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**“Am iz kwiin” (I’m his queen):**

**An exploration of mothers’  
disclosure of maternal HIV to their  
children in Kingston, Jamaica**

**using feminist  
Interpretative Phenomenological Analysis (IPA)  
in a resource-constrained context.**

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**Submitted for the degree of Doctor of Philosophy**

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## Acknowledgements

This thesis has taken more than 6 years to write, which seemed to me an unimaginably long period of time when I began, in Jamaica, in Feb 2012, when my older children were 1, 2 and 4 years old. They are now 7, 9 and 11, and like my thesis, have travelled from Jamaica, to Bulgaria to Uganda and have grown and developed alongside it. They have been very encouraging of “Mummy’s big book” throughout and patient with my writing time. Maya has let me practice presentations on her, Zhanara has kept me company in the early mornings and Ksenia has decorated the walls of my office with artwork to “help with my thinking”. Rowan was with me from full draft onwards and was born a few weeks after my viva. Special thanks to my husband, Simon, for his unfailing encouragement and support and for completely refusing to believe me when I said that I couldn’t do it.

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# **Abstract**

## **Introduction**

World Health Organisation (WHO) policy presents parental HIV disclosure to children as beneficial and encourages parents to disclose. Most research on disclosure has been conducted in high income countries and tends to represent women's choices in terms of a disclosure/non-disclosure binary which, I argue, is premised on rationalist theory models of decision making and disclosure which fail to contextualise women's experiences, particularly those women who live in the Global South. This research study aimed to address gaps in existing research by exploring the maternal disclosure experiences of HIV positive Jamaican mothers to their seronegative children and offers a critique of existing WHO policy.

## **Methods**

I carried out in-depth interviews with 15 HIV positive Jamaican women with at least one seronegative child aged over 10 years, associated with one clinic and one NGO in Kingston, Jamaica.

I adopted a feminist approach to Interpretative Phenomenological Analysis (IPA) and applied Hochschild's concept of emotion work to make sense of women's experiences. In attending to the structural factors shaping health actions, a feminist approach highlights the relationship between Jamaican contextual factors of poverty, violence and complex familial formations and women's disclosure decisions. Conceptual resources drew on feminist critiques of dominant discourses of motherhood, including governmentality and responsabilisation, which, I argue, underpin policy imperatives on disclosure to children.

## **Results**

Mothers' experiences of maternal disclosure to children occurred on a spectrum, rather than a disclosure/nondisclosure binary, and included: full disclosure, partial disclosure, nondisclosure, denial of HIV, differential disclosure (telling only some of their children) and disclosure by others. Experiences of disclosure were affected by financial risks and practical issues as well as consideration of children's long-term physical and mental health, education prospects and the impact on other family relationships. Mothering at a distance (mothers living apart from their child/ren) and the fear or reality of 'downfallment' (a child being HIV positive) further complicated disclosure experiences. The women described strategies which challenged negative characterisations of HIV positive women in order to present themselves as capable mothers and manage their own and their children's emotions.

## **Conclusion**

Disclosure of maternal HIV to children is a complex issue, carrying risks as well as benefits, which are particularly heightened in low income contexts. When women disclose this could be seen as a form of governmentality and when they don't disclose their mothering is called into question within policy discourses predicated on evidence from the Anglo North. The over simplistic disclosure /non-disclosure binary fails to consider the emotion work women engage in to manage their illness and their mothering identity in the context of their relationships with their children. This research adds to the HIV disclosure literature from low and middle income countries and extends maternal HIV disclosure research through the use of a novel approach, feminist IPA, to understand women's experiences. The research findings point to the need for a more nuanced policy on disclosure in low and middle income countries.

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*“Miebi di big wan wud krai an di sekan wan wud krai tuu. Kaaz iiz sein dat am iz ienjel so ...Am iz kwiin. So a doh no – if iz kwiin mesd op...aving dat I doh no ou ii would fiil. Miebi ii wud iet iz faada.”*

*[Maybe the big one would cry and the second one would cry too. ‘Cause he is saying that I am his angel, so...I’m his queen. So I don’t know— if his queen messed up— Having that (HIV), I don’t know how he would feel. Maybe he would hate his father.]*

Sandra (162–166), Jamaican HIV+ mother of three, talking about how she thinks her older children might react if she told them that she is HIV+.

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## List of abbreviations

AAA: American Anthropology Association  
ART/ARV: Anti-Retroviral Therapy/Anti-retrovirals  
ASA: Association of Social Anthropologists of the UK and Commonwealth  
CSW: Commercial sex workers  
CUL: City, University of London  
E4L: Eve for Life (a Jamaican NGO which supports young, HIV positive mothers)  
ESRC: Economic and Social Research Council  
HAART: Highly Active Anti-Retroviral Therapy  
HIV: Human Immunodeficiency Virus  
HICs: High Income Countries (World Bank classification)  
ID: text identifier. These numbers correspond to numbered chunks of text in the transcripts of individual interviews.  
IPA: Interpretative Phenomenological Analysis  
JASL: Jamaica AIDS Support for Life  
JCW +: Jamaican Community of [HIV] Positive Women  
J-FLAG: Jamaica Forum of Lesbians, All-Sexuals and Gays  
J MoH- Jamaican Ministry of Health  
LGBT: lesbian, gay, bisexual, transgender  
LGBTQIA: lesbian, gay, bisexual, transgender, queer, intersex and asexual people  
LMICs: Low and Middle Income Countries (World Bank classification)  
MARPs: Most at Risk Populations  
MSM: Men who have sex with men  
MtCT: Mother to Child Transmission (of HIV)  
NGO: Non-Governmental Organisation  
NHS: National Health Service  
NIH: National Institutes of Health  
ODPEM: Office of Disaster Preparedness and Emergency Management  
PAHO: Pan American Health Organisation  
PANCAP: Pan-Caribbean Partnership Against HIV/AIDS  
PIOJ: Planning Institute of Jamaica  
PLWHA: People Living with HIV/AIDS  
PLWHIV: People Living with HIV  
PMtCT: Prevention of Mother to Child Transmission (of HIV)  
REC: Research Ethics Committees  
Seronegative: HIV negative  
STI: Sexually Transmitted Infection  
TCK- Third Culture Kid, refers to a person who grew up outside of their home country  
UNAIDS: Joint United Nations Programme on HIV and AIDS  
UNICEF: United Nations Children's Fund  
UWI: University of the West Indies  
Vertical transmission: Mother to child transmission of HIV  
WB: World Bank  
WHO: World Health Organisation

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# **SECTION 1: INTRODUCTION, LITERATURE REVIEW & JAMAICAN CONTEXT**

## **Chapter 1: Thesis Introduction**

### **1.1 Background**

Jamaica demonstrates features of a generalised and concentrated AIDS epidemic (PAHO/WHO, 2010) with approximately 1.8 % of the adult population infected with HIV (Jamaican Ministry of Health, 2014). In high income countries (HICs), maternal disclosure of HIV to children has been shown to have a positive impact on maternal physical health (Chaudoir and Quinn, 2010) and mental health (Wiener, Battles and Heilman, 1998), to increase social support (Letteney, 2006; Wiener *et al.*, 2007) and encourage closer family relationships (Tenzek *et al.*, 2013). WHO Guidelines (WHO, 2011) encourage parental disclosure to children of school age. Parental disclosure research in low and middle income countries (LMICs) is scarce and focuses on Asia and sub-Saharan Africa. The literature argues for culturally appropriate interventions to support parental disclosure in low resource settings, but there is a lack of evidence on women's views and experiences of talking to children about their HIV status in low income contexts.

There is limited research looking specifically at maternal disclosure to children in low and middle income countries, particularly in the Caribbean, and limited work providing detailed accounts of women's own views and experiences. This thesis describes a study undertaken to address these gaps. Adopting a feminist approach to Interpretative Phenomenological Analysis (IPA) allowed me to embed researcher reflexivity and a consideration of power dynamics throughout the research and interpretation process; this approach is unusual within existing disclosure models which, I argue, draw on rationalist staged models (*e.g.*, Disclosure Process model (Chaudoir, Fisher and Simoni, 2011); Disease Progression Theory (Serovich, 2001); Consequences theory of disclosure (Serovich, Lim and Mason, 2008) and policy-driven research encouraging HIV disclosure (*e.g.*, WHO, 2011)). Existing guidelines, such as the WHO Guidelines on disclosure to children (WHO, 2011), advise caretakers and professionals to disclose children's and their caretakers' status to children, despite a lack of evidence on the views and experiences of caretakers concerning disclosure, and a lack of information concerning the potential benefits and implications of doing this in resource-constrained settings (WHO, 2011:12).

This introductory chapter provides brief background information on maternal disclosure of HIV to children in Jamaica, including gaps in knowledge, and describe the aims and objectives of my



study. I also introduce my approach to the research, explain my background and my interest in maternal disclosure of HIV to seronegative children. I then introduce some key terms referred to throughout the thesis, concluding with an outline of the sections and chapters that follow. This thesis uses a feminist approach alongside Interpretative Phenomenological Analysis which focuses on providing an in-depth examination of the experiences of a small group (HIV positive Jamaican mothers). IPA recognises the ‘double hermeneutic’ (Smith and Osborn, 2003): participants interpret their experiences and I, as researcher, interpret the accounts that they present to me. This emphasis on interpretation is complemented by a feminist focus on reflexivity and power.

A systematic review of empirical studies up to June 2010 (Krauss *et al.*, 2012:13) found “evidence that disclosure to children of caregiver’s HIV status will benefit well and infected children between 6 and 12 years old”. This was based on 15 studies but did not distinguish between high, middle or low income settings and did not include information on social, cultural or economic contexts. There was a focus on the role of healthcare workers in supporting families. The authors acknowledged the complexity of disclosure decisions due to “HIV related stigma, mental health and social support concerns, family functioning and parenting problems, and worry about children’s emotional and maturational ability to cope with and understand the nature of the illness” (*ibid.*). The review therefore called for “evidence-based guidelines for paediatric HIV disclosure counselling” (*ibid.*). This approach is supported by existing research in LMICs which recommends culturally specific support to disclose but does not make clear what this means in specific contexts (Obermeyer, Bajjal and Pegurri, 2011; Qiao, Li and Stanton, 2011; Rochat *et al.*, 2011). Bearing this in mind, I began to question how applicable the WHO guidance might be to the experiences of HIV positive mothers in Kingston, Jamaica. As little is known about maternal disclosure in the Jamaican context, I planned to carry out in-depth interviews with HIV positive Jamaican mothers to explore their views and experiences. My **research question** is: What are the experiences and views of Jamaican HIV positive mothers regarding talking to their seronegative children about their maternal HIV status? My **aim** is: To explore Jamaican HIV positive mothers’ decisions about whether and how they tell their children about maternal HIV status, whilst acknowledging the broader socio-economic factors which may affect these decisions. To achieve this aim, I :

- a) Explore how HIV positive mothers make sense of motherhood and living with HIV;
- b) Identify the strategies or approaches that HIV positive mothers use to communicate with or conceal maternal HIV status from their children;
- c) Make recommendations for policy and practice.

## 1.2 Women and HIV in Jamaica

HIV/AIDS and other sexually transmitted infections have become the number one cause of morbidity and mortality for both men and women aged 30–34 years in Jamaica (WHO, 2002). Behavioural surveillance has highlighted multiple partnerships, early age of first sexual experience, high levels of transactional sex and inadequate condom use as the main drivers of the epidemic (Jamaican Ministry of Health, 2014). Although the reported total number of men living with HIV (54%) is greater than the total number of women living with HIV (46%) in Jamaica, the gap is narrowing (Jamaican Ministry of Health, 2014, reporting on the period 2009–2012). Girls aged 14 to 24 years have twice the risk of boys in the same age group of acquiring HIV; for girls aged 10 to 19 years the risk is three times higher (PAHO/WHO, 2010). This has been attributed to sex with an older infected male partner, as well as non-consensual and transactional sex (PAHO/WHO, 2010). HIV rates are higher amongst Most at Risk Populations (MARPs), including men who have sex with men (32.8%), commercial sex workers and informal entertainment workers (4.1%), and homeless people (12%) (Jamaican Ministry of Health, 2012). According to statistics from the Jamaican National HIV/STI Programme, there were 993 reported HIV cases among women between January and December 2009 (53 per cent of the total) (Jamaican Ministry of Health, 2009). Despite substantial increases in HIV testing, an estimated 30% of HIV infected people are unaware of their status, an important factor in the spread of the disease (Jamaican Ministry of Health, 2014). Loewenson and Whiteside (1997) reported that urban prevalence may be two to three times higher than rural prevalence, with the highest HIV prevalence rates in two parishes, St. James and Kingston/St. Andrew (Jamaican Ministry of Health, 2002).

Jamaica is significant in that it is one of the Caribbean countries where the epidemic has spread from high-risk groups to the general population (PANCAP, 2002); this has important implications for prevention programmes and highlights the need to focus on the general population in addition to programmes targeting MARPs. To date, most funding has targeted MARPs. However, several NGOs working at grassroots level (*e.g.*, Eve for Life, Jamaica AIDS Support for Life, Jamaican Community of Positive Women) have identified needs amongst women and children which are not being met by existing programmes. Issues include non-disclosure of HIV status to partners, cross-infection, and non-disclosure of status to children born with HIV, causing a range of problems as they mature and become sexually active themselves. UNAIDS found that the vulnerability of women to HIV infection appears to be increasing and has worked to develop partnership programmes which challenge “harmful gender norms such as masculine dominance and feminine submission, cross generational sex, multiple partners, gender based violence and homophobia” (UNAIDS, 2012). Women are often caregivers and breadwinners and bear much of the responsibility for the health of their family.

Thus, the impact on the family of a woman becoming HIV positive can be significant, in terms of potential loss of earnings, a reduced ability to care for family members, and the potential for mother to child transmission.

Bearing in mind the high cultural value placed on motherhood in Jamaica (Ellis, 1986; Silva and Alexander, 2013) and that HIV is often diagnosed through antenatal testing, a significant proportion of women with diagnosed HIV are also mothers. There are cultural differences in how mothers perceive the concept of protecting children in relation to disclosure of maternal HIV and, even within the same culture, women may make very different choices with the aim of protecting their children. This can result in varied experiences, including full, partial and non-disclosure of maternal HIV to children. Global literature shows that children, whether disclosed to or not, may already be aware of their mother's HIV status or know that their mother is unwell and that it is common for children to help mothers take their HIV medication (*e.g.*, Nam *et al.*, 2009 in Botswana; Kyaddondo *et al.*, 2013 in Uganda; Kennedy *et al.*, 2010 in the USA). In cases where children adopt the role of informal carer, this subverts the usual construction of mother as "carer" and child as "cared for". The mother-child relationship can be complex in the context of HIV and the boundaries blurred between the said and the unsaid, the known and the unknown. The dual impact of a disease which is sexually transmitted and which carries connotations of sickness and death combine to make HIV an emotive and complex subject for mothers to address with their children.

We know very little about the emotional preparatory work that mothers in the Jamaican context might undertake with their children, although there is some evidence from other countries. In Kenya, Gachanja and colleagues (2014) identified preparation activities including reading, thinking and praying about HIV and disclosure, working to improve family relationships, teaching children about HIV and attending support groups, religious activities and counselling. They found that parents spent years undertaking preparation activities and disclosed to their children when they felt that both they and their children were sufficiently prepared. In their work in Canada, DeMatteo *et al.* (2002) found that preparations included creating a safe environment and taking practical steps to provide support and information to children. Parents preferred to disclose when the infected person was in good health and found praying, talking to professionals or other trusted adults helpful in preparing to talk to their children. However, contrary to their expectations of significant parental anxiety and preparation, DeMatteo *et al.* (2002:340), found that, due to "parenting and coping styles, gender, the nature and history of parent-child relationships, and circumstances or events," it was not unusual for disclosures to be "immediate, spontaneous, relief-generating, unplanned, pressured or initiated by someone besides parents". In Jamaica, there is an unwillingness to talk about sex with children and young people. Lawson suggests this is due to women's historic lack of control over their own

sexuality, continued sexual violence in Jamaica today, the influence of Christianity, lack of experience with this type of conversation and a lingering belief that confronting the issue might make it worse, so avoiding the topic may help to avoid the issue altogether (though in practice this carries the risk of repeating cycles) (Lawson, 2013:111–128). Traditional discomfort with issues surrounding sex, pregnancy, illness and death may mean that these conversations are somewhat vague or take place in other mediums such as through storytelling: while the message may be powerful, some of the specific practicalities may be lost or confusing to children. This can also be seen in European cultures, where, for example, traditional fairy tales are used to help children cope with and make sense of life. Vom Orde's exploration of Bettelheim's psychoanalytic analysis of the importance of fairy tales sees these stories as a safe avenue for exploring difficult concepts and emotions such as violence, fear, sexuality, jealousy and separation anxiety "represent[ing] the essential developmental steps towards independent existence" (vom Orde, 2013:17).

The limited information that exists about HIV disclosure in Jamaica tends to have a public health focus, with priority given to disclosure to partners and disclosure to HIV positive children before they become sexually active, in an effort to reduce the spread of HIV. I have not found any published Jamaican articles on disclosure to HIV negative children, but local NGOs have conducted work on preventing mother to child transmission (PMtCT) which highlights some of the challenges facing HIV positive women, including interacting with professionals, accessing accurate information and communicating with partners and other family members about their HIV (Watson and Crawford, 2011). Women's decisions surrounding disclosure exist against a backdrop of lack of understanding and acceptance of female reproductive rights. Watson and Crawford (2011) found that healthcare workers discriminate against HIV positive women within the healthcare setting. It is difficult for women to feel confident in their parenting and to be open with their children about their status when many health professionals believe that HIV positive women should not have children at all. The same Jamaican study found that the lack of professional counselling and support for HIV positive women was unhelpful for women wishing to plan pregnancies whilst simultaneously protecting their partners from HIV:

*And she [the doctor] was saying to me "Yes it is possible [to have another baby after being diagnosed with HIV] but don't think about it. Don't think about it." [...] I felt as if I was no longer a full functioning human and that that part of me should be dormant – it should be dead. I still feel like I would love to have another child.*  
(Female respondent, Watson and Crawford, 2011:20).

### 1.3 My background and views: How this will inform my research

My background and experiences inform the approach I bring to this work. Recognition of this is important, both for researcher reflexivity, a key element of feminist approaches (*e.g.*, Burman, 1992, 2006; England, 1994; Ackerly and True, 2008, 2010) and for the interpretative aspect of IPA. I present here a short overview of my background and views to help illuminate my overall approach to the research.

Although my higher education was mainly in the UK, I have lived overseas for most of my life; I lived in The Gambia until age 19. My educational choices (a BA in Development Studies, a Masters in Health and Community Development), as well as time spent living, working and studying in Mexico, Ghana, Azerbaijan, Jamaica, Bulgaria, Scotland and England developed my interest in understanding how others see and experience the world. Living in countries with a different cultural and religious approach to gender issues has informed my views, as has becoming a mother to three daughters. A professional qualification in youth and community work allowed me to explore the benefits and challenges of working towards change; I retain an interest in the practical applications of knowledge whilst considering how, and by whom, changes can best be implemented.

I grew up in The Gambia, as a ‘toubabnding’— a word of Mandinka origin, meaning ‘small white person’: small because I was a child, and white because of my skin colour. The word ‘toubab’ is generally not considered to be derogatory, functioning as a descriptor of skin colour; however it does carry connotations: toubabs are often tourists, wealthy in comparison to the local population, and considered naive. I lived until I was two years old in Keneba, “up-country”, in a caravan; we later moved to the coast, which had a larger toubab population. At seven weeks old, I was enrolled in a research trial as the ‘control’, and a source of additional information in a UK Medical Research Council (MRC) maternal nutrition project, in Keneba<sup>1</sup>, designed to help reduce the high child mortality in the region at that time (1978). I’m struck now by the incongruity of using a toubab mother-child dyad, with a different culture, diet and child-rearing practices and expectations, as the control, with its connotations of ‘normal’, ‘standard,’ or ‘ideal’. This story about my early childhood mirrors the assumptions within mainstream feminism of the needs and issues faced by white middle class women as the normal or standard experience. There is a tendency within the literature for black and minority ethnic families to be focused on in cases where issues are seen as problematic, but to remain invisible when issues are seen as normalised: the ‘normalised absence/pathologised presence’ approach (Phoenix, 1987; Phoenix and Husain, 2007:8). This is echoed by McLoyd *et al.* (2000:2) who

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<sup>1</sup> <http://ing.mrc.ac.uk/>

find that “normative work is conducted using European American families and the ‘minority’ perspective is represented via an examination of African American families”. My role as the ‘control’ positions me, almost from birth, within the complex and often over-simplified historical postcolonial relationship between science and (women’s) experience, between white and black, (male) researcher and (female) subject, powerful and powerless, active and passive. These “contrast schemas” are critiqued by feminists such as Harding (1986:174–176) as being created by those in a position of social dominance, as over-emphasising certain differences, whilst simultaneously over-promoting intragroup commonalities. I return to and develop these ideas throughout this thesis. In particular, Chapters 6 and 10 challenge these binaries through highlighting how women enacted their agency, by, for example, declining to be interviewed, refusing to answer questions, evading, deflecting or saying what they thought I wanted to hear. Additionally, Chapter 11, the final discussion chapter, demonstrates the links between the women’s experiences and wider contextual factors.

By the time I finish this thesis I will be about forty years old and I will have lived as a white minority in predominantly black countries for approximately half of my life (16 years in The Gambia, 3 years in Jamaica, a semester at university in Ghana, a year in Uganda). In these countries I was privileged and protected in many ways- economically, educationally, through being white, being British, and through my association with particular agencies (*e.g.*, my father’s role as a veterinarian, my position as a PhD student at a London university (U.K.), my husband’s role as a civil servant). The common use of English enabled me to communicate more effectively, although many also had the option of excluding me through the use of their other languages. I have spent a further 8 years in non-English speaking countries, where I am less visibly an outsider (Azerbaijan, Bulgaria, Mexico) but have often struggled with language, and that has served as a barrier to communication. I have spent ten years of my life in the UK, my ‘home’ country, where I visibly and verbally fit in on a surface level. My daughters were born in England, but have each spent only one or two months of their lives there and have a very limited understanding of what it means to be British. I have spent the majority of my life—whether in the UK or abroad, not quite fitting in—the legacy of being a ‘third culture kid’ or TCK, a term introduced in the 1950s (Useem, Useem and Donoghue, 1963) to describe the children of American citizens living and working outside of their home country. TCKs share more cultural norms with other TCKs than with their home or host culture. As is often the case with defining experiences in our lives, both good and bad, my children are also TCKs.

Who am I to undertake this research? I am a woman and a mother, but here the similarities between myself and my participants mostly end. I am white and have many of the privileges that often accompany this: I am university educated, I am middle class, I am married, I have

worked sporadically and part-time since my children were born, I have the opportunity for further study, I am HIV negative. My three children were aged 4 and under when I began this thesis. My participants are black, are educated to primary, sometimes secondary level, live in poverty, are mostly unmarried, combine childcare with income generation when they can, and are HIV positive. To meet my interview criteria, all had to have at least one child aged over 10. Although there are many differences between us, I have some awareness of the issues they may face through my experiences of living and travelling overseas for most of my life. I worked as a youth and community worker, with a focus on women, young people and sexual health in the UK, Ghana, and Mexico, and I volunteered with NGOs in Jamaica throughout my stay there (2010–2013). My academic qualifications have focused on health promotion, gender, development, multiculturalism, youth and community work, and anti-discriminatory practice. I have a deep interest in the issues that affect women, particularly disadvantaged women, and in their views and interpretations of their experiences. By acknowledging and working to stay aware of the differences (as well as the similarities) between myself and the participants, I hoped to be as open and sensitive as possible to the experiences of the women I interviewed. I reflect on this throughout the thesis.

## **1.4 The WHO Guideline on HIV disclosure counselling for children**

The WHO Guideline on HIV Disclosure Counselling for Children up to 12 Years of Age (WHO, 2011) states that:

*“There is evidence of health and life planning benefit for the children, with and without HIV, of HIV-positive caregivers if the caregiver discloses to them. There is some perception by caregivers that their children’s behavioural problems increase and the quality of the relationship decreases after disclosure. These perceptions are not verified by children’s self-reports. Parents do report that expected and understandable initial emotional reactions improve with time. Disclosing appears to pose no harm to caregivers” (WHO, 2011).*

This guidance makes clear recommendations that children should be told about their parents’ or caregivers’ HIV status. However, the quality of evidence for this is low or absent. The two key recommendations pertaining to disclosure of parent or caregiver HIV status are:

*“Children of school age should be told the HIV status of their parents or caregivers; younger children should be told this incrementally to accommodate their cognitive skills and emotional maturity.*

***Conditional recommendation, low quality of evidence.***

*The decision on who will disclose to the child should be guided by the intent to improve/promote the child's welfare and minimise the risk to his or her well-being and to the quality of the relationship between child and parent/caregiver.*

***Conditional recommendation, absent evidence.***”

**(WHO, 2011:12).**

The WHO report attempts to synthesise a broad range of articles from across the world (140 background studies and 61 empirical studies) which look at parent or caregiver disclosure of parent/caregiver and/or child HIV status to both HIV positive and HIV negative children. The report draws on existing expertise and disclosure models utilised by country specific programmes (see WHO, 2011, Appendix I: 25–26). There are references to specific articles from LMICs, including South Africa (Palin *et al.*, 2009), China (Li, Barnett and Fang, 2009), Thailand (Ishikawa *et al.*, 2010), Togo (Polisset *et al.*, 2009), Puerto Rico (Blasini *et al.*, 2004), Romania (Ferris *et al.*, 2007), and Uganda (Bikaako-Kajura *et al.*, 2006; Nabukeera-Barungi *et al.*, 2007; Rwemisisi *et al.*, 2008). However, the majority of the 201 studies analysed for this report are from the USA and Western European countries. There is some acknowledgment of the complex and varied circumstances facing families affected by HIV, the impact of discrimination and stigma, and the need for institutional and community tolerance and support (WHO, 2011:11). The report does not detail country or culture specific factors and does not attempt to make any recommendations which take these issues into account.

These policy and research assumptions are not shared by all health professionals. In early discussions (2012), prior to data collection, several health professionals working in HIV in Kingston told me they saw no reason why Jamaican mothers would tell their children about their HIV and they were convinced that the majority of women would not consider telling their children. They attributed this to social attitudes of judgment towards people who are HIV positive in Jamaica. Similarly, a Jamaican counsellor told me about the advice she gives recently diagnosed patients:

*[...] Because I tell my patient when they are just diagnosed, just be calm, don't rush to tell anybody, be calm, absorb the news, fine, see how you going to work it out where you going from here, then after you pass that stage now then you decide if you want to disclose and then you have to decide to accept whatever consequence comes your way after disclosure. But if you run to disclose because of fright later*



*on it come back to haunt you so disclose because you want to disclose not because of fright or somebody force you to disclose, nobody can force you to disclose, we can encourage you but we cannot force you and we cannot disclose for you. (Counsellor, Interviews with HIV professionals in Jamaica, 2012:7)<sup>2</sup>*

This quote highlights the awareness of HIV professionals in Jamaica about the local context and the potential challenges that women who follow policy advice to disclose may face as a direct result of their decision to disclose. Here, we see more culturally specific assumptions incorporating Jamaican concepts of motherhood, childhood, privacy and an understanding of the local perception of HIV as stigmatised and shameful. My findings, discussed in detail in chapters 7–9, highlight the flaws in both the Anglo-Northern policy imperative to disclosure and local assumptions that women do not (and possibly should not) disclose.

## **1.5 Overview of my research**

*“My daughter, she knows we go to the [HIV NGO], so she’s started asking questions “Why do people go there? What’s this? What causes AIDS? Why do people get AIDS?” and stuff like that, she’s asking me. But she doesn’t know that I am like that.”*

*“When I told him [my son] I know he went through my papers, he just went to the bathroom and cried. I knew that he was crying because I could hear his sobs, so... but that’s it... life has to go on....he... he was just...he was just so shocked. He just told me one day “I am not the one who gave you HIV and AIDS” when I was trying to...he had done something and I said to him “Why are you doing this?” He said “Don’t make me, I am not the one who made you like that.” But... I mean... that was his reaction anyway to it....”*

Lindiwe, HIV+ Zimbabwean mother living in the UK (Clifford, 2006, unpublished Master's dissertation).

This study developed from my Master's dissertation (2006), where I conducted interviews with HIV positive Zimbabwean women living in the U.K. One of the themes which emerged, but which I was not able to pursue, was the issue of maternal disclosure to children, as described by

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<sup>2</sup>This quote comes from an interview in 2012 with an HIV counsellor for which I obtained ethical approval. I subsequently decided to use professional interviews for background and familiarisation only. This is discussed further in Section 6.1.

Lindiwe<sup>3</sup>, above. I found that in, for example, Uganda, disclosure to children has been identified as an issue of particular concern to many women: “Parental worries about disclosing their own HIV status to children represent a major psychological burden for many parents and a potential barrier to testing and care for their children”(Rwemisisi *et al.*, 2008). An opportunity to live in Jamaica for 3 years from 2010 to 2013 provided a chance for me to explore maternal disclosure to children in a different context. Discussions in 2011 with NGO and clinic staff in Kingston, Jamaica, confirmed that maternal disclosure had been identified as an important issue by both staff and the women themselves. In my initial search of the literature in 2012, I found no published work on maternal disclosure of HIV in Jamaica or the Caribbean (although a Haitian article by Conserve *et al.* was published in 2014) and scant published work referring to disclosure to friends or family in Jamaica (*e.g.*, Weller *et al.*, 2008; Clarke *et al.*, 2010) and the Caribbean (Kumar *et al.*, 2006; Bouillon *et al.*, 2007; Padilla *et al.*, 2008). There was limited work dealing with maternal or parental disclosure in resource-constrained countries in the global context, although more has been published in recent years (see Chapter 2).

‘Disclosure’, defined as “the act of making something known” (Merriam Webster Dictionary Online, no date) implies that the information being revealed is secret or new to the recipient. As the word ‘disclosure’ is widely understood and recurrent in the literature, I use this word throughout this thesis, but in reference to my own research I use it to mean a disclosure spectrum, rather than the more common understanding of disclosure as a binary (Armistead *et al.*, 2001; Moore, Kalanzi and Amey, 2008), which does not recognise the range of partial knowledge and understandings which lie between known and not-known. Recent articles have begun to recognise a wider definition of communication about HIV with children which encompasses all of the possible variations of disclosure, including non-disclosure, the ‘wall of silence’, in Thailand (Ishikawa *et al.*, 2010:308); accidental disclosure, in Canada (Kennedy *et al.*, 2010) and in the USA (Woodring *et al.*, 2005); partial disclosure, in Kenya (Gachanja, Burkholder and Ferraro, 2014); differential disclosure in the USA (Tompkins, 2007a); and disclosure by others, in the USA (Wiener *et al.*, 1996). An interesting addition to this work is an article by Murphy, Roberts and Hoffman (2003) on American mothers’ feelings of regret after maternal disclosure. Moses and Tomlinson (2013) recognise the fluidity of the disclosure process in their exploration of the experiences of South African women who are pregnant or new mothers; this is, however, applied to women’s experiences of telling friends or family members rather than talking to their children. The majority of the research exploring maternal disclosure to children takes place in HICs and tends to focus on disclosure or non-disclosure, rather than including the full breadth of possibilities, thus reinforcing the disclosure binary. This is discussed in more detail in Chapter 2.

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<sup>3</sup> All names are pseudonyms.

### **1.5.1      *Why is maternal disclosure of HIV to children important?***

The issue of maternal disclosure to HIV negative (rather than HIV positive) children is a growing concern, particularly given the increased prevention of vertical transmission and improvements in HIV treatment (Jamaican Ministry of Health, 2014), which now enable people with HIV to live longer and healthier lives. Maternal disclosure of HIV is important because HIV positive mothers themselves describe it as something which concerns them. Research in HICs suggests that maternal disclosure is a crucial issue with an impact on individual and family health (Schrimshaw and Siegel, 2002; Vallerand *et al.*, 2005), maternal depression, parent-child relationships and child functioning (Murphy, Roberts and Herbeck, 2011). In a broader sense, disclosure can contribute to increased adherence to medication (Ingram and Hutchinson, 2000) and increased attendance at medical appointments (Mellins *et al.*, 2002), which can, in turn, reduce the risk of transmission, with corresponding public health benefits. Concerns about maternal disclosure have been identified locally by Jamaican women, NGOs and clinics as a significant source of anxiety, impacting on both physical and mental health, but little is known about women's experiences or views. Other factors, such as poverty, HIV stigma and discrimination (PANCAP, 2010), violence (Amnesty International, 2006), mental health stigma (Arthur *et al.*, 2008) and limited counselling and support (Weller *et al.*, 2008:319) may act as additional barriers for Jamaican HIV positive women to disclose their status to their children, care effectively for their own and their children's health and make plans for the future. Equally, little is known about the potential benefits for mothers who choose not to disclose to their children, as articles tend to focus on the drawbacks to non-disclosure (*e.g.*, the 'wall of silence' identified by Ishikawa *et al.*, 2010:308). The implicit assumption that it is good to disclose has skewed the focus of research in this area and left the potential benefits of non-disclosure or partial disclosure unexplored. I believe that the disclosure experiences of HIV positive mothers are wider and more complex than the disclosure/non-disclosure binary suggests. Through this thesis I aim to provide an insight into the lived experiences of fifteen of these women in Kingston, Jamaica, by using a feminist approach to Interpretative Phenomenological Analysis (IPA) that includes the wider context alongside a detailed exploration of the issues the women I interviewed identified as important.

### **1.5.2      *What is already known about HIV disclosure in Jamaica?***

Although there has been an increasing interest in issues surrounding maternal disclosure, it is still a relatively new area. The majority of research has focused on women in North America and Europe although some studies are starting to emerge from sub-Saharan Africa and Asia. The literature review in Chapter 2 provides a detailed breakdown and discussion of these articles. There is very limited research into maternal disclosure in the Caribbean; in 2014, Conserve *et al.* published the first Caribbean article on maternal disclosure, based on research

with mothers and seronegative children in Haiti. Cultural and economic factors in the Caribbean differ from those in the Anglo-North, sub-Saharan Africa and Asia and may affect the choices that women make. Although there is evidence from HICs suggesting mental and physical health benefits to women who disclose (Ingram and Hutchinson, 2000; Mellins *et al.*, 2002; Vallerand *et al.*, 2005; Murphy, 2008; Murphy, Roberts and Herbeck, 2011), maternal disclosure is a complex issue and some studies (*e.g.*, Lee and Rotheram-Borus, 2002) have highlighted negative impacts of disclosure for women and their children, particularly where disclosure has been unplanned (Murphy, Roberts and Hoffman, 2003), disclosure is by someone other than the mother (Wiener *et al.*, 1996) or where there has been differential disclosure and secret-keeping amongst family members (Tompkins, 2007a). Disclosure, therefore, may need to be considered carefully and weighed according to the needs and circumstances of individual families.

At the point of my initial search (and which still holds true in early 2018), there were no published studies on maternal disclosure to HIV positive or HIV negative children in Jamaica, hence my interest in exploring this area in the Jamaican context. Two studies (Weller *et al.*, 2008; Clarke *et al.*, 2010) looked at aspects of disclosure (but not maternal disclosure) in Jamaica. Clarke and colleagues' study (2010), showed a disclosure rate (to family and sexual partners) of 60% among female patients with age, sexual orientation, mode of transmission, and especially perception of family support significantly associated with likelihood of disclosure. Clarke *et al.*, suggest that the relatively low rate of disclosure could be attributed to cultural attitudes, as identified by Elford *et al.* (2008) in their examination of the role of ethnicity in HIV disclosure in London, UK. Carrier's (1989) study of sexual behaviour and AIDS in Mexico proposed that disclosure might be more difficult in societies with high levels of homophobia, traditional values and a strong emphasis on typical gender roles; Clarke *et al.* (2010) believe that similar factors could inhibit HIV disclosure in the Jamaican context.

Weller and colleagues' study (2008), found that more than half of their sample of Jamaican HIV-infected women had told family members about their illness. Among women who had yet to inform a relative, 58% did not feel able to tell any family members about their illness and 76% were not interested in referral to someone who could help them to prepare to tell a relative (Weller *et al.*, 2008). Although their reasons were not examined in detail, the reported reluctance of a significant number of Jamaican women to tell any member of their family gives us a small insight into the challenges that they face regarding disclosure. In addition to the medical view that disclosure to partners supports a reduction in HIV transmission, there is also a perception that disclosure to friends and family can lead to increased emotional support for People Living with HIV (PLWHIV).

Anecdotal evidence from local Jamaican HIV NGOs suggests that maternal disclosure to children in Jamaica may be very low, with NGO staff stating, for example, that they are aware of only 3 or 4 women who have disclosed to their HIV negative children (HIV NGO, 2012; personal communication). An additional factor may be that Jamaican culture tends to result in little discussion of sex within families (Lawson, 2013), making disclosure even more difficult for mothers; this is discussed in more detail in Chapter 7, Section 7.3.4. Local NGOs recognise the importance of family support and are beginning to devise programmes to include family members, but they report that it is still unusual for HIV positive participants to choose to involve their children; more commonly they include a partner, parent or sibling (HIV NGO, personal communication 24.04.16). Nonetheless, in Jamaica, an HIV NGO (2010, personal communication) found that women express a desire for support to disclose their status to loved ones (parents, partners, siblings and children).

## **1.6 Rationales**

### **1.6.1 *Rationale for focusing on mothers***

Within the global literature, there has been a recent shift towards a focus on parenting rather than mothering in order to reflect the involvement and participation of fathers as well as mothers. Much HIV disclosure literature refers to ‘parents’ (*e.g.*, Asander *et al.*, 2009; Nam *et al.*, 2009; Qiao, Li and Stanton, 2011) or ‘caregivers’ (*e.g.*, Xu, 2007; Palin *et al.*, 2009). In low income countries where there has been high HIV-related mortality, the term ‘caregiver’ is often used to reflect the fact that many children are cared for by relatives, following the deaths of their parents. A number of studies based in Africa or looking at the experiences of people of African origin in Europe (*e.g.*, Nostlinger *et al.*, 2004; Geiselhart, Gwebu and Krüger, 2008; Palin *et al.*, 2009; Rochat *et al.*, 2011) have emphasised the importance of recognising and including wider family networks and traditional family norms which impact on caregiving.

Although the role of fathers and extended family networks is important in the Caribbean context, the experience of many poor Jamaican families is that much of the childcare, income-generating and health-related activities in a family unit (however this is defined) are primarily the responsibility of mothers. I wanted to retain the focus of working with a clearly defined group, an aim that aligns itself well with IPA’s focus on small homogeneous groups of participants. As ARV (antiretroviral) effectiveness and availability have improved and PMtCT programmes have become increasingly successful (Jamaican Ministry of Health, 2014), the majority of children are now born HIV negative and HIV positive mothers are leading longer and healthier lives. Most Jamaican HIV positive mothers who are accessing healthcare and following their treatment regime will give birth to HIV negative babies and will live to see them

grow up. This raises a host of questions for mothers about how they manage their illness and if/how they communicate with their children about their HIV. I do, however, recognise the importance of fathers and wider family networks on the experiences of mothers and so, whilst this is not my main focus, I include the women's references to these relationships.

### ***1.6.2 Rationale for interviewing mothers of seronegative children aged over 10 years***

Recent advances in HIV treatment have led to a sharp reduction in vertical transmission in many parts of the world. In Jamaica, as a result of PMtCT programmes, MtCT rates were down from 10% in 2005, to 4.6% in 2010 and 1.9 in 2012 (Jamaican Ministry of Health, 2014). This has resulted in an increase in the number of HIV seronegative children born to HIV seropositive women. There has therefore been increased interest in the psychosocial aspects of disclosure and the potential costs and benefits to mothers and children, particularly as this relates to seronegative children. Prior to this, a significant percentage of children born to HIV positive mothers would themselves also have been HIV positive, resulting in different issues and, possibly, in some cases, a higher disclosure rate. The Paediatric and Perinatal HIV/AIDS Programme in Kingston, Jamaica, has a disclosure protocol to assist in disclosing children's HIV status to them between the ages of 6 and 12 years (Christie, 2012, personal communication); no such tool currently exists to assist families in making decisions about disclosing a mother's (or other family member's) status to either seronegative or seropositive children or with the actual process of disclosure. Because I was told anecdotally that Jamaican mothers wouldn't talk to young children about their HIV, I chose to interview mothers with at least one seronegative child aged over 10 years to try to allow for the possibility that some participants might have told their children. Jamaican women often have several children and I had no upper age limit for seronegative children and no age or serostatus limits at all for additional children. My research therefore includes the experiences of mothers who, in addition to having at least one seronegative child aged over ten years, also have adult children, younger children, and HIV positive children.

### ***1.6.3 Rationale for using World Bank country classification system***

The terminology used to describe the situations of different countries across the world changes frequently and often follows a presumed and somewhat patronising dichotomy: third world/first world, developing countries/developed countries, less developed countries/more developed countries or less economically developed countries/more economically developed countries. The implication is that countries belonging to the latter categories are 'better' and that countries belonging to the former categories should aspire to and work towards transformation. This categorisation implies that there is one ideal way to be and one, already prescribed route to get there. It does not value difference. More recent terms include global south/global north, two

thirds world/one third world, majority/minority world. Many of the more recent terms can be considered mathematically or geographically problematic and many of the earlier terms sound patronising; none takes into account variation within countries, the rich in poor countries, the poor in rich countries or different ways of measuring or valuing ‘development’. Bearing this in mind, I have chosen to use the term ‘Anglo-Northern’ to describe approaches which originate in English-speaking Northern Countries (*i.e.*, the UK, USA, Canada, Australia, New Zealand) in an attempt to capture concepts of white patriarchy and how this affects culture and attitudes. I will refer to other countries (which elsewhere are often called the ‘third world’ or ‘less developed countries’) as the Global South or Majority World. I have chosen the term Global South because it is a clear counterpart to ‘Anglo-Northern’, although neither is entirely geographically accurate. The term Majority World was coined by writer and photographer Shahidul Alam in the 1990s (Alam, no date) and emphasises that these countries contain the majority of the world’s population and highlights the contrast between the total population of the G8 countries and the far-reaching impact that their decisions and policies have across the world. Both avoid the inherent superiority implied by the terms ‘third world’ or ‘less developed’ and act as a counterpoint to the tendency to see the populations of Anglo-Northern countries as ‘the majority’, implicitly following power-based assumptions.

For the purposes of the literature review (Chapter 2), I use World Bank (2016) country classifications (low income, lower-middle income, upper middle-income and high income countries). This, too, is an imperfect tool to describe countries. However, this system of classification is well known across the world, has an important impact on the work of charities and NGOs, including those working in HIV, and has a substantial impact on funding eligibility. This has been significant for Jamaican HIV NGOs in recent years because in 2010 Jamaica was reclassified as an upper-middle income country, thereby reducing their eligibility to apply for a number of important funding streams. For example, in 2012/13 when I carried out my interviews, the Global Fund had already significantly reduced funding for HIV programmes and planned to withdraw altogether by 2017 (UNAIDS, 2013). Thus, the somewhat abstract concept of country classification has a clear link to the day-to-day experience of the HIV positive women I interviewed.

## **1.7 The disclosure spectrum**

The proliferation of studies reporting the benefits of disclosure (*e.g.*, Thorne, Newell and Peckham, 2000; Dane, 2002; Nostlinger *et al.*, 2004; Xu, 2007; Geiselhart, Gwebu and Krüger, 2008; Rwemisisi *et al.*, 2008; Nam *et al.*, 2009; Thomas, Nyamathi and Swaminathan, 2009; Zhou *et al.*, 2013) and recommending interventions to increase the rates of disclosure (*e.g.*, WHO, 2011; Krauss *et al.*, 2012) implies that most authors consider parental disclosure

desirable. This appears to be based on Anglo-Northern ideals of open and honest communication within the conventional nuclear family. It becomes more complex when applied to other family configurations, different religious and cultural norms and less resourced contexts. The use of models involving concepts such as risks and danger or stigma to help understand people's disclosure decisions implies that it is necessarily challenging for people to disclose. However, in LMIC settings, whilst there is evidence of relatively low disclosure rates, there is also evidence of a number of parents who do disclose, suggesting that parental disclosure is not considered equally challenging or stigmatising by everybody, that there are, in fact, a range of attitudes and approaches taken by parents: a disclosure spectrum rather than a disclosure/non-disclosure binary. This is echoed by Allison and Siberry's 2015 review of the literature on maternal and child HIV disclosure: the authors propose that researchers use a "continuum" (Allison and Siberry, 2015:S117) to measure disclosure.

Additionally, most literature assumes that the concept and the term 'disclosure' is one which is readily understood, although it is a relatively technical word, which is unlikely to be used in daily life unless individuals have been exposed to it through medical or NGO staff. Disclosure is frequently presented as a binary—parents either disclose or do not disclose. There is evidence from HICs of an acknowledgement of the complexity of disclosure. For example, authors (DeMatteo *et al.*, 2002; Corona *et al.*, 2006; Tompkins, 2007a) write of differential disclosure, where parents disclose to some children but not others. In disclosure literature based in LMICs, there is more limited recognition of the range of disclosure options. In this thesis, I refer to 'the disclosure spectrum' to indicate the wide range of experiences and views of HIV disclosure. The WHO (2011) states that there is no evidence of harm to caregiver or child as a result of disclosure. However, there does not appear to be any recognition that those who have or have not disclosed may have made a decision which is right for their family at that time; forcing or strongly encouraging disclosure which would not otherwise have occurred may have negative effects which cannot be predicted according to the experiences of those who have freely chosen to disclose without advice or support from professionals.

## **1.8 Chapter summary**

The quote which gives this thesis its title is from the first participant in my research, Sandra. Although this extract is only a few lines long, I think it provides an insight into the issues that Sandra, and many other HIV positive mothers, must deal with. She describes a number of issues that are not often addressed in the literature: the complexity of managing the reactions of different children; the potential impact of HIV disclosure on the mother-child relationship, and additionally on the father-child relationship; and the challenges of dealing with emotions: sadness, the loss of a particular characterisation of herself (as a queen, an angel), and fear of



hatred. Although research has suggested that maternal disclosure is an issue with positive impacts on individual and family health (Murphy, 2008, Vallerand *et al.*, 2005, Scrimshaw & Siegel, 2002), maternal depression, parent-child relationships and child functioning (Murphy *et al.*, 2011), this research has mostly taken place in high income settings and there is limited information on the actual process of disclosure for mothers, particularly in low income settings. A body of global research on maternal disclosure exists, particularly from HICs, but increasingly from LMICs; some of this presents a more complex, nuanced picture of parental experiences of disclosure in these contexts. My study will contribute to this body of research by investigating the lived experiences of HIV positive mothers in Jamaica and the effects that their particular social and cultural circumstances have on their choices and views of disclosure. I add to the small existing body of literature on maternal disclosure of HIV to children LMICs, extend existing IPA work by combining a feminist approach with IPA in a resource constrained setting and apply Hochschild's concept of emotion work to maternal disclosure of HIV. I argue that our understanding of the experiences of HIV positive women, particularly in the global south/majority world can be enhanced through a focus on the experiences of the women themselves, told in their own words, as well as a recognition of the wider societal factors that affect their experiences. I am conscious of the apparent contradiction in my expressing this viewpoint: I am not a poor Black Jamaican HIV positive woman and my attempts to interpret and express the views that they expressed to me will necessarily be filtered through the lens of my own experiences and viewpoints, as well as being affected by the way in which participants chose to portray themselves to me, a white British woman. Nevertheless, this is my goal.

## 1.9 Outline of chapters in the thesis

I have divided this thesis into 4 sections. The **FIRST SECTION** provides introductory and contextual information about maternal disclosure in the Jamaican context and a literature review of parental disclosure of HIV to children in LMICs. This **introductory chapter (Chapter 1)** sets out the key issues and questions which inform my research and provided some background on the reasons for my personal interest in maternal disclosure of HIV in the Jamaican context. I introduced some terminology I will use throughout the thesis and an overview of current policy and rationales which begin to explain and ground my approach. **Chapter 2** provides three separate literature reviews which, combined, provide an overview of the parental disclosure of parental HIV to children in LMICs as well as HICs, with a focus on literature from LMICs in Africa and the Caribbean. The review describes my search processes and inclusion criteria, highlights the key findings of the research and identifies some of the gaps in both findings and approaches. **Chapter 3** provides contextual information on the issues and challenges which affect HIV positive mothers in Kingston, Jamaica, including cultural attitudes towards HIV,

parenting and motherhood as well as more structural factors such as poverty, violence and migration.

The **SECOND SECTION** looks at the theoretical, methodological and practical issues of the research and analysis process. In **Chapter 4**, I introduce the conceptual resources I refer to throughout, including decoloniality, gender, motherhood, responsabilisation (Lupton, 2011), emotion work and the ‘pinch’ (Hochschild, 1979, 1983). **Chapter 5** describes my methodology, a feminist approach to Interpretative Phenomenological Analysis (IPA). I position a feminist approach to IPA within qualitative methodologies, describe the origins of IPA and what it means to apply a feminist approach to IPA. **Chapter 6** describes the interview process, including sampling and sample size, obtaining ethical approval, gaining access to organisations and participants and my experience of working with Jamaican Patois. The chapter concludes with an introduction to the participants and an overview, with examples, of the analysis process. I introduce the themes and describe how I used the concept of emotion work to structure them.

The **THIRD SECTION** describes and discusses my findings and themes. **Chapter 7** examines how HIV positive mothers attempt to live up to the culturally idealised concept of the ‘good’ mother who visibly provides for and protects all aspects of her children’s physical and emotional health. This occurs whilst simultaneously (and often secretly) coping with the challenges of living with a stigmatised disease. **Chapter 8** uses two experiences, mothering at a distance and ‘downfallment’, to explore the ways in which HIV positive mothers work to present themselves as ‘good’ and ‘responsible’ mothers, in the context of the particular challenges of their lived experiences of mothering. **Chapter 9** explores how HIV positive Jamaican mothers challenge cultural norms of authoritarian parenting and carry out emotion work to establish more collaborative and reciprocal relationships with their children and describes the women’s varied approaches to disclosure.

The **FINAL SECTION** draws together and discusses these findings, beginning with **Chapter 10**, which provides reflections on applying a decolonial approach to the research, as well as my experience of interviewing as an outsider in Jamaica, with participants speaking Jamaican Creole, and on the power dynamics at play within the interviews. In the concluding chapter, **Chapter 11**, I synthesise the three thematic findings chapters, developing the discussion and highlighting the key conclusions. I identify the contributions of the study, make recommendations and suggest areas for further research.

## **Chapter 2: Global parental disclosure to children: Three literature reviews**

### **2.1 Introduction**

My focus in this thesis is to examine the experience of maternal disclosure from the perspective of Jamaican mothers. This chapter reviews the existing literature on maternal and parental disclosure of HIV to children in LMICs (Low and Middle Income Countries) and HICs (High Income Countries), introduces the key themes identified, and highlights the gaps in the literature, in order to situate my own research. I concentrate particularly on the literature from LMICs in Africa and the Caribbean, rather than the literature from HICs or other LMICs. My rationale for using the World Bank classifications of LMICs and HICs is to help recognise the impact that cultural and income based differences have on people's lives, health and choices (see Section 1.6.3).

This literature review chapter is guided by the following question: How relevant or useful is existing maternal disclosure guidance for HIV positive Jamaican mothers? Thus, my starting point was to consider how the WHO guidance (2011) might be applied in the Jamaican context, and to examine subsequent reviews and guidance to see what they might add to the body of literature. I then describe, in the order in which they were conducted, the three literature reviews I carried out to address this question: **Review 1** gives a brief overview of existing global parental disclosure literature, with a focus on global review articles (which include both HICs and LMICs articles) and a brief overview of maternal disclosure in HICs. **Review 2** provides a description of a published narrative review of parental disclosure in LMICs in Africa (Clifford *et al.*, 2013), including a brief additional section (Section 2.3.3) to include parental disclosure articles from LMICs in Asia, which were not included in the original article. **Review 3** provides an updated and more comprehensive mapping review of parental disclosure in LMICS in Africa and the Caribbean.

All three reviews were initially conducted in 2012, but (except for the published article in Review 2) have been updated to include literature up to 2017. For all aspects of this literature review which pertain to LMICs I have included studies which focus on parental or caregiver disclosure as well as maternal disclosure, and studies which include HIV positive or HIV exposed children, because most existing studies in LMICs do not focus only on maternal disclosure or only on seronegative children. I excluded all studies from the point of view only of children or of professionals which did not include mothers'/parents'/caregivers' experiences or views, and all studies focusing only on HIV infected children. For all aspects of the literature review, I read the articles repeatedly and identified common themes. Searches included articles going back to 1995, when studies on parental disclosure began to emerge. Articles from peer-

reviewed journals were included, as these represent a generally accepted standard of research. The databases that were searched and the keywords used can be found in Appendix I. Individual methodologies for each of the reviews can be found at the beginning of the relevant sections.

## **2.2 Review 1: Parental HIV disclosure across the world**

### **2.2.1 Methodology and approach for Review 1**

Review 1 examines the global parental disclosure literature, including maternal disclosure literature from HICs. Grant and Booth (2009:99), define an overview as “a generic term used for any summary of the literature”, rather than as a synonym for a systematic review. This overview is intended to provide a broad introduction to parental disclosure of HIV to children in areas other than Africa and the Caribbean, as a lead in to the more detailed mapping review on disclosure in LMICs in Africa and the Caribbean (Review 3, Section 2.4).

