetches me from wherever I am. Sometimes I take the pills without him noticing and I hear him asking mom, did you take pills and I say yes my boy, I have."*
(37 year-old mother of a 7 year-old boy)

*"She is the first one to hear the sound of the alarm clock when it's time for me to take pills."*
(49 year-old mother of an 8 year-old girl)

The health care staff concurred that disclosing to children was instrumental in supporting HIV-infected women to access and adhere to HIV treatment.

*"Maternal HIV-disclosure is important because mothers rely on their children to remind them to take their treatment. It is important for a child to know what they are dealing with. I have noticed that even at school, children are given projects about HIV and ARVs. If the mother does not disclose, children might see the pills being drawn on the [chalk] board at school and realise that these are their mother's pills. That will not be a correct way to tell a child."*
(36 year-old female HIV counsellor)

*"Disclosure is important for them [mothers] because children help them with taking of their medication. The child does not forget easily."*
(30 year-old male HIV counsellor)

*"Maternal disclosure is good if you can explain to the child and they understand and know the reason. They can also help her to take medication on time. I sometimes hear others say "Ey, he is the one helping me now saying, mom, it's medication time, he says I don't want you to die mom because he knows if the mother takes medication she will live longer."*
(40 year-old female nurse)

*"It's important to disclose to a child because sometimes the parent might get sick and not be able to do anything but if they tell their children they will remind them to take pills on time."*
(37 year-old female counsellor)

The majority of women expressed that they would advise other women in similar circumstances to disclose their HIV status to their children to obtain social support. The social support provided by children increases family cohesion and improves ART adherence. The same sentiments about family cohesion were echoed by the health care staff:

*"Yes, disclosing [an HIV status] to a child is a good idea because it strengthens the relationship between a mother and a child. It does not come as a surprise when a child has become wise on their own. She then tells the child and maybe the child has realised this long time ago. Maybe they were even suspecting that she is taking these pills forever and not finishing them. Then, it is a surprise. However, if she started bit by bit, that would strengthen the relationship and trust."*
(58 year-old female nurse)

*"The child becomes very affectionate towards the mother if she is told the truth. Being close to the mother makes the child confident in whatever she is doing rather than being told by other people from outside. The teacher is there, but the mother is the first person and the love gives her strength and the child can see that mom loves me and trusts me."*
(58 year-old female security guard)

### *5.1.3 HIV-disclosure and access and adherence to HIV treatment*

#### *5.1.3.1 Health service-centred interventions can reduce clinic level stigma*

Though two women in a sub-sample did not access HIV treatment and care clinics, the majority of women in the study were openly accessing HIV treatment and care without any fear. Some women had even moved between clinics for convenience. The woman below candidly articulated how she boldly attended HIV clinics and did not care that she had become shapeless due to the side effects of ARVs. She expressed that the most important thing was being alive just like those who were managing their own chronic illnesses such as diabetes and high blood pressure.

*"….You see others hiding by corners [when walking to the HIV clinic], I do no such!* Ngishaya isidanasi. *[I strut my stuff]"*

*NM: "What is* isidanasi*?"*

*"It means not hiding anything. People are taking their own pills. They take pills for BP [blood pressure], why? They want to live. They take pills for arthritis so they can live. So, if I take my HIV pills, is there anything wrong with me? Must the whole world now give me a strange look? And must I now hide? I also want to live just like the people with BP and diabetes. I'm taking ARVs because I want to live. When we all die, the tomb does not say this one was killed by AIDS, this one was killed by BP, this one was shot, and this one was stabbed. We are all dead! We could go to the cemetery right now and if you could please just count for me the number of tombs there written: 'This one was killed by HIV.' [Huge laughter]. We all die, so if we want to live we should all want to live. When I go to the clinic I even strut my stuff* [Ngishaya ngize ngidwale]. *I don't care that these ARVs have made me have thin legs. Eish,* nesishwapha *[and a flat bum] [Laughter]."*
(46 year-old mother of a 7 year-old boy)

The women quoted below were able to openly access different HIV clinics and to do so at their convenience:

*"I started taking ARVs in 2007 at Clinic A*. Even now I collect them from there because I was still staying near that clinic. Then I came back. They then said it is better that I move to Clinic B* because it is closer to where I stay now."*

(37 year-old mother of a 7 year-old boy)

*"…. I am now taking ARVs. It does not matter, you cannot hide this thing. There is no one without AIDS now, I'm better because I will live and those who are hiding will die."*
(32 year-old mother of a 6 year-old boy)

#### *5.1.3.2 Child-friendliness definition*

When asked to define a child-friendly clinic, the majority of the clinic staff made reference to both what they believed a child-friendly clinic should be, and what it should not be for children. The health staff expressed that clinics should represent a safe and a welcoming place for children, and should not be: a scary place for children, a place where people are rude to children, or a place where people discriminate against children.

*"I think [child-friendliness] means that if a child is below the age that they can go to the clinic by themselves, they should not be scared of going to the clinic when they have a running stomach and they are left alone at home. They should just have that confidence that I'm used to going to the clinic and I know that they are going to help me. They can just go because they know that children are welcome at the clinic, they don't get scolded and they are not in that frightened state."*
(47 year-old female nurse)

*"I think if we make children familiar with the clinic that can also help us if we want to give them injections because children are usually scared of injections. However, if you are always smiling they will know that they can come to the clinic. Even when the mother is getting an injection, they can see that it is painful but in the end they will know that it is a passing phase and when it is about them in the future they will know."*
(57 year-old female nurse)

#### *5.1.3.3 Facilitators of child-friendliness*

In providing safe and welcoming places for children, participants noted several key activities as important facilitators of child-friendliness. Firstly, the emotional tone of the front line clinic staff, in particular, the way in which health care staff offer a warm greeting to a visiting

child, and make 'small talk' with children, were considered an important aspect of ensuring child-friendliness. For example, one nurse said:

*"We greet children, ask them who they are, and we introduce ourselves, and even ask them what they would like to study to be when they grow up? Some even say: "I would like to study to become a nurse." Maybe it is because we have talked to them nicely."*
(40 year-old female nurse)

Clinic staff emphasised the importance of communication style and approach with children. They reported that ensuring developmentally appropriate language and 'coming down to the level of a child' were critical to helping children feel welcome and respected.

*"It's [referring to an ideal child-friendly clinic] a clinic where children are made to be relaxed and feel at home. Anyone who works there can come down to the level of a child and talk the language that is spoken by the child so that they can understand what the child is saying."*
(37 year-old male nurse)

Participants highlighted the value of having child-friendly tools available that helped children to learn about health care in a developmentally appropriate manner:

*"Playing DVDs on the clinic TV may help. Maybe they can learn because I often hear children talk about things they learned from cartoons; educational stuff. I think we can also pick educational cartoons from Health [Department]."*
(70 year-old female nurse)

#### *5.1.3.4 Health intervention experience*

The clinic staff expressed that it was rewarding for them to interact with the children as a result of the Amagugu intervention. Over and above the intervention materials, the staff reported that they enjoyed the cleverness and the energy displayed by the Amagugu children in their busy and sometimes overwhelming work environment.

*"I was happy to see them [Amagugu children] because of their cleverness. Even the way they do things. You can see that if these children can continue with this thing they have started,*

*they can be able to help even a person they meet on the road. Maybe they meet a person on the road and notice their state of health, they can suggest that the person goes to a clinic. They seem knowledgeable when they carry their stuff; they look like they know everything. You enjoy being with them even if it is for a short period, if we can have enough time it would be wonderful."*
(55 year-old female nurse)

*"And also this [Amagugu] programme is good because before, children knew that if they go to the clinic they will be given an injection. They have to be dragged in. When they arrive at the gate once they see a nurse they start crying. Being friendly to children is good and makes children get used to the clinic. Even during immunisation it is easy for children to flock to the clinic and know that nurses are our friends."*
(44 year-old female general assistant)

A male nurse expressed his fascinating experience of interacting with the Amagugu study children in the following quotation:

*"The one [child] that I saw was clever and was asking questions, she was checking the stethoscope out and asking whether it was for looking inside? They come with different ideas and expectations; like the one that came and said she was here to work. She ended up making orders on behalf of her mother: "Give my mother this one, check her BP, use a thermometer etc."*
(34-year-old male nurse)

#### *5.1.3.5 Health intervention materials*

Following the health promotion clinic visit, maternal reports on intervention tools used by the clinic staff indicated that nurses referred to the child-friendly poster (233/281; 83%). Fewer nurses, but still the majority, were reported to have made use of the doll (204/281; 73%) and the medical play kit (197/281 or 70%) while just over half made use of HIV specific educational materials including the HIV Body Map (169/281; 60%).

After the health intervention some of the staff members agreed that the Amagugu study materials assisted them in being child-friendly during the activities with the children during

the health promotion clinic visit. Despite working in an overcrowded rural clinic one nurse was pleased with the intervention and stated:

*"We orientate children using Amagugu materials and we are able to present health information in a fun-filled way. They start there at the front desk by the clerk and we try to welcome them. Sometimes the time is against us but we try. We show them whatever we can show them. Sometimes they just get excited and jump if they recognise Amagugu stuff because they can see it on the [clinic] wall."*
(25 year-old female nurse)

A role played by the intervention materials in making children less frightened of the clinics was expressed by another nurse:

*".....to know what is happening in the clinic is important, sometimes painful stuff like injections need to happen but it is important for children to get the knowledge. For instance because there are these play kits, we can demonstrate that your child is sick, he must get an injection. It's important that the child knows that sometimes an injection is needed in order to get better."*
(40 year-old female nurse)

#### *5.1.3.6 Barriers to child-friendliness*

The clinic staff reflected on the importance of providing mothers with education and support to ensure that they were able to allow the child to have a good clinic experience. Frequently this included encouraging mothers not to be harsh with children and advising mothers on sensitive care while recognising that mothers were in a stressful position often exacerbated by the stressors of their own, or their child's illness. For example, one nurse stated:

*"Sometimes we have a problem because the child's mother is harsh to the child and maybe she is even scolding them. We end up telling them not to beat the child up in our presence. Sometimes we find them scolding children and we will say leave the child alone and say to the child come to aunty or if I want I say come to* gogo *[grandmother] and the child will come running to me."*
(60 year-old female nurse)

Health care workers highlighted the importance of orientating children and adolescents themselves about appropriate behaviours in clinical settings. This included reducing the anxieties and fears that children may bring to the clinic as a result of their families and communities teaching children that clinics are frightening places.

*"To us child-friendliness is easy but the child comes with an attitude that you are an enemy. He has been told that back home. You try to reach out and the child pulls away. There was a child here this morning. The counsellor tried to play with him and the problem was that the counsellor was dressed as a nurse. The child became so quiet as if something had shocked him. You could see that he was quiet because he was very frightened. You wish to compliment them even on their clothing and say you look so handsome young man, but the child is just scared that you are up to something."*
(55 year-old female nurse)

However, the point of discordance which came through strongly in all focus groups related to the gap between knowing and believing that child-friendliness was the 'right thing to do', and being willing to do it, but not having the tools, capacity or human resources support to implement it. In the pre-child-friendliness training questionnaire some of the staff articulated their frustrations with the conflict they found between their willingness to be child-friendly and their inability to do this:

*"Yes, we try our best to be child-friendly but there are no toys or fun things that the staff can use to be friendly. We do not have enough time for it because this is a busy clinic and we have many patients with different sicknesses. We need to attend them and give quality treatment or counselling."*
*(*36 year-old female HIV counsellor)

A common theme from the focus groups indicated that participants recognised that health care workers' inherent emotional capacity and willingness to be child-friendly could become degraded over time in contexts where health care was highly pressurised and where health care providers were offered little emotional support themselves. Most participants highlighted one or more of three key barriers to maintaining child-friendliness: lack of emotional support for staff members themselves; poor infrastructure and workflow; and high nursing workloads.

*"As you can see, we are always [busy] like this. On day-to-day basis child-friendliness is possible but sometimes you find that we are waking up in the early hours of the morning as we are an early bird clinic. Let's say there is a sick child and you have to come here and you have just woken up from sleep, it's not easy then. Even if you are not frowning but ah ah you are not ok."*
(38 year-old female nurse)

Participants expressed that health care work was emotionally draining, and that at times they found it difficult to put on a 'friendly face' when they themselves were feeling overwhelmed with the difficult task of managing a variety of patients who presented with serious illnesses. This was particularly difficult when the child was not sick, but had just come for a health promotion visit.

*"Maybe it is [hard] because children that come for health promotion are not sick, they have an image they are expecting. They expect that they will find a person that will be smiling and then they are met with not what they expected. Maybe they find someone who does not have time. It's not that you want to be like that but you have this workload."*
(40 year-old female nurse)

*"Sometimes it happens that the children come to the clinic and the clinic is busy in such a way that even if you want to give them the attention that they deserve as children, you end up not doing it and you cheat them. It could be due to bad timing or maybe you are running around, delivering babies, immunising and maybe it's only the two of you at the time and the child gets cheated of the attention they deserve."*
(34 year-old male nurse)

Many participants highlighted that the physical structure of the clinic environment could be intimidating, even for adults, who attend clinic in a vulnerable state of illness. Accommodating children with an appropriate infrastructure was considered a useful way to create a more child-friendly atmosphere.

*Maybe the walking areas, for instance if there are steps in the clinic there should be areas where even the child can walk. You find that sometimes there are high steps where only adults can walk."*

(30 year-old male nurse)

However, one nurse reported that even though the intervention was there, she sometimes forgot about it and continued to do things 'the old way'. However, when she finally remembered about the intervention she tried to change her attitude and to be friendly to the children because she remembered the training she had received. She said:

*"I beg to differ. I don't have the same views because we don't have time for these children. I for instance, forget about them and find myself asking them "Who are you by the way?" Because I'm seeing someone that is disturbing me while I'm busy and then I remember and I try to do damage control."*
(40 year-old female nurse)

However, busy clinical settings, and in particular limited human resources, were cited as the most important barriers to the implementation of child-friendliness. It was also difficult for the clinic staff to view child-friendliness as part of their service to those attending the clinics. Instead they viewed child-friendliness as an extra chore that they could only fulfil when they were not busy.

*"The workload is not an easy thing. Sometimes the mother comes with the child and the child does not get attention, especially if the child is not sick. You only attend to the mother because you are pushing the workload and you don't even have time to be playful with the kid. It's not easy in a busy clinic. You only attend to the illness and do what you have to do."*
(42 year-old female nurse)

#### *5.1.3.7 Rewards of child-friendliness*

Importantly, clinic staff recognised the reciprocal value of providing kind and sensitive care to children for their own sense of wellbeing and pride in their work. They reported that engaging more directly with children in this intervention helped them feel like they were good role models for children, which in turn fostered a sense of pride in health care work. In turn this made child-friendliness easier to maintain and contributed to the sustainability of child-friendliness in their clinic. This pride in health care work was most commonly expressed in participants' enjoyment of children's expressed aspirations to become health care providers themselves as a consequence of their clinic experiences.

*"They have these name tags and use the playing cards that you gave us [during the training] and a doll. We are playing with them and sometimes they end up wanting to take the clinic doll they are playing with to their home. They end up seeing themselves as part of health workers for instance if you give them a stethoscope and let them use it. They see themselves as doctors or see themselves as nurses."*
(42 year-old female nurse)

#### *5.1.3.8 Recommendations for child-friendliness in clinics*

Health care workers had ideas about how to organise clinical services around child specific services to benefit both the child and the health care providers. This would assist the capacity of clinic staff to implement child-friendliness in their facilities. Allowing children and families to attend on specific days and encouraging group sessions with children attending clinic were seen as feasible solutions to work flow challenges.

*"It's good that children have their own clinic day. On that day at least you know that if you see a motor-bike [toy] anywhere it's children's day. You also prepare yourself that today I am going to play. You prepare your own atmosphere from the minute you enter the clinic gate. It's a bit difficult when there is a mixture; here is an old man and then suddenly you have to smile to a child in front of you."*
(42 year-old female nurse)

*"Maybe it could be that Amagugu children don't come individually but in groups. We can choose this room and have a counsellor that will just attend to them and it could be fun while the mothers are consulting nurses with their many files. The counsellor can just keep them busy; the nurse will not have to do much."*
(29 year-old female HIV counsellor)

### 5.2 Conclusion

These results demonstrate how the three themes, HIV-related stigma, family strengthening and access and adherence to HIV treatment and care, impact on women's disclosure of their status. These themes are intertwined and shape women's management of their HIV infection and their relationship with their family, community and primary health care clinics.

This illustrates that in communities where HIV-stigma is minimal, it is easier for HIV-infected women to disclose to their families and thus obtain social support. This social support strengthens family relations and is instrumental in assisting women to access and adhere to their HIV treatment. The important role played by primary health care clinics in supporting HIV-affected families, including offering child-friendly services cannot be underestimated.

## 6. Overview of scientific papers

### 6.1 Paper I

**Mkwanazi NB,** Rochat TJ, Imrie J & Bland RM. Disclosure of Maternal HIV Status to Children: Considerations for Research and Practice in sub-Saharan Africa. Future Virology (2012) 7 (12) pages 1159-1182

Research question: Where have maternal HIV-disclosure studies been conducted, with whom and what lessons can be adapted to rural settings in sub-Saharan Africa?

Methods: A review of maternal HIV-disclosure literature based on 56 studies included in two literature reviews and a systematic review identified after searching for maternal HIV-disclosure studies conducted between 2000 and 2010. A further two studies were identified after searching on Pubmed and Google Scholar for studies conducted between 2010 and 2012.

Findings: Improvements in HIV treatment have resulted in increasing numbers of mothers surviving to care for their HIV-uninfected children. One of the challenges these mothers face is when and how to disclose their HIV status to their children. Many benefits of maternal HIV-disclosure have been documented for both mothers and children of primary-school age, including improved mental health for the mother and increased HIV knowledge for the child. International research on maternal HIV-disclosure is mostly descriptive from resource-rich settings; few studies report on HIV-disclosure intervention or include children under the age of 12 years. The most cited reasons for non-disclosure to children are the perception that children will not be able to maintain confidentiality, and that they too young to understand about HIV.

## 6.2 Paper II

**Mkwanazi NB**, Rochat TJ & Bland RM. Living with HIV, disclosure and partnerships a decade after the introduction of HIV programmes in rural South Africa. AIDS Care (2015) (27) **Suppl 1**: pages 65-72

Research question: How have HIV-infected women experienced living with HIV in an ART-era, ten years after their diagnosis?
Methods: An interview guide was developed and used to conduct in-depth interviews with a sub-sample of 20 women that had participated in a maternal HIV-disclosure intervention. (Amagugu). Some additional questions in the interview guide were designed for a structured interview (a separate analysis for Paper III, see below).

Findings: Women's median age was 32 years (IQR 29-37) and their children's median age was seven years (IQR 6.5-7.5). Twelve women had current partners and approximately half were in stable relationships with biological fathers of the study child. Approximately half were living with their partners and had disclosed their HIV status to partners first before disclosing to family and friends. Partners were reported to be supportive following disclosure. Most women (N=14) were on ART and social exposure to HIV was high as most women (N=14) were aware of another adult family member infected with HIV in their household. Two women had not disclosed their status to anyone due to fear of stigma. Some women were in sero-discordant relationships and that contributed to the complexity of disclosure.

### 6.3 Paper III

**Mkwanazi NB**, Rochat TJ & Bland RM. The Amagugu intervention: A qualitative investigation into maternal experiences and perspectives of a maternal HIV-disclosure support intervention in rural South Africa (accepted in the journal *Health Policy and Planning* on 26 April 2017).

Research questions: What motivates HIV-infected mothers to enrol in a maternal HIV-disclosure intervention for primary school-aged uninfected children and what do they report post intervention? Why had they not disclosed to their children before the maternal HIV-disclosure intervention and what advice can they give to other HIV-infected women?

Methods: An interview guide that was developed for Paper II above also had a component for a structured interview which was analysed for Paper III conducted with the sub-sample of 20 women that had participated in the Amagugu maternal HIV-disclosure intervention.

Findings: Most women had not disclosed their status to their children prior to the intervention because they were concerned about their children's developmental capacity to contain the information. Some expressed that their children were too young for HIV-disclosure, and others reported that they, themselves, were not equipped to handle questions that their children might ask during the disclosure process. The majority of mothers stated that they would advise other mothers to disclose to their children because children offered social support following disclosure and reminded them to take their HIV treatment.

### 6.4 Paper IV

**Mkwanazi NB,** Rochat TJ, Coetzee BJ & Bland R.M. (2013) Mothers and health workers' perceptions of participation in a child-friendly health initiative in rural South Africa. Health (2013) 5 (12) pages 2137-2145

Research questions: What were women and their children's experiences of a clinic intervention to support maternal HIV-disclosure? How can primary health care clinics be supported to assist HIV-affected families to access and adhere to HIV treatment and care?

Methods: As part of a larger intervention ("Amagugu" Intervention), 281 mothers were invited to attend a primary health clinic with their primary school-aged children, and afterwards their views on child-friendliness of the clinic staff were documented using the Clinic Follow-Up and Child Experience Form (a structured questionnaire). Clinic staff including nurses, HIV counsellors and clinic clerks were trained on child-friendliness and assessed on their experiences of providing child-friendly services through focus groups post intervention (N=87). A sub-group of mothers (N=20) also participated in in-depth interviews about child-friendliness post intervention.

Findings: Mothers rated 65% of clerks and 70% of nurses as "very friendly". Qualitative data indicated that heavy clinical loads, limited human resources and inadequate infrastructure were perceived as barriers to child-friendliness while good clinic leadership and appropriate resources facilitated child-friendliness.

# 7. Discussion

The Amagugu intervention is the first structured intervention for maternal HIV-disclosure to their children delivered to women in sub-Sahara Africa. It was designed for use in resource-poor high HIV prevalence settings with a low intensity, lay counsellor-led model, aimed at mothers with young children (6-10 years old). The counsellors did not directly intervene with children, instead mothers of primary school-aged children were provided with training and support which empowered them to communicate with their children independently (73, 76, 185). The Amagugu intervention proved to be acceptable and feasible and led to increased disclosure of mothers' HIV status to their HIV-uninfected children, improvements in family health care engagements, and custody planning for the children (73, 74, 76, 185).

The study described here adds to the disclosure literature, as experiences of women participating in maternal HIV-disclosure interventions have not previously been documented in Africa. Women's participation experiences have however, been reported in a longitudinal pilot intervention from the US which was also designed to support mothers to disclose their status to their primary school-aged children (251). This PhD study set out to explore, in greater depth, the experiences of HIV-infected women who were involved in the Amagugu maternal HIV-disclosure intervention. The exploration included investigating women's interaction with the clinic staff and their access to HIV treatment and care during the health intervention that they undertook with their children. The additional findings from this study have led to new recommendations for future interventions designed to assist maternal HIV-disclosure.

An encouraging finding from this work is the indication that a decade after being diagnosed with HIV, women in this resource-poor, rural setting are generally living positively with HIV. The majority were in good health and on ART with relatively high CD4 cell counts. Very low morbidity rates were observed among the women in the Amagugu study.

Despite concerns raised by mothers prior to the intervention, it is very encouraging that mothers expressed no regrets following disclosure and no adverse reactions from children were reported. Mothers expressed that they would advise other mothers in similar situations to disclose their status to their children because disclosure increases children's HIV knowledge, builds trust with their children and assists mothers with their ART adherence (66, 67, 83, 89, 111, 251). This study has assisted in the understanding of the lives and experiences of HIV-infected women almost ten years on from their original HIV diagnosis.

We have learned how HIV-related stigma affects their lives, and how disclosure has assisted them to receive relevant social support, including access and adherence to HIV treatment and care.

The findings from this study suggest that HIV-disclosure to adults does not necessarily translate into disclosure to children, and that parents require specific interventions to assist them with disclosure to children, and to appreciate what children can understand at different developmental stages. The study shows that interventions to assist parents need to be contextual and address the needs of parents and children. As children grow older, their relationships with parents evolve. Parents may require added support with intergenerational communication, including skills and knowledge to discuss issues such as sex with children, which should be considered in the design of future interventions. It would also be beneficial for HIV-affected families to think more about fathers and male care givers, and how they should be involved in processes of parental disclosure. As this study indicates, men are often involved in parenting of HIV-affected children, but do not always receive attention and support, either with parenting or participation in the HIV-disclosure interventions.

It was encouraging that staff from the primary health care clinics welcomed the child-friendliness and maternal HIV-disclosure training. They recognised the role that they could play in health promotion and increasing children's participation opportunities in health facilities and that this was possible, provided they received support to address logistical constraints including workload, lack of infrastructure and staff shortages. The clinic staff found interacting with children in child-friendliness activities rewarding, suggesting that if such activities could be incorporated into daily clinic routines, they could boost the morale of the health facilities staff.

This study demonstrates that when provided with culturally and age-appropriate disclosure tools, HIV-infected mothers are willing and able to disclose their status to their children. Although the study was conducted in a resource-poor, rural, high HIV-prevalence setting with high social HIV-exposure, it could be tested in other settings. Researchers can contribute to the literature by addressing the issue of how to conduct culturally acceptable disclosure research in different settings, and how to best assist and support healthcare staff and HIV-affected parents to navigate through the process of HIV-disclosure. This is often perceived as being very difficult, but also to be necessary and important by mothers and health care staff. The important role played by families including extended families and health care facilities in

managing HIV in sub-Sahara African context cannot be underestimated when designing such interventions.

### 7.1 Exploration of key findings from the PhD

The key findings from this exploration are summarised in relation to three main areas which are central to this study.

i. HIV-related stigma
ii. HIV-disclosure and family strengthening
iii. HIV-disclosure and access and adherence to HIV treatment

### 7.2 HIV-related stigma

The fear of HIV-related stigma was one of the primary reasons most women had not disclosed to their children prior to the Amagugu intervention (73, 76). Women in this study reported that they did not trust their children to be able to maintain confidentiality, and perceived that their children lacked the developmental capacity to cope with maternal HIV-disclosure. Non-disclosure of maternal HIV status due to perceptions that children are too young has also been reported in studies in China (122), Thailand (203) and the US (64). Other literature suggests that a child's young age is related to their inability to maintain confidentiality about their mothers' HIV status (52, 54, 66).

In line with the findings from China, South Africa, Kenya, and the US (53, 90, 95, 101, 183, 187, 252), our study suggests that HIV-related stigma may impact on access to and adherence to HIV treatment in some cases. Two of the twenty women in the sub-sample reported having not accessed HIV treatment, care and support, despite knowing their HIV status for almost a decade. Not accessing health care due to fear of stigma is not a unique finding, and has previously been reported in a systematic review and meta-synthesis on the effect of the relationship between stigma and ART adherence (253).

Despite the challenges of HIV-related stigma and other factors, this study has shown that HIV-infected mothers, and the health care staff responsible for their treatment and well-being, view maternal HIV-disclosure as a necessary step to enable mothers to obtain adequate social support (97). Although HIV-related stigma has been reported in other settings (96, 126, 128, 129, 254), with increased ART roll-out in areas of high HIV prevalence, including this

study area, decreased levels of HIV-related stigma are being observed (184). In this study the majority of women reported that they were openly accessing HIV treatment and care. This could be partially attributed to the high social exposure to HIV in the study area, where most adults and children are aware of someone who is HIV-infected, or taking ART, in their family or community (204). Both mothers and the clinic staff indicated that children were also receiving HIV education as part of Life Orientation teaching - a subject taught from primary school through to the school-leaving matriculation - which has increased their exposure to HIV and accurate information about the infection.

### 7.3 HIV-disclosure and family strengthening

Maternal HIV-disclosure benefits children by opening up communication channels for HIV education and prevention between mothers and their children (185). In line with findings from elsewhere, contained in the international literature, this study has shown that maternal HIV-disclosure has benefits for mothers, children and families (66, 67, 83, 89, 111, 251). It has also demonstrated that HIV-disclosure to children improves maternal mental health, promotes health care behaviours, increases HIV and health education, and strengthens parent-child and family relationships (90, 255, 256).

Enhancing children's psychological well-being through maternal disclosure can prevent the possible negative effects of disclosure, including lack of health education, psycho-social problems and poor parent-child communication, all of which are reported in the literature (257-260). When children's psychological well-being is enhanced, they are more likely to grow up to be responsible adults, better able to take responsibility for their own health, and to minimize risky behaviours in the future (73, 74, 76, 185, 261). This will, in turn, improve their life chances, making them better equipped to maximize educational and employment opportunities (73, 74, 76, 185, 261).

This study suggests that the main reason for maternal HIV-disclosure is to obtain social support from their children (88, 97, 184), a finding that has been reported elsewhere in the literature (81-84). Mothers reported being pleasantly surprised by the amount of HIV knowledge their children displayed during the disclosure process, and they appreciated the chance of providing HIV education to their children during the intervention, a finding also described in studies from the US (103, 251) and in a systematic review (89). Mothers also appreciated the support they received from their children in reminding them to take their HIV

treatment, thus improving their adherence. Similar reports of closeness and supportive behaviour from children have been found in other studies and indicate the role of disclosure in family-cohesion and ART adherence (66, 107, 112).

Most parental HIV-disclosure studies have been conducted with mothers, and the perspectives of HIV-infected fathers and the children who have been disclosed to, have been lacking. Only interviewing mothers leaves a gap in the research findings and takes the focus away from the children, who are also beneficiaries of maternal HIV-disclosure (67). One challenge of involving children in parental HIV-disclosure research is the risk of inadvertent disclosure that has been reported in other studies (107, 262). Another challenge is that children's reports of their experiences of disclosure may differ from those given by their mothers (54, 67, 90, 113). Limitations of two studies, that interviewed children in Kenya (183) and China (263), included small sample sizes, and a lack of data collection from fathers. A further challenge in the Kenyan study, was that the interviews were not conducted in the participants' home language (183).