### **2.2.2 Review 1: General overview of global parental HIV disclosure review articles in LMICs and HICs**

In addition to the WHO guidelines (2011), there are a number of review articles concerning global parental disclosure of HIV status to children. HICs tend to be well represented (although articles in LMICs have increased in recent years). There are two literature reviews of maternal disclosure to children in the USA, both published about a decade ago. Hawk (2007) examined 30 articles published between 1995 and 2007, focusing on predictors and reasons for disclosure, planning disclosure, the disclosure process and the impact of disclosure and calls for further research on age-related reactions of children, long and short term reactions and the impact of culture. Murphy (2008) reviewed 9 articles published between 1996 and 2006 looking at maternal disclosure rates, reasons for disclosure and long and short term reactions and called for further studies to examine access to support services, and an inclusion of the family context. The majority of parental HIV disclosure articles in HICs are based in the USA or Canada. However, several articles based in European countries focus on parental disclosure as experienced by migrants from sub-Saharan Africa. For example, Nostlinger *et al.* (2004) explore the experiences of African HIV positive caregivers living in Flanders, Belgium; Åsander *et al.* (2009) address the disclosure experiences of HIV-infected African parents living in Stockholm, Sweden; and Thorne, Newell and Peckham (2000) write about HIV positive African and European parents across 7 European countries. These articles are interesting in that they highlight some of the challenges of cross-cultural work: participants may be living in a high income country and have access to high quality universal medical care, but their views, experiences and relationships are shaped by their culture.

A systematic review and analysis of caregiver's HIV disclosure to children 12 years and under (Krauss *et al.*, 2013), has very similar findings to the WHO guidance (2011): that children aged 6–12 can be told of their caregiver's status and younger children can be partially told in an age-appropriate manner. This study included 15 studies from 13 countries, but the results are not reported in such a way as to make it possible to draw conclusions about more and less highly resourced settings or cultural factors.

The most comprehensive review article is that written by Qiao, Li and Stanton (2011), a global systematic review of 39 articles about parental disclosure of HIV to children, focusing on the process of disclosure, the reasons for and impact of disclosure and non-disclosure. The authors grouped the studies into qualitative (15) and quantitative (26); two studies included both qualitative and quantitative work. Disclosure rates worldwide were found to be low, with forced or unintended disclosures common. Decisions were linked to parents' perception of benefits to children, children's ability to understand, and stigma and parenting norms. In keeping with other work (*e.g.*, WHO, 2011), the authors concluded that, although findings were mixed, in general, disclosure is of long term benefit to children, parents and families and call for "evidence-informed developmentally and culturally appropriate interventions" to be developed, especially for low resourced settings (Qiao, Li and Stanton, 2011:1). However, the majority of the studies included in this review were from HICs (26 from the USA, 2 from Canada and 5 from Europe), with only 8 studies from LMICs (4 from Africa and 4 from Asia). LMICs are therefore not well represented here, as noted by the authors who identify "significant knowledge gaps regarding culturally and developmentally appropriate psychological intervention and services for HIV positive parents and their children, especially in developing countries and other resource-poor settings" (Qiao, Li and Stanton, 2011:18).

Obermeyer, Baijal and Pegurri (2011) examine disclosure across diverse settings, but only a small part of their article is focused on disclosure to children. Rochat *et al.* (2011) summarise research supporting the development of a family-centred approach to HIV treatment and care for families in poorly resourced settings, with a focus on sub-Saharan Africa. However, parts of this article simply extend findings from HICs to LMICs, without allowing for the cultural and economic differences which exist in those settings. For example, all of the benefits of disclosure for mothers living with HIV (Rochat *et al.*, 2011: 14, Box 2) were identified in studies which took place in the USA (Hawk, 2007; Murphy, 2008). Vreeman *et al.* (2013) conducted a systematic review which examines disclosure in low resourced settings but their focus is on disclosure to children who are themselves HIV positive.

A more recent review (Allison and Siberry, 2015) recognises that disclosure occurs on a continuum and may not always be beneficial; Kennedy *et al.* (2015) identify a lack of culturally

specific research. Allison and Siberry (2015:S117) state that disclosure is not always appropriate and should not be the goal for all study participants. The authors call for research on optimal circumstances for disclosure, the development of culture-specific disclosure protocols, and research on the mental, physical and social outcomes for children of HIV disclosure. Similarly, Kennedy *et al.* (2015) found that results were mixed and called for more research to investigate whether current approaches were effective (although this review included disclosure to family, partners and HIV positive as well as HIV negative children).

### **2.2.3     *Maternal disclosure of HIV status to children in HICs***

In addition to the review articles, there is a considerable body of work on maternal disclosure of HIV status to children in HICs which includes both qualitative and quantitative research and a range of approaches and methodologies. The main themes in the HIC literature are related to rates of disclosure, factors affecting disclosure (*e.g.*, age/gender of child, maternal health, ethnicity), reasons for and against disclosure, and the impact of disclosure on mothers and children. There is some work on regret (Murphy, Roberts and Hoffman, 2003), unplanned disclosure (Kennedy *et al.*, 2010), preparation activities (DeMatteo *et al.*, 2002), and differential disclosure (Tompkins, 2007a).

## **2.3     Review 2: A narrative review of parental disclosure literature in LMICs (summary of published article, 2013)**

### **2.3.1     *Methodology and approach for Review 2***

As a first step to familiarising myself with the parental disclosure literature in LMICs and considering the implications of these findings for Jamaica, I conducted a narrative literature review in 2012 which led to a published article (Clifford *et al.*, 2013, see Appendix II). Grant and Booth (2009:94), in their analysis of types of reviews, define a narrative literature review as a “generic term [referring to] published materials that provide examination of recent or current literature”. For this article, I conducted a systematic search of the English language literature on parental disclosure in LMICs published between January 1991 and September 2012. The search process for the article was necessarily constrained by time factors and includes articles up to September 2012. The addendum section on LMICs in Asia includes articles up to 2017 and is intended to extend the original review which did not include LMICs in Asia.

### **2.3.2     *Review 2: Parental disclosure of HIV to children in LMICs***

In researching this article I found that global estimates of parental disclosure rates varied from 20–97% in HICs and 11–44% in LMICs, with the mean age of children at disclosure ranging from 10–18 years (Clifford *et al.*, 2013). Barriers to disclosure included fear of

stigma/discrimination, not knowing how to tell the child, fear of the child disclosing to others and believing a child was too young to cope. Of the 16 articles identified which met the search criteria, the majority (Thorne, Newell and Peckham, 2000; Dane, 2002; Nostlinger *et al.*, 2004; Xu, 2007; Geiselhart, Gwebu and Krüger, 2008; Rwemisisi *et al.*, 2008; Nam *et al.*, 2009; Thomas, Nyamathi and Swaminathan, 2009; Zhou *et al.*, 2013), including three review articles (Obermeyer, Baijal and Pegurri, 2011; Qiao, Li and Stanton, 2011; WHO, 2011), found that disclosure had a positive effect on parental health and the parent-child relationship. Several studies (Geiselhart, Gwebu and Krüger, 2008; Nam *et al.*, 2009; Palin *et al.*, 2009; Obermeyer, Baijal and Pegurri, 2011) identified the potential for both heightened risks and heightened benefits in resource constrained settings, where emotional and psychological benefits may be secondary to practical and financial needs. A review article (Obermeyer, Baijal and Pegurri, 2011) highlighted HIV related stigma and discrimination and the additional financial and social challenges associated with HIV as factors which may discourage families from providing support to PLWHIV. Authors (UNAIDS, 2010; Obermeyer, Baijal and Pegurri, 2011) found that disclosure rates are higher when people expect to receive help and lower when they expect blame and discrimination; this may help to explain the lower rates of disclosure in LMICs.

This review article (Clifford *et al.*, 2013) sought to provide an overview of the issues identified by existing studies of disclosure in LMICs which might have potential implications for Jamaica. I found that studies identified a need for professional and social support to parents and families dealing with disclosure issues. Authors suggested culturally sensitive and adaptable intervention programmes (Dane, 2002; Thomas, Nyamathi and Swaminathan, 2009), which address parenting, family support and social networking issues (Rochat *et al.*, 2011). Programmes would include practical guidance on age-appropriate disclosure to children (Qiao, Li and Stanton, 2011; Rochat *et al.*, 2011), managing parental fears and children's responses (Nam *et al.*, 2009), planning for the future (Nam *et al.*, 2009), using tools such as story and memory books (Rwemisisi *et al.*, 2008), and balancing advantages and disadvantages in specific family contexts (Nostlinger *et al.*, 2004). Globally, authors (*e.g.*, Thorne, Newell and Peckham, 2000; Nostlinger *et al.*, 2004; Xu, 2007; Geiselhart, Gwebu and Krüger, 2008; Nam *et al.*, 2009; Palin *et al.*, 2009; Obermeyer, Baijal and Pegurri, 2011; WHO, 2011) identified the importance of psychosocial factors such as family involvement and communication, planning for the future, providing peer support, and reducing stigma and discrimination in supporting families affected by HIV. The article concludes by recognising the strong track record in Jamaica of reducing MtCT (Jamaican Ministry of Health, 2014) and providing effective medical treatment to PLWHIV (Duncan *et al.*, 2010). I suggested that the gaps in providing psychosocial support to families (including supporting parental disclosure to seronegative children) might be addressed by adapting successful global programmes to the Jamaican context. Conducting this review

highlighted the fact that much existing literature is extrapolated from HICs to LMICs and that, although many authors call for culturally specific research for LMICs, to date, little exists. The rest of this chapter seeks to extend the findings of this article by collecting additional, more recent information and clarifying how this could inform HIV disclosure work in Jamaica.

### **2.3.3 Addendum to review 2: Parental disclosure of HIV to children in LMICs in Asia**

Although I did not initially include LMICs in Asia, I have added a short overview here in order to make the review of LMICs more comprehensive. There are a number of maternal disclosure studies emerging from LMICs in Asia, including India (*e.g.*, Thomas, Nyamathi and Swaminathan, 2009) and Thailand (*e.g.*, Dane, 2002). A larger number of studies focus on parental disclosure of HIV, particularly in China (*e.g.*, Zhou *et al.*, 2012; Qiao, Li and Stanton, 2014; Qiao *et al.*, 2015a, 2015b; Simoni *et al.*, 2015). Although many Asian countries are classified by the World Bank as LMICs, the social and cultural context is very different from Jamaica, including generally higher marriage rates, smaller family sizes and different cultural norms. Lee *et al.* (2005) note that China is highly family-oriented with a high level of parent-child interdependence and a tradition of respect towards elders, making disclosure less likely than in many HICs. Xu (2007) found that Chinese caregivers and community key informants suggested it was best not to tell children about parental HIV, some going as far as to tell children whose parents had died of HIV that they had, in fact, travelled to work elsewhere. Li *et al.* (2011) describe HIV stigma in China as acute; other research found that the prospect of HIV disclosure causes significant distress (Chen *et al.*, 2007). Several studies of HIV in China note a wider pattern of disease non-disclosure, where illness is considered a burden and health care professionals frequently seek to protect patients from the knowledge of their diagnosis (*e.g.*, Chen *et al.*, 2011). Simoni *et al.* (2015) note that their intervention resulted in no full disclosures of HIV by parents, despite their children all being over 18 years of age. This contrasts sharply with interventions in countries such as the USA, which reports 33% full disclosure (Murphy *et al.*, 2011) or South Africa with all intervention participants fully (61%) or partially (39%) disclosing (Rochat *et al.*, 2014).

Despite these differences, some articles on parental disclosure in Asia mirror recent findings from Africa (see below). For example, Qiao *et al.* (2015a) examine decision making amongst HIV positive parents in China and find that positive coping strategies and good parent-child relationships lead to increased parental disclosure of HIV. They found that increased resilience was linked with lower parental disclosure, perhaps because parents with higher resilience had less need of support from their children and therefore felt that the potential risks outweighed the benefits. Ishikawa *et al.* (2010) identify a possible tension between what is best for the children and what is best for their mothers. Their study in Thailand found that adults created a “wall of silence” around children in an attempt to protect them from sadness and bullying, but instead



created isolation and “increased their psychosocial vulnerability” (Ishikawa *et al.*, 2010:308). The study calls for families and schools to work together in a participatory and culturally appropriate way, whilst recognising and promoting children’s resilience and agency to “promote more open communication” (Ishikawa *et al.*, 2010:308). The study does not provide details as to how this might be achieved, particularly regarding the discrimination and ostracism families may face from communities and institutions as well as other potential risks of breaking this silence.

## **2.4 Review 3: LMICs in the Caribbean and Africa: a mapping review**

### **2.4.1 Methodology and approach for review 3**

I chose to carry out a mapping review for this key aspect of my thesis in order to contextualise my study and identify gaps in the evidence base (Grant and Booth, 2009:97). The authors define a mapping review as a review which “Map[s] out and categorise[s] existing literature from which to commission further reviews and/or primary research by identifying gaps in research literature” (Grant and Booth, 2009:94). They find that a mapping review “characterises quantity and quality of literature, perhaps by study design and other key features [and] may identify [a] need for primary or secondary research” (Grant and Booth, 2009:94).

A significant number of articles in LMICs have been published after 2012. I therefore repeated the online literature search that I had conducted for reviews 1 and 2 in early 2016, spring 2017 and autumn 2017. I also tightened my criteria to focus only on LMICs in Africa and the Caribbean, to exclude review articles and to exclude articles which focus on participants from LMICs who are living in HICs.

### **2.4.2 Mapping review findings: An overview of parental HIV disclosure studies in LMICs in the Caribbean and Africa**

I now examine in detail the literature from LMICs in Africa and the Caribbean. Table 1 (below) provides information on methodologies, participants and disclosure rates; a more detailed table can be found in Table 1, Appendix III. I had originally intended to focus on studies from the Caribbean but my literature search identified only one article from the Caribbean (Conserve *et al.*, 2014), so I expanded the search to include African countries, recognising that some of the issues will necessarily be different because of social, historical, economic and cultural factors. I included articles which focused on the views or experiences of mothers or parents on maternal or parental disclosure of HIV to seronegative children (although some studies also include seropositive children). I found 23 articles meeting these criteria.

**Table 1: Maternal or Parental disclosure of HIV to children in LMICs in Africa and the Caribbean**

Authors	Methodology	Participants	Participants' children: Number Age HIV status	Rate of disclosure as reported As a percentage
<b>Caribbean Low Income</b>				
Conserve <i>et al.</i> (2014) Haiti	Qualitative thematic analysis	Mothers (25) and children (26)	26 ages 10–17 HIV - and HIV +	Brief disclosure (16/25) <b>64%</b> Explicit disclosure (9/25) <b>36%</b>
<b>Africa Middle Income</b>				
Geiselhart, Gwebu and Krüger (2008) Botswana	Qualitative No details on specific methodology	Mothers (36), fathers (14), young people (10), households (11) and professionals (16)	Not stated Not stated (assumes age 6/7 suitable for disclosure). HIV +, HIV- & unknown	20/50 told their children <b>40%</b>
Nam <i>et al.</i> (2009) Botswana	Qualitative Grounded Theory	Mothers (12) and fathers (9)	24 children ages 5–18 HIV - and HIV +	4/21 had disclosed (2M, 2F) <b>19%</b>
Palin <i>et al.</i> (2009) South Africa 2009	Quantitative	mothers (103) (primary caregiver, may not be biological mother)	Not stated (assume 103. If more than one child, reported on oldest child in age range). Aged 11–16 Not stated	<b>44%</b> of mothers had disclosed
Rochat, Mkwana and Bland (2013) South Africa	Qualitative (Pilot intervention) No details on specific methodology	24 mothers	24 families with at least one child aged 6–9 years HIV -	By end of project 11/24 fully disclosed ( <b>46%</b> ) and 13/24 partially disclosed ( <b>54%</b> )
Rochat <i>et al.</i> (2014)	Qualitative (Intervention)	281 mothers	281 women with an HIV-negative child aged 6–10	By end of project: One hundred and seventy-one ( <b>61%</b> ) women

South Africa	No details on specific methodology		HIV -	‘fully’ disclosed and 110 ( <b>39%</b> ) women ‘partially’ disclosed their HIV status to their child.
Rochat <i>et al.</i> (2015) South Africa	Qualitative (Follow up to intervention) No details on specific methodology	281 mothers	281 women with an HIV-negative child aged 6–10 HIV -	<b>61%</b> women had ‘fully’ disclosed <b>39%</b> women had ‘partially’ disclosed their HIV status to their child during this intervention.
Rochat <i>et al.</i> (2016) South Africa	Qualitative No details on specific methodology	281 mothers	281 women with an HIV-negative child aged 6–10 HIV -	<b>61%</b> women had ‘fully’ disclosed, <b>39%</b> women had ‘partially’ disclosed their HIV status to their child during this intervention
Rochat <i>et al.</i> (2017) South Africa	Qualitative No details on specific methodology	281 mothers	281 women with an HIV-negative child aged 6–10 HIV -	<b>61%</b> women had ‘fully’ disclosed <b>39%</b> Women had ‘partially’ disclosed their HIV status to their child during their participation in the Amagugu intervention
Madiba (2013) South Africa	Qualitative No details on specific methodology	26 nondisclosed biological parents	60 children 7–18 years HIV - (implied, not stated)	26/44 <b>59%</b>
Madiba and Matlala (2012) South Africa	Qualitative thematic analysis	21 disclosed HIV positive parents aged 20-50 years, with 1-3 children	39 children 7 –18 years. One child was HIV +.	16 parents told all children about parental HIV; 5 told only some. (33/39 children told; 6/39 children not told).
Gachanja, Burkholder and Ferraro, (2014a) Kenya	Qualitative  Phenomenology: Van Kaam method	16 HIV positive parents (aged 30-54, 11 women, 5 men) with 1-6 children, including one married couple Plus, 7 HIV + children, 5 HIV – Children aged 8-17 years	7 HIV + children, 5 HIV- children aged 8–17 years HIV – and HIV +	9/16 ( <b>56%</b> ) fully disclosed (to at least 1 child) 5/16 ( <b>31%</b> ) partially disclosed or disclosed child’s illness but not parents’ 2/16 ( <b>13%</b> ) not disclosed

Gachanja, Burkholder and Ferraro, (2014b) Kenya	Qualitative Phenomenology: Van Kaam method	16 HIV positive parents (aged 30–54, 11 women, 5 men) with 1–6 children, including one married couple Plus, 7 HIV + children, 5 HIV – Children aged 8–17 years	7 HIV + children, 5 HIV- children children aged 8–17 years HIV – and HIV +	9/16 ( <b>56%</b> ) fully disclosed (to at least 1 child) 5/16 ( <b>31%</b> ) partially disclosed or disclosed child's illness but not parents' 2/16 ( <b>13%</b> ) not disclosed
Gachanja (2014) Kenya	Qualitative Phenomenology: Van Kaam method	An HIV positive couple (parents of 5 children)	5 (same family) 25 M, 24M, 22F and 20F and 15M) HIV- & unknown	4/5 children ( one family) So had disclosed to at least one child <b>100%</b>
Gachanja and Burkholder (2016) Kenya	Qualitative Phenomenology: Van Kaam method	16 HIV positive parents (aged 30–54, 11 women, 5 men) with 1–6 children, including one married couple Plus, 7 HIV + children, 5 HIV – Children aged 8–17 years	7 HIV + children, 5 HIV- children children aged 8–17 years HIV – and HIV +	9/16 ( <b>56%</b> ) fully disclosed (to at least 1 child) 5/16 ( <b>31%</b> ) partially disclosed or disclosed child's illness but not parents' 2/16 ( <b>13%</b> ) not disclosed
Avornyo and Amoah (2014) Ghana	Qualitative No details on specific methodology	26 parents (18 mothers, 8 fathers) aged 20–50+	21 children Aged 2–20's Majority HIV negative	18/26 parents (2/8 fathers, 16/18 mothers) had not disclosed their status.
<b>Africa Middle Income</b>				
Rwemisisi <i>et al.</i> (2008) Uganda	Qualitative  No details on specific methodology	Interviews with 10 parents, plus interviews about counselling policy with directors and counsellors from 5 counselling institutions.	51 4 to 36 years HIV +, HIV- & unknown	Half of parents interviewed had disclosed to all or some children, aged 8+. <b>50%</b>
Kyaddondo <i>et al.</i> (2013) Uganda	Qualitative  No details on specific methodology	12 in-depth interviews (6 adults over 32 yrs 3F, 3M); 4 unmarried young people aged 18–24; heterosexual infection; 2 aged 19–20, perinatal infection. Also 2 single sex focus groups discussions of 8 people each.	Not clear Children's ages not specified HIV – and HIV +	Not stated

		And open-ended survey questions (100 F, 48 M)		
Osingada <i>et al.</i> (2016) Uganda	Quantitative	344 HIV positive parents	Not stated Aged over 5 years Not stated.	<b>37 %</b> had told at least one of their children that they were HIV positive.
De Baets <i>et al.</i> (2008) Zimbabwe	Quantitative (Hypothetical: participants asked what they think people should do not what they have actually done)	64 health care workers 131 community members	64 health care workers & 131 community members Not specified: questions were hypothetical Not stated: hypothetical	<b>Hypothetically 89% to child age 14+.</b> Participants suggested partial disclosure from the age of 10.8 years and full disclosure from the age of 14.4 years.
Tiendrebeogo <i>et al.</i> (2013) Burkina Faso	Qualitative and Quantitative  Grounded Theory	mothers (37), fathers (26)	37 women (59%) and 26 men (41%) with at least one child 7 to 30 years of age. HIV + and HIV - (Five women had children who tested positive, not clear how many children this is)	<b>47.6 %</b> of parents had disclosed
Muparamoto and Chiweshe (2015) Zimbabwe	Qualitative thematic analysis	12 mothers, 7 fathers	Not stated Most had at least 1 child aged over 15. HIV - (implied, not stated)	5/14 had disclosed <b>36%</b>
Moore, Kalanzi and Amey (2008) Togo	Qualitative  No details on specific methodology	151 men and women living with HIV in Lomé, Togo. Average age 35, 59% had children	Average age of children was 12. Only two participants reported having an HIV positive child.	16 % had disclosed to children.

These articles are all from 2008–2016, reflecting the impact of antiretroviral therapy on life expectancy and relationships, as highlighted by Kyaddondo *et al.* (2013) and Tiendrebeogo *et al.* (2013). Only six of these articles were published prior to 2012, when I began my research, demonstrating the increased interest in the issue of parental disclosure in recent years. There are, however, fewer studies than implied by the number of articles. The five articles by Rochat and colleagues (Rochat, Mkwanaazi and Bland, 2013; Rochat *et al.*, 2014, 2015, 2016, 2017) refer to one South African intervention, ‘The Amagugu Intervention’; the articles refer to a pilot, the study, follow ups and a description of the conceptual model. Similarly there are 4 articles from Kenya which met my criteria and are based on the same study (Gachanja, 2014; Gachanja and Burkholder, 2014, 2016; Gachanja, Burkholder and Ferraro, 2014). The De Baets *et al.* (2008) article, based in Zimbabwe, is hypothetical in that it asks participants what they think they would do or what they think others should do rather than what they have actually done. Only 2 studies (although 6 articles) focus on experiences of mothers specifically rather than parents or caregivers (Rochat, Mkwanaazi and Bland, 2013; Conserve *et al.*, 2014; Rochat *et al.*, 2014, 2015, 2016, 2017). No articles specify that the children are seronegative (*i.e.*, the children’s statuses are unknown or a combination of negative and positive).

The majority of studies report qualitative methodologies, although three (De Baets *et al.*, 2008; Palin *et al.*, 2009; Osingada *et al.*, 2016) are quantitative and one is both quantitative and qualitative (Tiendrebeogo *et al.*, 2013). Some articles provide more detail on the specific methodology used; this information, where given, is included in Table 1 (above). Most of the literature is exploratory, with a focus on identifying key themes within the experiences of participants; many articles provide no details on how data was collected. Of those which do provide some detail, several (*e.g.*, Geiselhart, Gwebu and Krüger, 2008; Nam *et al.*, 2009; Palin *et al.*, 2009; Conserve *et al.*, 2014) were part of larger research projects. As such, the interviews were not tailored specifically to issues of disclosure, but deal with wider issues pertaining to living with HIV. For example, the aim of one research project was “to highlight changing inter-generational relationships and communication patterns in the wake of the HIV and AIDS crisis in Botswana and to identify the conflicts involved” (Geiselhart, Gwebu and Kruger, 2008:100). The qualitative study on which the Haitian article is based was part of “a larger feasibility study of a psychosocial support intervention for youth affected by HIV and their caregivers” (Conserve *et al.*, 2014: 2310) and involved participants who had declared suicidal thoughts, histories of abuse or being underfed. Some articles combine data from various projects and participant groups: for example, a Botswanan study includes 36 mothers, 14 fathers, 10 young

people, 11 households and 16 professionals (Geiselhart, Gwebu and Kruger, 2008). Similarly, Kyaddondo and colleagues' Ugandan study (2013) includes 12 in-depth interviews (with adults, young people and perinatally-infected young people), single-sex focus-group discussions, and open-ended survey questions. It is difficult to see exactly how this information was analysed and interpreted within the study as it was collected in different ways, using different methods and different participant groups.

None of the articles detail the way in which the interviews were set up or conducted or the power dynamic between the researchers and the participants. I will return to this later in the thesis as I think that it is an important consideration, especially in low income contexts or with participants who could be considered disadvantaged. This information would help to situate the research by providing an insight into power dynamics and underlying assumptions and how these impact on the research process. There is a lack of information on the impact of poverty and gender in the context of existing studies and limited appreciation of individual power and agency and how this is utilised, including where limited by poverty and other factors. With regard to understanding the experiences of participants, descriptions are sometimes superficial and do not explore participants' meanings in-depth. For example, children are 'too young' is often given as a reason for non-disclosure but this is rarely explored to investigate the potential meanings which may lie beneath this statement, such as possible parental uncertainty about whether or not they actually want to tell their children, the fact that they themselves are not ready to talk about it with their children or circumstances which mean that all of their energy is directed towards survival or care.

Examples of issues which affect parental disclosure that have been identified in the literature on LMICs (which are not or only infrequently identified in HICs) include: death/illness of multiple family members (*e.g.*, Moore, Kalanzi and Amey, 2008; Madiba, 2013) cultural concepts of the parent-child relationship as more authoritarian (Moore *et al.*, 2008); extended family networks (*e.g.*, Geiselhart, Gwebu and Kruger, 2008); high prioritisation of children's schooling (Gachanja, Burkholder and Ferraro, 2014a); witchcraft (Rwemisisi *et al.*, 2008); and difficulty challenging negative portrayal of HIV in national/community/school HIV education (Madiba, 2013; Muparamoto and Chiweshe, 2015). Issues which are mentioned in both settings but which may manifest themselves differently in LMICs include: Managing communication/emotions, preparation, partial disclosure, unplanned disclosure, practical assistance, concepts of childhood, and differential disclosure. Whilst many of the factors identified in HICs also hold true globally, the impact of additional factors including religion, culture, poverty, unemployment, lack of ARVs, violence, varied family structures and the ways in which these interact can have a

significant impact on how women experience HIV and their choices regarding disclosure. Although it is generally agreed that disclosure is beneficial in the long term to mothers, the particular circumstances of women in LMICs may make disclosure more challenging and less beneficial for many women. Global policies promoting disclosure (*e.g.*, WHO, 2011) may fail to take into account the realities of many women's lives and fail to recognise individual agency. Research extrapolated from HICs and applied directly to LMICs does not take into account the impact of culture or poverty. Research which is conducted in LMICs using patriarchal Anglo-Northern methodologies fails to account for power inequalities or alternative interpretations and so does not present a sensitive or nuanced picture of participants' experiences and views.

However, there are examples of sensitive and ethical practice. For example, Gachanja's research (Gachanja, Burkholder and Ferraro, 2014a, 2014b, Gachanja and Burkholder, 2016) was careful to protect children and their families from inadvertent disclosure during the research process. This was done by selecting children with partial or full disclosure of their own or their parents' HIV and children with partial disclosure of illness were interviewed "based on what illness (for example, tuberculosis or backache) those children knew they themselves or their parents were suffering from" (Gachanja, Burkholder and Ferraro, 2014a:3). Similarly, sensitive and nuanced findings are described in some of the more recent African research, which examines cultural factors, and the roles of parents, children and counselling in the era of HAART (Tiendrebeogo *et al.*, 2013); concepts of identity, family communication about sexual activity, and the desire to protect children from stigma and judgment (Muparato and Chiweshe, 2015); and concepts of childhood, family relationships, morality and practical considerations (Kyaddondo *et al.*, 2013). Interestingly, Palin *et al.* (2009) in their South African study identify closer parent-child relationships as protective whether or not the parents disclose and calls for interventions to support stronger familial relationships.

The majority of studies consider parental disclosure to be desirable and propose increased professional support to facilitate this. Interestingly, Palin *et al.* (2009) shift the focus away from professional interventions to promote disclosure. They found that strong relationships between mother and child and mother and other caregivers were protective for children whether or not mothers disclose and that interventions which intend to facilitate disclosure may be enhanced by a focus on strengthening relationships. Similarly, Kyaddondo *et al.* (2013) and Muparamoto and Chiweshe (2015) focus on emotions within considerations about disclosure, specifically the importance to parents of protecting parental identity and of protecting their children. The Amagugu Intervention articles (Rochat, Mkwanaazi and Bland, 2013; Rochat *et al.*, 2014, 2015, 2016, 2017) document a long journey to plan, design, carry out and evaluate a maternal HIV



disclosure intervention to young children in the South African context. Madiba and Matlala (2012) highlight the need to focus on the pros and cons of both disclosure and non-disclosure.

### **2.4.3 Findings: Themes and discussion**

#### **a) Reasons for and against parental HIV disclosure**

Table 2 (below) shows the reasons given by parents in African and Caribbean LMICs for disclosure or non-disclosure of parental HIV status to their children. The reasons participants gave for talking to their children about HIV tend to prioritise the rights and responsibilities of the child as an individual (*e.g.*, their right to know about their parents' health, their right to have the information they need to protect themselves from HIV or from the reactions of others, and their right to be prepared for future parental ill health or death). Other parents focussed on the importance of trust and openness for the parent-child relationship (*i.e.*, disclosing to protect their relationship by ensuring that the information comes from the parent) or in order to receive practical help from children. Less common reasons included a child accidentally finding the test result paper, guessing or being told by others, anger between parents or because of the encouragement of support staff. It is difficult to say whether these were welcome developments for parents who had wanted to disclose or additional challenges for parents who had not intended to disclose. Overall, it seems that parents who do disclose prioritised openness within the parent-child relationship and felt that children should be treated as independent and responsible.

Conversely, the reasons given for not telling children tended to be linked to parent or child emotional or developmental readiness, stigma/discrimination, uncertainty as to how to tell children or fear of damaging the parent-child relationship. The most common reason given for not telling children was that they are 'too young/immature', although perceptions of how old is old enough varied depending on the individual and the culture. In later chapters, I explore what this means in the Jamaican culture. Geiselhart, Gwebu and Kruger (2008:111, 112) state that it is not children who are too young but parents who are unable or unwilling to discuss their HIV with them. I propose that this apparently simple statement encompasses a wide range of emotions and beliefs about emotional and physical readiness, cultural concepts of childhood and the ability, willingness and scope of control that parents have or feel they have with regard to communicating with their children about their HIV within their particular circumstances and culture. Many parents were also concerned about how their child will react to the news, either because of their particular character, their age or stage of life (*e.g.*, school exams). Implicitly, this concerns how they as parents cope with their child's potential emotional reaction and whether/how this impacts on family life, school performance, *etc.* Additionally, some parents

recognised that they themselves had not come to terms with their diagnosis and were not yet ready to discuss it with their children.

There are a number of reasons given by parents which relate to fear of experiencing stigma or discrimination. The most common of these was the fear that the child would not keep the secret and that they would experience stigma and discrimination in the community or wider family. Some parents stated that they were afraid their children would judge/blame them for their own and/or family HIV. An unfortunate result of the increased education about HIV in the community and at schools is that the negative way in which HIV is often portrayed can make it more difficult for parents to disclose their status as they must also attempt to counter portrayals of HIV positive people as promiscuous or irresponsible and HIV as a fatal disease. Participants in a Togo study (Moore *et al.*, 2008) stated that it is none of their children's business, telling children serves no purpose, or it is difficult to tell children who do not live with them.

Parents who have not disclosed to their children gave another perspective related to parent-child communication by stating that they do not know how to tell their children. This is frequently interpreted in the research as a request for professional support to disclose. Rather than a request for help this may be a comment on how they feel about their status or how they feel about childhood and the type of information that can or should be communicated to a child. Some studies found that parents are afraid their children will think they are dying if they tell them. Some parents felt uncomfortable discussing HIV, sexual activity or sexual health with their children, although Madiba and Matlala (2012) found that parents do talk to their children about sexual health matters. It is possible that some parents wish to explore ways to teach their children about protecting themselves from HIV and other STIs without necessarily disclosing their own HIV status. Alternatively, parental statements about not knowing how to tell their children could be indicative of power imbalances within the research process and may also imply a tactful expression of their view that they do not want to tell their children. Parents may not have the emotional resources to support their child at that time. They may fear their child's reaction or the response of others and this fear may be well founded. They may have judged that because of some other factor(s) related to their community or society (*e.g.*, stigma, school exams, recent changes), the child (developmental stage, personality) or the parent (current pressures, parental support systems, how the parent currently feels about their diagnosis, parent's personality) that they do not wish to tell their children now or ever. A number of articles appeared to be making assumptions about what parents' decisions mean, without having explored this thoroughly with the participants. The tone of some articles seemed dismissive and judgmental, and implied that the researchers were imposing their world view onto participants

who may have a different perspective.

**Table 2: Reasons For and Against Disclosure given by HIV+ parents in Low and Middle Income countries in the Caribbean and Africa**

Related to....	Reasons for telling children	Reasons for NOT telling children
<b>Stigma/discrimination</b>	To protect children from the reactions of others	Fear child cannot keep the secret  Fear of being judged/blamed for own and/or family HIV  Fear of Stigma and discrimination  Difficulty challenging negative/judgmental view of HIV from school education or TV.
<b>Parental physical health/death</b>	To prepare children for parental death/sickness  To explain parental ill-health  To receive practical support from children	Do not want child to think parent is dying
<b>Child's physical health/medication</b>	To encourage HIV + children to take their medication	Might imply child is positive
<b>Child's autonomy/rights</b>	To encourage child to protect self from HIV  Child has a right to know	No perceived benefits to child of telling  It is not the child's business
<b>Parent –child relationship/communication</b>	To ensure information comes from parent  To protect parent-child relationship/reassure children  Confirming after child accidentally found test result or guessed or was told by others	Not knowing how to tell child- skills, support/subject inappropriate  Fear of damage to parent-child relationship (loss of power, respect or closeness)  Child does not live with HIV+parent
<b>Parent or child emotional or developmental readiness</b>		Child too young/too immature  Fear of negative impact on child/child's personality  Not ready- still managing own reaction
<b>Parental relationship difficulties</b>	Anger, relationship conflict with partner	
<b>External influence</b>	'Encouragement' from psychosocial support workers  Child told by others	

### ***b) The disclosure spectrum***

I introduced the disclosure spectrum in Section 1.7. In examining the LMIC parental disclosure literature, I found that some LMIC authors do distinguish between ‘full’ and ‘partial’ disclosure (*e.g.*, De Baets *et al.*, 2008; Gachanja, 2014; Gachanja, Burkholder and Ferraro, 2014a, 2014b; Gachanja and Burkholder, 2016) or ‘brief’ and ‘explicit’ disclosure (Conserve *et al.*, 2014). Nam *et al.* (2009) divided children into ‘told’, ‘not told’ and ‘thought to have guessed’. Similarly, Kyaddondo *et al.* (2013) wrote of ‘non-verbal’ disclosure methods such as leaving medication around the house, asking children to collect medication or accompany parents to treatment centres. Parents differed in whether they believed children in these types of situations have guessed or continue to be unaware of their parent’s status. None of these articles specifically mentioned differential disclosure and some excluded this possibility by asking respondents to focus only on one particular child (*e.g.*, Palin *et al.*, 2009, asked participants to focus on the oldest child in the age range 11–16). However, Rwemisisi *et al.* (2008) and Osingada *et al.* (2016) noted that parents have disclosed to all or some of their children, implying recognition of different approaches for different children. Similarly, Gachanja’s case study (2014) of a couple with 5 children found they had disclosed to only the oldest four children. Additional issues exist for parents with both seronegative and seropositive children. There is limited research examining whether parents disclose differently to children with different HIV statuses, although the issues of families with seronegative and seropositive children were recognised in the Gachanja articles (Gachanja, 2014; Gachanja, Burkholder and Ferraro, 2014a, 2014b; Gachanja and Burkholder, 2016).

### ***c) Cultural concepts of the family and relationships***

Several articles highlight the importance of family structure and relationships and recognise that in LMICs, for cultural or practical reasons, the wider family may play an especially important role (*e.g.*, Geiselhart, Gwebu and Kruger, 2008). The roles ascribed to mothers, fathers and other family members differ according to various factors including local norms, religion, culture, economic situation and the impact of HIV in that area. This has been recognised by a number of authors, who include both mothers and fathers (Rwemisisi *et al.*, 2008; Geiselhart, Gwebu and Krüger, 2008; Moore, Kalanzi and Amey, 2008; Madiba and Matlala, 2012; Tiendrebeogo *et al.*, 2013; Kyaddondo *et al.*, 2013; Madiba, 2013; Avornyo and Amoah, 2014; Gachanja, 2014; Gachanja and Burkholder, 2014, 2016; Gachanja, Burkholder and Ferraro, 2014; Muparamoto and Chiweshe, 2015; Osingada *et al.*, 2016); non-biological parents (Palin *et al.*, 2009; Osingada *et al.*, 2016); households (Geiselhart, Gwebu and Kruger, 2008); and community members (De Baets *et al.*, 2008) in their research. A number of studies interviewed

a range of participants, including parents, caregivers, wider family members, professionals, community members and children. It can be useful to get a wide range of perspectives on an experience in order to get an overview of the experience in that context; however, it can also mean that the details of that experience for a particular group can be lost, confused, misinterpreted or diluted. Because the mothering role, although in different forms, tends to be considered important throughout cultures and regions, my research focused specifically on the experiences of mothers, allowing for a depth which would not have been possible, had I interviewed a wider range of participants.

*d) Beliefs about the best age for disclosure*

Until recently, in LMICs, the focus in the literature has tended to be in areas where there are public health implications, such as disclosure to sexual partners or PMtCT. The significance of disclosure to children, particularly HIV negative children, has been less clear. The impact of disclosure on maternal health, on child health and on family wellbeing is challenging to assess, although there is some evidence, from African and Caribbean LMICs (*e.g.*, Geiselhart, Gwebu and Kruger, 2008 in Botswana) that disclosure does have a positive impact on maternal health. There are additional challenges in defining what is meant by the family and what is meant by a child. Although there are many types of family structure in high income, Anglo-Northern countries, the conventional nuclear family is often considered the norm; these assumptions have been critiqued by, for example, Craig and O'Dell (2010). Similarly, in other countries and cultures there is a wide range of socially accepted family dynamics: family structures vary according to factors such as religious and social norms, the position of women in that society, whether it is urban or rural, high or low income. Concepts of childhood also vary, depending on cultural and social factors and the topic being considered. These ideas will have an impact on whether and how parents decide to tell their children about their HIV status. Parents have different ideas of ages at which they consider their children able to understand disclosure information or the age at which they feel comfortable talking to their children about HIV.

Articles on parental disclosure in LMICs do not have a common age range for the children of participants (See Table 1, column 4 in Section 2.4.2 and Table 2 in Appendix III). Because of the range of ages of children in these articles and the fact that disclosure choices are not linked to child age, it is not possible to comment on parental views about disclosure and the age of children in Africa and the Caribbean. Where parents are asked what age they think is suitable to disclose to their own children, they often pick an adult or almost adult age, suggesting that it is something which they intend to do once their children have 'grown up'. For example, participants in Madiba's study (2013) said they intended to tell their children at age 15 and at

age 19; similarly, participants in Tiendebaego and colleagues' study (2013) stated that they would tell their children when they were 14–15 years old and when they were 'grown up'. Conversely, in one study (De Baets *et al.*, 2008), where parents were asked to comment hypothetically about disclosure age, they tended to choose younger ages, with over 63% of parents stating that children aged 7–8 years should be given some information about their parents' HIV status and more than 62% stating they believed that 13 year old children should receive full disclosure. This suggests that disclosure is easier to consider in theory or when thinking about what others should do, but harder to follow through in practice. This is supported by Gachanja, Burkholder and Ferraro (2014a) who found that participants recommended partial disclosure beginning at 5 years of age, with full disclosure at 10–14 years, although few parents in their study had followed through on these recommendations with their own children. However, the Amagugu intervention in South Africa (Rochat *et al.*, 2015) which involved 281 women with an HIV-negative child aged 6–10 years found that mothers were able to disclose fully to children as young as 6 and 7 years. In this intervention 61% of mothers fully disclosed and 39% partially disclosed to their children; children were found to respond with emotions and questions, demonstrating the ability of primary school age children to understand disclosure information. A follow up to this intervention (Rochat *et al.*, 2017) suggested that conversations about HIV and death may increase child resilience. Madiba and Matlala (2012) found that parents told their older children before their younger siblings. Osingada *et al.* (2016) found that Pentecostal parents, parents who had a friend or relative who had agreed to take care of their children and parents who were older and had lived with HIV for longer, were more likely to disclose to their children. Unexpectedly, they found that parents with tertiary education were less likely to disclose and speculated that this may be because they had more to lose in terms of social status (Osingada *et al.*, 2016).

*e) Beliefs about professional involvement in parental HIV disclosure*

A number of studies included data collected from professionals, including support group leaders (Kyaddondo *et al.*, 2013), healthcare workers (De Baets *et al.*, 2008), HIV support staff, NGO, religious and government staff (Geiselhart, Gwebu and Kruger, 2008,) and counselling centre directors and counsellors (Rwemisisi *et al.*, 2008). Findings on the expectations that participants have of professionals were very mixed. Some authors (Rwemisisi *et al.*, 2008; Nam *et al.*, 2009; Madiba, 2013; Muparamoto and Chiweshe 2015) found that parents disclosed specifically to ensure that the information comes from them and not somebody else. Madiba (2013) found that mothers and some fathers stated that they believed that disclosure information about parental or child HIV should ideally come from the mother. However, several studies found that participants requested help with disclosing or for professionals to counsel or disclose to

children. Madiba (2013:58) suggested that “Parental need for support provides an opportunity for health care providers to develop interventions to prepare parents to disclose their HIV status to children.” Some authors agreed that parents would benefit from professional support in exploring disclosure methods (Conserve *et al.*, 2014:2313); with “managing age-appropriate disclosure” and with supporting their children in developing life skills and sexual health knowledge (Nam *et al.*, 2009:389); as well as the extension of existing counselling support (Tiendrebaego *et al.*, 2013:57). Other authors suggested the need for further exploration and development of current counselling practices to “explore and reinforce parental disclosure to their children, key actors in care and treatment support” and suggested the development of programmes to counteract stigma and discrimination (Avornyo and Amoah, 2014), as well as interventions to equip parents with skills and knowledge to disclose to their children (Madiba and Matlala, 2012; Avornyo and Amoah, 2014).

Professional support to disclose is likely to be helpful to parents who wish to talk to their children about their HIV. However, there is a danger that this can be interpreted to mean that all parents should disclose and that services which do not pay careful attention to cultural assumptions and power inequalities might inadvertently pressure people to do so even in cases where it may not be in the best interests of the individual or their family. There is a risk that the voices of parents who choose not to disclose could be lost, misunderstood or disregarded. It is unusual in the literature to hear the voices of individuals who chose to take a different path from that which is encouraged by professionals. Giles *et al.*, (2009) describe an interesting and unusual example of a single woman in an Australian study (out of a sample of 45) who described how she chose not to accept all the PMtCT interventions offered to her. This is a reminder of the importance of research design which allows for unusual or unpopular views to be explored.

## **2.5 Chapter summary**

In this chapter I have presented three literature reviews, looking first at global review articles and HIC literature, then looking at literature from African LMICs up to 2012 and Asian LMICs up to 2017 and then focusing in more detail on the literature that is specific to Caribbean and African LMICs, up to 2017. I have sought to provide a different perspective from other review articles which tend to either focus on HICs (Hawk, 2007; Murphy, 2008) or combine LMICs and HICs (Obermeyer, Baijal and Pegurri, 2011; Qiao, Li and Stanton, 2011; RoCHAT *et al.*, 2011; WHO, 2011). The majority of the existing research has taken place in HICs, mainly the USA and Europe, which in addition to cultural differences, also have far more developed health

and psychosocial support systems. Research in HICs tends to come from a predominantly white, middle class perspective which does not recognise the challenges of the social and economic position of women, including poverty, violence, and complex family dynamics which are common in many LMICs. As a result of the lack of research into parental disclosure of HIV to children in the Caribbean (limited to a single article, Conserve *et al.*, 2014), I was forced to expand my search to LMICs globally, and included articles from LMICs in Africa in order to begin to identify some of the issues Jamaican mothers might encounter when considering disclosure of their HIV to their children. In addition, I wanted to explore the approaches and theories used by authors to investigate issues of HIV disclosure and non-disclosure.

In this chapter I have argued that the existing literature on maternal disclosure is limited in terms of both location (*i.e.*, very limited research in LMICs, particularly the Caribbean region) and in its focus (*i.e.*, most research in LMICs looks at parents/caregivers rather than mothers and combines both seronegative and seropositive children). Much of the research presents disclosure as a binary (either women do or do not disclose) and uses, from a feminist perspective, Anglo-Northern patriarchal approaches (discussed in Chapter 4) to research and interpret disclosure behaviour, without including women's own perspectives or acknowledging wider social and cultural factors. The majority of the research in LMICs in Africa and the Caribbean does not explicitly address issues of power and difference within the research process (*e.g.*, Conserve *et al.*, 2014). I suggest that this is as a result of applying HIC research recommendations to LMIC contexts without fully considering the impact of structural and contextual issues on participants' lived experiences, combined with a lack of reflexivity and awareness of power inequalities. This is evident in guidance from international bodies such as the World Health Organisation (WHO, 2011) which advises that children of school age are told their own and their parents' or caregivers' positive HIV statuses despite 'absent' or 'low quality' evidence from LMIC settings. Much of the existing research begins with the assumption that disclosure is desirable and beneficial, focuses on rates of disclosure, and the reasons which parents give for and against disclosure; these reasons are rarely explored in-depth. Few studies explore the social, cultural or emotional factors which influence disclosure decisions or recognise the challenges inherent to resource constrained settings. In this thesis, I contend that existing literature is often underpinned by Anglo-Northern and androcentric approaches based on assumptions about the nuclear family structure and the benefits of disclosure, which may not be relevant to women living in resource constrained contexts. I attempt to counter this by using a feminist approach, with attention to reflectivity and power dynamics; this is discussed in more detail in Chapters 4, 5 and 6.



I now return to the question posed in the introduction to this literature review: How relevant or useful is existing maternal disclosure guidance for HIV positive Jamaican mothers? Many of the recommendations offer vague suggestions, such as “culturally-appropriate” programmes (*e.g.*, Dane, 2002; Thomas, Nyamathi and Swaminathan, 2009), with little advice that is specifically applicable to Jamaica or other low and middle income countries. Jamaica is a small island state with a very specific culture as a result of historical, social and economic factors. In this thesis I build on existing work, which has identified the issues which are of relevance to parents living with HIV globally and the more recent qualitative work which has started to identify some of the issues which are more relevant to families in LMICs. Additionally, and unlike the majority of existing articles, I focus specifically on the views and experiences of mothers in order to explore the links between HIV disclosure, mothering and emotion work in the Jamaican context. In this chapter I have argued that the existing literature is limited in terms of geographical location and does not illustrate the complexity of views and experiences of mothers’ communication about their HIV with their children. In order to challenge these limitations, my research uses feminist IPA (discussed in Chapter 5) to explore and interpret the experiences of a small homogenous group (HIV positive mothers) in a specific geographical location (Kingston, Jamaica). The next chapter provides contextual information about HIV and mothering in the Jamaican context.

## **Chapter 3: Mothering with HIV in the Jamaican context**

### **3.1 Introduction**

As discussed in Chapters 1 and 2, policy (*e.g.*, WHO, 2011) and research (*e.g.*, Geiselhart, Gwebu and Krüger, 2008) on disclosure of parental HIV to children is based on Anglo-Northern assumptions that disclosure is positive and beneficial to parents and children. This concept originates from high income, highly resourced countries, which place a high cultural value on openness and honesty and which have resources such as counselling services to provide support. Regarding HIV disclosure, this view appears in the development of resources encouraging and supporting disclosure within the family (*e.g.*, UK Family Project, 2008). Much of the research and recommendations for LMICs has been extrapolated from findings in HICs (*e.g.*, Rochat *et al.*, 2011) and is underpinned by assumptions about the traditional, white, middle class, two parent, heteronormative, nuclear family and the mother-child dyad. How disclosure is experienced may be very different in a resource constrained setting and within alternative family formations. My aim is to highlight the very different family formations in Jamaica and problematise these assumptions by providing an historical and contextual overview of Jamaican mothering in the HIV context. The middle class nature of the image of the idealised mother requires an analysis of the economic and social context of parenting which also informs the good/bad mother dichotomy: it is easier for highly resourced mothers to live up to (or appear to live up to) images of the idealised mother.

This chapter explores the issues affecting the experiences of the women I interviewed, including poverty, assumptions about mothering roles, marriage and female-headed households, violence and migration. I introduce the concept of young motherhood in Jamaica because, while all the women I interviewed were aged over 18, many had become mothers at a young age. This chapter provides contextual information about some key social, economic, and historical factors affecting the lived experiences of HIV positive Jamaican mothers, thus situating the women's views and experiences and the themes I identify later in the thesis.

### **3.2 Jamaica: brief historical & geographical background**

Jamaica is a small island state, with a geographical size of 10,991 square kilometres, though much of the inland area is mountainous (including the Blue Mountain and John Crow ranges) and covered with nearly-impenetrable terrain such as that of Cockpit Country (Statistical

Institute of Jamaica, 2017). The population is concentrated in coastal areas and numbered 2,730,894 people in 2016, with 670,810 in the parishes of Kingston and St Andrews (Statistical Institute of Jamaica, 2017). The country is divided into 3 counties (Cornwall, Middlesex and Surrey) and 14 parishes (Statistical Institute of Jamaica, 2017). The small size of the Jamaican population has an important impact on the HIV response. In a positive sense, the small population has made HIV testing, treatment and follow up relatively straightforward, but it can mean that people living with HIV are fearful about confidentiality issues, leading them to avoid seeking medical treatment or to travel long distances to do so. This can affect the frequency and quality of their medical visits, as well as being expensive and having an adverse effect on their work and family commitments. My research took place in Kingston, although several of my participants travelled for 2–3 hours to access services there.

Jamaica obtained independence from British colonial rule on August 6<sup>th</sup>, 1962 and remains a member of the UK Commonwealth (Senior, 2003:242), a group of 52 countries, mostly former territories of the British Empire. Commonwealth countries are united by language, history, culture and shared values (*e.g.*, democracy, free speech, human rights and the rule of law) rather than by legal obligation (The Commonwealth, no date). The legacy of colonialism is evident in Jamaica in numerous ways, including the ethnic makeup of the population, descendants of African slaves, white European slave owners, the original Arawak residents of Jamaica, and Chinese and East Indian indentured labourers (Senior, 2003:243). All of these groups have influenced modern day Jamaican culture, food and language. In addition to English, most Jamaicans speak Jamaican Creole, usually referred to as Patois or ‘Patwa’. Jamaican Patois is a language which has evolved over many years and fuses traditional British English with traditional West African dialects and includes words from Spanish, Portuguese, Hindi, and Arawak. Jamaican Patois has quite different grammatical structures from British English, and when spoken fast, as it usually is, it can be difficult for an English speaker without prior exposure to Jamaican Patois to understand. I will discuss issues of language in detail in Chapters 6 and 10. Skin colour and ethnic origins continue to have an impact in Jamaica today. Despite the Jamaican motto “Out of many, one people” (Senior, 2003:349), wealth and privilege continue to be concentrated amongst those with lighter skin, spawning a host of recent blogs on the shifting complexities of being a white/brown/black Jamaican (*e.g.*, Lyon, 2014; Miller, 2014) and comments in the national press such as: “Thereafter, in Jamaica, the 'haves' have been light-skinned while the 'have-nots' have been dark skinned” (Espeut, 2010).

Jamaica has a hot climate throughout the year with hurricane season lasting from November to June, bringing frequent tropical storms and occasional hurricanes. Dengue fever and other

mosquito borne illnesses are common during the wetter months and present a challenge to public health services. Recent hurricanes which have caused significant damage, loss of livelihood and some loss of life, include Hurricane Ivan (2004), Hurricanes Dennis and Emily (2005), Hurricane Dean (Category 4, 2007), and, a few months before I carried out my interviews, Hurricane Sandy (October 24th, 2012). In Jamaica, Hurricane Sandy killed one person and caused damage estimated at the equivalent of about USD 55.96 million (ODPEM, 2013). Electricity supplies were severely disrupted, many houses lost their roofs (including at least two of the women whom I interviewed) and important crops such as banana and plantain fields were destroyed. Tropical storms can also cause significant damage: Tropical Storm Nicole hit Kingston on September 28th, 2010, shortly after my family and I arrived in Jamaica, with heavy rain of 940mm causing severe flooding, destruction of houses and water pollution. This storm caused approximately USD \$239.6 million in damage and losses, killing 16 people and injuring 42 people (PIOJ, 2010). Events such as these highlight the inequalities in Jamaican society: wealthier residents are able to stock up on food, water, candles, batteries, and are protected by better quality housing. Unlike some of the women I interviewed, my home was not located in a flood-prone area. Although I felt vulnerable in some senses (*e.g.*, for Tropical Storm Nicole, I was newly arrived in Jamaica, with limited support networks, I was unsure of what to expect, I was pregnant and, with my husband travelling, sole carer for two toddlers), we lived in a safe, well-constructed house, had hurricane shutters, a back-up generator, access to drinking water and money to buy emergency supplies and to take care of repairs had they been necessary. Two of the women I interviewed in December 2012 had been unable to properly repair or replace their roofs which had been severely damaged by Hurricane Sandy, more than 6 weeks previously.