In this PhD study mothers were interviewed in their home language, but children were not interviewed due to logistical constraints and the ethical complexities of interviewing children. The scope of this study was therefore limited to the perspectives of mothers who had participated in the Amagugu HIV-disclosure intervention. Future studies could, and most probably should, investigate children's perspectives, but additional caution will be required in designing such interventions, in order to reduce the negative consequences of an inadvertent disclosure. The inclusion of males in disclosure interventions would also be beneficial, so that the child's support network is further extended through the disclosure process.

Despite women in this study reporting high levels of disclosure to other adults, HIV-infected women and health care staff from primary health care clinics noted that assistance is required with maternal HIV-disclosure to primary school-aged children. Addressing the socio-cultural context including HIV-related stigma, social exposure to HIV and the child's developmental capacity (101, 114, 183, 187, 263, 264) are required to encourage and support maternal HIV-disclosure. Normalisation of ARVs in the study area - to the extent of them being likened to everyday substances that are openly shared like teabags was - an interesting and encouraging finding that showed a high degree of de-stigmatisation of HIV in some parts of the study communities.

### 7.4 HIV-disclosure and access and adherence to HIV treatment

The WHO's Parental Disclosure Guidelines recommend HIV-disclosure as part of the continuum of care for HIV-affected families (46). This, and other studies, have demonstrated that HIV-disclosure leads to increased social support (103, 114), better ART and clinic appointment adherence (89, 101, 113, 187), and improved family cohesion (66, 67, 83, 111, 251). The wide roll-out of HIV treatment and care programmes provides an enabling environment for maternal disclosure because HIV-infected parents survive much longer and are able to care for their children to adulthood, as compared to the pre-ART-era where many children were orphaned (88).

Most women in this study were in stable partnerships and were still in a relationship with the father of the study child from the Vertical Transmission Study. Reports on disclosure to partners are documented in other studies (92, 93, 173, 205, 265). That most women disclosed to their partners first, before disclosing to anyone else (184), suggests that stability of partnerships is an important factor to be considered when designing HIV-disclosure interventions.

One critique of the existing theoretical models and frameworks that could guide future parental HIV-disclosure interventions is that most of them were developed prior to the availability of ART, when HIV was regarded as a fatal, rather than a chronic, illness (78, 135). As a result, the models tend to focus on disclosure as a process between two individuals, and did not necessarily take into consideration the complexities of the family context in which the two individuals, for an example a child and a parent, exist (90). For this reason, it is also argued that the theoretical models used for parental HIV-disclosure interventions should be applied with caution in collectivist cultural settings, including those commonly found in Asia and Africa (78, 135). In such settings children may have multiple caregivers who hold contrasting views regarding parental HIV-disclosure, and thus, the theoretical models need to make provision for these cultural differences (78, 135) and not adopt a 'fits one, fits all' model. Providing family-centred HIV care to infected women and their families may be more beneficial than individual-centred care in areas of high HIV prevalence (68, 69, 266).

It is encouraging that in recent years there has been an emerging literature addressing parental HIV-disclosure to children in low and middle income countries such as Kenya (183), South

Africa (73, 74, 76) and China (95, 252, 263, 267). The health intervention which was part of the Amagugu study and the current study, also demonstrated that in areas of high HIV prevalence, providing the primary health care clinics with child-friendliness and health promotion activities was acceptable to both mothers and health care staff (97). Heavy clinical loads, limited human resources, and inadequate infrastructure were perceived as barriers to child-friendliness, while good clinic leadership and appropriate resources facilitated child-friendliness.

## 7.5 Strengths and limitations of the current study

### *7.5.1 Strengths*

This study contributes to the global scientific literature on maternal HIV-disclosure (88) and the lives of African, rural women who have been living with HIV in an ART-era for almost a decade (184). It describes their living arrangements, disclosure patterns, and partnerships. The study also contributes to the literature on the perspectives of health staff, and their involvement in supporting HIV-affected families in resource-poor settings with high HIV prevalence (97). Finally, it also explores in depth, the mothers' experiences of participating in an HIV-disclosure intervention, including reports of their own children's reactions to disclosure.

All the interviews and the focus group discussions were conducted in isiZulu, the participants' and the interviewer's home language. I viewed being Zulu and from the local area as an advantage and not a disadvantage throughout the research process. I did not need a translator and I felt I had control driving the interviews and the focus groups and probing appropriately according to my research questions. I was comfortable with the language and most participants appeared to be at ease when they expressed themselves in their home language. However, with some participants, in both interviews and focus groups, there was an assumption that: "as a Zulu, you should know these things" especially when I probed on some issues that were related to the Zulu culture, such as being involved in a polygamous marriage. On a few occasions, I had to "defend" myself and declare my ignorance and state that I was unaware of some of the Zulu cultural practices that I was "assumed" to share or have experienced. These included rituals that are only performed by some families that I was not exposed to in my household. My ignorance of some aspects of the Zulu culture enabled

me to have no assumptions, and to probe and be open to new information and to interrogate those narratives further in detail, when listening to the audio-recordings.

During the home visits I would make sure that I dressed appropriately; I wore skirts or dresses instead of pants and politely declined a chair but instead sat down on a reed mat with the participant so that we could be on the same level. Being an approachable person by nature, helped to neutralize the influence I might have had over the participants as I am from a prominent local Mkhwanazi royal family. In this context it was even more important to emphasize that participation in this research was completely voluntary. At all times I strove to make participants feel as comfortable as possible, because I was conscious of how my family name could impact on my research. I believe conducting the interviews in the comfort of participants' homes made them more relaxed, and with all 20 participants I was able to negotiate private space with minimum interruptions, which assisted with ensuring the quality of the audio-recordings.

Since I have not given birth to, or raised, a child, I could ask questions relating to disclosure of an HIV status to a child with few preconceived ideas, which I believe contributed to the richness of the data collected. At times the naiveté I displayed in matters relating to bearing and raising children seemed to empower women to display their skills and knowledge, as they had something which I, 'an educated researcher', did not have. I assumed that this 'upper hand' and my lack of experience mitigated any tacit power relation imbalance that might have existed between me, a researcher, and them, as participants.

### *7.5.2 Limitations*

Ideally it would have been more beneficial to have had bilingual members in the research team to assist with the verification of transcript translations. My co-investigators and the co-authors on the study publications could not speak or read isiZulu, and therefore, they could not listen to the audio-recordings or verify the interview and focus group transcript translations. For that part of the process I had to rely on a bilingual, first-language isiZulu-speaking colleague, who was not part of the research team, to verify a few translations of both interviews and the focus group discussions.

The staff rotation at the clinics made it challenging to assess whether there were significant changes in the knowledge and attitudes before, and after, the training in child-friendliness and

maternal HIV-disclosure had taken place. In most cases, when I returned to administer questionnaires after the clinic training (the post-clinic training questionnaires), I found that there were clinic staff members present who had not been part of the original training. However, the focus groups provided an opportunity for everyone to express their views on the child-friendliness and maternal HIV-disclosure materials and training. The majority of clinic staff who participated in the focus groups had, in one way or another come across, or interacted with, Amagugu study mother-child pairs, who had come to the clinics for health promotion visits and could share their experiences.

Although the women in this study were from a high HIV prevalence area, they were different to other HIV-infected women from the general population, in that they had been exposed to two home-based interventions previously, the Vertical Transmission Study and the Amagugu Study. It is possible therefore, that they were more receptive to research involving their children and were more used to adhering to research procedures than other women, and hence the high rates of maternal HIV-disclosure reported. It would be interesting to examine results from future studies using the same intervention materials, but enrolling HIV-infected women with uninfected children from the general population, not previously involved in research.

# 8. Conclusion, implications and future research

## 8.1 Summary

In this Discussion section, I have highlighted how this PhD study contributes to the literature of HIV-infected women who have been living with HIV and have been part of a maternal HIV-disclosure intervention, and the role health care workers have in supporting HIV-affected families in areas of high HIV prevalence. I have also discussed the research findings in relation to the three main themes of the study and how they are similar or different to what is already known from the international scientific literature. I have demonstrated how my background and the way I conducted and presented myself as a researcher could have impacted on the research process, and the steps I took to minimise researcher biases from data collection to data analysis.

## 8.2 Implications for future interventions and research

The Amagugu intervention shows promise as a method of assisting HIV-infected mothers to disclose their HIV status to their primary school-aged children, using a counsellor-led, home-based, model. The work of this PhD further explored the experiences of the women who took part in this intervention, and my findings lead to the following recommendations for future interventions and research:

1. The important role played by families including extended families, and primary health care clinics, should be considered when designing HIV-disclosure interventions for sub-Saharan Africa.
2. Specific interventions are needed to assist with HIV-disclosure to children. It should not be assumed that adult disclosure will automatically lead to disclosure to children.
3. It would benefit HIV-affected families if future research involves fathers because they are also caregivers.
4. That most women disclosed to their partners first, before disclosing to anyone else, suggests that stability of partnerships is an important factor to be considered when designing HIV-disclosure interventions.
5. That the mothers expressed no regrets in actively engaging their children about their HIV, and that their experience was reported to be highly satisfying regardless of their circumstances, are findings that could be used to promote maternal HIV-disclosure interventions more widely.

6. Provided there are culturally and age-appropriate intervention tools, HIV-disclosure can be a basis for health and sex education with children, which most parents struggle with in sub-Saharan Africa.
7. When conducted in an age-appropriate manner, maternal HIV-disclosure interventions may lead to children assisting mothers with their treatment adherence.
8. Providing child-friendly services at health facilities not only helps to establish a productive and trusting health care relationship, but has the potential to improve the experience of health visits for children and their parents and be rewarding for health staff.
9. The barriers to child-friendliness articulated by the clinic staff could be a starting point for recognising what needs to be done to incorporate child-friendliness and health promotion activities into a model of family-centred care.
10. Persisting incidents of HIV-related stigma indicate efforts to mitigate stigma need to be continued and strengthened at all levels, including in households, the communities and health facilities.

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## 10. List of Appendices

Appendix A: Scientific papers (Papers I-IV)

Appendix B: Training manual for clinic staff

Appendix C: Data collection forms (Baseline Information Form, Parental Disclosure Interview, Clinic Visit Follow-up and Child Experience Form, Pre-Clinic Training Questionnaire and Health Update Form)

Appendix D: Focus Group Guide

Appendix E: Ethical clearances (the University of KwaZulu-Natal BREC and the University of Witwatersrand HREC)

Appendix F: Approval letters (the Africa Centre Community Advisory Board and the Hlabisa Hospital Management)

Appendix G: Consent forms (Amagugu mothers, sub-sample of 20 mothers and clinic staff)

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# Disclosure of maternal HIV status to children: considerations for research and practice in sub-Saharan Africa

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An estimated 2.8 million children are born to HIV-infected mothers each year, 2.5 million of whom are likely to be HIV-exposed but uninfected. In sub-Saharan Africa up to 40% of pregnant women are HIV-infected, resulting in large numbers of HIV-uninfected children living with at least one HIV-infected parent. These parents face many challenges, including the dilemma of when and how to disclose their HIV status to their children, particularly those who are pre-adolescent. This article summarizes the current evidence on maternal HIV disclosure to their HIV-uninfected children, explores the reported benefits of disclosure to children and mothers, highlights the gaps in knowledge and areas for future research, and discusses possible future intervention models focusing on primary school-aged children in sub-Saharan Africa.

Sub-Saharan Africa is disproportionately affected by HIV. The region is home to 10% of the world's population, but includes two-thirds of all people with HIV, and an estimated 40% of all HIV-infected women [1]. Improvements in HIV-treatment and prevention have resulted in substantial decreases in mother-to-child transmission of HIV in sub-Saharan Africa [1], and a higher proportion of parents surviving to care for their HIV-uninfected children [2–5]. This has resulted in large numbers of HIV-uninfected children living with at least one HIV-infected parent [2,5–7].

Children exposed to HIV *in utero* and raised by HIV-infected mothers face a number of potential adverse consequences of HIV exposure including delays in cognitive and motor development [5,8]. Furthermore, they reach school-going age (6–10 years), and the journey into adolescence facing possible vulnerabilities associated with the HIV-positive status of their parents [2,5,9,10]. The early years of school are a crucial time in a child's development, when their life and educational chances, and their moral and social development, are highly dependent on consistent and attentive care and a sense of hope for the future [11,12]. The quality of that care may be affected by a number of factors associated with their parents' status, including possible maternal ill health, maternal hospitalization and, in some cases, death [2,5,13,14]. These are often compounded by stigma and discrimination, and a lack of adequate familial and social support [15].

One particular challenge faced by HIV-infected mothers is when and how to disclose their HIV status to their children [14,16–21]. There is limited research relating to maternal HIV disclosure globally [20,22,23], and particularly in the African context. Furthermore, only a few studies from the USA [9,16,22,24–34] and one from Thailand have included mothers with primary school-aged children [35]. This article offers a critical overview of existing research, and conceptualizes models for disclosure interventions for younger children living in high HIV prevalence regions.

## Overview of current literature

Two literature reviews [14,36] and a recent systematic review [22] have examined the issue of maternal HIV disclosure, finding 56 published studies. We further searched the online database Pubmed and Google Scholar for studies published in English from 2010 onwards, with the following search terms 'maternal HIV disclosure and HIV-uninfected children'. Two further studies were identified, giving a total of 58 studies, which are described in Tables 1 & 2 for adolescent research and in Tables 3 & 4 for pre-adolescence

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Keywords
■ family interventions ■ HIV ■ HIV-uninfected children ■ maternal HIV disclosure ■ maternal HIV status ■ pre-adolescents ■ primary school-aged children ■ sub-Saharan Africa

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**Table 1. Studies relating to adolescents in the USA, Canada and Europe.**

| Author (year) | Study design | Sample | Location and participant recruitment | Findings | Ref. |
|---|---|---|---|---|---|
| Armistead *et al.* (1997) | Cross-sectional; quantitative | 67 parents and 67 children (3–17 years) | USA: families with a hemophiliac, HIV-infected father recruited from hemophilia treatment centers. Only the eldest child in each family included | Thirty out of 67 (45%) fathers disclosed their HIV status to one of their children. Older children were more likely to be disclosed to compared with younger children; disclosure was more common if the father's health was poor. Parent–child relationship was assessed using the Interaction Behavior Questionnaire; child depression was assessed using the Child Depression Inventory. Lower levels of child depression and externalizing problems were observed where more positive parent–child relationships were reported | [64] |
| Rotheram-Borus *et al.* (1997) | Longitudinal; quantitative | 151 parents and 171 children (12–18 years) | USA: HIV-infected mothers, fathers and their HIV-uninfected adolescent children recruited from the New York City Division of AIDS Services | The majority, 86.6% of the sample, were mothers. Parents were interviewed once. Adolescents were interviewed and reassessed at a follow-up interview 3–6 months later. Disclosure rate was 74%. Mothers (87%) and fathers (73%) were significantly more likely to disclose to adolescents compared with younger children (23%). Disclosure to younger children was the same for both mothers and fathers. Adolescents, who had been disclosed to reported more externalizing behaviors, such as engaging in more sexual risk acts, smoking more cigarettes and participating in more severe substance abuse than adolescents who had not been disclosed to. The majority of parents, 80%, discussed custody plans with members of their social networks; however, only 30% initiated legal custody plans for their children | [47] |
| Murphy *et al.* (1999) | Cross-sectional; qualitative | 40 mothers (children's ages not specified) | USA: HIV-infected mothers with both HIV-infected and uninfected children were recruited from an HIV clinic | The study investigated patterns of disclosure and psychological adjustment among HIV-infected mothers. The disclosure interview asked to whom participants had disclosed their own or their infected child's HIV status to. All mothers disclosed their status to someone, but only 39% disclosed to children. All mothers with an HIV-infected child disclosed the child's status to someone. Some women adjusted their lives positively following an HIV diagnosis. Half of mothers disclosed a child's diagnosis to a child | [120] |
| Simoni *et al.* (2000) | Cross-sectional; quantitative | 188 mothers and 267 children (1–19 years) | USA: HIV-infected mothers recruited from outpatient clinics in New York City | Only mothers were assessed. Disclosure rate was 53%. Mothers made disclosure decisions on a child-by-child basis. Child's age influenced disclosure; children that were disclosed to were older compared with those who were not disclosed to. The child's age influenced whether the mother fully disclosed that she had HIV or partially disclosed that she had an illness. A total of 57% of mothers had made formal plans for the children's future care | [50] |
| Pilowsky *et al.* (2000) | Cross-sectional; qualitative | 29 mothers (children aged 4–17 years) | USA: women living in two community residences for adults living with AIDS recruited | Disclosure was assessed with a Maternal Disclosure Interview developed by the first author. Children were not assessed. A total of 17 mothers disclosed their status, 12 of whom stated that disclosure was 'the right thing to do'. The cited reasons given by the 12 mothers who did not disclose was that the child was too young to understand and that they were concerned about discussing death with their children | [46] |
| Rotheram-Borus (2001) | Longitudinal; quantitative | 307 mothers and 412 children (11–18 years) | USA: HIV-infected mothers with their HIV-uninfected adolescents were recruited from the New York City Division of AIDS | Mother–child pairs were assigned into either an intervention or control group. The purpose of the intervention was to help parents and their adolescents cope with illness-related tasks. Parents' depression scores and multiple problem behaviors from 3 to 15 months decreased among the intervention group. 71% of mothers in both groups had disclosed their status to at least one adolescent and 66% had disclosed to all adolescents in the family. At 2 years adolescents in the intervention group reported four-times fewer problem behaviors and 2.4-times fewer conduct problems than the control group | [121] |

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**Table 1. Studies relating to adolescents in the USA, Canada and Europe (cont.).**

| Author (year) | Study design | Sample | Location and participant recruitment | Findings | Ref. |
|---|---|---|---|---|---|
| Kirshenbaum and Nevid (2002) | Cross-sectional; qualitative | 58 mothers and 58 children (4–18 years) | USA: HIV-infected mothers and their HIV-uninfected children recruited from HIV/AIDS service centers in the New York metropolitan area | Disclosure rate was 57%. In 75% of the cases the children were disclosed to by the mother and 66% were not asked to keep disclosure a secret. Children that were asked to keep disclosure secret displayed more behavioral problem scores when assessed using the Child Behavior Checklist than those who were not asked to maintain the secret | [40] |
| Lee and Rotheram-Borus (2002) | Longitudinal; quantitative | 301 parents and 395 adolescents (11–18 years) | USA: HIV-infected mothers and fathers with HIV-uninfected adolescents recruited from the New York City Division of AIDS | Participants were followed up for 5 years. Parents were more likely to disclose to older (75%) than younger (40%) children. Mothers were more likely to disclose than fathers, and were more likely to do so at a younger age. More mothers compared with fathers disclosed to daughters than sons. Children's sex did not influence disclosure among fathers. Disclosure was associated with more problem behaviors and negative family life events among adolescents. Parents who had disclosed had a higher number of stressful life and family life events. Disclosure was higher among parents with a poor health status. Parents with larger social networks were more likely to disclose to children. At recruitment, adolescents that were disclosed to reported significantly higher problem behaviors; however, problem behaviors decreased over time and increased among adolescents who were not disclosed to | [41] |
| Lee *et al.* (2002) | Cross-sectional; quantitative | 121 mothers and 121 children (11–18 years) | USA: HIV-infected mothers and uninfected adolescent daughters were recruited from the Division of AIDS Services in New York | Both mothers and daughters were assessed. At the time of recruitment 75% of mothers had already disclosed to their daughters. There were no differences between mothers' and daughters' reports of attempted suicide during their lifetime (21–25%). Decision to disclose was not associated with mothers' stage of disease. Poor school reports were associated with mothers' emotional distress. More mothers than daughters reported history of sexual abuse during their lifetime (37 vs 10%) | [122] |
| Mellins (2002) | Longitudinal; quantitative | 128 mothers (children aged <18 years) | USA: HIV-infected mothers were recruited from an infectious disease clinic | Children were not assessed. Baseline data from a longitudinal study investigating factors that affect ART and medical appointment adherence in HIV-infected mothers are reported here. Disclosure was assessed with a disclosure questionnaire developed by the study investigators. The majority of mothers (95%) had disclosed to their adult family members, while in 48% of the families none of the children were disclosed to. Mothers had disclosed to all of their children in 9% of the families. Of the 69% of mothers who were on ART, 20% reported missing medication in the past 2 days and 43% of the sample reported missing medical appointments in the past year. ART and medical appointment adherence was associated with disclosure to a live-in partner and children; more adherence was reported by those who had disclosed to partners and children they were living with | [123] |
| Mellins *et al.* (2003) | Longitudinal; quantitative | 128 mothers (children aged <18 years) | USA: participants recruited from the same cohort as above study [123] | Children were not assessed. Data from a 6-month follow-up are reported here. More mothers reported missing medical appointments in the 6-month follow-up compared with baseline (43 vs 54%). Poor medical appointment adherence was associated with less disclosure to children. Presence of a psychiatric disorder and higher levels of stressful life events were associated with poor medical appointments in 6-month follow-up | [124] |

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**Table 1. Studies relating to adolescents in the USA, Canada and Europe (cont.).**

| Author (year) | Study design | Sample | Location and participant recruitment | Findings | Ref. |
|---|---|---|---|---|---|
| Letteney and LaPorte (2004) | Cross-sectional; quantitative | 88 mothers (children aged 5–18 years) | USA: HIV-infected mothers recruited from an outpatient medical clinic in New York City | Children were not assessed. Disclosure rate was 67%. Disclosure behavior was measured by the Disclosure Inventory (a 14-item instrument) developed by the investigator. Apart from age and education those who disclosed and those who did not were similar in most sociodemographic characteristics. Nondisclosers cited fear of stigma as the main reason for not disclosing | [42] |
| Murphy *et al.* (2006) | Cross-sectional; quantitative | 118 mothers and 118 children (10–17 years) | USA: HIV-infected mothers and HIV-uninfected adolescents recruited from a cohort in the PACT study | A total of 51% of adolescents had no immediate reaction to disclosure; 49% expressed an emotional reaction. Adolescents who were disclosed to had lower depression scores. A total of 49% children reported worrying more since they have been disclosed to. There were discrepancies between mother and child reports. Fear of stigma was the most cited reason for nondisclosure | [25] |
| Corona *et al.* (2006) | Cross-sectional; quantitative | 274 parents and 453 children (5–17 years) | USA: HIV-infected mothers and fathers receiving HIV care and HIV-uninfected children were recruited | This study analyzed data from the HIV cost and services utilization study which used multi-stage sampling to select a random sample of HIV-infected adults [125]. Disclosure rate was 44%. Reasons for nondisclosure included; worry about emotional consequences of disclosure (67%), children would tell other people (36%) and lack of skills and knowledge on how to disclose (28%) | [65] |
| Letteney (2006) | Cross-sectional; quantitative | 88 mothers (children aged 5–18 years) | USA: HIV-infected mothers were recruited from an outpatient HIV clinic | Children were not assessed. Mothers who had disclosed their HIV-status to their children were compared with those who had not disclosed. Disclosure rate to children was 66%. Of those who did not disclose, 19% had no intention of disclosing in the future. Those who disclosed were less likely to perceive HIV diagnosis to be stigmatizing than those who did not disclose. There were no differences in psychological and physical levels of stress between the two groups of mothers. Those who disclosed reported high levels of social support | [18] |
| Tompkins (2007) | Cross-sectional; qualitative | 23 mothers and 23 children (9–16 years) | USA: HIV-infected mothers and HIV-uninfected children who had been part of a longitudinal study investigating psychosocial adjustment, risk behavior and social contexts (the UCLA-Drew Women Project, in Los Angeles) | Disclosure rate was 61%. Children who had been asked to keep disclosure secret scored higher on the teacher report form which assessed behavioral problems and mothers reported higher externalizing problems in the child behavior checklist | [126] |
| Brackis-Cott (2007) | Longitudinal; quantitative | 220 mothers and 220 children (10–14 years) | USA: HIV-infected and uninfected mothers of uninfected early adolescents recruited from HIV clinics and non-HIV clinics | Baseline data for the study which investigated risk and resilience in youth with HIV-infected mothers were used. HIV-infected mothers displayed more depressive symptoms than uninfected mothers when assessed with the Beck Depression Inventory. No significant differences were observed in depressive symptoms of children of HIV-infected mothers and uninfected mothers. There were no differences in anxiety scores between children who were disclosed to and those who were not disclosed to, and no differences were observed in anxiety scores between children of HIV-infected mothers and uninfected mothers. Children who were disclosed to were less depressed than those who were not disclosed to when assessed using the Child Depression Inventory | [127] |

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**Table 1. Studies relating to adolescents in the USA, Canada and Europe (cont.).**

| Author (year) | Study design | Sample | Location and participant recruitment | Findings | Ref. |
|---|---|---|---|---|---|
| Delaney *et al.* (2008) | Cross-sectional; quantitative | 66 mothers and 66 children (5–18 years) | USA: HIV-infected mothers and HIV-uninfected children recruited through AIDS service organizations | Disclosure rate was 61%. The cited reasons for disclosure included: wanting children to hear the diagnosis from mothers and that children had a right to know. Reasons for nondisclosure included: believing children deserved a carefree childhood and not wanting to worry children. Mothers wanted to take a leading role in disclosing depending on the children's ability to handle information, provided the process was not harmful to children. A total of 90% of mothers did not regret disclosing to children | [63] |
| Mellins *et al.* (2008) | Cross-sectional; quantitative | 220 mothers and 220 children (10–14 years) | USA: HIV-infected and HIV-uninfected mothers and HIV-uninfected adolescents recruited from HIV clinics, community-based organizations and other care providers | Data on the disclosure process were not collected, but mothers were asked if children were aware of their mothers' status. Adolescents' knowledge of their mothers' HIV infection and overall health was associated with worse adolescent mental health outcomes, including higher child depression scores in the Child Depression Inventory | [43] |
| Dematteo *et al.* (2002) | Cross-sectional; quantitative | 51 adults and 54 children (5–19 years) | Canada: HIV-affected families from pediatric hospitals and AIDS service organizations were recruited | Most children, 67%, knew about their parents HIV infection, 35% knew about their own infection and 9% were told about their siblings' or other family members' HIV infection. Compared with boys, more girls were disclosed to (59 vs 39%). Asked about preparations for disclosure: 78% of caregivers reported that they talked with someone they trusted, 71% waited for improved health, 50% prayed and 49% talked with professionals | [54] |
| Thorne *et al.* (2000) | Cross-sectional; quantitative | 121 parents, 50 caregivers and 226 children (≤19 years) | Germany, Italy, The Netherlands, Portugal, Spain, Switzerland and the UK: data reported in this study were collected from participants as part of a larger survey conducted in ten pediatric HIV centers located in seven European countries | The majority, 89%, of parents were originally from Africa and had immigrated to Europe mainly as refugees or asylum seekers. Both HIV-infected (92%) and HIV-uninfected parents or caregivers of HIV-affected children were recruited. A total of 62% of children were HIV-infected, and 55% of children were aged ≤6 years. Disclosure rate was 11%. Parents who disclosed had on average known their diagnosis for longer than those who did not disclose. Most children were disclosed to by the age of 10 years. A total of 50% of HIV-infected parents had made long-term plans for their children's future social care. Disclosure was not associated with gender, marital status or continent of origin, or with the child's own infection status. Few (15%) infected parents wanted support from a professional to help with disclosure to children | [56] |
| Nöstlinger *et al.* (2004) | Cross-sectional; quantitative | 168 parents and 279 children (≤17 years) | Belgium: caregivers living with HIV and their HIV-infected and HIV-uninfected children, and people living with HIV without children recruited from three Flemish AIDS reference centers | The majority of children were pre-adolescents and adolescents (median age 11 years). The majority of participants were predominantly of Belgian origin. Disclosure rate was 10%. More women (58%) were caregivers. Most participants (82%) took ART at the time of data assessment. There were no differences in medical parameters such as CD4, viral load and median time since HIV diagnosis between caregivers living with HIV and people living with HIV without children. Disclosure information is only reported on caregivers living with HIV | [37] |

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**Table 1. Studies relating to adolescents in the USA, Canada and Europe (cont.).**

| Author (year) | Study design | Sample | Location and participant recruitment | Findings | Ref. |
|---|---|---|---|---|---|
| Nöstlinger *et al.* (2006) | Cross-sectional; quantitative | 718 parents and 1136 children (≤18 years) | Ten western European countries: data were collected from participants of EUROSUPPORT IV, a network of 15 HIV-treatment centers and research organizations located in ten western European countries | Caregivers were HIV-infected and the majority of children (83.5%) were HIV-uninfected, only (8.5%) were HIV-infected and 8% had an unknown HIV-status. A total of 55% of HIV-infected children were aware of their own status, while 21% were aware of maternal HIV status. A total of 74% of caregivers were on ART. Various reactions to disclosure were reported by parents: a total of 64% reported they felt the child was coping better, 10% felt the child was coping worse and the remaining 26% noticed no change in children following disclosure when assessed using an adapted version of the child behavior checklist and indirectly through parents' reports | [55] |
| Niebuhr *et al.* (1994) | Cross-sectional; qualitative | 54 parents and their children/adult children (4–48 years) | USA: HIV-infected parents were recruited from an HIV clinic | Children were not assessed, but participants reported five of their children (all <5 years of age) to also be infected. From 242 parents with 138 children, a subset of 54 parents with children >4 years of age were analyzed for this study. A total of 55.7% of children were disclosed to. When specifically asked, almost half of the parents (48%) reported that they did not need help in dealing with children with HIV-related issues. A total of 53.5% of parents reported that their children would be discriminated against because of parents' HIV diagnosis. A total of 47% of parents were worried about who would take care of their children if they died | [128] |
| Forsyth *et al.* (1996) | Cross-sectional; qualitative | 26 mothers and 26 children (6–16 years) | USA: HIV-uninfected children from HIV-affected families and unaffected families (controls) were recruited from an HIV clinic and a primary healthcare clinic | Both mothers and children were assessed. The study investigated mental health problems of children of HIV-infected mothers. The subjects were interviewed in their home, while the controls were interviewed in the clinic. There was an agreement between mothers' and children reports; children of infected mothers reported themselves to be more depressed and their mothers reported children to be more withdrawn than children of uninfected mothers | [129] |
| Wiener *et al.* (1998) | Cross-sectional; qualitative | 17 parents and 17 children (5–18 years) | USA: HIV-infected children attending the pediatric branch of the National Cancer Institute, Bethesda, and their parents were recruited | Seven of 17 parents disclosed their own status and children's status to children. Maternal disclosure often led to disclosure of child's own diagnosis. Reasons for disclosure included: not wanting children to hear from other people, preparing children for maternal death and addressing children's questions about HIV. Reasons for nondisclosure included: concerns that children would be negatively affected psychologically and were not developmentally ready to understand about HIV | [53] |
| Tompkins *et al.* (1999) | Longitudinal; qualitative | 91 mothers (children aged <18 years) | USA: HIV-infected mothers were recruited from a longitudinal study on family structure and parenting challenges | Children were not assessed. A total of 9% of the children were also HIV-infected and 75% of mothers had disclosed to their social networks. Approximately half of the HIV-infected children knew their and their mothers' status. Most mothers had disclosed to their children, but there were a few inadvertent disclosures, in some cases other people had disclosed without the mother's permission. A third of children reacted to disclosure by showing concern, 10% were accepting and more than 10% distanced themselves and refused to talk about the disclosure. Several had behavioral problems, and were worried and sad. More than half of the children did not ask any questions during disclosure. Those who asked questions commonly asked about modes of transmission and about the mothers' health, such as if she was taking her medication and keeping doctor's appointments. Most mothers reported an increase in closeness with children after disclosure | [21] |

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**Table 1. Studies relating to adolescents in the USA, Canada and Europe (cont.).**

| Author (year) | Study design | Sample | Location and participant recruitment | Findings | Ref. |
|---|---|---|---|---|---|
| Ingram and Hutchinson (2000) | Cross-sectional; qualitative | 20 mothers (children's ages not specified) | USA: HIV-infected women recruited from HIV organizations and HIV clinics | Only mothers were interviewed. The study described the reproductive and mothering experiences of HIV-positive mothers. Many mothers perceived healthcare workers to have negative attitudes towards HIV-infected mothers' reproduction; they reported receiving little support regarding their reproductive choices. Stigma was one of the major themes for mothers; they did not want to be seen in HIV clinics. Most mothers reported that mothering is hard work even for HIV-uninfected children. Some mothers cared for HIV-negative children who had other medical conditions including epileptic seizures, severe asthma and mental illness. Most mothers reported the unconditional love they received from and gave to their children. One of the recurring themes was the struggle about whether to disclose to the children about their HIV status. However, some mothers reported feeling guilty about bringing HIV into their children's lives. Approximately half of the mothers disclosed their status. Children that were disclosed to were often protective of their mothers' physical and emotional health, monitoring their mothers' HIV medication, defending them against HIV-related stigma and taking on more responsibilities at home. Mothers who disclosed wanted to open communication regarding future custody of children. Those who did not disclose cited that they were worried that children were too young and were concerned about the negative emotional impact of disclosure | [66] |
| Winstead and Derlega (2002) | Cross-sectional; qualitative | 25 mothers (children/adult children aged 1–31 years) | USA: HIV-infected mothers were recruited from HIV service organizations with HIV-infected and uninfected children | Children were not assessed. The study investigated the impact of HIV disease on the interpersonal relationships and social support experiences of mothers living with HIV. Most mothers struggled with whom to disclose to among their social networks, because of the fear of stigma. Reasons cited for disclosure to others included the need for social support, wanting to educate others, doing the right thing and relieving themselves from the burden of keeping the secret. Fear of stigma was the most cited reason for nondisclosure. Most women had disclosed their children's HIV diagnosis to the children. Most uninfected children that were disclosed to were reported to be accepting, loving and protective after disclosure. Most children reminded mothers to take their medication. Some children asked for more information about HIV/AIDS. Few children were perceived to be angry after disclosure. The majority of mothers had made custody plans for their children. Most mothers of pre-adolescents and adolescents had explicitly talked about safe sex with their children | [130] |
| Schrimshaw and Siegel (2002) | Cross-sectional; qualitative | 45 mothers (children aged ≤25 years) | USA: Subsample of HIV-infected mothers were recruited from a larger sample of women who participated in a study of psychosocial adaptation to living with HIV/AIDS | Children were not assessed. Disclosure rates were 66%. Main reasons for wanting to disclose to children included: educating children about HIV, wanting to be honest with children, wanting to be the ones disclosing to children and wanting to disclose before mothers became ill with HIV | [49] |

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**Table 1. Studies relating to adolescents in the USA, Canada and Europe (cont.).**

| Author (year) | Study design | Sample | Location and participant recruitment | Findings | Ref. |
|---|---|---|---|---|---|
| Black and Miles (2002) | Longitudinal; qualitative | 48 mothers (children's ages not specified) | USA: HIV-infected mothers were recruited from infectious disease clinics. Data from a larger randomized clinical intervention study with HIV-infected mothers were used | Only mothers were assessed. Fear of being stigmatized once their status was known to others was a major theme; mothers therefore weighed risks and benefits of disclosure to others. Three general patterns of disclosure among women were observed; secretive (keeping a secret to all but few trusted individuals), full (disclosed to all relevant adult relationships) and selective disclosers (disclosure to selective individuals in the family but not outside). Weighing risks and benefits was an ongoing process but was disrupted at times when family members or healthcare professional betrayed mothers' confidence. Most children were not disclosed to because mothers felt they were too young and might disclose to others. Many women planned to disclose to children when they were older but no specific age was mentioned | [131] |
| Brackis-Cott *et al.* (2003) | Longitudinal; qualitative | 30 mothers and 28 adolescents (10–15 years) | USA: HIV-infected mothers and their uninfected children were recruited from HIV clinics and community-based organizations. The participants were part of a larger study investigating sexual behaviors and drug behaviors of HIV-affected adolescents | The focus groups explored concerns and priorities of HIV-affected families. The main concerns for adolescents were sexual behaviors, safety, violence and drugs. Adolescents reported they were also concerned about positive life choices such as getting good grades. Some adolescents reported that their mothers' HIV had brought them closer with them. Some adolescents admitted that at times they were scared, sad, angry and concerned about their mothers' health and hoped for a cure for HIV. Mothers reported the same main concerns for adolescents such as sexual behaviors, safety, violence and drugs. Mothers were worried about bringing up children of this age group. HIV-related stigma, disclosure, becoming ill and having adolescents taking adult roles were other concerns expressed by mothers | [73] |
| Vallerand *et al.* (2005) | Longitudinal; qualitative | 35 mothers and 19 children (10–18 years) | USA: HIV-infected mothers and HIV-uninfected adolescents were recruited from a longitudinal study of persons living with HIV | Reasons for disclosure included: protecting adolescents from HIV, feeling adolescents were developmentally ready and fear of forced disclosure if health status deteriorated. Reasons for nondisclosure included: the child would not understand because of their developmental status and fear of stigma. Mothers and adolescents reported different perspectives of the disclosure event. Most mothers' reports were positive, while most adolescents (18 out of 19) reported negative perspectives of the disclosure event | [52] |
| Woodring *et al.* (2005) | Cross-sectional; qualitative | Nine adolescents (11–17 years) | USA: HIV-uninfected adolescents who were aware of their parents' HIV diagnosis were recruited from a mentoring program and support group for adolescents affected with HIV/AIDS | Most adolescents needed their friends' support because of their parents' HIV infection, but feared friends might have negative reactions. Transition to high school made adolescents realize the impact parents' diagnosis had on them. Many adolescents reported they started skipping school after disclosure because they felt demotivated by life events. Some adolescents endeavored to achieve good grades at school so as not to stress parents and lower parents' immune system. Most adolescents appreciated sharing with others with similar circumstances in support groups | [13] |

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**Table 1. Studies relating to adolescents in the USA, Canada and Europe (cont.).**

| Author (year) | Study design | Sample | Location and participant recruitment | Findings | Ref. |
|---|---|---|---|---|---|
| Kennedy *et al.* (2010) | Cross-sectional; qualitative | 33 parents, 15 caregivers and 46 children/adults (≥18 years) | USA: HIV-infected parents were recruited from the HIV cost and services utilization study [125] about their memory of disclosure | Only children with prior knowledge of maternal HIV status were included. All parents had disclosed to one or more children. Most common reason for waiting was children's perceived lack of maturity. Families reported that sometimes children gave immediate emotional support by displaying affection. Increased familial closeness was reported over time as a result of disclosure | [72] |
| Dematteo *et al.* (2002) | Cross-sectional; qualitative | 51 adults and 54 adolescents (5–19 years) | Canada: same cohort as Dematteo (one of the quantitative studies above [54]) but used qualitative methods. HIV-infected and HIV-uninfected adults from HIV-affected families and HIV-infected and HIV-uninfected children were interviewed retrospectively (from 1995 to 1998), recruited from the pediatric HIV program at the Hospital for Sick Children in Toronto and AIDS service organizations | Minimum age for children was 5 years, no maximum age was set. Disclosure involved telling the child about their own, parents' or family members' HIV infection. Because participants were interviewed retrospectively, most children who had been disclosed to at a younger age (before age 11 years) felt the right age for disclosure should be 11 years. More girls than boys were disclosed to prior to age 11 years. A total of 86% of children said they were disclosed to at the right time or age and 91% said they were disclosed to in a good way. Trust was a major theme upon which disclosure decisions rested for both parents and children | [54] |
| Nöstlinger *et al.* (2004) | Cross-sectional; qualitative | 13 caregivers and 27 children (children aged ≤17 years) | Belgium: caregivers living with HIV recruited from Flemish AIDS reference centers | Children were not assessed. Every consecutive patient was offered a survey and, in addition a small-scale qualitative study was conducted among 13 African caregivers of 27 children, disclosure rate was 10%. However, those who did not disclose expressed that they were not convinced they had taken the right decision. Reasons for not disclosing included: disclosure would be too emotionally disturbing for the child, the child was too young, stigma-related negative consequences, perceived incapability to disclose and no perceived benefits of disclosure for the child | [37] |
| Åsander *et al.* (2009) | Cross-sectional; qualitative | 47 parents and 87 children (≤18 years) | Sweden: a subset of 773 HIV-infected immigrants of African origin living in Sweden and receiving healthcare at two departments of infectious diseases were recruited | Parents and children interviewed. Disclosure was rate was 12%. Median age for disclosure was 11 years. Only mothers disclosed to their children, no fathers disclosed. Five out of 87 children were HIV-infected and none knew about their own infection. The majority of participants, 30 out of 47, had a custody plan for their children in case they were orphaned in Sweden | [38] |

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**Table 2. Studies relating to adolescents in Asia and Africa.**

| Author (year) | Study design | Sample | Location and participant recruitment | Findings | Ref. |
|---|---|---|---|---|---|
| Dane (2002) | Cross-sectional; qualitative | 26 women (children aged 3–19 years) | Thailand: HIV-infected mothers recruited from a home care program when they came for their clinic check-ups | Only mothers were interviewed. Eleven out of 26 mothers disclosed to their children. The majority of mothers requested that children keep disclosure a secret in order to protect them from stigma at school. All mothers were widowed due to AIDS and all reported that their husbands were infected through prostitutes. Twenty five out of 26 mothers disclosed to other members of their families | [39] |
| Xu *et al.* (2007) | Cross-sectional; qualitative | 16 caregivers, five key informants and 16 children (8–17 years) | China: HIV-negative children affected by HIV, their caregivers and key informants were recruited through local health service providers working with HIV-infected people in the community | The majority of children were orphans (11 out of 16). Only three out of 16 children knew their parents' HIV diagnosis. Most children were cared for by their grandmothers. Two main reasons for disclosure were: children heard other people talking about HIV and asked about medication taken by caregivers. Reasons for nondisclosure included: children were too young to understand, caregivers did not know how to answer questions about HIV, and children might tell other people about caregivers' status and the family would be stigmatized | [59] |
| Thomas *et al.* (2009) | Cross-sectional; qualitative | 60 mothers (over 40% of children aged ≥10 years) | India: HIV-infected mothers were recruited from two maternity hospitals, sexually transmitted infection clinics and an HIV-treatment clinic in a government hospital | Children were not assessed. Majority of mothers agreed that disclosure was a very sensitive issue and were mostly concerned about stigma. Some stated that it was best not to disclose to children until they were older; an age of 15 years was perceived to be appropriate for disclosure. The majority reported stigmatization by doctors and other healthcare workers in accessing healthcare | [57] |
| Zhou *et al.* (2012) | Cross-sectional; qualitative | 39 parents and 93 children/adults (8–21 years) | China: HIV-infected parents with uninfected children were recruited from voluntary counseling and testing clinics | Twenty two out of 93 children were disclosed to. A total of 67% of participants were male and the majority of disclosers were men. Approximately 27% of fathers and 15% of mothers had disclosed to one or more children. Half of disclosers were on ART. Reasons for nondisclosure included: children are too young to understand, fear of stigmatization, concerns about children's study and concerns about increased psychological burden to children | [60] |
| De Baets *et al.* (2008) | Cross-sectional; qualitative | 61 primary healthcare workers and 131 community members | Zimbabwe: participants were recruited from primary healthcare centers and a community in rural Zimbabwe | Children were not assessed. Partial disclosure (disclosing an illness but not specifically HIV) was preferred for 10 year olds, and full disclosure (disclosing that the mother has HIV) was preferred for adolescents. More than 63% of the participants would want to disclose their HIV-status to children when they were aged older than 6 years rather than younger children | [61] |
| Rwemisisi *et al.* (2008) | Cross-sectional; qualitative | Ten parents, directors of HIV support organizations and HIV counselors (children/adults aged 4–36 years) | Uganda: participants were recruited from the AIDS support organization | Only adults were interviewed. Half the mothers had disclosed their HIV-status to their children. Disclosure was mainly for the sake of children and next of kin who would be left behind in case the mother died, so they would know the truth and not suspect witchcraft as the cause of death. Four out of five of those who disclosed reported supportive reactions from children. Reasons for nondisclosure included: uncertainty about the appropriate age to disclose and lack of perceived benefits for children. Healthcare staff reported lack of training and policy on maternal disclosure | [20] |

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Table 2. Studies relating to adolescents in Asia and Africa (cont.).

| Author (year) | Study design | Sample | Location and participant recruitment | Findings | Ref. |
|---|---|---|---|---|---|
| Palin *et al.* (2009) | Cross-sectional; quantitative | 103 mothers (children aged 11–16 years) | South Africa: HIV-infected mothers recruited from three communities in Pretoria through AIDS organizations | Children were not assessed. Disclosure was assessed by a questionnaire specifically developed for the study. A total of 44% mothers reported that their children were aware of mothers' HIV infection. Of all disclosures, 96% were reported to have been done by mothers themselves. Most cited reasons for not disclosing included: the children would be disturbed psychologically, and they would not be able to keep a secret | [62] |
| Nam *et al.* (2009) | Cross-sectional; qualitative | 21 parents (children aged 5–18 years) | Botswana: participants on ART were recruited from two clinical sites: a specialist public-sector ART clinic and a private general family practice | Parents reported that professional support was needed in order to manage age-appropriate disclosure, especially because traditionally parents did not talk about sexual and reproductive health topics with children | [23] |

*ART: Antiretroviral therapy.*

research. Given the maturity and demographics of the HIV epidemic in the USA, most of the research to date on maternal disclosure has been undertaken among low-income African–American families [36]. Several more recent studies have emerged from Europe, important given the high levels of African immigration to this region (see for example [38]) [37–39]. Of the 58 studies, 43 (75%) have been conducted in the USA [18,21,25–32,40–53], one in Canada [54], four in Europe [37,38,55,56], six in Asia [35,39,57–60] and only four in sub-Saharan Africa (**Figure 1**) [20,23,61,62].

Although the largest population of HIV-infected parents live in Africa, very little research has examined maternal HIV disclosure in this region [22] and, to date, there are no reported intervention studies [14]. Similarly, the international research on maternal HIV disclosure is mostly descriptive, is almost exclusively conducted in resource-rich settings, with few studies reporting on interventions, and hardly any targeting children under the age of 12 years [14]. Only 13 studies were reported with primary school-aged children [9,16,25–35]; seven of these are by the same author [25–31], and six [25,27–31] use the same cohort in the USA. The pilot intervention trial (the TRACK program; Teaching, Raising And Communicating with Kids program [26]), designed to prepare HIV-infected mothers for disclosure to their children aged 6–12 years, showed that mothers in the intervention group were six-times more likely to disclose their HIV status to their HIV-uninfected primary school-aged children than those in the control group over a 9-month follow-up period (33 vs 7.3%) [26].

Published studies show that HIV disclosure rates to children vary across studies from as low as 11% [37,38,56,59] to as high as 84% [41–43,49,63], with most studies reporting rates between 30–45% [32,47,53,54,62,64,65]. In one of the few studies with nationally representative samples of HIV-infected adults in the USA, Corona *et al.* reported disclosure to be 44%, with 90% of the children that were disclosed to, also being informed that HIV or AIDS might lead to their parents' death [65]. Research suggests that mothers are willing to disclose once children reach primary school-going age [36], but do not feel equipped to do so for a variety of reasons, including feeling unsure of the appropriate age to undertake disclosure, not feeling confident about how to answer HIV-related questions their children might ask, and not having age-appropriate tools to help them during the disclosure process [20,23,30,37,46,57,59,62,65,66].

**Table 3. Studies relating to primary school-aged children in the USA and Europe.**

| Author (year) | Study design | Sample | Location and participant recruitment | Findings | Ref. |
|---|---|---|---|---|---|
| Armistead *et al.* (1999) | Cross-sectional; quantitative | 231 mothers and 231 children (6–11 years) | USA: HIV-infected mothers were recruited from an HIV outpatient program clinic and were part of the Family Health Project [132]. HIV-uninfected mothers were recruited through schools in which their children were enrolled | Both HIV-infected and uninfected mothers were recruited. Understanding of illness and HIV were compared between two groups using a protocol developed by the investigators, adapted from the conception of health and illness questionnaire and concepts of AIDS protocol. There was no difference in children's understanding of HIV between the two groups; both groups showed little or no understanding. Mothers from both groups also showed no understanding of HIV (63% mothers of 8–9 year olds vs 47% of mothers of 10–11 year olds) | [33] |
| Armistead *et al.* (1999) | Cross-sectional; quantitative | 100 mothers and 100 children (6–11 years) | USA: HIV-infected mothers with 6–11 year old HIV-uninfected children recruited from the HIV outpatient program clinic | Participants were part of the abovementioned Family Health Project [132]. Children were not assessed. The study investigated disclosure patterns to partner, mother, father, children, extended family and friends. A total of 94% of women had disclosed to at least one of the above categories; however, only 23% had disclosed to their 6–11-year-old children. The majority of women had disclosed to their mothers (66%), more than half (56%) to partners and disclosure to women's own fathers was lowest (23%) | [34] |
| Armistead *et al.* (2001) | Cross-sectional; quantitative | 87 mothers and 87 children (6–11 years) | USA: HIV-infected mothers and their HIV-uninfected children were recruited as part of the Family Health Project [132] | Mothers and children were assessed. Disclosure rate was 30%. Older children were more likely to be disclosed to than younger children. Girls were more likely to be disclosed to than boys. Approximately half of the children (47.8%) were perceived by their parents as reacting in a positive manner following disclosure, while 17.4% were fearful, 8.7% disappointed, 8.7% angry, 4.3% rejected mothers and 13.5% did not show any reactions. Disclosure was not significantly predictive of either maternal or child reports of internalizing problems nor was it significantly predictive of mother or child reports of externalizing behaviors using the child behavior checklist | [16] |
| Shaffer *et al.* (2001) | Longitudinal; quantitative | 99 mothers and 99 children (6–11 years) | USA: HIV-infected mothers with HIV-uninfected children were recruited from a primary health clinic that treated women with HIV | Mothers and children were assessed. Disclosure was associated with increased externalizing behaviors using a child behavior checklist. 68% of children did not know their mothers' status. Of the children disclosed to, 81% were female. Most children were disclosed to by age 10 years. A total of 79% of those who had not disclosed reported that they planned to disclose eventually when they perceived children to be mature enough to understand | [32] |
| Murphy *et al.* (2001) | Cross-sectional; quantitative | 135 mothers and 135 children (6–11 years) | USA: HIV-infected mothers with HIV-uninfected children were recruited from 11 primary care sites and three AIDS service organizations | Mothers and children were assessed. Disclosure rate was 30%. Children who had been disclosed to did not exhibit higher psychological distress; they showed lower levels of aggressiveness and negative self esteem as measured by the Child Behavior Checklist and Child Depression Inventory compared with those who had not been disclosed to. Reasons cited for nondisclosure included fear that: the child was too young (85%), child would disclose to others (42%), child would misbehave (21%), child would be angry and withdrawn (18%), child would be afraid of mother (17%) or child would lose respect for the mother (9%) | [31] |

**Table 3. Studies relating to primary school-aged children in the USA and Europe (cont.).**

| Author (year) | Study design | Sample | Location and participant recruitment | Findings | Ref. |
|---|---|---|---|---|---|
| Bauman *et al.* (2002) | Cross-sectional; quantitative | 193 mothers and 193 children (5–12 years) | USA: HIV-infected mothers were recruited from the New York City Division of AIDS | Both mothers and children were assessed. Mothers in the sample were physically sick and many had serious psychological symptoms when assessed using the number of hospitalizations, number of bed days and the presence of opportunistic infections and psychiatric symptom index. Children were assessed with the child behavior checklist among other measures. A total of 39% of mothers had not disclosed to children, 16.9% told children they had a health condition, 5.1% told children they had a serious health condition, 30.3% disclosed that they had HIV/AIDS and 8.2% told children they had an illness they could die from. Children of mothers with higher psychiatric symptom index values had higher child behavior checklist scores | [9] |
| Murphy (2002) | Longitudinal; quantitative | 81 mothers and 81 children (6–11 years) | USA: from the above Murphy *et al.* 2001 cohort [31], data from a subset of 81 mothers were analyzed | Mothers and children were assessed. Children's depression was assessed using the child depression inventory and behavioral adjustment was assessed using the child behavior checklist. A total of 93% of mothers were on antiretroviral therapy. Better maternal health status and higher CD4 cell counts were associated with decrease in negative mood in children. Children whose mothers had not disclosed showed higher negative self-esteem scores than children whose mothers had disclosed | [28] |
| Murphy *et al.* (2009) | Longitudinal; quantitative | 135 mothers and 135 children (6–11 years) | USA: a longitudinal follow-up of participants in the Murphy study [31] discussed above | Mothers and children were assessed. This study assessed the efficacy of selected variables from the 'parents and adolescents coping together' model designed by the investigators to predict maternal HIV effects on child/adolescent outcomes. The 6–12 year olds who were enrolled earlier were followed up when they were transitioning to early–mid adolescence (13 years upwards). Disclosure was associated with higher depression as measured by the Children's Depression Inventory, however, negative self-esteem decreased and household responsibilities increased in children over time | [27] |
| Murphy *et al.* (2011) | Longitudinal quantitative | 80 mothers and 80 children (6–11 years) | USA: HIV-infected mothers and HIV-uninfected children were recruited through HIV/AIDS service organizations and randomized to intervention or control groups | The Teaching, Raising, And Communicating with Kids study – a longitudinal pilot-trial intervention designed to assist mothers living with HIV to disclose their HIV-status to their primary school-aged children. Those in the intervention group were six-times more likely to disclose their HIV status to their children than those in the control group (33 vs 7.3%). A total of 69% of those who disclosed reported that children reacted positively to disclosure. None of the children who were disclosed to were reported to have been (upset) crying or angry after disclosure. Overall, the intervention group showed increased communication between mothers and children comparing baseline and to 9-month follow-up period. The intervention had positive outcomes for both mothers and children such as improved family cohesion. Happiness and greater freedom from anxiety was noted in the intervention group using the Piers–Harris Anxiety and Happiness Scale | [26] |
| Murphy *et al.* (2002) | Longitudinal; qualitative | 47 mothers and 47 children (7–14 years) | USA: qualitative data from Murphy *et al.* [31] were collected from a subset of mothers who had disclosed their HIV-status to their children | Mothers and children were interviewed. The aim of the study was to explore how mothers communicated with children about disclosure. The majority explicitly asked children to keep disclosure a secret because they feared stigma for both themselves and the children. Approximately one quarter of mothers identified 'safe people' that the child could share the maternal HIV status with. Qualitative interviews with children indicated that the burden of keeping a secret caused stress and they worried that they could not talk to anyone about maternal disclosure | [29] |

Table 3. Studies relating to primary school-aged children in the USA and Europe (cont.).

| Author (year) | Study design | Sample | Location and participant recruitment | Findings | Ref. |
|---|---|---|---|---|---|
| Murphy *et al.* (2003) | Longitudinal; qualitative | 47 mothers and 47 children (6–11 years) | USA: mothers who had disclosed their HIV status to their children in Murphy *et al.* [31] were qualitatively interviewed about preparation and the process of the disclosure event | Mothers and children were interviewed. Most mothers did not regret disclosing. However, those who did not plan disclosure regretted not having prepared themselves. Mothers who disclosed recommended self-preparation with a well-planned disclosure approach and content, and recommended control of emotions to make the event less stressful for the child. Most mothers felt that the best age to disclose is 6–10 years | [30] |
| Murphy *et al.* (2006) | Longitudinal; qualitative | 47 mothers and 41 children (6–11 years) | USA: qualitative data from Murphy *et al.* [31] were collected from a subset of mothers who had disclosed their HIV status to their children | This study investigated the impact of disclosure of maternal HIV infection to young children (aged 6–11 years). Only children who volunteered knowledge of their mother's HIV-infection were interviewed (41 out of 47). Half of the children did not have an immediate reaction to disclosure. Approximately half of children reported no worry following disclosure. Other reactions after disclosure included anxiety about maternal health, fear of maternal death and worry about HIV stigma. Some children offered reassurance that they still loved their mothers. More than half became protective of their mothers, especially their physical health, reminding them to take their HIV medication. Over time anxiety decreased among the majority of children and they appeared to adjust well following disclosure | [25] |

The decision to disclose or not is most commonly linked to the age and gender of the child, and the stage of disease or illness of the mother [16,36,41,52]. While few mothers disclose their HIV status to a child before the age of 7 years, many are forced to do so during HIV-related illnesses or hospitalization, which has been shown to impact negatively on a child's emotional and behavioral outcomes [14,41,43,47,52,65]. Mothers who deferred disclosure until adolescence reported more behavioral and emotional difficulties in their children than those who disclosed pre-adolescence [41,43,47,52,65].

One of the limitations in the disclosure literature is the lack of studies that address paternal disclosure of HIV status to children; only 18 of the 58 studies reviewed (31%) included fathers as participants [56]. A study conducted with parents in the USA found that mothers were more likely to disclose their status, and to disclose earlier, compared with fathers [41]. In a qualitative study, fathers did not want to disclose their status to children because of concerns that they would not understand about HIV, while the mothers who delayed disclosure did so because they wanted their children to enjoy a normal childhood [54]. Compared with fathers, mothers were more likely to use written materials such as books and pamphlets when they were preparing for disclosure [54].

A further limitation of the maternal disclosure literature, and a consequence of most papers emanating from the USA, is a lack of exploration of differences in sociocultural factors across regions. In the sub-Saharan context, sociocultural factors that might influence maternal disclosure include the presence of HIV-related stigma [20,23,61,62,67] and social exposure to HIV, with more children being exposed to HIV at younger ages and often witnessing several family members living with HIV [68]. In studies conducted in Africa, some mothers have expressed discomfort in talking to their children about sexuality, as such issues are considered taboo [23,68,69]. The same discomfort extends to talking to children about illness and death [68,69].

However, it is reasonable to hypothesize that maternal HIV disclosure interventions in Africa could benefit families in similar ways to the developed world. These benefits could include increased family cohesion [21,31], improved antiretroviral therapy (ART) adherence by HIV-infected mothers [21,42], consideration about custody planning for children [42], improved maternal mental health [22] and increased social support for the mother and child following disclosure [18,31].

It is possible that issues such as gender inequality, discrimination and stigma, and the complex nature of HIV epidemiology (with the epidemic being generalized rather than concentrated in specific risk groups) may limit the applicability of western models in Africa [70]. We therefore recommend further research in high HIV prevalence regions and suggest that a balance needs to be sought between what is culturally appropriate and what has been shown to work in the developed world.