### **3.3 Parenting in the Caribbean**

A number of well-known Caribbean authors (Marshall, 1959; Kincaid, 1983; Danticat, 1994; Adisa, 2013:67) have compared the Caribbean mother-child relationship to the coloniser-colonised relationship. In an interview with Eleanor Wachtel, Kincaid states: “The truth is that the legacy of colonialism everywhere is cruelty and brutality and theft. What the colonizers did in a mild way we now do to each other in an exaggerated, grotesque way” (Wachtel, 1996:58). Caribbean parenting is generally described as authoritarian (Evans and Davies, 1997), characterised by domestic violence, poor communication (between parents as well as between parents and children) and absent fathers (Chevannes, 1999). Authors write of a communication style that can cause shame and result in low self-esteem (Bailey, Branche and Le Franc, 1998), as well as parents complaining about children asking too many questions (Evans and

Davies,1997). Poverty and lower levels of parental education are linked to more restricted parent-child interaction (Leo-Rhynie, 1996; Rickets and Anderson, 2005). These factors are likely to make talking to children about maternal HIV more challenging, and an awareness of this context highlights the disconnect between policy expectations and the reality of women's lives. Conversely, parents who are more educated have been found to communicate and reason with their children more and to use varied (including non-physical) forms of discipline (Leo-Rhynie, 1996). In a session I delivered on parenting with young HIV positive mothers in 2011, the young women described hitting babies or very young children in an attempt to discipline them. The other issues raised by the young mothers during this session (baby safety issues, financial challenges and strategies, dealing with a clingy baby, challenges of juggling child care and paid employment) give us an insight into some of the difficulties experienced by these young mothers, in addition to managing their own (and sometimes their child's) HIV.

Democratic or positive parenting (*e.g.*, Nelson (1981) based on Adler's (1870 – 1937) concepts of natural and logical consequences, encouragement and mutual respect, currently popular in Anglo-Northern countries) focuses on supporting children to understand and express their emotions and opinions, and respects children's voices as "meaningful contributions to family discussions" (Berkowitz and Grych, 1998:385–6). In the Caribbean generally, parenting tends to be more traditional or authoritarian (Baumrind, 1966, 1967) and children are often expected to be quiet, obedient, and respectful. Shorey-Bryan (1986:69) argued that the key values that Caribbean mothers work to instil in their children are "respect for elders and sharing within families". A parallel can be seen with traditional parenting philosophies in the Anglo-North, where children were expected to be 'seen and not heard' until intensive parenting became popular from the 1960s onwards. Intensive parenting can be defined as a style of parenting that is "child-centered, expert-guided, emotionally absorbing, labor intensive, and financially expensive" (Hays, 1996:8), involving anticipatory problem solving and increased enrolment in structured activities for even very young children (Hays, 1996). Although democratic and intensive parenting are distinct, and may exist independently, many parents who engage in one, do also adopt the other. It has also been noted that there is often a class element to parenting approaches, with working class women, as well as having different life demands on their time and energy, also having a different style of interacting with their children (Nelson, 2010). These authors are writing from an Anglo-Northern perspective and it was notable that, with the two women who brought their toddlers into interviews, it was I who talked and interacted with the toddlers. At the time I had a daughter of a similar age and did so almost without thinking. The women held their children and were attentive to their basic needs, but did not interact, play with, stimulate or attempt to distract them; they expected the toddlers to sit quietly while we, the

adults, talked. In this, they may have been showcasing their good mothering skills through their expectations that their small children would be quiet, obedient and well-behaved.

In situations where communication is limited to more practical aspects, mothers are likely to find it challenging to talk about sex or HIV with their children. At some point (depending on the culture) children cross from childhood to the adult sphere and communication styles may change; although talking about difficult topics can continue to be challenging if the groundwork has not been laid in childhood. The difficulties that women experienced in beginning or maintaining a conversation about their HIV status are discussed in more detail in Chapters 7–9; examples of more open and collaborative parenting styles are also addressed.

### **3.4 Mothering in the context of poverty**

#### **3.4.1 *Poverty, mothering and HIV***

Poverty has important implications for families and impacts on mothers' experiences and options; these may be amplified for mothers who are also living with HIV. It is arguably more challenging for women mothering in poverty to conform to the idealised mother narrative. According to the World Bank, Jamaica was classified as an upper Middle Income Country (MIC) in 2007. This classification has serious consequences for Jamaica's ability to access funding: an 'upper middle income' classification implies a greater level of prosperity and equality than actually exists in many areas, as noted by NGOs: "The term 'middle-income' is an artificial classification that is not linked to public health realities on the ground" (Médecins Sans Frontières, 2015). It assumes that basic necessities are met, yet currently, according to Médecins Sans Frontières (2014), 75% of the world's poor live in countries classified as Middle Income countries, which makes the classification system illogical and impractical. A practical example of the impact of Middle Income classification for HIV services can be seen through the use of tiered pricing systems by pharmaceutical companies. Atripla (a brand of a commonly used first-line HIV treatment) costs US\$ 613 per patient per year in Low Income Countries but at least US\$1033 per patient per year in Middle Income countries (Médecins Sans Frontières, 2014). As a result of donor reliance on World Bank classifications to reduce financial assistance, increasingly, Middle Income Countries, which have the highest proportion of people living with HIV, are also receiving less funding, making it increasingly challenging to combat HIV (NGO Coalition on the World Bank MIC Classification, 2015).

Poverty also has important implications for the work of HIV agencies. For example, some professionals talk about the tensions of working with people living in poverty, where what is

intended as a small compensation can unintentionally become an incentive for a particular behaviour. For example, HIV positive women may be willing to disclose to their families (or say they have) in order to acquire goods or services from the agency involved, if that agency launches a programme to promote disclosure. Other examples from HIV professionals include the shift in experience whereby PLWHIV are able to access effective medications and live longer, healthier lives, and have inadvertently become the provider for their family through their involvement with HIV projects which provide them with stipends or meals for attending events and sharing their experiences of living with HIV. This can cause family tensions in cases where the PLWHIV was willing to do this for a short period as they thought they would die, but does not wish to continue long term once their health improves. Conflict may also occur where families, dependent on this contribution, pressure family members living with HIV to access funds or goods or abandon their HIV positive relative if they become sick and unable to do so. This issue can also arise when making decisions about appropriate payment or compensation for taking part in research, where poor women may make decisions based on their need for food or money. There are several anecdotes about women who stopped using HIV support services once those services ran out of funding and were no longer able to provide food, (for example, Interview 11, Anna, 127), implying that women's needs are often mainly practical and that some of the support services provided become hoops that the women have to jump through in order to access the practical support they need. Organisations and researchers should be careful that what is intended as small compensation does not become accidentally coercive; I discuss my approach to interview compensation in Chapter 6.

HIV relates to poverty in complex ways, particularly where women keep their HIV status secret from the community or family members. In the context of Jamaican healthcare, where frequent appointments are required, accessing prescription medication requires a complex bureaucratic process, and waiting times are often long; this can present a time intensive and costly challenge for many women. Several times at healthcare conferences in Jamaica, I heard professionals assert that patients are happy to wait as they use this time to socialise. In the HIV clinic where I conducted my interviews, I saw no examples of patients socialising and it seems presumptuous and unrealistic to assume that patients are happy to spend a significant part of their day in clinics waiting for appointments. It seems to me more likely that patients accept long waiting times as part of the process of accessing medical care and that, in some settings, they make the best of it by chatting with other patients. The reality for many women is that time spent waiting impacts negatively on their livelihoods by jeopardising short term insecure work, either through requesting time off, or, more directly, in the case of 'higglers' (those who sell foodstuffs or

other items on the street or in marketplaces (Senior, 2003: 230–231)), where time away from selling is money lost.

### **3.4.2     *Poverty, education and young motherhood***

Although living conditions for many in Jamaica have improved, with the percentage of people living in poverty declining from 19.9% in 1997 to 9.9% in 2007, there continue to be particular areas of concern (including HIV, violence, disabled children in care and on the street) and additional challenges resulting from the global economic crisis (UNICEF, 2009a). Children are disproportionately affected by poverty with one in every four children in Jamaica living in poverty (UNICEF, 2009). My study participants were women who could be considered to be living in poverty. I did not formally collect information on income or living conditions, but the women described challenges with funding small expenditures such as bus fare and school lunches, and described themselves as not currently working or in low paid, insecure work such as ‘higgling’ (Senior, 2003: 230–231).

In Jamaica, access to education is high: access to primary schooling is 99.7 per cent and secondary schooling is 83 per cent (UNICEF, 2010). Despite this, educational achievements are relatively low, especially amongst children from the poorest communities with high levels of violence. There are concerns that attendance is lower for boys and that violence and supplementary school costs negatively affect attendance (UNICEF, 2009: 8–9). Education is seen as a priority by mothers, although the practicalities of ensuring attendance and meeting associated schooling costs are a challenge for many. Meeting their families’ basic needs (food, shelter, education), whilst juggling income generation and childcare is a complex affair, further complicated for mothers with HIV who have additional health related costs and practical issues, as well as emotional ones. Jamaican women consider their responsibility for their children's schooling to be crucial, linked as it is to their future prospects. An additional threat to the educational prospects of female children is the frequency of young motherhood (UNICEF, 2010), an occurrence which, although in many ways both normalised and common in Jamaica, is often responded to in Jamaican society with shame and condemnation (Watson and Crawford, 2011). Mothers warn their daughters against young motherhood, despite being unable to address the root causes, including poverty, violence, and lack of power. I will return to issues of poverty in my later analyses of women’s accounts, particularly in Chapter 7.

Baumgartner *et al.* (2009:21) classify teenage pregnancy in Jamaica as a “major public health problem”. Teenage pregnancy contributes to lower educational achievements, higher unemployment and higher child and maternal morbidity and mortality, according to studies in



the US, sub-Saharan Africa and South America/the Caribbean (Buvinic, 1998; Zabin and Kiragu, 1998; Albert, Brown and Flanigan, 2003). However, pregnancy is sometimes seen as a way of increasing status: Leo-Rhynie (1996) finds that in some rural areas in Jamaica, girls aged over 17 who have not yet had a child are encouraged not to use contraception and are called “mules”. A United Nation's report (2000) attributed poor parenting and dysfunctional children to the high levels of young parenthood in Jamaica. Watson and Crawford (2011) found evidence that young mothers were treated badly by hospital staff during labour and delivery: “They treat you like dirt” (Watson and Crawford 2011:16). Many mothers are keen to avoid their daughters becoming pregnant during their teens and encourage them to focus on school. Despite this, the teenage pregnancy rate in Jamaica is high: pregnancies among girls 15–19 accounted for 18 per cent of live births in 2008 (UNICEF, 2010). In 2012, the year I carried out my interviews, the adolescent fertility rate (births per thousand women aged 15–19 years) in Jamaica was reported to be 64, compared to 18 in the United Kingdom (World Bank, no date).

The fact that so many women become mothers for the first time whilst they are teenagers (UNICEF, 2010) highlights a number of issues within Jamaican society. Motherhood is highly valued (Ellis, 1986), leading some young women to seek out early motherhood as a way of raising their status (Leo-Rhynie, 1996). Furthermore, sexual violence (UNICEF, 2011) and skewed power dynamics in Jamaica give women only limited control over their own sexual activity: The Jamaican Ministry of Health found that “over 33 per cent of girls and 18 per cent of boys aged 10–15 did not consent to their first sexual encounter” (reported by UNICEF, 2011:4). Additionally, this report finds that “37 per cent of sexually active respondents had engaged in sex in exchange for money or gifts in the past 12 months and 43 per cent had not used a condom the last time they had sex” (UNICEF, 2011:4). Young motherhood is normalised in Jamaica due to its frequency and, despite maternal aspirations for delayed motherhood for their daughters, sex education within the family is limited (Lawson, 2013). Becoming a young mother adds significantly to financial challenges for the mother and often also for the child's grandmother(s) and other female relatives. It is difficult for young mothers who have not completed their education to access employment opportunities and childcare presents an additional challenge.

### **3.5 Role of mothers in Jamaica**

The concept of motherhood and mothering in the Jamaican context is key to my research, which looks at the experiences of mothers specifically. However, the majority of debates about mothering and motherhood have taken place in Anglo-Northern countries, where concepts of

individualism, the mother-child dyad and the nuclear family are prized (*e.g.*, intensive mothering, Craig and O'Dell, 2010). Mothering has been defined as the individual relationship between a mother and her child/ren (Rich, 1977). An important factor in the Jamaican and Caribbean context is a wider definition of the mothering role to include surrogate mothering, mothering by maternal grandmothers and mothering within a network (rather than within the idealised nuclear family structure in the Global North). Assumptions of the nuclear family are predicated on the hetero-normative family unit with a married mother and father, and male breadwinner. Hodge (2002) explains the futility of assumptions about women beginning to work outside the home, single parent families, and men as breadwinners within the context of the Caribbean society. In the Caribbean, Hodge (2002) argues, women have always worked, there is little focus on the nuclear family, children are brought up by family networks, and breadwinners are both male and female. Momsen (2002) argues that, as a result of the legacies of colonialism, although Jamaica remains in many ways a patriarchal society, there are nonetheless many contradictions and complexities of mothering within a structure of (predominantly) male power and violence. However, the mother's role carries power and status and mothers are expected to be independent, resourceful, providers and protectors (like Nanny Maroon, a powerful and popular symbol of Jamaican women's courage and determination (Senior, 2003: 343–4)).

### **3.5.1     *Marriage and the idealisation of the nuclear family***

It is relatively unusual in Jamaica and especially amongst poorer sectors of the community for people to be married. According to the Statistical Institute of Jamaica, the marriage rate in Jamaica in 2009 was 7.94 per 1000 population (Statistical Institute of Jamaica, 2017). In the same year in the UK, the marriage rate was 21.3 per 1000 for men and 19.2 per 1000 for women (The Office for National Statistics, no date). It is common to hear Jamaicans refer to the other parent of their child as their “biebifaada” (babyfather) or “biebimada” (babymother)<sup>4</sup>. The linguistics professor Peter Patrick states that the terms are often used to refer to partners with whom one is no longer involved or married to and tend to imply a merely biological relationship (Turner, 2006).

Despite the high incidences of unmarried mothers, absent fathers and multiple babyfathers seen in Jamaican society (Jamaican National AIDS Committee, 2002), the nuclear family structure continues to be seen as desirable by some individuals, who aspire to marriage. This belief is also echoed by some policy makers. For example, the Jamaican National AIDS Committee (2002:12) quotes the UN & Partners Theme Group on HIV/AIDS as ascribing a breakdown in

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<sup>4</sup>According to Turner (2006), the first recorded citation of the term ‘babymother’ is from the Kingston Daily Gleaner in 1966.

“family structures and values” to a “lack of positive parental role models” and “a total breakdown of the nuclear family, with the majority of low-income households headed by a single female parent who is often indifferent to, or encourages daughters to have sex with older men.” The report goes on to state that “The Theme Group ascribes the lack of parenting skills to teenage pregnancies and early fatherhood, which leads to a self-perpetuating cycle of unskilled parents and socially and emotionally dysfunctional children” (Jamaican National AIDS Committee, 2002:12). Dreher and Hudgins (2010), whose work is discussed in the next section (3.5.2), challenge the assumption that the nuclear family and marriage are necessarily beneficial to children, and trace these policy assumptions back to colonial times. In 1938, British Parliament appointed a Royal Commission, which “made recommendations to address the ‘disorganisation’ of Jamaican domestic life and apparent ‘promiscuity’, resulting in a preponderance of ‘illegitimate’ births” (Dreher and Hudgins, 2010:503), and leading to the Mass Marriage Movement which aimed to legitimise common-law relationships.

This idealisation of certain forms of motherhood continues in Jamaica as in the UK (Craig and O’Dell, 2010). The concept of who is ‘fit to parent’ (Alldred, 1996) could be extended to Jamaica and may serve to demonise young mothers and HIV positive mothers (Watson and Crawford, 2011) who are seen as unfit parents, not just because of their age and possible health issues, but also because HIV is viewed as unclean and immoral (Sontag, 1991; Berger, Ferrans and Lashley, 2001; Wolitski *et al.*, 2009). These judgments make talking to children about maternal HIV even more challenging: how does a mother navigate the discussion of maternal HIV with the very children whom society does not believe she should even be allowed to have? Silva and Alexander (2013:x) write of the importance of including issues which are specific to Caribbean mothers: “the dichotomies of maternal power and loss, binary of maternal loving and loathing, and mobility and restriction as fundamental aspects of the Caribbean’s colonial history.” Authors such as Gustafson (2013:24–30) challenge the use of simplistic binaries such as the ‘Good’ mother/‘Bad’ mother to represent women. This thesis will go beyond this categorisation and present a more nuanced picture of women’s experiences, exploring the ways in which mothers respond to these judgments, either by exerting their agency and challenging them or by presenting themselves as ‘good’ mothers, despite factors which society typically uses to discredit them.

### **3.5.2 *Female-headed households in Jamaica***

Dreher and Hudgins (2010) wrote an interesting article about the economic and educational benefits to children of belonging to a female-headed household with multiple babyfathers as compared to being in a more conventional nuclear-family arrangement. This study follows 59

Jamaican mothers and their children from birth to age 5. Assessments, adapted for the Jamaican context, included: a measurement of the extent to which the household is supportive of the child's development; an assessment of general cognitive index (similar to IQ), height/weight ratio and school attendance. The authors found that unmarried mothers and multiple, absent babyfathers do "not necessarily result in poorer developmental outcomes for preschool-aged children" (Dreher and Hudgins, 2010:495). They propose that this family structure, is, in fact, "a strategic adaptation to the conditions of poverty that may [...] provide developmental advantages for poor children in rural Jamaica" (*ibid*:495). Dreher and Hudgins (2010) illustrated this using some powerful comparative case studies demonstrating that, in the Jamaican context, the nuclear family structure may actually be disadvantageous to children. In their study, the children in a traditional nuclear family unit score much lower on school attendance and measures of child development, compared to a female-headed family structure with multiple, absent babyfathers. The authors suggest that the latter family structure confers a number of advantages, including increased access to financial and practical resources via each babyfather as well as practical and childcare support provided by maternal and multiple paternal grandparents.

Although this study looked specifically at rural families in Jamaica, I think they are also relevant to poor urban families in Jamaica. These findings challenge assumptions that marriage and male-headed households (*i.e.*, the conventional nuclear family assumed by many Anglo-Northern writers) provide the best social and academic outcomes for children (*e.g.*, Moynihan, 1965). The Moynihan Report (1965) has been used as a basis to judge and demonise family structures which include absent fathers, unmarried mothers, and female headed households as found within many Black communities across the world. The concepts of stigmatised mothering identities and issues of regulating women's sexuality are also found in the UK (Alldred, 1996; Craig and Scambler, 2006) and these attitudes have implications which can be applied to a range of settings. HIV positive mothers in Jamaica struggle to preserve a positive mothering identity in the context of HIV, a stigmatised disease. Nuclear families, male-headed households and married parents are not typical family formations in many parts of the world, including Jamaica; policies which reflect and respect diversity in familial formation may have wider applicability to families organised in different ways. Dreher and Hudgins (2010) find that, in rural Jamaica, women have developed strategies which are, in fact, often more successful than the nuclear family model, in supporting the physical, academic and emotional development of their children. This acknowledgment has potential implications in other Jamaican and Caribbean settings, as well as farther afield: arguably the nuclear family model no longer applies nor is seen as desirable in many settings, as, increasingly, single parent families, same-sex parent

families, merged families, and extended families are the norm (Alldred, 1996; Craig and O'Dell, 2010).

The centrality of mothers to Jamaican culture and the structure of family life is illustrated in these reflections of a Jamaican mother: “The home is nothing without the mother—and the grandmother— there” and “the idea that the mother knows what is best for the family and the mother takes the lead in doing what is best”(Ali, 2010:233). In Jamaica, as in much of the Caribbean, becoming a mother offers an opportunity for increased social status and female agency (Ellis, 1986). The flexibility inherent in the role of Caribbean motherhood leads to wide variation in family structure and mothering roles and the importance of the mothering role (as compared to the role of wife/partner) can reduce female subordination (Silva and Alexander, 2013:viii). Adisa (2013: 45) describes the range of emotions inherent to the typical depiction of Caribbean motherhood: fierce love, absolute selfless commitment to children, determination and hard work, strict and demanding obedience, mother as “provider and protector”. These depictions provide insight into the mothering characteristics which are valued (strength, hard work, perseverance) and those which must be avoided (neglect, laziness, lack of attention to children’s long term well-being).

### **3.5.3     *The role of men and fathers in a matrifocal society***

Jamaica is generally understood to be a matrifocal society, meaning women as household heads, although Senior (1991) has problematised how household heads are identified. Rowley (2002:24) sees matrifocality as implying a “cultural and affective centrality of women within their kinship group” and that in the Caribbean context it is possible for matrifocality to exist even where men are present. Matrifocal households can be seen as “economically optimal” (Morrissey, 1998:81), because, as a result of the economic situation, men were unemployed or underemployed and unable to fulfil the traditional economic role of man-as-breadwinner and thus became a drain on resources. Mothers (or often networks of women) were therefore primarily responsible for providing for their children. Whilst agreeing that many households are matrifocal (due to mothers’ economic responsibility and control of relationships), Morrissey (1998) critiques this view as overly simplistic. She sees it as not fully taking into account men’s role in families— through financial contributions (as a result of migration or local employment) and through social or emotional support provided by the father or the father’s family. This is supported by a 2006 Jamaican study which found that although just over 40% of children lived apart from their fathers (usually because the father had migrated or the parental relationship had broken down), 81% of fathers provided financial support and 74% provided emotional support (Brown and Williams, 2006). Fathers, including those who are absent, may contribute

financially and in-kind to their children's upbringing. However, this contribution may be sporadic and may only apply to biological children.

Fathers' emotional involvement is harder to measure. A study of University of West Indies students reported "poor emotional relationships" between Caribbean fathers and their children and suggested that "matriarchal households, male absenteeism and extramarital relationships" (Sharpe, 1996:261–262) were normalised and cyclical through generations. However, I think that the phrase 'extramarital relationships' has unhelpful moral and religious undertones and is out of place in a society where marriage is neither the norm nor the ideal for many. Furthermore, Senior (1991:96) critiqued the "glib" use of the adjective "matriarchal" in the Jamaican context, suggesting that its use helps to perpetuate assumptions about black women as strong or "dominant". These comments illustrate some of the complexities of parental relationships and parents' support of their children. The picture is further complicated in that some literature makes assumptions about normative familial formations, portraying male authority within the family as the 'ideal' (Momsen, 1993). Other literature recognises that families may move in and out of matrifocal households depending on economic circumstances (Morrissey, 1998), and identifies reasons why female-headed households may be beneficial to women, in terms of status (Rubenstein, 1987), freedom from violence (Morrow, 1994) and increased family and community support.

### **3.6 Violence**

Violence is a major issue in Jamaica. With a homicide rate of 36/100,000 in 2014, Jamaica has one of the highest per capita national homicide rates in the world (Overseas Security Advisory Council, 2015). For comparison, the homicide rate in the UK for 2013 was 1/100,000 (World Bank, 2013). There were 1200 murders in Jamaica in 2013 and 1005 in 2014 (*ibid.*). Other violent crime reported in 2014 included: 1,227 shootings, 580 aggravated assaults, 792 rapes, 2,631 robberies, 2,443 break-ins (*ibid.*). The population of Jamaica is small (approximately 2.7 million people) and much crime goes unreported, or, for example, in the case of rape, unrecognised. The poor are heavily affected by violence, partly because it is expensive to protect oneself. Those with access to more resources live in safer, more expensive areas (often in gated compounds), install metal grills, employ security patrols (often armed and with dogs), avoid dangerous areas and drive rather than walk or use public transport. This is echoed in a report by the Human Rights Watch: "High levels of violent crime, public mistrust of police, low levels of crime reporting, low prosecution rates, and a perception that the criminal justice

system is skewed against the poor are widespread in Jamaican society” (Human Rights Watch, 2014:2).

Violence was not explicitly mentioned in detail by any of the women I interviewed. However, several women made passing reference in an understated way to examples of violence they had experienced. Had I not been aware of the very high levels of violence in Jamaica, I might have missed these references altogether. Violence is so widespread and ubiquitous, that it is often taken for granted and not specifically referred to. However, the threat of violence permeates the lives of everyone in Jamaica, particularly the poor and vulnerable and it affects everyone’s behaviour and choices as they seek to protect themselves and their families. Fear of violence affects where people choose to go, and at what time of day, the instructions they give their children (about routes to walk home from school and where to hide in the home if they hear gunshots), how people react to everyday situations and the information that people share. Although rarely directly referenced, I am certain that violence affected virtually every aspect of the day to day lives of the women I interviewed, just as it did mine, albeit in different ways, during the time that I and my family lived in Jamaica.

Evidence exists that high levels of violence affect behaviour and wellbeing in parts of Jamaica, where “residents are afraid to leave their homes and interact less often with friends and family who live elsewhere” (UN/World Bank., 2007:44). Children are heavily affected by violence in Jamaica: UNICEF (2010:2) reports that “The cumulative effect of children’s exposure to violence has a devastating impact on learning and behaviour”. The same report states that daily, “between 2006 and October 2009, 17 children and adolescents aged 0–19 were treated in emergency rooms for intentional violence related injuries” including more than “11,100 cases of sexual assault, stab wounds, gunshots and blunt force injury” (UNICEF, 2010:2). Additionally, from January to July 2009, “26.2 per cent of all intentional injuries, 30 per cent of all stab wound cases, 35 per cent of all attempted suicides, 17 per cent of all psychiatric cases and, notably, 61 per cent of all Jamaicans who reported being sexually assaulted (mainly girls)” (UNICEF, 2010:2) were children aged 10–19 years. Certain groups, such as the LGBT community, are particularly affected by violence, but the widespread nature of violence against other groups, such as women and children, is increasingly recognised within Jamaica. Several NGOs have begun to include raising awareness about violence against women and sexual abuse of children as a major part of their work (*e.g.*, Eve for Life’s “Nuh Guh Deh!”<sup>5</sup> Campaign 2014–15 and JCW+’s Elimination of Violence Against Women Project 2013–14). The complex

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<sup>5</sup>“Don’t Go There!”

relationship between violence and HIV is increasingly recognised globally (*e.g.*, Maman *et al.*, 2000; WHO, 2004).

### 3.7 Migration

An important factor affecting the roles of mothers in Jamaica is local and transnational migration, both forced and free, historically and currently. Migration is an important issue in Jamaica, which has high unemployment and remains dependent on services, tourism, and remittances sent from overseas (Glennie and Chappell, 2010). UNICEF (2009b) states that more than 17,500 people migrated in 2008, slightly higher than the annual average since 2006 of 16,833 migrants. This equates to more than 6/1000 Jamaicans migrating and ensures that a significant proportion of the population, including mothers, and their children, are directly affected by migration. The entire history of Jamaica has been one of movement: with the exception of the indigenous inhabitants of Jamaica, the Arawak-speaking Taino, all descendants of present Jamaicans came from afar: Africa, Europe, India, and China (Senior, 2003:5–8).

Historical possibilities for work such as the Panama Canal, South American railroads, USA farm work, and Cuban sugar plantations have mostly involved the migration of men. The emigration of women, often mothers, to provide low-paid nursing, health care assistant, domestic helper or factory worker roles in Europe or North America is a more recent phenomena, and one which has demanded a high price from mothers as well as the children and other family members left behind. Transnational mothering, which occurs across the world, is mothering across borders (*e.g.*, Hondagneu-Sotelo and Avila, 1997; Parrenas, 2001; Phoenix, 2010), and generally occurs when mothers migrate to another country, usually for financial reasons, to take up paid employment. As I interviewed Jamaican mothers in Jamaica, I was unable to access mothers who migrated internationally. However, the high numbers of mothers migrating locally (*i.e.*, leaving their children with relatives in rural areas while they travel to Kingston) meant that some of the interviewees in Kingston lived apart from their children and encountered similar issues; I refer to this as ‘mothering at a distance’.

The terms ‘child shifting’, ‘barrel children’<sup>6</sup> and ‘Western Union children’<sup>7</sup> were all coined to describe the circumstances of children left behind in Jamaica whilst their mothers travelled

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<sup>6</sup>‘Barrel’ refers to the barrels of food, clothing and other supplies sent back to children in Jamaica. Pollard (2013:145) argues that “barrel children are the major casualties of the migratory experience.”

<sup>7</sup>Western Union is a money transfer company commonly used by Jamaicans overseas to send money home to their children.



overseas for work<sup>8</sup>. Russell-Brown, Norville and Griffith (1997) define child shifting as the practice of ‘shifting’ childrearing responsibilities from biological parents to friends or other family members, for a period of a few days or many years. Child shifting may occur in a variety of situations where the biological parents are unable to care for their children; as one would expect, it is more common within low income families who have fewer resources to buffer them and provide options. Evans and Davies (1997) estimated that 15 to 30 percent of Caribbean children are brought up by relatives or neighbours. Possible reasons for child shifting include the biological parent dying or migrating, the birth of a sibling or a new relationship where the child is not wanted. Alternatively, child shifting may take place where the new carer does not have their own children or is considered to be in a better position, financially or otherwise, to take care of the child (Barrow, 1996; Evans and Davies, 1997). It is not unusual for a child to be shifted multiple times from relative to relative. Russell-Brown, Norville, and Griffith (1997) write that children are shifted because mothers believe it is in the best interests of their child/ren and that the decision represents an enormous sacrifice on the mothers’ part, rather than demonstrating a lack of love or affection. The emotional toll this experience can take on children and mothers is well-documented. Gadsby (2006) sees seeking migratory work as the ultimate sacrifice as Caribbean mothers ‘suck salt’— endure and overcome hardships including discrimination, isolation and depression. There may be a greater risk of neglect and abuse for these children; this is less well documented and abuse of children within families is an issue that is only beginning to be recognised in Jamaica (See ‘Nuh Guh Deh!’ Campaign, 2015). However, there is also the potential for a better standard of living, and better educational opportunities for the children of migrating mothers. Phoenix (2010) writes of the paradoxical experiences of two Caribbean mothers, reflecting on their migration to the UK: the trauma of leaving children behind in the Caribbean alongside the hope intrinsic to working to establish a new life for the family as a whole. Although these terms are generally used to refer to children whose parents are overseas, many of these issues also affect children whose mothers/parents are in-country but who have moved to (usually) Kingston for work and have left their children with relatives in rural areas. These issues are reflected within my interview sample both through cases where mothers are caring for non-biological children and where their biological children are being cared for by others (discussed further in Chapter 8)

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<sup>8</sup>Pollard (2013:152) believes there are experiential differences in that a Western Union child may be “bringing up him/herself and siblings with a greater sense of abandonment and neglect than the barrel child”. However, their mothers, although in these circumstances unable to be physically present and provide emotional care, are working, often as sole breadwinners, to provide materially for their children and are therefore, to the best of their ability at that time, working to be ‘good’ and ‘responsible’ mothers (see also, *e.g.*, Hondagneu-Sotelo and Avila, 1997; Parrenas, 2001; Phoenix, 2010).

Child shifting is common and normalised in Jamaica (as in other countries, including the Philippines and South Africa) for both mothers seeking work overseas and mothers moving from rural areas to the city to find work. This experience shifts the concept of what it means to be a good mother, from one who is physically present and provides, amongst other things, day to day emotional support, to one who is geographically distant and provides financial support. This contrasts with the concept of intensive mothering, where mothers are physically present and provide round-the-clock child-centred care (Hays, 1996). In this construct, where mothers working outside the home are demonised, the idea of migrant mothers is almost inconceivable, and largely absent from policy documents which continue to prize the mother-child dyad and the biological mothering relationship. There is however, some recognition, within HIV policy, particularly in areas with high HIV mortality, of the wider childcare possibilities, hence the references to ‘caregiver’ (WHO, 2011). Some authors, writing about Botswana (Geiselhart, Gwebu and Kruger, 2008) and South Africa (Palin *et al.*, 2009) highlight different family configurations and the importance of extended family involvement in HIV programmes.

### **3.8 Chapter summary**

In this contextual chapter, I have brought together a range of structural factors which I believe have an important impact on the day to day lived experiences of HIV positive mothers in Jamaica. After providing brief historical and geographical background information, I introduced the situation for HIV positive women in Jamaica, including the social and cultural role of mothers, family communication norms and the impact of poverty, violence and migration. It is helpful to have an understanding of these issues when considering the key themes presented later in this thesis. In the next chapter I introduce the conceptual resources which I draw on throughout the thesis and which interact with the contextual factors I have presented here.

## **SECTION 2: CONCEPTUAL RESOURCES, METHODOLOGY, METHODS & ANALYSIS**

### **Chapter 4: Conceptual Resources**

#### **4.1 Introduction**

In this chapter I introduce the key concepts that I will refer to throughout this thesis. I use a feminist approach as a counterpoint to rationalist decision making models, which, to some extent, dominate the disclosure literature, and to provide an alternative perspective to existing androcentric policy and research. In order to do this I draw on a number of conceptual resources, particularly the idealisation of motherhood (Craig and O'Dell, 2010), emotion work (Hochschild, 1979; Hochschild, 1983) governmentality (Foucault 1978–9 in Burchell, Gordon and Miller, 1991) and responsibilisation (Lupton, 2011). I also briefly introduce the concept of stigma, which, while not a key conceptual resource in this thesis, is nonetheless an important issue which underpins HIV positive women's experiences.

In this chapter, I juxtapose the idealised image of the black Jamaican mother as a strong “provider and protector” figure (Adisa, 2013) against the backdrop of violence, sexual violence and poverty in Jamaica (discussed in the previous chapter). Neither the image of the strong black mother nor the imagined idealised mother underpinning policy and practice based on Anglo-Northern constructions of mothering adequately captures women's experiences in the Jamaican context. I wish to problematise both idealisations by discussing mothering in the context of the poverty and violence which informs mothers' practices and places constraints on their agency.

#### **4.2 Applying a decolonial approach to research**

My research works to incorporate a broadly decolonial approach insofar as this is possible. Some would argue that my position as a white middle class researcher precludes this, but I believe that it is important to try to include an understanding of these issues. My thesis explores the experiences of Jamaican women in present-day Jamaica, a context which is strongly affected by the legacies of colonialism. A central tenet of this thesis is that policy based on the experiences of the rich industrialised Anglo-North is unhelpful and possibly harmful for failing to understand gender, motherhood and HIV in a post-colonial setting. Women in a country like Jamaica with high levels of sexual and other violence face additional risks. Throughout this

thesis, I have worked to use a decolonising approach to challenge the assumptions and actions which may arise from applying Anglo-Northern thinking to the experiences of women in the Global South.

#### ***4.2.1 Why is this important?***

Maori author Linda Tuhiwai Smith (1999) argued that the term ‘research’ is considered a dirty word in Indigenous vocabulary, due to Indigenous experience of research and its links with colonisation. Historically, there have been an array of ethical violations, especially in the biomedical field, which have involved the exploitation of participants, especially vulnerable participants (such as psychiatric patients, orphaned children, prisoners, homeless people, people belonging to minority ethnic groups) for the benefit of researchers or to extend medical knowledge. My reading has highlighted a number of examples, including the 1932-1972 Tuskegee Syphilis Study (Reverby, 2009) which involved African American men; the consent issues of the development of the cell line of Henrietta Lacks, a poor Black woman, in 1951 (Skloot, 2010); and experiments which involved intentionally infecting mentally disabled children with hepatitis and observing them (Krugman and Giles, 1970). Historically, researchers, particularly Western or otherwise privileged researchers going into resource-limited countries or settings were able to take the information that they wanted and leave with little consideration for the impact on participants/the resident population: the so-called ‘smash and grab’ approach (*e.g.*, Kovach, 2009). Costello and Zumla (2000) critique the continued existence of ‘postal’ and ‘parachute’ research, where medical samples in Global South countries are posted to or quickly collected by Anglo-Northern researchers with scant regard for ethical considerations affecting participants.

Despite increased recognition of these issues, ethically questionable practices within the HIV and other medical fields, continue. For example, Ammann (2009) published ‘Optimal Versus Suboptimal Treatment for HIV-Infected Pregnant Women and HIV-Exposed Infants in Clinical Research Studies’ which has since been criticised as exposing the women and children in the suboptimal treatment group to unfair risk of HIV progression and earlier death. Similarly, Ethics in Health (2014)<sup>9</sup> argues that exploitation of poor HIV positive pregnant women in resource constrained countries continues: “And so, even now in 2014, NIH (National Institutes of Health) -supported studies, against all recommendations by other organizations, still discontinue potent antiretroviral treatment in HIV infected pregnant women after they deliver their infants”. These issues, and the fact that they persist in the present day, highlight the importance of researchers

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<sup>9</sup> <http://ethicsinhealth.org/?p=221> Accessed 12.12.2014

being aware of the impact of colonial thinking and the consequences of colonialism, and which have an ongoing impact on the way in which research is designed, conducted and disseminated.

#### ***4.2.2 Post-colonialism, postcolonialism and critiques of postcolonialism***

Maldonado-Torres (2007:243) defines colonialism as “a political and economic relation in which the sovereignty of a nation or a people rests on the power of another nation, which makes such nation an empire.” In line with other writers, I use ‘postcolonialism’ (without a hyphen) to refer to “a reactive resistance discourse of the colonized who critically interrogate dominant knowledge systems in order to recover the past from the Western slander and misinformation of the colonial period” and ‘post-colonialism’ (with a hyphen) to refer to “the historical period aftermath of colonialism” (Sugirtharajah, 2002:12-13). However, I quote authors directly and so in some cases the term ‘post-colonialism’ may be used by them to refer to work challenging colonialism.

Postcolonialism emerged in response to increased critical awareness of the impact and aftermath of colonialism (McInturff, 2000) and seeks to challenge concepts such as class, order, the other, or colour domination. Postcolonialism is complex and definitions abound, with some scholars (e.g., Young, 2001) believing that rather than being a theory, postcolonialism is, in fact, a collection of concepts, sharing political and social objectives and drawing on theories such as poststructuralism, postmodernism, feminism, and Marxism (Loomba, 2015). It can be argued that there are in fact, multiple ‘postcolonialisms’, which emerged individually from within former colonies and later developed into a global intellectual movement, as theorised by, for example, Fanon (1952) and Césaire (1956). Later, in the UK and the USA, writers such as Said (1978) and Spivak (1988) argued for increased recognition of these issues through the inclusion of postcolonial studies as a discipline within universities.

Postcolonial work has been critiqued, by, for example, Macleod and Bhatia (2008:576-577), who highlight some of the concerns raised by various authors regarding postcolonialism: assumptions that experiences of colonialism are homogenous rather than diverse; overemphasising the impact of colonisation on those who were colonised (Ahmed, 2000; Young, 2001); a lack of emphasis on the socio-material conditions resulting from colonialism (Parry, 2004) and that work on postcolonialism is generally conducted by Anglo-Northern countries such as the USA and the UK (Young, 2001). Mignolo (2007) draws on José Saldívar’s belief that knowledge is linked to “a locus of enunciation”, i.e., to think from where you are located (Mignolo, 2007:158). Being aware of this, I worked to increase my knowledge and understanding of the Jamaican context, and attempted, as far as I was able, to locate myself

with the experience of the HIV positive women I interviewed. This thesis argues that knowledge produced in the Anglo-North and applied to indigenous communities can be harmful.

#### ***4.2.3 Decoloniality***

Maldonado-Torres (2007:243) defines coloniality as “long-standing patterns of power that emerged as a result of colonialism, but that define culture, labor, intersubjective relations, and knowledge production well beyond the strict limits of colonial administrations” and therefore continues after colonialism has come to an end, preserved in, for example, books, cultural patterns, concepts of common sense, self-image, and aspirations (Maldonado-Torres, 2007:243)

The term decoloniality is often used to refer to an intellectual movement that first developed in former Spanish colonies in Latin America and then extended to other former colonies across the globe. Decoloniality recognises that knowledge continues to be defined and controlled by the Anglo-North and believes that the current violence in ex-colonies results from colonialism (Mignolo, 2007a:452-453). A decolonising approach seeks to “privileg[e] Indigenous voices, pursu[e] agendas of self-determination for Indigenous peoples on their terms and eschew colonizing agendas that further marginalizes Indigenous peoples” (Antoine, 2017:117). Kovach (2009:81), believes that a decolonising methodology can act as a “‘unifier’ by giving voice to the distinctive experiences of Indigenous peoples”. Decolonial writers attempt to extend the work of postcolonialism by recognising that colonialism and colonial thinking continue to exist in the present day and attempt to reimagine/restructure the world in a way that eliminates this colonial thinking.

Maldonado-Torres (2007) proposes caution concerning knowledge and being, believing that our knowledge has been collected using Anglo-Northern assumptions and are therefore skewed, representing only a small part of experience. These assumptions are predicated on concepts of Anglo-Northern superiority, in terms of thought and knowledge, which categorise those from the Global South as different, inferior, lacking or dispensable. Assuming that there is only one, ‘correct’ way to know and understand the world, allows for those who think or understand differently to be ignored, dismissed, discriminated against, forced to comply, denied land rights, denied human rights or killed. Examples abound: colonialism, Nazism, the experiences of Indigenous and First Nation peoples. Current assumptions about increased violence, food insecurity or income inequality amongst particular racial groups presume that those individuals have failed in some way- by not accessing services, by not working hard enough- rather than recognising systemic injustices and failure to acknowledge and incorporate difference, which

make that nearly impossible. Fanon (1952:228) writes: “For the black man there is only one destiny. And it is white.”

Thus, the colonial can be seen as the voice of the dominant narrative (*i.e.*, the former colonisers, the Anglo-North), whilst the post-colonial seeks to give voice to and facilitate the agency of those who were colonised. Decoloniality seeks to undo the legacies of colonialism or re-imagine the world after colonialism, from the perspectives of those who were colonised. Postcolonial work has been critiqued as continuing to exist within an Anglo-Northern framework, whereas decolonial work attempts to challenge this and begin from the perspectives of those in the Global South. As stated by Mignolo (2007a:452). “The de-colonial shift, in other words, is a project of de-linking while post-colonial criticism and theory is a project of scholarly transformation within the academy”.

It is my understanding that decoloniality extends postcolonialism in that it includes a recognition of violence as a legacy of colonialism and asserts that, albeit in a different form, colonialism continues in the present day. Additionally decoloniality recognizes the global nature of Anglo-northern dominance of thought (rather than being limited to seeing this dominance as occurring merely within countries, where the dominant culture asserts itself over minority groups living within that culture). It is my belief that current policy, such as the WHO guidelines on disclosure to children (WHO 2011) and much of the HIV disclosure research, retain an implicit or, in some cases, explicit Anglo-Northern perspective, which fails to fully recognise the experiences and perspectives of many research participants, who reside in or originate from the Global South. I have discussed these examples in more detail in sections 10.1 and 11.5.4 and reflect on how I have worked to address issues arising from my Anglo-Northern background in Chapter 10.

### **4.3 Gender and intersectionality**

Gender is commonly understood to refer to cultural and social differences between men and women, whereas sex refers to the biological differences (Connell, 2002). There has been increasing recognition of varied sexual orientation (*i.e.*, LBGTIQ) rather than simply male or female, heterosexual or homosexual; the distinction between sex and gender can also be seen to reinforce a binary. However, historically, feminists have used this distinction to challenge essentialist ideas about women and reproduction (*i.e.*, assumptions that all women ‘should’ have and are destined to have babies: Russo’s (1976) ‘motherhood mandate’). Becoming a mother is often seen as ‘natural’, desirable and expected (*e.g.*, Woollett and Marshall, 2000:313). Clarke (1957), in her early ground-breaking research on the family in the Caribbean,

acknowledged the complexity of Jamaican family structures and produced a more nuanced image of Jamaican women; unlike previous work which stereotyped black working class women as passive, Clarke recognised female agency and independence. However, she also noted that women's sexual agency was closely tied to procreation: "[...] a woman is only considered 'really' a woman after she has borne a child" (Clarke, 1957: 96). Furthermore, sexually active women not pursuing motherhood continue to be labelled promiscuous (Clarke, 1957, Leo-Rhynie 1996).

Highlighting and separating the concept of gender served as a useful rhetorical device to challenge biological essentialism. It has, however, since been criticised for reproducing another binary when women's subjectivity involves the intersection of both (when biology is influenced by culture and vice versa). One of the key writers credited with the origins of the concept of intersectionality, Crenshaw (1989:149), compares the discrimination experienced by many who are disadvantaged in multiple ways, to the traffic at an intersection: "if a Black woman is harmed because she is in the intersection, her injury could result from sex discrimination or race discrimination". Crenshaw (1989:149) goes on to suggest that the discrimination experienced by Black women may share both similarities and differences with the discrimination experienced by Black men and by white women, adding that "[...] often they experience double-discrimination—the combined effects of practices which discriminate on the basis of race, and on the basis of sex. And sometimes, they experience discrimination as Black women—not the sum of race and sex discrimination, but as Black women" (Crenshaw, 1989:149). In the case of my research, all of the women are located at the intersection of being black, being women, being poor and being HIV positive and their experiences are influenced by all of these things and the complex interactions between them. Additionally some of the women have experienced the impact of additional, often interrelated factors, some of which are issues of gender rather than of motherhood: being an unmarried mother, having their partner die of HIV, domestic violence, geographical separation from their own mothers and/or their child/ren for economic reasons.

Gender issues are addressed by Adichie in her book 'We should all be Feminists' (Adichie, 2014): "I have learned a lot about systems of oppression and how they can be blind to one another by talking to black men. I was once talking about gender and a man said to me 'Why does it have to be you as a woman? Why not you are a human being?' This type of question is a way of silencing a person's specific experiences. Of course I am a human being but there are particular things that happen to me in the world because I am a woman. This same man, by the way, would often talk about his experience as a black man" (Adichie 2014:43-44). Several of the women I interviewed made explicit reference to the challenges of being a women, through their comments on gender



and society, for example:

*Because everybody is at risk because nobody [...] because when a man steps outside his house, nobody knows what he's going to do. When a woman steps outside her house, nobody knows what is going to happen to her, so no one should discriminate against anyone else.*<sup>10</sup> (Winnie 57)

The experiences of the women I interviewed are those of poor, HIV positive, Black women, not simply that of class + HIV status + race + sex, but as a “co-constitutive phenomena” (Grzanka, 2014:XV). The women’s lives and experiences of mothering are also impacted by the cultural, historical and social factors, as well as the geographical and environmental factors that affect Jamaica today.

Many Anglo-Northern feminists have failed to theorise the intersection of gender and race as it pertains to the post-colonial Jamaican context. “Up until now, decolonial theorising has strongly focused on the concept of ‘race’ as a mechanism of geopolitical and social hierarchisation and as a symbol of global power asymmetries caused by the coloniality of power” (Borst, Fuchs and Urioste-Buschmann, 2018:2-3). Authors such as Lugones (2010) believe that this approach does not include gender; neither does it nor recognise the potential of gender to further highlight concepts of coloniality/decoloniality and power. Borst, Fuchs and Urioste-Buschmann (2018:2-3) draw on Lugones’ explanation of the current “modern/colonial gender system” as “characterised by a biologically motivated dimorphism and by a patriarchal-heterosexual viewpoint” thereby doubly discriminating against the “colonised/non-Western woman”, a view which has “infiltrated non-Western cultures and their self-image”.

This thesis, which explores communication, disclosure and relationships between mothers and their children, necessarily has a focus on mothers, rather than non-mothers, women, fathers or men; I therefore focussed on the wider mothering and feminist literature, rather than gender literature (although there is some overlap between them). In the Jamaican context, where mothering is highly valued (Ellis, 1986) gender is often assumed to be synonymous with mothering. I felt it was clearer to explicitly focus on the mothering literature in order to highlight my focus on mothering (see, for example, Sections 4.5 and 4.6) and not on wider issues which may be encompassed by the broader category of gender. I do however, recognise that gender policy and local cultural and social concepts of gender impact on the lives and

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<sup>10</sup> Bikaaz evribadi iz at risk bikaaz nobadi xxx [five or six words] bikaa wen a man step – step outsaid iz ous nobadi nouz wat iiz gana du. Wen a uman steps out er ous nobadi no wat shi iz gana hapen so nat tu diskriminiet agens enibadi els.

experiences of the women I interviewed; these contextual issues (*e.g.*, gender based violence, stigma and poverty affecting women) are addressed in Chapter 3. In Jamaica, as in much of the world, the majority of childcare responsibilities fall to the mother (see sections 3.4 and 3.5). However, Johnson (2014: 268) describes intensive mothering as “an institutionalized form of discrimination against single, poor, and minority mothers that seeks to “other” and shame women who cannot and/or will not mother this way.” Authors such as Taylor (2011) have critiqued intensive mothering as unrealistic and impossible for many women. In this thesis, I seek to challenge research and policy which penalises women from the Global South who do not conform to Anglo Northern concepts of good mothering. The mothers I interviewed faced additional challenges as the HIV stigma experienced by women who are also mothers may be heightened by societal expectations of mothering; this is addressed in section 4.6.

#### **4.4 Using a feminist approach to counter androcentrism**

Feminist research involves an analysis of power and gender (Harding, 1987: 8–9), which is not often seen in existing research on disclosure of maternal or parental HIV to children. The policy imperative to tell children about maternal HIV (*e.g.*, WHO, 2011; Krauss *et al.*, 2012), I argue, is infused with notions of the idealised nuclear family —popularised in the cultural imaginary as white, middleclass, heteronormative and, seen as the norm, perhaps, in high income countries. These assumptions (albeit in other contexts) are critiqued by feminists such as O’Reilly (2010b) and Craig and O’Dell (2010). There is a tendency, particularly in the more highly resourced Anglo-North, to psychologise problems. Burman quotes an example of a school responding to a child’s death with information letters and counselling (Burman, 2006:319). The child in this example is constructed as vulnerable and in need of protection and these assumptions inform policy responses. The assumed harm caused by the death of child warrants counselling by adults; assumptions are made about the needs of children and appropriate interventions. Similarly, Burman critiques the international response of providing counselling and psychological support rather than practical aid, after large scale humanitarian crises. Burman (2006) sees these responses as paternalistic and prioritising Anglo-Northern assessments of psychological need over the needs which may be identified by survivors. Implicit within disclosure policy (*e.g.*, WHO, 2011) and documents such as the HIV disclosure support document ‘It’s Good2Talk’ (UK Family Project, 2008) is the assumption that disclosure is the ‘right’ thing to do and that ‘good’ or ‘responsible’ mothers disclose their HIV to their children. Policy tends to equate close relationships between children and parents with honesty and openness and assumes that honesty with children is necessarily positive and essential to

good parenting. These values, I argue form part of the rationale of encouraging disclosure to children.

In the context of maternal HIV in Jamaica, there is a disconnect between these assumptions, and the reality of women's lives (discussed in Chapter 3), which may include poverty, discrimination, violence, multiple babyfathers (see Section 3.5.1), mothering at a distance, non-biological mothering, complex health issues and an HIV positive child. In this context, maternal disclosure of their HIV status to children who are seronegative may be less of a priority. Similarly, honesty in relationships may be less of a priority in the context of women struggling to provide for their families.

Power inequalities can be seen in the WHO guidance about maternal disclosure of HIV to children. The WHO is a powerful body with a significant impact on the lives of professionals and patients across the world. The WHO has issued guidelines on disclosing HIV to children under 12 (WHO, 2011). The focus of this document is on disclosing to children who are themselves HIV positive. Although there is a section on disclosing caregiver's status, there is no focus on different caregiving roles, including care provided by siblings, grandparents, and other relatives or friends; policy assumes a particular kind of family structure which may not exist in, for example, Jamaica. The guidelines are intended to be global but do not take into account variations in circumstances in different countries. Many of the studies on which these guidelines are based are from sub-Saharan Africa where mother to child transmission is greater than in other areas of the world. In Jamaica, mother to child transmission has dropped from 10% in 2005 to 1.9% in 2012 (Jamaican Ministry of Health, 2014). Few children are now born HIV positive and mothers' disclosure decisions generally relate to children who are HIV negative, making guidelines specific to disclosure to seronegative children increasingly relevant.

Authors such as Squire (2007: 7–9) have described the tendency of High Income Countries (HICs) to portray HIV as a chronic, but manageable illness limited to 'others', individuals or groups that are traditionally socially excluded, ignoring the continuing health challenges faced by some PLWHIV and the impact of race, gender and class on the epidemic. Alternatively, in LMICs, HIV is often seen as a "pitiful matter of unsafe sex, victimised women, untreatable illness and inevitable death, all orchestrated by fear, ignorance, resource shortages and, poor governance and failures of democracy" (Squire 2007:8). HIV in the Caribbean context needs to be understood in the context of complex power relations which are gendered, raced and classed and affected by colonial, historical, economic and social factors as a result of European, African and American cultures coming together (Senior, 2003).

I argue that the context within which Jamaican women live retains androcentric and patriarchal features, which have an important impact on women's experiences. Patriarchy is defined by (hooks, 2010:1) as "a political-social system that insists that males are inherently dominating, superior to everything and everyone deemed weak, especially females, and endowed with the right to dominate and rule over the weak and to maintain that dominance through various forms of psychological terrorism and violence". Bem (1993:41) provides a definition of androcentrism commonly used within psychology: "the privileging of male experience and the 'othering' of female experience; that is males and male experience are treated as a neutral standard or norm for the culture of the species as a whole and females and female experience are treated as a sex-specific deviation from that allegedly universal standard". Hawkesworth (1994:105) writes that androcentrism suggests a gendered element to "assumptions, concepts, beliefs, arguments, theories, methods, laws, policies, and institutions", where one gender is implicitly or explicitly "privileged over the other". Hawkesworth argues that social practices can be gendered in a variety of ways, from overt (*e.g.*, excluding women from participation) to more subtle forms of gender bias. Policies which claim to be gender neutral "may also be gendered if certain factors make it more difficult for women than for men to achieve the same outcome by following the same procedures" (Hawkesworth, 1994:105). Methodologically, "androcentric bias may be incorporated in problem selection, research design, definition of key terms, identification of relevant evidence and counter-evidence, data collection and analysis, as well as in the interpretation of results" (Hawkesworth, 1994:105). HIV is an emotive topic, as is HIV disclosure; disclosure of HIV is therefore not a neutral phrase.

A feminist approach provides a counterpoint to the masculinist rationalist decision models which appear to dominate the disclosure literature, and arguably, script out emotions and the social and cultural contexts of health decisions about disclosure. To counter androcentric approaches, Harding, (1987) argues for three key features of feminist research: a focus on women's experiences, research which is designed for women and includes a focus on the researcher (*i.e.*, reflexivity).

Feminists (*e.g.*, Burman, 1992, 1996; Craig and O'Dell, 2010; O'Reilly, 2010b; Phoenix, 2010) have criticised constructions of the universal family based on Anglo-Northern concepts of the often white, middle class, heteronormative nuclear family. I suggest that these normative constructions about "the family" and parenting underpin policy imperatives to disclose (*e.g.*, WHO, 2011) and are not helpful to the many families, including those in Jamaica, where alternative family formations are common. Moreover, in many contexts, pressure for parents or caregivers to disclose will disproportionately affect women, as they are responsible for the

majority of childcare responsibilities and may actually disadvantage women and children and hence risk harm.

In this thesis, I have worked to acknowledge the impact of my own background as a researcher and mother and recognise that my research is my interpretation of the participants' interpretation of their experience as they chose to present it to me (which is also shaped by my own biography and assumptions about parenting). I use a feminist approach to IPA, including feminist reflexivity, to illuminate power dynamics and to theorise power and difference in research relationships (Burman, 2006), given my outsider status as a non-Jamaican (which I discuss further in Chapters 6 and 10). I define reflexivity as the researcher's awareness of the impact that they, their background and views, have on the research process. I worked to include reflexivity throughout the process, to ensure that my interactions with participants were open and non-judgmental and that I considered them to be the 'experts'. My position as an 'outsider', as a white British woman in a postcolonial context, highlights the importance of these issues. Attention to these feminist elements complements the key elements of IPA, in particular the detailed focus on individual experience and sense-making and the emphasis on interpretation by both the researcher and the participants (Smith, Flower and Larkin, 2009).

## **4.5 The idealisation of motherhood**

Mothering has been defined as the individual relationship between a mother and her child/ren (Rich, 1977). Rich argues that the institution of motherhood consists of clearly defined practices and standards of mothering (which may be experienced as oppressive by some women) and are reproduced through generations as children internalise these messages and transmit them to their own children (Rich, 1977). Ruddick (1989) argues for mothering as a practice and that those (who need not necessarily be mothers) engaged in maternal work are committed to the defining elements of mothering practice, that of ensuring "preservation, growth and social acceptance" of children through "preservative love, nurturance and training" (Ruddick, 1989: 17). Craig and O'Dell (2010:6) define motherhood "as a collection of embodied identities" and mothering "as a series of social practices" and argue that both are rooted in "different physical and psychological locations". Referring to the work of Carpenter and Austin, (2007), they recognise that "intersections of class, race, (dis)ability, expert/novice status and others serve to render some women's lives marginal and others as central to dominant constructions of mothers, mothering and motherhood" (*ibid.*). O'Reilly (2010a) writes of the patriarchal construct of motherhood as limited to biological heterosexual mothers, with the concept of what it means to be a good mother, defined as "white, heterosexual, middle-class,

able-bodied, married, thirty-something, in a nuclear family with usually one to two children, and, ideally, full-time mothers” (O’Reilly, 2010a:7). Clearly, this excludes a sizable proportion of the population within the Anglo-North and virtually the entirety of mothers in the Global South. Mothering and motherhood in the Jamaican context are key concepts throughout this thesis. I will explore the meaning women attribute to the role of mothering whilst also living with HIV and this will, necessarily, also be affected by their interpretation of how this is viewed by the society in which they live.

Current conversations about contemporary motherhood in the Anglo-North centre around issues such as the pros and cons of being a stay-at-home mother versus being a working mother (Dillaway and Paré, 2008), the struggle to recognise wider concepts of motherhood (see, for example, Kosciw and Diaz's (2008) book about the experiences of gay, lesbian, bisexual or transgender parents of elementary school children in the USA) and debates about parenting (as opposed to mothering) and the role of the father (*e.g.*, Amato and Rivera, 1999; Bronte-Tinkew, Moore and Cabrera, 2002). The focus on these issues reflects the Anglo-Northern bias in the literature and fails to reflect mothering in resource constrained contexts where choices about parenting may be quite different. In the Jamaican context, many poor mothers combine caring for their children with whatever sporadic work they can find to support their families, sexual orientation other than heterosexuality is highly stigmatised, fathers are often absent, and mothers parent non-biological children. Research, policy and procedures developed from an Anglo-Northern perspective cannot unproblematically be transplanted into contexts shaped by different historical, political, cultural and economic forces. Disclosure policy reflecting Anglo-Northern constructions of mothering, parenting and child development may not be applicable to the experiences of poor urban mothers in postcolonial settings in middle income countries such as Jamaica. My research seeks to open a space to understand mothering in a resource constrained context and provide greater contextual detail of the experiences of Jamaican mothers in the context of diverse family formation and modes of parenting. Using a feminist approach, I aim, not to pathologise women’s experience by focusing on why women don’t disclose as if this is the norm (hence looking through the lens of privileged heteronormativity), but instead, I aim to understand those contexts shaping women’s parenting and ideas around sharing HIV diagnoses with their children (see Chapter 5).

## **4.6 Stigma, HIV and motherhood**

Mother to child transmission of HIV has been almost eliminated in HICs over the last 10–15 years and significant reductions have been achieved in LMICs (McKenna and Xiaohong, 2007).

In addition to the decrease in mother to child transmission globally (Msellati, 2013), the increased availability and efficacy of ARV treatment means that in most countries, including LMICs, people living with HIV are able to live longer and healthier lives. In HICs such as the USA, the availability of HAART (Highly Active Antiretroviral Treatment) has meant that HIV is now categorised as a chronic illness (Connor *et al.*, 1994). Although this may encourage people to disclose their status, as HIV can be seen more as a manageable and treatable condition, the stigma associated with HIV continues to be high in many countries (Liamputtong, 2013). Deng *et al.* (2007:1561) identify stigma as linked to culture, history and other contextual factors. Stigma can lead to discrimination, where stigmatised individuals, perceived as deviant, are “treated unfairly” (Deng *et al.*, 2007:1561). Although stigma is not a key conceptual resource in this thesis, the fear and effects of stigma influence the experiences of the women I interviewed. However, I draw on Craig and Scambler’s (2006) work in which they extend the concept of stigma to one of governmentality in their work on mothering disabled children. The authors argue that mothering disabled children is not merely stigmatised, but subject to a regulatory discourse governing the mothering of children; this provides a rationale for drawing on Foucault’s concept of governmentality which I discuss later in this chapter (Section 4.7). Additionally, stigma in the context of HIV has been shown to hinder HIV disclosure, and access to HIV care and prevention services (Herek, Capitanio and Widaman, 2002). I will therefore briefly introduce the concept of stigma in this section.

Goffman, in his pioneering work on stigma and identity, defined stigma as “the situation of the individual who is disqualified from full social acceptance” (Goffman, 1963:9) due to “an attribute that is deeply discrediting” (Goffman, 1963:13). Goffman (1963:14) distinguishes between those who are discredited (whose stigma is visible and immediately known) and those who are discreditable (whose stigma is invisible and may be concealed). PLWHIV tend to be discreditable, but they may also fear visible symptoms (such as a rash or losing weight) or behaviour (such as not breastfeeding, being seen to take tablets or attend numerous medical appointments) which might lead others to make assumptions about their HIV status. The stigmatised individual is “reduced in our minds from a whole and usual person to a tainted, discounted one” (Goffman, 1963:3). Goffman went on to write about the shame people may feel when they do not behave or appear according to societally approved standards and how they manage this, often through concealing the condition, or avoiding fellow sufferers in order to avoid the degradation associated with the stigmatised condition (Goffman, 1963). Goffman (1963:43–44) also writes of ‘courtesy stigma’ which may be extended to an “individual who is related through the social structure to a stigmatised individual — a relationship that leads the wider society to treat both individuals in some respects as one.” Mothers may be concerned that

if their status becomes known, in addition to the potential loss of work, income, and practical and emotional support that the mother might experience (which will also have an impact on her children), the children themselves, though HIV negative, may experience bullying or exclusion within the community or at school as a result of courtesy stigma.

In the years since Goffman published ‘Stigma: Notes on the Management of Spoiled Identity’ (Goffman, 1963), a large body of work on stigma has emerged and the concept of stigma has been applied to a wide range of experiences and conditions, including HIV. Studies (*e.g.*, Fife and Wright, 2000) have found that HIV/AIDS is highly stigmatised because of its association with sexual activity, and activities perceived as deviant, irresponsible or immoral, as well as being seen as dangerous, fatal, and easy to catch. Zhou observes that people living with HIV/AIDS are socially constructed as “others” who are “disgracefully different from and threatening to the general public” (Zhou, 2007:2856). Sontag argues that women with HIV are often portrayed as ‘promiscuous’ or ‘deviant’: “AIDS reveals all but long-term monogamous sex as promiscuous (therefore dangerous) and also as deviant, for all heterosexual relations are also homosexual ones, once removed” (Sontag, 1991:159). This is an especially powerful message in a country such as Jamaica, where homosexual contact between men continues to be illegal, and though under-reported, there is evidence of frequent violent attacks on members of the Lesbian Gay Bisexual and Transgender (LGBT) community, which perpetrators often see as their moral duty (Human Rights Watch, 2014). HIV stigma therefore has real material consequences in terms of discrimination and violence and can further exacerbate poverty through loss of income or work. HIV related stigma has been recognised as a major issue throughout the Caribbean and in 2009 The Pan-Caribbean Partnership Against HIV and AIDS (PANCAP) established the Regional Stigma and Discrimination Unit to develop evidence-based approaches to addressing stigma and discrimination (PANCAP, 2010). Fear of stigma and discrimination and the fact that many people living with HIV appear well due to effective treatment regimes, may mean that some mothers find it easier to hide their status from family and friends, including their children.

In more recent work on stigma, Link and Phelan (2001:363) define stigma as “the co-occurrence of its components— labelling, stereotyping, separation [of ‘us’ and ‘them’], status loss, and discrimination— and further indicate that for stigmatisation to occur, power must be exercised.” Link and Phelan (2001), critique existing work on stigma as having been conducted by those who have not experienced stigma and so have a different perspective. They also critique existing work for continuing to see stigma as something actually in the individual rather than as referring to a label that has been affixed by others to that individual. Parker and Aggleton



(2003:14) believe that, although useful, Goffman's framework has limited research into HIV and stigma as it has tended to be applied "as though stigma were a static attitude rather than a constantly changing (and often resisted) social process". Parker and Aggleton also see previous stigma and HIV work as being too individualistic and too focused on the views and experiences of those responsible for discrimination, rather than those experiencing it. They propose an alternative analysis of discrimination put forward by Marshall (1998), which "concentrate[s] on patterns of dominance and oppression, viewed as expressions of a struggle for power and privilege" (Marshall, 1998:522) rather than the Oxford dictionary definition of discrimination as "treating unfairly". Parker and Aggleton (2003:16) propose considering stigma and discrimination in relation to "broader notions of power and domination". They see stigma as "producing and reproducing relations of power and control, [...] caus[ing] some groups to be devalued and others to feel that they are superior in some way" and link stigma to social inequality, and the ways in which social exclusion is caused and maintained. Thus, their suggestions concerning the further development of the concept of stigma in relation to HIV, draw on Foucauldian concepts of power. Although Foucault's work (discussed further in Section 4.7) focuses on the relationship between culture, knowledge, power, and notions of difference, Parker and Aggleton (2003:17) believe that these ideas, taken alongside Goffman's work on stigma, can create a helpful way to conceptualise, understand and respond to issues of stigma and HIV: "Stigma and stigmatisation function [...] at the point of intersection between culture, power and difference." They propose that stigma can only fully be understood by considering it to be "central to the constitution of the social order", rather than as a cultural phenomenon or individual attitude (Parker and Aggleton, 2003:17).

## **4.7 Governmentality and the responsibilisation of mothers**

The concept of governmentality was developed by Foucault in the late 1970s and encompassed, not just the control exerted by a government upon its population, but also the control exerted by institutions such as schools and hospitals. He goes on to extend this definition to include the control exerted by knowledge, leading to individuals internalising discourses and thus governing their own behaviour (see Foucault 1978–9 in Burchell, Gordon and Miller, 1991). The "technologies of the self" (Foucault, 1988:18) refer to the ways in which individuals influence "their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality". This is linked to the concept of responsibilisation whereby the government uses the technology of responsibility to control or influence the population without taking responsibility for them. In the context of HIV, this can be seen as the pressure to be married,

monogamous or abstain from sex in order to remain free from HIV and able to work and care for children and other dependent family members.

Craig and Scambler's work on mothering disabled children with feeding difficulties (2006:1117) suggested that Goffman's (1963) theory of stigma with its "focus on the structure of interaction" does not take into account discourses of blame in the governing of women's mothering when feeding disabled children. These discourses are also gendered, raced and classed. Craig and Scambler (2006) argued that women were blamed for having a disabled, "malnourished" child, for "failing" to establish a feeding relationship and for their child's poor growth. Moreover, when women did not accept (contradictory) expert advice, they were blamed again and constructed as bad mothers. The authors argued that women were not merely stigmatised but blamed through regimes of governmentality (Foucault 1978–9 in Burchell, Gordon and Miller, 1991) and their parenting called into question. Similarly, assumptions of blame concerning behaviour or morals (*e.g.*, promiscuity and immorality) which are commonly levelled at those with HIV (Sontag, 1991) work to discredit (Goffman, 1963) women's moral identities as women and mothers.

Lupton (2011) develops ideas about blame drawing on the concept of responsibilisation. Responsibilisation is related to the concept of familialism, a set of gendered "ideological assumptions and expectations, operationalised in practices and policies, that promote a particular view of what kind of and how much care work should be performed by the family" (Treloar and Funk, 2008:S33), particularly by women. Lupton draws on Hays' work (1996) on 'intensive mothering' which requires mothers to invest intensive time, energy, money and effort in caring for and nurturing their children, as well as concepts of the child as vulnerable and in need of protection and nurturing (Christensen, 2000). Like Craig and Scambler (2006), Lupton also draws on the concept of governmentality (see Foucault 1978–9 in Burchell, Gordon and Miller, 1991), to understand why women participate in intensive parenting practices and hence responsibilisation. Foucault, she argued, proposed that "individuals' behaviours and subjectivities in relation to health, risk and embodiment are constructed through imperatives emerging from a diverse array of sites: the mass media, government agencies, medical, scientific and public health professionals, experts and institutions, educational institutions, the family and other personal relationships" (Lupton 2011: 637–8). Lupton, drawing on Foucault's (1988) concept of "technologies of the self" argued that in daily life, and influenced by institutional structures, people begin to "accept and act on certain beliefs about health, risk and embodiment". She gives the example of the recent increase in social discourses which place responsibility on mothers and pregnant women to care for their pregnant bodies and young children and correspondingly, which imply blame towards the mother if the child develops

physical, behavioural or other health issues. Responsibilisation can be used to refer to women who engage in self-surveillance to conduct themselves and their behaviour in line with expert advice and avoid risks that might harm the unborn child. These women willingly participate in the surveillance of the self in order to present themselves as responsible citizens.

Lupton (2011:649), writing of mothers caring for themselves during pregnancy and, later, their babies and children, found that women did not resist these discourses. Rather, she found that societal pressure to conform to the idealised image of the good and responsible mother was very strong, particularly regarding visible elements such as being seen to smoke or drink alcohol during pregnancy or to bottle feed babies (Lupton, 2011:649), practices which are frowned upon as they are seen as harmful. She found that women appeared to voluntarily police, not only their own bodies and behaviours but also those of other women. She attributes this to an emotional desire to protect children, who are perceived as precious and vulnerable, to avoid short term illness or discomfort, to promote longer term good health and prospects and, through these actions, to view the self and be viewed by others as a 'good' mother (Lupton, 2011:649). As in Craig and Scambler's earlier work (2006, quoted above), mothers who do not comply with professional and social pressures to care for their own and their children's health are thus demonised; hence, the policy imperative to disclose is a form of governmentality. In this thesis I aim to bring into relief the ways in which women do resist the policy imperative to disclose by highlighting a range of disclosure practices and their rationales in the context of Jamaica.

## **4.8 Emotion work and associated concepts**

### **4.8.1 *Emotion work***

If policy assumes best practice is for mothers to disclose their HIV status to their children then there is a danger that those women who do not disclose and deviate from this normative standard will be constructed as 'bad' mothers and their parenting called into question. Moreover, as will be discussed in Chapters 7–9, my interviews with women challenged the notion of the disclosure binary (*i.e.*, to disclose/not disclose); rather women's accounts revealed a spectrum of disclosure positions. Indeed, the over-simplistic disclosure binary fails to take into account the emotion work women engage in when managing their relationships with children and others, their emotions and the emotions of others.

Emotion work is a concept proposed by Hochschild (1979) which describes the work, often unrewarded and unrecognised, which people (often women) do to manage their own and other people's emotions. I will refer to this concept in relation to the work carried out by the women I

interviewed to protect their children from the impact of their mothers' HIV. I refer to this as 'protective mothering' and argue that, despite policy assumptions, this work is undertaken by mothers of all positions on the disclosure spectrum. Hochschild introduced the concept of emotion work to refer "to the act of trying to change in degree or quality an emotion or feeling" (Hochschild, 1979:561). Hochschild uses the terms 'emotion work', 'emotion management' and 'deep acting' interchangeably. To carry out emotion work, an individual must first be "conscious of a moment of 'pinch' or discrepancy, between what one does feel and what one wants to feel (which is, in turn, affected by what one thinks one ought to feel in such a situation). In response, the individual may try to eliminate the 'pinch' by working on feeling" (Hochschild, 1979:562). Hochschild distinguishes between 'emotion work', which takes place within the family or other close relationships and 'emotional labour', where a person regulates their emotions within a paid work setting (Hochschild, 1979).

I was inspired to focus on the concept of emotional work (Hochschild, 1979) on reading an Australian study where a woman resisted medical interventions in relation to Prevention of Mother to Child Transmission (PMtCT) of HIV. Giles *et al.* (2009) chart the experiences of 45 Australian women and the emotional work they undertook regarding their use of PMtCT interventions; all but one of the women accepted all of the PMtCT interventions offered to them. This woman resisted medical advice in a number of ways: she breastfed her child (after pasteurising the milk); she did not complete the course of Anti-Retroviral Therapy (ART) medication prescribed to prevent her child developing HIV; and she accepted only one of the six HIV tests offered to her child at prescribed intervals. She felt that breastfeeding was crucial to her identity as a mother, that the risk of HIV transmission was relatively low, that the ART was toxic to her baby and that the additional HIV tests were of more benefit to the hospital reporting systems than to her family (Giles *et al.*, 2009). She based much of her assessment of the risks on the fact that her first child remained HIV negative despite her discontinuing ART. This case is reported as unique within the study, as it is an interesting example of empowerment and resistance. It is possible that many similar cases exist but are hard to uncover as women who are choosing to go against medical advice may not be willing to talk about their choices.

Although the identified types of emotional work are specific to PMtCT, I wanted to draw on these ideas to inform my study as they have the potential to be adapted within a feminist framework and with regard to mothers' disclosure decisions. I found this story interesting because it is the story that is rarely told or heard as the woman risks being judged as a 'bad' mother for not following the advice of medical professionals (as discussed in relation to Lupton's (2011) and Craig and Scambler's (2010) work in Section 4.7). I am interested in the

range of stories and perspectives that might exist in relation to maternal disclosure and in exploring how resisting medical advice intersects with maternal identity. As discussed in Chapters 7–9, some women I interviewed did not disclose to their children despite medical advice to do so (*e.g.*, Sandra), whilst others (*e.g.*, Cupcake, Laura) refused or did not access ART medication antenatally.

Giles *et al.*, (2009) reported that the three existing studies at that time on mothers' experiences of PMtCT interventions were located in developing countries and question the appropriateness of extrapolating findings to developed countries, which is interesting in view of how frequently researchers do the reverse (*i.e.*, extrapolate findings from HICs to LMICs). Similarly, I think it is likely that, rather than reporting on the 'unique case' of a woman refusing PMtCT interventions, Giles *et al.* (2009), are in fact reporting on an unusual admission by a woman, of a relatively common occurrence. Patients, particularly women with a stigmatised condition such as HIV, which can lead to judgments against their character, identity and ability to mother effectively, generally do not admit to actions which contravene the advice of medical professionals to researchers, particularly as both roles can be considered to hold some power over the women and their children's medical care. The greatest risk is borne, as always, by those with less power, who are forced to navigate complex expectations and assumptions to obtain medical care. I will discuss my experience of power dynamics in the interview process in Chapter 10.

#### **4.8.2     *Feeling rules***

Hochschild finds that, contrary to social expectations, close relationships (*e.g.*, parents and children, husbands and wives) demand more emotion work: "In fact, the deeper the bond, the more emotion work and the more unconscious we are of it" (Hochschild, 1983: 68). She suggests that, although governed by culture, the feeling obligations of the parent-child relationship are the clearest, perhaps because parental love is considered 'natural'. "It needs no normative shield, no feeling rules, we think, because nature does the work of a convention for us. In fact, however, we do seem to need feeling rules here— not because parental love is unnatural, but because it is so essential to security and sometimes so difficult to sustain" (Hochschild, 1983:69). Hochschild defines 'feeling rules' as the social norms associated with emotions and the ways in which emotions are expressed (Hochschild, 1979:563). Feeling rules may be influenced by a desire to avoid pain or for social gain. Feeling rules "guide emotion work by establishing the sense of entitlement or obligation that governs emotional exchanges" (Hochschild, 1983:56). Garey and Hansen (2011) define feeling rules as the "patterned

expectations of what people are supposed to feel, or not feel in particular situations” and highlight the cultural nature of feeling rules, which also vary according to role.

Hochschild suggests that we can identify feeling rules by “focusing on the pinch between ‘what I do feel’ and ‘what I should feel’, for at this spot we get our best view of emotional convention” (Hochschild, 1983:57). Emotion work explores not only how people think and feel about an experience, but how they think they should feel and how they think others think they should feel (Garey and Hansen, 2011), as well as what they do about any disconnects (or ‘pinches’) among these feelings. I use this concept of the ‘pinch’ to guide my identification of themes within the women’s accounts (see Chapters 7–9), focussing on the disjuncture between the ways in which mothers feel about maternal disclosure of HIV to their children, the ways in which they think they should feel and the ways in which they think others think they should feel. I apply these concepts to the maternal disclosure experiences of HIV positive Jamaican mothers through three key themes: Garey’s (1999) concept of maternal visibility (Chapter 7), Lupton’s (2011) concept of responsibilisation, and Hansen’s (2011) concept of the asking rules of reciprocity (Chapter 9).

#### **4.8.3     *Emotion work, mothering and maternal disclosure in the Jamaican context***

Rather than portraying women’s parenting as problematic for not disclosing their HIV status, I demonstrate the varied and complex strategies women utilise to preserve their maternal identity and manage emotions. As Garey (2011:178) states: “Contradiction is at the root of emotion work”. I seek to expose the contradictions or ‘pinches’ inherent in mothering with HIV and to illuminate some of the strategies (emotion work) which mothers carry out in an attempt to reconcile the idealisation of mothering in Anglo-Northern spheres (Craig and O’Dell, 2010) with women’s lived experience. I demonstrate how women struggle to manage (Anglo-Northern) expectations of the mothering role as involving an open and honest relationship with their children and their desire to keep their status private from their children in order to protect their children (from distress or the negative reactions of others, to protect their image in the eyes of their children and the community or to protect the image of the children’s father). These feelings may create a ‘pinch’ when set against some women’s desire for openness and honesty with their children, their need for practical and emotional support from their children or a desire to protect their children from assumed future distress. Women follow different paths in seeking to manage these contradictory feelings. Experiences are further complicated by professional pressure to disclose, by relatives telling women’s children about their HIV without their consent, by living apart from some children, and by fears about children’s HIV status, as well as by practical considerations relating to poverty and violence.

Yoo *et al.* (2010) wrote about women's experiences of emotion work in the context of breast cancer. The authors identified three categories of emotion work for women who have considered and planned disclosure: managing others' worry, protecting and soothing others and educating and instructing others. Interestingly, they found that women who disclosed without "calculating emotional management" (*ibid.*:205) often received unexpected support. Their study examined women's disclosure to friends and family and did not focus on the mothering role, but there are interesting parallels with the preoccupation felt by the women I interviewed with protecting and managing their children's emotional responses, as well as with the support received from their children by those women who disclosed to their children immediately after their diagnosis.

## **4.9 Chapter summary**

This chapter has introduced the key concepts that I draw on throughout this thesis, including decoloniality, emotion work, responsabilisation and governmentality. I have described my decision to use a feminist approach to counter androcentrism in existing policy and research on parental disclosure of HIV to children. The next chapter introduces my use of feminist IPA as a research methodology in the Jamaican context.

## **Chapter 5: Research methodology: Feminist Interpretative Phenomenological Analysis (IPA)**

### **5.1 Introduction**

In this thesis, I critique existing policy related to disclosure (*e.g.*, WHO, 2011), through a detailed, in-depth study of the experiences of a small number of participants from a relatively homogeneous group: poor, urban, HIV positive Jamaican mothers, with at least one seronegative child aged over 10 years. My research seeks to provide a counterpoint to research and policy (*e.g.*, Geiselhart, Gwebu and Krüger, 2008; WHO, 2011; Conserve *et al.*, 2014) suggesting the benefits of mothers disclosing their HIV status to their children. I contend that these approaches are based on Anglo-Northern assumptions which overlook the reality of many women's lives in resource constrained contexts, where disclosure of HIV may pose greater personal, emotional and practical risks to a mother and her family. Research is skewed by studies which extrapolate findings from high income settings to low income settings (*e.g.*, Rochat *et al.*, 2011) and by review articles which do not adequately distinguish between well-resourced and resource-constrained settings (*e.g.*, Obermeyer, Bajjal and Pegurri, 2011).

The existing literature's main conceptual gaps (see Chapter 2) concern assumptions and approach. The majority of existing literature starts with an (often implicit) assumption that disclosure is the 'right' thing to do. This links into assumptions about gender and motherhood, particularly from an Anglo-Northern perspective. For example, critiques of the mothering and child development literature (Burman, 2005a, 2008) have highlighted how child development is predicated on Anglo-Northern models; mothering and childhood in the context of poverty, violence and complex family dynamics in the Jamaican context are very different experiences. Existing literature does not always take into account wider contextual factors such as poverty or gender, and a proportion of the literature has a clear Anglo-Northern perspective in terms of research design and interpretation (*e.g.*, Geiselhart, Gwebu and Krüger, 2008; Conserve *et al.*, 2014). Most literature on parental disclosure does not mention either researchers' backgrounds or approaches, nor does it provide any detail on researchers' reflexivity during data collection or interpretation, implying an objectivity which does not exist.

To address these critiques, my chosen methodology is a feminist approach to Interpretative Phenomenological Analysis (Leve, Rubin and Pusic, 2011). In using feminist IPA, I employ feminist reflexivity to reflect on power in research relationships (Burman, 1994, 2006) and to include wider contextual factors. I discuss this further in Sections 5.3, 5.4 and 11.3.



## **5.2 Interpretative Phenomenological Analysis (IPA)**

### **5.2.1 What is IPA?**

Jonathan Smith introduced IPA in 1996 as an alternative to the positivist, empirical, experimental paradigms popular at the time within psychology (Smith, 1996). He intended to create, from within the field of psychology, a qualitative, experiential approach, still able to engage with mainstream psychology (Smith, Flowers and Larkin, 2009). IPA first became established in health psychology and a considerable body of work uses IPA to examine personal experiences of health and illness (*e.g.*, Arroll and Senior (2008) on chronic fatigue syndrome, Smith and Osborn, (2007) on chronic back pain, Borkoles *et al.* (2008) on multiple sclerosis, and Dickson, Allan and O'Carroll (2008) on spinal cord injury). The majority of IPA studies exploring HIV focus on the experiences of gay men in the UK and are classified as sexuality studies. These include the experiences of gay men, sexual health and risk (Flowers, Hart and Marriott, 1999), and gay men and their understanding of the HIV antibody test (Flowers, Knussen and Duncan, 2001). A more recent paper explores the experience of black HIV positive Africans living in the UK (Flowers *et al.*, 2006).

### **5.2.2 Phenomenology, hermeneutics and idiography in IPA**

IPA draws on three long-established areas of philosophical knowledge: phenomenology, hermeneutics and idiography. Phenomenology, the study of human experience, has its roots in philosophy and it is only relatively recently that aspects of phenomenology as philosophy began to influence research (Holloway and Wheeler, 2010:213). The development of phenomenology has overlapping and sometimes contradictory ideas, as key thinkers have extended and applied concepts. Smith and colleagues acknowledge the challenges of merging traditional phenomenological philosophy with the practicalities of collecting, analysing and communicating findings (Smith, Flowers and Larkin, 2009:33). The challenge of establishing a practical research approach has occupied many authors and researchers and led to a significant body of work (*e.g.*, Giorgi, 1985; van Manen, 1990; Smith, 1996; Todres, 2000).

In developing IPA, Smith drew broadly from phenomenological approaches: most phenomenologists agree that the key focus of phenomenology is a “return to embodied, experiential meanings... fresh, complex, rich descriptions of a phenomenon as it is concretely lived” (Finlay, 2009:6) and that phenomenological research methods should be “responsive to both the phenomenon and the subjective interconnection between the researcher and the researched” (Finlay, 2009:7). Phenomenologists agree that subjectivity is key to the phenomenological research process and that the researcher should work to be open to other

viewpoints and to try to see the world anew. This phenomenological attitude has been referred to as “naïve openness [combined with] critical self-awareness” (Finlay, 2008:29) or “wonder that is highly empathic” (Wertz, 2005:172) and can also be traced back to Husserl’s writings on the natural (everyday) attitude (explored in Moran, 2002:128) and the phenomenological (reflexive) attitude (explored in Moran, 2002:138). IPA is concerned with “human lived experience, and posits that experience can be understood via an examination of the meanings that people impress on it. These meanings, in turn, may illuminate the embodied, cognitive-affective and existential domains of psychology” (Smith, Flowers and Larkin, 2009:34). IPA prioritises the participant’s views. The participant, rather than the researcher, is considered the expert, making IPA, like many other qualitative approaches, a ‘bottom-up’ approach. IPA explores the meaning-making process of individuals, so it explores not just what the participant describes as having occurred, but the significance of that experience to the participant, including the language that they choose to use. Smith defines IPA as “an attempt to unravel the meanings contained in ... accounts through a process of interpretative engagement with the texts and transcripts” (Smith, 1997:189). IPA retains a focus on the individual experience whilst also seeking to identify commonalities shared by other individuals with a similar experience; hence the focus on selecting a homogenous group of participants.

The second main influence on IPA is the field of hermeneutics (interpretation). Smith, Flowers and Larkin (2009) identify key thinkers whose work is relevant to IPA: Heidegger, Gadamer, Schleirmacher and, more recently, Ricoeur. Smith’s approach is less prescriptive and more interpretative than approaches following descriptive phenomenology, but he offers more guidance than many of the hermeneutic approaches. IPA analyses divergence and convergence across experiences, while retaining a focus on the texture of individual experience. IPA studies tend to result in interpretative commentaries on experiences of a particular phenomenon, which include references to and extracts from individual accounts. IPA combines aspects from both phenomenology and hermeneutics in that it attempts to get as close as possible to the lived experience of the participant, whilst recognising that interpretation is a key and inevitable part of the process, for both the participant and the researcher (Smith, Flowers and Larkin, 2009:37). IPA acknowledges the effect of the researcher’s own world view and the interaction between the researcher and the participant (Willig, 2001:52); thus, the resulting analysis is the researcher’s interpretation of the participant’s interpretation of the experience, the ‘double hermeneutic’ (Smith and Osborn, 2003). This links well with my initial aim of gaining an insight into the experiences of participants, whilst recognising the impact that I will inevitably have as the researcher. Because IPA analysis is a subjective interpretation, it is especially important that the process is transparent and plausible to others: IPA requires researcher reflexivity throughout the

process. As my methodology is feminist IPA, I apply a feminist approach to reflexivity, as discussed in Sections 5.3 and 5.4.

Finally, IPA is influenced by idiography, a focus on the particular. IPA studies generally focus on a small number of experiences or accounts, sometimes even on a single experience (Eatough and Smith, 2006; Shinebourne and Smith, 2009b; Rhodes and Smith, 2010). Each case is analysed individually and then a picture of the shared themes of that experience across cases is developed, whilst retaining the individual experiences and distinctive accounts of each participant. Focusing on a small number of participants allows for a depth and richness that would not be possible with larger studies. Focusing on the particular supports increased understanding of the phenomenon, rather than seeking to test a hypothesis. There is a parallel between critiques of the feminist tradition of ‘giving voice’ (Tarule, 1996) and IPA’s idiographic focus; both run the risk of neglecting wider social, cultural and political influences and how these may affect or limit participants’ choices and stories (*e.g.*, Bordo, 1997). I have sought to guard against this by including a contextual chapter (Chapter 3), through references throughout the thesis to wider contextual factors and through the development of a micro-meso-macro framework (Section 11.3).

### **5.2.3     *Choosing IPA***

My aim of exploring experiences from the perspective of HIV positive mothers clearly pointed to a qualitative methodology. There are many qualitative approaches (see, for example, Willig and Stainton-Rogers, 2008), including grounded theory and narrative enquiry. I ultimately decided on a phenomenological approach, both because it is well suited to topics with little existing research and because it emphasises women’s lived experiences; I was interested specifically in exploring Jamaican mothers’ lived experiences concerning disclosure of maternal HIV to their children. There are several phenomenological research options, but IPA is the most suited to fully recognising the impact of the researcher on the research process. I felt this was particularly important given my position as an outsider in the Jamaican context.

As discussed above (in Section 5.2.2), IPA is informed by phenomenology, hermeneutics and idiography: IPA is unique in its combination of these three fields. IPA focuses on lived experience, working to identify the essence of a phenomenon or shared experience. Unlike other more descriptive forms of phenomenology, IPA focuses on interpretation, that is, the participant’s interpretation of the experience and the researcher’s interpretation of their account, the double hermeneutic (Smith and Osborn, 2003). Having considered both grounded theory and phenomenology, I concluded that a phenomenological approach was more suited to my study because of my interest in exploring the women’s experiences from their perspective, with

a view to gaining an insight into their lives, decisions and behaviours. Streubert-Speziale and Rinaldi-Carpenter (2007) see phenomenology as well suited to areas with little or no existing research, making it ideal for this study, which seeks to illuminate an experience of which little is known, in order to help inform practice. Todres and Holloway (2006) find that focusing on key human perspectives means that, unlike other methods, such as participant observation, phenomenology is attractive and meaningful to both researchers and participants, in line with my desire for a bottom-up study. IPA is concerned with lived experience and especially with how participants make sense of that experience; it is therefore well-suited to gathering participant interpretations of a particular phenomenon (in this case, maternal disclosure experiences), and through reflection and analysis, to putting the perspectives together to create a body of characteristics representing the essence of that phenomenon. Smith (2011:10) states that the meaning making process, which includes both participants and researcher, demonstrates “a chain of connection between embodied experience, talk about that experience and a participant’s making sense of, and emotional reaction to, that experience.”

#### **5.2.4     *The 'double hermeneutic' and the 'hermeneutic circle'***

*“In the social sciences, there is only interpretation. Nothing speaks for itself.”*

(Denzin and Lincoln, 1994:500).

I also needed to consider how to interpret the interpretations of the experiences expressed by my participants. The ‘hermeneutic circle’, from Heidegger’s work, refers to the spiralling process whereby the researcher examines the individual parts of lived experience, then the whole text and back again, until a level of understanding and meaning is reached. In my research, this is necessarily through the lens of an outsider. A feminist approach enhances this understanding by considering the impact of power and difference on the research process, on women’s experiences and on how these experiences are represented. The hermeneutic circle refers to the relationship between the ‘part’ and the ‘whole’, with the ‘part’ only being fully understood within the context of the ‘whole’. For example, the meaning of a single word may only be understood when seen within a complete sentence (Smith, Flowers and Larkin, 2009:28). Smith (2007:6) illustrates this concept by describing the process by which he takes his place, pre-interview, on the hermeneutic circle, complete with his own preconceptions, which he attempts to acknowledge. He begins the interview, focussed on the participant, open and non-judgemental, and together throughout the interview, they co-construct an account. After the interview, Smith returns to his point on the hermeneutic circle, where he retrieves his

preconceptions (whilst still recognising them), but he is also different now, influenced by the interview with the participant. This process continues as he reviews, questions and analyses the interview.

IPA is always interpretative but there are different levels of interpretation: the initial interpretation offered by the participant (which may be simple or sophisticated, and may be contradictory or evolve during the interview) and the subsequent layers of interpretation developed by the researcher. Section 6.6.3 details my analysis process, from initial comments on content, language and possible meaning, through to the application of more conceptual tools to develop the interpretation. Smith, Flowers and Larkin, (2009:36–37) give an example of researcher interpretation which involves the comparisons put forward by a particular participant, who experienced back pain, about how she was losing out in comparison with a set of other ‘selves’, followed by an examination of metaphors and finally an examination of temporal shifts.

IPA takes a middle ground in terms of the hermeneutics of empathy and of suspicion, as identified by Ricoeur, with the researcher making decisions as to the most appropriate response for drawing out the meaning of the experience (Smith, Flowers and Larkin, 2009:36).

Conforming to IPA expectations, I engaged with both the hermeneutics of empathy (empathising, identifying, understanding) and questioning hermeneutics (*i.e.*, probing, questioning, exploring participant’s interpretation) but did not go so far as Ricoeur’s (1970) hermeneutics of suspicion, which involve doubting and disbelieving. Smith and Osborn (2007) provide some specific questions the researcher can use to develop the questioning hermeneutics aspect of the analysis: “1. What is the person trying to achieve here? 2. Is something leaking out here that wasn’t intended? 3. Do I have a sense of something going on here that maybe the participants themselves are less aware of?” (Smith and Osborn, 2007:53). This emphasis on interpretation is important to avoid the analysis being too descriptive, a common criticism of IPA (Larkin, Watts and Clifton, 2006:103).

### **5.2.5 *Bracketing and hermeneutic reflexivity in IPA***

A key debate within IPA, as well as other phenomenological approaches, is the concept of bracketing. Bracketing (also sometimes referred to as the epoché or phenomenological reduction) means that the researcher should aim to set aside or ‘bracket’ all prior understandings/knowledge, including culture, context and history to access the essence of the phenomena. Edmund Husserl (1859–1938), the ‘father’ of Phenomenology, who introduced this process, believed in “pure phenomenology” and that phenomenology is “inferior in

methodological rigour to none (*sic.*) of the modern sciences” (Husserl in Moran, 2002:124). He defined phenomenology as “the science of consciousness” (Husserl in Moran, 2002:127) and stressed the importance of “going back to the things themselves” (Husserl in Moran, 2002:67) and the “intentionality” of consciousness (Husserl in Moran 2002:84–5). Other authors (*e.g.*, Ashworth, 1996) believe that the researcher must set aside scientific theories and knowledge, thoughts about the ‘truth’ of what the participant says and the researcher’s own personal views/experiences. The bracketing attitude must pervade the entire research process, rather than just being the first step, as is often presumed by novice researchers (Finlay, 2009); it is much more than merely acknowledging one’s own possible preconceptions at the start of the research process. A great deal of debate exists amongst phenomenologists about what bracketing means and whether it is genuinely possible to achieve. Heidegger (1889–1976) in his 1962 work ‘Being and Time’ moved away from Husserl’s focus on consciousness and became interested in the idea of *Da-sein* or being-in-the-world (Heidegger in Moran 2002:288–9) and the contexts in which people exist. He challenged Husserl’s concept of bracketing and believed that it is impossible for us to bracket as we cannot separate ourselves from our views and experiences or be completely neutral—the best we can manage is interpretation.

Smith, Flowers and Larkin (2009:24) link the more traditional concept of bracketing with more contemporary and practical concepts of researcher reflexivity. Researcher reflexivity can be defined as an awareness on the researcher’s part of the impact that they, as a particular individual, necessarily have on the research process, recognising that “knowledge cannot be separated from the knower” (Steedman, 1991:53). As described by Smith, Flowers and Larkin (2009), I sought to be open, accepting and non-judgmental, rather than to ‘bracket’ in the Husserlian sense. This approach is in line with feminist research which requires an examination of researcher beliefs and investments as part of the reflexive process (see Section 5.4.1.)

As IPA does not involve bracketing in the Husserlian sense of setting aside one’s prior knowledge and understanding (Smith, 2004), IPA therefore does not conform to the definition of phenomenology put forward by Giorgi (1985). However, Smith argues that the method explores the lived experiences of individuals and is therefore phenomenological in its concern for personal meaning-making. In line with other methods which draw on hermeneutic phenomenology, IPA focuses on interpreting findings within their context, including prior experiences as potential sources of knowledge and the opportunity for sensitisation towards issues and meanings (as opposed to descriptive phenomenology’s focus on describing universal structures and bracketing prior experiences) (Holloway and Wheeler, 2010:228). Some scholars, such as Finlay (2009), prefer to blur the distinction between descriptive and interpretative

approaches and see them more as a spectrum. Similarly, Langdrige (2008:1131) sees such distinctions as “antithetical to the spirit of the phenomenological tradition that prizes individuality and creativity”. For IPA purposes, it is not necessary to ‘bracket’ one’s preconceptions to this extent; indeed it is recognised as impossible to fully do so because “we will always fall short of this as the researcher is also part of the world and we can never fully escape the preconceptions our world brings with us” (Larkin, Watts and Clifton, 2006:107).

In IPA it is sufficient to attempt to recognise and acknowledge one’s influences and preconceptions. This interpretation of bracketing sits well with the concept of hermeneutic reflexivity in IPA and is more compatible with the hermeneutic branch of phenomenology, rather than the ‘purer’, descriptive form of Husserl, and more recently, Giorgi (1985). Husserl wanted to capture the essence of experience itself, to examine the very nature of consciousness (Smith, Flowers and Larkin, 2009:14); IPA has the simpler, and more practical aim of examining the “particular experiences” of “particular people” (Smith, Flowers and Larkin, 2009:16). In recognition of the challenges of acknowledging preconceptions, Smith, Flowers and Larkin (2009:35) advocate a “cyclical” approach to bracketing as well as researcher reflexivity. The authors see IPA as more closely linked to Heidegger’s connections between interpretation and fore-understanding, making bracketing in IPA more dynamic and cyclical, whilst acknowledging that true bracketing can never be fully achieved (Smith, Flowers and Larkin, 2009:24).

Reflexivity is a challenging undertaking. Shaw (2010) detailed her reflexivity experience in practice whilst using IPA to research young women's experiences of breastfeeding. She described an interaction between herself and a 16 year old mother who becomes accidentally pregnant with her second child whilst her first baby is 2 months old. Shaw used this example to highlight the role of hermeneutic reflexivity to support her in managing how she interacted with participants and to explore how these interactions affect her “pre-existing beliefs and knowledge—[my] fore-understandings—” and bring new insight to the experience being explored (Shaw, 2010:241). Shaw linked her response to being told about the pregnancy to her own religious upbringing, and social, political and health discourses which discourage teenage pregnancy and disparage young mothers. In this way she demonstrated the challenges of remaining open and non-judgmental in practice: her response was “[intake of breath] ‘Oh my God!’” (Shaw, 2010:237). Shaw went on to describe how she moved from a position of “unreflective consciousness ... living in the moment” (Finlay, 2003:109) to a position of “reflective consciousness” or “self-reflective consciousness” (Finlay, 2003:109), where experience and/or the self becomes the object of reflection.

### **5.2.6      *Limitations of IPA***

The main critique of idiography is shared across many qualitative methodologies: the small study size means that findings are not statistically generalisable, although they aim to have theoretical relevance. The goal of IPA studies is not to produce generalisable results; rather, they aim to illuminate a particular experience, and to provide insight to help others understand aspects of that experience. These insights might provide ideas for further study, help change or develop a service to better meet its users' needs, as well as illuminating aspects of wider experiences. Sarantakos (1998) discusses the qualitative approach to representativeness and generalisability. In line with his analysis, the participants in this study would not necessarily be representative of the population being studied (*i.e.*, HIV positive mothers) and the sample size will be too small to draw conclusions generalisable to all HIV positive mothers. However, the study will give some insight into the experiences of the women involved and can help inform future work: having identified the existence of an experience, we know that it exists within a particular population or culture, although we cannot know how many people might share it, or elements of it (Willig, 2001:17).

Some authors have questioned the ability of IPA studies to have wider relevance and to acknowledge broader contextual factors, such as race, poverty and gender (Willig, 2001:64–64). Braun and Clarke (2013:180–183) express similar concerns, stating that the “role of social-cultural context in IPA is often unclear”. I worked to overcome this by interweaving these issues throughout the process, through applying feminist principles to the research process, including feminist reflexivity and by applying a macro-meso-micro framework to the themes, as discussed in Chapter 11. Braun and Clarke (2013:180–183) also find that, due to a lack of clear guidance about higher level interpretative analysis, IPA studies may risk merely describing the participants' experiences. I countered this by applying conceptual resources including emotion work (Hochschild, 1983), governmentality (Burchell, Gordon and Miller, 1991), responsibilisation (Lupton, 2011), maternal visibility (Garey, 2011) and reciprocity (Hansen, 2011).

## **5.3      Combining a feminist approach with IPA**

### **5.3.1      *What is feminist research?***

Feminist research takes women's experience as its focus (Harding, 1987). IPA prioritises the views and experiences of the participants (Smith, Flower and Larkin, 2009) and takes into account the double hermeneutic (Smith and Osborn, 2003). A feminist approach to IPA additionally allowed me to use feminist reflexivity to focus on issues of power within research



and within the participants' wider experiences. Hawkesworth, (1994:98) believes that the "goal of feminist scholarship is to transform traditional disciplines, purging them of androcentric bias, reshaping dominant paradigms so that women's needs, interests, activities, and concerns can be analysed and understood systematically, and generating research methodologies that are neither gender-biased nor gender-blind." Feminist attention to power problematises inequalities both within the research relationship and within wider society thus highlighting issues within the research and policy construction processes. A feminist approach allowed me to challenge underlying assumptions prevalent in the existing literature (including the belief that it is 'right' for women to disclose their status to their children).

Feminist reflexivity is a key element of feminist research. Specifically, while conducting my research, I considered my position as an 'outsider' in the Jamaican context, the impact of race, class, education, age and the respective power of myself as researcher and of my participants within the interviews. I believe that a feminist approach can enhance conventional IPA by further emphasising reflexivity to attend to issues of power and difference within the research relationship (Burman, 2006) and increasing awareness of power dynamics in wider society (Burman, 2006; Ackerly and True, 2010), whilst exploring and interpreting lived experience. Focusing on these areas helped me to design my research carefully, conduct interviews, analysis and interpretation sensitively, consider ethical issues and the potential impact of my research on participants' lives and on research outcomes (Shaw, 2010).

I draw on Shefer's (2004) understanding of feminism as a collection of intellectual, social and political movements whose aim is the equality of women. These movements challenge existing institutional and social structures, which, through tradition and attitude, disempower and subordinate women (Shefer, 2004). I am interested in 'feminist research' or a 'feminist approach to research'. How does feminist research differ from research which is simply about women or gender? I argue that feminist research is feminist because of the focus, approach and purpose the researcher brings to the work and these are characterised by particular principles, though these, too, vary, according to different authors. I adhere to the definition proposed by Ollivier and Tremblay (2000) who state that feminist research has three key elements. Firstly, feminist research both constructs new knowledge and seeks to create social change, particularly in relation to challenging the multiple forms of social oppression women face. My thesis explores the experiences of HIV positive women in relation to their experiences of talking to their children about HIV; this is an area about which little is known in the Jamaican context. My research challenges assumptions about the disclosure binary, that disclosure *per se* is necessarily positive or desirable, and aims to inform future research, policy and practice in relation to this.

Secondly, Ollivier and Tremblay (2000) believe that feminist research is grounded in feminist values, which guide the entire research process and inform all decisions. My research focuses on women's experiences, voices, and sense-making whilst recognising that the world and institutions within which the research is conducted are still patriarchal, that is, that power is generally held by men. I did this by linking women's experiences to the wider literature on, for example, mothering and emotion work (Hochschild, 1983). I sought to conduct my research in an ethical, sensitive and respectful manner, from formulating my research question, which is itself informed by women's experiences, albeit in a different context (Clifford, 2006), to recruiting, interviewing, analysing, interpreting and disseminating the results. I recognised the women as 'experts' in their own experiences, included their full quotes in the original Jamaican Patois where applicable (in footnotes) as well as alongside my questions or comments to give context and an insight into the interview dynamic. I also referred to the Jamaican context and sought to recognise women's choice and agency within the constraints of their day to day lives.

Thirdly, Ollivier and Tremblay (2000) see diversity as a key element of feminist research. It is both inter- and trans-disciplinary, utilises multiple methods and methodologies and is constantly evolving and developing. It therefore incorporates a recognition of diversity and antiracist perspectives and focuses on empowering all women, including those traditionally marginalised. This feminist research emphasis on diversity adds an additional dimension to the more focussed approach of IPA; in terms of my research this diversity is demonstrated through my focus on poor, black HIV positive women, who can be viewed as marginalised (see Section 6.6.1), and in my attempts to include a reflexive approach with attention to the impact of power and difference. Additionally, I, as a white, British HIV negative woman, was an 'outsider', which brought additional considerations to the interview, interpretation and analysis processes. I also employed feminist reflexivity (Burman, 2006) to theorise power and difference within research relationships through a critical feminist lens and reflected on my position as a white middle class mother researching the experiences of poor black mothers.

### **5.3.2 *Existing research using feminist IPA***

Combining elements of a feminist approach to IPA is not unusual, but few authors are explicit about how this approach is developed and applied. The articles I identified are all based in countries from the Global North, although one focuses on Muslim women, the headscarf, and emancipation in The Netherlands (Lorasdagi, 2009), thus highlighting a traditionally Majority World/Global South issue, increasingly emotive in light of recent political events. Lorasdagi (2009) does not describe in detail how her approach to IPA is feminist, but the article focuses on traditionally feminist issues such as the oppression of women, patriarchal social structures, and

the feminist practice of ‘giving voice’ (Tarule, 1996). The author also expressed her hope that the research will contribute to “feminist and liberation psychology” (Lorasdagi, 2009:328). Kastrani, Deliyanni-Kouimtzi and Athanasiades (2015), using IPA to explore the experiences of the gendered therapeutic relationship from the perspective of Greek female clients also drew on a feminist viewpoint to understand gender as a political, social and psychological influence, although there is little detail on how this is done in practice. Bowyer, Swanston and Vetere (2015) studied the experiences of girls aged 10–16 years transitioning into temporary accommodation following domestic violence perpetrated by men against their mothers. The authors applied “a feminist and systems perspective” addressing issues of power, responsibility, safety and violence in the mothering role (Bowyer, Swanston and Vetere, 2015:306).

Leve, Rubin and Pusic (2011), writing about the risks and responsibilities associated with elective cosmetic surgery in the USA, included a more detailed explanation of how they combine a feminist approach with IPA. They identify a tension in previous work between voice-centred (Tarule, 1996) or ‘agency’ perspectives (Pitts-Taylor, 2007) and culture-centred (*e.g.*, Bordo, 1997) or ‘structure’ perspectives (Pitts-Taylor, 2007). They seek to address this tension by exploring women’s experiences of cosmetic surgery whilst also situating these narratives within wider social, cultural and political frameworks. Thus, they address issues of normalisation, responsibilisation, (*e.g.*, Lupton, 2011), ‘good’/‘bad’ patients (Leve, Rubin and Pusic, 2011:134) and the concepts of risk and responsibility (*ibid.* 124), obligation and ‘choice’ (*ibid.* 137). The authors explore how individual women undergoing elective cosmetic surgery reflect or resist the “dominant cultural repertoires of risk” (Leve, Rubin and Pusic, 2011:123). They seek to explore medical and cultural discourses surrounding cosmetic procedures and perceptions of the physical body as well as the process of individual choice, responsibility and the perception of risk. In this way, they merge the particular with the wider sociocultural context. The thematic findings (Chapters 7–9) and my reflections (Chapter 10) illustrate similar concepts in relation to maternal disclosure of HIV, particularly responsibilisation, maternal visibility, reciprocity in mother-child relationships, and the ways in which mothers utilise emotion work as a strategy to challenge negative constructions of mothers living with HIV. Women work to present themselves as ‘good’ mothers in the context of HIV and through the choices they make concerning talking to their children about their HIV and their decisions to have children after an HIV diagnosis.

Other IPA articles, whilst not explicitly using feminist IPA, reference feminism or a feminist perspective. Wood *et al.* (2016) write about women choosing a non-hospital birthplace in Canada, stating that their study “was framed through a feminist perspective to ensure that

women's voices and experiences are understood for the goal of improving care" (Wood *et al.* 2016:14) but do not provide additional detail on how this perspective was applied or by which feminist theories it was informed. Some themes the authors identify (such as personal agency and women's empowerment) are aligned with a feminist perspective. In an IPA article on 'free birthing' in the UK (Feeley and Thomson, 2016), one of the researchers (interviewed by the other as part of their commitment to reflexivity) identifies herself as a midwife-researcher with a women-centred approach to midwifery care. An identified theme: "Contextualising 'herstories'" has clear feminist connotations and the article refers to concepts such as agency, autonomy and reflexivity throughout.

## **5.4 What are the benefits of combining a feminist approach with IPA?**

I will now describe the practicalities of combining IPA with a feminist approach. The two may appear contradictory in some areas; here I describe how these tensions are managed within my research, and how, in some cases, these apparent contradictions can, in fact, complement each other and strengthen the approach. I believe there are two distinct, but overlapping benefits to combining a feminist approach with IPA. Feminist reflexivity, with its attention to power and difference (Burman, 2006) enables a more robust approach to considering my position as an outsider researcher and how this impacts on the research. The second benefit is related to how a feminist approach supports the inclusion of broader structural and contextual factors, which affect the women's lives, and which IPA, with its idiographic focus, is less well positioned to achieve.