## Lessons learnt from maternal disclosure studies

### Reasons for maternal disclosure

Studies report a variety of reasons given by mothers desiring to disclose their HIV status to their children [16,20,39,42,49,53]. These are remarkably similar across all studies, regardless of geographical situation. The most often cited reason for wanting to disclose was practical, including not wishing the child to discover the mother's status from someone else. The most common reasons for nondisclosure were more emotional, such as perceiving that the child was too young to understand about HIV or illness, and concerns that the child would be distressed or tell someone else (**Box 1**). Interestingly, in a recent study from China examining secondary disclosure of maternal HIV status by children, a high proportion of children did not want to disclose maternal HIV status to others [71].

### Benefits of disclosure for mothers & their children

Numerous studies have suggested that maternal HIV disclosure has benefits for mothers in terms of mental health, healthcare behaviors including adherence to HIV medication, family relationships and support [16,26,41,42,47,49,52,53,65,72]. Ensuring timely, age-appropriate disclosure of maternal status to HIV-uninfected children has also been shown to increase the quality of custody and emergency care planning for children living in HIV-affected families [38]. Similarly, several studies have shown improvements in children's emotional and social functioning, with children reporting feeling better prepared for the future, more involved in family decision-making, closer to their mothers and less afraid following maternal HIV-disclosure [14,21,28,31,42,49,73]. While children's first reaction to disclosure might include worry, shock, anger or sadness, there is consensus in the literature that younger children, in particular, exhibit no significant long-term adjustment problems as a

**Table 4. A study relating to primary school-aged children in Asia.**

| Author (year) | Study design | Sample | Location and participant recruitment | Findings | Ref. |
|---|---|---|---|---|---|
| Ishikawa *et al.* (2010) | Longitudinal; qualitative | Nine caregivers, 12 teachers and eight children (10–13 years) | Thailand: HIV-uninfected orphans were recruited through schools if their families had already disclosed to school authorities | Five out of nine caregivers did not disclose the parents' positive status because they feared negative impact of disclosure to children. All five caregivers were grandmothers. Four out of nine caregivers, including two HIV-infected mothers, had disclosed maternal HIV status to children. Six out of eight children interviewed already knew maternal HIV status through their neighbors. Nine out of 12 teachers reported that there was no bullying and discrimination related to HIV, but there had been in the past; however, seven out of eight children reported that they had been bullied and stigmatized by their peers in school | [35] |

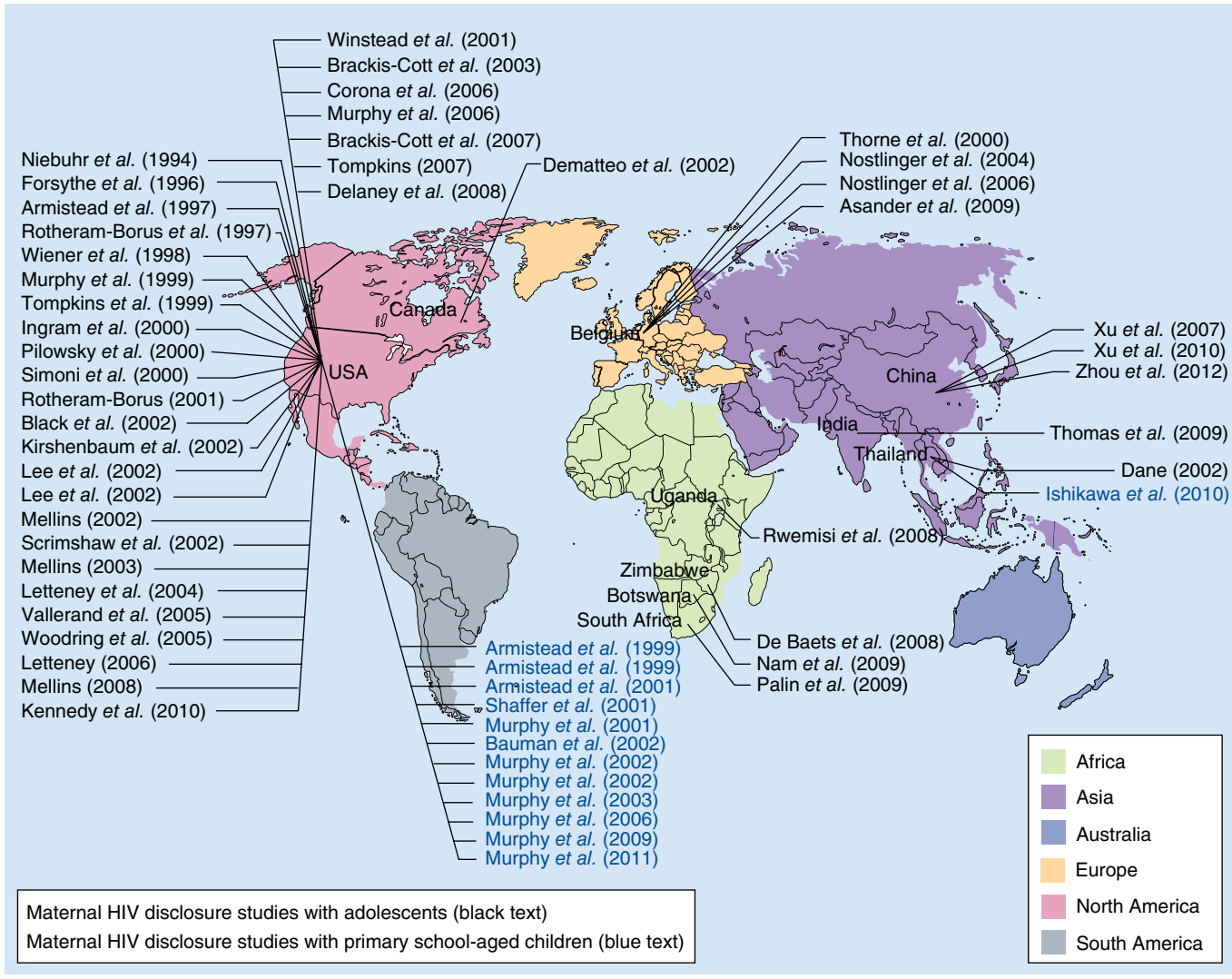



**Figure 1. A global overview of maternal HIV disclosure studies.**

result of HIV disclosure [16,21,24,64]. Maternal HIV may become normalized in children's lives, especially if the mother's health remains good. The literature suggests that few mothers regret disclosing, and that disclosure improves the quality of the mother–child relationship and increases the mother's social support network (**Box 2**) [30].

### Theoretical approach to maternal HIV disclosure for children

Research examining child development and HIV disclosure has focused on the disclosure of HIV to HIV-infected children. In 1999, the American Academy of Pediatrics first published guidelines on HIV disclosure, emphasizing that disclosure should be viewed as an ongoing process involving parents, children and healthcare providers, and not as a one-off event [74]. The importance of this approach to disclosure is also supported by research in southern Africa [75]. More recently, recognizing the scale and impact of the HIV epidemic in resource-limited settings, the WHO released a systematic review and guidelines on HIV disclosure for children up to 12 years of age, recommending that they should be told about their own or their parents' HIV status at primary school age [76]. These documents also highlight the importance of understanding a child's developmental stage in considering HIV disclosure, and the limited availability of research on interventions for HIV-uninfected children living with HIV-infected parents [76].

The few published intervention studies, including the work of Murphy *et al.* [26], have tended to rely on adult models for understanding HIV-disclosure, including the integrative disclosure theory [77] and the HIV disclosure process model [78,79]. These adult models focus on factors that influence decisions to disclose,

and do not address the complexities of disclosure involving children, for example maternal and child characteristics [14], the family environment and culture [80], and stigma [81]. A further critique of using adult models of disclosure for parent–child interventions is the narrow focus that disclosure is a process between two individuals (i.e., in this case a parent and a child), an assumption which ignores the complexity of the family environment in which the parent–child dyad is embedded [72].

In the childhood chronic disease literature Bibace and Walsh developed one of the first models to inform our understanding of a child's developmental capacity to understand their own, or their parents' illnesses [82]. According to this model, children aged 7–10 years are considered to fall into a stage known as the 'concrete–logical stage', where distinctions of self and other, and the assigning and understanding of internal and external causes of disease become more developed. As a result children begin to understand something that is known as the 'concept of contamination'; that many diseases are caused by factors whose origin is external to the body (e.g., bacteria and viruses), but that illness itself is internalized within the human body. The Bibace and Walsh model has evolved and developed and has been applied and validated for many illnesses [82]. However, in general, research in the area of childhood understandings of disease is critiqued for its methodological weaknesses, small sample sizes, observer bias and poor attention to reliability and validity [83].

More recent literature specific to managing parental terminal illness has further informed what we understand about a child's developmental capacity to understand parental illnesses such as cancer and HIV [84]. Findings show that providing age-appropriate information at the time of illness disclosure is key to ameliorating the impact of later parental loss, and has a positive impact on a child's well being. Children aged between 6 and 8 years, when confronted with parental terminal illness, may have difficulty containing emotions, are likely to blame themselves when bad things happen and can easily misunderstand the cause and effect of events. If a child misinterprets the reason for parental ill health, this can be difficult to correct later [84]. Key points that can be drawn from a developmentally sensitive approach to discussing terminal illness include:

- Provide the child with well-timed illness-related information [23,46,85];
- Repeat the information, in addition to carefully explaining what the child will observe and what the child should expect [36,84];
- Offer frequent reassurance to the child that they will be looked after, even in difficult circumstances [11,12,86];
- Allow and encourage the child to initiate conversations about the illness and to ask questions [14,16];
- Reassure the child that being upset is a normal and accepted response [14,36].

Both this broader literature, and the literature on the process of disclosure of maternal HIV to children suggests that the quality of the disclosure event, especially how it is planned and executed, can influence the child's ability to cope with the information in the future [14]. The existing HIV intervention literature offers few examples of interventions that are developmentally framed, offer age specific information on HIV, and that have been tested in high-HIV-prevalence settings such as southern Africa.

## Future perspective

The literature presented in this article introduces a number of challenges for the design and scale-up of maternal disclosure interventions in high HIV prevalence settings where they are most needed. Evidence suggests that HIV-infected men and women with access to HIV treatment express desires and plans to have further children despite their status, and thus the challenges of maternal HIV disclosure will continue for at least another decade [87–89]. A key issue for disclosure research in sub-Saharan Africa is how maternal HIV disclosure should be undertaken, how best to help HIV-infected mothers, and how to support healthcare staff in high-HIV-prevalence, low-resource areas to facilitate this process that we already know is fraught with its own challenges.

Following a systematic review and meta-analysis [90], there is growing support in prevention and implementation science for a shift in focus to positive prevention. This concept targets HIV-infected individuals, with the expectation of a broader impact among the multiple HIV-uninfected individuals in relationships with them. While most positive prevention has focused on serodiscordant couples, maternal HIV disclosure interventions scaled through HIV treatment programs may offer one such opportunity to maximize and strengthen the

**Box 1. Reasons given by mothers for disclosure and nondisclosure of their HIV status.**

***Reasons for disclosure***

- Practical reasons:
  - Wanted children to hear their HIV status from them and not from other people [49,53,63]
  - Wanted to respond to their children's questions about HIV/AIDS after hearing about HIV from others or observing their parents taking medication [53,59]
  - Wanted to educate their children about HIV and protect them from HIV [49,54]
  - Concerned that their own health was deteriorating [16,41,52]
  - Felt children were developmentally ready for disclosure [52]
  - Wanted to make arrangements for their children's future [46]
  - Sought support from their children [20,57]
- Moral reasons:
  - Felt that disclosure was the right thing to do [46]
- Emotional reasons:
  - Did not want to keep their HIV status a secret from their children any longer [46]

***Reasons for nondisclosure***

- Practical reasons:
  - Did not know how to disclose [20,23,31,65]
  - Lacked perception of benefits of disclosure for children [19,20,37]
  - Concerned that children might ask how their mothers got infected [46]
  - Perceived inability of children to keep secrets [31,46,57,62,65]
- Emotional reasons:
  - Felt their children deserved a worry- and care-free childhood [46,54,63]
  - Concerned about children internalizing problems [31,37,49,59,62,65]
  - Felt children were too young [23,31,37,49,59,60,126]
- Stigma-related reasons:
  - Wanted to protect children from stigma [23,25,35,37,42,52,57,59,60,126]

capacity of HIV-infected mothers to continue to prevent infection in their HIV-uninfected children long after successful completion of prevention of mother-to-child transmission. Conceptualizing this in the sub-Saharan context introduces several feasibility challenges. Feasibility challenges for the sub-Saharan context include where the intervention is to be conducted (family setting or health facility), who the unit of the intervention is (individual or family), what human resources are available to conduct the intervention (healthcare staff or community health workers) and how the interventions can be scaled up. These are discussed below.

### The family as a context for interventions

The review by Kennedy *et al.* illustrates the point that many HIV-infected individuals have limited contact with healthcare settings, and given resource limitations it is reasonable that contacts in clinical settings should focus on the initiation and management of HIV treatment [90]. Leverage of the home and family context may thus be an important intervention design element. There is growing acknowledgement of the key role played by families in managing the burden of HIV care in southern Africa [20,23,61,62,91,92]. While there is increasing acknowledgement of the central, supportive and educational role that parents play for their children, and of the importance of family-centered services in the context of HIV, interventions that render services to children in the family context in high HIV prevalence areas have been slow to emerge [93]. Instead, HIV interventions frequently emphasize settings outside the family, such as healthcare facilities where professional assistance can be sought, possibly with the implicit message that these external efforts are needed to compensate for the failure or limitations of parents [94]. Children stand to benefit from models that strengthen and engage families and focus on building parents' capacity to provide psychological and social care for their children within the family.

The concept of families in Africa is complex and more broadly defined than the traditional nuclear family, and frequently includes the extended family [92]. Research undertaken in southern Africa indicates that most children live in the same households as, and are raised by, their biological mothers [95]. However, due to migrant labor many African communities are mobile, resulting in children being absorbed into extended families, and being raised by other caregivers including fathers, grandmothers and aunts [92]. Qualitative research in South Africa has highlighted the interconnectedness of households, suggesting that 'households are not isolated from events occurring in their immediate social networks as well as elsewhere in the community' [92]. These extensive social networks have historically provided support such as fostering and adoption to children in times of crisis [68]. Intervention research around HIV disclosure needs to consider not just the mother, but all the possible primary caregivers of the child.

Research on health behavior change in chronic illness suggests that the characteristics of family relationships that are important to facilitate effective and consistent management of chronic disease include the fact that family relationships persist over time, are emotionally intense and involve high levels of intimacy in day-to-day life [96]. Family-centered HIV disclosure support approaches are thus likely to be effective because it is in the context of family life that we expect health-related behavior changes to occur [97].

Intervention studies that involve other family members are more common in childhood than in adult diseases [96], including research on childhood diabetes [98–100], asthma [101,102], cystic fibrosis [103] and cancer [104]. These interventions included giving information on disease management and psycho-education to child and adult, strategies to improve the quality of family relationships and functioning, or provision of direct family therapy.

### Supporting maternal skills & care-giving capacity

While there is a clear need for further research demonstrating models for effective maternal HIV disclosure, and an increasing focus on the family as the unit of intervention, there is less consensus on the methods of intervention. One of the reasons cited by mothers for not undertaking disclosure with their children is being unsure how to initiate the discussion and how to proceed thereafter, in particular how to impart difficult information about potentially serious illness and how to address questions that may include issues relating to death or sexual relationships [20,23,46,59,65].

Examples of structured interventions that focus on passing on skills and competencies to parents are available in the literature outside of HIV. One example is breastfeeding support where simply providing information about the benefits of breastfeeding alone does not necessarily lead to increased rates of exclusive breastfeeding [105]. However, several interventions, led by breastfeeding counselors and based on training from the WHO breastfeeding counseling course [106], supported mothers with practical and problem-solving skills, and demonstrated substantial increases in exclusive breastfeeding rates [107–109]. What can be learned from the breastfeeding example is the importance of standardized intervention approaches and developing generalized training models based on a train-the-trainer approach, minimum standards of competence in both the trainers and participants, and the development of counseling skills in those being trained.

A recent review examined core concepts and key practices that resulted in successful interventions with families affected by HIV in the USA, Thailand and South Africa [110]. Several lessons can be drawn from this review that are of relevance to skills building for maternal HIV disclosure. These include positive framing of the desired behavior change using a strengths-based approach focused on family wellness as opposed to HIV illness management; addressing barriers to change; and providing information in a manner that makes it practical and applicable to real life. The interventions themselves included demonstration tools, games and activities, as opposed to simply giving information; building of cognitive and behavioral skills using techniques that increased relaxation and self awareness; and skill building in evaluating options and the consequences of decisions.

**Box 2. Benefits of maternal disclosure of HIV status to children.**

***Benefits to the mother***

- Psychological benefits:
  - Relieved the burden of secrecy and resulted in supportive responses from others [49]
  - Improved mothers' mental health by decreasing stress related to keeping HIV status a secret [133]
  - Improved maternal mental health and healthcare behaviors [42]
  - Increased social support resulting in decreased depression, stress and anxiety [16,47,53,63]
- Social and physical health benefits:
  - Mothers reported higher levels of social support [18,31]
  - Improved physical health due to behavioral changes following antiretroviral therapy initiation and family support [21]

***Benefits to the child***

- Psychological benefits:
  - Improved custody planning with indirect benefits for children in the longer term [42]
  - Decreased depression in children over time following disclosure [28]
- Social benefits:
  - Increase in HIV/AIDS knowledge following disclosure [32]
  - Positive association between disclosure and plans for children's future [42,46,50]

***Benefits to both mothers and children***

- Higher family cohesion, with more affection between mothers and children [27,52]
- Improved mother–child relationship [45,46,49]

While this review clearly illustrates the important impact of such intensive interventions, applying these to scale remains a challenge given the human resource limitations in health systems in the most affected regions [110].

### Lay counseling models for interventions

Any conceptualization of psycho-social interventions at the primary healthcare level is restricted by critical shortages of adequately trained healthcare professionals and the absence of disclosure counseling or intervention guidelines. Task shifting of primary care and prevention functions to community healthcare workers or lay counselors is showing promise in improving health outcomes at reasonable cost, including examples of cognitive behavioral interventions for postnatal depression and complex treatment regimes such as ART. In resource-limited settings, lay HIV counselors are responsible for psycho-social education within HIV-treatment programs, including HIV counseling and testing, health promotion, training to initiate ART and monitoring of treatment adherence [111,112]. Mental health research has illustrated the capacity of community healthcare workers to deliver psycho-social interventions [113], including interpersonal group therapies [114] and cognitive behavioral therapies [115], and other treatments for depression [116]. Given adequate training and support, community healthcare workers would be well positioned to provide disclosure support at a family level. Ensuring that interventions are appropriate for community healthcare workers to deliver is in line with current priorities in task shifting of healthcare to lay professionals where possible and feasible [112,117].

Given this potential, it is important that intervention design focuses carefully on the structure, support and training required to make such lay counselor-driven interventions not only feasible, but of high impact.

### Scalable models for HIV–disclosure

Lastly, given that most research to date in the field of maternal HIV disclosure has been undertaken on a small scale and has tended to use intensive resources, there is a need for larger demonstration projects designed to assess the feasibility and acceptability of such lay counselor-driven interventions delivered at scale in resource-limited, epidemic settings [118]. Such projects need to address human and other resource capacity challenges, and test the acceptability of maternal HIV disclosure interventions in traditional African cultures. There is increasing concern in the field of HIV about the practical application of interventions at scale, with examples from prevention of mother-to-child transmission programs illustrating the loss of intervention effect when small-scale effective interventions are delivered at population level [119]. Research that not only establishes effective intervention models but also clearly describes the key mechanisms by which it achieves its effect will be important in the future.

## Executive summary

***The problem***

- Sub-Saharan Africa is disproportionately affected by HIV; up to 40% of pregnant women are HIV-infected, but most of their children will be HIV-uninfected owing to the availability of effective prevention of mother-to-child transmission regimens.
- Improvements in HIV-treatment have also resulted in increasing numbers of mothers surviving to care for their HIV-uninfected children.
- One challenge faced by HIV-infected mothers is when and how to disclose their HIV status to their children.

***Overview of current literature***

- International research on maternal HIV disclosure is mostly descriptive from developed world settings; few studies report on HIV disclosure interventions or include children under the age of 12 years.
- There are many documented benefits of maternal HIV disclosure both for the mother and a child of primary school age.
- Disclosure should be an ongoing process and take into account a child's stage of development and ability to understand illness.

***Future perspective***

- When considering models of HIV disclosure interventions for sub-Saharan Africa the following should be considered:
  - The key role played by the family and the potential benefits of interventions that strengthen and engage with families;
  - Empowering mothers with skills and competencies is likely to be more effective than simply providing relevant information;
  - The documented ability of lay counselors to deliver health interventions, potentially relieving already overburdened medical staff at health facilities;
  - The need for larger demonstration projects designed to assess the feasibility and acceptability of HIV-disclosure interventions delivered at scale in resource-limited settings with high-HIV prevalence.

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# Living with HIV, disclosure patterns and partnerships a decade after the introduction of HIV programmes in rural South Africa

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# Living with HIV, disclosure patterns and partnerships a decade after the introduction of HIV programmes in rural South Africa

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Prevention of mother-to-child Transmission and HIV Treatment programmes were scaled-up in resource-constrained settings over a decade ago, but there is still much to be understood about women's experiences of living with HIV and their HIV disclosure patterns. This qualitative study explored women's experiences of living with HIV, 6–10 years after being diagnosed during pregnancy. The area has high HIV prevalence, and an established HIV treatment programme. Participants were enrolled in a larger intervention, "Amagugu", that supported women ($n$ = 281) to disclose their HIV status to their children. Post-intervention we conducted individual in-depth interviews with 20 randomly selected women, stratified by clinic catchment area, from the total sample. Interviews were entered into ATLAS.ti computer software for coding. Most women were living with their current sexual partner and half were still in a relationship with the child's biological father. Household exposure to HIV was high with the majority of women knowing at least one other HIV-infected adult in their household. Eighteen women had disclosed their HIV status to another person; nine had disclosed to their current partner first. Two main themes were identified in the analyses: living with HIV and the normalisation of HIV treatment at a family level; and the complexity of love relationships, in particular in long-term partnerships. A decade on, most women were living positively with HIV, accessing care, and reported experiencing little stigma. However, as HIV became normalised new challenges arose including concerns about access to quality care, and the need for family-centred care. Women's sexual choices and relationships were intertwined with feelings of love, loyalty and trust and the important supportive role played by partners and families was acknowledged, however, some aspects of living with HIV presented challenges including continuing to practise safe sex several years after HIV diagnosis.

**Keywords:** maternal HIV disclosure; partnerships; HIV treatment; stigma; family

## Introduction

Successful prevention of mother-to-child-transmission (PMTCT) and HIV treatment programmes have reduced mortality and resulted in HIV-positive women living longer to care for their children who are mostly HIV-uninfected (WHO, 2013). Keeping women alive is beneficial for children, and associated with decreased child mortality in highly prevalent HIV settings (Ndirangu, Newell, Tanser, Herbst, & Bland, 2010; Ndirangu, Newell, Thorne, & Bland, 2012).

Much is known about the clinical health of HIV-infected women in resource-constrained settings (Coutsoudis et al., 2010; Miiro et al., 2009), however, less is known about their experiences of living with HIV several years after their diagnosis, and to whom they have disclosed. Emerging literature on HIV disclosure describes both positive and negative outcomes following disclosure; increased social support has been reported (Bouillon et al., 2007; Groves, Maman, & Moodley, 2012; Maman et al., 2003) violence and abandonment have also been documented (Linda, 2013; Medley, Garcia-Moreno, McGill, & Maman, 2004). There is a dearth of evidence from longitudinal research in African settings to inform adherence support programmes (Bärnighausen, Tanser, Dabis, & Newell, 2012; Dewing et al., 2012; Santer, Ring, Yardley, Geraghty, & Wyke, 2014) and limited data on client perspectives of antiretroviral treatment (ART) services (Orner et al., 2008).

This qualitative study explores the experiences of 20 HIV-infected women, who learnt their HIV diagnosis during pregnancy as participants in the Vertical Transmission Study (VTS; 2001–2006), rural South Africa (Bland, Coovadia, Coutsoudis, Rollins, & Newell, 2010; Coovadia et al., 2007; Mkwanazi et al., 2008). It explores their experiences of living with HIV and taking ART, their partnerships and issues of access and equity to treatment.

## Methods

### *The setting*

This study was conducted in northern KwaZulu-Natal, at the Africa Centre for Health and Population Studies

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(www.africacentre.com). The setting is rural, resource-limited and predominantly Zulu speaking (Bärnighausen, Tanser, Malaza, Herbst, & Newell, 2012; Tanser et al., 2008).

In 2001 the Department of Health, in partnership with the Africa Centre, launched a PMTCT programme and, in keeping with policy at the time, single-dose Nevirapine was offered to HIV-infected women during labour, and their infants post-partum. Since then PMTCT regimens have changed, and now all HIV-infected pregnant women, not already on treatment, receive ART at their first antenatal visit (WHO, 2013). Since 2004 an HIV Programme has provided free HIV treatment and care in a devolved programme at primary health care clinics in the area (Bland & Ndirangu, 2013; Houlihan et al., 2010; Janssen, Ndirangu, Newell, & Bland, 2010). Initially, the eligibility criteria for ART was a CD4 cell count of ≤200 cells/ml, but since 2014 has been extended to include all those with a CD4 cell count of ≤500 cells/ml (WHO, 2013).

### *Measures*

This qualitative study was undertaken with a sub-sample of women who had participated in two intervention studies, one to support exclusive breastfeeding to reduce vertical transmission of HIV ("VTS"; Bland et al., 2010) and the other to support maternal HIV disclosure ("Amagugu"; Rochat, Arteche, Stein, Mkwanazi, & Bland, 2014). The aim of this qualitative research was to better understand women's experiences of living with HIV over a long period of time, and to explore their experiences of participating in the VTS and Amagugu interventions. A two-part interview guide was developed: Part One was open-ended and explored women's experiences of being HIV-infected since their diagnosis in the VTS and is the subject of this manuscript. Part Two focused on their experiences of participating in the Amagugu intervention, the subject of a separate analysis. The interview started with an open-ended narrative and then included topic area probes. The open-ended question was: "Tell me about your life since we last saw you in the VTS". Through these interviews we sought to address less understood psychosocial topics about women of child-bearing age, highlighted in the literature, including HIV testing during pregnancy, safe sex negotiations and experiences of living with HIV (McGrath, Richter, & Newell, 2013; Rochat et al., 2006; Varga, Sherman, & Jones, 2006). The probes explored the following:

(1) Women's experiences of access to HIV care and treatment.
(2) Women's experiences of their sexual partnerships since the VTS.

### *Sample*

HIV-infected women included in these analyses were a sub-sample of participants enrolled in the Amagugu study, who had received support to disclose their HIV status to their 6- to 10-year-old child (Rochat, Mkwanazi, & Bland, 2013; Rochat et al., 2014). Women had first been tested for HIV in the local PMTCT programme and had known their HIV status for at least six years (Mkwanazi et al., 2008). The Amagugu disclosure intervention targeted the VTS index child specifically, but mothers were encouraged to disclose their status to their other children post-intervention. Resources and time available determined the initial sample size and we purposefully selected 20 participants from five of the nine clinic areas in which the Amagugu study operated, representing urban and rural settings. After completion of the 20 interviews a preliminary round of data analysis was undertaken and it was concluded that saturation had been reached.

### *Data collection*

Socio-demographic and disclosure data were collected during a baseline survey in the Amagugu intervention. Two months after completing the intervention one of the researchers (NM) contacted the sample of women by telephone, explained the qualitative study and requested an appointment to conduct individual in-depth interview; all 20 women agreed to participate and provided written, informed, consent.

### *Data preparation and analysis*

The in-depth interviews lasted approximately 60 minutes at the women's homes were tape recorded, transcribed verbatim and translated from isiZulu to English by NM. All interviews were read several times for familiarity with the data and the transcripts were entered into ATLAS.ti computer software for coding of common themes (Friese, 2012). NM analysed the interviews by category to determine common elements, patterns and themes within each participant's interview. These were coded and compared across interviews to determine dominant thematic areas within the content areas. To ensure researcher reflexivity, NM, who is herself a Zulu woman, kept detailed daily notes of personal reactions to, and reflections on, interview content, which might inform interpretation bias. Transcripts were then independently reviewed by the second author (TJ) after which all three authors reviewed the results to reach consensus on the most salient themes, their organisation and to explore aspects of researcher reflexivity.

## Results

The characteristics of participating women are shown in Table 1. Their median age was 32 years (IQR 29–37); their children's median age was seven years (IQR 6.5–7.5). Of the five women reported as married, two were legally married and three were engaged; of those reported as unmarried ($n$ = 14), 12 had current partners and approximately half were living with their current partner. HIV exposure in the households was high with most women ($n$ = 14) reporting that another adult family member was HIV-infected. The majority of women were on ART ($n$ = 14), with a median CD4 cell count of 430 (IQR 310–554) cells/ml; one woman eligible for treatment had not accessed ART.

Table 2 presents people to whom the women had disclosed their HIV status. More than half had disclosed to their current partners ($n$ = 13), half of whom were also HIV-infected. Two women had not disclosed to anyone due to fear of HIV-related stigma.

In total, the 20 women had 56 biological children, aged 2–18 years, of whom 43 were reported to have been tested for HIV and were HIV negative. One mother reported that she had disclosed her HIV status to her 12-year-old, HIV negative, child, a sibling of the study child, prior to the intervention. Post-intervention, all mothers had disclosed to their study children – 10 fully (i.e., explained they had HIV) and 10 partially (i.e., explained they had a "virus" of whom six mothers subsequently fully disclosed).

In data analysis two main themes emerged:

(1) Living with HIV and normalising ART.
(2) Love, partnerships and sex.

### Theme 1: Living with HIV and normalizing ART

At the time of diagnosis, HIV testing had recently been introduced into the study area, and HIV prevalence amongst pregnant women was high (approximately 40%). This led to suspicion or disbelief about a positive HIV test, for the women and some of their families:

> You know when you are at the clinic and you are checking and you ask one another: "How come we all are found to be infected?" They must be playing with us. You don't pay attention to anything. When you suffer from things such as headaches then you start paying attention. (29-year-old)

However, given the increased access to ART in the years following the VTS, the majority of women shared experiences of living positively with HIV. Availability of ART was considered a privilege previously denied to many, and this changed how women perceived HIV:

> At home we were eight, now only four are left. My sister left a 9 month old child who is now 16 years old. So,

Table 1. Characteristics of the 20 women that were interviewed.

| Study Number | Maternal age (years) | Child age (years) | Child sex | Marital status | PMTCT Site | Currently employed | Bore child after index child | Last CD4 cell count result cells/ml | Currently on ART |
|---|---|---|---|---|---|---|---|---|---|
| 1 | 26 | 7 | F | Single | Peri-urban | No | Yes | 105 | Yes |
| 2 | 32 | 6 | M | Single | Peri-urban | No | Yes | 568 | Yes |
| 3 | 32 | 7 | F | Single | Rural | Yes | Yes | 379 | No[a] |
| 4 | 44 | 8 | M | Single | Peri-urban | Yes | No | 800 | Yes |
| 5 | 46 | 7 | M | Married | Peri-urban | No | No | 700 | Yes |
| 6 | 36 | 6 | F | Married | Peri-urban | Yes | No | 297 | Yes |
| 7 | 37 | 7 | M | Single | Rural | No | No | 487 | Yes |
| 8 | 49 | 8 | F | Widowed | Rural | No | No | 219 | Yes |
| 9 | 28 | 6 | F | Single | Rural | No | No | 212 | Yes |
| 10 | 39 | 8 | F | Married | Rural | Yes | No | 467 | Yes |
| 11 | 28 | 7 | F | Single | Rural | No | Yes | 629 | No |
| 12 | 32 | 7 | M | Married | Rural | No | Yes | 518 | Yes |
| 13 | 37 | 7 | M | Single | Rural | No | Yes | 400 | Yes |
| 14 | 38 | 6 | F | Married | Rural | Yes | Yes | 350 | Yes |
| 15 | 31 | 8 | F | Single | Rural | No | Yes | 709 | No |
| 16 | 36 | 7 | F | Single | Rural | Yes | Yes | 459 | No |
| 17 | 28 | 6 | F | Single | Rural | No | Yes | 300 | Yes |
| 18 | 29 | 8 | M | Single | Rural | Yes | Yes | 320 | No* |
| 19 | 32 | 7 | F | Single | Rural | No | No | 540 | No |
| 20 | 29 | 7 | F | Single | Rural | No | Yes | 394 | Yes |

[a]At the time of the interview ART eligibility criteria was ≤350 cells/ml.

Table 2. HIV disclosure of participating women.

| Study number | In a relationship with the child's father | Lives with current partner | Partner HIV positive | Aware of other adult family members with HIV | Disclosed to current partner | Disclosed to parent | Disclosed to sibling | Disclosed to friend | Disclosed to other relative | Disclosed to religious person | Whom disclosed to first |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 1 | No | No | No | Yes | No | No | No | No | Yes | No | Partner |
| 2 | No | No | No | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Parent |
| 3 | No | Yes | Yes | Yes | No | No | No | No | No | No | No disclosure |
| 4 | Yes | Yes | Yes | Yes | Yes | No | No | No | Yes | No | Partner |
| 5 | Yes | Yes | No | No | Yes | Yes | Yes | Yes | Yes | Yes | Parent |
| 6 | Yes | Yes | Yes | Yes | Yes | Yes | No | Yes | No | No | Partner |
| 7 | No | Yes | No | Yes | Yes | No | Yes | Yes | Yes | No | Sibling |
| 8 | Yes | No | Yes | Yes | Yes | No | Yes | No | Yes | Yes | Partner |
| 9 | No | No | Yes | Yes | Yes | No | Yes | Yes | No | No | Sibling |
| 10 | Yes | Yes | Yes | Yes | Yes | No | Yes | Yes | Yes | No | Friend |
| 11 | No | No | No | No | Yes | No | Yes | Yes | No | No | Friend |
| 12 | Yes | Yes | No | Yes | Yes | No | Yes | Yes | Yes | No | Partner |
| 13 | Yes | No | No | Yes | No | No | No | No | No | No | No disclosure |
| 14 | Yes | No | No | No | Yes | No | No | Yes | No | No | Partner |
| 15 | Yes | No | No | No | No | No | No | No | No | No | Partner |
| 16 | Yes | Yes | Yes | Yes | Yes | No | No | No | No | No | Partner |
| 17 | No | No | No | Yes | No | Yes | No | No | No | No | Parent |
| 18 | No | No | No | Yes | No | No | No | Yes | Yes | Yes | Other relative |
| 19 | No | No | No | No | No | No | No | No | Yes | No | Other relative |
| 20 | No | Yes | Yes | No | Yes | Yes | Yes | Yes | Yes | No | Partner |
| Total | 10 | 9 | 8 | 14 | 13 | 5 | 9 | 11 | 11 | 4 | |

> when we take pills [ART] now, we are taking them for the reason that we had siblings who died without getting help. Children were left without parents. I have survived, and now free pills are available. (46-year-old)

Most women were taking ART, regularly attending ART clinics and knew other HIV-infected people, which helped to reduce stigma:

> Sometimes you see others hiding by the corners when they attend HIV clinics, I do no such [thing]! People are taking their own pills for BP [blood pressure problems], arthritis, why? They want to live. I'm taking ARVs [antiretroviral drugs] because I want to live. If we all die, the tomb does not say this one was killed by AIDS, this one was killed by BP. We are all dead! When I go to the clinic I even strut my stuff. I don't care that ARVs have made me have thin legs and flat buttocks, eish! [Laughter]. (46-year-old)

There was a sense of HIV causing a chronic, rather than fatal, illness and pride rather than shame in going to HIV clinics:

> Most of my neighbours are open now; we even lend each other pills. They come and say we have come to borrow our "teabag". I was counting that I have been taking ARVs for 10 years. We are going to push my husband in a wheel barrow [when he gets sick] because he does not want to test. (46-year-old)

As women settled into longer term HIV care they became increasingly concerned about the quality of health services and understanding more about their illness. Women described becoming selective about ART clinics based either on the quality of care received, or on being able to attend the same clinic as a partner:

> I also want to change from Clinic A to Clinic B, they are not safe there. They sometimes give you pills that are not enough. They are careless. I go to Clinic B because my partner also took his ARVs there and sometimes we can walk to town together. (26-year old)

Some women expressed confusion over the clinical course of HIV infection, and were perplexed about the relationship between CD4 counts and their physical health:

> I just started ARVs six months ago. When I checked I discovered that my CD4 count was 112. I was beyond shocked, I can't explain it. I was dead walking. I felt fine. I realised that is why people just drop dead. (37-year-old)

### Theme 2: Love, partnerships and sex

All women agreed that partnerships were complex and discordant HIV results presented particular difficulties:

> He showed me his negative results. I thought how can I show him my positive result? I told my sister my fear was if I say I'm positive he will say I am the one who brought the virus. We discussed with my sister that we have to plan how we are going to tell him because he has to be protected and we should not practise unsafe sex. (37-year-old)
>
> When I disclosed, he did not want to accept it. He did not fight me though; I think it is because he knows of his ways. We continued getting other children. I also do not want to lie; when I discovered my HIV status, it was not such an issue. (29-year-old)

Women reported that some partners were accepting of their HIV status, and supportive, despite discordant results:

> I am a kind of a person that discloses everything. I always have my ARVs with me, openly. I'm visiting here but I have them openly with my cosmetics. When I disclosed to my partner he said: "I wonder how you got it". I said maybe I have had too many children, maybe I was helping someone. He did not fight with me. He said he was also going to go to the clinic to test and he did. He goes every six months and is negative. Maybe he has strong soldiers [CD4 cells] because they cannot detect it [HIV]. I tell him he will end up starting treatment or he will just fall and die but we are using condoms. (32-year-old)

Some partners provided finances for women's children, although they were not the biological fathers. While this made the partner more attractive, it also complicated disclosure due to women's fears of abandonment:

> … on Thursday he said let's go and see "o-small" [the small ones, my children not his] and we first went to the shop. I thought we were just buying snacks but he said: "Don't they eat? Take rice". And we packed the trolley and took the stuff to them. So, when you have such people you don't want to spoil things and you think this is my last chance if I do not use it I will not find someone like him. (32-year-old)

Despite knowing about safe sex, women articulated that they were not consistent with condom use, talking about their own weaknesses, rather than male coercion which is often reported in the literature:

> Sometimes there are things that make you weak and your resistance crumbles. Sometimes it happens that someone judges you and they think this one is fine she has nothing. That mistake happens sometimes, I don't want to lie but it's not an everyday mistake, I try to avoid it. I try to be strict. (29-year-old)

## Discussion

This qualitative study adds to the literature about the lives of rural, African, women living with HIV, including

their disclosure patterns (Stevens & Galvao, 2007; Varga et al., 2006). We found high levels of stability in partnerships with half the women still in a relationship with the biological father of the child, only two of whom had not disclosed to them. Approximately half the women had disclosed to their partners first and their broader family network subsequently, suggesting that stability of partnerships (reflected by duration and co-residency) is an important facilitator of partner disclosure, as documented in the literature (Alemayehu, Aregay, Kalayu, & Yebyo, 2014; Antelman et al., 2001; Bachanas et al., 2013; Mayfield Arnold, Rice, Flannery, & Rotheram-Borus, 2008; Medley et al., 2004). Our finding that partners were generally described as being supportive is similar to findings from other parts of Africa and Asia (Deribe, Woldemichael, Wondafrash, Haile, & Amberbir, 2008; Medley et al., 2004; Skunodom et al., 2006). Importantly, for many women HIV disclosure did not necessarily facilitate low risk behaviours, raising questions about the support couples might need beyond the disclosure itself. The 2012 WHO Couple Counselling Guidelines highlights that couple counselling has not received programmatic attention especially in situations of HIV sero-discordance (WHO, 2012), and studies have shown that couple counselling support has an important role in facilitating long-term ART adherence (Anglemyer, Horvath, & Rutherford, 2013; Brown et al., 2011).

High HIV prevalence rates in the study area, and the political climate during women's diagnosis at pregnancy, led to suspicion about the existence of HIV, but women reported gradual acceptance of HIV as a chronic illness. In the early years of the epidemic there was significant focus on stigma and its impact on testing, however, this research suggests that, with increased access to treatment, stigma is reduced (Maman et al., 2009), and most women were living positively with HIV and taking ART without fear. However, as they stabilised on ART their needs changed and they expressed new concerns including quality of health care and counselling support. With large numbers of people attending HIV clinics, counsellors are often trained to give generic information to everyone to maximise efficiency, and seldom have time to address individual concerns or for health promotion. Counselling training curricula need to evolve to include issues such discordant results in relationships (Dworkin & Ehrhardt, 2007), the challenges of living with a chronic disease and ART adherence (Rochat, Bland, Coovadia, Stein, & Newell, 2011). Offering family-centred, rather than individual, care may hold particular advantages for women and their families in high prevalence settings (Betancourt, Abrams, McBain, & Fawzi, 2010; Kairania et al., 2010; Richter, 2010).

To date literature on gender and HIV has often portrayed men as determinants of women's HIV risk (Dunkle et al., 2004; Greig, Peacock, Jewkes, & Msimang, 2008), and while this is mostly correct, the contribution of this research is important as it presents a more assertive, women's voice, with women gaining autonomy over their health through access to care, and the ability to make decisions about their sexual health. The vast majority of research supporting a particularly gendered perspective on risk is cross-sectional rather than longitudinal, and may, by its design, preclude a clear understanding of how women's power and independence in relationships may change over time in stable partnerships. This research highlights that sexual health resides within love relationships which are complex, and it is this complexity that informs the decisions women make in relation to HIV care.

## Conclusion

The wide-scale roll-out of HIV prevention and treatment programmes have brought about considerable changes for women who are now surviving to parent children in a society that has less HIV-related stigma. However, the transition to longer term care raises new challenges, including securing quality family-centred care and dealing with disclosure in new sexual partnerships. The narratives of this group of women contribute to understanding the challenges of African HIV-positive women of childbearing age in the ART era.

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**The Amagugu intervention: A qualitative investigation into maternal experiences and perspectives of a maternal HIV disclosure support intervention in rural South Africa.**

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Key Messages:

- Participant engagement and involvement in intervention development and evaluation can improve outcomes
- Specific interventions are needed to support and encourage parental HIV disclosure to children
- Child's developmental capacity and inability to handle HIV information is the most common barrier to disclosure
- Flexibility and the intervention package are motivators for participation

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**Author contributions**

NM was responsible for the study conceptualization, design, data collection, analysis and the preparation of this manuscript. TR was responsible for the study conceptualization, analysis, and preparation and reviewing drafts of this manuscript. RB was responsible for the study conceptualization, analysis and reviewing drafts of this manuscript. All authors have reviewed and approved the final version of the manuscript.

**Abstract (300 words)**

The World Health Organization recommends disclosure of parental HIV to children aged 6-12 years. The maternal HIV-disclosure intervention (Amagugu), a lay counsellor-led, home-based intervention with six sessions, was implemented. The intervention included provision of disclosure tools, training and support for mothers, a family session and health promotion clinic visit for mothers and children. Amagugu demonstrated success as a maternal disclosure support programme but less is known about the experiences of participants. A sub-sample of HIV-infected mothers (n=20) with primary school-aged HIV-uninfected children, from Amagugu, was purposely selected. Using semi-structured interviews and interview-guide, we explored maternal perceptions of disclosure prior to participation and experiences of participating in Amagugu. Audio-recorded interviews conducted in participants' homes, in isiZulu, were transcribed, and content analysis was undertaken. The most common reasons for prior non-disclosure were concerns about children's developmental capacity to understand HIV, fear of HIV-related stigma towards mothers and their families, and lack of skills to undertake disclosure. Intervention materials, rapport with counsellors, and flexibility of the proposed disclosure process motivated mothers to participate. While expressing satisfaction with the intervention, some mothers remained concerned about their children's understanding of HIV and ability to maintain confidentiality. Mothers also requested support in discussing sex-related topics with their children. Despite prior high rates of disclosure to other adults, mothers had little awareness about the importance of disclosure to children and lacked skills to undertake this. The intervention approach, rapport with counsellors, and practicality of the materials, helped overcome child disclosure barriers. Mothers reported their children as very supportive following disclosure and stated they would advise other women to disclose to children for practical support around HIV treatment adherence. This qualitative evaluation suggests that mothers with primary school-aged children may require structured support when disclosing to children, which could be achieved through supportive home-based counselling and user-friendly materials.

## Introduction

Advances in HIV treatment and prevention have resulted in fewer HIV-infected children born to HIV-infected mothers (Burton, Giddy et al. 2015). HIV-exposed but uninfected children are a growing population with estimates suggesting that between 30-50 % of HIV-uninfected children in Sub-Saharan Africa currently live with HIV-infected parents, most frequently their mothers (Short and Goldberg 2015). A growing body of literature on the impact of parental HIV on children has illustrated that these children are at risk of poor health and educational outcomes (Chi and Li 2013, Cluver, Boyes et al. 2013, Goldberg 2014, Jao, Hazra et al. 2016) and that their parents need support with the complexities of parenting with HIV (Rochat, Bland et al. 2011, Mkwanazi, Rochat et al. 2012, Lachman, Cluver et al. 2014, Sherr, Cluver et al. 2014). An important issue facing all HIV-infected parents is how and when to disclose their HIV status to their children and families.

In 2011, based on growing evidence on the benefits of disclosure to children (Krauss, Letteney et al. 2013), the World Health Organization (WHO) recommended that parents disclose their own HIV status to their children, between 6 and 12 years of age (World Health Organization 2011). Benefits of disclosure include improved family cohesion and mother-child relationships (Pilowsky, Sohler et al. 2000, Schrimshaw and Siegel 2002, Vallerand, Hough et al. 2005, Murphy, Marelich et al. 2009), improved maternal mental health, (Armistead, Klein et al. 1997, Wiener, Battles et al. 1998, Armistead, Tannenbaum et al. 2001, Schrimshaw and Siegel 2002, Brackis-Cott, Mellins et al. 2007), increased social support and improved maternal physical health due to improved ART adherence (Tompkins, Henker et al. 1999, Murphy, Steers et al. 2001, Letteney 2006). However, despite these reported benefits, disclosure rates are low (Qiao, Li et al. 2011, Mkwanazi, Rochat et al. 2012, Krauss, Letteney et al. 2013) and very little research on parental support to undertake disclosure has been conducted in low and middle income countries (Li, de Wit et al. 2015). A systematic review (Simoni, Yang et al. 2015) found only 13 disclosure intervention studies, 12 of which focused on adult disclosure while only one, the Amagugu intervention reported on here, focused on parental disclosure to children (Rochat, Arteche et al. 2014,

Rochat, Arteche et al. 2015) Amagugu is a low intensity intervention designed to be delivered by lay counsellors in a task shifting approach. It was developed through careful formative work (Rochat, Mkwanazi et al. 2013), and the conceptual framework (Rochat, Mitchell et al. 2016) and evaluation which found Amagugu to be acceptable and effective at increasing parental disclosure are described in detail elsewhere (Rochat, Mkwanazi et al. 2013, Rochat, Arteche et al. 2014, Rochat, Arteche et al. 2015). The intervention led to high maternal disclosure rates (61% full disclosure with the mother using the words 'HIV', and 39% partial disclosure with the mother using the word 'virus'). An uncontrolled evaluation study found that Amagugu led to substantial decreases in maternal and child psychological morbidity, and parenting stress, and helped mothers to communicate with their children about the nature of HIV, its treatment and the possibility of illness and death (Rochat, Arteche et al. 2014, Rochat, Arteche et al. 2015). Children's understanding of HIV and death remains an under-researched area in epidemic regions (Rochat, Mitchell et al. 2017). Amagugu was an evaluation study with no control group; a randomised controlled trial of the intervention has recently been completed (NCT01922882).

While Amagugu has been extensively reported on, less is known about the perspectives and experiences of the mothers participating in the intervention. Understanding maternal perspectives on participation is important because there is a growing recognition that participant engagement and involvement in intervention development and evaluation can improve outcomes (Armstrong, Herbert et al. 2013). It is argued that the successes of interventions at scale are strongly associated with the extent to which participants report feeling engaged in the intervention and consider it responsive to a clearly identifiable, relevant need. Qualitative research on participant perspectives can help researchers understand - at least indirectly- whether the intervention facilitated behaviour change in the manner conceptualised, and what facilitated or impeded its success. There is a dearth of literature on participant perspectives in health and social intervention research (Armstrong, Herbert et al. 2013, Brett, Staniszewska et al. 2014). The primary aim of this qualitative study was an in-depth exploration of HIV-infected mothers' experiences of the Amagugu intervention.

## Methods

*Setting*

This research took place at the Africa Centre for Population Health (Africa Centre), now Africa Health Research Institute (AHRI) (www.ahri.org). The research community is predominantly rural, isiZulu-speaking and impoverished, with one peri-urban area (Tanser, Hosegood et al. 2008). HIV prevalence amongst women attending antenatal clinics was estimated at 35% in 2012 (Department of Health 2012). Prevention of Mother-to-Child Transmission services were implemented in the sub-district in 2001, and an HIV treatment and care programme providing antiretroviral therapy (ART) through public health facilities, was introduced in 2004 (Houlihan, Bland et al. 2010).

*Sample*

In this qualitative study (Mkwanazi, Rochat et al. 2015), we purposely recruited a sub-sample of twenty HIV-infected women, who were part of the larger Amagugu intervention evaluation (2010-2012) of 281 HIV-infected women and their HIV-uninfected 6-10 year old children (Rochat, Arteche et al. 2014). To be eligible to participate in this qualitative study the women had to have been tested for HIV during pregnancy (Mkwanazi, Patel et al. 2008) as part of the Vertical Transmission Study (VTS) (Bland, Coovadia et al. 2010) and to have participated in Amagugu.

*Sample size and selection*

The sample size was determined by the time and resources available, and the expectation of reaching saturation with an estimated sample of 20-30 mothers (Mason 2010). Geographical area served as the main selection criteria to ensure participation of mothers across a variety of settings within the research population. The 20 women were purposely selected from nine geographic areas representing both peri-urban and rural settings. While mothers were purposely selected to represent all geographic areas, within each geographic area the mothers selected for the qualitative interview were randomly selected from the pool of mothers available. The researcher, using a list of participant identifiers (IDs), selected each tenth participating ID - by area – using a round robin technique until 20 participants had been selected across all areas. After completion of the 20 interviews a preliminary

round of data analysis was undertaken, and the authors concluded that saturation had been reached, and no further mothers were recruited.

*The Amagugu Intervention*

The intervention included six home-based counselling sessions, led by a lay-counsellor. The counsellor provided the mother with specifically designed age-appropriate materials and tools to use during disclosure with the child. The counsellor did not intervene directly with the child; instead they provided training and support to the mother who then disclosed to her child independently. The sessions and the conceptual framework by which each session contributes towards disclosure are summarised in Figure 1, and a detailed description of the intervention is available in open access elsewhere (Rochat, Mitchell et al. 2016). By completion of the Amagugu intervention 170 (61%) women had fully disclosed their HIV status to their children using the words 'HIV' and 110 (39%) had partially disclosed their HIV status using the words 'virus' or 'illness'(Rochat, Arteche et al. 2014, Rochat, Arteche et al. 2015).

*Data collection*

The first author, a PhD candidate who is isiZulu speaking and from the local area, contacted each participating mother by phone and scheduled an appointment for a home visit to explain the study and invite participation. At this home visit the researcher obtained written consent, and immediately completed the semi-structured interview. The semi-structured interview guide addressed specific questions regarding women's participation in the Amagugu intervention and their experiences of using the disclosure materials. All 20 women who were contacted and approached agreed to participate, and granted permission for the interviews to be audio-recorded. Interviews took place in the women's homes, two months after completion of the Amagugu study, and each woman was interviewed once for approximately one hour. The first author also took extensive notes of non-verbal cues, and observed the home surroundings during the interviews, to inform the interpretation of the results.

*Data triangulation*

Additional data were available and extracted (with participant consent) for each woman participating in the qualitative study from the main Amagugu database, including socio-demographic data collected at baseline in the Amagugu study. Data collected post-disclosure on what the women enjoyed most about the intervention were extracted from a post-disclosure interview which was part of the Amagugu study. Using the semi-structured interview guide, content areas, including motivations for participating in the intervention, whether mothers perceived the intervention to be valuable and relevant, their views on the intervention package, and children's reactions following disclosure, were explored.

*Ethical considerations*

The study was approved by the relevant institutions.

*Data analysis*

The first author (NM) transcribed the audio-recordings verbatim and translated them from isiZulu to English. To familiarise herself with the data NM listened to the audio-recordings, read and re-read the transcripts several times (Burnard 1991), and developed a code list derived from the literature. After a thorough review of all data, the two co-authors independently generated their own code lists. Preliminary findings were presented and discussed amongst the three authors in an analysis meeting. The three code lists were discussed, reviewed to reach consensus and the final list was adjusted accordingly to reflect the thematic areas identified.

Each mother's data were organised to reflect her specific content areas based on responses to questions in the interview guide. NM then studied the content of the transcripts looking for patterns within data chunks across all women linked to each of the specific questions in the interview guide and the thematic areas raised by the mothers in response to these questions. The coding approach was deductive, based on the interview questions in the guide which were developed to cover common

areas in the patient engagement literature. In reviewing the data the researchers made an exhaustive code list of all the participants' responses. This list was then summarised into a code book which was used to code all the transcripts and make comparisons across the participants to determine which experiences were common for most of all participants. A further data analysis meeting was convened and consensus reached on the main research findings.

**Results**

Table 1 shows socio-demographic information of mothers and their children. The median age of the women was 32 years (IQR 29-37) and of the children seven years (IQR 6.5-7.5). There were substantially more girl children in the sample (girls 13: boys 7), and mothers had predominantly undertaken full disclosure to the child as part of the intervention (full 16: partial 4). Almost all women (18/20) reported being in stable partnerships, half were living with their partners (9/18), and disclosure to partners was high (13/18). Most women were unemployed (14/20) and had attended at least some secondary school. The majority of mothers were on ART. When comparing these characteristics to those of the larger sample of Amagugu mothers, apart from the over-representation of girl children and mothers who had undertaken full disclosure, we did not find noticeable differences between characteristics of this sub-sample and the larger Amagugu study group.

Following coding and counting, three categories of content areas were identified:

1. Barriers to disclosure prior to intervention
2. Facilitation of behavioural change towards disclosure
3. Satisfaction with the intervention package and unmet intervention needs

We present data for each of these categories, below.

**Category 1: Barriers to disclosure prior to intervention**

We summarised the codes reflecting what the mother reported had prevented them from disclosing prior to the intervention (disclosure barriers) along with the codes for aspects of the intervention

(facilitators) which the mothers reported motivated and facilitated their change towards child disclosure as part of the intervention.

Child's developmental capacity: n=11

The most common barrier that prevented disclosure prior to the intervention was related to children's developmental capacity, in particular their ability to contain information disclosed to them.

*'There was that question in the beginning, that how can you tell such a young child about that? I told their father about Amagugu and he said, how can you tell a child that? But I said let's do it!'* (44 year-old mother of an 8 year-old boy)

*'I had told myself that I would disclose to my children when they were older and when I was sick. I have two children including a boy who is 15 years old and a 7-year old girl. I thought she was too young and even the boy I thought I was going to hurt him.'* (29 year-old mother of a 7 year-old girl)

HIV-related stigma n=6

More than a quarter of mothers cited fear of HIV-related stigma, which included worrying that the child may disclose to others, view the mother differently, or would be stigmatised themselves, as a reason they had not disclosed to their children prior to the intervention.

*'I could not bring myself to tell her because I feared that she would go around telling other people.'* (49 year-old mother of an 8 year-old girl)

*'When the counsellor came and told me about telling my child about my HIV status I told her that I cannot tell my child about HIV because she is talkative.'* (26 year-old mother of a 7 year-old girl)

Protective of child (n=2)

A minority of women perceived their children to be too sensitive to handle their mothers' HIV information and therefore wished to protect them emotionally.

*'As I said it was not easy because I knew it was going to sadden him…I don't think I was going to tell them. Oh! I was going to say I will wait until they were older, but then again, it was going to be more difficult when they were older.'* (46 year-old mother of a 7 year-old boy)

Mother's capacity (n=1)

One woman reported that she did not feel confident about her capacity to answer questions the child might raise during disclosure.

*'With Amagugu they really helped us because how could you disclose to your child? Where can you even start?'* (31 year-old mother of an 8 year-old girl)

**Category 2: Facilitators of behavioural change towards disclosure**

Most women were motivated to move towards behavioural change around disclosure based mostly on the intervention approach and intervention content, materials and tools (n=11/20 or 55%). Some were motivated by the supportive relationship developed with the counsellor (n=5/20 or 25%); while others (n=4/20 or 20%) were motivated more by pragmatism, as the intervention was considered both important and timely, and allowed flexibility in the level of disclosure that could be undertaken.

Each of these motivations is presented in greater detail below.

***Behavioural change motivated by the intervention approach, content, materials and tools (n=11)***

For over half of the mothers (11/20) the intervention approach and content was the primary motivating factor in facilitating behavioural change towards disclosure. Mothers reported that the intervention approach made the task feel more manageable, and the simplicity and user- friendliness of the materials made them feel empowered to undertake disclosure.

*'The way the intervention was presented had a big impact because we first learnt and then educated our children. The materials made it easy.'* (31 year-old mother of an 8 year-old girl)

Mothers reported that the intervention approach also increased their confidence in their abilities to communicate more generally.

*'…What I was taught at the Amagugu gave me strength. I even got tricks on how to start with things such as playing; you know just from playing, something profound comes out….. This is where this thing [Amagugu] helps because you don't just shout: "My child I am sick!" No, you start slowly, and tell them step by step.'* (39 year-old mother of an 8 year-old girl)

The mothers' favourable perspectives on the intervention content were reinforced by their children's positive responses to the intervention. This served to solidify that disclosure was a positive step, resulting in healthy parent-child interaction and communication with the child. That the intervention approach aimed to deal with HIV disclosure at a time when the parent was healthy and illness-free, in order to reassure the child, was important for mothers and children alike.

*'There were pictures and when he saw pictures he got excited. He even had questions. What he enjoyed the most was that I am healthy; when he comes from school I am here, I have cooked, and he eats and goes out to play.'* (44 year-old mother of an 8 year-old boy)

***Behavioural change motivated by the supportive relationship with the counsellor (n=5)***

A second, but less common reason for being motivated to change disclosure behaviour was linked to the quality of the counsellor relationship, conferring trust and confidence, which was reported by 25% of mothers. These made reference to counsellor attributes which inspired a sense of trust and confidence in the intervention process. The counsellor was thus experienced as a supportive expert advisor and teacher who inspired mothers to undertake disclosure with children.