### **5.4.1 What does feminist reflexivity add to my research?**

This section highlights the differences between feminist reflexivity (Burman, 1994, 2006) and hermeneutic reflexivity (Shaw, 2010). Burman (1994) proposes that the focus on power distinguishes feminist reflexivity from other forms of reflexivity. Burman (2006:316) takes "reflexivity to broadly identify research that refuses the scientific positioning of the neutral observer, to instead highlight and explore the nature of researcher involvement as a relevant resource." Burman (2006), whilst noting the increasing popularity of reflexivity and the participation agenda within health, education and development, urges caution, pointing out the risk that reflexivity "educates the emotions, and normalises some subjective accounts while pathologising or silencing others" whilst the drive for increased participation risks "producing a reified, homogenised and consensual model of 'communities' under investigation (in ways that reinforce colonial paternalism and privilege) and of reducing structural issues to personal ones" (Burman, 2006: 324). Burman suggests addressing this by efforts to "locate reflexive analysis

within institutional relationships that precisely interrogate and challenge the constitution of the narrative position of the accounter, rather than explore their identity” Burman, 2006:327). Resolving these issues is beyond the scope of this thesis; however, in my research I sought to keep these concepts in mind, throughout the analysis process and in my reflections in Chapter 10. Bondi and colleagues (2005) link reflexivity to emotions and extend the definition to include the concept of emotional geographies: “the location of emotion in both bodies and places, the emotional relationality of people and environments, and representations of emotional geographies” (Bondi, Davidson and Smith, 2005:4).

Feminist reflexivity supports the interpretative element of IPA by emphasising, not only the impact of the researcher on the research process, but also the power dynamics at play both on an individual and a societal level. I recognised my likely impact on the research process and sought to examine this and acknowledge the pros and cons of, for example, my position as an ‘outsider’ in the Jamaican context. I avoided voicing my own opinions or experiences and emphasised that the participants were the experts on their experiences. Whilst working to allow the participants to identify and explore the issues related to disclosure important to them, I also strove to recognise the impact of my views, experiences and background on the interview and analysis process. I hope this focus on reflexivity helped me conduct my research with sensitivity, considering the needs, priorities and realities of participants and interpreting their accounts according to their implicit and explicit meanings. I have incorporated this reflexive approach throughout my research, by, for example, including a short section on my personal views and background in the Introduction (Section 1.3), and by being clear and transparent about the views and processes which inform my interpretation, analysis and writing process.

#### **5.4.2     *How does an 'outsider' interpret other people's experiences?***

As with all research studies, several factors may affect the interviews and the conclusions drawn from them. One of these is the ‘interviewer effect’ (Denscombe, 2003:190) which describes the difference between what people actually do and what they say they do. People may present themselves differently depending on the interviewer and context. Perceptions of the interviewer may vary depending on factors such as the ethnicity, age, gender, religion, and HIV status of the interviewer when compared to themselves. Researchers conducting research with populations they themselves belong to are considered insider researchers (Kanuha, 2000). Asselin (2003) considers insider research to be when the researcher and study participants share an identity, language, and experiential base. Outsider research is the reverse, where researchers and participants do not share these commonalities. Many researchers are drawn to particular areas of work because of their own experiences; insider status can be considered beneficial when it

provides additional insights and detrimental when it leads to presumed understanding or assumptions which may not reflect individual experience (Kanuha, 2000).

A feminist approach, with its focus on reflexivity and power, highlights my position as an outsider, from the Anglo-North, working in Jamaica, a postcolonial and resource-constrained setting. Although I am a woman and a mother, I was different from my participants in terms of class, race, education and HIV status, and these differences have an impact on my experiences and views, as they do on those of my participants and on the ways in which we interact. I was conscious of this position presenting both challenges to my understanding and relationships as well as benefits in eliciting more detailed descriptions and reflections as participants attempted to describe their experience to someone perceived as not having pre-existing knowledge of it. Additionally, in the small and close-knit community of Kingston, being perceived as different and separate can have the additional benefit of engendering trust and encouraging people to be more comfortable and detailed in their communication, assuming that I did not have local connections. This is discussed further in Chapter 10.

## **5.5 Chapter summary**

This chapter introduced and situated IPA, introduced the concept of feminist research and identified and described existing work using feminist IPA. I then went on to describe how I applied a feminist approach to IPA to my research, paying particular attention to my use of interpretation and feminist reflexivity and the ways in which combining these methodologies can strengthen the research. For example, this approach allowed me to address some of the issues of applying IPA, a methodology originating in the UK and emerging from historical factors within psychology, a predominantly positivist, quantitative field in the Anglo-North, to a resource-constrained context. Although IPA is idiographic and focuses on the experiences of a small number of participants, these experiences can help shed light on the disclosure experiences of HIV positive mothers and draw attention to contextual factors affecting these experiences.

Using a feminist lens throughout the research process allowed me to include a feminist approach to reflexivity (Burman, 2006), as well as the more hermeneutic reflexivity commonly applied in IPA (see Shaw, 2010). This helped me to include reflections on working as an outsider, and to consider power dynamics whilst retaining a focus on the experiences and views of the women I interviewed. It allowed me to challenge simplistic and judgmental assumptions and to include a more nuanced and sensitive picture of women's experiences, incorporating wider issues of gender and power (Harding, 1987:8–9) and recognising the women's emotion

work and protective mothering activities. I have argued that this approach allows me to put women at the centre of the research process, not only in terms of the topic but through the process of prioritising women's voices and experiences, in line with both feminist research and IPA. This openness is intended to allow women to discuss their choices and agency, and myself as researcher to discuss issues of power, both within the research process and within wider society. The next chapter describes the research process (including ethical approval, accessing organisations and participants, the interview process), as well as introducing the themes, participants and analysis process.

## **Chapter 6: Methods, Participants and the Analysis Process**

### **6.1 Introduction**

I carried out single interviews with 15 HIV positive mothers associated with one HIV clinic and one HIV NGO, in Kingston, Jamaica in 2012. The women I interviewed were HIV positive, aged over 18 years and had at least one seronegative child aged over 10 years. In this chapter, I first describe how I obtained ethical approval, considered issues of sample size and homogeneity, accessed organisations and worked with gatekeepers within them. I then discuss the process of participant recruitment and consent and describe the interviews themselves, including language issues. The chapter concludes by introducing the participants, themes and analysis process.

In addition to the interviews with HIV positive mothers, I spoke with and interviewed a range of HIV professionals in Kingston in 2012 and 2013. Although I obtained ethical approval and individual consent for these interviews, I did not analyse them in-depth as I wanted to retain a clear focus on the perspective of the HIV positive mothers I interviewed. Instead, I used them as a resource to help familiarise me with the HIV context in Jamaica.

### **6.2 Obtaining ethical approval**

I obtained ethical approval for my study in 2012 from two ethical review boards (City, University of London, School of Health Sciences and the University of the West Indies, Faculty of Medical Science) and later, from the Jamaican Ministry of Health. Ethical review exists to protect interview participants, researchers and institutions. The three focal points of ethical approval are: respect for persons, beneficence, and justice. *Respect for persons* is generally understood to mean that research participants should be treated as autonomous agents and that those with diminished autonomy, such as children, are entitled to protection (Vanderpool, 1996). This principle also includes the requirement for informed consent to be obtained from participants, with most studies giving some assurance of confidentiality and anonymity (Hemmings, 2006). *Beneficence* refers to researchers' obligation to maximise potential benefits and minimise potential harm (Hemmings 2006). *Justice* considers who should receive the benefits of research and bear its burdens (Hemmings 2006).

I committed to safeguarding the confidentiality of participants (including organisations), by removing identifying information to de-identify all data and by referring to participants by



pseudonyms in any publication arising from the research. Additionally, participants were not required to give me (as researcher) their real name at the time of the interview. I explained the information leaflet and consent forms verbally to participants as well as providing information in a written form. Participants had the opportunity to ask questions and to withdraw at any time. Data was kept in a locked filing cabinet and a password protected computer. The information leaflet, consent form and ethical approval letters can be found in Appendices IV–VI.

## **6.3 Sampling issues**

### **6.3.1 Sample size**

My research is at the upper end of typical IPA sample sizes with 15 participants. I found that the analysis process generated a large number of themes and sub-themes and that the process was time-consuming and unwieldy at times. It can be difficult to move from individual analysis to cross case analysis and to retain the idiographic focus, especially when working with larger numbers, as I was. At several points during the planning and data collection processes, I considered how many women I should interview and whether, as an ‘outsider’ researcher, there would be some benefit in multiple interviews with each participant. This would have been straightforward with the NGO participants, and, although more challenging, I believe that it would have been possible with at least some of the participants from the clinic. However, after some preliminary analysis, I decided against this approach because I felt that the interviews contained sufficient depth and richness and I was not sure what would be gained by additional interviews. I felt that the women had shared with me what they could (and what they couldn’t or chose not to say was also interesting) and that to develop relationships further would take much more than simply one or two additional interviews. This was further supported by the examination of the interview with a participant with whom I already had an existing relationship: it did not seem to offer more richness than the other interviews, and was, in fact, slightly confusing due to her assumptions about what I might already know.

Sample size is a recurring debate in IPA. Due to the depth of analysis and the idiographic focus of IPA, sample sizes are small compared to many methodologies. However, study designs vary considerably from those using IPA alone (including studies using multiple groups, multiple interviews or multiple types of data) to mixed methods studies. As a result, research studies using IPA may look very different, ranging from a single participant (*e.g.*, Eatough and Smith, 2006; Shinebourne and Smith, 2009; Rhodes and Smith, 2010), to more typical sample sizes of 4–8 participants (*e.g.*, Smith, 1999; Phillips, Elander and Montague, 2014; Wagstaff *et al.*,

2014). There are also a few studies with slightly larger sample sizes of 10–18 participants (*e.g.*, Flowers, Knussen and Duncan, 2001; Dibb and Kamalesh, 2012).

### **6.3.2     *Issues of homogeneity***

In line with IPA's ethos, I selected my sample purposively rather than using probability methods so that the women I interviewed could give me an insight into their specific experience. There have been numerous discussions within the online IPA group and at London IPA meetings I have attended about the issue of homogeneity. Smith and colleagues suggest that researchers use a 'fairly' or 'pretty' homogenous sample (Smith, Flowers and Larkin, 2009:49–50). My understanding of this is that it depends how much existing research there is on the topic in question and thus how much information is already known about that particular group or topic. The more research there is, the more specific the criteria and the more homogenous the group. There is very little research on maternal disclosure of HIV to seronegative children in the Jamaican context and so my criteria were quite broad: a) HIV positive mothers aged over 18; b) diagnosed at least one year ago/comfortable talking about their HIV status; and c) with at least one seronegative child aged over 10. Within my sample, there was therefore variation in women's ages, number of children, living arrangements, educational level, employment status, whether they had fully, partially or not disclosed to their children. The small sample size and the focus on one homogenous group tends to mean that effective IPA studies focus on the perspective of one particular group, in my case HIV positive Jamaican women.

## **6.4     Access**

### **6.4.1     *Accessing organisations and working with gatekeepers***

Over a period of several months, as I explored the organisations and individuals active in the HIV field in Jamaica, I established strong links with one clinic (hereafter referred to as 'the HIV clinic' or 'the clinic') and one NGO (hereafter referred to as 'the HIV NGO' or 'the NGO'). In developing these relationships, I (inadvertently, as I did not discover this article until much later) made use of most of the seven tactics identified by Shenton and Hayter (2004:224–227) as those employed by researchers to gain access to organisations: 1. The "known sponsor approach"; 2. Phased entry; 3. Reciprocity; 4. Openness; 5. Demonstration of professional suitability; 6. Exploitation of past links with the organisations; 7. Receptiveness to suggestions. I was fortunate that I was based in Kingston, Jamaica for a year before I started the study and two years afterwards, as this provided me with some background knowledge on working in Jamaica and reduced the time pressures on data collection. However, I had not worked in Jamaica previously and I did not have existing links with organisations and individuals, crucial

in Jamaica's close-knit working community, so I was unable to employ Tactic 6 (Exploitation of past links with the organisations). To some extent, I did employ a version of the other six tactics. Whilst no specific links between City, University of London and the University of the West Indies exist, as far as I am aware, City, University of London is known as a reputable British university (Tactic 1). The HIV clinic has an explicit aim to support research; allowing me access was a relatively straightforward way of helping to meet that aim (Tactic 3). My role as a PhD student and previous experience helped to establish my professional suitability (Tactic 5) and I endeavoured to be open (Tactic 4), receptive to suggestions and willing to collaborate (Tactic 3).

With the HIV NGO, I took a slightly different approach, focusing more on phased entry (Tactic 2) and reciprocity (Tactic 3), although the HIV NGO also has a commitment to supporting research. I had not initially intended to interview women from the HIV NGO so my relationship with them was more about developing my knowledge and experience of the Jamaican context and giving something back through my role as a volunteer. During my time in Jamaica, I sat on the HIV NGO advisory committee, assisted with funding bids and business plans, and supported their Eliminating Violence Against Women project (by giving advice, helping with planning, interviewing women and enabling the use of a venue for the launch of their audio-visual presentations). My support of the HIV NGO continues, although geographical distance makes the face-to-face aspect impossible. The HIV NGO was very keen to have women involved in my study and when I was finding it a little slow getting participants at the HIV clinic, they quickly arranged interviews with several of their members.

I interviewed 12 women from the HIV clinic and 3 women from the HIV NGO. Smith, Flowers and Larkin (2009:48–9) suggest that participants are contacted through referral by gatekeepers, one's own contacts and snowballing (*i.e.*, referral by existing participants). For my study, as far as I am aware, all participants, from both the clinic and the NGO, were referred to me by gatekeepers. The role of gatekeepers is recognised in the literature as important in allowing the researcher access to particular groups (Aluwihare-Samaranayake, 2012). At the HIV clinic, gatekeepers included the clinic director, social workers, nurses, adherence counsellors and the receptionist. Although I could also have approached patients directly, I refrained from doing so because I did not want to disrupt the patients' often-complicated sequence of appointments. At the HIV NGO the gatekeepers included the coordinator and advisory board members.

The two anecdotes below help to explain my experiences of working with gatekeepers. Several weeks into my interviewing period at the HIV clinic, I felt I was getting fewer patients referred, which I thought might be a result of a change in the nursing staff, which meant that they were

less aware of my study. I was also conscious that staff were busy with their patients and perhaps did not have much time to talk to patients about participating in my study. I therefore started spending time in the waiting room, asking questions such as: “What about her? Does she meet my criteria?” I believe that I then began to get women who could not read and write confidently and who spoke in much stronger Patois. My sample is very small, but this is an indication that the staff may have been adding their own criteria to mine, either in an attempt to make my research easier or more ‘successful’, or, as one of the doctors suggested, because staff tend to work less closely with the patients of lower socioeconomic status. The interviews accessed in this way tended to be a little more challenging for me in terms of language and understanding. One of these women was the only interviewee to refer to ‘obeah’, indigenous traditional medicine used for protecting and restoring health (Hickling and James, 2008:465).

I asked the volunteer staff member responsible for organising my interviews with the HIV NGO members how she had selected the women whom she contacted to participate in my interviews. She said she used my criteria and also chose women who could read and write well, who were happy to tell their stories to me and who she thought wouldn’t ask me for anything, thereby adding the idea of protecting me from the potential demands or requests of participants. In fact, she was unable to protect me as her assumption was reflected in reality: many of the poorer women from both the clinic and the NGO directly or indirectly asked me for financial, practical or other help (*e.g.*, for clothes, for money to fix their back door, for help in getting a visa, to take their child to my home for Christmas). This strategy reflected the women’s day to day reality and their constant need to be resourceful and proactive in supporting themselves and their families and also perhaps my position as a white privileged outsider with (assumed) access to resources. Similarly, Clark (2010) in her work interviewing South African women, found that participants, even whilst acknowledging her relative lack of power, positioned her as “being able to facilitate access to assistance or solutions to problems” (Clark, 2010:4).

#### **6.4.2      *Participant recruitment and consent***

As stipulated by ethics, I displayed posters and leaflets about my study at the HIV clinic for 5 weeks prior to the beginning of the study. During this period, patients who were interested in participating could collect consent forms from the HIV clinic staff, which they were asked to sign and bring back to their next appointment. In the event that patients forgot to bring their forms or were uncomfortable taking information regarding HIV home with them, they were provided with a new copy of the consent form to sign at the beginning of the interview. In all cases, the research and process of consent was explained verbally and participants given time to read the form and consider their involvement prior to the beginning of the interview.

I decided to be present at the HIV clinic on Wednesday and Friday mornings as these days were allocated for blood tests and general appointments.<sup>11</sup> I was aware that attitudes towards time in Jamaica tend to be quite relaxed, and so I tried to be as flexible as I could. Staff (doctors, nurses, social workers, counsellors) were provided with a copy of the inclusion criteria. Patients who met these criteria and wished to participate, were directed to me immediately after their appointment. I attended the HIV clinic on 10 mornings between October 31<sup>st</sup> and December 19<sup>th</sup>, 2012 and carried out 12 interviews with clinic patients. In mid-November, I also conducted interviews at other locations with three members of the HIV NGO. The majority of the interviews were 30–45 minutes. Many (though not all) of the participants appeared to read and write reasonably confidently (one was educated to Masters level).

Shenton and Hayter (2004:227–229) write of four main tactics used by researchers to gain access to individual participants: prolonged engagement; the “chameleon” approach (where the researcher attempts to blend in); the use of “incentives”; and emphasis on the value of personal contributions. With both organisations, I found that once I had the support of the project coordinators, other key staff were supportive and helpful in facilitating access to individuals. I did find that one or two peripheral members of staff essentially ignored me through the 10 weeks that I conducted interviews, although one had begun to acknowledge me towards the end of this period. With both organisations I had contact with staff over a period of time (a longer period with the HIV NGO but more frequent contact at the HIV clinic). I did not attempt the ‘chameleon’ approach at either institution, but at the HIV clinic, when I began to take a more active role in the recruitment of participants, I sometimes stood beside the reception desk, where observing student nurses often stand, so this may have led to assumptions about my role. In addition, the fact that I am white would tend to lead to assumptions that I am a visitor, a student or staff. Although there are white Jamaicans, they make up only 0.2% of the population (*Oxford African American Studies Center*, no date) and they are not generally visible within the HIV clinic patient population. On occasions early in the process when I waited in the waiting room to see the doctor, I was conscious of being different from other patients.

With regard to the importance of personal contributions (Shenton and Hayter, 2004), I stressed to participants that they were the experts and that I was looking for their views for my study. I thanked all participants several times and I am confident that they were aware of the value of their contribution. One or two women had previously had conversations with student nurses and several had been involved in television interviews on HIV so these participants had a history of

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<sup>11</sup> Mondays were for new patients, which might mean those who have been newly diagnosed and would certainly mean those who were new to the service, so I felt that this would not be an appropriate day. Thursdays were designated for homeless people and this was not a group I was looking at in particular.

giving information or telling their stories for the benefit or education of others. Several women clearly had strong relationships with doctors and other staff at the clinic and were keen to support their work, perhaps as a way of repaying them for their support. Similarly the women from the HIV NGO may have felt that part of their role with the NGO was to support projects endorsed by the coordinator, that this was a way of giving back. It is worth noting that all of the women I interviewed from the NGO had disclosed to at least one of their children. An NGO sample may be different from a clinic based sample because participation in NGOs is voluntary and women who choose to be active members of an NGO may have different attitudes and more experience of talking about their HIV.

I touched on the issue of incentives while discussing poverty in Chapter 3. All of the women I interviewed received compensation for their participation, in the form of a drink and biscuits during the interview, a small selection of pre-packaged snacks to take away with them and a 'contribution' to their bus fare, which, for all of the women, will have more than paid for the actual costs of their travel. The compensation was more important for some women than others: those who came in specifically for the interview appointment would have needed it to cover their costs. In fact, one woman explained to me during the course of the interview that she had borrowed money to come and see me and that her costs included bus fare for herself and her ten year old and a visit to KFC for her son. For women already attending an appointment at the HIV clinic, and who would therefore have already budgeted for their travel, the money represented a small compensation for their time. The women appeared glad to receive bus fare, but did not make an issue of it beforehand; when I explained that they would receive a small compensation for their time/travel costs, but would not be paid for their participation, nobody asked how much the compensation was or made their participation dependent on it.

Overall, I felt that the support of the coordinators, nurses and social workers was a key factor in securing participation and I drew on their existing relationships to gain access to participants. Prior to the interviews and during the consent process, women were assured that their participation was voluntary and that they would not experience any disadvantage in accessing treatment if they did not want to participate, but I had felt some concern that women might feel obliged to participate. However, on my first day at the HIV clinic, the first potential participant refused to participate because she was unhappy with the use of the audio recorder. The second potential participant did agree to participate, but was quite uncomfortable about the audio recorder; no other participants mentioned any concerns about the recorder and all consented to its use. A number of women said that they could not participate due to work commitments or needing to catch their bus home. One woman said she would come up to me after her medical

appointment but did not; another agreed to an interview at an alternative location outside her working hours, but upon follow up did not return my calls. I have no way of knowing whether these were genuine reasons or polite excuses, but I felt reassured at these examples of women exercising their right to opt out of the study.

## **6.5 Interviewing and transcribing**

### **6.5.1 *Carrying out the interviews: Location and other factors***

Smith, Flowers and Larkin (2009:57) state that IPA can be used alongside a variety of methods of data collection, including interviews, diary/journal entries, personal accounts, letters or open questionnaires. However, the alternatives are all written forms of communication, and I felt that, as Jamaica is a country with a strong oral tradition and as some participants may not have a high level of education, interviews would be the most appropriate form of data collection for this study. The questions were used as a very rough guide for the purpose of ethical approval: they demonstrated the range and types of questions that I might ask (see Appendix VII). In practice, the order and wording varied from interview to interview and not all questions were used for each interview. The questions were used more in the first few interviews and with participants who were less forthcoming. In most interviews, I asked a few general questions about diagnosis, relationship with children and disclosure issues and then followed up on what the women said. For some interviews, the women told me a ‘story’ about their experiences and I occasionally responded with short prompts or by saying ‘mmm’; in these interviews I only needed to ask one or two questions. In the interviews, I sought to work through the events in the women’s lives which they perceived to be significant in terms of communicating about their HIV status with their children. The intention was that the questions would follow a chronological order, where possible, but due to the nature of interviews and recollection, information often emerged in a non-chronological order. I attempted to clarify meanings, including those which may seem obvious, avoided using new or different vocabulary or correcting the interviewee, asked open (not leading) questions and allowed the interviewee time and space to answer questions (Sin, 2010). In practice, these strategies proved a little challenging, although I became more adept as I conducted more interviews, particularly with regard to allowing silences, avoiding leading questions and gaining familiarity with local terminology. There were times when my attempts to clarify meanings were taken as lack of understanding. It is difficult to judge whether I was able to keep my reactions neutral whilst still conveying empathy and understanding, but I felt I was able to get detailed information on sensitive topics from most of the women.

At the HIV clinic, I was interviewing in a clinical setting, during normal working hours, so medical and support staff were busy with their standard duties. Like other researchers operating in clinic settings, I needed to be flexible about interview locations and timings. Craig, Joly and Zumla (2014), interviewing tuberculosis patients in a clinical setting encountered similar challenges in accessing private space, dealing with frequent interruptions, and having patients reschedule appointments due to the need to see a doctor or nurse or a desire to take a break, for example, to smoke. When planning my study, it had been agreed that I would use the conference room for my interviews. However, when I began the study, some downstairs rooms were being refurbished and the conference room was in use by a data entry clerk and at times, the nurse. I was therefore allocated the doctor's office, which was only used when staff needed a private space, for example for counselling or an HIV test. At times, I had to begin an interview in the staff kitchen (*i.e.*, introduction and consent) and then continue in the office when it became available. There were a few interruptions when staff needed to collect items such as gloves, and distractions such as the phone ringing. The space was a functioning doctor's consultation room and so was very medical with an examination couch, and medical paraphernalia such as gloves, stethoscope, and antibacterial gel. It was, for the most part, quiet, private and cool (an important consideration in Kingston). There was also a desk, a computer and three chairs; the space was very cramped and so I was unable to move the furniture into a more informal configuration. In order to eliminate the barrier of the desk and make the setting more conducive to conversation, I opted to sit in one of the chairs designated for the patient or patient's companion, so I and the participant both sat at the patient's side of the desk and left the doctor's chair unoccupied.

The HIV NGO had no formal office space but good links with a number of local organisations. The NGO interviews therefore took place in two locations. One interview took place in a doctor's consultation room at Jamaica AIDS Support for Life, another HIV NGO. This space had very similar issues to those at the HIV clinic. The other two interviews took place in a Ministry of Health building, in a large lecture room used for nurse training sessions. We occupied a small corner of the room, again sat side by side on one side of a desk. Again, we had a few interruptions as this room housed the water cooler for the building. Additionally, the air conditioner was periodically very loud, forcing the women to raise their voices.

At the HIV clinic I had an introduction through a health professional with whom participants had an ongoing (and hopefully positive) relationship. Participants were thus in a familiar setting (the clinic) where their status was known. In previous HIV work (separate from this study) in Jamaica, I had an existing relationship with some of the women and we were in a more relaxed



setting with substantial waiting time and hence we had plenty of time to get to know one another. The clinic represented a more formal setting with fewer familiar ‘anchors’ for the women, so I expected that I would need to work a little harder to establish a connection. bell hooks writes of the concept of a ‘homeplace’, a place of comfort and safety (as well as of resistance), “where black people could affirm one another” (hooks, 1990:383–384). Nelms applies this to the comprehensive AIDS Service Organisations (ASOs) where she carried out her research, stating that the ASOs “are one of the few true homeplaces for HIV-infected individuals and a space where any ancient properties, cultural bearings and HIV traditions, if such exist, can be created, maintained and shared” (Nelms, 2012:121). This could be applied to the HIV NGO, which existed as a kind of floating community, making use of various partnerships to coordinate activities and meetings, safe spaces or ‘homeplaces’. To some extent, the concept can also be applied to the HIV clinic, as the women seemed comfortable talking about their status with staff at the centre and, for many women, this was the only place that they felt able to do so. However, this attitude appeared to be reserved for interactions with staff, as I observed little interaction between patients in the waiting room, despite long waiting times. The only participant to comment on patient interaction, described how, on the day of her interview with me, she happened to see a friend in the waiting room, but prior to this neither knew that the other had HIV; when they saw each other, they said “Nuhting” (Nothing)(Sandra, Interview 1).

Referrals mainly came from the nurses and the social workers at the HIV clinic. The majority of the women who were referred to me met my criteria. In the course of one interview, I discovered that one woman had only been diagnosed with HIV 6 months previously. I continued with the interview because she clearly stated that she wanted to (the 1 year criteria was intended to protect patients who might not yet be ready to talk about their diagnosis). One other woman had been diagnosed 11 months prior to the interview and a third had a child who would turn 10 a few weeks after the interview. Both these women were also included in the data, as I considered the criteria to be a guide and was not concerned about a few weeks’ difference.

HIV positive mothers in Kingston are a relatively hard-to-reach group, partly because HIV is highly stigmatised and therefore few people disclose their status to friends and family. Mothers, especially those with young children, tend to have competing demands on their time due to childcare, housework and income generation. Because many of the women lived in deprived downtown areas of Kingston which are not considered safe for outsiders, I conducted my interviews in a clinic/NGO setting, rather than attempting to access women in their local community or homes. This meant that the women would be as comfortable as possible with regard to confidentiality, they would have already allocated the time for a clinic appointment

(which generally involves a long wait) so would not be inconvenienced (and would benefit a little as I reimbursed their bus fare) and the location is secure. Many of the women have busy and unpredictable lives and many of the clinics therefore operate, at least partially, on a drop-in basis and are amenable to appointments being rescheduled. In the event, 5 of the 15 participants were appointments, made by the social workers and NGO coordinators (3 at the HIV NGO and 2 at the HIV clinic); the other ten participants saw me after their scheduled appointment with clinic staff.

### 6.5.2 *Language*

IPA pays some attention to language, but far less than methodologies such as discourse analysis or linguistic ethnography. Smith, Flower and Larkin (2009:196) state that IPA is broadly social constructionist, but takes a less strong position on this than discursive methodologies. IPA is more concerned with making sense of a particular experience for a particular person in a particular context, focussing on hermeneutics, idiography and context, seeing experience as the topic and the individual and their meanings as the unit of analysis (*ibid*:195). In contrast, Foucauldian discourse analysis sees the focus as performative, the topic as identifying patterns of discursive action (interaction) and the unit of analysis as discursive representations (*ibid*:195). According to Pérez-Milans (2016:7) linguistic ethnography researchers use language as a tool to study “the interrelations between culture, language and social differences”. Researchers in the field of linguistic ethnography believe that language and the social world affect and shape one another (Rampton, 2007).

IPA tends more towards a treatment of language as a conduit or window into a particular experience and is less focussed on language as constructing experience (*e.g.*, Scott, 1987) as is seen in much feminist work. I see language as shaped by gender, culture and experience, as something reflexive, variable and affected by context although this view is not easily given full expression within IPA. However, IPA is a flexible methodology, which offers guidelines, rather than prescriptive steps and which does allow for some additional attention to be paid to language. I took great care in my treatment of Jamaican Patois throughout, as demonstrated by my use of a Jamaican transcriber and the reproduction of full quotes in Jamaican Patois. I also believe that the women used language to reflect on their material realities and used both language and silence as part of identity construction and presentation within the interviews. As discussed in Section 10.2, women, recognising me as an ‘outsider’, altered their language when speaking to me, in order to try to help me understand or to present themselves as more educated or more ‘respectable’. This suggests they are sophisticated users of language and adjust their

speech according to the situation, resist questioning through silence and present themselves in a positive light to counter possible assumptions of bad mothering that my questions might, inadvertently, promote.

IPA relies on verbal or written language (usually interviews, but sometimes also diaries or other written accounts) to collect information on an experience, thus assuming that language is an appropriate tool to capture a particular experience (Willig, 2001). Willig critiques the lack of attention paid to language in IPA through asking a series of questions:

*“Does language actually construct rather than describe reality?*

*Does a transcript tell us, not about the experience, but about the way in which a participant talks about the experience?*

*Rather than allowing us to describe what we think and feel, does language actually prescribe what we can think and feel?”*

(Willig, 2001: 63)

I believe that language does both—that it simultaneously prescribes what we can think and feel as well as giving us the tools to express what we think and feel. My view is based on my own experience of gradually developing my language skills over a period of a year living and working in Uruapan in Mexico where nobody I knew spoke English. I began with only a few words of Spanish and slowly became more proficient; as this happened, I became aware, of almost being another person, that originally I was constrained by my inability to express myself in Spanish, but that later, even as my language skills grew, my expression, and hence, my views and even personality, (at least as perceived by others) was still constrained by the language itself. This can be mitigated against, to an extent, depending on how articulate and creative an individual is in their quest to express their thoughts and feelings. Willig does not suggest an alternative here to the use of language, and language is a key way that people express themselves and a central element of most research and data collection. However, it might be interesting to supplement IPA with more visual methods (*e.g.*, photos, drawings, models taken or created by participants). Chambers (1983:106) argues “that poor and exploited people can and should be enabled to analyse their own reality”. To promote inclusion of under-represented groups, his methods avoid writing wherever possible and are primarily visual (pictures, symbols, physical objects). However, these methods link to oral communication and group memory, so do not entirely avoid the link to language. My participants were urban not rural,

but, to varying degrees, they can be considered to be poor and exploited. One participant (Anna), chose to show me family photographs on her phone, in an attempt to communicate her lifeworld to me.

IPA allows for language to be accounted for and the researcher may reflect upon the use of language throughout the process, beginning with the first step of analysis which calls for exploratory, linguistic and conceptual comments. Furthermore, the researcher can comment, as I have done, on the language chosen and the meanings which might lie behind this. Thus, the double hermeneutic (Smith and Osborn, 2003) can also be used as a tool to acknowledge and explore language, presentation and interpretation by both participants and researchers; this is discussed further in Chapter 10. This is an interesting debate for my thesis where there are many issues of language and understanding due to the partial or complete use of Jamaican Creole by many of my participants. I am not Jamaican and, although I lived in Jamaica for several years, my exposure to Jamaican Patois (or Creole) is limited and my understanding is not comprehensive<sup>12</sup>. I can understand and read Patois to a reasonable level, but I do not speak it and I cannot write it. It is fairly straightforward to understand written Patois, at least on a surface level; some allusions and references may escape me. As Ford-Smith (2005) writes, language “expresses the soul of the people” (Ford-Smith, 2005: xxix) and for this reason I have chosen to keep all of the interviews as they were spoken, in Patois, standard English, or something in between.

### **6.5.3      *Meaningful Pseudonyms***

I spoke with all of the women about anonymity. Some women felt uncomfortable with the tape recorder and uncertain of the process (in one case so much so that she declined to participate), whereas others asked me to use their real names (despite not having told family members about their status). Some researchers (Tilley and Gormley, 2007) see it as potentially unethical to deny a participant the right to be named and heard. However, I did not use any participant’s real name, explaining that I would give everybody a pseudonym. I did this with the intention of protecting participants: I felt that they may have been given a sense of security by my being a foreigner and that I was unable to tell at that stage where and what might be published later.

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<sup>12</sup>I had the opportunity in June 2012 to undertake some interviews on violence in the context of HIV for a local NGO; this experience gave me the opportunity to explore interviewing in the Jamaican context and helped to familiarise me with vocabulary, styles of story-telling and the issues which many women face. For example, one of these sessions introduced me to the Jamaican term ‘licky-licky’, which means ‘greedy’ (not to be confused with ‘lick’ which means ‘hit’) and to a Jamaican regional pronunciation of the word ‘uncle’ which sounds like ‘hunker’ and caused me some temporary confusion.

Afterwards, I reflected that these assumptions might have been patronising on my part and that perhaps I should have explained my reasoning in more detail. I gave the women the opportunity to choose their own pseudonym if they wished. About two thirds of the women opted to, and the remainder asked me to choose a pseudonym for them. In these cases, I was careful to choose names commonly used in Jamaica. As Vandermause and Fleming (2011) found, many of the women I interviewed chose a name reflecting something ‘good’ and important to them, using a pet name or a name associated with a family member: “participant pseudonyms can reflect meaningful real-life identities that enliven the research project and represent lived experience” (Vandermause and Fleming, 2011).

#### **6.5.4     *A note on transcription***

Due to my lack of experience in working with Jamaican Patois, I risked overlooking subtleties in language, of nuance or implication. To help reduce this, I enlisted the help of transcribers trained in Cassidy-Le Page transcription. Cassidy, working alone (Cassidy, 1961) and with Le Page (Cassidy and Le Page, 1980), developed a standardised written form of Jamaican Patois, commonly known as the ‘Cassidy System’ or the ‘Cassidy-Le Page System’. As with all translation, there is the risk that some meaning, particularly that which is culturally specific, may be lost or misunderstood. I tried to limit this by asking the transcribers to provide standard English clarification of particular words or phrases to help extend my understanding of possible meanings. I carefully checked and, where necessary, amended the transcriptions myself.

Davidson (2009) writes of the challenges of multi-language transcription and the potential impact on layout, representation and power. Davidson (2009) also promotes explicit discussion of how transcription was carried out and provides useful tips (such as spot-checking, providing guidance and providing examples) for ensuring the trustworthiness of transcription when using a hired transcriber. Prior to beginning my research, I consulted with both the Language Institute at UWI and an American professor experienced in linguistic work in Jamaica, who shared his transcription guidance with me. I interviewed a number of candidates to transcribe for me. The first transcriber I chose was a qualified social worker, with experience working with HIV and domestic violence, as well as experience of transcription in both standard English and the Cassidy system. I felt that her background would be helpful both in producing an accurate transcription and in detecting nuance and meaning. She was asked to provide separate notes on meaning and cultural interpretation of the interviews where appropriate. For example, she added this comment to one of the interviews: “Susie here is saying that she doesn’t want her mom knowing because she would worry. In the Jamaican context, the implications of her worrying could be a heart attack, stroke or death. It is often believed that a shocking news or stress can prompt a stroke, heart attack or death.” In addition, her rates were reasonable and she was able

to transcribe around her day job. As I was concurrently fulfilling the tasks related to my thesis, I did not require all of the transcriptions back immediately.

The transcriber was asked to transcribe verbatim. In order to support the accuracy of the transcriptions, I then listened to the recordings repeatedly, and assessed the transcriptions alongside the recordings. I asked the transcriber to make changes as appropriate, where I found inaccuracies or where I was able to fill in a section of the recording which had been inaudible to the transcriber. I asked the transcriber to be true to the voices of the women and to transcribe in a combination of standard English and Jamaican Patois as this reflects the reality of how Jamaicans speak. Patois is on a spectrum and its use varies from person to person. The transcriptions mirror this and the same word may be written differently depending on an individual's pronunciation, so, for example 'brother' may be written 'broda', 'bretha' or 'breda'. I did encounter a number of issues with the transcriber, which relate to the realities of women's lives in Jamaica, where women are often solely responsible for family income, childcare and caring for older relatives. Ultimately, the initial transcriber completed the 12 HIV clinic interviews and a second transcriber (a court stenographer, recommended by lecturers at UWI) completed the 3 NGO interviews. Both women used transcribing work as an additional source of income, fitting it in around other paid work and caring responsibilities and both requested numerous extensions as a result of work and family obligations. It therefore took almost two years to obtain all completed transcripts. I worked with the transcriptions in the original, some in standard English, some in Patois and some in a combination. However, for the reader who may not be familiar with written Jamaican Patois, I present my own translation alongside the Patois throughout this thesis. I checked my translation against the spoken Patois as well as the written words and asked Jamaican friends to assist with particular words which caused me difficulty. Any errors here are entirely mine. I retain the original Patois in footnotes, both in the interests of transparency and so as to include the women's original words, as they spoke them to me in the interviews. Quotations from participants are followed by the pseudonym of the participant and a text identifier, a number that corresponds with the numbered text in the full transcription of the interview, so that all quotations can be traced back and seen in context.

I did not return either the transcripts or my interpretation of them to participants for checking. McConnell-Henry, Chapman and Francis (2011:30) believe that "member-checking is incongruent with phenomenology" as it contradicts the values of interpretivism. IPA seeks to gain an insight into participants' experience of a phenomenon at a particular moment in time, as interpreted by the participants and by the researcher and does not generally use member-checking of transcriptions. It would have been logistically complex to reconnect with

participants who only attend the clinic infrequently and sometimes at short notice. Mero-Jaffe (2011:244) writes of the “methodological problems, ethical problems, and problems of research credibility” of member-checking, which can cause a number of dilemmas for researchers and complications in the data collection process. These dilemmas centre around power issues and include: the participant wishing to delete data the researcher considers important; the participant altering and refining the content of the interview; the participant updating the interviewer on things that have happened since the interview; and some participants declining to comment on the transcript at all (*ibid.*, 2011). Mero-Jaffe (2011) also comments on the discomfort which some participants feel when reading their spoken words, which may seem less coherent than they had hoped. I can relate to this, from my own experience of reading my interview prompts written in the transcripts, which, without the benefit of hearing the tone of voice that I used, I felt sounded much more abrupt than I had intended. Standing (1998:190) writes of the disconnect between natural speech and academic writing and how the two written side by side may appear jarring.

Moran (2002) describes Gadamer’s (1960, 1990) belief that understanding the text is more important than understanding the person. It is often the case with research, especially during the process of analysis, that we have only the text (and perhaps some notes on observations during the interview). In terms of practicalities, it is arguably impossible to fully know or understand another person; the attempt to fully understand a particular text—which represents a snapshot of that person’s attempts to articulate their experience to another particular person—seems a much more realistic ambition. The term ‘fusion of horizons’ comes from Gadamer’s work on intersubjectivity and refers to the meeting of the researcher’s ideas (the ‘interpreter’ of the text) and the participant’s ideas (the text); although these ideas and perceptions are distinct, there is also an overlapping common ground where they have shared ideas and perceptions (Holloway and Wheeler, 2010:228). Gadamer also talks of fore-understandings/fore-having, fore-sight/ fore-conceptions and how to ensure that these are made secure by “working out these fore-structures in terms of the things themselves” (Gadamer in Moran 2002:316–17). Smith, Flowers and Larkin (2009:37) describe Schleirmacher’s somewhat contradictory stance which suggests that we as researchers can know the author better than they know themselves. This is the idea of not being able to see the wood for the trees, that the person who is experiencing something is so immersed in their experience that they struggle to find any distance from it. This concept sits well with IPA, with the idea that we as researchers can make sense of the making-sense process of participants, the double hermeneutic (although the researcher can only begin with the interpretation provided by the participant).

## **6.6 Participants, themes and analysis**

### **6.6.1 *The participants***

Table 3 (below) describes the basic characteristics and family circumstances of the 15 HIV positive mothers who participated in my study. Pseudonyms are used throughout and data presented to protect confidentiality, by, for example, giving age ranges rather than the particular age of participants. Many of the women were lone mothers or had a ‘visiting relationship’ with a partner, meaning they were responsible for most daily parenting tasks. The pattern of matrifocal households (discussed in Chapter 3) is reflected in my sample: all the women (except for two whose children were adults) lived with one or more of their own children, and often other relatives, including siblings (5), own mother (3), stepfather (1) and non-biological children (2). Five said they lived with their current partner. One lived alone. The traditional African concept of ‘othermothering’ (James, 1993), where a woman cares for a child who is not her own, was seen within my sample. Two participants (Sandra and Margaret) said they lived with children other than their biological children, but these children were not mentioned again during the interview. I am unsure if it was their drawing a distinction between biological and non-biological children, or if—and possibly more likely—it was my assumptions about biological children which affected how I phrased questions and led to their exclusion. Neither Margaret nor Sandra had told their biological children their status; it would be interesting to compare disclosure to biological and non-biological children in a larger sample. Further information on participants’ living arrangements and family dynamics can be found in Appendices VIII and IX.



**Table 3. : Participants' characteristics**

<b>Name (Interview Number)</b>	<b>Age</b>	<b>Time since diagnosis</b>	<b>Children* Female (F) Male (M)</b>	<b>Disclosed to children?</b>	<b>Education (F.E. – Further education)</b>	<b>Employment</b>
Sandra (1)	30–49	More than 10 years ago	20–29 years (F: overseas) Teenager (M) Teenager (M)	No No No	Not known	Not known
Susie (2)	50–59	Less than 1 year	20–29 years (F)	No	Up to age 20. Completed exams**. Began F.E. but dropped out (financial reasons)	Employed
Laura (3)	30–39	More than 10 years ago	Teenager (M) Primary school age (M)	No (yes, by g/mother)  No	Left school age 16, no exams. Went on to F.E.(current)	Employed
Winnie (4)	40–49	1–9 years ago	20–29 years(F)	Yes	Left school age 18, no exams	Self employed
Patrice (5)	50–59	More than 10 years ago	30–39 years (F) 20–29 years (M) 20–29 years (M) Teenager (M) (HIV +) (Plus one grandchild)	Yes Yes Yes yes	Left school age 19, some exams.  F.E. Scholarship	Unemployed
Jay (6)	30–39	1–9 years ago	Teenager (F) Teenager (F) Primary school age (M) Pre-schooler (M)	Yes Yes Yes No	Left school age 15, no exams, 1 year F.E.	Unemployed
Tina (7)	30–39	More than 10 years ago	Teenager (M) Teenager (F) Teenager (M) Primary school age (F)	Yes Yes No No	Left school age 15, no exams	Unemployed
Maria (8)	30–39	2 years ago	Teenager (F) (USA) Teenager (F) Teenager (F)	No Yes Yes	Left school at 18. Completed exams	Unemployed

Cupcake (9)	30–39	More than 10 years ago	Teenager (M) Teenage(M) Primary school age (M)	No No No	Left school age 18, Completed exams	Self employed
Margaret (10)	30–39	1–9 years ago	Teenager (F) Primary school age(F)	No No	Left school age 17, Completed exams	Employed
Anna (11)	40–49	More than 10 years ago	30–39 years(M) 20–29 years(M) Teenage(M) (Plus 3 grandchildren)	Yes Yes Yes	Left school at 15, no exams	Occasionally employed
Johnnett (12)	40–49	Less than one year	20–29 years(M) 20–29 years(F) Teenage(M)	No (yes, by g/mother) Yes No	Left school age 15, no exams	Occasionally employed
Tracy (13)	30–39	1–9 years ago	Primary school age (F) (HIV +) Primary school age (M) Pre-schooler (M)	No No No	Left school age 16, completed exams	Occasionally employed
Sarah (14)	50–59	1–9 years ago	30–39 years (M) 30–39 years (M) 20–29 years (F) Primary school age (M) (HIV +) (Plus 2 grandchildren of preschool/primary school age)	No No No (yes, doctor, but Sarah denied it) No	Left school aged 17, didn't do exams	Employed
Nora (15)	30–39	More than 10 years ago	Teenage (F) (pregnant) Primary school age (M) Primary school age (F) Preschool(F)	No No No No	Did not pass exams	Unemployed

**Key:**

\*Baby (0– 11 months)

Pre-schooler (1–4 years

Primary school child (5–12 years)

Teenager (13–19 years)

\*\* Exams: Refers to CXC's, similar to GCSEs.

### **6.6.2     *Themes and subthemes***

As discussed in Chapter 4, I applied Hochschild's concept of emotion work to help make sense of the themes the women identified in their accounts. I also referred to the work of scholars who have applied and extended these concepts, in particular Garey (1999, 2011), who addresses issues of maternal visibility and Hansen (2011), who examines the concept of reciprocity. I used the concept of the 'pinch' (Hochschild 1983:57) defined as the disconnect between what a person feels and what they think they should feel. When this occurs, women then carry out emotion work in an attempt to either align their feelings with social convention or to present themselves in a way which appears to be socially conventional (Hochschild 1983:57). I applied the pinch concept in the context of maternal HIV, where women worked to demonstrate the close and loving relationship between themselves and their children in the face of possible judgment or condemnation regarding their HIV status and their ability to effectively mother their children. Reflecting on the women's accounts and the themes generated through my early analysis, I identified three key pinches which became the three themes discussed in Chapters 7–9 and shown below, in Table 4. All three themes incorporate elements of seeking social acceptance and fulfilling social expectations related to caring for children; social acceptance and caring are two of the four reasons given by Bolton and Boyd (2003) for carrying out emotion work.

**Table 4: Themes and subthemes**

<b>Theme</b>	<b>Subthemes</b>
<b>Chapter 7 (Theme 1): Maternal visibility: Providing and protecting</b>	<b>Mother as provider</b>
	- HIV and Poverty
	- HIV and young motherhood
	- HIV and living with violence
	<b>Mother as protector</b>
	- Protecting children's social standing
	- Protecting children's education and employment prospects
	- Protecting children's emotional and physical health
	- Protecting children's sexual health
	- Protecting the children's father
<b>Chapter 8 (Theme 2): The responsible mother: HIV, mothering at a distance and 'downfallment'</b>	<b>Maternal responsibility: mothering at a distance</b>
	- What is mothering at a distance?
	- The responsible mother and mothering at a distance
	- Managing disclosure by grandmothers
	<b>Responsible mothering &amp; 'downfallment'</b>
	- What is 'downfallment'?
	- The responsible mother and 'downfallment'
	- Denying HIV in the context of fearing 'downfallment'
<b>Chapter 9 (Theme 3): HIV and reciprocity in mother-child relationships</b>	- Experiencing 'downfallment'
	<b>Safeguarding reciprocal relationships with children</b>
	<b>Medication support from children</b>
	<b>Emotional support from children</b>
	<b>Emotion work and approaches to disclosure</b>
	- Preparing to disclose: Patrice's story
	- Unreflective disclosure
	- Promoting tolerance
	<b>Disclosure and maternal intentions</b>
	- Disclosure as an expression of love and trust
	- Disclosure as empowerment
	- Disclosure as preparation for maternal illness or death

Throughout this thesis I resisted dividing the women's experiences according to whether or not they have told their children about their HIV, as I feel that this is an unhelpful and simplistic dichotomy. Instead, I used the concept of emotion work to include a broad range of maternal experiences, including the experiences of women who have partially told their children, have told some of their children or whose children have been told by others. The three main themes I discuss in detail relate directly to my research question and challenge some common assumptions about mothering with HIV and the choices women make concerning disclosing their status to their children. Note that, particularly in relation to diagnosis, women expressed feelings of fear, distress, shock and loss. My intention is not to deny that these more negative feelings exist, but to

demonstrate that, in reflecting upon motherhood in the context of HIV, women described their strategies for confronting HIV, protecting their children and developing strong, supportive relationships with them, as well as their desire to take control and their feelings of hope for the future. Thus, they challenge images of themselves as passive victims who lack agency or the ability to mother effectively. They describe their strategies for moving forward in their lives, despite multiple challenges.

These thematic chapters are neither objective nor factual; rather, they are my perception of the information the women chose to present to me on the particular day their interview occurred. As such, it is, once again, a double hermeneutic: my interpretation of their interpretation of mothering with HIV and communicating about HIV with their children. The use of inverted commas around the words such as ‘good’ in the phrase ‘good mother’ indicates the idealised concept.

### **6.6.3     *The process of IPA data analysis***

Phenomenological researchers have identified a series of steps to be followed in the analysis process (*e.g.*, Colaizzi, 1978; Giorgi, 1985; van Manen, 1990). In practice there are similarities among these approaches and all argue for flexibility. Todres (2000) emphasises the importance of going beyond a series of mechanical steps to ensure that meaning is explored so as to tell a story which readers can relate to and empathise with (Todres, 2000:43). In line with other phenomenological approaches, Smith and colleagues emphasise that IPA’s detailed analytical steps are intended as a guide, which can be adapted as appropriate (Smith, Flowers and Larkin, 2009:79). These analytical steps help in identifying and integrating themes into clusters and extending this process across multiple cases whilst retaining a flexibility that allows the researcher to adapt the process for different contexts, modes of data collection and sample sizes (see Smith, Flowers and Larkin, 2009).

The interviews I conducted produced rich, detailed accounts of the participants’ experiences and views, which I then analysed in detail to elicit key experiential themes. I followed the analysis guide suggested by Smith, Flowers and Larkin which proposes working case by case to carry out careful line-by-line analysis and identification of themes, “emphasising both convergence and divergence, commonality and nuance” (2009:79–80). First, I checked the transcribed interviews and amended them as necessary, read and listened to them repeatedly, and identified and clustered themes. I paid particular attention to reasons given for choices in relation to disclosure/HIV communication and to how these related to concepts of fear, trust and protection regarding motherhood, as well as to comments highlighting the broader impact of community and social factors. I also focused on apparent contradictions within interviews, times where a participant

repeatedly revisited the same idea, and concepts which appeared difficult for the participant to express. Smith, Flowers and Larkin encourage deeper interpretation through a “dialogue” between the researchers, their coded data, and their psychological knowledge” (2009:79–80).

I analysed each interview transcription individually; an extract of the analysis process for the interview with Cupcake can be found in Appendix X. I then moved on to subsequent cases and eventually developed a structure (in my case, a table) to illustrate the relationship between themes. The initial table, which includes the themes drawn from all the interviews, can be found in Appendix XI. This represents an early step in the analysis process. As a novice researcher, I was not sufficiently conceptual at this stage; a more experienced researcher may have been able to include more conceptual comments at the initial stage, rather than only exploratory and linguistic ones. I found that these emerging themes needed a great deal more interpretation to be more than simply a descriptive analysis of the women’s experiences.

I found the analysis process iterative, time consuming and messy. The interviews generated an enormous number of themes and subthemes, as is typical of the detailed analysis process required by IPA. In my case, this was magnified because I worked with (for IPA) a relatively large number of interview participants. Additionally, because I was addressing a sensitive topic in a clinical setting, with participants different from myself, I devoted the early part of the interview helping participants feel comfortable talking with me. This produced additional information relevant to their experience of living with HIV but not specifically to my research question. This tendency was amplified because my study is exploratory and I wanted to be open to the range of issues the women might identify; although I gently guided the interview, I did not shut down topics the women were keen to talk about.

I found combining cases to be particularly problematic and developed several different ways of doing this before identifying a method which I felt worked for the participants and their interviews. Smith, Flowers and Larkin (2009) believe the process should be clear and transparent, should use supervision or collaboration to enhance coherence and should include researcher reflections. I used supervision, study groups, presentations and the IPA groups to help “test and develop the coherence and plausibility of the interpretation” (Smith, Flowers and Larkin, 2009:79–80); this thesis represents my “full narrative”, with “detailed commentary” (*ibid.*, 2009:79–80), which leads the reader thematically through the interpretation and my reflections on the process. Although I analysed all interviews completely, to retain a clear focus on the disclosure and mothering experiences of HIV positive mothers in Jamaica, I subsequently excluded two overarching themes and their associated main themes and subthemes. These excluded themes dealt with issues related

to making sense of an HIV diagnosis, caring for the self and sources of support (other than children). A breakdown of these excluded overarching themes is in Appendix XII.

## **6.7 Chapter summary**

This chapter has provided a detailed overview of the preparation, interview and analysis phases of this research project, including obtaining ethical approval, identifying host organisations, and deciding on a sampling strategy and data collection method. I described my experience, in the Jamaican context, of negotiating informed consent, working with gatekeepers, recruiting participants and carrying out the interviews. I clarified my approach to issues such as sample size and defining a homogenous sample, as well as addressing issues of language and transcription when working with Jamaican Patois. I also introduced the participants, described the IPA analysis process and explained how I identified themes. The following chapters (Chapters 7–9) describe the themes and subthemes in detail, illustrated with participant quotes.

## **SECTION 3: PRESENTATION AND DISCUSSION OF THEMATIC FINDINGS**

### **Chapter 7: Maternal visibility: providing and protecting (Theme 1)**

#### **7.1 Introduction**

In Chapter 4, I introduced the concepts of familialism (Treloar and Funk, 2008) and responsibilisation (Treloar and Funk, 2008; Lupton, 2011). I suggest that this pressure to be a visibly ‘responsible’ mother is the precursor to much of the emotion work performed by the women I interviewed. Conscious of the ‘pinch’ (Hochschild, 1983:57) between the idealised concept of the ‘responsible’, wholesome, healthy mother who prioritises and protects her child’s physical and emotional well-being, and society’s negative portrayals of women with HIV as irresponsible, promiscuous and dirty (Sontag, 1991), women redouble their efforts to care for and be seen to care for their children. Maternal visibility is “the attempt to call attention to or emphasise one’s performance of motherhood” (Garey, 1999:29). This can be done through public actions (*e.g.*, assisting at the child’s school) or verbally, by telling others about “mother-appropriate actions” which are imbued with meaning and validation (Garey, 1999:29). Another requirement of the cultural expectations of mothering is that, in addition to the physical work of mothering, mothers should also make it appear as if this work is effortless (Garey, 2011:174). Maternal visibility renders the physical mothering work as highly visible, but the associated emotion work invisible (Garey, 2011:174).