*'I learnt a lot from [the counsellor] … the way he communicated was so kind. He has love for the children and makes you feel welcome. He also taught me that you cannot underestimate children, because they know a lot.'* (32 year-old mother of a 7 year-old girl)

***Behaviour change motivated by the practicality and flexibility of the intervention approach (n=4)***

For a slightly smaller proportion of mothers (4/20) the pragmatic nature of the intervention, and the fact that it responded to what the mother considered to be a valid need (which she had been feeling concerned about) was what motivated the mother to make behavioural change towards disclosure, rather than the counsellor relationship or the intervention approach per se.

*'Being sick without your children's knowledge, when this disease is so common, is not good. I would advise the person to sit down with children and explain the situation so that children will know.* (37 year-old mother of a 7 year-old boy)

The flexibility to adjust the intervention to the level of disclosure she preferred, and being able to start with partial disclosure and move towards full disclosure over time was an important attraction in moving forward with the intervention. It allowed the mother to feel she could take steps to protect her child (for example through education about universal protections) without having to enter into full disclosure, for which she did not necessarily feel ready. Interestingly for both of these mothers, their experience of undertaking partial disclosure led them to understand that their child was already receiving education about HIV in other settings, such as at school.

*'I didn't tell her directly that I have HIV because I thought she was still young. I was not specific. I taught her about the virus but I found out that she already knew a lot.'* (32 year-old mother of a 7 year-old girl)

*'I told her that I am educating her about diseases. It is important that she does not use my toothbrush and my facecloth and to use gloves if there is blood. She told me that at school they also teach them about HIV. I did not tell her a lot of things because she is 7 years old, she is young.'* (26 year-old mother of a 7 year-old girl)

**Category 3: Satisfaction with the intervention package and unmet intervention needs**

As illustrated in Table 2, mothers reported a variety of positive experiences in relation to the intervention approach and materials package, and highlighted various aspects of the intervention that yielded satisfaction. These were coded under four categories:

Communication (n=6) These mothers stated that the increased communication and having tools to use to increase communication about health messages and family life with the child were the most satisfying parts of undertaking the intervention.

Child capacity (n= 5) The opportunity to see the child's capacity to understand health and to understand the mother's HIV infection was the most satisfying part of undertaking the intervention with the child.

HIV Education (n= 5) Access to, and use of, education tools about HIV as a disease (most especially the HIV body map) were the most satisfying part of undertaking the intervention with the child.

Play and Health Promotion (n=4) Mothers reported that the play tools, including the activities and games, were the most satisfying part of undertaking the intervention.

Beyond these aspects of the intervention and the specific intervention content, for a few women who had been ill since the intervention, the most satisfying aspect of the intervention was linked to the discovery, post-disclosure, of the child's capacity to understand HIV, to provide support, and assist them in managing their illness and adherence to medication.

*'I had boils on my breasts and I would be so hot that I would not know what to do. By 8pm I would be so drowsy, he would ask me: "How many pills do you take?" If I happen to fall asleep at 8pm I would feel water spilling on me as he tried to give me pills [ARVs] in my sleep.'* (32 year-old mother of a 7 year-old boy)

*'She asks me all the time if I have taken my pills, even when they get finished she would tell me that your pills are running out. She is very supportive.'* (39 year-old mother of an 8 year-old girl)

All women, even those who were not ill, stated that the most beneficial aspect of disclosure was the support they received from their children after disclosure. While their original fears had been that they would be stigmatised by their children, on the contrary, most children were supportive. Mothers reported that their children assisted them with HIV medication adherence by reminding them to take their pills on time:

*'Sometimes when I am upset I go to bed early, she would come, wake me up and say: "Mama it's 8 o'clock you have to take pills."* (36 year-old mother of a 6 year-old girl)

*'What makes me happy is that my children are now my alarm clock. Before, they were just looking at me taking pills and they could not even ask what the pills were for. Now, even when I have gone to sleep and if they did not see me taking pills, they would wake me up and ask': "Did you take the pills"?* (46 year-old mother of a 7 year-old boy)

One aspect which mothers raised as a challenge that was not addressed by the intervention was the general taboo in Zulu culture around intergenerational communication about sex. Mothers expressed a desire for specific guidance (and tools similar to the HIV education tools which could provide assistance) with intergenerational communication around sexual behaviour and life as children become older. Mothers highlighted this as a significant need as they expected that, in due course, the discussions about the mother's HIV might shift to exploring the mode of infection with HIV and that this provided an opportunity for parent-led sex education.

*'You know that it is hard to talk about sex with children being a Zulu. As Zulus we regard that as being disrespectful….what is still difficult is an appropriate way of telling them. Yes there are other ways [of contracting HIV] but it is difficult to tell your child about sex.'* (46 year-old mother of a 7 year-old boy)

*'I wish there could be something motivating children and educating them about how to conduct themselves and be careful about [dangers] in life.'* (39 year-old mother of an 8 year-old girl)

Absence of questions and lack of negative reactions by children following disclosure were perceived by mothers to mean that children did not understand disclosure:

*"I am saying maybe she forgot because things were just normal after I told her, nothing changed."* (32 year-old mother of a 7 year-old girl)

Despite all mothers having disclosed to their children, a few questioned the effectiveness of the 'Safety Hand' in ensuring that children maintained confidentiality.

*'You cannot trust that they will keep quiet.'*

*NM: 'Did you not use the Safety Hand? '*

*'I did but I think he will tell other people.'* (37 year-old mother of a 7 year-old boy)

**Discussion**

We find that our qualitative sample reflects closely the characteristics of the larger group of mothers who participated in Amagugu, except that in this sample we report an over-representation of girl children, and that more mothers had undertaken full as opposed to partial disclosure. There is some evidence in the literature (Qiao, Li et al. 2011) that mothers tend to disclose to girl children prior to disclosing to boy children, linked to expectations that the girl child will assist with caregiving during periods of illness. While the larger Amagugu study did not find these gender effects (Rochat, Arteche et al. 2014), it is important to consider that the views expressed in this research reflect those of mothers with a girl, rather than boy child. While this limits generalizability, the literature (Cluver, Boyes et al. 2013) suggests that girl children exposed to, or affected by, HIV are particularly vulnerable, thus these results make an important contribution to understanding how to approach support for that population.

Children's supportive behaviours, including expressed affection following disclosure that are reported in this study, have also been described in the disclosure literature (Tompkins, Henker et al. 1999, Schrimshaw and Siegel 2002, Brackis-Cott, Mellins et al. 2003). A significant role played by children

in assisting their mothers with adherence to clinic appointments and HIV treatment is beneficial for HIV-affected families and needs to be supported.

Mothers in this study cited similar barriers to child disclosure as those highlighted in the literature. Specifically mothers were concerned about the children's developmental capacity to understand HIV (Kennedy, Cowgill et al. 2010, Madiba and Matlala 2012, Gachanja, Burkholder et al. 2014, Li, Li et al. 2016), the potential negative psychological impact of disclosure on a child (Murphy, Roberts et al. 2006, Murphy, Marelich et al. 2013, Qiao, Li et al. 2015), the potential effects of stigma particularly given the perceived inability of a child to contain information and not disclose to other people (Tiendrebeogo, Hejoaka et al. 2013, Jao, Hazra et al. 2016), and a lack of skills and confidence to undertake disclosure (Qiao, Li et al. 2011). We show that for the overwhelming majority of mothers, the Amagugu intervention has a powerful mobilizing effect, minimising these barriers and shifting mothers to change their disclosure behaviour.

In the larger Amagugu study we reported high rates of current partnerships and disclosure to current partners. We demonstrated that full disclosure to a current partner prior to the intervention was associated with full disclosure to children in the intervention (Rochat, Arteche et al. 2014). In this sample we see similarly high rates of partnerships, disclosure to partners, and full disclosure to children. Importantly, we demonstrate here that at baseline, despite these relatively high rates of disclosure to significant adults in the mother's life, mothers had not undertaken disclosure to their children. This finding suggests that if rates of disclosure to children are to be increased, additional interventions focused specifically on supporting disclosure to children are required to overcome barriers to child disclosure (Dass-Brailsford, Eckman et al. 2014, Edwards, Donovan-Kicken et al. 2014, Gachanja, Burkholder et al. 2014). Interventions which focus on adult disclosure alone are not likely to increase disclosure to children (Kennedy, Fonner et al. 2015, Li, de Wit et al. 2015).

We found that the supportive counsellor relationship played an important role in the mother's ability to engage with, and achieve, intervention success. The quality of the participant-counsellor

relationship has been shown to influence outcomes in other research on home visiting programmes in southern Africa (Thurman, Kidman et al. 2014) and this may be particularly true in communities where stigma remains high and where mothers feel isolated. Other studies report HIV-related stigma as the most common reason for non-disclosure (Letteney and LaPorte 2004, Palin, Armistead et al. 2009, Qiao, Li et al. 2015). However, research conducted in this study area illustrates that access to HIV treatment and care has significantly reduced HIV-related stigma and women feel supported by their partners and families (Evangeli, Newell et al. 2014, Mkwanazi, Rochat et al. 2015).

Our results show that specific facilitators play an important role in shifting a mother's behaviour towards disclosure. Most importantly, mothers reported that the intervention approach, content, materials and tools, were the strongest facilitators in behaviour change toward disclosure. We have reported previously (Rochat, Mkwanazi et al. 2013) that mothers and counsellors in the pilot study highlighted the importance of the branding and presentation of the materials as central to their engagement with, what would otherwise be considered, a daunting task. Here we again demonstrate that the design of Amagugu as a user- friendly, interactive, participatory, activity-driven process, which provides age-appropriate games and activities, and makes learning about HIV a fun and engaging activity, contributes to successful engagement with disclosure (Rochat, Mitchell et al. 2016).

That the intervention content, approach and materials matter is an important finding, particularly in resource-constrained settings where the design of intervention packages may be primarily driven by the need to keep costs to a minimum. However, it is plausible that the additional investment in materials which are colourful, engaging, practical and user-friendly, may make an important contribution to participant engagement with the intervention, and the resulting behavioural change. In the longer term, this may result in the intervention package becoming more cost effective, particularly since without this active engagement of the target population of parents, most community-based interventions aimed to enhance parenting would be ineffective (Staudt 2007).

There is substantial support in the literature on the importance of fostering participant engagement as a means to enhancing prevention and intervention outcomes (Snell-Johns, Mendez et al. 2004). There is also substantial evidence to suggest that increased engagement is related to improvements in prevention and intervention outcomes in research (Brown, Goslin et al. 2012). An important aspect of the Amagugu intervention, which is linked to the design of the intervention, is the flexibility with which mothers were allowed to adjust the intervention to meet their specific needs. Accommodating such variations, or allowing participant autonomy, may appear counter-intuitive to keeping intervention design simple and low cost, but we illustrate here that this removes barriers to behavioural change for participating mothers. This may serve to increase the applicability of the intervention to a wider audience of mothers with differing needs, capacities and circumstances. Further research is required to establish the cost-benefit ratios of providing a bespoke designed intervention package such as Amagugu, in a low-resource setting.

Despite mostly positive results in terms of participant engagement in Amagugu, and the additional benefits of ongoing treatment support to mothers within the family, some new challenges were raised by participating mothers that were not addressed through the intervention content and approach. There were concerns that the 'Safety Hand', a tool provided by the intervention to assist mothers to negotiate confidentiality of their HIV status with their children, was not trusted by some mothers to be effective in achieving that purpose. Absence of questions and lack of negative reactions by children following disclosure made some mothers doubt whether their children had fully understood the implications of their HIV status. Mothers also highlighted that, as children become older, the relationship between a parent and a child demands additional knowledge in dealing with issues such as sex education (Bhana, Petersen et al. 2004, Visser, Finestone et al. 2012). Women expressed a desire for Amagugu to be augmented with materials on sex education, including teenage pregnancy, and they requested something to motivate and educate their children about how they should conduct themselves in social situations. An age-appropriate illustrated 'Where do babies come from?' sex education storybook has been developed by the authors, and was tested as part of the randomised controlled trial of the intervention recently completed and currently being analysed.

**Limitations**

This study did not aim to address community stigma, however, future studies could assess the impact of maternal HIV disclosure on stigma outside the family setting. Women in this study had been exposed to two home-based interventions previously, the VTS and the Amagugu Study. Therefore, it is possible that they were more receptive to research involving their children and were more used to adhering to research procedures than other women, hence the high rates of maternal HIV-disclosure reported. It would be interesting to examine results from future studies using the same intervention materials, but enrolling HIV-infected women from the general population, who had not previously been involved in research. It is also possible that social desirability bias resulted in fewer mothers complaining about the intervention despite the researcher's assurance that this would be acceptable. In the context of poverty, participants with very little access to services and support may not feel comfortable to give negative feedback about a programme designed to support them. Due to logistical constraints and ethical complexities, children were not interviewed directly. Future studies could, and most probably should, investigate children's perspectives on maternal HIV disclosure.

**Conclusion**

It should not be assumed that adult disclosure will automatically lead to disclosure to children. Specific interventions are needed to support and encourage disclosure to children. The design and the practical content of the intervention, and investments in the branding and quality of materials, are the most important factors which elicit participant engagement. To a lesser extent the quality of the counselling support relationship also matters for mothers who have concerns about stigma. Providing mothers with the opportunity to engage their children in active participation about their HIV is highly satisfying to mothers, regardless of their circumstances.

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**Figure 1: Outline of the home-based sessions in the Amagugu Intervention with expected behaviour change paths (Rochat, Mitchell et al. 2016)**

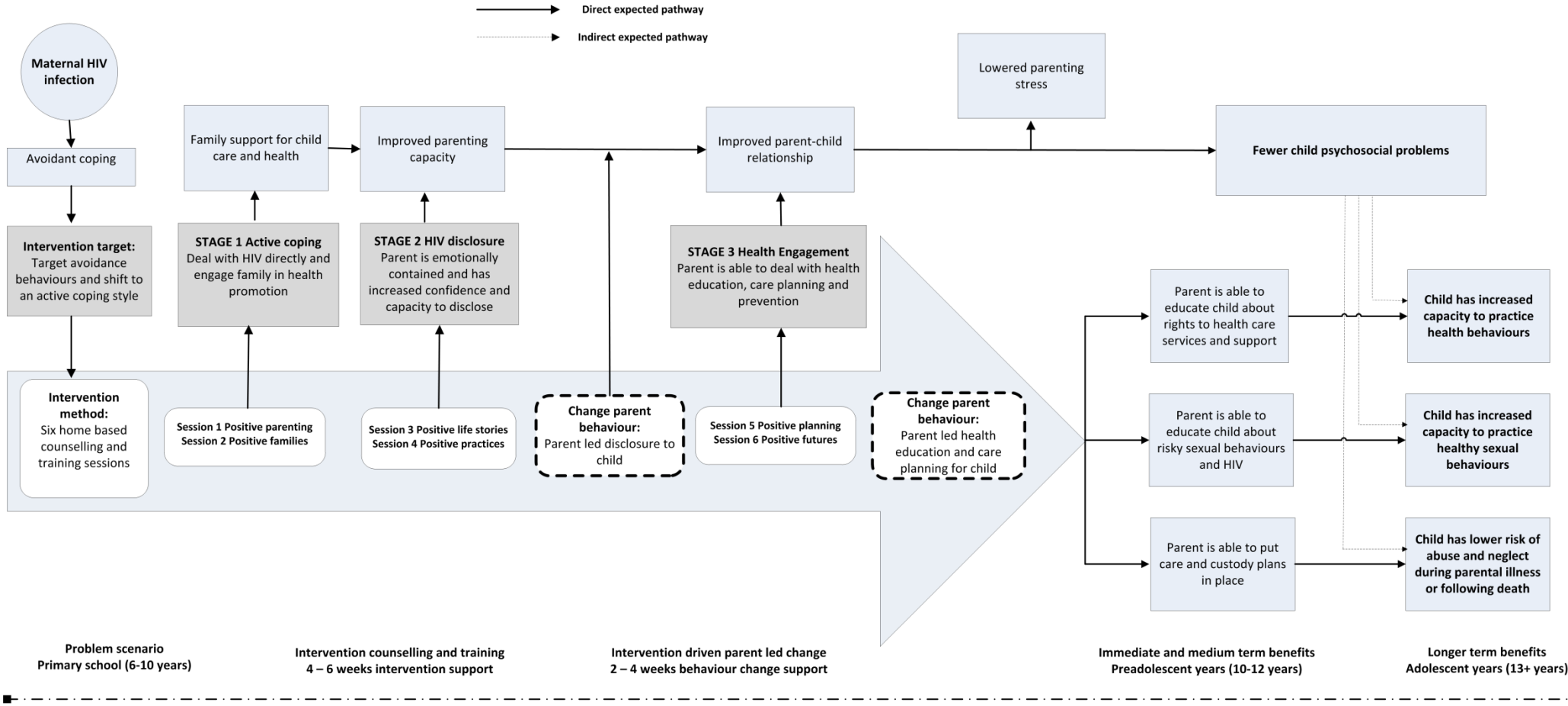


**Figure 2: Interview Guide**

1. What were your initial thoughts when you were first informed about the maternal HIV disclosure intervention?
2. What made you decide to take part in the HIV disclosure intervention?
3. Please take me through your Amagugu experience; what do you think worked for you and what do you think did not work for you?
4. Did you choose to fully disclose or partially disclose your status as part of the intervention?
5. Please share your thoughts on the disclosure materials that you were provided with to help you during disclosure process
6. What do you think are the important lessons that you learned during the disclosure intervention?
7. If giving advice to another HIV-infected mother who has not disclosed to her child, about disclosure, what would your advice be?

**Table 1: Characteristics of mothers and their children (N=20)**

| Study ID | Maternal Age (Years) | Child Age (Years) | Child Sex | Marital Status | Employment Status | Length of time on ART in Years | Last CD4 Cell Count Results cells/ml | Type of Disclosure To Child | Disclosed to Current Partner | Lives with Current Partner |
|---|---|---|---|---|---|---|---|---|---|---|
| 1 | 26 | 7 | F | No current partner | Unemployed | 4 | 105 | Partial | No | No |
| 2 | 32 | 6 | M | Current partner | Unemployed | 1 | 568 | Full | Yes | No |
| 3 | 32 | 7 | F | Current partner | Employed | Not on ART* | 379 | Full | No | Yes |
| 4 | 44 | 8 | M | Current partner | Employed | 7 | 800 | Full | Yes | Yes |
| 5 | 46 | 7 | M | Current partner | Unemployed | 6 | 700 | Full | Yes | Yes |
| 6 | 36 | 6 | F | Current partner | Employed | 1 | 297 | Full | Yes | Yes |
| 7 | 37 | 7 | M | Current partner | Unemployed | 5 | 487 | Full | Yes | Yes |
| 8 | 49 | 8 | F | Current partner | Unemployed | 6 | 219 | Full | Yes | No |
| 9 | 28 | 6 | F | Current partner | Unemployed | 1 | 212 | Partial | Yes | No |
| 10 | 39 | 8 | F | Current partner | Employed | 2 | 467 | Full | Yes | Yes |
| 11 | 28 | 7 | F | Current partner | Unemployed | Not on ART | 629 | Full | Yes | No |
| 12 | 32 | 7 | M | Current partner | Unemployed | 2 | 518 | Full | Yes | Yes |
| 13 | 37 | 7 | M | Current partner | Unemployed | 1 | 400 | Partial | No | No |
| 14 | 38 | 6 | F | Current partner | Employed | Less than 1 year | 350 | Full | Yes | No |
| 15 | 31 | 8 | F | Current partner | Unemployed | Not on ART | 709 | Full | No | No |
| 16 | 36 | 7 | F | Current partner | Employed | Not on ART* | 459 | Full | Yes | Yes |
| 17 | 28 | 6 | F | Current partner | Unemployed | Less than 1 year | 300 | Full | No | No |
| 18 | 29 | 8 | M | Current partner | Employed | Not on ART* | 370 | Full | No | No |
| 19 | 32 | 7 | F | No current partner | Unemployed | Not on ART | 540 | Partial | No | No |
| 20 | 29 | 7 | F | Current partner | Unemployed | 3 | 394 | Full | Yes | Yes |

*****At the time of the study the cut-off for ART initiation was CD4+ T-cell count $\leq$ 350 cells/$mm^3$

**Table 2: Aspects of the intervention reported as key to maternal satisfaction**

| Maternal satisfaction aspect | Quotations from mothers in support of maternal satisfaction |
|---|---|
| **Communication (n=6)** | "I enjoyed that our talk brought back hope of life to me as we were talking." |
| | "I enjoyed telling my child about my status and *Family Life Line*." |
| | "I enjoyed opening up to my child about the pills I take every day." |
| | "I enjoyed the *Playing Cards* and their messages the most." |
| | "I enjoyed our *Family Life Line*." |
| | "I enjoyed the *Family Life Line* the most because (before this) the child did not know about her father." |
| **HIV education (n=5)** | "I enjoyed the *HIV Body Map* the most." |
| | "I enjoyed explaining the *HIV Body Map* the most." |
| | "I enjoyed the *Body Map* because it helped to clarify my illness." |
| | "I enjoyed the *HIV Body Map* the most." |
| | "I enjoyed the *HIV Body Map* the most." |
| **Child's developmental capacities (n=5)** | "I enjoyed that my child answered all the questions well when I confirmed that he understood." |
| | "I enjoyed that my child showed more HIV knowledge." |
| | "I enjoyed that my child easily understood what we were talking about the most." |
| | "I enjoyed that my child easily understood what we were talking about the most." |
| | "I enjoyed that my child understood what we were discussing and had sympathy for me." |
| **Play and health promotion (n=4)** | "I enjoyed the *Playing Cards* and the *Story Book* the most." |
| | "I enjoyed the *Playing Cards* the most because my child understood the messages." |
| | "I enjoyed the *Playing Cards* the most." |
| | "I enjoyed the *Playing Cards* the most." |

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# Mothers' and health workers' perceptions of participation in a child-friendly health initiative in rural South Africa

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## ABSTRACT

**Background: Primary health care clinics promote health in addition to treating illness, but are often perceived as unfriendly and frightening places for children. This research aimed to improve child-friendliness in primary health care settings in a rural, high HIV prevalence area in South Africa. Methods: As part of a larger intervention ("Amagugu" Intervention) health staff in nine primary health care clinics were trained in a child-friendliness approach. 281 enrolled mothers were invited to attend clinic with their primary school-aged children and assessed child-friendliness via structured questionnaires administered by independent assessors; a sub-group also participated in in-depth interviews. Post intervention, focus groups were conducted with 87 primary health staff to determine their experiences of providing child-friendly services. Results: Mothers rated 65% of clerks and 70% of nurses as "very friendly". Qualitative data showed that heavy clinical loads, limited human resources and inadequate infrastructure were perceived as barriers to child-friendliness, while good clinic leadership and appropriate resources facilitated child-friendliness. Post intervention most health workers reported that child-friendly health promotion activities were rewarding. Conclusions: Providing child-friendliness training and support to primary health care facilities in low-resource settings is feasible, acceptable and yielded encouraging results.**

**Keywords:** Primary Health Care; Child-Friendliness; Health Promotion; HIV; South Africa

## 1. INTRODUCTION

In South Africa HIV care is commonly delivered in primary health care clinics (PHCs) where health workers are instrumental in supporting good adherence to antiretroviral treatment (ART) [1]. In the family context HIV-uninfected children often play an important role in supporting their HIV-infected parents, including helping them to adhere to their medication [2-5]. Therefore, increasing children's access to health care support networks has the potential to improve health outcomes in families.

However, PHCs are often not perceived as child-friendly spaces [6,7]. Barriers reported to lower child-friendliness includes inappropriate physical structures and job dissatisfaction or fatigue amongst health workers [8,9]. Facilitators include staff training on child-friendliness and engaging children with toys and activities [10,11]. In resource-poor settings PHCs are often overburdened, so health promotion is a low priority [12-14]. A multi-site study in Uganda, Kosovo and Pakistan found that children, parents and health workers shared frustrations with rigid health care structures and poor systems for disseminating health information [6]. Even in resource-rich settings health workers acknowledge the challenges of promoting health amongst children in primary health care [6,15].

Despite being home to most of the world's families living with HIV, literature addressing the health care support needed by HIV-affected families in South and

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southern Africa is minimal [3,12,16-18]. Most has focused on the utilization of health services by sick people [13,14,17,19,20] and suggests that children are often marginalised as they find health care facilities frightening [21,22] and do not understand the terminology being used [23,24].

A family-centred HIV disclosure intervention, the "Amagugu intervention" [25], was developed and tested in rural South Africa to support HIV-infected mothers to disclose their HIV status to their 6 - 10-year-old, HIV-uninfected, children. The intervention was tested with 281 families and found to increase maternal HIV disclosure [25]. After disclosure the mother was encouraged to engage in a health promotion activity by taking her child with her to a clinic visit. The mothers were educated on the importance of early health promotion for children and provided with health education tools for use at the clinic visit. In addition, an intervention to support child-friendliness at the nine participating health facilities was developed and implemented. This research used qualitative and quantitative methodology to explore health workers' perceptions of delivering child-friendly services and presents maternal data to support improvements in child-friendliness as a result of this intervention.

## 2. METHODS

***The research setting*:** This study was undertaken at the Africa Centre for Health and Population Studies (www.africacentre.com) in northern KwaZulu-Natal, South Africa, in a predominantly rural area with a high HIV prevalence [1,26]. Health care, including HIV care, is delivered through 17 PHCs and one district hospital with a comprehensive, decentralised, HIV Treatment and Care Programme [13,27,28].

***Research design*:** This research used both quantitative rating data from structured questionnaires administered to mothers, and qualitative data from focus groups with health workers and in-depth interviews with a sub-group of mothers. Mixed methodology was chosen because of its value in understanding health behaviours and perceptions in under-researched issues and populations [29,30].

***Health care initiative*:** A health facility intervention was developed specifically for this research, using participatory qualitative techniques to increase its relevance and acceptability for health staff. Thereafter, the training was piloted at four of the nine implementation clinics, selected to include both rural and peri-urban settings. During piloting, dialogue and feedback were elicited from staff at participating clinics to finalise the training programme and clinic resources for a child-friendliness component (see **Box 1**). The training was then implemented at the five remaining PHCs. The health worker training targeted a diversity of staff including nurses, HIV counsellors and clerks to maximise opportunities for improving the quality of interactions with children during clinic visits.

**Box 1.** Health care educational materials provided as part of the Amagugu intervention.

**Materials provided for the children as part of the "Amagugu" intervention**

The Amagugu Name Tag: Each child was provided with a name tag to assist the child to have a sense of identity and pride, and serve as a visual reminder to health staff of their commitment to ensuring that children were welcomed in the clinic.

The Clinic Checklist: The clinic checklist was designed as an "I spy" activity, to encourage the child to explore the clinic. It is a "learn by doing" tool which helped the child become familiar with the clinic processes (including patient registration and medical procedures); the infrastructure (including the waiting area and toilet); and to meet and engage with health care providers (including the clerk, other patients and the HIV nurse).

The Uthando Doll: The larger intervention included a play-for-communication component where children were provided with ethnically-appropriate dolls. Children were encouraged to take their doll to the clinic and participate in "pretend play" of medical procedures such as checking temperatures and giving injections. Including the doll in the clinic activities encouraged the child to learn about medical procedures in a fun and non-threatening way.

Clinic Visit Reminder Card: This A5 illustrated card was a reminder tool for mothers, to help them organise, plan and execute the health care visit. The card also served as an advocacy tool in the clinic where the mother could use it as a reminder for busy health staff of the commitments to provide a child-friendly clinic visit.

**Materials provided for the clinic facilities**

Health promotion posters: An A3 poster was designed, titled "Let's Make Clinics Child-friendly!". The poster provided key health promotion messages and reminders about child-friendliness, including: children should be welcome at clinics even when they are not ill, health care environments are spaces for information and advice, a health care support network is important for children whose parents have chronic illnesses, play is important for children to reduce anxieties and allow health promotion learning.

A Medical Play Kit: A commercially sourced medical play kit and an Uthando doll were provided to each HIV nurse to engage the child in health demonstrations. The play kit included a stethoscope, thermometer, syringe and otoscope.

Amagugu intervention materials: As part of the intervention mothers were provided with an HIV Body Map with stickers, and health promotion playing cards. These tools were also available in the nurses' examination room during the child's visit, so that the nurses could reinforce the messages mothers had taught their children during disclosure.

***Data collection tools*:** Three data collection tools were utilized in this research: 1) Interviews with mothers (N = 281): These structured interviews followed the health promotion clinic visit and collected maternal ratings of child-friendliness; 2) In-depth interviews with a sub-set of mothers (N = 20): A group of mothers were interviewed at their homes two weeks after the Amagugu intervention, to explore their experiences of participating; 3) Health care worker focus groups (N = 87): Focus groups were conducted with health staff at all nine participating clinics, three months after the intervention. Focus group methodology was used to explore perceptions, opinions and attitudes towards child-friendliness.

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Prior to the research we identified five key issues from the literature [10-12,19-21,31-33] which were important for the development and uptake of this kind of intervention: 1) willingness to engage in child-friendliness; 2) activities to support child-friendliness; 3) barriers and 4) facilitators of child-friendliness; and 5) contributors to sustainability. These formed the basis of the focus group guide and were also used as guiding categories in focus group analyses.

***Data analysis*:** *Quantitative data analysis*: Mothers' data from the post clinic interviews were entered into an Access database and imported into STATA 11 for analysis. Descriptive statistics were used to quantify and describe the demographic characteristics of the participants including mothers and health workers. *Qualitative data analysis*: Focus groups and in-depth interviews were transcribed verbatim, translated from IsiZulu to English, imported into ATLAS. ti version 7 for analysis [34,35], and organised using the themes explored in the focus group and interview guides. Categories were reviewed for redundancy and similar codes and categories grouped under a single higher order category. Higher order categories which resulted from collapsing codes with similar ideas together reflected the important thematic areas linked to the focus group and interview guide categories.

***Ethics permissions*:** Approval was granted by the University of KwaZulu-Natal Biomedical Research Ethics and the University of Witwatersrand Human Research Ethics Committees.

## 3. RESULTS

***Sample*:** All 281 HIV-positive mothers enrolled in Amagugu completed the health promotion training; their socio-demographic and health characteristics are shown in **Table 1**.

***Maternal intervention impact*:** Mothers' experiences of the clinic visit, including ratings of child-friendliness of health workers are shown in **Table 2**. Almost all the mothers took their child to the clinic, with a third reporting waiting less than 5 minutes to see the nurse. Approximately two-thirds of the mothers rated the clerks and nurses as "very friendly", and most reported that the nurses had used the medical play kits and the childfriendliness posters, although only a third used the HIV Body Map.

***Characteristics of health workers participating in focus groups N* = 87:** Forty-one (47%) participants were nurses, 23 (26.5%) HIV counsellors and 23 (26.5%) clinic clerks. The median age of participants was 39 years (IQR 31 - 49); six were male. Sixty two (71%) participants were from rural, 17 (20%) from peri-urban and 8 (9%) from urban clinics.

Themes from the focus groups of health workers and in-depth interviews of mothers:

**Table 1.** Maternal and child characteristics.

| **Maternal characteristics** | | |
|---|---|---|
| ***Age* (*years*)** | | |
| Median | 35 | |
| Range | 23 - 54 | |
| | **N** | **%** |
| ***Education*** | | |
| No education | 17 | 6.0 |
| Completed some or all primary | 108 | 38.4 |
| Completed some or all secondary | 148 | 52.7 |
| Post school education | 5 | 1.8 |
| Missing | 3 | 1.1 |
| ***Employment*** | | |
| Employed | 90 | 32.0 |
| Unemployed | 188 | 66.9 |
| Missing | 3 | 1.1 |
| ***Regular income*** | | |
| Receives regular income | 73 | 26.0 |
| Does not receive regular income | 208 | 74.0 |
| ***Hospitalisation* (<12 *months*)** | | |
| Yes | 30 | 10.6 |
| No | 250 | 89.0 |
| Missing | 1 | 0.4 |
| ***CD4 count* (*most recent*)** | | |
| ≥501 | 77 | 27.4 |
| 351 - 500 | 53 | 18.9 |
| ≤350 | 71 | 25.3 |
| Missing | 80 | 28.5 |
| ***HIV treatment status*** | | |
| On ART (1) | 118 | 42.0 |
| Not on ART (2) | 155 | 55.2 |
| Missing | 8 | 2.8 |
| **Child characteristics** | | |
| ***Age* (*years*)** | | |
| Median | 7 | 7 |
| Range | 5 - 10 | 5 - 10 |
| | **N** | **%** |
| ***Gender*** | | |
| Female | 140 | 49.8 |
| Male | 141 | 50.2 |
| ***Hospitalization* (*since birth*)** | | |
| Yes | 43 | 15.3 |
| No | 221 | 78.6 |
| Missing | 17 | 6.0 |

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**Table 2.** Maternal experiences of child-friendliness at the health promotion clinic visit.

| Mother reported data from clinic visit | N = 281 |
|---|---|
| ***Did you take your child for a clinic visit?*** | |
| Yes | 277 (98.58%) |
| No | 4 (1.42%) |
| ***Did your child wear his/her name tag?*** | |
| Yes | 276 (98.22%) |
| No | 5 (1.78%) |
| ***Did your child meet the clerk and complete the register?*** | |
| Yes | 263 (93.59%) |
| No | 17 (6.05%) |
| Missing | 1 (0.36%) |
| ***How would you rate child-friendliness of the clerk that you met?*** | |
| Very friendly | 184 (65.48%) |
| Neutral | 73 (25.98%) |
| Unfriendly | 5 (1.78%) |
| Don't know (did not meet one) | 18 (6.41%) |
| Missing | 1 (0.36%) |
| ***Did your child complete his/her clinic checklist?*** | |
| Yes | 271 (96.44%) |
| No | 8 (2.85%) |
| Missing | 2 (0.71%) |
| ***Did you see the Amagugu child-friendliness poster at the clinic?*** | |
| Yes | 259 (92.17%) |
| No | 21 (7.47%) |
| Missing | 1 (0.36%) |
| ***How long did you wait to see the nurse for the health care visit?*** | |
| <5 min | 90 (32.03 %) |
| 5 - 20 min | 82 (29.18%) |
| 20 - 60 min | 79 (28.11) |
| >60 min | 25 (8.90 %) |
| Missing | 5 (1.78%) |
| ***How would you rate friendliness of the nurse?*** | |
| Very friendly | 196 (69.75%) |
| Neutral | 62 (22.06%) |
| Unfriendly | 3 (1.07%) |
| Don't know (did not see the nurse) | 18 (6.41%) |
| Missing | 2 (0.71%) |
| ***Did the nurse use any of the following Amagugu educational tools?*** | |
| HIV Body map education tool | 112 (39.86%) |
| Medical play kit | 197 (70.11%) |
| Child-friendliness posters | 233 (82.92%) |

**1) *Willingness to participate in, and acceptability of, child-friendly initiatives and health promotion for children***

The importance of children's rights to friendly and accessible health facilities, emphasised in the training, resonated with most participants. In focus groups, discussion centred on beliefs about what a child-friendly clinic should or should not be. Participants felt that clinics should represent safe and welcoming places where children were not discriminated against. One 47-year-old female nurse stated: "*I think it* (*child-friendliness*) *means that if the child is below the age that they can go to the clinic by themselves*, *they should not be scared of going to the clinic when left alone at home and they have a running stomach*. *They should just have that confidence that I'm used to going to the clinic and I know that they are going to help me. They can just go because they know that children are welcome at the clinic*, *they don't get scolded and they are not in that frightened state.*"

Mothers agreed that the health promotion visit encouraged their children to visit the PHCs. A 49-year-old mother of an 8-year-old boy said: "*From there* (*after disclosing*) *I started talking to him about positive living*, *and we continued educating each other about sickness and pills and I made him have an interest in going to the clinic and enjoy it. He used to be that person that fears going to the clinic*; *he feared that they will give him an injection*. *He ended up liking the clinic and being interested in going there and wants us to go there all the time*."

A 36-year-old mother of an 8-year-old girl echoed the same sentiments: "*Through participating in the Amagugu intervention I got encouraged to go to the clinic because we sometimes forget. The child also enjoyed visiting the clinic*".

**2) *Activities that support child-friendly initiatives***

**Table 3** summarises the activities thought to support child-friendliness in the focus groups.

**3) *Barriers to child-friendliness***

Busy clinical settings and inadequate human resources were cited as the most important barriers to child-friendliness. A 38-year-old male nurse stated: "*Sometimes it happens that the children come to the clinic and the clinic is busy in such a way that even if you want to give*

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**Table 3.** Activities supporting child-friendliness identified in focus groups.

| **Activities which health workers believe support child-friendliness** | |
|---|---|
| ***Actions required by health workers*** | ***Statements made by health worker*** |
| **Orientate and welcome children**<br>• Come down to the level of the child and use developmentally appropriate language | "*Anyone who works there can come down to the level of the child and talk the language that is spoken by the child so that they can understand what the child is saying.*"<br>"*This should be a place where children feel relaxed and at home.*" |
| **Provide information and support**<br>• Offer reassurance to reduce fears and anxieties of clinics | "*It is easy for us, but for the children it is harder. They arrive with an attitude that you are the enemy. They have been told that back home. You try to reach out and the child pulls away. There was a child here this morning. The counsellor tried to play but the problem was that she was dressed as a nurse, the child became so quiet as if something had shocked him. You could see that he was quiet because he was very frightened.*"<br>"*You wish to compliment them even on their clothing and say 'you look so handsome young man' but the child is just so scared that you are up to something.*" |
| **Set boundaries for children**<br>• Set boundaries and explain acceptable behaviour in the clinic | "*It's a problem when these school children visit the clinic. They can misbehave, make noise, ring their phones, play with wheelchairs and other stuff that helps patients. Then you have to show that no, what they are doing is wrong. Not because you don't want them to come to the clinic but you explain that wheelchairs are not for playing but they are for very sick patients-maybe one day you will also be very sick and use a wheelchair or your parent.*" |
| **Providing parental guidance**<br>• Demonstrate sensitive care to parents | "*Sometimes we have a problem because the child's mother is harsh to the child in front of us and maybe even scolding them. We end up telling them not to do that.*" |

*them the attention they deserve as children you end up not doing it. You cheat them because of the bad timing. Maybe you are running around, delivering babies, immunising and maybe it's only the two of you at the time and the child gets cheated of the attention they deserve*."

A 42-year-old female nurse stated: "*The workload is not an easy thing. Sometimes the mother comes with the child and the child does not get attention. Especially if the child is not sick, you only attend to the mother because you are pushing work and you don't even have time to be playful with the child. It's not easy in a busy clinic. You only attend to the illness and do what you are doing*."

Some health workers supported the child-friendliness intervention but complained about the mothers and did not appear to appreciate the "service role" of the clinics that remain open until 16:30 hours. A 43-year-old female nurse complained about the mothers: "*Maybe you can rectify with them* (*mothers*) *that they cannot come whenever because some mothers arrive at* 4 *pm and you have already locked the room and they say* [*Imitating the mother*] "*This is the only time I could come, I was told to come whenever*"*... then it will be like we have an attitude towards them whereas we know we have to attend to them*."

A point of discord that featured strongly in the focus groups related to the gap between being willing to practise child-friendliness and not having the tools or human resources to do this. A 36-year-old female counsellor stated: "*Yes, we try our best* (*to be child-friendly*) *but there are no toys or fun things that the staff can use. We do not have enough time for it because this is a busy clinic and we have many patients with different sicknesses*."

The lack of child-friendly spaces was frequently raised, as one 30-year-old female HIV counsellor stated: "*Because there is no place where the children can play as children, so sometimes it can appear as if they are not taken good care of, but it* (*child-friendliness*) *is doable*."

Participants also highlighted that health care work was emotionally draining, and at times they felt overwhelmed with critically ill patients. For example, a 40-year-old female nurse stated: "*Maybe it is* [*hard*] *because children that come for health promotion are not sick. They have an image they are expecting—they expect that they will find a person that will be smiling and then they are met with not what they expected... It's not that you want to be like that but you have this load*."

**4) *Facilitators of child-friendliness***

Participants discussed ways to be child-friendly in the face of staff shortages. One idea was to share tasks among health workers. A 39-year-old female HIV counsellor's idea was: "*... we can choose this Room* 2 *and have a counsellor that will just attend to them* (*children*) *and it could be fun whilst the mothers are consulting nurses with their many files. The counsellor can just keep them busy*."

Participants agreed that the Amagugu materials assisted them despite working in an overcrowded, rural, clinic. A 25-year-old female nurse was pleased with the intervention and stated: "*We orientate children using Amagugu materials and we are able to present health information in a fun-filled way. They start there at the front desk by the clerk and we try to welcome them. Sometimes the time is against us but we try. Sometimes they just get excited and jump if they recognise Amagugu stuff*'.

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For many participants, the ability to be child-friendly was connected to the leadership of the clinic, and how emotionally supportive they were to the health staff. In one clinic the sister-in-charge was regarded by the clinic staff to be "loving and caring"; participants from this clinic reported that it was easy to follow her lead. A 44-year-old female general assistant made the following statement: "*We are grateful for Clinic X because the mother* [*referring to the sister-in-charge*] *that is managing*, *the supervisor*, *is loving*. *Even when she is busy she can allocate someone else to take children around. This is a friendly clinic to anyone*, *not just children*."

**5) *Sustainability of child-friendly initiatives and rewards for participating health staff***

Participants highlighted, and recognised, the value of providing kind and sensitive care to children for their own sense of wellbeing and pride in their work. This made child-friendliness easier to maintain and sustain. This was most commonly expressed in participants' enjoyment of children's expressed aspirations to become health care providers themselves. A 42-year-old female nurse gave the following example: "*We greet them (children*), *we welcome them very nicely and ask them who they are*, *and introduce ourselves and even ask them* '*what would you like to study to be* (*when you grow up*)'? *Some even say*, '*I would like to study to be a nurse*'. *Maybe it is because we have talked to them nicely*".

A 55-year-old nurse stated: "*I was happy to see them* (*the Amagugu children*) *because of their cleverness. Even the way they do things. You can see that if these children can continue with this thing they have started*, *they can be able to help even the person they meet on the street. ... You enjoy being with them even if it is for a short period. If we can have enough time it would be wonderful*".

Participants felt that the activities in the intervention package encouraged a positive interaction between them and the children. A 42-year-old female nurse explained how they participated in the intervention: "*They have these name tags and use the playing cards that you gave us and the doll. They end up seeing themselves as health workers. For instance if you give them a stethoscope and let them use it. They see themselves as doctors or see themselves as nurses*".

A 40-year-old female nurse was impressed by some of the Amagugu children that came for the health promotion visit: "*What I can say is there are those that are quiet and those that are open..... we had twins*, *one twin was quiet and the other one was energetic and talking about HIV and saying what she learnt at Amagugu*, *showing how the HIV enters the body*".

A 34-year-old male nurse expressed his exciting experience of interacting with the study children: "*The one* (*child*) *that I saw was clever and was asking questions*, *she was checking out the stethoscope and asking* '*is this for seeing inside*'? *She even wanted to leave with the doll and was putting it in her bag. They come with different ideas and expectations. Like the one that came and said* '*I am here to work*'. *That child ended up ordering for her mother*: '*Give my mother this one*, *check her BP*, *use the thermometer*'. *When that Amagugu child came and said I am here to work*, *I got interested and thought* '*that is an idea*' *and wanted to see and I said* '*let's work*'. *It becomes fun*".

Participants talked of the challenges of performing painful procedures on children, and the important role played by the intervention materials in making children less frightened of the clinics. A 40-year-old female nurse said: "*... to know what is happening in the clinic is important—sometimes painful stuff like injections-but it is important for children to get the knowledge. For instance because there are these play kits*, *we can demonstrate that your child is sick*, *s/he must get an injection. It's important that the child knows that sometimes an injection is needed in order to get better*".

A few people were not enthusiastic about the child-friendly intervention. One 40-year-old female nurse reported that even though the intervention was there, she sometimes forgot about it.... but when she remembered she tried to be friendly to children. She said: "*I beg to differ*. *I don't have the same views because we don't have time for these children. I for instance*, *forget about them and find myself asking them*: "*Who are you by the way*?" *Because I'm seeing someone that is disturbing me while I'm busy and then I remember and I try to do damage control*."

A 28-year-old female counsellor agreed and went on to say: *I agree with* [*referring to Nurse*] *when they* (*children*) *come we are really busy*, *I did not even know who they were*. *I just heard* Igugu, *but I did not know what* Igugu *was*. *I did not even attend to them because here at Clinic X it's really busy*. *Things are turning upside down*, *and it's not a child's play. I don't want to lie I have not entertained them* (*children*).

## 4. DISCUSSION

This study demonstrated that providing training and simple tools for child-friendliness and health promotion in a resource-poor, high HIV prevalence area was well accepted by health workers and mothers. This intervention was specifically aimed at the large group of HIV-uninfected but exposed children, on whom there is limited literature regarding their psychosocial support [18]. However, the child-friendliness approach that was introduced has benefits for all children irrespective of their HIV status.

Encouragingly, most health workers believed that child-friendliness was a good idea, an important step in

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eliciting behaviour change [36,37]. Nevertheless, most admitted they had not considered this before the intervention, an observation supported in the literature which suggests that health professionals lack awareness of the importance and benefits of child-friendliness [15]. In our study, health workers suggested activities to support child-friendliness, not all of which included purchasing materials or tools, but also recognising that they could draw on their instinctive caring and parental instincts to improve their communication with children during their consultations. Some suggested allocating specific people to attend to the children where possible, a model frequently was adapted in resource-rich settings [6,32], but not feasible in many poorer settings. Indicators of child-friendliness in previous reports have included whether the environment was conducive for child play, whether toys and health promoting activities were provided, and whether someone had been allocated to lead play [10,11, 32].

Participants in the focus groups also appreciated the role of health promotion, despite the clinics being overwhelmed with sick patients. Health promotion enables people to increase control over, and improve, their health [15], and participants were surprised by the knowledge of the relatively young children in this project around HIV issues, and their enthusiasm to learn more. Children of different ages and with different illnesses may need different types of health promotional support. Increasing opportunities for child participation in clinic visits may improve the quality of health care provider relationships.

Many barriers to implementing child-friendliness were highlighted, mainly resulting from the great burden of HIV and tuberculosis at the clinics, leading to inadequate space for additional activities, and exhausted health staff [8,9]. These high levels of occupational stress have not only been reported in high HIV prevalence countries including South Africa [9] and Uganda [8] but also resource-rich settings including England [38]. The problem of dealing with painful procedures was also identified, with participants suggesting that children themselves can present barriers to engaging with health staff because of their innate fear of PHCs, something highlighted in previous research [10,21,22,24,39,40]. However, participants recognised the role of play in helping children understand about medical procedures.

Participants expressed their appreciation of the children's responses to child-friendly activities, using words such as "fun", "happy" and "enjoy" when describing their encounters with the children in this intervention. Often health workers in resource-poor settings are criticised for their lack of motivation and poor attitude to patients [9], but the demands on them are immense. Providing training on child-friendliness appeared to be something that health workers appreciated, responded to, and found rewarding. An important point brought up by one participant was the clinic leader being a good role model. She explained that being friendly to all children, and in fact to all patients in her clinic was something that was easy to do as the sister-in-charge provided a loving and empathetic example. Placing more emphasis on the qualities of the person in charge of PHCs has the potential to change the overall quality of services provided. Further, interactions with children which are rewarding may help to re-sensitise busy over burdened nurses in their caring role.

This was a small study in a specific geographic area. However, the findings are likely to resonate with other areas of southern Africa with similar problems. While some South African research exists to guide the use of play in health settings and the provision of psycho-social support for children [12,16,41,42], very little research has examined children's own experience of health care services. The existing evidence base is limited to a few, mostly qualitative studies in Europe, Australia and North America [11,19,33,43]. It would be important to explore children's experiences in future studies.

In conclusion, ensuring child-friendly services at health facilities not only helps to establish a productive and trusting health care relationship but also prepares children for periods of illness and hospitalisation [10,33]. Although child-friendliness and health promotion are not priorities in PHCs in resource-poor settings, introducing them has the potential to improve the experience of health visits for children and their parents and be rewarding for health workers.

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# The Clinic Visit Guide for Clinic Staff

## Amagugu aims for the clinic visit:

- To work together with clinic staff towards developing a more child friendly clinic
- To extend children's social support network
- To familiarise children with clinics

## Guiding principle

Children have a right to have access to information on health promotion and prevention and treatment

## Why do we want a child friendly clinic?

- Most of our clinics are not child friendly
- Clinics are extremely busy
- Nurses are often focused on illnesses

## What is a child friendly clinic?

A child friendly clinic puts children's interests at its heart and does not discriminate. Children are then able to:

- Visit clinics freely without fear
- Feel loved and cared for at the clinic
- Get good healthcare and health education at the clinic
- Get a chance to laugh and play at the clinic
- Feel better and valued when they leave the clinic

## Amagugu tools for making a child friendly clinic

1. Child's name tag
2. Clinic visit checklist
3. Marking pen
4. Doll

5. Body map (with stickers; red dots for HIV, spears and shields)
6. Medical play kit (with stethoscope, BP machine, syringe for injection, thermometer, and ophthalmoscope).
7. Amagugu poster

**What is Amagugu Project requesting from the clinic staff?**

Amagugu child will present themselves to a clinic staff with the following:

- Their name tag
- A clinic visit checklist
- A marking pen

**Why a name tag?**

- It has each child's unique name so that the child can have a sense of belonging
- The child can feel proud and have ownership of the clinic
- The child can be easily identified when s/he comes to the clinic

**Why a clinic checklist?**

- It helps orientate a child to clinic surroundings
- A child can move around the clinic and feel sense of ownership
- A child can engage in conversations with other people in the clinic

**We request that the clinic clerk:**

- Be friendly to Amagugu children when they visit the clinic
- Greet and introduce themselves to the child
- Tell them the name of the clinic
- Tell them the name of Sister-in-charge
- Tell them the name of the doctor
- Show them the clinic register and record their names on it
- Tell them the telephone number of the clinic

**We request that the nurse:**

- Be friendly to Amagugu children when they visit the clinic
- Greet and introduce themselves to the child
- Play a quick card game with the child
- Offer the child a play medical kit to play with and show the child what each tool is for
- Examine the mother if she has come for a regular check-up or pretend to examine the mother if the mother has not come for a regular check-up while the child plays with their kit

"Today I will put a smile on a child's face because s/he is the future"

***Thank you very much for your cooperation!***

Study ID _____

Child No_____

**Africa Centre** **Amagugu Project (Family-Based Disclosure)**

## Form 2: Baseline Information – BLI - Visit 1

**Form completion details**

Form completion date Y Y Y Y M M D D  Field worker  Study ID

**1. Study child's details**

Child 1

Surname  Date of birth Y Y Y Y M M D D

First name  Second name  Gender: O Female O Male

**2. Clinic details**

Which is your nearest clinic? Please tick one of the following:

| | | | | |
|---|---|---|---|---|
| O KwaMsane | O Nkundusi | O Madwaleni | O Machibini | O Other |
| O Mpukunyoni | O Gunjaneni | O Hlabisa | O Khula | If other, specify |
| O Mtuba | O Somkhele | O Cingci | O Ezwenelisha | _____ |
| | | | | _____ |

Which clinic do you use most of the time?_____ _____

**3. Information about the father of the study child**

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| 3a. Is the study child's father still alive? | O | Yes | O | No | If **No** go to q4 | | |
| 3b. Are you still in a relationship with him? | O | Yes | O | No | If No, go to q 3d | | |
| 3c. Does he live with you? | O | Yes | O | No | If **Yes** go to q3e | | |
| 3d. Where does he live? | O | Hlabisa district | O | Elsewhere | O Don't know | | |
| 3e. Does he provide for the child financially? | O | Yes | O | No | | | |

**4. Please tell me about the adults you live with. Do you live with?**

(Interviewer: This question refers to persons age 18 or older who live with the respondent)

| | | | | | | |
|---|---|---|---|---|---|---|
| Adult children (Children 18 or older) | O | Yes | O | No/ Not applicable | O | No response |
| Your siblings (sister/ brother) | O | Yes | O | No/ Not applicable | O | No response |
| Husband | O | Yes | O | No/ Not applicable | O | No response |
| Boyfriend | O | Yes | O | No/ Not applicable | O | No response |
| Your father/ mother | O | Yes | O | No/ Not applicable | O | No response |
| Relatives | O | Yes | O | No/ Not applicable | O | No response |
| Friends or other adults | O | Yes | O | No/ Not applicable | O | No response |

**5. Mother's employment details**

| | | | | | |
|---|---|---|---|---|---|
| Are you working? | O | Yes | O | No | If **No** go to q 5.1 |
| If yes, do you work full or part-time? | O | Full-time | O | Part-time | |

Do you work on:

| | | | | | | |
|---|---|---|---|---|---|---|
| i. Saturday | O | Yes | O | No | O | Sometimes |
| ii. Sunday | O | Yes | O | No | O | Sometimes |
| iii. Public holidays | O | Yes | O | No | O | Sometimes |

What time do you start work? ☐☐ hour ☐☐ min What time do you finish work? ☐☐ hour ☐☐ min

**5.1 Other source of income**

Do you receive any social security grants? O Yes O No

What types of social security grants do you receive (please tick all that apply)

☐ Old age ☐ Disability ☐ Social relief of distress

☐ Child support for how many children ☐☐

☐ Foster care for how many children ☐☐

☐ Care dependency for how many children ☐☐

Do you receive any remittance on a regular basis? O Yes O No

If Yes, from whom?_____ What amount? R_____

Do you partake in any other **income generating activities** (selling snacks from home, frequent catering, etc)? O Yes O No

If Yes, please describe:_____

**6. Mother's physical assessment**

6a. Are you on ART? O Yes O No If No go to q6c

6b. If yes, when was this commenced? Y Y Y Y M M **If can't recall:-** O ≤ 12 months O > 12 months O Don't know

6c. Which clinics do you attend for your HIV treatment/ care? _____

6d. What was your most recent CD4 count result? ☐☐☐☐ O Don't know O Not done If not done go to q7

6e. When was it done? Y Y Y Y M M **If can't recall:-** O ≤ 12 months O > 12 months O Don't know

**7. Children**

How many biological children do you have in total? (All children <18 and >18 years old) | Please list below children <18 years who are alive and deceased.

| Name of the child | Gender | Alive | Dead | Date of birth | Name of the father | Alive | Dead | DK |
|---|---|---|---|---|---|---|---|---|
| 1. | O M O F | O | O | Y Y Y Y M M D D | | O | O | O |
| 2. | O M O F | O | O | Y Y Y Y M M D D | | O | O | O |
| 3. | O M O F | O | O | Y Y Y Y M M D D | | O | O | O |
| 4. | O M O F | O | O | Y Y Y Y M M D D | | O | O | O |
| 5. | O M O F | O | O | Y Y Y Y M M D D | | O | O | O |
| 6. | O M O F | O | O | Y Y Y Y M M D D | | O | O | O |
| 7. | O M O F | O | O | Y Y Y Y M M D D | | O | O | O |
| 8. | O M O F | O | O | Y Y Y Y M M D D | | O | O | O |
| 9. | O M O F | O | O | Y Y Y Y M M D D | | O | O | O |
| 10. | O M O F | O | O | Y Y Y Y M M D D | | O | O | O |

**8. Child feeding information**

How did you feed other children after Mamanengane child? (for first 6 months) O Not applicable (N/A)

| Child category | Name of child | Feeding mode for first 6 months (indicate by the abbreviation of the feeding modes given below) |
|---|---|---|
| **1st child** | | |
| **2nd child** | | |
| **3rd child** | | |
| **4th child** | | |
| **5th child** | | |

***Feeding modes:**

1) Exclusive breast feeding (EBF) 2) Formula feed only (FFO) 3) Mixed breast feeding (MBF) 4) Other (OTH)
5) Exclusive breastfeeding < 6 months (BRF)

**9. Study child's school and care-giving arrangements**

Please list all crèche and/schools your child has attended

| Name of crèche/school | Grade | Year |
|---|---|---|
| | | |
| | | |
| | | |
| | | |

**Name of current school:**_____ **Current grade:**_____

Do you have any travelling plans for the study child during school holidays over the next 6 months? **O** Yes **O** No

If No, go to q10

If yes, (i)When? _____ _____(ii) For how long? _____

**10. Study child's hospitalization**

Has the Mamanengane child been hospitalized since birth? **O** Yes **O** No. If No, go to q11

If yes,

(i) How many times ☐☐

(ii) What was the diagnosis given to you on each admission?

_____

_____

_____

_____

_____

**11. Vaccination.**

Please tick vaccinations received. Use RTHC and Maternal recall

| Age of child | Vaccines | Tick appropriately | | | | | |
|---|---|---|---|---|---|---|---|
| **At birth** | (a) BCG | O | Yes | O | No | O | Don't know |
| | (b) OPV | O | Yes | O | No | O | Don't know |
| **6 weeks** | (a) DTaP-IPV.HiB (1) | O | Yes | O | No | O | Don't know |
| | (b) Hep B (1) Hepatitis B vaccine | O | Yes | O | No | O | Don't know |
| **10 weeks** | (a) DTaP-IPV.HiB (2) | O | Yes | O | No | O | Don't know |
| | (b) Hep B (2) Hepatitis B vaccine | O | Yes | O | No | O | Don't know |
| **14 weeks** | (a) DTaP-IPV.HiB (3) | O | Yes | O | No | O | Don't know |
| | (b) Hep B (3) Hepatitis B vaccine | O | Yes | O | No | O | Don't know |
| **9 months** | (a) Measles vaccine (1) | O | Yes | O | No | O | Don't know |
| **18 months** | (a) DTaP-IPV.HiB (4) | O | Yes | O | No | O | Don't know |
| | (b) Measles vaccine (2) | O | Yes | O | No | O | Don't know |
| **6 years** | (a) Td vaccine | O | Yes | O | No | O | Don't know |

**Africa Centre** **Amagugu Project (Family Based Disclosure)**

## Form 2: Baseline Information (BLI) – Twin 2 details – Visit 1

### 1. Study child's details – Twin 2

Surname _____ Date of birth Y Y Y Y M M D D

First name _____ Second name _____ Gender: O Female O Male

### 2. Study child's school and care-giving arrangements – Twin 2

Please list all crèche/schools your child has attended

| Name of crèche/school | Grade | Year |
|---|---|---|
| | | |
| | | |
| | | |
| | | |

**Name of current school:**
**Current grade:**

Do you have any travelling plans for the study child during school holidays over the next year? **O** Yes **O** No If No, go to q3
If yes,
(i)When? _____(ii) For how long? _____

### 3. Child's hospitalization – Twin 2

Has the Mamanengane child been hospitalized since birth? O Yes O No. If No, go to q 4
If yes,

(iii) How many times ☐☐

(iv) What was the diagnosis given to you on each admission?