This chapter addresses the first theme, *Maternal visibility: providing and protecting*. The ‘pinch’ in this case is the challenge of living up to social norms which require mothers to provide for and protect their children whilst managing the physical and mental health issues and complex social interactions which accompany living with HIV, a stigmatised disease. HIV exacerbates many pre-existing challenges, by adding physical and emotional health issues associated with an HIV diagnosis and the practical issues of accessing healthcare, to an already precarious and challenging existence. Additionally, an HIV diagnosis can threaten social and support networks if HIV status becomes known. In this chapter I illustrate how mothers perform emotion work to present themselves as responsible mothers and live up to the idealised image of the Caribbean mother as a strong, capable figure who provides for and protects (Adisa, 2013:45) her children’s physical, emotional and sexual health whilst managing her own health issues and her family’s social standing within the community.



## 7.2 Mother as provider

### 7.2.1 HIV and poverty

In Jamaican households, where mothers are often the main or sole provider for their children, income generation may be particularly challenging when women have limited qualifications and can only obtain low paid or informal work, such as selling small items by the roadside. Women with HIV must also manage their own health and healthcare appointments (and sometimes those of other family members). Poverty was implied by many and referred to explicitly by a few. Many of the challenges of living in poverty were exacerbated by also living with HIV. I argue that the increased potential for societal judgment resulting from living with a stigmatised disease may lead HIV positive mothers to feel additional pressure to showcase their mothering in a positive light, as illustrated by Tina, below. Tina believed that providing for her children both financially and emotionally was a key aspect of being a ‘good’ mother (although this was almost impossible for her to do simultaneously, as her older three children lived with relatives). She found it hard to maintain emotional closeness with her older children whilst they lived apart from her, and felt pressure to provide for them financially by moving to Kingston to seek work. In practice, she was mostly unemployed and struggled with her health, making it hard for her to send money for their care, but also unwilling to return to the countryside, having ‘failed’ to succeed in the city. She felt it would be shameful to admit defeat and return to live in her father’s house:

**Tina:** *I just want to be in Kingston (smiles).*

**Gayle:** *Okay.*

**Tina:** *I guess— First... I used to believe that you have a betta [better] life in Kingston than in country. Well, now I see that hamm [umm], it’s not really a betta life because hamm – Right now I would rather go back to country, to [name of town] to live but hamm, I don’t have anything to take back with me for the majority of time that I live here, and that, just that keeping me right now from not going back to country.*

**Gayle:** *Explain to me.*

**Tina:** *Well, in Kingston, if you are in Kingston you are supposed to be able to maintain yourself and your children, going back home broke, with no money, your children should be able to depend on you – I don’t – I wouldn’t have a roof over my head if I go back to country right now. So – you know, I don’t have a money to like start a house.../[If I] go back*

*home– I would have to go to my father’s place and stay there and – I am [age] years old. (Tina 118–124)<sup>13</sup>*

Tina felt that ‘successful’ mothers should be able to provide for their children: she was not willing to return to the country if she would not be seen as visibly successful and financially independent.

Financial challenges were frequently referenced, including struggles to afford small expenditures such as bus fare, food, or school lunches. Sarah spoke about juggling priorities and negotiating financial and practical challenges in caring for the health of her HIV positive son:

*If I don’t even have the [bus]fare I borrow it just to bring him like when [the] nurse called me and said he had an appointment this morning I said “Jeez and I’m not going to get paid until next week Monday”. So I went to one of my girlfriends and I said to her last night, “[My son] has an appointment which I hadn’t remembered you know, can you lend me a thousand dollars [about £7’]?” And she said “You’re not going to get far with a thousand dollars?” I said “Yes man. All I have to do is explain to him and tell him that I can’t buy a Kentucky Fried Chicken because I don’t have the money”. And he said, “Come Mummy, and I will eat a patty [a cheap meat pie] and a juice”... (Sarah 94)<sup>14</sup>*

Here, Sarah reveals a support network of friends from whom she can borrow money when needed and a relationship with her son which allows her to negotiate and downgrade treats when necessary. This alludes also to the concept of reciprocity (Hansen, 2011) which Sarah is negotiating and the terms she needs to be on with her friends to borrow money from them, a relationship which might be disrupted were they to become aware of her and her son’s HIV status. Later, Sarah (178–180) acknowledges that, depending on the time of year, getting time off work from a job which is an important source of family income can be difficult. She is also navigating a form of reciprocity at work, in order to request and receive time off when she or her son needs to attend medical appointments.

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<sup>13</sup> Well, in Kingston, if you are in Kingston you suppose to can maintain youself’ and yuh children dem, going back down bruk, no money, yuh children them call pon u – mi nuh – a don’t have a roof ova’ mi head if mi go back to country right now. Suh – you nuh, a don’t have a money to like start a house.../...go back down to mi house– mi haffi go back down in my father place and stay there and – I am [age] years old.

<sup>14</sup> If a doh iivn av di fier a baro it jos fi bring im far wen Nors B kaal mi an tel mi se im av apaintment dis maanin, a se jeez an a nat goin to get pie til neks wiik monde. So a go tu wan a mi gorlfren an a sed tu ar laas nait [my son] av a apaintment an mi neva memba ino, yu kyan yu len mi a touzn dala? An shi se den fi go so far wid touzn dala? Mi se ye man. Aal mi afi du iz eksplien tu im an tel im se im kyaah bai no kentoki fah a doh av di moni. An im se a – kom mami a mi wi iit a pati an a juus.

Cupcake's experience of being denied entry to the USA highlights one way HIV impacted negatively on her life. When Cupcake was 19 years old and had just given birth to her first son, her father applied for her and her siblings to join him in the USA. During the visa application process, she tested positive for HIV and was denied entry<sup>15</sup>, so she was forced to remain behind in Jamaica, whilst her siblings joined her father. This made her HIV status known within her family, and caused physical and emotional disruption to their relationships. Her interview was characterised by feelings of sadness and loss, linked to losing the majority of her family (her mother remained in Jamaica) and the educational and employment opportunities which she may have had in the USA.

Cupcake later experienced additional loss at the failure of her small business, selling pre-packaged foodstuffs at a local market, because people suspected she was HIV positive and refused to buy from her. She now travels outside her local area to sell food once a week at a Saturday market. The link between feelings about HIV and food is extremely strong and people will often not eat food (including pre-packaged food) that someone with HIV has touched. Conversely, the greatest sign of acceptance is eating food cooked by someone with HIV and women often used this example to demonstrate the love and acceptance they experienced from family members who knew about their status: "They eat from me, same way". In fact, Cupcake used this example later in the interview, when she talked about having told her sister about her HIV status: "I still have to cook for her and everything. She have no problem with...dat" (Cupcake 536).

### **7.2.2 HIV and young motherhood**

Many of the participants had been young mothers: 11 of the 15 interviewees were aged 20 or under when they had their first child; of these, 4 were aged 15 or 16. One participant had a pregnant teenaged daughter at the time of the interview:

*So – I didn't want it – to be a grandmother as yet. I wanted her to finish her school. / But I just have to accept it. (Nora 52/54)*

In African, Caribbean and Black diaspora communities, babies are generally seen as positive and welcomed after an initial negative reaction due to disappointment because of financial worries, fears of disrupting the young mother's education and possible shame within the community (Lawson, 2013:122). This is hinted at by Nora's quote above. She later identifies the possibility of her daughter providing childcare for her younger siblings whilst Nora goes to work, thus transforming a challenge into a benefit:

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<sup>15</sup> This restriction was lifted by Barack Obama on January 4<sup>th</sup>, 2010, but for many years a positive HIV status prevented PLWHA from travelling to the USA. More information can be found at: <http://www.hivtravel.org/Default.aspx?PageId=143&CountryId=12>, accessed 05/05/2017.

*“...and by time they [her younger siblings] come home [from school] um, somebody will be there to look after them. My daughter will be there with her baby” (Nora 339)[...]*  
*“And instead of giving day care the money, I could just give it to her” (Nora 347).*

In overcoming her disappointment and finding a possible solution for her family which will allow her to obtain regular paid work, Nora shows herself to be adaptable and resourceful. She is sensitive to her daughter's needs, stressing that this is only “if she can manage” and that she will pay her. Childcare is an expensive and complicated issue for many Jamaican families, particularly for those who do not have family members able or willing to provide free childcare<sup>16</sup>.

It is interesting to reflect on the combination of factors in Nora's and her older daughter's lives preceding her daughter's pregnancy. Her daughter's pregnancy disappointed Nora: she had hoped she would finish school, get a good job and move on to a 'better life'. Nora gave birth at age 20, and was diagnosed with HIV a year later. This daughter's father subsequently died of AIDS and Nora had another three children. All four children are HIV negative. Nora's account leaves much unsaid, but clearly many of the complex and interlinked factors that made Nora vulnerable to HIV are also factors in her daughter's current pregnancy. These factors include: poverty, limited education and lack of employment opportunities, having darker skin (which continues to be a disadvantage in Jamaica), increased risk as a woman of experiencing gender based violence, cultural and gender norms which make simultaneous relationships acceptable for men and difficult for women to insist on condom use, the biological vulnerability of women to HIV (Ramjee and Daniels, 2013) and cultural pressures on women to have children. Anecdotally, a Jamaican HIV professional told me she was aware of five girls aged 16–17, who, shortly after learning of their mothers' HIV status, intentionally became pregnant to prove their ability to attract a partner and to counter rumours about their mothers' HIV statuses. This further underscores the complexity of conversations about HIV within the family, the potential impact of outside forces and reinforces the range of issues that mothers considering telling their children must take into account. Even if this is an urban myth, it carries a powerful deterrent to mothers who are considering telling their children but who are also trying to protect their children's future educational prospects by encouraging them to delay relationships and concentrate on school.

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<sup>16</sup> Non-familial day care is used by fewer than 20% of children under 3 (UNICEF, 2010). That formal day care is generally used by high-income families (UNICEF, 2010) suggests that the cost is an issue for poorer families. Conversely, although often of poor quality, community based preschools (and therefore, presumably free or of nominal cost) for older children aged 4-6 are used by 98% of families with preschool aged children (UNICEF, 2010).

### 7.2.3 *HIV and living with violence*

I did not specifically ask about violence during the interviews. However, I know from previous work with HIV NGOs in Jamaica that a very high proportion of Jamaican women living with HIV have experienced violence, although, as discussed in Chapter 3, violence is so widespread and normalised in Jamaican society that it is not always recognised or mentioned. For this reason, I think it important to recognise the impact of violence on the lives of the women I interviewed, as it often presents an additional challenge for women in both a practical and an emotional sense and interacts with living with HIV in complex ways. Tina referred to the limited choices she had had throughout her life and obliquely referenced the multiple challenges she had faced: intimate partner violence, homelessness, unemployment, health issues and a premature baby:

*I get into some argument wid [with] my baby father and him put mi out and [...] —/ [...] When I have the baby in hospital, I went back to [name of area] where I stayed for a while ...until hamm, I—I actually come back in Kingston, back to the baby father, and is there I stayed until ...things get worse again suh we-we-we separated and it-it -it end[ed] up that he-he-he took the child.../: ...and now – from then on his mother has the child right now, his mother. (Tina 48–52)*

Three of Tina's four children live with their respective fathers' families. It is not clear from Tina's account whether this was something she agreed to. The repetition of words in this extract may indicate distress or difficulty explaining what happened. Because of the factual and understated way that the women I interviewed referred to violence, the emotion work associated with it was not always clear. However, I suggest that emotion work is inherent to women's attempts to preserve these relationships, as evidenced by Tina's returning to her abusive partner, above. Similarly, Rhine (2011:128) found that Northern Nigerian "HIV positive women devote themselves to meeting the bodily, emotional, and sensual needs of others" [in order to] "secure their [own] wellbeing."

Other women also referred to violence within the interviews. For example, Maria refers to a violent relationship with an "older man":

*[...] ...and when I left him – because he was so possessive and he was always like – if [I] am here now he would be calling down my phone and he would xxx [one word] "weh yu de?" ["where are you?"] because he was promiscuous and everytime I would like say "use a condom" he would want to beat me up and said am scorning him and him "nah uuz*

*no kandom” [he “won’t use a condom] and him waah fait mi an lik mi aal di time [he wanted to fight me and hit me all the time] so...when I decided to leave him now, one day he come and he was like “I want to tell you somp [something]. I want to talk to you.” A said “I don’t care. If iz AIDS, mi no kier.” [“Even if it’s AIDS, I don’t care”]. And from that day like when I said that to him? That stayed in my head and I was like – and den [then] after dat [that]...he was killed – he didn’t die, he was shot and killed and then I was like “oh maybe that was what he wanted to tell me” [...]* (**Maria 67**)

In this account she addressed the gendered nature of violence and power relations within that relationship and her difficulties in negotiating condom use. Maria eventually ended this relationship and implied that she acquired HIV from this partner.

Anna recounted the aggression she experienced from her partner’s family, who blamed her for his death (suspected to be of AIDS), possibly as a way of protecting his memory and distancing him (and them) from possible suspicions about his HIV status:

*Yes. His family came down upon me. One day when I went out where he used to live? They scrap my house and take away my furniture. All of my furniture. His sister and his brother and his mother take away the whole of my things. Food stuff, bed, TV, table— I didn’t have anything to sleep upon. Empty house. I had to go over to my mother’s with the two children.* (**Anna 161**)<sup>17</sup>

These references are generally quite understated, but the women were commenting on issues of violence that affected them directly or indirectly: domestic violence, incest/child rape, beating children, fighting, ransacking properties. None of the women during the interviews mentioned Jamaica’s widespread gang violence which contributes to the very high murder rate, although Maria may have been referring to this when she said that her ex-partner was shot and killed. I have heard other women talk about the fear they feel about their children walking home from school and how they instruct children who are home alone while their mothers are at work to hide under the bed if they hear gunshots.

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<sup>17</sup> *Ye. Im famili kiem dong pan mi. Wan die wen taim mi gaah out wier im uus tu liv? Im skrap mi ous an tek we mi fornicha dem. Wol a mi fornicha? Im sista an im breda an in mada tek we di wol a mi tingz dem. Fuud stof, bed, TV, tiebl – a didn’t av noting tu sliip pan. Empti ous. Mi av tu go ouva mi mada dem wid di tuu children dem*

## 7.3 Mother as protector

### 7.3.1 *Protecting children's social standing*

My interviewees acknowledged society's perception of HIV. Both Anna and Winnie implied a societal view of HIV as a punishment or moral judgment. Below, Winnie demonstrates the impact of societal views which demonise and blame (Sontag, 1991) those who are HIV positive, with assumptions that women are "vectors" of disease or "prostitutes" (Ndinda *et al.*, 2007:93).

*And I start to pray and I said "God? Why did this have to happen to me?" [starts crying] [...] "I'm not a prostitute xxx [crying]. (Winnie 37)<sup>18</sup>*

Maria referred to the concept of shame associated with HIV (Sontag, 1991), particularly society's treatment of people with HIV as 'promiscuous', clearly articulating the assumptions surrounding HIV, particularly for women:

***Maria:** [...] I was like "I don't want my worse enemy to have this" because of – it's not like xxx [one word] a lot of pain but because of the shame 'bout it? [...]*  
***Gayle:** So talk to me about shame. Tell me what that means to you.*  
***Maria:** Oh – that's the part that you just don't want nobody to say y - you have AIDS. You HIV positive....because...it's like they like – people make it looks like it's the worst thing and they make it look like you're y-y-you had to be a promiscuous person to get it or an – and it's not true so when like yo- you – people talk 'bout other people and AIDS and so? It kaina [kind of] make you draw back and go in di shadows. I don't like to hear...nhn....(Maria 151 [...])154–155)*

Maria's image of "draw[ing] back and go[ing] in di shadows" is a powerful description of feeling alienated, excluded and despised. Several women countered this attitude by telling me they were married (hence 'respectable') or not 'running up and down' (*i.e.*, not 'promiscuous'):

*Honestly, I'm not really a person who is...overly sexually active. (Susie 20)<sup>19</sup>*

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<sup>18</sup>*An a staat prie an a se 'gad? Wai dis afi apen tu mi?' [starts crying] [...] 'am nat a prastituut xxx [crying]*

<sup>19</sup>*Anesly am nat riili a persn wuu dat.....ova seksual aktiv*

*[...]They may think that I'm in town running up and down when it's not like that. (Susie 40)<sup>20</sup>*

*[...] I wasn't a person that was running up and down and all this stuff so...that's where the blank is. (Tracy 116).*

For Maria, the first step towards telling her children was to address, within herself, society's assumptions about people with HIV being promiscuous and to feel comfortable that she was not to blame for getting HIV:

*Like...gradually coming and getting educated about it, I'm like "Why should I be ashamed of this and I didn't go and just get it from a shop or anything?" I said "This could happen to anybody who is having sex and if you're not protecting yourself, if you are not using a condom because...if you have a husband you can still get it 'cause he might be promiscuous and go out there and get it and give it to you", so I'm like "Why should I be so ashamed?" [...] (Maria 89)<sup>21</sup>*

Maria described moving on from feeling ashamed, and, like Susie, came to believe it was not her fault, "It's just an unfortunate thing / that happened." (Susie 42)<sup>22</sup>

### **7.3.2 Protecting children's education and employment prospects**

Many women described their children's education as a crucial focus. Mothers were keen to support their children in getting good qualifications so they could have a better life: not distracting them from their schoolwork was often quoted as an important reason for not telling them about their mother's HIV. Additionally, for Nora, teaching her children manners was a key part of her role as a mother:

*I tell them go to somebody at the school and tell them [if] anybody hit[s] them. Don't go to school and fight. Don't go to school and curse any badword to [other] children. You [they] must learn to behave themself. I*

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<sup>20</sup>[...] Dey mie tink dat am in town ronin op an down wen its nat laik dat

<sup>21</sup>Like...gradually coming and getting educated about it am like "Why should I be ashamed a this and I didn't go and just take it up from a shop or sop'm?" Mi se "Dis kud apm tu enibadi once you are having sex and once you're not protecting yourself; once you are not using a condom because...if you have a husband you can still get it cause he can be promiscuous and go out there and get it and carry it come give you", so am like "Why should I be so ashamed?"

<sup>22</sup>Iz jos an anfaatunet ting / dat apend



*always tell them that. And don't go on the street and beg. And don't eat on the street. (Nora 297)*

Nora focused on supporting her children's education and their future ability to support themselves. She also referenced their current poverty: telling her children not to beg or eat on the street, thereby implying that they are not getting fed at home. These behaviours reflect negatively and publicly on her ability to mother effectively and provide for her children. Nora dealt with multiple challenges: living with HIV, living in poverty, being unemployed, having four children aged 2–17, one of whom had a “learning disorder” (Nora 496) and one of whom was pregnant.

Several of the women (Nora, Tracy, Susie) talked specifically of their hope for the future in terms of their children and grandchildren. These women worked to provide a strong basis for their children's future:

*I teach them to save, to be independent – don't depend on nobody. [...] teach them those stuff. Tell them that the world is hard but if they uhm, they concentrate and focus on what they doing, they can come out. Come out to something good too...[...](Tracy 286)*

Similarly, Nora (317/319) worked to model taking control and being independent for her children: she planned to get a job at Kentucky Fried Chicken. Her plan was not only to provide simple things like soap and food for her children, but also to inspire them to do well at school, so they too could get jobs and be independent in the future.

Anna seemed to have gained status in her expertise about living with HIV; it represented an opportunity for her to take on an advisory role by giving talks about her experience. However, over time Anna became concerned about the possible impact of this on her children. She observed how another woman with younger children was talked about and began to worry that her children, who were older, would overhear similar gossip about her:

*But I never went [on the radio] because my sons were big by then and aware?/ I didn't go on it because I didn't want them to feel bad./Because you see the girl, the girl who went with Ainsley [Reid, well-known Jamaican HIV activist]?/She said sometimes she's on the road and they talk about “See the AIDS girl there”. (Anna 535/357/359/541)<sup>23</sup>*

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<sup>23</sup> *Bot a neva go chuu mai son did big dem taim de nou an sensibl?/ A neva go pan it kaah a doh waah dem fiil no wie./ Bikaaz yu si di gorl – di gorl we go wid Ienzli?/ Shi se somtaim shi de pan di ruod dem taak bout 'si di AIDS gyal de'.*

Anna stopped participating in public education to protect her children; in choosing to tell me this story, she positioned herself as a 'good' mother, who puts her children's needs first.

Similarly, Patrice described a woman she knew who, because her HIV status was known in the community, could not prepare the food for her mother's funeral, because if she did, no one would eat it.

*When I look at it and I saw the humiliation that she went through, I said to myself it's best I keep this thing undercover. But then I realised – at that time I used operate a grocery shop. When I realised that I had less and less customers, until one day I got so fed up and I said, you know something, I am going to just eat what in there and whatever until it finish and – but all that time I didn't know, I didn't know, you nuh.*

**(Patrice 151)**

HIV (or rumours of HIV) disrupt social ties and traditions, as well as women's ability to generate an income. Disclosing to children may carry the risk that children disclose to others and this can carry very serious risks for women, especially poor women as it may affect their ability to work (if people will not buy from them) and to call on others for favours (e.g., small loans, childcare, food). Protecting their own and their children's social standing and ability to participate in social life and associated exchanges is crucial for women, not just emotionally, but also for survival. HIV may exacerbate these needs, in that women are likely to need regular medical care, necessitating childcare, time off work, and bus fare. Upon reflection, Patrice thought that others may have been aware of her status, demonstrating the very close links individuals may have with the community in which they live and an awareness of the negative impact that rumours about HIV can have, not just for an individual woman but for her whole family. It is not clear from Patrice's account how people guessed she was HIV positive, but there are parallels with Meinert and Whyte's work (2017) on social sensations of symptoms in Uganda. They write of cases where family and community members notice physical symptoms of HIV and trauma, sometimes even before the person experiencing them becomes aware of them.

### **7.3.3     *Protecting children's emotional and physical health***

Margaret wanted to protect her daughters from worry and distress, putting her daughters' need for peace of mind ahead of her own (although she does allude to the possibility that she herself may not be ready to tell them):

**Gayle:**— how do you feel about that [not having told your children about your HIV]?

**Margaret:** Ahh.... It's kind of eating me but I have to — when I can talk to the big one, I cannot tell the little one. I know that would kill her. / Um, after her father died, she had a hard time in school so I don't think I am ready to tell her. I don't think so.

**Gayle:** But the older one would feel differently about it.

**Margaret:** Yeah. She you can talk to um, one xxx [one or two words] but for this? I don't think she is ready for it. She's not. (**Margaret 85–90**)

Sandra expresses a similar view:

*Maybe comfortable with my daughter but I don't want to tell her because I don't want her to worry. (**Sandra 57**)*<sup>24</sup>

She found the idea of telling her daughter easier than considering telling her sons, due to how she thinks one of her sons might react:

**Sandra:** Because um.... My last son, if you cough and he's eating he's... you know? He doesn't want you to cough on him or anything, or if I'm picking my nose "Go wash your hands, man". That's how he is so I- I'm afraid to tell him.

**Gayle:** Because you – what do you think he would do?

**Sandra:** Maybe he would scorn and start worrying. (**Sandra 158–160**)<sup>25</sup>

Her son's focus on hygiene makes her fear that he might reject her and fear catching HIV from her.

Like Maria, who didn't want to tell her oldest daughter because she was too 'cry-cry', Nora was also concerned about her children fretting (worrying); in particular she feared that if her children worried they might become sick. This concept of mental health affecting physical health came up several times during the interviews, but usually in relation to the women themselves: they felt they became physically unwell from worrying about their illness or they intentionally avoided dwelling on their illness to avoid becoming physically unwell as a result. This was the only time I heard one of the women apply this to her children:

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<sup>24</sup>*Miebi komfatebl wit mai dawta bot a doh waah tu tel er bikaaz a doh want er tu wori.*

<sup>25</sup>**Sandra:** .... Bikaaz um...ma laas son, if yu kaaf an iiz iitin iz – yu no? Im doh waan yu kaaf an im ar noting ar if a pikin ma nouz 'go wash yu han man'. Dats ou im iz so a - am afried tu tel him.

**Gayle:** Because you – what do you think he would do?

**Sandra:** Miebi ii wud skaan an staat woriing.

*Nora: [If I tell them] they might fret. They might worry. Some people can cope with those kind of things when you tell them, you know. You always have to tell somebody who can – who will be able to understand and who – person who won't break down. (Nora 187–188)*

*[...]*

*Gayle: And what would happen if they fretted?*

*Nora: They might get sick.*

*Gayle: They might get sick?*

*Nora: Yeah. (Nora 206–209)*

Squire (2007: 103) found that interviewees in South Africa also identified a strong link between worry and physical illness, but that they used this link to support disclosure, believing that “keeping HIV ‘inside’ you like a poisonous secret, and yourself hidden away ‘inside’ too will kill you”.

For Nora, her daughter's pregnancy was an additional complication:

*Nora: I want to tell her like when she reach like eighteen – adult stage.*

*Not yet./ I wouldn't tell her during her pregnancy right now.*

*Gayle: So what – what's different then about eighteen? ... Why is that a good time?*

*Nora: Maybe 'cause she is pregnant she might to stress. I don't want to tell her right now. (Nora 166–170)*

There was an apparent contradiction here: Nora was waiting for her daughter to reach “adult stage” to tell her about her HIV status, but her daughter was already part of an adult world in that she was sexually active and pregnant with her first child. Nora felt that her daughter did not need any additional stresses during her pregnancy. Later in the interview, Nora also used the euphemism ‘leave’ to introduce the possibility that she might die and described her wish to shield her children from worrying about this: “Just to let them not to fret on mommy. Well, mommy might leave us soon. Mommy might get sick” (Nora 349). Confronting their own mortality and the prospect of helping their children to deal with this, was introduced, usually tearfully, by several of the women, and their reluctance to confront this may be another underlying reason for their decision not to discuss their HIV.

As discussed in Chapter 3, a key element of Caribbean motherhood is self-sacrifice (Adisa, 2013). This is not unique to Caribbean mothering: white, middle-class mothers have clearly articulated the concept of the self-sacrificing mother (*e.g.*, Lupton, 2000). In Anglo-Northern ideologies, this is

often encapsulated in the stay-at-home versus working mother debate: both, in different ways, intimate that the mother sacrifices her own needs to care for or provide for her children. In Jamaica, and much of the Caribbean, mothers are often responsible both for their children's daily care and financial provision. In the context of HIV, mothers also struggle to manage their own health issues, as Cupcake, described below:

*They doh [don't] have nobody [anybody]. But me./ So you know how they see me... [unintelligible, voice too low] [long pause]/ I'm still trying. I'm still trying. I work very hard just for dem to be happy. B – but HIV? It's – it's not easy, especially when you have a flu. (Cupcake 214–218)*

She explicitly referred to the emotion work she carried out as 'work' and as an ongoing effort. There is a sense of the pressure she felt as the sole parent, that her children relied entirely on her for everything, that they have no one else and that this effort came at a personal cost to her. She identified HIV as an additional challenge, on top of other challenges, which put extra pressure on her, both physically and emotionally.

Other women also described their efforts to give their children what they need:

*Yeah I don't, I don't give them a negative life, I give them everything I try to do?/ I try to make it positive. As positive as possible. [...] I'm not wealthy or anything like that but I try my best to give my kids what they want... I try my best... (Tracy 290/292)*

*I give her enough – I give them love, take care of them, I give them food... give them basically what I have I can give and more. (Tracy 150)*

*And the first two, I give them everything. (Tina 98)*

The women didn't explicitly tell me they were self-sacrificing or putting their children first, but this is implied in the way they talk about their children. For many mothers, protecting children's emotional health means protecting them from the potential distress and worry they believe maternal disclosure will cause, although this may cause additional worry and stress for the mothers themselves. The children's potential distress in suspecting their mother has HIV is not generally acknowledged; instead, women emphasise the emotional work they do to protect their children, whether this is by fully or partially sharing their status with them or by keeping it a secret.

Cupcake did not want her children to suffer for something she saw as her fault, her responsibility, demonstrating her feelings of guilt for having acquired HIV, with the words “my mistake”. Below, she reports a conversation with a friend, also HIV positive (who has since died as a result of not taking her HIV medication) and who also had children of a similar age:

*Cause we [my HIV positive friend and I] talk about it. We always say dat we [are] not going sacrifice the kids...for our mistake [...]./ And I think God have them dier [‘there’ but meaning ‘here’] for a reason because he could have let them be HIV but he didn’t...because they were born from an HIV mom. (Cupcake 270–272)*

Cupcake identified the potential “sacrifice” of her children’s happiness because of her “mistake” as fundamentally wrong. She presented herself as a passive recipient of God’s kindness and presented her children as special, chosen and protected. Nonetheless, despite medical pressure, financial implications and Jamaican cultural norms, Cupcake made certain that she did not breastfeed her children, demonstrating her determination and agency:

*At first – because a [I] always know dat um...not giving dem breastfeed – all when a [I] was in di hospital and di nurse was like [telling me to] breastfeeding dem, I would ask ma mom to take di formula an di bakl [the bottle] – hide it and bring because a just had it in di back a mi head but ma mother was wondering why – /— but a [I] didn’t tell anybody but I just knew I was HIV. (Cupcake 82–84)*

In Jamaica, HIV positive mothers are advised not to breastfeed and are provided with free formula for six months (Harvey and Thame, 2004). If a woman’s HIV status is known, no financial challenges are associated with formula feeding. However, there may be practical challenges (*e.g.*, bus fare, time off work to collect formula) and significant social challenges in a culture where, particularly amongst poorer sectors of society, breastfeeding is considered the norm. Refusing to breastfeed can be seen to signify HIV infection; hence, Cupcake’s request for her mother to hide the formula and bottle. Similarly, ‘taking vitamins’ has come to be understood as code for HIV medication (see also Squire, 2007:105):

*[...] I heard him say he was going to take his vitamin tablet you know. It's true I know that normally vitamins— people who take vitamin tablets? [...] [...] That's how I know it was him I caught it [HIV] from. Mmm... (Johnett 228–230)<sup>26</sup>.*

#### **7.3.4 Protecting children's sexual health**

The women I interviewed had a complex and sometimes contradictory relationship with the concept of what protecting children meant for them in practice and how this may change over time. Lawson (2013:111) believes that many Caribbean women find talking about sex with their children difficult. This discomfort leads some mothers to avoid direct conversations about sexual activity, for example, by replying to children's questions about where babies come from with the somewhat confusing Jamaican proverb: "How water walk go a pumpkin belly? Through the vine!" (Lawson, 2013:118). Lawson argues that this attitude within many black Caribbean families results from religious beliefs as well as the colonial legacies of rape and exploitation which continue to marginalise black women today and create a "culture of silence" (Lawson, 2013: 113–114).

For the Jamaican women in Lawson's Canadian study (2013), the fear of an unwanted early pregnancy often motivated mothers to overcome their discomfort and talk to their children about sex. The women I interviewed were more likely to be motivated by a desire to give their children information to help them protect themselves from HIV and tended to be very direct, but were much less likely to address the emotional issues (loving or trusting a partner), procreation (wanting to have a child with a partner) or power dynamics (having limited control over own sexual activity) even though these were often the issues which resulted in their own HIV infection. Connors (1996:114–115), writing about HIV and poor women in the United States, questions the assumption that women simply need to be taught assertiveness skills so they can negotiate condom use as overlooking the power imbalances between men and women (particularly where women are poor) or issues of trust, where women believe that their partners do not have HIV.

Cupcake found that she could warn her sons about the dangers of unprotected sex, thus fulfilling her maternal duty to protect her children without telling them that she had HIV:

*Why would I tell them then? Because they are all boys so I just don't want dem to make the mistake. Because even now the fourteen year old and the sixteen year old, I warn them every day about using condoms. Because they are big so I warn them every day about it. (Cupcake 236)*

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<sup>26</sup> *[...]an mi ier im se im a tek im waitamin tablit ya nou. So chruu mi nuo se naamali vaita – person tek waitamin tablet? [...] [...]Dats wai mi nuo se a im mi ketch it fram. Mhm.*

Similarly, Sandra, who had not told any of her children about her HIV status, tried to inform them about the dangers of unprotected sex, as does Tina who had told two of her four children:

*Um....maybe if I told them, they would try and protect themselves too...but I still instil in them: if they have a partner, use a condom.*  
(Sandra 134)<sup>27</sup>

*Well umm – just just for them to know that hamm, HIV do exists and them can ketch [catch] it. Yes, as young as them be them can ketch it as long as them a have sex. (Tina 253).*

Sandra acknowledged the advice might be easier for her children to follow if they knew their mother had HIV, but she tried to advise them anyway and hoped they would listen. Nora also incorporated this idea of knowing your mother has HIV strengthening a (grown up or teenage) child's ability to understand the risks of getting HIV and the importance of protecting themselves:

*So they can prevent their self [from getting HIV] when they get older. / They can say “look mommy – we know that mommy has HIV and...” I would explain to them so that they understand. (Nora 184/186)*

Maria, who had told her two younger daughters about her HIV, tried to put aside her own perceptions about the suitable age for sexual activity to warn her daughters about the danger of judging by appearances. “Long-sleeved shirts” is a reference to men who appear, by their dress, to be affluent, successful and, by implication, healthy.

*[...] Like really really um, the other two now, they were underage but then when I found out now I was like “Underage? Kids that are twelve are getting pregnant” so I was like “No, no it’s my time to tell my kids about it” and I was like “I – if you gonna have sex use a condom. It doh mata [doesn’t matter] who.” I said “Some people look pretty. Some people look nice” and bring dem [brought them] up here [to the clinic] too and I show[ed] dem. Di man dem inna dem lang taal sliiv shirt [The men in their long sleeved shirts] look ok and fine and they got it. (Maria 109)*

Maria also described abstaining from sex herself, partly to protect her daughters:

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<sup>27</sup> *Um...miebi if a tel dem, dem wud chrai an protek demself tu. .. bot a stil instil tu dem - if dey av a partna, uuz a kandom.*



*Since I have been HIV positive I have not had sex and I – a lot a times I go out and man be “psst psst” and “I want to date you.” Am like – a jos lost all interest in men, don’t want to go out wit dem ar even if I talk wit dem on di phone and den it coming close like to relationship I just like ‘Nah...’ I don’t want – ‘cause I have a cousin and she was like “If it was me I give everybadi.” Am like “Yu mad? I can’t go around – I might give somebody and dem give back my **chrii** daata dem [three daughters].”.* (Maria 69)

This extract illustrates Maria presenting herself as a responsible citizen, protecting other members of society. Additionally, it demonstrated her perception of Jamaican society as small and interconnected; it seemed conceivable to her that she might have sex with someone who might then proceed to have sex with one of her daughters.

### 7.3.5 *Protecting the children’s father*

Several women illustrated the complexities of family relationships through their unwillingness to expose their children’s fathers to their children’s anger or disappointment should the children realise it was through their father that their mother contracted HIV. Sandra took responsibility for her status, saying that she “messed up”, but in the same sentence said she feared her son might blame his father, implying it was he who gave her HIV and demonstrating her fears of HIV disclosure impacting on multiple relationships within her family:

*So I don’t know, if his queen messed up... having that [HIV], I don’t know how he would feel. Maybe he would hate his father. (Sandra 166)<sup>28</sup>*

References to women as queens may be traced back to African cultural practices. Stuart, examining the influence of African culture in Jamaica argues that the use of “mother/queen titles hold deeper meanings; connecting their status and role as ruler, head, decision maker, possessor with that of the *inabanza* [possessor or head of the home] in Central African households” (Stuart, 2005:154). The author also suggests that the use of the term queen in Jamaica is connected to the practice of Myal (an African-Jamaican spiritual and cultural practice, connected to Obeah and sometimes described as witchcraft (Stuart, 2005)). Additionally, the much-revered figure of Nanny Maroon (Senior, 2003: 343–4) is also sometimes referred to as Queen Nanny, thus conflating the idealised mother as head of household figure with the powerful leader of the Maroon community of escaped slaves.

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<sup>28</sup> *So a doh no – if iz kwiin mesd op...aving dat I doh no ou ii would fiil. Miebi ii wud iet iz faada.*

Like Sandra, Laura found that telling her son affected his relationship with his father:

*Well, um...it [telling my son about my HIV] went pretty well. He didn't ask me much about it and stuff but he's upset with his father.... (Laura 124)*

However, for Laura, who was living with a new partner, this may have been of less concern than for Sandra who lived with her husband and father of her younger two children.

To illustrate her close relationship with her children, Sarah told me how, when she was surprised by her pregnancy with her youngest (as she had had a tubal ligation 18 years previously, after her third child was born), rather than tell her boyfriend, she told her oldest son. He advised her to keep the baby, rather than risk a potentially dangerous abortion:

*[...] And I felt so frightened, I didn't even go to my boyfriend and tell him. It's the thirty five year old son I go to and explain it to him.[...] "Mami? I won't tell you what to do, but all I'll tell you is try not to bother following your friends and doing foolishness. For your friends that get pregnant, they go and do... abort it, so try not to bother listening to them and killing yourself off." You know? And me and him sit down and have a good relationship. (Sarah 186)<sup>29</sup>*

When I asked her why it was harder to talk about HIV than an unintended pregnancy, she said that it wasn't, but wasn't able to answer me; instead she began to talk about trust and how you can't tell who has HIV:

*I don't know. It's not that it's hard to talk about. Well you know some people feel that they can't have it, and you don't know who for the best— /—and anybody can have it. (Sarah 188–190)<sup>30</sup>*

Possibly she worried that conversations about who brought HIV into the relationship and into the family (her youngest son is HIV positive) might disrupt the balance she has worked to create. Like

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<sup>29</sup> *An di wie a fiatn a didn iivn go tu mai bwaifren an tel im. Iz di terifaiv ier uol son a go tu an eksplien it tu im. [...] mami? A na - a nah tel yu wa fi du ino bot aal mi a tel yu, chrai no bada fala yu fren dem an du no fuulishnis. Faa yor fren dem az dem get pregnant dem go du - abaat it so chrai no bada go lishn tu dem an kil aaf yuself. Yu no? An mi an im sidong an av a gud rilieshanship.*

<sup>30</sup> *Sarah: A - a doh no. Iz nat se it aad tu taak about ino. Wel yu nuo som piipl dem fiil dat DEM kyaah av it an yu doh no uu fah di bes —*

*Gayle: Mhm.*

*Sarah: — a enibadi kyan av it.[...]*

Sandra, she silenced herself (Jack and Ali, 2010) to protect the relationships within her family. Below, she talked about the sense of companionship she has created within the family:

*Right. Yes, Even sometimes... “No, Mami, I don’t want to take the medication”, I say “You have to take the medication until God is ready for you” and he [my son’s father] says “See it here, I take my one. Daddy takes his one”. But we still don’t tell him the reason why. (Sarah 286)<sup>31</sup>*

Sarah worked hard to preserve the relationship with her youngest son’s father and avoided accusations about who brought HIV into the relationship which might lead to conflict. Similarly, Rhine (2016:72–74) in her work with HIV positive women in Northern Nigeria found that women worked to protect relationships though maintaining secrecy about their own and their husband’s HIV status. Sarah recounted:

*And as I told you, when I met my little boy’s father, I never tested for HIV to see if I had it and he never tested for it. You understand? [...] / To be truthful, he says “I don’t understand it” and I say “I don’t understand it either, but we can’t blame each other. For when you and me met, you never got tested for HIV. I didn’t get tested. We just went and had a relationship. Now that [our son] came into play we realise that something was wrong somewhere along the line.” (Sarah 196–200)<sup>32</sup>*

For Margaret, telling her children her own status would expose other family secrets, such as her daughters’ father having died of AIDS. She was not ready to have this conversation, to protect herself and her daughters from distress and possible damage to their relationship, as well as to protect their father’s memory. The extract below hints also at concepts of childhood (implying that 9 is too young) and responsibility (‘they’ didn’t tell her):

**Margaret:** *I don’t know how to tell her.....don’t know.....and I don’t know what her reaction will be like when I tell her.....*

**Gayle:** *Do you think — does um —does she know what her dad died of?*

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<sup>31</sup> Rait. Yes. Iivn somaim xxx [three or four words] ‘no mami a doh waah tu tek di medikieshan’ a se ‘xxx yu av tu tek di medikieshan til gad redi fi yu.’ An im – an im se “si it ier a tek mai won. Dadi tek im won.” Bot wi bout stil doh tel im di riizn wai.

<sup>32</sup> An az a tel yu, wen a miit ma likkl bwai faada, a neva tested fa HIV fi nuo se if a ad it, im neva tested far it. Yu andastan? [...] Tu bi chruutful im de pan ‘xxx a doh andastan it’ an a se a doh andastan it aida bot wi kyaah bliem wan anada. Fa wen mi an yu miit yu neva get tested fi HIV. A didn tested. Wi jos go an av a – av a rilieshanship. Nou dat [our son] kom in plié wi rialaiz se somting woz rang somwier alang di lain.

*Margaret: No.*

*Gayle: No.*

*Margaret: She was um, she was what? Nine years old when he died.*

*So...they didn't tell her. (Margaret 106–110)*

Margaret portrayed herself as a selfless mother, protecting her children and supporting their school participation and career aspirations. She highlighted the difficulties she faced in parenting alone, and the sense of betrayal she felt towards her husband, who died of AIDS. For her this created a complex emotional response: she felt angry with him for acquiring HIV, for dying of AIDS, for giving her HIV, and for leaving her to parent alone, but she also felt sadness at his death and wanted to preserve his identity in her children's eyes: telling them about her HIV would mean telling them about their father's HIV.

Although clear about their strength and agency in other areas of their lives, several of the women constructed a narrative of their experience of acquiring HIV which positions them as blameless and innocent (not so different from the 'passive victim'). These women were angry with their husbands or partners and were less concerned about protecting their identity in the eyes of their children. For example:

*[...] Because I was faithful to him [sniffles; stops crying]. When I went home I told him, I said to him: "All the while, I always say to you 'If you are going outside, you use a condom' and now look what you have made happen" [sniffles][...](Winnie 37)<sup>33</sup>*

*[...] And the reason why I told them is I'm not afraid to walk or nothing. Or afraid to talk? Cause it's not my fault. It's their father's fault. (Anna 413)<sup>34</sup>*

*Well...when I first found out I was just thinking what would I do, where do I go from here – because I'm married and everything like that and I just caught up in this situation, you understand? So I was very mad at my husband. (Laura 70)*

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<sup>33</sup> [...] kaaz a woz fietful tu im [sniffles; stops crying] wen a went oum a toul im a se tu im se aal i wail a aalwiez se tu yu se 'if you ar goin outsaid yu uuz a kandom' an nou luk wat yu mek apen [sniffles][...]

<sup>34</sup> [...] An di riisn wai stil a tel dem se a doh fried fi waak ar notn. Ar fried fi taak? Kaaz iz nat mai faalt. Iz dem faada faalt.

In the final extract, above, Laura implied that her husband gave her HIV and this is why she was angry with him. She portrayed herself as responsible and respectable through her status as a married woman and as passive and blameless: “just caught up in this situation”.

Winnie described her views of men and women conforming to typical gender stereotypes, where men are active and women are passive: men “do” and women have things “happen” to them. Winnie was clear that having an outside relationship was to be expected of male partners, but the lying and not using a condom made her angry:

*Because, ummm, no man has just one woman. And if you're having an affair, you must use a condom because you are not faithful, so you must use a condom. And he said [xxx] "I'm not having sex with anyone else" Me: "You're having sex with somebody else" ... and. it was so...[...]*  
(Winnie 53–54)<sup>35</sup>

She was angry with her husband for infecting her with HIV, she has since left him and gone to live with her sister.

*[...] — what is going on now in the world, you can't, you can't trust in anybody any more. Don't care who you— it's my husband or somebody [inaudible] you just cannot be trusted. You cannot put down your guard.*  
(Winnie 141)<sup>36</sup>

Winnie moved from third person to first person as she spoke and ended talking about trust, returning to the sense of blame and betrayal she felt when her husband, who she believed brought HIV into the relationship, refused to admit this. She saw his denial of HIV as weak and possibly even murderous, comparing knowingly giving another person HIV to the actions of “a bad man, putting a gun to somebody’s head” (Winnie 141).<sup>37</sup>

## 7.4 Chapter summary

Mothers carried out emotion work against a backdrop of poverty and violence, and continuing stigma in relation to HIV status, demonstrating skilful navigation of social norms to safeguard their children’s physical, sexual and emotional health as well as their education and employment

<sup>35</sup> Bikaaz, aahm...no man doh av wan uman. An yu avin an after so yu mos uuz a kandom kaah yu nat fietful so yu mos uuz a kandom. An im se xxx [one or two words] a nat avin seks wid noba els. Mi yu avin seks wid sombadi els.....an...iz so... [...]

<sup>36</sup> [...]– wat iz goin aan nou in di werl yu kyaah – yu kyaah chos en - enibadi no muor. No kier ou yu – iz ma ozban ar sombadi xxx [one word] yu jos kyanat bi chosted. Yu kyanat put down yu gard —

<sup>37</sup> a bad man, put a gon to sombadi ed

prospects. Additionally, some women described how they attempted to protect their children from acquiring HIV by defying cultural norms and discussing sex and sexual health with them. The women described emotion work designed to protect their children regardless of their experiences of full, partial or non-disclosure to their children, thus demonstrating the importance of emotion work, even when it doesn't conform to policy expectations. I continue to address issues of responsabilisation in the next chapter (Chapter 8) where I illustrate the emotion work associated with two particular experiences, mothering at a distance (living apart from one or more children), and 'downfallment' (the fear or reality of a child being HIV positive).

## **Chapter 8:       The responsible mother: HIV, mothering at a distance and ‘downfallment’ (Theme 2):**

### **8.1     Introduction**

Cupcake (82–84, see Section 7.3.3) used the phrase ‘I was HIV’ rather than ‘I was HIV positive’ demonstrating how all-encompassing HIV can feel; HIV is not something you have, it becomes part of you: it is something that you are. Cupcake demonstrates the powerful sense of HIV seeping into all aspects of her sense of self; something which she does not want her children, or others, to be aware of. Throughout the interviews the women sought to present themselves to me as ‘good’ mothers, wives, people, patients, and interviewees. As mothers with HIV, they are aware of potential judgment and so seek to counteract the negative discourses (Sontag, 1991) of HIV positive women as promiscuous, deviant, unclean, passive victims, or unfit mothers (Alldred, 1996). HIV can create multiple challenges for mothers: physical (illness, fatigue, medication side effects); emotional (depression, fear for the future, secrecy); and practical (finding time and money to attend appointments and collect medication). In attempting to live up to the unrealistic concept of the idealised mother (Craig and O’Dell, 2010), HIV positive mothers must work extra hard to overcome these challenges and present themselves as healthy and responsible.

This chapter examines the second theme, *The responsible mother: HIV, mothering at a distance and ‘downfallment’*. I explore how the experiences of mothering at a distance and ‘downfallment’, in the context of maternal HIV, present particular challenges for mothers working to protect their maternal identity. The ‘pinch’ in these cases is experienced as the challenge of working to be a culturally accepted ‘good’ mother, despite multiple experiences which are perceived as being negative and the antithesis of ‘good’ mothering: mothering at a distance (*i.e.*, living apart from their children, which, although not unusual in many countries, including Jamaica, is not well recognised in policy); having a stigmatised disease associated with promiscuity and irresponsibility; and the possibility or reality of transmitting this disease to their children (‘downfallment’). The HIV positive mothers I interviewed used various strategies to manage feelings of guilt, blame or judgment and to present themselves as ‘responsible mothers’ (Lupton, 2011) to counteract the Victorian concept of the ‘fallen women’. Women managed feelings of blame and judgment, deflected negative characterisations of HIV positive women and presented themselves as capable and morally responsible mothers. These feelings were intertwined with their decisions regarding disclosure to their children.

McDonald (2013), writing about maternal disclosure of HIV to children in Australia, found that women worked to present themselves as “‘normal’ women living ‘normal’” lives by “resist[ing] a spoiled identity and present[ing] accounts of themselves as informed and responsible within their sexual relationships with HIV-negative men” (McDonald, 2013:131). In this chapter, I extend this concept to mothering by suggesting that HIV positive Jamaican mothers work to present themselves as ‘responsible’, capable, ‘good’ mothers. This chapter demonstrates how the women challenged these characterisations by presenting images of themselves as faithful, supportive wives (Sontag, 1991); as healthy, capable women (Rhine, 2016); and as ‘responsible’ mothers (Craig and Scambler, 2006; Lupton, 2011). For mothers with HIV, who risk judgment and loss of emotional, financial and practical support if their HIV status becomes known, protecting their maternal identity may be considered especially important.

## **8.2 Maternal responsibility: mothering at a distance**

### **8.2.1 *What is mothering at a distance?***

As discussed in Chapter 3, many of the challenges faced globally by women who migrate transnationally for economic reasons are also faced by Jamaican women who move to Kingston to seek work, leaving their children with relatives in the rural areas. HIV positive mothers practising mothering at a distance employ emotion work to preserve a positive maternal identity and present themselves as ‘responsible’ mothers. By ‘mothering at a distance’, I refer to the experience of mothering children who live with their father or other family members overseas or elsewhere in Jamaica. At the time of the interviews, 7 of the 15 women had at least one child living elsewhere. Susie, Laura, Tina, Sarah and Johnett all had at least one child living (or in the case of adult children, who had lived) in a different part of Jamaica and being cared for by extended family, often grandmothers. Maria and Sandra both had their oldest child living ‘abroad’, with the child’s biological father or paternal grandparents. This is but a snapshot; over time these issues likely become even more widespread: child-shifting arrangements are well recognised as fluid and transient (Russell-Brown, Norville and Griffith, 1997). Whilst navigating family separation issues, the women all worked to fulfil social and cultural concepts of ‘responsible’ mothering (Lupton, 2011) in the Jamaican context, whilst living with HIV.

The ‘pinch’ for women practising mothering at a distance is the challenge of maintaining the emotional closeness expected by society as proof of a close mother-child bond, despite the reality of physical distance and infrequent contact. This is compounded by the challenges of managing HIV. Mothers are aware they stand to be doubly judged: there is considerable pressure on Jamaican mothers to provide financially for their children, resulting in some women living apart from their



children. Although normalised in Jamaica, mothers practising mothering at a distance may still feel judged for not living with their children (although perhaps less judged than if they neglected pursuing work opportunities). Mothering at a distance is an emotionally complex experience, full of challenges and contradictions. Many women presented their decision to implement mothering at a distance as either outside their control (usually decided by their own mother or by the child's father) or as in their child's best interests (such as taking the opportunity to live overseas or remaining in rural areas with relatives while their mother worked in the city and sent money for their care). Some women (*e.g.*, Susie) harboured regrets, whilst others, like Maria, were more pragmatic; for some women (*e.g.*, Laura) it was a fluid arrangement whereas for others (*e.g.*, Johnnet) it was longer term. However, in all cases, the physical distance between mothers and their children made disclosing maternal HIV to those children practically and emotionally more challenging than to the children living with their mothers. This is illustrated by women such as Maria who describe disclosing to the children they live with and not to the child living apart from them.

### **8.2.2     *The responsible mother and mothering at a distance***

Susie expressed feelings of sadness and exclusion from her daughter's relationship with her daughter's grandmother (Susie's mother) and Susie's twin sister, who raised her daughter while Susie worked in Kingston. Susie was diagnosed not long before the interview and I felt it represented an opportunity to explore and make sense of her feelings. Her HIV diagnosis made her reflect on her life, and she expressed sadness and regret at allowing her daughter to grow up with her own mother (her daughter's grandmother), reflecting that, although it made practical and economic sense for them as a family, even at the time she had had misgivings. However, mothers, often the sole providers for their children, feel pressure to go wherever there is work. In practice this often means Kingston, where the cost of living is higher. Thus, it often makes financial sense for children to live with relatives in rural areas, so the mother need not pay for childcare, and where the child and caregivers can benefit from the remittances.

*[...] my mother said to me, send her down and I will take care of her for you./ —And I said to her “No, Mama”. I didn't want to do it. I didn't want to do it because you're not going to... bring up the child— / —to know me and have a bond. She said to me “No”. I went to this lady next door and said to the lady “You know that my mother wants me to send the baby to the country?” She said “Don't send your daughter down*

*there because you will regret it”. /And so said, so done. When her father came to Jamaica, she preferred her father over me. (Susie 154–161)<sup>38</sup>*

As a result, Susie felt that she and her daughter did not have an emotional bond. She touches on the long standing racism inherent within Jamaican society (Leo-Rhynie, 1996) where those with lighter skin are treated more favourably than those with darker skin:

*Susie: You understand me? You see, the bond that me and my daughter have?—should have? We don’t have it.*

*Gayle: So tell me a little bit about that.*

*Susie: ooh...I believe— I don’t know if I’m blaming my family, but I feel that... they didn’t want me to have much to do with her. They feel like she’s too good for me.*

*Gayle: Your daughter?*

*Susie: Yes. She’s a pretty girl. Sh— and because I have dark skin and my twin sister is brown, she’s brown, you understand me?/ She doesn’t call me Mami, she calls my sister Mami. (Susie 142–148)<sup>39</sup>*

She highlighted the loss of her relationship with her daughter, where her daughter failed to acknowledge even their biological relationship and chose to call Susie’s twin sister “Mami” instead of Susie. She described trying to fulfil a traditional maternal role, advising her daughter to abstain from sex and focus on her studies:

*’Cause I remember one day, my mother said something to me about, about boy— she’s with this guy and blah blah blah and I called and said to her, said, “Now is not the time for boyfriends, now is the time for education./ As a matter of fact, I can’t tell you not to have a boyfriend*

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<sup>38</sup>*Susie: [...]* mai moda se tu mi se send er doun an a wil tek kier af er fay u.