_____
_____
_____
_____
_____

**4. Vaccination.**

Please tick vaccinations received. Use RTHC and Maternal recall

| Age of child | Vaccines | Tick appropriately | | | |
|---|---|---|---|---|---|
| **At birth** | (c) BCG | O | Yes | O | No |
| | (d) OPV | O | Yes | O | No |
| **6 weeks** | (c) DTaP-IPV.HiB (1) | O | Yes | O | No |
| | (d) Hep B (1) Hepatitis B vaccine | O | Yes | O | No |
| **10 weeks** | (c) DTaP-IPV.HiB (2) | O | Yes | O | No |
| | (d) Hep B (2) Hepatitis B vaccine | O | Yes | O | No |
| **14 weeks** | (c) DTaP-IPV.HiB (3) | O | Yes | O | No |
| | (d) Hep B (3) Hepatitis B vaccine | O | Yes | O | No |
| **9 months** | (b) Measles vaccine (1) | O | Yes | O | No |
| **18 months** | (c) DTaP-IPV.HiB (4) | O | Yes | O | No |
| | (d) Measles vaccine (2) | O | Yes | O | No |
| **6 years** | (b) Td vaccine | O | Yes | O | No |

**Africa Centre** **Amagugu Project (Family-Based Disclosure)**

## Form 17: Clinic visit follow-up and child experience - Visit 6

**Form completion details**

Form completion date Y Y Y Y M M D D

Field worker ___

Study ID ___

**Child's education**

**(Note for field worker: Before starting to ask the mother about the child clinic visit, check about child's schooling)**

1. Name of school/crèche currently attending _____

2. Current grade ____

**Mother's experience of the clinic visit**

3. Did you take your child to the clinic visit? O Yes **(if yes to go q4)** O No

**If No, specify the reason(s) and stop the questionnaire here. (If child has not been to clinic, stop here and rebook the appointment for later date).**

_____

_____

_____

4. Which clinic did you go to? _____ Date Y Y Y Y M M D D

5. At what time? H H M M

6. Did the clinic visit reminder card help you to prepare for the health care visit? O Yes O No O Don't know

7. Did your child wear his/her name tag? O Yes O No

8. Did your child meet the clerk and complete the register? O Yes O No **If No, skip to q10**

9. How would you rate the friendliness of the clerk at the clinic?
O Very friendly O Neutral O Unfriendly

10. Did your child complete his/her clinic checklist? O Yes O No

11. Did you see the Amagugu clinic poster at the clinic? O Yes O No

12. How long did you wait to see the nurse for the health care visit? | H | H | M | M |

13. Did your child see the nurse and complete the health care visit? O Yes O No **If No, skip to q16**

14. How would you rate the friendliness of the nurse who did your health care visit?

O Very friendly O Neutral O Unfriendly

15. Did the nurse use any of the following in the demonstration? (tick those that were used by the nurse)

☐ Doll ☐ Medical Play kit ☐ Body map ☐ Posters

**Child's experience of the clinic visit**

**Ask the child:**
**I understand that you went to the clinic with mum:**

16. Did you like going to the clinic with your mother? O Yes O No O Don't know

17. Why do you think it is important for children to go to the clinic with their mothers?

_____
_____
_____
_____
_____
_____

18. What would make your clinic a nicer place for you to visit?

_____
_____
_____
_____
_____
_____
_____

**Child competency on family support**

| 19. When we started Amagugu project, we did the family tree together. Can you tell me who helps mum look after you? | |
|---|---|
| **Name** | **Relationship** |
| | |
| | |
| | |
| | |
| | |
| | |
| | |
| | |
| | |
| | |

**Experience of the materials**

**Instruction: Don't prompt the child by naming any material:**

20. Mum did some fun things with you at home as part of this project. Can you tell me what you remember doing?

_____

_____

_____

_____

_____

**21. Remind the child of each material and ask them what they liked about each of them**

| **Activities** | **Comments (can include no response/ don't remember)** |
|---|---|
| a. Family life line | _____ |
| b. Body Map | _____ |
| c. Playing cards | _____ |
| d. Disclosure hand | _____ |
| e. Story book | _____ |
| f. Clinic checklist | _____ |
| g. Doll | _____ |

**22. Which activity did you like best? (Please select only one option)**

O Family life line
O Body Map
O Playing cards
O Disclosure hand
O Story book
O Clinic checklist
O Doll

**NOTE: PLEASE PHOTOGRAPH THE CLINIC CHECKLIST BEFORE YOU LEAVE**

**Amagugu Project Pre-Disclosure Training Questionnaire for Clinic Staff**

Form completion date

| Y | Y | Y | Y | M | M | D | D |
|---|---|---|---|---|---|---|---|

Age

| | |
|---|---|
| | |

Sex

| F | M |
|---|---|

Number of biological children that are below 18 years

| | |
|---|---|
| | |

Occupation…….Role/responsibility (e.g. ART nurse)…….....

Clinic……..

1. In your role in this clinic approximately how many children do you see per day?.....

2. Are children allowed to come and explore this clinic even if they are not sick? **O Yes** **O No**

   **If No why not?**.....
   ……
   ……
   ……

3. Do you have health promotion information that you distribute to children aged 6-10 in this clinic? **O Yes** **O No**

   If yes, what kind of health promotion information do you offer children?.....
   ……
   ……

4. Have you given 6-10 year old children information about medical conditions such as HIV and TB? **O Yes** **O No**

   How do you feel about giving 6-10 year old children information about HIV and TB?.....
   ……
   ……

5. When children come to consulting rooms, do you offer them anything to make them less nervous?

   **O Yes** **O No** **O Not Applicable (I do not consult children)**

   **If Yes, what do you do or what do you offer them?**……
   .....
   ……
   ……

6. Does this clinic have any play materials such as, books, crayons, paper and toys that are suitable for children between ages 6-10? **O Yes** **O No**

   **If Yes, what kind of play material is there?**.....
   .....
   .....
   ……
   ……

P.T.O.

**Child friendliness**

***Below is Amagugu Project definition of child friendliness. Please read it before you answer questions that follow.***

Clinics can be made a fun place for children as opposed to scary. Friendly and welcoming clinic staff is what children need in order to feel free to approach clinics whether they are sick or are just seeking health information. In the clinics healthy living information can be presented in a fun way that children can easily understand.

7. When you read the above definition of child friendliness, would you say this clinic is able to achieve this?

   **O Yes O No If Yes why? If No why not?**.....
   .....
   .....
   .....
   .....

**Disclosure of mother's HIV infection to children**

Many HIV-infected mothers are giving birth to HIV-uninfected children due to access to ARVs. One of the challenges faced by HIV-infected mothers from this community is whether to disclose their HIV infection to their children or not.

8. Do you think it is important for HIV-infected mothers to disclose their HIV status to their children? **O Yes O No**

   **If Yes, why? If Not, why not?**.....
   .....
   .....
   .....
   .....

9. In your opinion at what age should HIV-infected mothers disclose their HIV status to their children?.....

**Africa Centre** **Amagugu Project (Family- Based Disclosure)**

## Form 20: Health update – Visit 7

**Form completion details**

Form completion date Y Y Y Y M M D D

Field worker

Study ID

**Introduction:** When I interviewed you at the beginning of this project, I asked you about your health and now I want to check if anything has changed since then.

1. At the start of the project, were you on ART? O Yes **(skip to q3)** O No

2. Since then, have you started ART? O Yes O No **(skip to q4)**

3. Which clinic do you attend for your HIV treatment/ care? _____

4. What is your recent CD4 count result? ____ O Don't know O Not done **(stop the questionnaire here)**

5. When was it done? Y Y Y Y M M

**Amagugu Project Clinic Staff Focus Group Discussions Guide**

1. Child friendliness
    - What kinds of things do you think of when someone says a clinic should be child friendly?
      Would you say this clinic is child friendly? If yes why and if not why not?
    - Is being child friendly an easy thing to do?
    - Are there opportunities to show friendliness to the children at this clinic?
    - Are there any barriers to being friendly to the children that come to this clinic? If yes what are they?
    - What can be done to remove barriers to child friendliness in this clinic?
    - How do you feel about talking to 6-10 year olds about medical conditions such as HIV

2. Maternal disclosure of HIV infection
    - What are the advantages and disadvantages of an infected mother disclosing her HIV status to a child?
    - What can be done to help mothers disclose their HIV status easily?

UNIVERSITY OF
KWAZULU-NATAL

**RESEARCH OFFICE**
**BIOMEDICAL RESEARCH ETHICS ADMINISTRATION**
Westville Campus
Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604769 - Fax: 27 31 2604609
Email: BREC@ukzn.ac.za
Website: http://research.ukzn.ac.za/ResearchEthics/BiomedicalResearchEthics.aspx

**26 October 2010**

Dr Ruth Bland
Africa Centre for Health and Population Studies
PO Box 198
Mtubatuba
3935

Dear Dr Bland

**PROTOCOL: Family Based Disclosure: A support programme for HIV-positive mothers, their children and families. The isiZulu name for this project is "Amagugu" which means "treasures". The title is hoped to capture the value and potential of each child, and our responsibility to do as much as we can to give them a good start in life. REF:BF144/010**

The Biomedical Research Ethics Committee (BREC) has considered the abovementioned application.

The study was provisionally approved by a quorate meeting of BREC on 10 August 2010 pending appropriate responses to queries raised. Your responses dated 27 September 2010 to queries raised on 31 August 2010 have been noted by a sub-committee of the Biomedical Research Ethics Committee. The conditions have now been met and the study is given full ethics approval and may begin as from 26 October 2010**.**

The following related study documents have been reviewed and approved:

Amended Information Sheet
Materials development reference group
Clinical Care Intervention and Research Agenda family Based Disclosure
Maternal assessment tools
Child assessment tools
Study Information sheets and Consent forms

**Please provide details regarding University of Witwatersrand PhD registration and approval as they become available.**

This approval is valid for one year from **26 October 2010.** To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to BREC on the appropriate BREC form 2-3 months before the expiry date.

Any amendments to this study, unless urgently required to ensure safety of participants, must be approved by BREC prior to implementation.

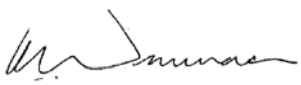
Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (2004), South African National Good Clinical Practice Guidelines (2006) (if applicable) and with UKZN BREC ethics requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at http://research.ukzn.ac.za/ResearchEthics11415.aspx.
BREC is registered with the South African National Health Research Ethics Council (REC-290408-009). BREC has US Office for Human Research Protections (OHRP) Federal-wide Assurance (FWA 678).

The following Committee members were present at the meeting that took place on 10 August 2010:

| | |
|---|---|
| Professor V Rambiritch | Pharmacology (CHAIR) |
| Professor D J Pudifin | Medicine |
| Mrs P Naidoo | External |
| Dr Z Khumalo | KZN Health (External) |
| Dr U Govind | Private Pract. – Gen. Practitioner |
| Ms J Hadingham | External |
| Mr R Moore | IPO – Research Office |
| Prof Puckree | Physiotherapy |
| Dr M A Sathar | Medicine |
| Professor S Collings | Psychology |
| Prof R Bhimma | Paediatrics and Child Health |
| Dr S Paruk | Psychiatry |
| Ms T Esterhuizen | Statistics |
| Professor T E Madiba | General Surgery |
| Dr T Hardcastle | Surgery – Trauma |

We wish you well with this study. We would appreciate receiving copies of all publications arising out of this study.

Yours sincerely



**PROFESSOR D R WASSENAAR**
**Chair: Biomedical Research Ethics Committee**

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Ms Ntombizodumo Mkwanazi

| | |
|---|---|
| CLEARANCE CERTIFICATE | M111035 |
| PROJECT | Factors Associated with Disclosures of Maternal HIV Status to School-Age HIV Un-infected Children in Families Affected by HIV in Rural KwaZulu-Natal, South Africa |
| INVESTIGATORS | Ms Ntombizodumo Mkwanazi |
| DEPARTMENT | School of Public Health |
| DATE CONSIDERED | 28/10/2011 |
| DECISION OF THE COMMITTEE* | Appoved unconditionally |

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 29/06/2012 CHAIRPERSON .....
(Professor P E Cleaton Jones)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Dr Ruth Bland

Ntombizodumo Mkwanazi 30 July 2012

Ruth M Bland

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

HEALTH
KwaZulu-Natal

**HLABISA HOSPITAL**
Private Bag x 5001, Hlabisa 3937
Tel : 035 838 1003 ext 250
Fax : 035 838 1103/ 086 624 3786
Email : Dawn.Zungu@kznhealth.gov.za
www.kznhealth.gov.za

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| | | |
|---|---|---|
| **TO** | : | **DR RUTH BLAND - AFRICA CENTRE** |
| **FROM** | : | **MRS D.L.L. ZUNGU** |
| **DATE** | : | **07 SEPTEMBER 2010** |
| **FAX NO** | : | **035 550 7565** |
| **SUBJECT** | : | **A FAMILY-BASED DISCLOSURE STUDY WITHIN THE HLABISA SUB-DISTRICT** |

**TO WHOM IT MAY CONCERN**

This serves to advise that subsequent to the study presentation made on **Tuesday, 20 April 2010**, the Hlabisa Hospital Management has no objection to the above named research. This study aims to address an important need in the Hlabisa community and was aligned with hospital goals for providing support for home based interventions which use community lay-counselors and community health care worker resources to support health services.

As a norm, we request that the findings of the said research be presented to our Management as soon as they are available.

We take this opportunity to wish you every success with the planned research project.

Thank you

**MRS D.L.L ZUNGU**
**HOSPITAL MANAGER**

COMMUNITY ADVISORY BOARD

AFRICA CENTRE FOR HEALTH AND POPULATION STUDIES

The Principal Investigator
Dr. Ruth Bland
Family Based Disclosure Study
Africa Centre for Health and Population Studies
University of KwaZulu-Natal
P. O. Box 198
Mtubatuba
3935

30 September 2010

**RE: LETTER OF SUPPORT AND APPROVAL FOR A FAMILY- BASED DISCLOSURE STUDY**

This letter serves to confirm for the Canadian International Development Agency (CIDA) that the Africa Centre Community Advisory Board (CAB) fully supports the Family-Based Disclosure (Amagugu) Project. The project was presented by the project team on 29 July 2010 for input. The CAB members asked questions about a wide range of aspects relating to the study. The questions were adequately answered

It is from that premise that the CAB hereby unconditionally grants support and permission to the Africa Centre for Health & Population to conduct the proposed project.

Yours sincerely

**CAB Chairperson**

**CAB Secretary**

**Additional Member of CAB Committee**

**Management Committee Chairperson:** Mr T K Mkhwanazi

**Members:** Mrs N. Simelane Mr M. Biyase Ms S. Buthelezi. Mr T Mgenge and Mrs T. Ntombela

**Postal:** PO Box 198, Mtubatuba 3935, South Africa **Physical:** Africa Centre, R618 en route to Hlabisa, Somkhele
Tel: +27 (0)35 550 7500 Fax +27 (0)35 550 7565 E-mail: info@africacentre.ac.za
Website: www.africacentre.ac.za

**Amagugu - Africa Centre Family Based Disclosure Project**

**AMAGUGU RESEARCH PROJECT - STUDY INFORMATION SHEET**

**WHO ARE WE?**

We, Amagugu Team at the Africa Centre are doing research on disclosure of parents' HIV status to their children.

**WHO WILL BE INVOLVED IN AMAGUGU AND HOW LONG WILL IT LAST?**

We are inviting you and your child/ren to participate in this research study. If you also want to include other members of your family you are welcome to do so, however, we would also like their permission. We would like to visit you in your home five times over a year.

**WHAT ARE WE TRYING TO LEARN?**

Research is just the process to learn the answer to a question. In this study we want to learn when, where and how mothers disclose their HIV status to their children.

**WHY IS THIS IMPORTANT?**

Some studies show that disclosure of maternal HIV infection may be beneficial to her child, helping the child to understand why the mother attends clinic, takes pills and sometimes has to go to hospitals. Therefore we want to help mothers before, during and after the disclosure process.

**WHAT WILL IT MEAN IF YOU PARTICIPATE IN AMAGUGU?**

We would like to visit you in your home five times over a year. During these visits will talk to you about the process of disclosing your own HIV status to your child/ren. We will not tell your child your HIV status, and many of these sessions will take place with you alone. We will provide you with materials, games, and activities to use with your child/ren which will help you to explain to them what HIV is. You will only be expected to disclose your HIV status to your child/ren if, and when, you feel ready. We will provide you with a cell phone so that you can contact your counsellor at any point if you wish for extra support. Part of the study involves a visit to your clinic nurse so that your child/ren can be introduced to them, learn more about the clinic and get to know at least one of the nurses at the clinic. In addition to talking to you about disclosure we will ask you and your child some questions during some of the visits, so that we can assess the effect of the support package.

**HOW MAY YOU AND YOUR CHILD BENEFIT FROM BEING IN AMAGUGU?**

We will work closely with the HIV Treatment and Care Programme leader, and coordinators, to ensure optimal care and support for you and your family. Any child found to be physically unwell will be offered referral to the family clinic, which is run by Dr Ruth Bland at one of the local government clinics. Further psychological help will be offered by senior psychologist, Ms Tamsen Rochat.

**IS THERE ANY DISADVANTAGE FROM BEING IN AMAGUGU?**

We realize that in some places HIV carries with it fear of stigma and discrimination. We will endeavour to keep all information relating to the project confidential, and we will not reveal your HIV status to others.

**WILL THERE BE ANY CHARGE FOR AMAGUGU?**

There will be no charge for participating in Amagugu.

**WHAT IF I CANNOT DECIDE NOW OR I CHANGE MY MIND LATER?**

Refusing to participate in the study or withdrawing at anytime will not result in penalty or loss of benefits. If you do not wish to decide now whether you want to participate we can come back later when you have had more time to think about this.

**WHO WILL SEE THE INFORMATION THAT WE COLLECT?**

All records will be kept completely confidential. Only senior members of the study team will have access to the information once it is collected. We would also like to access the information collected on you and your child in the original 'Mamanengane' or Vertical Transmission Study.

**WILL THE INFORMATION COLLECTED BE USED FOR ANYTHING ELSE?**

Yes some of the information collected will be used by one of the researchers for PhD (higher degree) purposes but confidentiality will still be maintained.

**WHO TO CONTACT IF YOU WANT TO KNOW MORE, OR IF YOU HAVE A PROBLEM AT ANY TIME?**

If you want more information on Amagugu before deciding on whether or not to participate, or if you participate in Amagugu and later have questions, please call:

Dr. Ruth Bland Africa Centre, Mtubatuba,
Tel: 035 550 7500

Ms. Tamsen Rochat Africa Centre, Mtubatuba,
Tel: 035 550 7500

Ms. Ntombizodumo Mkwanazi
Tel: 035 550 7500 Africa Centre, Mtubatuba,

**Contact details of BREC Administrator or Chair** – for reporting of complaints/ problems:
**Biomedical Research Ethics, Research Office, UKZN, Private Bag X54001, Durban 4000**
Telephone: +27 (0) 31 260 4769 / 260 1074
Fax: +27 (0) 31 260 2384
Administrator: Ms P Ngwenya Email: ngwenyap@ukzn.ac.za
Chair: Email: Prof D R Wassenaar c/o ngwenyap@ukzn.ac.za

**Amagugu Project - Africa Centre**

**CTP - Consent to participate in Family Based Disclosure Project**

I understand the benefits and difficulties of participating in Amagugu Project and also the implications for myself, my child/ren and my family. I understand that participation is voluntary and I am free to stop at any time. I understand that if I choose not to participate there will be no repercussions for my child/ren, myself, and my family. The study has been explained to me orally. I have been given a chance to ask questions and I know who to contact if I have questions later on. I also give permission for the study team to access the data collected on my child and myself in the original 'Mamanengane' or Vertical Transmission Study.

Signature: _____

Name: _____

Date: _____/ _____/ _____

WITNESS

Signature: _____

Name: _____

Date: _____/ _____/ _____

**Amagugu Project - Africa Centre**

**CFFM - Consent for family member to participate in Family Based Disclosure Project**

I understand the benefits and difficulties of participating in Amagugu Project and also the implications for myself and my family. I understand that participation is voluntary and I am free to stop at any time. I understand that if I choose not to participate there will be no repercussions for myself and my family. The study has been explained to me orally. I have been given a chance to ask questions and I know who to contact if I have questions later on.

Signature of family member: _____

Name of family member: _____

Date: _____/ _____/ _____

Signature of mother: _____

Name of mother: _____

WITNESS

Signature: _____

Name: _____

Date: _____/ _____/ _____

**Amagugu - Africa Centre Family Based Disclosure Project**

**CFC CONSENT FOR CHILD**

I agree to allow my child/ren to participate in this family based disclosure study. I understand that I can give my child consent to participate but if my child does not want to participate he/she has the right not to take part in the activities without any repercussions to me or my child. My child will be asked if he/she would like to verbally assent to being involved in the study. The response will be recorded by my child or the researcher on the consent form.

I understand that my child is participating freely and without being forced in any way to do so. I understand that my child can stop being involved at any time if s/he chooses. I understand that my child might like to take part in some activities and not others - s/he is free to do this. I also understand that I can stop any session at any point should I not want my child to continue and that this decision will not in any way affect me or my child negatively.

I also give permission for the study team to access the data collected on my child in the original 'Mamanengane' or Vertical Transmission Study.

I have received the telephone number of a person to contact should I need to speak about any issues which may arise.

……..……..…..  ……...

**Signature of mother**  **Date**

……..……..…..  ……...

**Verbal/written assent of child**  **Date**

……..……..……  ……

**Signature of translator (if applicable)**  **Date**

**Amagugu Project - Africa Centre**

**Study Information Sheet for the interviews**

**Greetings:** Good day. Thank you for allowing us to visit you again.

**Introduction:** You would remember that we have been visiting you for the Amagugu Study and filling in some forms with you. Now, we would like to interview you about your experience of participating in the Amagugu disclosure intervention.

**What is involved in the interviews?** We would like to have in-depth interviews for approximately one hour with some of the mothers that were involved in the Amagugu study.

**What are we trying to learn?** We would like to learn more about the mothers' feelings regarding maternal HIV disclosure to HIV-negative children, their thoughts on the materials that they were provided with to help them disclose to their children. The information we will collect will be analyzed and used by Ntombizodumo Mkwanazi for her studies in the University of Witwatersrand.

**Why is this important?** Some studies show that disclosure of maternal HIV infection may be beneficial to her child, helping the child to understand why the mother attends clinic, takes pills and sometimes has to go to hospital. Therefore, we want to understand the physical and psychological situation of mothers before, during and after they have taken part in the disclosure intervention so that future disclosure interventions may be designed better.

**Invitation to participate:** We are inviting you to take part in the in-depth interviews.

**Risks of participating in the Amagugu Study in-depth interviews for you and your child:** We realize that in some places HIV carries with HIV-related stigma and discrimination. We will endeavour to keep all information relating to the project confidential, and we will not reveal your HIV status to others. We do not foresee any difficulties if you participate in the interviews because you already participated in the Amagugu Study.

**Benefits of participating in the Amagugu Study in-depth interviews for you your child:** We are working closely with the HIV Treatment and Care Programme leader and coordinators, to ensure optimal care and support for you and your family.

**Will there be any charge for participating in Amagugu Study in-depth interviews?** There will be no charge for participating in the in-depth interviews.

**What if I cannot decide now or I change my mind later?** Refusing to participate in the in-depth interviews or withdrawing at anytime will not result in any penalty or loss of benefits. If you do not wish to decide now whether you want to participate in the in-depth interviews we can come back later when you have had more time to think about this.

**Who will see the information that we collect?** All recordings and transcripts of the interviews will be kept completely confidential. Only senior members of the study team will have access to the information once it is collected. Amagugu study numbers instead of names will be used to identify you and. However, if required by law we will have to disclose personal information.

**Who to contact if you want to know more, or if you have a problem at any time?**
If you want more information on Amagugu before deciding on whether or not to participate, or if you participate in Amagugu and later have questions, please call:

Ms. Ntombizodumo Mkwanazi
Tel: 035 550 7500 Africa Centre, Mtubatuba,

Dr. Ruth Bland Africa Centre, Mtubatuba,
Tel: 035 550 7500

Dr. Tamsen Rochat Africa Centre, Mtubatuba,
Tel: 035 550 7500

**Contact details of Wits Research Office**– If you want to complain about the way the research is being conducted please contact Anisa Keshav, Wits Research Office, 10th Floor Senate House, East Campus at 011-717-1234 Fax: 011-717-1265 Email anisa.keshav@wits.ac.za

**Alternatively** you can call Mduduzi Mahlinza at Africa Centre Community Engagement Office. Tel: 035 550 7500 Fax 035 550 7565. Email mmahlinza@africacentre.ac.za

**Amagugu Project - Africa Centre**

**Consent to participate in the interviews**

I understand the benefits and difficulties of participating in Amagugu Project interviews and also the implications for myself and my family. I understand that participation is voluntary and I am free to stop at any time. I understand that if I choose not to participate there will be no repercussions for myself and my family. The study has been explained to me orally. I have been given a chance to ask questions and I know who to contact if I have questions later on.

Signature of mother: _____

Name of mother: _____

Date: _____/ _____/ _____

WITNESS

Signature: _____

Name: _____

Date: _____/ _____/ _____

**Amagugu - Africa Centre Family-Based Disclosure Project**

**AMAGUGU RESEARCH PROJECT - STUDY INFORMATION SHEET FOR CLINIC STAFF**

**WHO ARE WE?**

We, Amagugu Team at the Africa Centre are doing research on disclosure of parents' HIV status to their children.

**WHO WILL BE INVOLVED IN AMAGUGU AND HOW LONG WILL IT LAST?**

We are inviting you to participate in this research study. We are asking you to complete the pre- and post disclosure training questionnaire. We might ask you to participate in focus group discussions later.

**WHAT ARE WE TRYING TO LEARN?**

Research is just the process to learn the answer to a question. In this study we want to learn about your views on maternal disclosure of HIV status and child friendliness in the clinics.

**WHY IS THIS IMPORTANT?**

This is important because many HIV-infected mothers have HIV-uninfected children and we want children not to be frightened to come to the clinic for support.

**WHAT WILL IT MEAN IF YOU PARTICIPATE IN AMAGUGU?**

We would like to visit you complete a pre and post disclosure training questionnaire and also participate in a focus group discussion about mothers' disclosure of HIV status to their children and clinic child friendliness.

**HOW MAY YOU BENEFIT FROM BEING IN AMAGUGU?**

We will provide you with training on maternal disclosure of HIV status to children and how to become a child friendly clinic.

**IS THERE ANY DISADVANTAGE FOR BE PARTICIPATING IN AMAGUGU STUDY?**

No.

**WILL THERE BE ANY CHARGE FOR PARTICIPATING IN AMAGUGU STUDY?**

There will be no charge for participating in Amagugu.

**WHAT IF I CANNOT DECIDE NOW OR I CHANGE MY MIND LATER?**

Refusing to participate in the study or withdrawing at anytime will not result in penalty or loss of benefits. If you do not wish to decide now whether you want to participate we can come back later when you have had more time to think about this.

**WHO WILL SEE THE INFORMATION THAT WE COLLECT?**

All records will be kept completely confidential. Only senior members of the study team will have access to the information once it is collected.

**WILL THE INFORMATION COLLECTED BE USED FOR ANYTHING ELSE?**

Yes some of the information collected will be used by one of the researchers for PhD (higher degree) purposes but confidentiality will still be maintained.

**WHO TO CONTACT IF YOU WANT TO KNOW MORE, OR IF YOU HAVE A PROBLEM AT ANY TIME?**
If you want more information on Amagugu before deciding on whether or not to participate, or if you participate in Amagugu and later have questions, please call:

Ms. Ntombizodumo Mkwanazi
Tel: 035 550 7500 Africa Centre, Mtubatuba,

Dr. Ruth Bland Africa Centre, Mtubatuba,
Tel: 035 550 7500

Dr. Tamsen Rochat Africa Centre, Mtubatuba,
Tel: 035 550 7500

**Contact details of BREC Administrator or Chair** – for reporting of complaints/ problems:
**Biomedical Research Ethics, Research Office, UKZN, Private Bag X54001, Durban 4000**
Telephone: +27 (0) 31 260 4769 / 260 1074
Fax: +27 (0) 31 260 2384
Administrator: Ms P Ngwenya Email: ngwenyap@ukzn.ac.za
Chair: Email: Prof D R Wassenaar c/o ngwenyap@ukzn.ac.za

**Amagugu Project - Africa Centre**

**CTP - Consent for clinic staff member to participate in Family-Based Disclosure Project**

I voluntarily agree to participate in the focus group discussions about making clinics child friendly and mothers' disclosure of HIV status to their children. These discussions will be used for research conducted by Amagugu Project as well as for PhD studies by Ntombizodumo Mkwanazi. I understand that what is discussed in the talks will be kept confidential. I understand that I can stop being part of this research at anytime without any penalty or loss of benefits. I agree to have these discussions recorded. Research has been explained to me verbally and I was given a chance to ask questions. I know who to contact if I have questions at a later stage.

CLINIC STAFF MEMBER

Signature: _____

Name: _____

Date: _____/ _____/ _____

WITNESS

Signature: _____

Name: _____

Date: _____/ _____/ _____