*Gayle: Okay.*

*Susie: An a se tu er se ‘no moma’. A didn want tu du it. A doh waah tu du it bikaaz yu nat gona aahm...gruo di chail –*

*Gayle: Yeah.*

*Susie: -fi nuo mi an av a bandin. Shi se tu mi se ‘no’. A went tu dis liedi neks duor a se tu di liedi se ‘yu nuo dat mi moda waah mi fi sen di biebi go a konchri?’ Shi se ‘doh sen yu dawta go doun dier bikaaz yu goin rigret it.’*

*Gayle: Mhm.*

*Susie: An az so sed, so don. Wen ar faada kiem tu Jumieka shi prefa ar faada ova mi.*

<sup>39</sup>*Susie: ... Yu andastan mi? Yu si di bondin dat mi an mai daata av? – shud av? Wi dozn av it.*

*Gayle: So tell me a little bit about that.*

*Susie: Ooh...ai biliiv – ai doh no if am bliemin ma famili dem bot a fiil dat... dey didn waah mi tu av moch tu du wit har. Dey fiil laik shiiz tuu gud fi mi.*

*Gayle: Your daughter?*

*Susie: Yes. Shiiz a priti gorl. Sh – an bikaaz am daak skin an ma twin sista is broun – shii broun, yu andastan mi?*

*Gayle: Mhm.*

*Susie: Shi doh kaal mi mami, shi kaal ma sista mami.*

*but don't have sex because once you start having sex, it will complicate your education". And then her remarks to me were that I- I wanted a— how did it go?— I'm not perfect and I want a perfect daughter. Because her father said to her that she— he never wanted me and I chased after him./You understand me? So that was the remarks. So that's why I [inaudible] say even if I was on my deathbed I don't think I could tell her.(Susie 164–168)<sup>40</sup>*

This conversation made Susie feel that her character and choices were being attacked and that her daughter felt closer, not only to Susie's mother and sister, but also to Susie's ex-partner (her daughter's father). Susie believed she got HIV from her daughter's father and the perceived unfairness and lack of understanding illustrated by this conversation made Susie feel certain that she could never, even on her "deathbed", tell her daughter that she had HIV.

However, Susie talked about her hope of having a second chance to mother, by mothering her future grandchild and establishing with her or him the bond she did not have with her own daughter. She talked of her fears that HIV will rob her of this possibility and of her hopes that it will not, that she will be able to see her grandchild. Her hope developed quickly from just seeing the child, to watching the child grow up, graduate and marry. I was aware of Susie's recent diagnosis (6 months prior to the interview) and that she was still in the process of understanding what this might mean for her.

*Being a mother and HIV positive is kind of sad because sometimes – I don't have grandchildren yet—/ — [...] And I would like to live to see my granddaughter—/ —Or grandson. That is one of my greatest desires. I am a great believer in God. And I only trust that God will give me long life that I can see my granddaughter. If I'm living to watch the child grow up—/ —To graduate from high school and get married too, you understand me? ...(Susie 327–333)<sup>41</sup>*

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<sup>40</sup>**Susie:** Kaah a rimemba wan die ma moda sed somting tu mi about – about bwai – shi avin dis gai an rei rei rei an a kaald er an se tu er se, nou iz nat di taim fa bwaifren, nou iz di taim fa edikieshan.

**Gayle:** Mhm.

**Susie:** An mata a fak mi kyaah tel yu fi no av bwaifren bot du doh av seks kaah wans yu staat di seks it a go kompliket yu edikieshan. An den er rimaaks tu mi woz dat mi – mi want a – ou it go? – mi wozn porfek an mi want a perfek daata. Bikaaz er faada se tu ar se shi – im neva want mi a mi luk im.

**Gayle:** Mhm.

**Susie:** Yu andastan mi? So dat woz di rimaaks. So dats wai mi xxx [four or five words] se iivn if am on di dain bed mi no tink mi kudaan tel har.

<sup>41</sup>**Susie:** Biin a motha an HIV pasitiv iz kain af sad bikaaz somtaim – a doh av a gran – granchildren yet –

**Gayle:** Mhm.

**Susie:-** an aahm, ma sista av a grandaata. An a se dat a wud laik tu liv tu si ma grandaata -

Tina highlighted the challenges of working to provide both financially and emotionally for her children:

*I would visit them. And the first two, I give them everything. Hamm, before meeting the second baby father when I was here in Kingston, I work, I work at [a dry cleaner's], I do evening jobs, I make sure that they got money every week to go to school, I make sure that they got everything. Just one thing they need that was me being there for them, I mean like literally being there... (Tina 98)*

Here Tina summed up the difficult decisions many low income Jamaican mothers must make between providing for their children financially and being there for them emotionally. Being a visibly 'good' mother in the context of geographical separation is a huge challenge for women whose children live with others for financial, practical or other reasons. Mothering at a distance affects both HIV positive and HIV negative mothers, but presents additional challenges for HIV positive mothers trying to establish emotional closeness prior to talking to their children about their HIV. Women worked to manage feelings of guilt and blame as well as other interconnected and often uncomfortable feelings: loss, anger, sadness, fear, anxiety, love. These feelings are complicated by family dynamics; mothers and children exist within a complex web of familial relationships, with siblings/half-siblings, partners (who may also be fathers/step fathers), grandparents, aunts, uncles and cousins, as well as relationships with teachers, neighbours and others within the wider community. Laura mentioned some factors leading to her sons sometimes living with her mother:

**Laura:** *Oh, the other one is getting rude and she [my mother] can't manage him so I have him now with me.*

*[...]*

**Gayle:** *Okay. And how is that?*

**Laura:** *Well it's ok. They normally back and forth living with me now and den but because um, they not gonna be supervised like how I want them to, that's why they stay with her because am an only child so they*

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**Gayle:** *To see your granddaughter.*

**Susie:** *- ar grandson. Yu andastan? An dat iz wan af ma grietes dizaya. And am a griet biliiva in gad – som piipl don't bot am a griet biliiva in gad. An a onli chos dat gad wi giv mi lang laif dat a kyan si ma grandaata. If a livn tu wach di chail gruo op –*

**Gayle:** *Mhm.*

**Susie:** *- tu gradiet fram hai skuul an get marid tu, yu andastan mi? ...*

*are a company but the smaller one is living with me now. Ye, ye he's ok but he visits on weekends. He go over by her house on weekends.*

*(Laura.56–62)*

For Laura, this flexible, fairly fluid arrangement shifts according to the needs of individual family members.

Maria compares her close relationship with her younger two daughters (who live with her and whom she has told about her HIV) with her much more distant relationship with her older daughter:

*[...] It's just that she is sentimental and because I had to send her away wid her dad from then, and I knew the child she was before she left here she was so cry-cry. Everything she cry about and even now she still cry. So I was like "No I'm not gonna tell her. Why should I tell her anything? And she is not even here?" and so that's why I decided not to tell her. It's not like she is here and she is gonna see me going through the phases and getting sick. (Maria 117)*

Maria seems to have mixed feelings concerning her older daughter; her words (“cry-cry”, “sentimental”) appear dismissive. She has decided specifically to exclude her from knowing her status and has instructed her other daughters not to tell her. There may be a clue in the words “because I had to send her away wid her dad”, and her mentioning her “bond” with her other two daughters. Perhaps she feels that the lack of a close relationship with her daughter was something outside her control, and that now, without that history and bond, she is unable to navigate the emotional minefield of talking to her distant daughter about her HIV status. Differential disclosure was identified by Dane (2002) as associated with the child’s age, but in the Jamaican context, particularly amongst those living in poverty, it seems to be more often associated with the challenges of maintaining emotional closeness while mothering from afar.

Only one mother, Tina, had herself talked to children who do not live with her about her HIV: “Because I think umm all my children them should know” (Tina 196). At the time of the interview she had told her older two children and was in the process of indirectly telling her third child. Despite living apart from her son, she devised a way to tell him: by enrolling him in a programme run by a local NGO specifically designed for the children of HIV positive mothers. The extract below is quite stilted and illustrates the difficulties she felt in telling her third child; note the “ummmms” and repetition of words.

*Gayle: And what about your children?*

**Tina:** Yeah.

**Gayle:** All of them?

**Tina:** No, the two first one. Well, the third one because hamm, I am having 'im in some ummm – With [a local NGO] .../...I have him down there some ummm support group, ummm not really support group but some-something that-that-that will teach him about HIV./ So I – I haven't spoke him that I'm HIV positive, but ummm I haven't been in all this ummm, groups.../Suh umm, maybe, maybe he knows because when he went there he saw friends and those friends are child of a HIV positive parent. (*Tina 133–136*)

Initially, Tina implied that she had told all her children; only when I queried this did she acknowledge having told the older two, not her third, nor her fourth, aged 6 at the time of the interview. Tina was active in several NGOs, evident sometimes in the words she used and also possibly in some concepts she embraced. Her expressed desire to tell her children seemed to be influenced by NGO encouragement of family disclosure: “Because hamm, I was kind of jealous when mi hear everybody sey them disclose to them child you nuh.” (Tina 224).

### **8.2.3 Managing disclosure by grandmothers**

A further challenge for mothers living apart from their children occurs when their caregiver, often the maternal grandmother, discloses the mother's status to her child. These grandmothers may feel they have rights conferred by their relationship and as a result of their caregiving role, though this view is not always shared by their daughters. Disclosure of maternal HIV by maternal grandmothers can complicate the relationship between mothers and their children and can lead to additional emotion work for mothers not ready to talk about their HIV with their children and who may feel angry or betrayed by their own mothers. Despite her flexible approach to her sons' living arrangements, Laura considered talking to her sons about her HIV to be her responsibility as her children's mother. However, Laura's mother disclosed Laura's status to her oldest son whilst Laura was in hospital with HIV-related complications. Laura's interview was characterised by avoidance and control, so it is not surprising that she would feel angry that her mother took this task from her or that she would avoid detailed discussion of it with her mother. However, it is also easy to imagine the challenges Laura's mother would have faced, caring for her two grandsons while their mother (her daughter) was in hospital. This extract highlights some of the communication challenges faced by families affected by HIV, particularly where other family members are involved in childcare responsibilities:

**Laura:** *Well at first...um...and even now – I – I – am upset. I was upset about it.[...] but I – I wish for her was to wait and let me tell who I wanted to tell. ‘Cause she has now told my bigger son and I think that she should have waited and let me sit and talk to him about it. I was upset with her about that whole situation. [...] So I was upset and said “Mom, you should have allowed that to be done by me. You should not have done that.”*

**Gayle:** *And what did she say?*

**Laura:** *She didn’t say anything about it. She just bypassed it as if it’s nothing. (Laura 101–110)*

Although Johnett began by saying that she told her eldest son, when I asked for details she said that, in fact, her mother had told him:

**Johnett:** *Yes I told my big son, but I didn’t tell the small one. I didn’t tell the small one.*

**Gayle:** *So when did you tell the big one?*

**Johnett:** *Well, I didn’t really tell him you know. My mother told him. My mother told him. My mother told him but he still hasn’t asked me about it. (Johnett 84–86)<sup>42</sup>*

She attributed this to the close relationship her mother had with her children, which she believed was closer than the relationship she herself had with them:

*He and my mother have a good relationship— my big son?/ And my mother, who is his grandmother? They have a good relationship, better than me. Because my mother grew him [brought him up] from when he was ten months old. /You understand? Even my daughter too. So they have a closer relationship with my mother—with their grandmother— than with me. Ye./[...]He is not really going to say it to me. (Johnett 244–252)<sup>43</sup>*

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<sup>42</sup>**Johnett:** *Yes mi tel mi big son bot a doh tel di smaal wan. A doh tel di smaal wan.*

**Gayle:** *So when did you tell the big one?*

**Johnett:** *Wel a no mi riili tel im ino. A mi mada tel im. Mi mada tel im. A mi mada tel im bot im doh aks mi stil.*

<sup>43</sup>**Im an mi mada av a gud rilieshanship – mi big son?**

**Gayle:** *Mhm.*

**Johnett:** *An mai mada wich iz fi im granmada? Av a gud rilieshanship muo dan mi. Bikaah mi mada gruo im fram im a ten monts.*

**Gayle:** *Ok.*

**Johnett:** *Yu andastan? Iivn mi daata tu. So de mu – dem muo av a rilieshanship wid mi mada – wid dem granmada muo dan mi.*

The combination of their more distant relationship and the fact that the information came from his grandmother made it more difficult for Johnett and her son to discuss her status. However, her son mentioned it to her obliquely and she took this opportunity to reassure him that she is taking care of her health:

*Yes. The only thing I know— the only thing I realised, although he didn't tell me— that my mother must have told him? He said to me “You're sick, you know? You shouldn't drink alcohol or mess yourself up” and all that. I said “I know I shouldn't drink alcohol and anyway you know I don't drink alcohol. I have told you that”. I said “You know that if I do anything I won't mess up my body, mess up myself, do a whole heap of work...and all that”. (Johnett 254)*

Laura, whose mother told her older son about her HIV, considered finding out specifics about the disease to be her son's responsibility:

*[...] But I didn't go in much detail cause he's more advanced. He's – he does research and he knows about it. That's him. (Laura 120)*

Laura did not wish to discuss her HIV in detail with her son or consider learning about HIV to be a shared journey; for her, it was enough for him to simply be aware of it and up to him to research it further if he wished. For women whose children were told without their consent, it was difficult to have ongoing conversations about their HIV status, possibly because they had not yet fully thought through the disclosure and its implications for their relationship.

## **8.3 Responsible mothering and the fear of 'downfallment'**

### **8.3.1 What is 'downfallment'?**

In this section, I explore the interaction between HIV and maternal disclosure decisions and the fear (or reality) of 'downfallment', a child being HIV positive. Although mother to child transmission is now very low in Jamaica (Jamaican Ministry of Health, 2014) and much progress in this area has been made over the last decade, three women in my sample had HIV positive children, and most of the women expressed ongoing concerns about their children's HIV statuses. Women often remained anxious about their children's HIV status, despite multiple negative HIV tests.

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*Gayle: Mhm.*

*Johnett: Ye.*

*Gayle: And so that was why she felt ok to tell him.*

*Johnett: Mi fiil se shi tel im stil. Im naah go riili se it tu mi*



Several women referred to a child's diagnosis with HIV as 'downfallment'. The word 'downfall' usually designates a government, dynasty or person in power and refers to their loss of power, status or prosperity. Synonyms include ruin, ruination or undoing. Mothers using this word to describe their child's HIV status are implying that they see (or believe others see) the child as permanently ruined or spoiled, that they have lost status and the future possibility of power and prosperity. This is a particularly damaging prospect in the context of a culture placing such emphasis on the importance of education and a mother's responsibility to safeguard and promote access to education.

The feelings that women associated with the fear or reality of having a child with HIV demonstrated the links between mother and child health (underlined by the vertical nature of HIV transmission to babies) and the ways in which they felt liable to be judged as having failed in their maternal duty to protect their child from HIV. The association between HIV and death provides a strong contrast with the image of the mother as giving and protecting life. 'Downfallment' is a powerful word, which I believe carries connotations of the downfall of the mother as well as of the HIV positive or potentially HIV positive child. Ussher (1989) refers to the Madonna/whore dichotomy: a woman "cannot be a good mother and a sexual person at the same time...women's sexuality is dangerous and threatening and... at odds with the stereotype of the 'good mother'" (Ussher, 1989:15). The 'good' mother in her most extreme (and unrealistic) form is represented by the Madonna: pure, virtuous, clean and virginal. In contrast, the whore is immoral, promiscuous and diseased. Women whose children have acquired HIV stand to be doubly judged: not only should 'good' mothers be healthy (and in particular free from a sexually transmitted disease carrying connotations of immorality) but, in passing HIV on to their children, they are seen to have failed in their maternal duty to safeguard their children's health.

A baby or young child receiving a positive HIV test result, or 'downfallment', carries an implicit challenge to mothering identity. Firstly, as it is extremely unlikely a young child has acquired HIV other than perinatally, a mother may fear judgments of promiscuity or immorality. These assumptions often accompany an HIV diagnosis and help explain women's determination to present themselves as respectable, responsible and clean. Secondly, in Jamaica, with free HIV treatment and a successful record of preventing maternal transmission of HIV to children, an HIV positive child implies the mother failed to obtain a diagnosis or treatment for herself and her child or that she behaved contrary to medical advice by, for example, breastfeeding her child. A myriad of reasons might explain a child becoming HIV positive (including, for example, medical negligence) but the assumption is that the mother failed in her duty to protect her child. In addition to feelings of sadness, guilt and anger which a mother might experience upon receiving an HIV

diagnosis for her child, she is likely also to encounter practical and financial challenges in caring for that child's health. All of these factors will have an impact on the decisions a mother makes about whether or not to tell her HIV positive child about their and her HIV statuses.

### 8.3.2 *The responsible mother and 'downfallment'*

Just under half of the women talked explicitly about their fears that their children had HIV and addressed these fears by ensuring they were tested, sometimes repeatedly, and usually without the children's full understanding. Many of the women had given birth to some of their children after their own diagnosis and so they would understandably have concerns about their children acquiring HIV perinatally. Three women (Tina, Cupcake and Laura) were diagnosed antenatally and avoided antenatal treatment altogether; in doing so they also avoided antiretroviral treatment which would have provided a very high level of protection from HIV for their unborn babies:

*[...] I sta – and I wasn't on any medication, they told me to come and take the medications and stuff and while I was pregnant I didn't go through with taking any medication. They told me to – to take the baby for him to get antiviral syrup and stuff?— /— I did not. I didn't do anything like that. Only thing I – I took him back to do was the test when they say I can take him back within six months' time for him to do the test and he was negative. That was good for me. (Laura 222–224)*

*...I get [got] into some argument wid my baby father and him put mi out [he threw me out] and — that now — I just rememba why I didn't do the PMTC because him put mi out and – that was in Kingston so now I didn't have anybody to go to in Kingston so I had to actually go back to [rural area]./ [...] –I- I didn't go to any clinic in [rural area] because I was scared of them knowing-knowing my HIV status and hamm, I went to a clinic in [another area] –[...]and they referred me to hospital and – When I go at the hospital I see the doctor for the day yes, but he didn't do anything, just check up, only a check-up. And before I could go back to a next [another] doctor I have the baby [...] (Tina 48–50)*

All three women later had HIV negative babies and described their feelings of relief and happiness at their children's negative HIV tests. It is likely that their children's HIV negative status enabled them to talk to me about refusing or not accessing antiretroviral treatment during their pregnancies.

The women took their own steps to try to protect their children, such as not breastfeeding. However, they continued to feel great anxiety about their children's possible HIV positive status and ensured that their children were tested for HIV. In Laura's case, this included testing her older son as well, as she wasn't certain when she acquired HIV and did not have full confidence in the testing regime. Laura's sons' negative test results were a key factor in enabling her to move on:

*[...] Ye they are negative so I was elated so that didn't bother me – I was just thinking about dealing with myself and how to accept it and how to move on. (Laura 266)*

For other mothers, like Cupcake, the anxiety about her children possibly having HIV was very deep-rooted and not always alleviated by receiving a negative HIV test result. This was evident in her need to have her children tested repeatedly. In some cases, this can be explained by the children being older, and possibly sexually active, so their mother worried about their acquiring HIV. However, Cupcake's anxiety was focused on her youngest son, aged 11 at the time of the interview:

*... A [I] would always have it in di back a mi head? /— that the baby is HIV./ But he wasn't. He did the test two times. (Cupcake 160–164)*

Although Anna was diagnosed about a year after her last child's birth, she also talked of testing her sons repeatedly, partly because a nurse told her that HIV sometimes "shows up late". This concept may originate from clinical guidance<sup>44</sup> advising that children of HIV positive mothers should be tested up to the age of two years because of the possible presence of maternal HIV antibodies.

*[...] And some people now, sometimes it takes long to show./ Because, you see my son? I take him often you know, go and take the test. Since he's 17? And last June, he was 18, they say he doesn't have it from in a little bit til now, I keep checking. Umm one of the nurses told me that sometimes it shows up late./ Sometimes it shows up late. (Anna 597)<sup>45</sup>*

Nora, diagnosed after her first child's birth, had three more children; all four are HIV negative. After the stress of HIV tests for all her children, she decided to "go on family planning". She spoke positively of her counselling experience while pregnant with her fourth child:

<sup>44</sup> <https://aidsinfo.nih.gov/guidelines/html/2/pediatric-arv-guidelines/55/diagnosis-of-hiv-infection-in-infants-and-children>

<sup>45</sup> **Anna:** *Ye. Dat kyan apm tu ino. An som piipl nou, somtaim it tek lang fi shuo.*

**Gayle:** *Mhm.*

**Anna:** *Bikaah, yu si mai son? Ai kyari im aaftin ino, go an tek di tes. Sins im sevntiin? An Juun gaan im iz ietiin, dem se im no av it fram in likl bit til nou, a kiip chekin. Aahm, wan a nors tel mi se somtaim it shuo op liet.*

*Nora: It make me feel good. It make me feel like I want to live. It make me feel like um, I can mother a next [another] child again.*

*Gayle: And what – what were you worrying about? Why did you think that you couldn't mother another one?*

*Nora: Oh gosh. Just the coming to the clinic with the baby every minute – to the – I didn't want to feel – feel – to feel the feeling of a next [another] baby being tested again.*

*Gayle: The testing must be difficult.*

*Nora: Yes. A next [another] baby to be testing again. So when I found out she was negative, and they discharge her, I said no more babies again. I just went on the family planning. (Nora 499–404)*

She made reference to feeling despairing, possibly even suicidal. In contrast to some other accounts, where HIV positive Jamaican women said they felt judged for wanting to have children and pressured to use long-term forms of contraception (Watson and Crawford, 2011), Nora presented this as something she has actively chosen and feels is in the best interests of her and her family.

Several women talked about having children as a choice. Tracy, diagnosed following the birth of her first daughter (also HIV positive), had two more children and talked about possibly trying for a fourth. Tracy's HIV status has made having children more complicated, necessitating taking "risks" and illustrating the determination Tracy felt to try to have the family size she wanted:

*When I didn't know about it — I didn't know anything about it...didn't want to have any more children because you know if I have any more my baby's gonna – when the doctor told us about the xxx [one word] virus, the chance that the child might not — /So I took that risk and my risk was good. And I went back and took a next [another] risk and it was good also. But I mean, if the last one was a girl then I wouldn't, I wouldn't want to take a next [another] one but — I would have one girl and two boys. I need a girl. I need a next [another] girl. (Tracy 234–236)*

Tracy was not explicit about why she needed another daughter: I wondered if it might be linked to her later comment about fearing she had "shattered" her daughter's dreams of having children. Possibly she felt more likely to have a closer relationship with her daughters' children rather than her sons', and feared that, as a result of her eldest daughter being HIV positive, she might lose this opportunity. Women decided to have children post-diagnosis despite the negative pressure that

HIV positive women may be subjected to by health professionals in Jamaica. In contrast, Tracy looked to the future and was optimistic about her chances of having another daughter, one who would be HIV negative.

The women expressed their feelings of guilt and anger over their children's positive status but also took pride and felt relief in their children's continued good health and in their ability to care for them. In this way, they presented themselves as competent and responsible mothers:

*...For, to be truthful, from when he left hospital, when he was— the last time he was admitted to the hospital was when he was a year and 7 months old and since he was discharged that time? He has never been admitted again. (Sarah 246)<sup>46</sup>*

This links to the concept of mothers' protecting and caring for their children, which holds across most societies, but may be especially strong in the Caribbean, where the colonial legacy leaves the recognition that this was not always within a mother's grasp (Adisa, 2013:67) and where supporting a child's educational and employment prospects are such a crucial part of motherhood. Tracy spoke of her sadness and feelings of guilt:

*[...] I going shatter her goals and her dreams and things like that so I really don't want to tell her as yet. [...] I don't know if I have shattered her dreams of having kids. (Tracy 214–216)*

Her daughter wanted to be a police officer and Tracy believed she would need an HIV test as part of the recruitment procedure and that her positive result would exclude her from consideration. Tracy's use of the word "shattered" was very powerful, creating images of complete destruction. Tracy felt the news would utterly destroy her daughter's hopes and dreams: her career plans, her hopes of having a family of her own. She used 'I', implying a sense of responsibility for her daughter's HIV status and the impact that learning about her own and her mother's HIV status might have on her life.

### **8.3.3 Denying HIV in the context of fearing 'downfallment'**

It was not unusual for women, when asked a direct question by their children about their illness or medication, to tell a half truth, by saying it was connected to an illness they already have, like diabetes (Johnett 154). Thus, they acknowledged their illness and the need to take care of their health, but avoided discussing HIV and its implications, which may call for more complex emotion

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<sup>46</sup> ....Far tu bi chruutful? Fram im liiv aspital wen im woz... - di laas taim im admit ina aspital iz wen im woz a ier an sevn monts oul an fram im dischaaj dat taim? Im neva admit agen

management. Two of the women I interviewed took this a step further and directly denied having HIV. Sarah talked about a misunderstanding that led to a doctor accidentally telling Sarah's daughter about the HIV status of her younger brother (Sarah's son), which implied that Sarah was also HIV positive:

**Sarah:** *Well my daughter— once the doctor thought that she was my son— the mother of my son./ So when he got sick and was admitted up here [to hospital] [...] And she was— she came home and she was crying and she said to me that the doctor told her that [her brother] has H— was HIV positive and what have you. And she told him “No”. I said ‘Don’t listen to the doctor’ and I’ve still never opened up to her. Explained to her.*

**Gayle:** *And what do you think she thinks?*

**Sarah:** *I don’t know. Because I don’t know how they are going to react with it. You understand?/ So I just keep it.. because I tell myself, that since I wasn’t treated for so long, and I’ve come so far, I just work around it.(Sarah 134–140)<sup>47</sup>*

For some, disclosing their status linked to additional family secrets. Sarah would need to admit that, as well as her son having HIV, she and his father are also HIV positive: her daughter would learn about three family members' HIV statuses simultaneously. Additionally, this example highlights class assumptions within the medical profession about family structures. In Jamaica, young motherhood is common, particularly within poorer sectors of the community and so the doctor assumed that Sarah's daughter (her son's sister) was in fact his mother. It also emphasises the futility of pressuring women to disclose when they do not feel ready; when directly confronted, Sarah did not want to discuss her HIV and denied it. Sarah's daughter's tears indicate her distress. Her mother's inability to discuss her HIV with her means that her daughter has not had the opportunity for reassurance: she has been denied both ignorance and the chance to discuss HIV and support her mother if she wished to.

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<sup>47</sup>Sarah: *Wel mi daata – wan taim di dakta did taat shi woz mi son – di mada fa mi son.*

**Gayle:** *mmmm*

**Sarah:** *So wen im tek sik an admit op ier wan maanin shi woz taakin tu mi an shi tel mi bout it. An shi woz – shi kom uom an shi woz krain an shi se tu mi dakta tel ar bout [her brother] av H – iz HIV pazitiv an wat av uu. An shi tel im no. A sed doh lisen tu di dakta an mi stil neva uopm op tu ar. Eksplien tu ar.*

**Gayle:** *And what do you think she thinks?*

**Sarah:** *A – a doh nuo. Fa a doh nuo ou de gona riak wid it. Yu andastan?*

**Gayle:** *mmmm*

**Sarah:** *So a jos kiip it.....fa a tel miself se sins a didn't triit so long, an komin fram so far, a jos werk aroun it.*

Cupcake described how she convinced her sons that she doesn't have HIV. She took her sons to the HIV clinic and had the whole family undergo an HIV test. When the results came through as negative for her sons, she allowed them to believe that she had also received a negative result that day:

*No, they came back for their result. I came back with them and then when the lady told us that de are negative den I called dem inside and give dem di paper./ So they all think dat we [are] all, all negative./ But they don't know about my status.*  
**(Cupcake 182–186)**

She took very deliberate action to ensure her sons felt certain she did not have HIV, and she felt happy with her decision, proud that she had fulfilled her maternal duty to protect her children from what she saw as her “mistake” (Cupcake 270) in getting HIV. She has very thoroughly and effectively silenced herself (Jack and Ali, 2010) in her determination to protect her sons’ happiness. The link between self-silencing and depression has been clearly identified (Jack and Ali, 2010) and I think it is not a coincidence that Cupcake, who has silenced herself almost completely, also provided clear and explicit descriptions of feeling depressed:

*[...] Sometimes – sometimes I lay down you know and I think about it and I cry to myself. A lot a times I go chruu [through] depressions. And I lie down and I cry about it [...]* **(Cupcake 334)**

Unlike many of the other mothers, who emphasised a feeling of closeness as a reason to tell their children and a lack of a close bond as a barrier to telling them, Cupcake felt that the close bond she shared with her children was a reason not to tell them:

*[...] Because as a [I] said di eleven year old and fourteen year old we – we just have this bond together. If a [I'm] feeling sad he will say “Mommy, I don't like how you look”. [...] So I don't want to tell dem and just – a – a [I] think that it is gonna have a very big impact on them. So I just don't want nothing to come wid dem [affect their] happiness./ So I just try not to tell them. Until the day come – the sickness times come?/ I think that's the time they should, should know.* **(Cupcake 190–196 )**

Cupcake saw her role as caretaker of her children’s happiness. She had a sense, too, of its unfairness to them, that it was not their fault, it was her “mistake” and they should not be made to feel unhappy for something they did not do. Additionally, she wanted to avoid the possibility of

their blaming her for acquiring HIV. She was concerned about the “very big impact” their knowing her status will have on them. Although she intended to tell them when the time comes, she was unable or unwilling to describe what she would say due to her fears about the negative impact she anticipated it would have on them and her sense of being everything to her children:

*...cause dem riili lov mi. [they really love me]. They don't have a father right now. It's just me alone./ They doh [don't] have nobody [anybody]. But me. (Cupcake, 212–214)*

There was a sense of pressure here, that she felt a burden in being the sole parent and in having to manage the practical and emotional issues alone. As found in other studies (e.g., Nam *et al.*, 2009) one of her coping strategies was to push the emotional concerns aside and plan to worry about them later, if her physical symptoms leave her no choice.

In the extract below, Cupcake described her reasons for not wanting to tell her sons about her HIV:

*'Cause a [I] don't really want that to, to — first that's their education — I'm thinking about that first — a still trying to fight for my life, aaldo a can go out dier [although I can go out there] and meet in an accident or sopm [something] bad can happen — /— but for the time being, am [I'm] still — a [I] still want them to finish up their schooling and all a dat.. When sikniss [sickness] time comes, I just tell myself that, well, dem afi go go chruu [they'll have to go through it] it but right now a [I] don't think it is fair to really let dem think about it. (Cupcake 188–190)*

Cupcake did not want to tell her children because she wanted them to focus on their education and not be distracted by her illness. However, she had a sense of impending doom, evoked by her phrases “still trying to fight for my life” and ‘when sickness time comes’. She invoked an image of a future time, when she will be very sick, bedridden, helpless and covered in spots; then it will be impossible for her to continue hiding her condition and she will feel obliged to tell them. There is a sense of inevitability, perhaps more common among people diagnosed with HIV long ago (in Cupcake’s case, 16 years prior to the interview), when medication was more limited and the outlook less positive.

### **8.3.4    *Experiencing ‘downfallment’***

The three women with HIV positive children (Sarah, Tracy and Patrice), were all diagnosed after their children were diagnosed with HIV. In fact, Sarah said she was not diagnosed with HIV until



her HIV positive son was three years old. It is difficult to understand how she was not tested earlier; it must have been assumed that her new-born acquired HIV perinatally from his mother:

*And by breastfeeding him, that is his downfallment. Because he was born as a healthy baby and seven months later, he just got sick. Everything you give him, he just passed it out. And when I brought him, they ran tests on him, they said he is HIV positive...Because looking at the pictures when he was a baby, you can see how he looked so healthy and fat and nice? An' that, looking fat and nice still doesn't mean that you don't have it [...] So looks are deceiving. (Sarah 388 [...] 394)<sup>48</sup>*

Tracy explained that the hospital failed to inform her of her HIV positive antenatal test result, and that her child's HIV should therefore have been preventable:

*So it's long after – you see when I found out I was HIV positive and I went to the clinic and I said “Excuse me um, I did do a HIV resul — I did a HIV test when I was five months pregnant and I don't get the result. What's the problem? And now I'm hearing that I am HIV positive.” When they check it out they say “Oh” but I said “That's slackness! That's stupidity! I mean you let me give my child HIV.”/ They didn't get the result —/— until after my baby was born. And they didn't even call me back to say “Um, Tracy...” – just nothing at all./ Did not do anything at all like that. So that was where, she got it so she was at the – the downfall. She was the first...who got downfall. (Tracy 194 –200)*

Both women used the word ‘downfall’ or ‘downfallment’. Tracy blamed the clinic that failed to give her the results of her antenatal HIV test. She believed that had she known about her HIV status before delivery, she would have been able to protect her child. She expressed considerable anger about what happened, as she felt it was entirely preventable. Sarah, on the other hand, believed it was her doing, her decision to breastfeed which led to her “healthy” baby getting HIV. However, she also acknowledged the impossibility of her knowing she had HIV. The very qualities of “fatness and niceness” that made her certain her son was born healthy were also the qualities that made it impossible for her to tell if she herself or a potential or existing partner had HIV.

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<sup>48</sup>An bai bresfidin im, dat iz di dounfaalment. Far im baan az a elti biebi an sevn monts aafte im jos tek sik. Evriting yu gi im, im jos paas it out. An wen a bring im dem ron tes an im, dem se im HIV pastiv.....Far lukin an di pikcha wen im a biebi im se ou im luk so elti an fat an nais? An dat – lukin fat an nais stil doh se yu doh av it [...] So luks iz disiivin.

## 8.4 Chapter summary

Mothering at a distance and ‘downfallment’ are two specific examples of challenges faced by the mothers I interviewed in presenting themselves as responsible mothers. Additional challenges resulted from attitudes towards HIV and other factors such as poverty. To counter negative stereotypes, avoid the loss of social support and present themselves as good mothers, the women carried out emotion work. Women described how they managed their own and their children’s emotions (sometimes also the emotions of other family members or friends) whilst mothering their children from afar or managing the possibility or reality of downfallment. Mothering at a distance is not unique to Jamaica or to HIV positive mothers, but it does present additional challenges in deciding whether and how much to tell children living elsewhere and the implications this may have for sibling relationships, particularly whilst striving to perform the responsible mother role. In general, mothers found it much more difficult to maintain emotional closeness with children living apart from them, and were less likely to have told distant children about their HIV, even when they had told the children living with them. These mothers may carry out additional emotion work to present themselves as ‘good’ mothers, by, for example, showcasing their close relationship with the children who do live with them, or focusing on the financial support they provide as a result of living apart from their child/ren. Some mothers present themselves as without choice on where their children live, whilst others believe it is in their children’s best interests, although they themselves may regret the impact on their relationship.

Although only three of the children of mothers in my sample were HIV positive, the fear of ‘downfallment’ was extremely powerful and several mothers had their children tested repeatedly, finding it difficult to be reassured by a negative result. The guilt associated with the possibility of maternal transmission of HIV to children was powerful and often presented an additional barrier to telling children about HIV; few of the women who described strong fears of ‘downfallment’ had told any of their children about their own HIV or told their children why they were being tested. Only one of the mothers with an HIV positive child had told that child about his and his parents’ HIV status; the other two continued to keep both child and parental HIV secret, despite clear policy to tell HIV positive children their own status by the age of 10 years. It is likely that children of this age, who can read and regularly attend HIV treatment clinics, will have had some idea about their HIV status. The next chapter addresses the third and final theme, which explores the reciprocal relationships which many participants described having with their children, despite popular assumptions about authoritarian parenting in the Caribbean.

## **Chapter 9: HIV and reciprocity in mother-child relationships (Theme 3)**

### **9.1 Introduction**

This chapter addresses the third theme, *HIV and reciprocity in mother-child relationships*. The ‘pinch’ refers to the way HIV positive mothers, living in a culture of predominantly authoritarian parenting, and working to present an image of themselves as strong and capable, nonetheless value and foster reciprocal relationships and accept practical and emotional assistance from their children. Social psychology defines reciprocity as a social rule which requires individuals to repay, usually in kind, material goods, favours or support that another person has provided to them (Cialdini, 2006). Reciprocity is usually used to refer to the behaviour of adults, the unwritten rules governing requests for and acceptance of help, in the context of social favours and their repayment. I mentioned the reciprocity experiences of the interviewees in relation to other adults in the poverty section (7.2.1) in Chapter 7. In the context of emotion work, Hansen (2011:112) describes a particular kind of feeling rule, the asking rules of reciprocity, which “specify the conditions under which a person can ask for help in the context of assessed need and capacity”. The author goes on to apply this to the self-imposed hesitation, where employed parents pause to consider the trade-offs before requesting help with caring for school age children. Hansen sees asking rules as “premised on trust, obligation and mutuality” (Hansen, 2011:112).

In this thesis, I extend the concept of reciprocity to refer to the behaviour of children towards their HIV positive mothers, alongside a recognition of greater emotional and practical reciprocity than is generally ascribed to the Caribbean family dynamic. I bring into relief different discourses of family relationships which serve as a counterpoint to assumptions about authoritarian parenting in the Caribbean. Children caring for adults disrupts the vertical relationships of care usually associated with parenting children. In the context of maternal HIV, these asking rules guide the give and take within the mother-child relationship, especially as children grow older, are required to take on more practical responsibility and are seen as able to provide more emotional support to their mothers. I explore how mothers ask for or accept help from their children in the context of maternal HIV, despite norms which may position children as innocent, helpless and subservient (see *e.g.*, Burman, 2005a, 2005b, 2008, 2012). The presentation of disclosure as a discrete event fails to acknowledge the wider context of parenting and the caring roles children perform.

Edwards *et al.* (2012) explore unexpected sources of social support for HIV positive African American women and its impact on adherence, health and well-being. The authors examine

‘parentification’, where children take on traditional parental roles and responsibilities, in contrast with the idealised Anglo-Northern concept of the nuclear family. Keigher *et al.* (2005) see parentification as including emotional and practical care, taking care of siblings and managing interactions with the wider community. There is limited research on the parentification of children of HIV positive mothers, and none in the Caribbean context, but Tompkins (2007b), found that children in a USA sample who supported their mothers in this way presented with fewer depressive symptoms and greater social competence. Motherhood in the Caribbean is generally considered to fit the authoritarian model described by Baumrind (1966,1967), with mothers responsible for the behaviour and wellbeing of their children and children expected to be obedient and respectful (Shorey-Bryan, 1986). However, the women I interviewed demonstrated that, for them, safeguarding their relationship with their children was an overall priority and this often included reciprocal elements which are not well-recognised in the literature.

## **9.2 Safeguarding the self and fostering reciprocal relationships with children**

In contrast to the image of the selfless and self-sacrificing mother, some mothers acknowledge the need for further emotion work on themselves before they are ready to manage their children’s emotions. Margaret gave me an insight into her desire to protect herself from her children’s distress and possibly an unwillingness to deal with her own emotional reactions in addition to all the other practical, medical and emotional issues she was already dealing with:

*Ah, for one um — well it depends on the relationship that you have with your - with your child or your children, to be honest and open with them. And see um, how best um, after telling them see how best you can, ‘cause you have to help to repair them after telling them that and you have to be in a position emotionally, physically to do that and I’m really not in that position right now. (Margaret 234)*

Here Margaret shifted the focus from what was best for her daughter, to the position she would need to be in to support her daughter to deal with the information about her mother’s illness. Concepts of good mothering were illustrated here. For example, Margaret presented herself as a selfless mother, denying herself feelings of relief through telling her daughters, and focusing on her daughters’ education and emotional wellbeing. She went on to explain her feeling that it is part of her role, as a good mother, to support her child in navigating her feelings about her (Margaret’s) HIV and that she cannot do that at the moment. Margaret admitted to not being emotionally ready to talk to her children about her HIV, an unusual admission, though occasionally seen in the literature (Thorne, Newell and Peckham, 2000; Dane, 2002; Rwemisisi *et al.*, 2008). More

commonly, mothers present their choice not to disclose as in the best interests of their children, rather than acknowledging that it may be in their own interests or something they are unable to deal with at that time. Margaret may have been referring to how her own emotional lack of readiness means that in her view she won't be able to disclose in a way which will help her children to process the information and that she is not ready to deal with any distress they may express. She may have preferred to wait until she feels more prepared and thus able to fulfil this idealised mother role.

The women talked about the importance of their relationships with their children in giving them a reason to live and care for their physical health. Safeguarding these relationships was of paramount importance, regardless of their disclosure choices. Tracy (who has not told her three children) described powerful feelings of hope and strength which she felt her children imparted to her:

*[...] Because really and truly maybe if I did not have my kids, I would have died already. I'm telling you the truth. My kids give me hope.*

**(Tracy 150)**

Tracy challenged assumptions about a close relationship necessarily being open and honest; although she has not discussed her HIV with her children, she described her relationship with them as close and as essential in keeping her alive. In reality, most relationships are likely to have some secrets or omissions, but the idealised concept of equal, transparent relationships as a prerequisite for closeness persists within concepts of authoritative parenting (Baumrind, 1966, 1967) which is generally considered the 'ideal' in Anglo-Northern cultures.

In the context of HIV, some women feel more aware of the unique and crucial role that they, as mothers, play in their children's lives and are conscious of the role their children play in motivating them to stay alive. Nora, mother to three young children and a pregnant teenager, talked of how her role as their mother is irreplaceable:

*But me now I have four children but three is very small and need my help./ If I don't take my meds I'll get sick and I can't take care of them.*

*Nobody can take care of them like how I will take care of them. (Nora*

**415/417)**

Her children's need for care motivated Nora to take her medication and try to stay healthy. With this simple statement, Nora communicated her desire to live, to be present for her children and the value she placed on mothering her own children in her own way.

Patrice worked to foster a supportive, trusting and collaborative relationship with her children:

*[...] My children, no matter what happens in school, no matter how bad it is they are not allowing anybody to tell me anything, they come home they tell me. / And as big as my biggest son is right now as a man, if anything happens as he comes home he say it to me. Sometimes him call mi from work and say “Mummy so and so”. (Patrice 330/332)*

This was echoed by Jay, who established a feeling of mutual trust and support between herself and her children:

*The bond what we have when we share together, right? I always tell them seh [I say] listen, “Don’t afraid to tell me anything because I am not afraid to tell you anything” so that bond what we have together.../ We can sit down and we share each other problem and we sit down and work it out. So that’s, that is it. Because we have that real children/mother or – I can end up and seh wi [by saying that we] are sisters and brothers, connection where wi sit down and wi talk and so forth, yes. (Jay 165/167)*

Jay valued this bond, this “sisters and brothers connection” highly and strived to maintain it. She emphasised the importance of finding time and space with the phrase “sit down”. She believed the relationship must be two-way, like “close friends”, contradicting the perception of parenting in Jamaica as distant and authoritarian. Adisa states that “most Caribbean mothers rule out the possibility that you can be both a good mother and a friend to your child” (Adisa, 2013:51). Jay, however, has created a different kind of relationship with her children:

*[...] Because with my children, they have that secrecy [understanding of secrecy], I say, listen I will tell you this but nobody have to know. That is just for me and you alone. (Jay 190)*

Fear of children telling others is referred to frequently in the literature as a reason for not telling children about maternal HIV status (Moore, Kalanzi and Amey, 2006; Rwemisisi *et al.*, 2008; Palin *et al.*, 2009; Tiendrebeogo *et al.*, 2013; Avornyo and Amoah, 2014; Gachanja, Burkholder and Ferraro, 2014; Muparamoto and Chiweshe, 2015; Osingada *et al.*, 2016). However, Jay did not consider this a risk. She believed that she and her children have an unspoken understanding about what can and cannot be discussed outside the family. The women valued close relationships with their children, whether or not they had revealed their HIV, worked to develop and maintain these

relationships, and mourned when relationships, for whatever reason, were less close than they would have liked.

It is tempting to connect disclosure with a close supportive relationship and to assume that mothers who choose not to tell their children do not have or value this type of relationship. However, this often misplaced assumption may help support presumptuous and poorly informed policy prescribing that parents, regardless of their circumstances, should tell their children about their HIV status (WHO, 2011). My interviewees described a range of strategies to manage communication about HIV with their children, whether they had fully, partially or not disclosed their HIV status to them. Although concerned about issues relating to disclosure, protecting their relationships with their children was their first priority. Mothers valued the emotional and practical reciprocity provided by their children, regardless of their disclosure position. Mother-child relationships are generally complex and evolve over time; the concept of reciprocity can act as a window into deconstructing these, in the context of women's lived experiences.

### **9.3 Medication support from children**

Almost all the women interviewed discussed their children providing them with some kind of HIV-specific support, thus challenging the concept of mothers as wholly responsible and children as passive recipients of their care. Women are concerned with maintaining close relationships with their children, but for some mothers, there is a tension between receiving support from their children whilst withholding information. Women receive practical support from children, particularly help with remembering to take medication. This is well recognised in the global literature, including research from Botswana (Nam *et al.*, 2009), Uganda (Kyaddondo *et al.*, 2013) and the USA (Kennedy *et al.*, 2010; Edwards *et al.*, 2012) and applies even when children do not know what the medication is for. For mothers not ready or willing to tell their children their status, accepting help with medication allows them to receive needed support, enables children to feel responsible and capable, and marks a way of encouraging them to develop life skills and move towards adulthood. Mothers may also hope that this serves to gently introduce their illness to their children, although, without interviewing the children themselves, we cannot know how successful they were in this aim. Mothers' accounts of how they manage children's medication support varied: some mothers (like Cupcake) encouraged this support, others (like Sandra) were more reluctant. However, in general, mothers were grateful for their children's support and recognised it as an expression of love, even where they were unable to discuss or acknowledge it fully. Accepting help from children can, however, be awkward and challenging and both Sandra and Cupcake took steps such as hiding their medication or decanting it into other bottles; nonetheless, both accepted reminders to take their medication from their children.

Cupcake described her relationship with her sons and how she “tricks” them into thinking that her medication is for a previously existing condition, a “burst” in her head. Despite the complications involved in managing these discussions, Cupcake still valued the practical support her sons provided.

*[...] I — they know I have a sickness but they don't know it's HIV. Because a [I] have to take the meds and because sometimes when mi take di medication? it will like block me out for a likl [little] while? so what I do I tell dem a – a - a [I] just trick ma son and tell him dat because di burst a [of the burst I] have in my head, a [I'm] sick wit ma head./[...] ...— that's the reason I have to be on the medication — /— because I take the medication out of the bokl [bottle], keep them in something else? and they would give it to me every night before I go to my bed. That's their duty because I will forget to do it. So they was – they are always “Mumi yu tek yu medikieshan?” [“Mummy, did you take your medication?”] but they don't know what it is for. I don't tell them./ I don't. (Cupcake 130–138)*

Cupcake described these reminders as her children's “duty”, demonstrating her desire for their support and involvement. She devised a strategy to ensure they did this without knowing about her HIV: she decanted the medication into different bottles and told them it was for a pre-existing condition. For her, this involvement was linked to the close relationship she felt with her children, particularly her younger son, and also to the side effects: “block[ing]” out after taking her medication required some kind of explanation.

However, there was also a hint of exasperation in some of the women's words, a sense that they perhaps find it frustrating to be held accountable by their children, that as well as feeling loving and supportive, children's fixation on their mother's taking their medication can also feel suffocating and perhaps a little accusatory, as illustrated by Sandra below:

*Sandra: I-I don't show them it [the medication]. I hide it. [chuckles]  
Gayle: But they know?  
Sandra: Yeah. The big one always says “Mom, did you take your medication?” [...] Yes, because if I am getting sick they will ask me “Did you miss your medication?” (Sandra 318–320 [...])<sup>49</sup>*

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<sup>49</sup>*Sandra: A – a doh shuo dem it. A haid it. [chuckles]*



Like most children of mothers who have been hospitalised, Sandra's children were aware she had been ill, and tried to help her to stay well, although they were unaware of the details of her illness. Her children drew a direct parallel between their mother's medication and any symptoms of illness. Although, in the absence of disclosure, Sandra and Cupcake were unable to discuss their HIV in detail with their children, their nondisclosed children remained active in assisting their mothers with their medication and other practical and emotional issues; this was often a source of comfort to both mothers and children.

Jay had told her three older children and felt this enabled them to help her with things like medication side effects, especially excessive sleepiness. They helped by taking responsibility for getting themselves to school on time and helping her care for the baby.

*[...] Hamm, they used to help mi to fight that sleep because as soon as mi get up inna [in] the morning, mi haffi took [I had to take] the medication and then it just – it would let mi [make me] feel drowsy until 12:00/1:00 now mi can [I could] sleep. If mi alone is there about 12:00/1 o' clock before mi can wake up. So they would really want to help mi, even wid help mi with the baby, because at the time I had the baby so they would jump 'round and help. The time for them to go to school them would wake mi up, "Mommy, time for me to go to school now", so therefore this is the time I – therefore – they would help mi man. So it's good that they know and know what it can do and how to help me. (Jay 148–150)*

For Jay, medication was a key aspect of disclosing to her children; she was terrified of medication, struggled to take it and to accept that she needed to take it. For her, it was crucial that her children knew about her medication and could help her take it, and her children were an important motivation for her to take care of her health by overcoming her fears of taking her medication:

**Jay:** *And – mi and medication neva dida friend [was never my friend], mi did 'fraid a [I was afraid of the] medication, that's the time I break down and cry. But from mi get use to and so forth, it was okay, it's come back now, I am not afraid anymore. [...]*

**Gayle:** *You have been able to [take your medication]?*

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**Gayle:** *But they know?*

**Sandra:** *Yeah. Di big wan aalwiez a se 'mom you take you medication?' [...] Ye bikaaz if am getin sik de wil aks mi 'yu mis yor medikieshan?'*

*Jay: Yes, I have. I became — tell myself that this is what I have to do, not for the sake of me but for the sake of my children. So this is what I have to do. Suh, it's all right. (Jay 134–142)*

Some women talked about disclosure as improving and strengthening their relationship with their children and developed supportive and mutually comforting rituals around taking medication:

*[...]... And sometimes she will call me and say “Mummy, did you take your medication?” [laughs] and I say “Yeah, man, I took it”. Like when I just started to take it, she would always say, even if she was out that day, she would call me and say “Mummy, did you take your medication?” And I would say “Yeah, man, I took it”. And she would say “Remember, you have to take one every night, you have to take them at night” and I say “Yeah, man, I take them” [laughs]. And in the morning she wakes up and she will take care of breakfast and she-she-like she [xxxx] and she says “Mummy, did you take your medication?” and I say “Yeah, man, I took it”. She will say “oh cause I worry you know” she will always reach out, go out of her way [xxxx] Until gradually I start to remember that [xxx] I have to take it. So now she- she doesn't bother to ask me. She will only call and say “Mummy, you- when do you have to go to the doctor?” or with medication “Mummy, did you take your medication?” “Yeah, man, I took it.” (Winnie 63)<sup>50</sup>*

Winnie spoke in a breathless rush, reassured when her daughter, despite being abroad, called and checked that she was keeping her appointments, taking her medication, and following the doctor's advice. She remembered that when she first started taking her medication, her daughter would check on her almost constantly. She quoted the entire conversation, almost word for word, emphasising the repetition of her daughter's checking on her. She laughed when she recounted this story. She explained that it was as if her daughter were training her, until she started remembering on her own. Later, her daughter checked on her more generally, not for each dosage. Winnie seemed to enjoy this support, attention, almost mothering, and this checking routine also provided

<sup>50</sup>[...].....An somtaim shi wi kaal mi an se 'mumi yu tek yu medikieshan?' [laughs] an mi se ye man mi tek it. Laik wen mi jos staat tek it, shi wud aalwiez se, if shi iivn gaan tude shi wi kaal mi an se 'mumi yu tek yu medikieshan?' an mi se ye man mi tek it. An shi se 'mamba se yu fi tek wan evri nait ino, yu fi tek dem ina di nait' an mi se ye man mi tek dem [laughs]. An in di maanin shi wiek op an shi wi luk afta brekfaas an shi – shi – laik shi xxx [two or three words] an shi se 'mumi tek yu medikieshan?' an mi se ye man mi tek it. Shi wi se 'oh kaah mi did a fret ino'. Shi wi aal riich out - outa ruod xxx [one or two words] an gaan an shi wi kaal mi bak an se 'mumi yu tek yu medikieshan? Yu tek di sopm?' [said question in a louder tone] an mi wi se ye man mi tek it. An shi we se 'oh kaah mi did a fret se yu neva tek it.' An mi se ye man mi tek it. Antil gradual mi staat mamba se xxx [two or three words] mi affi tek. So nous hi – shi no bada aks mi. Shi wi onli kaal an se 'momi, yu - wen yu fi go a dakta?' ar wid medikieshan 'momi yu tek yu medikieshan?' Ye man mi tek it.

some structure and a sense of at least partial control for her daughter. They both seemed to enjoy the openness and honesty, the checking up ritual, which helped them both come to terms, adjust, and reconfigure their lives. Maria described a similar situation with one of her daughters:

*[...] And then my daughter now, when she goes and pick up the medication – because you know you have to sign a book – she – the – the pharmacist would like “Oh you know you need to take your medication like this” and she is like “No its not for me, it’s for my mom.” Then like every time people always stare at her but she say “Mommy I don’t care if they want to stare. I just know I’m getting your medication and you gonna do fine.” Ye. (Maria 131)*

Collecting medication on behalf of their mothers was not always straightforward: Johnett described a time she asked her daughter to help by picking up a prescription. This didn’t work out because prescriptions must be stamped at the clinic before medication can be collected at the pharmacy. Johnett was able to discuss her HIV and request support from her daughter. She believed they have an agreed shorthand; her daughter understood that going “down by the [place near the HIV clinic]” really meant going to the HIV clinic. Johnett may have thought the pharmacy experience made her daughter uncomfortable or was too much to ask; she quickly suggested: “All you do, give me bus fare and I will go and do it myself” (Johnett 264), thus requesting a less personally-demanding form of help.

These anecdotes demonstrate the medication support that children, positioned throughout the disclosure spectrum, provide to their mothers. These examples also subvert the traditional image of the authoritarian Caribbean mother and the passive, innocent child and extend the concept of reciprocity to relationships between adults and children as well as between adults.

## **9.4 Emotional support from children**

As discussed in Chapter 7, mothers’ concern about protecting their children from worry often acted as a barrier to talking to them about their HIV. However, women who approached HIV disclosure to their children as an ongoing process, often found that their children provided emotional support. Patrice talked about her children checking on her by phone throughout the day and how happy this made her feel:

*Patrice: “You get through, you all right? You reach home? You inna bus? How far you reach?” And on the road going home that’s just how they follow mi, right through the journey right till I reach home.*

**Gayle:** *And how do you feel about that?*

**Patrice:** *Oh, my God. I feel on top of the world. I feel as if I am on cloud nine.[...] (Patrice 269–271)*

Unlike women wanting to protect their children from the thought of their mother's potential death from HIV, Maria confronted the idea of death and her children comforted and reassured her:

*Nhn! No. They even love me more...I guess cause they are like always like – even when I try to push them aside and say “Oh God” like I would cry and say “Oh I want to just die” they are like “Mommy, no, don’t say that. You have we to live fa and why you saying that?” [...] But it hasn’t let us um, drift. No they are still close to me and we still hug and kiss and if I’m down they will come around and kiss me and “Oh mommy I love you. What you tinkin ‘bout? Don’t stress yourself man, evritings] gonna be fine.”(Maria 119)*

Maria cultivated a collaborative relationship with the two daughters living with her (her oldest daughter was overseas). She viewed HIV knowledge as positive and empowering and felt she had embarked on a shared journey of learning with her children (assisted by their more advanced research and technology skills):

*She [my daughter] was like “No, Mommy, no”. She cried and said “No. Why, God? God, let it be me and not my mother.” I’m like “No, it’s me.” And she doesn’t scorn me or anything. I cook for them as before. We hug up, we kiss up, we share things – even if I bite things, they’ll bite it. I’ll drink a juice and I was like – first, before we didn’t understand? Like if I drink out of this, I would say “No, no don’t drink it. I drank out of it already.” And then my - my daughter was like “No, Mommy, you can’t get it like that.” And if I’m drinking a soda and they’re like “Give me some soda!” They would be like “Tch! Let me drink it and show you nothing’s going to happen!” Like — ‘cause now they start to educate themselves about it. And then now? It doesn’t matter in the house. We just keep it to ourselves.[...] (Maria 97)<sup>51</sup>*

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<sup>51</sup> *She [my daughter] was like “no mommy, no”. She cried and said “no. why god? God mek it be me an nat mi mada.” Am like “no, its me.” And she – de don’t skaan me ar notn. A cook fa dem same way. We hug up, we kiss up, we share things – even I bite things, they’ll bite it. I’ll drink a juice and I was like – first, before we didn’t understand? Like if I drink out of dis, I would say “no, no don’t drink it. I drink out of it already.” And then ma – ma daata was like “no mommy it kyaah pass on so.” And if I’m drinking a soda and they’re like “gi mi som a di souda” they would be like “tch! Let me drink it and show you notn naah apm” and then they’ll drink it and stuff. If – if –*

Similarly, Tina described her daughter demonstrating acceptance through actions such as sharing her mother's cup. This is an important symbol, both of being well informed about how HIV is transmitted and of showing love and support. In Jamaica, people commonly show their fear and ignorance about HIV by refusing all contact with a person who has HIV. In particular, people commonly refuse to accept food touched or prepared by someone with HIV and this extends to refusing to buy pre-packaged food from someone with HIV. Therefore, family members accepting food and sharing crockery and utensils is a particularly powerful sign of support.

*...They tek [take] it, they tek it really well. Hamm, I am-am-am not sure if it's because they are not living here but – Hamm, my daughta, I-I have a better relationship with mi daughta than mi son because hamm, even when time I am not able to go to country, my daughta would be with me there or not and I don't si she like si mi drinking outta the cup and she wouldn't not drinking out of it or she wouldn't wipe it off first, I am not seeing that from har suh [her so] I guess she tek [took] it really good.*  
(Tina 218)

Perhaps the increased HIV education amongst young people in Jamaica (through school, public health campaigns and access to information on the internet), will, in the long term, reduce stigma and discrimination against PLWHA. Although many of the women were aware of factual information concerning HIV transmission and self-care, fully assimilating this can be difficult, particularly for those diagnosed prior to the ready availability of antiretroviral medication. This may be particularly powerful for women concerned about the possible perinatal transmission of HIV to their babies and who may be especially likely to view their own body as poisonous. In Ethiopia, Koricho, Moland and Blystad (2010:4) write about women who perceived their bodies as “poisonous” and themselves as “sinful”, and described the “loathing they felt for their own body as infectious and dirty and not being able to nourish the newborn with safe and clean mother's milk.”

Maria reassured her daughters she would do everything she could to remain healthy, including taking care of herself and taking her medications. She also took this opportunity to remind her children of the unpredictability of life, that not everything is within individual control; this is particularly powerful given the precariousness of the lives of poor HIV positive Jamaican women, as discussed in Chapter 3:

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*like when I used to go in the bathroom and I bathe with a soap, am like “dis soap is mines, don't use it. Don't use that. Don't use my stuff.” They would be like “yu kyaah ketch it so”. Like - cause now de staat edikiet demself about it. And then now? It don't come in like notn in the house. We just keep it to ourselves. [...]*

*[...] “If I take my medication right and I eat right and do di right ting I won’t go like that.” And den....mi se maybe sopm [then...I say maybe something] else kill me. Maybe mi walk out in [front of] a car and get lick [knocked] down.” I just joke about it sometimes because why – why am I going to sit and fret and pine over it? [...]* (**Maria 109**)

Several mothers commented that their children did not treat them differently after learning about their HIV status, and that, instead, they often responded by becoming closer to their mothers and offered additional support:

*[...] anything happens to me I tell her. And we-we-we have more— we are closer than we used to be.* (**Winnie 81**)<sup>52</sup>

*[...] Because I don’t think, I don’t think I would be living until now if I had – if I didn’t tell them./ No. The stress of it would kill me. [...] I don’t believe is HIV would kill mi, I think it would be the stress.* (**Patrice 229/231**)

Examples of emotional support provided by children were more commonly shared by mothers (like Winnie and Patrice) who had disclosed to their children. However, for Margaret, the death of her children’s father from AIDS meant that she grew closer to her children, although she had not spoken to them about her HIV or told them how their father died:

*[...] We have grown closer.... ’cause they were all about their father. So now that daddy is not in the picture any more, it’s all about mommy [sniffs].* (**Margaret 319**)

Margaret’s experience illustrated that disclosure is not necessarily a prerequisite for a close relationship and that mothers can find comfort in their relationship with their children despite the existence of family secrets.

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<sup>52</sup> *Wi bikom – wi bikom muor xxx [five or six words] eniting apen tu mi a tel ar. An wi – wi – wi av muor – wi ar muor kluosa dan wi uuzhali bi*

## 9.5 Emotion work and approaches to disclosure

### 9.5.1 *Preparing to disclose: Patrice's story*

Mothers commonly undertook activities to prepare for their eventual disclosure, including working on their own emotions to achieve 'surface' or 'deep' acting so as to present themselves to their children as calm and positive about their diagnosis and health. Patrice described a detailed and carefully considered process of preparing her children, particularly her youngest, HIV positive son. In addition to managing her children's responses to disclosing her own status, Patrice also needed to manage their responses to learning that her husband and youngest son were also HIV positive. Patrice related how, a few years after her own, her husband's and her youngest son's diagnosis, she told her three older children, aged 15–23 at the time. She described drawing strength and inspiration from her religious beliefs and her experience of her own mother telling her she had cancer:

*[...] I called everybody together and I said, "Suppose after all of this that I up and down, up and down, up and down and if I should go to the doctor and they tell me that I have AIDS", I didn't say HIV, I said have AIDS, "How would you guys take it?" And everybody start to look from one to the other. But the smallest one him didn't understand at the time because he was the youngest. And I remember my eldest son sey to mi, "Mummy, you didn't go and buy it. And – we never know what would happen to us tomorrow or the next day or the next year so we have to just work with each other and — nothing would change for me because I would love you just the same". And, well—the other two didn't say anything, they just confirmed what he said. And, at that point I felt good within mi, but then now I didn't know how to explain it to the smaller one because – you nuh [know], children are small and...(Patrice 68–70)*

Her children reassured her with a variation of the Jamaican phrase 'you didn't go and buy it in the shop', meaning that she didn't ask for this/deserve this/bring this upon herself. With this phrase, they expressed their view that she should not feel guilty or ashamed, that the world is unpredictable and there is no point worrying about dying of HIV. In this way, her eldest child expressed his love and support for Patrice, setting the scene for the younger siblings to follow. Patrice felt reassured but continued to worry about how to explain it to her youngest son, then aged about 4, as she felt he didn't understand this conversation.

Patrice waited another two years, until an opportunity presented itself for her to begin the process of telling her youngest son:

*[...] So I said, "How am I going to tell him?" I take mi time and I take mi time and I think when him around 6 thereabout one day him said to mi, "Mummy, there is a little boy in my class at school and nobody don't want to play with him because he has a disease they don't want to play with him." And, it's as if somebody stab mi right in the heart. It's as if I was speechless. And I said to him, said, "You play with him?" and he said, "Yes, I play with him and I share my things with him". And I said, "That's good". [...] So I sat with him and I said, "What kind of a disease you said your friend has?" He said, "I don't know but everybody said that him have disease, him have germs and them not playing wid him." I said—wonder if this is the right time?—And I said — He said to mi, "A [I] doing the right thing, mummy?" I said, "Yes, you are doing the right thing because if you was diagnosed with something that is not contagious in a way that if you talk persons will catch it, if I touch you, you will catch it, wouldn't you want persons to play with you the same?" And he said, "Yes". So, I said, "Play with your friend, don't stop play with him, share" — [...]*

She used her son's friend's experience to help him understand, to help him with empathy, and to help him relate his experience to that of others. She built the lesson up slowly over a period of about a year:

*I think it was on his 7th birthday I called him and I said to him, "I am going to tell you something but you are not to repeat it". [...] So I beat around and I beat around and I said to him, "I am thinking, I don't [know] what is wrong with your friend, but you notice that you and I and your father have to go to the doctor regularly and you did regular blood test?" Him said, "Yes". I said, okay. "I am not saying what is wrong with your friend is the same thing that is wrong with you because I don't know, but you could be as sick as your friend and if other people know they won't want play with you just like how they don't want to play with him and they are not going to want to share with you. So you are not going to say this to anyone". Him seh, "Mummy, I am not going to tell anyone". [...](Patrice 72–80)*



Patrice also used their shared experience to bind herself, her husband and her son together, to reassure her son and teach him to take care of his own health:

*So I told him [her son] and he [his father] said, “That’s awright, that’s awright. Because you and mummy and myself we have the same problem”. So he look on me and said, “Suh, we are going to die?” I said, “No man, wi not going to die. That’s why we go to doctor, and wi tek our medication.” [...] (Patrice 82)*

This extract showed her disclosure to her son as a slow process, carefully built up over time, in a calm, caring and age-appropriate way and linked to her son’s real-life experiences at school and his sense of place within his family. She also used it to reinforce other lessons she had been working to teach him: sharing, empathy, kindness, patience, trust, confidentiality within the family, and responsibility. Her account directly contradicts many assumptions about Jamaican mothers not telling young children (her son was 6–7 years old). Although affected by many of the same issues as other women (poverty, HIV related illness, family responsibilities, a desire for privacy) and clearly aware of discrimination issues at school, she was nevertheless able to find the time and emotional energy to work with her son to help him understand his own and his parents’ HIV statuses.

### **9.5.2 Unreflective disclosure**

It is worth noting that, although the majority of mothers go through a process of emotion work and preparation for telling their children about their HIV, this does not apply to all women. Several of the women I interviewed told their children immediately or very soon after diagnosis, with very little reflection or preparation:

*...[sniffles]. And my daughter wasn’t at home and I called her and she came home and she said “What’s wrong, mummy?” and I said “Nothing man, come home. I have something to tell you”. And when she came she—I told her and I was crying and she said, “Mummy, don’t cry...it’s not-it’s not the end of the world...and it’s not just you who has it. Other people have it and they are xxx [one or two words]” (Winnie 37)<sup>53</sup>*

**Gayle:** *So you -you spoke to them about it?*

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<sup>53</sup> ....[sniffles]. An ma daata wozn at uom an a kaal ar an shi kom uom an shi se wats wrang momi an a se notn man, kom uom. A av somting fi tel yu. An wen shi kom shi se – a tel ar an a woz krain an shi se mumi doh kraí.....iz nat – iz nat di end af di werl....an iz nat yu aluon av it. Ada piipl av it an de ar xxx [one or two words] ....

*Anna: Yeah man, yeah man and the whole of my family know.*

*Gayle: So how —tell me about how you to — how you told them.*

*Anna: How I told them? I did—from the first day I came from hospital.*

*From the first day. When ummm my brothers (inaudible). From that day.*

*Yes. (Anna 186–193)<sup>54</sup>*

Having older children in their early twenties, adults whom they believed could assume a supportive role and felt close to, may have precipitated these women's immediate, unreflective disclosure. This was also sometimes the case for women with slightly younger children. Maria told her younger two daughters, both then in their mid-teens, soon after her diagnosis and her daughters were very closely involved with her health care and journey to learn more about HIV. Additionally, these women all skipped over the actual disclosure conversation, choosing instead to focus on the comfort and reassurance their children expressed, demonstrating both how much they value this response and how aware they were that their children could instead have rejected or scorned them. As Johnett illustrates, it can sometimes be difficult to move disclosure from a single conversation at a time of great stress (diagnosis or illness) to an ongoing process embedded in the daily fabric of relationships:

*.. but from when I told her, from the time when I was in the hospital—/ I haven't talked about it again... [one word], I don't really— it's true that they know already?/ I haven't really sat down and discussed it with them or anything, because they know that I have it already. They treat me well, same as before. (Johnett 98/100/102)<sup>55</sup>*

Unreflective disclosure may, in fact, be of benefit to mothers: Yoo *et al.* (2010) found that women who spontaneously disclosed a breast cancer diagnosis without considering management of others' emotions were often surprised by the positive support they received. Yoo *et al.* (2010) suggested that this approach might be more beneficial for women's mental health as they are not focusing their energy on managing others' emotional reactions; instead, the focus is on their receiving care

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<sup>54</sup> *Anna: Wel.....dem tek it aarait. Dem doh skaan mi ar notn. Dem iit fram mi. Di chrii a dem iit fram mi. Dem doh skaan mi at aal.*

*Gayle: So you – you spoke to them about it?*

*Anna: Ye man, ye man. An di uol a mai fambili nuo.*

*Gayle: So how – tell me about how you to – how you told them.*

*Anna: Ou a toul dem? A did - fram di fors die a kiem fram aaspital. Fram di fors die. Wen aahm mi breda dem dem [inaudible] did de ya. Fram dat die. Ye.*

<sup>55</sup> *...bot fram mi tel ar fram di taim wen mi ina aspital – / Mi no taak tu ar bout it agen... [one word] mi no riili – chruu dem nuo aredi?/ Mi an dem no riili sidong an diskos it ar notn kaaz dem don nuo se mi av it aredi. Dem chriit mi gud siem wie.*

and support. This view was supported by the experiences of the women I interviewed who disclosed their HIV to their children with no or limited forethought.

### 9.5.3 *Promoting tolerance*

Margaret provided an insight into the challenges for HIV positive mothers presented by HIV education at school:

*It makes it more difficult./ They are aware of it. So it - it's - it's harder. It is harder. But that – that um, that research is something that is on the school curriculum —/ — something that they have to do. So now they are aware of it, they know the ins and outs and all of that, that is associated with it. But me telling them? Nhn.....I don't know how they would react.*  
(Margaret 134–138)

This may result the possible negative implications about behaviours, choice and morality within HIV education programmes at schools. HIV is unlikely to be taught in a particularly nuanced way; it is likely to emphasise individual behaviour and personal choice and may not address relationships, violence, and power dynamics. In this context, it may be more difficult for women to tell their children they have HIV, because it may be difficult for children to reconcile their maternal images with the negative images of HIV positive people presented at school, often as a warning against early sexual activity.

A study of parental disclosure in Kenya found that parents prepared themselves and their children for disclosure over a period of several years, undertaking a range of preparation activities including researching and thinking about HIV, teaching children about HIV, working to improve relationships, praying and attending counselling, support groups or religious groups (Gachanja, Burkholder and Ferraro, 2014:18–19). Several of the mothers I interviewed described broader long term activities as preparation for disclosure far in the future. These activities involve mothers very slowly beginning to lay the groundwork for disclosure by working to increase their children's general awareness, acceptance, or empathy and the promotion of values such as being kind and non-judgmental.

Tina spoke of wanting to teach her children not to stigmatise as a key reason to disclose to them:

*[...] And I am just put it out umm —and it kind a give them a likkle [little] information about not stigmatise against persons that have it, who are living with HIV because umm it*

*could be me. [...] So I tell them not to stigmatise about HIV.... And I think, I think they do understand. (Tina 253[...] 257)*

Laura described some of the broader preparatory work she has done with her sons to encourage them to be kind to others and to understand that life can be unpredictable:

*[...] I teach the smaller one because him might laugh at people because he see a person hand might turn like this, I say “Don’t laugh at them because this is the way that they were born or something can happen – can happen to you just the same and you wouldn’t want anybody to laugh at you. [...]. We are living in this life but anything can happen to you so just look and be sorry for people (even though sometimes you might not want to be too sorry for people because it tends to be too emotional and put a strain on your body as well)”. (Laura 282/284)*

In this extract, Laura also works to demonstrate the importance of balance, of taking care of your own health whilst simultaneously being kind and supportive to others—neatly encapsulating the balance that HIV positive mothers seek to find in their own relationships with their children.

## **9.6 Disclosure and maternal intentions**

### **9.6.1 Disclosure as an expression of love and trust**

Some women saw disclosure as an expression of their love for and trust in their children. Patrice, who has told all her children, acknowledged the differences in people’s circumstances and that disclosure might not be right for everybody, but believed that it is hard on the relationship if children learn their mother’s status from others. For her, the concept of trust within the relationship was crucial and she believed it essential to protect that trust by telling her children herself, so that they could not accidentally find out from someone else, thus jeopardising the relationship:

*[...]. Because I think, I think too, what throws off a lot of family members is that – I know, I didn’t feel you [my child] out or tell you anything, I wait for you to go out on the street and hear it, and since the whole world know, I am the last to hear. (Patrice 324)*

Similarly, Anna decided it was time to tell her son once other people in the community knew her status, to ensure the information came from her and that the trust and respect within their relationship was not damaged:

*Well, the reason I told him was because other people on the street already knew—/—And...he could have said how I didn't tell him and people know, you understand? So I never wanted him to feel like that. (Anna 525/527)<sup>56</sup>*

This is echoed by Tina, who equated telling her children with demonstrating her love:

*“Yeah. But hamm, how would they find out from somebody else? Unless umm I sick and then doctor would – or I died before I disclose and then the doctor would – might be they would feel left out that their motha didn't care for them because I had the sickness and I didn't tell them about it, yeh “ (Tina 351).*

However, Tina found it challenging to tell her children and at the time of the interview had told her older two children, was in the process of telling the third and wanted to tell her youngest child, who was aged 6.

Jay found it helpful to have earlier conversations with trusted adult family members, before talking to her children:

*I told my mum, my sisters before and my niece before I told my children. They just eventually ask mi and I told them [ ...] (Jay 128)*

Jay spoke of needing to find time and space amongst the pressures of mothering, working, and caring for her own health. She repeatedly used the phrase ‘sit down’ when she referred to talking to her children. For her it was important to find the time and space to sit down and address important topics and this was something she makes a point of doing regularly with her children:

*For instance, with my children, my children, we always have a one-and-one talk, we sit down and reason with our one another, so that's why might be it was easy to told them about it and tell them what about it or so forth. (Jay 76)*

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<sup>56</sup>Wel, di riizn wai a tel im bikaah ada piipl did nuo an di ruod - /- an...im guda se ou a doh tel im an piipl nuo, yu andastan? So a neva waah im fi fiil no wie

### 9.6.2 Disclosure as empowerment

For some women, disclosure was empowering, either for themselves or for their children. Maria, who had told the two daughters living with her, talked about how reassuring her daughters acted as an impetus for them to take control and learn more about HIV:

*[...] So I tell my ada daata [other daughter] – . And she was like “Oh God, mom! You going to die.” And I was like “No man, wi gonna [we’re going to] educate ourself about HIV and we gonna find out about it and how it works” [...]* (Maria 62)

As a result of telling her children about her HIV status, Maria had the opportunity to answer their questions and reassure them about issues such as illness and death, thus protecting them from the anxiety potentially experienced by children who have guessed (but not been told) about their mother’s HIV:

*[...] So I was like talking to her – cause she’s sixteen and xxx [one word] “Mommy, you know that HIV and AIDS are not as bad as people think?” she was like — yeah because she’s always like — if somebody looks really sick she says like “Tch! They look like they have AIDS and will soon be dead”. I’m like “I have AIDS and do I look sick? And do I look like am dying?” She was like “Mommy, is it true?” I said “Yup”. (Maria 89)<sup>57</sup>*

In addition to mothers working to protect their children by not telling them their status, there were also examples of women, such as Jay, who do the opposite. She believed that telling her children her status empowered them and protected them from bullying at school:

*But I think – for instance, my big daughter have a incident at school one time, where a child did look pon [at] him [her] and seh [said], “guh weh, yuh mumma have AIDS” [Go away, your mummy has AIDS] and her react[ion] was, “Do you know what your mother have?” / ‘I know what my mother have and I can live with it, do you know about your mother?’ / And that beat that child today [that day], right? So therefore when your child know and now can face the world out there... / ...it’s a*

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<sup>57</sup>*[...] So I was like talking to her – cause she’s sixteen and xxx [one word] “Mommy, you know dat HIV and AIDS are not as bad as people think?” she was like – ye because she always like - if somebody look sick sick she say like “Tch! Dem look like dem have AIDS an soon ded” Am like “I have AIDS and do I look sick? And do I look like am dying?” She was like “Mommy, a true?” a said “Yup”.*

*great empowerment. Because if she neva know and it was the first time she hear and she come and ask mi and I told her yes, might it would be a different reaction./So that — it's good when your child know and — it empower them to know what to do next. So it's good. (Jay 115–124)*

Unlike many other women, who believe that HIV should be kept secret either from or within the family, Jay believes that knowledge is power which can be utilised by children to confront accusations or bullying at school or in the community.

### **9.6.3 Disclosure as preparation for maternal illness or death**

Many of the women expressed a strong fear of death or serious illness, despite the free HIV care and anti-retroviral treatment in Jamaica and the excellent prognosis of most women accessing treatment. There has been a major shift in the epidemic from dying from HIV to living a long and often healthy life with HIV. This shift was not always fully recognised amongst the women I interviewed and the fear of dying remained, especially amongst those diagnosed more than ten years ago (Cupcake, Nora, Laura, Patrice, Tina, Anna and Sandra). This idea is echoed by Laura, whose mother told her oldest son and who plans to tell her younger son herself in the future:

*'I – I don't really have any reason really but I just want him to know my status so that anything goes wrong, he knows. (Laura 172)*

Maria also wanted to ensure her children learned from her and not from somebody else; she is clear that the impetus to tell them came from her fear of death:

*'Well, to be honest I was thinking about dying. And I said – I didn't want nobody [anybody] to tell them but me...' (Maria 79)*

These women confronted the idea of their own mortality and attempted to manage their children's future feelings by ensuring they are aware of their mother's illness before they become seriously ill.

## **9.7 Chapter summary**

In this chapter I addressed how mothers value and work to develop close relationships with their children and explored how they accept practical and emotional support from them. Crucially, although it may manifest in different ways, this reciprocal relationship is described by mothers who have not disclosed their HIV to their children as well as by those who have fully or partially disclosed. It may be that, in the absence of explicit disclosure, some children had guessed and wished to show their support; this form of implicit disclosure/knowledge is not addressed by

current policy. Assumptions about authoritarian parenting models do not allow for more complex relationships where parents and children both give and receive support. There is emotion work involved in cultivating these more collaborative relationships with children, which takes time, patience, strength and judgment. It can be challenging to accept help, particularly from children in a cultural setting where parents are expected to be strong, responsible and independent and children are expected to be passive recipients.

Women described how they used these relationships to support disclosure or to prepare children for future disclosure, but they also highlighted the importance of their relationships with their children in their own right, regardless of their views on disclosure; a number of women who had not disclosed to their children also described reciprocal relationships and accepted help from their children. The women I interviewed described both emotional and practical reciprocity. In addition to the emotional care provided by mothers towards their children, children also provided emotional support to their mothers. Whilst mothers cared for their children's physical health and education, children also supported their mothers in the home and provided support with their mother's HIV medication. These findings demonstrate another dimension to parent-children relationships in Jamaica and an extension of the concept of reciprocity and emotion work to include mother-child relationships.



## **SECTION 4: REFLECTIONS, FINAL DISCUSSION & CONCLUSION**

### **Chapter 10: Reflections on working with feminist IPA as an 'outsider' researcher**

In this chapter I reflect on some issues associated with applying a decolonial approach and working with emotive topics, in a culture and language different from my own. I go on to reflect on my experience of interviewing in Jamaica, as an outsider, using my first interview, with Sandra, to highlight issues of power in the interview setting.

#### **10.1 Reflections on working to apply a decolonial approach to my research**

In my thesis I wished to recognise and try to guard against the potential impact of Anglo-Northern thinking on the research and writing processes. I present here two examples of existing HIV disclosure research which demonstrate ways in which Anglo-Northern approaches can be problematic when conducting research in the Global South. In the first example, Geiselhart, Gwebu and Krüger (2008) wrote of an HIV positive mother in Botswana who stopped bringing her HIV positive child to the hospital for treatment, returning only when the child was very ill:

*“After 12 months her mother showed up with the child. The child was very close to death. The mum tear-free told us that she had not disclosed to her husband. And because she had not disclosed to her husband, her husband had stopped providing her with the transport support she needed to travel all the way from Kanye to Princess Marina Hospital”*  
(Geiselhart, Gwebu and Krüger, 2008:100).

This case inspired a family-based approach to HIV treatment and was clearly distressing and frustrating for hospital staff. However, the use of the word ‘tear-free’ here, implies some level of judgment about the mother’s priorities and reactions to her child’s illness and possible death and a lack of understanding about the woman’s circumstances and the context in which she lives. Her apparent strength leads to assumptions about her lack of feeling and feeds into a discourse of

‘other’ or ‘less than’. This raises questions about the approach employed by professionals and researchers and whether this service was able to prioritise and understand the needs and views of the patients whom it treated.

The second example is from a recent article on maternal disclosure in Haiti (Conserve *et al.*, 2014). The stated objectives of this part of the study (all participants were part of a wider intervention) were to “identify the factors influencing maternal HIV serostatus disclosure, examine the breadth of maternal HIV serostatus, and understand the impact on mothers and children” (Conserve *et al.*, 2014: 2309). This article states that almost a quarter of participating mothers told their children about their HIV during their involvement in the project as a result of “encouragement from psychosocial intervention workers” (*ibid.*:2309). There is no mention of how this spontaneous disclosure was managed, no recognition of reasons that participants might have had for not telling family members earlier, nor any support offered to participants following their disclosure to their children. It is also possible that participants did not, in fact, disclose, but merely stated that they did in response to what they perceived as pressure from staff members who were in a position of power. It is possible that these findings are influenced by Anglo-Northern assumptions about the benefits of disclosure, a lack of reflexivity about the implications of unequal power dynamics in research and a lack of understanding about participants’ life circumstances and the options or choices available to them.

These two examples highlighted some of the potential pitfalls of working as a researcher or professional from the Anglo North or using Anglo-Northern perspectives. To truly apply a decolonial approach, my research would have had to have been conceived, designed, carried out analysed and disseminated by Jamaican researchers committed to decolonial concepts. This was impossible for me to achieve, but I worked to increase my awareness of Anglo-Northern approaches and colonial thinking as they appear in HIV disclosure research and to attempt to guard against this in my own work.

### ***10.1.1 A decolonial approach in my thesis***

Values and judgments implicit in disclosure policy and assumptions that it is always ‘good to talk’ (Burman, 2006; UK Family Project, 2008) have been critically examined throughout the thesis, particularly in the findings chapters (Chapters 7–9). I have worked throughout this thesis to challenge assumptions rooted in coloniality and to trouble the implications of Anglo Northern policy when applied to the Global South, a central tenet of my thesis. This can be seen in three main ways. Firstly, I describe the Jamaica context, including current family structures (Chapter 3) and the ongoing racism within Jamaican society, which privileges those with lighter skin Secondly,

I committed to ethical practice throughout the entire research, transcription, analysis and interpretation processes and paid careful attention to language throughout the thesis. Thirdly, I committed to feminist reflexivity which includes reflection on power within research relationships (discussed in Chapter 10). I have demonstrated that women do enact agency within research interviews and highlighted the ways in which parental HIV disclosure guidance, based on Anglo-Northern thinking and contexts, fails to consider the lived experiences of women in the Global South. Whilst familiarising myself with the Jamaican context, prior to beginning my research, my assumption that it would be good to talk was challenged by a Jamaican university professor (see Section 10.3) which began to trouble ideas of disclosure, suggesting complexities around who knows best, the patient or the doctor, and leading me to consider further how their positions were informed, communicated and actioned.

## **10.2 Reflections on interviewing as an outsider in the Jamaican context**

Dwyer and Buckle (2009:60) write of “the space between”, which “challenges the dichotomy of insider versus outsider status”, recognising that “as qualitative researchers we have an appreciation for the fluidity and multi-layered complexity of human experience”. I wanted to recognise the differences between myself and my participants, but also to move beyond this, to explore the women’s experiences in collaborative, non-judgmental ways, to find, within the interviews, the “positional” spaces, of which Mullings (1999:342) writes: “...areas where the situated knowledges of both parties in the interview encounter, engender a level of trust and co-operation [...] often transitory and [which] cannot be reduced to the familiar boundaries of insider/outsider privilege based on visible attributes such as race, gender, ethnicity or class.” I have lived outside the UK for most of my life, and interacted with people with whom I do not share a language, a culture, or many common experiences or points of reference; however, I have often found that we are able to communicate, and to share an experience or connection.

Whether this kind of connection is possible within a research context is debatable, and has been queried by many authors who believe hidden racism lies within much cross-cultural research (*e.g.*, Stanfield, 1994; Smith, 1999) and who criticise privileged researchers acting as “saviours on white horses” in foreign contexts of which they are ill-informed (Gormley, 2005:376). The Jamaican relationship to this concept is multi-faceted. The way (usually) black Jamaicans relate to (usually) white foreigners is complex and includes resentment stemming from historical issues (slavery) and current issues (those with lighter skins in Jamaica, including foreigners, tend to enjoy higher status).

Tufford and Newman (2012:91) write of the potential challenges for researchers, who, like myself, come from very different backgrounds from their participants: "...a researcher from a dominant ethnocultural group or of relatively higher socioeconomic status may fail to appreciate how structural and social constraints shape the worldviews and behaviour of participants whose social location is different from that of the researcher, if participants' experiences are unreflexively filtered and interpreted through the researcher's social location and life experience." Suggested devices a researcher might use to support reflexivity include the use of memos (Cutcliffe, 2003), separate interviews with outside sources to highlight preconceptions (Rolls and Relf, 2006) and keeping a reflexive journal (Ahern, 1999). At different stages in my research process I endeavoured to use these techniques to support reflexivity. I hope these helped me give weight to a variety of narratives and to recognise the women's viewpoints. Without careful attention to reflexivity there is the risk that the experiences of poor urban HIV-positive Jamaican women could be simplified by my perspective as a white, middle class HIV-negative, British woman and through my potential feelings of shock, guilt, empathy, pity or judgment into narratives of victimhood, helplessness or hopelessness, thus obscuring the also-present stories of strength, resilience, determination and overcoming adversity (Tufford and Newman, 2012). I also wanted to recognise the impact of wider contextual factors, which have long been recognised in feminist work (*e.g.*, Harding, 1986; hooks, 1990) such as race, gender, poverty, the legacy of colonialism and the inevitable impact these factors have on the day to day experiences of women's lives (see Mohanty, 2003:4–5), all of which are particularly evident within a resource-constrained setting.

I tried to be open, receptive and non-judgmental. I found that I identified much more with some women than others and that this could happen on an emotional level with women I had very little in common with. Brodsky and Faryal, (2006:317) write of recognising the "distinction between that which is truly different, but can be worked through with sensitivity and discussion, and that which is assumed to be different but actually is not". I was conscious of both similarities and differences during the interview process. I was sometimes taken aback by what the women said (for example, when Laura spoke of refusing all HIV related medical treatment for herself and her unborn baby), although I tried not to show this through my expression or responses. This may be an example of how women inadvertently judge other women's parenting practices, resulting from the pervasive and powerful influence of 'good mother' discourses and the pressure to do what is "best for the baby" (Lupton, 2011:642).

I often felt very sad for the women, although the enormity of what they faced often did not sink in until later as many of the women had quite a resigned and understated way of talking. My experience echoed that of Pithouse-Morgan *et al.* (2012), researching HIV in South Africa. In their

study, they noted how their research brought to the fore the day-to-day concerns and experiences of South Africans, including violence, abuse, gender inequalities, “the complexity of denial of HIV and AIDS, and the ongoing legacy of racial and social inequalities” (Pithouse-Morgan *et al.*, 2012:51). They found that, as researchers, they were unable to separate their emotional and social selves from their research and that reflexivity and attention to the researchers’ own emotions and responses, can, in fact enhance the research and allow for a deeper understanding of “the emotional and social nuances of our research topics” (Pithouse-Morgan *et al.*, 2012:51). Both participants and researchers experience a range of emotions during an interview; acknowledging and exploring these feelings can serve to increase transparency and deepen our understanding of the research topic and process. Craig (2004:82) argued that feminist analysis of emotions can act “as a resource to disrupt dominant scientific paradigms that separate researcher and researched in the name of a disinterested (masculine) objectifying science”.

Strategies I used to connect with the women focused on making them feel comfortable: *e.g.*, eye-contact, handshake, showing respect through choice of words, tone of voice and form of address, mirroring and affirming, and encouraging (through nodding and verbal prompts). The human contact element in developing rapport is arguably of particular importance to HIV positive people in the Jamaican context, where HIV is highly stigmatised and physical contact of any kind is often avoided. Some of my behaviours within the interview setting may have helped interviewees to feel more comfortable and accepted. For example, I shook hands with participants, provided and shared biscuits with them, and when they brought toddlers into interviews (Jay, Nora), I held and played with them. One of the NGO participants had met and held my children; I am aware of how powerful these actions were likely to have been as symbols of acceptance.

Allen talks of the need to be aware of “symbols of power, status and cultural differentials between researchers and their subjects” and to avoid the use of, for example, laptops or expensive clothes (Allen, 1997:271). Technology has moved on substantially since that chapter was written, and now even the very poor often have mobile phones: Anna showed me pictures of her friends and family on a much more up-to-date and expensive phone than my own. I had my phone, my audio-recorder and sometimes my laptop at the interviews and only the audio recorder seemed at all unusual to participants. Most participants just glanced at it when I mentioned recording the interview, but, for those unfamiliar with audio recorders, I gave a brief demonstration of how it worked as part of the consent process.

In addition to Jamaican Patois having different grammatical structures to standard English, it is also common (as in standard English) for people to use pronouns and tenses in a confusing way when attempting to explain things. For example, a participant might say ‘you’ when they mean ‘one’ or

say 'would' when they mean 'had'. This can also show ambiguity, for example, where a memory is inexact and so someone is saying 'would' to indicate their belief that a person would have said a particular thing, although they cannot remember the exact words. I had to listen very carefully to distinguish between can (caan) and can't (cyaan) and to pay attention to double negatives which in Patois, appear not to cancel one another out, similar to some British regional dialects. Assumptions within research paradigms of a linear approach to time (McCourt, 2009) does not mesh with the lived experiences of the women I interviewed and approaches to time differ with culture, language, age and individual temperament. I found that it was not always meaningful or helpful for me to attempt to elicit specific ages of children when an event occurred. At the time of the interviews, my children were quite young, and I was perhaps more aware of linking ages to events or milestones at that point in our lives; this tends to be less the case as children grow older and differs with culture, generation and parenting approach. I think that collecting information prior to the interview would have been off-putting to participants in this context, but completing a quick verbal questionnaire with them at the end of the interview to collect facts including age, number of children, time of diagnosis, might have been helpful for me.

Both I and the women I interviewed modified our use of language during the interviews. In general, the women, noting my skin colour and accent, did not speak as much or as strong Patois as they might have when talking to some Jamaicans (not all Jamaicans speak or understand Patois so this is not a limitation unique to my nationality). Prior to my interview with Cupcake, I witnessed a conversation between her and two of the social workers, in which she spoke extremely rapidly and using very strong Patois which was difficult for me to understand. However, in our interview, she spoke almost entirely in standard English, using only a few Patois words. Women's tendency to use standard English or less Patois when talking with me can be considered both a limitation (some depth and richness may have been lost, they may have chosen to omit or simplify things) and a benefit (they may have felt more comfortable that the content would be kept confidential and at times they may have explained themselves more thoroughly in an attempt to help me, an outsider, understand). I can only speculate as to the reasons behind their language use; I imagine it was a combination of a desire to make it easier for me to understand and a desire to present themselves as educated and able to speak standard English (as in some settings individuals are looked down upon for having a limited ability to speak or write in standard English, although, conversely, within other social groups, the opposite occurs). In this way, the women demonstrated their awareness of power and difference and, like me, attempted to influence the course of the interview. Whilst occasionally somewhat impatient with me, the women were, for the most part, willing to explain, repeat and elaborate when I was unable to understand something they said. This impatience was partly linked to language but partly due to the nature of IPA and its focus on getting to the 'essence' of an

experience, which can sometimes be interpreted by participants as the interviewer repeating a question they feel they have already answered.

For my part, I did not attempt to speak Patois or to change my accent or grammar, but I did use some vocabulary I do not normally use (*e.g.*, ‘scorn’ and ‘fret’), to mirror the words the women used. I spoke a little more slowly, softly and clearly than I normally do. I tried to phrase my questions in as straightforward a way as possible, so I might ask “What was good about that?” rather than asking about the advantages of a particular behaviour. I noticed that certain of my phrases were almost always construed in a particular way. For example, if I asked how someone ‘reacted’ or how a relationship had ‘changed’ this was always assumed to be something negative and women often responded defensively. I therefore tried to avoid these words and instead asked “what happened next?” or “what were the good and bad things about this?”

Many of the women had an understated way of speaking, used clichés and sayings as a distancing tool and it was sometimes difficult to get beyond these comments. For example, Susie, referring to ARV side effects which made her think she was going to die, said: “It was rough<sup>58</sup>” and when she described telling somebody about her positive HIV test results, said: “I said, ‘They’re bad<sup>59</sup>’”. Laura said: “That was good for me” when describing receiving her 6 month old son’s negative HIV test results, after she refused ARV treatment during her pregnancy. Similarly, when considering the prospect of telling her sons she had HIV after she intentionally allowed them to think that she also received a negative result when the whole family was tested for HIV, Cupcake said it’s “just not gonna be easy”. Maria said “I don’t want to die and then my mother and me don’t have a good relationship. That would be too bad”, referring to her fear of dying of HIV and not having reconciled with her mother. Tina said “But that should not happen” when telling me of the sexual abuse of her step daughter by her biological father (Tina’s partner), which led to her step daughter becoming infected with HIV and subsequently dying. These are all examples of extremely difficult emotional or traumatic events which the women describe very calmly. I think this matter-of-fact manner of speaking helped the women protect themselves from the emotional enormity of negotiating family relationships, the prospect of death, sexual abuse, and their children’s HIV tests in the context of their own HIV infection. Parr, (1998) wrote about an Open University educational film (Course K668, Mental Handicap, Changing perspectives, 1990) which examined how those who have had difficult or traumatic experiences use emotional distance and matter-of-fact language when describing their experiences. Like Parr (1998:99), who stated that “people do not have the same ability to verbalise their experiences”, I felt that some of the women had had very limited

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<sup>58</sup>It woz rof.

<sup>59</sup>Mi se, “dem bad”.

opportunities to discuss and explore their feelings and so they were telling me as much as they could at that time. Other women were more forthcoming and provided detailed examples and anecdotes to help explain their feelings and reactions. Most of the women would have had only very limited opportunities to discuss the emotional aspects of living with maternal HIV and for some, this may have been their first opportunity to discuss these emotions.

The conversations evoked some difficult subjects for me as the interviewer as well as for participants. With hindsight, I perhaps shied away from some topics the participants might have been willing to discuss, such as death and negotiating sexual relationships after diagnosis—particularly in view of the number of women who had one or more children post-diagnosis. I did this partly to respect the participants’ choices about what they shared with me and also, possibly, to protect myself emotionally, either from hearing about a difficult topic or from worrying later that I had pushed the participant to say more than she wished to or had exposed feelings that could not easily be dealt with in her daily life. Letherby (2003:114–116) addressed issues of power and empowerment in the research relationship, finding them complex and multifaceted, with the balance of power apt to shift depending on individuals and circumstances. I found communication with two participants to be particularly challenging. My first interview with Sandra (discussed in Section 10.3) felt, to me, stilted and awkward. I attributed this to both of us being nervous. Anna was quite confused in her manner of expression and held relatively uncommon beliefs (*e.g.*, in ‘obeah’, the practice of traditional medicine) which may have been difficult for her to explain to me, a non-Jamaican. However, both were keen to participate and although I faced some challenges in analysing their data, they contributed interesting insights and demonstrated areas of convergence with other participants. Despite my fears about Sandra’s interview being unhelpful and uninformative, it is her quote (“I am his queen”) which forms part of the title of this thesis and, after analysis and reflection, her interview provided great insight into the concepts of maternal identity, protective mothering and emotion work, helping me to develop my analysis across all of the interviews, as discussed in the finding chapters (Chapters 7–9).

Like Mitchell and Irvine (2008:34), I found that women also “negotiat[ed] consent on an ongoing basis throughout the interviews [...] and felt able to exercise selectivity and control in what they shared during interviews”. Women generally did this in a non-confrontational manner, for example, by saying they did not remember or by answering a different question from the one which I had asked. I did not query this with the women at the time, but if challenged, it could have been easily explained by the differences in our spoken English. It is, of course, also possible that women genuinely did not remember or genuinely did misinterpret my question. There were examples in at least one interview of a participant (Sandra, discussed later in this chapter) seeking to please, to say



what they thought I wanted to hear and this was shown by subsequent direct contradictions as the interview progressed. Letherby, (2003:116) noted that researchers should avoid casting participants as passive victims as they have the option to “refuse to answer, take part, tell the truth, even...” Although several participants commented they found it helpful talking about their experiences, I do not know how comfortable they felt after the interview about the information they shared. However, examples throughout the interview process illustrate participants exercising control and refusing a passive role: One participant (Patrice) told me at the end of the interview that she had decided to participate because I had been friendly and respectful when I greeted her. Despite her interview being by appointment, accompanied by assurances of confidentiality from the NGO coordinator and involving a long bus journey, she had decided that she would reserve her final decision on participation until we met: if she was unhappy with me, she would just “disappear”.

In addition to consideration of the language that the women used (*i.e.* Jamaican Patois or standard English), I also considered their use of language in a broader sense (*i.e.* how they chose to present themselves to me). Compared to discursive methodologies, IPA views language as relatively unproblematic, providing an insight into experience, a “window” into the view or character of the person speaking. IPA’s flexibility allows for some exploration of the use of language, but this is limited, compared with, for example, discourse analysis. In accordance with authors such as Scott (1987), I see the women’s use of language as a tool that they use to position themselves, and to present a particular identity: “a notion of language that assumes a multiplicity of references, a resonance beyond literal utterances, a play across topics and spheres” (Scott, 1987:12). In the case of my research, the women worked to position themselves as respectable, as responsible, as ‘good’ mothers and ‘good’ members of society. This can be seen, for example, through their presentations of themselves as married and faithful to their partners (hence respectable), thus challenging characterisations of HIV positive women as promiscuous and immoral. Women worked to present themselves as good mothers and this is demonstrated throughout their accounts, through, for example, their descriptions of close relationships with their children (see Chapter 9), of working to provide financially for their children, often despite personal emotional costs (see Sections 7.2 and 8.2) and their expressions of love and the care work that they perform (see Chapter 9). Additionally, the interview with Sandra (discussed in detail in Section 10.3) suggests that Sandra, in her eventual declaration that she intended to disclose to her children, was seeking to present herself to me as responsible mother, in the assumption that I, through my repeated questions about disclosure, believed that maternal disclosure was the ‘right’ and ‘responsible’ thing to do.

I have attempted to reflect on the women's identity work, identifying times that they selectively engage with topics, and work to present themselves in particular (and sometimes contradictory) ways. I have used the flexibility of IPA, in particular through reflection and the double hermeneutic, to engage with this identity work to an extent. However, it is necessarily limited due to IPA's focus on, for example, phenomenology, whereby participants' talk about their experience is treated as a more unproblematic expression of their views.

### **10.3 Reflections on power in the interview: Interview with Sandra**

I want also to reflect on my own journey and views, which I have sought to examine and clarify, not only in relation to the interview experience, but on the topic as a whole. Early in the research process (July 16, 2012), I spoke with a Jamaican professor who seemed critical of my research concept. She asked why a Jamaican mother whose HIV is being successfully treated would contemplate burdening her young child with the knowledge that his or her mother was HIV positive? At the time of this conversation, I felt defensive, but, upon reflection, it helped highlight some of the key issues facing women in the Jamaican context and helped me to have a more open approach to the reasons women might choose not to tell their children. My view when I began the research was that it would probably be best for both the women and their children if mothers told their children about their HIV status in an incremental and age appropriate way (much as current policy in high income countries encourages adoptive parents to tell their children about their adoption). I began to recognise that although I have spent most of my life outside the Anglo-North, I am still very much influenced by Anglo-Northern perspectives. I felt this professor implied that more than being merely an outsider, I was a descendant of those instrumental in colonising Jamaica; and that I did not, possibly could not, understand the experiences of the women I wanted to interview nor the wider historical and social factors which had shaped their lives. She was not explicit and I cannot know whether this is what she meant to say, but, on reflection, I think she was using her status and influence within the institution and the country to confront and challenge my views and assumptions. This forced me to reflect on my position as an outsider in Jamaica and what this might mean for my interviews and my approach to the research. It is notable that it was she, a powerful educated Jamaican, who challenged me more directly; the women I interviewed were either very cooperative or challenged me in more subtle ways, through evasion, possibly intentional misunderstanding, or silence. These reflections raised my awareness of the disconnect between factors influencing daily life and policy recommendations as well as making me more conscious of how power inequalities could influence how policy is conceived, researched, disseminated and implemented. My reading and exploration of feminist research and approaches deepened my understanding of the ways this approach could positively enhance my research. I also

recognised similarities between a feminist approach and many of the ideals and concepts I consider important, many of which developed as a result of living in different countries or through studying global development, youth and community work.

I would like now to reflect on my first interview, with Sandra, whose words (“Am iz queen” (I’m his queen)) form part of the title of this thesis. It is simple and yet very powerful in its evocation of the special, regal role held by mothers in Jamaican society. This view is echoed by Adisa:(2013:40) “Mothers, married or unmarried, wore a crown; and children were said to be a woman’s insurance in old age”. When I asked how Sandra felt about the possibility of telling her children about her HIV status, she replied:

*Sandra: Maybe the big one would cry and the second one would cry too.*

*Because he’s saying that I am his angel so—*

*Gayle: [chuckles] the middle one?*

*Sandra: I’m his queen.[chuckles] (Sandra 162–165)<sup>60</sup>*

In this extract, Sandra hints at her discomfort with the distress the information is likely to cause her children, particularly its effect on their view of her. She talks about her middle son characterising her as an angel, a queen, and fears that knowing her HIV status would challenge his sense of her as a perfect, infallible, almost divine figure. Sandra silences herself (Jack and Ali, 2010) to protect her relationship with her children and preserve their image of her as pure and regal. She prioritises their emotional health over her own, later stating that, although she doesn’t want them to know, she might get more support if her children were aware of her HIV status (Sandra 198). For some women, it is easier to live up to social mothering expectations and display culturally appropriate emotions if they do not discuss their HIV with their children. They have not found a way to reconcile their own and cultural images of the ‘good’ mother, with the reality of their positive HIV status. They chose instead to avoid confronting this disconnect, even in the face of occasional pressure from professionals to tell their children their status. Sandra, who seemed anxious and tentative during her interview, showed she was able to demonstrate her agency by refusing to follow medical advice to tell her children about her HIV. Her laughter signalled her ambiguous feelings about this:

*[chuckles] First the doctor told me I must tell and I said “No”. (Sandra 302)<sup>61</sup>*

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<sup>60</sup>*Sandra: Miebi di big wan wud krai an di sekan wan wud krai tuu. Kaaz iiz sein dat am iz ienjel so —*

*Gayle:— [chuckles] the middle one?*

*Sandra: Am iz kwiin. [chuckles]*

<sup>61</sup>*[chuckles] Fers di dakta did se a mos tel dem an a se ‘no’.*

On ten separate occasions during the interview Sandra used a variation of the phrase “I don’t want to tell them”, indicating the strength of her feelings. Nevertheless, she mentioned being able to see one or two good things which might come of telling them, but these statements were always quickly followed by her saying that she didn’t want to tell them, demonstrating that she was still at an early stage of considering disclosure and was unlikely to do so in the near future.

Both Sandra and I were nervous during the interview and we also had several interruptions. To me, the interview felt stilted and awkward. Afterwards, I felt that I had been too pushy and did not have any useful or rich data to analyse. This is seen early in the interview, when I asked her about the positive things about her children not knowing her HIV status, and, following her long pause, I try, clumsily, to assure her that she is the expert of her own experience:

*Gayle: Okay. What are the things that are good about them not knowing?*

*Sandra: [long pause]*

*Gayle: And it’s up to you of course, you know. It’s your – your family, you’re their mother – (Sandra 88–89)*

I struggled to be open and encourage Sandra to share her experiences without prompting her; in later interviews, I felt more relaxed and learned to sit more comfortably with silence.

Throughout the interview, Sandra repeatedly tells me that she does not want to tell her children about her HIV:

*They don’t ask and I don’t tell them. (Sandra 63)<sup>62</sup>*

*So that’s the main thing—I try not to tell them. (Sandra 86)<sup>63</sup>*

*Just let it stay as it is. (Sandra 100)<sup>64</sup>.*

*But then again, I don’t want them to know. (Sandra 198)<sup>65</sup>.*

*I feel better not telling them now. (Sandra 310)<sup>66</sup>.*

Because Sandra had not told any of her children, I struggled with what questions to ask; it is difficult to discuss something which has not happened. I felt that, as the interview progressed, my continued questions about telling her children made Sandra think I wanted her to say that she was

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<sup>62</sup>*De doh aks mi an a doh tel dem.*

<sup>63</sup>*So dats di mien ting a – a chrai nat tu tell dem.*

<sup>64</sup>*Jos let it stie az it iz.*

<sup>65</sup>*Bot den agen, a doh want dem to no.*

<sup>66</sup>*A fiil beta nat telin dem nou.*

going to tell her children. Perhaps she felt my questioning implied that a responsible mother would tell her children about her HIV. Similarly, Lupton (2011) found that mothers were conscious of judgmental attitudes towards how they cared for their babies and worked to conform to concepts of the ‘good mother’. Towards the end of the interview, Sandra said she would, in fact, tell her children next month:

**Gayle:** — *test them [out] and see. And when do you think you would do that? What would make you ready to test them [out]?*

**Sandra:** *Maybe next month.*

**Gayle:** *Oh really? So soon? You are talking about soon. So why – why are you thinking about this for next month?*

**Sandra:** *To try and protect them.*

**Gayle:** *You want to protect them from?*

**Sandra:** *From catching it.*

**Gayle:** *From catching it. So you want them to...*

**Sandra:** *Be aware of it.*

**(Sandra 293–300)**<sup>67</sup>

I do not believe she intended to tell her children so soon; earlier in the interview she says she will tell them eventually, but she does not seem to have any clear plans to do so: “Yes, one day”<sup>68</sup> (Sandra 284). Throughout the interview, she gave several reasons why she did not think it was a good idea to tell her children:

*Maybe he would hate his father. (Sandra 166)*<sup>69</sup>.

*So I don’t know— if his queen messed up... having that [HIV] I don’t know how he would feel. (Sandra 166)*<sup>70</sup>

*[...] I’m afraid to tell him./Maybe he would scorn and start worrying. (Sandra 158/160)*<sup>71</sup>.

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<sup>67</sup>**Gayle:** — *test them and see. And when do you think you would do that? What would make you ready to test them?*

**Sandra:** *Miebi neks mont.*

**Gayle:** *Oh really? So soon? You are talking about soon. So why – why are you thinking about this for next month?*

**Sandra:** *Tu chrai an protek dem.*

**Gayle:** *You want to protect them from?*

**Sandra:** *Fram kyachin it.*

**Gayle:** *From catching it. So you want them to...*

**Sandra:** *Bi awier af it.*

<sup>68</sup> *Yes, wan die*

<sup>69</sup> *Miebi ii wud iet iz faada*

<sup>70</sup> *So a doh no – if iz kwiin mesd op...aving dat I doh no ou ii would fiil.*

<sup>71</sup> *[...] am afried tu tel him./Miebi ii wud skaan an staat woriing.*

*Right. I think that maybe if they knew that, then all focus on their bookwork would be dropped. (Sandra 80)<sup>72</sup>*

*I don't know...because I feel like if I tell them, they are going to say it to their friends... (Sandra 69)<sup>73</sup>*

I hope that my questions did not lead to her telling her children. I hope that the interview served as a helpful opportunity for her to explore some issues she had not been able to discuss in her daily life and a safe place to articulate her fears: “I worry that maybe I’m not going to live” (Sandra 332<sup>74</sup>) and possibly to practice a hypothetical scenario:

*Sandra: hmmm... I don't know. But one day I'm going to ask them if their mother has that [HIV] how would they react?*

*Gayle: Mhm. Mhm.*

*Sandra: —first—*

*Gayle: And see what they say.*

*Sandra: — and listen to what they say and if they say something bad, I wouldn't say anything. (Sandra 286–290)<sup>75</sup>*

I have no way of knowing how Sandra felt after the interview or what impact the interview might have had on her relationship with her children. I think this demonstrates how easy it can be, even unintentionally, to potentially influence the choices people make, or, more likely, influence the outcome of research: I could, from this discussion, assume that she genuinely does intend to tell her children next month. However, from the little I know of Sandra, I think (and hope) that she intends to do exactly what she wants to do. She gave me several hints throughout the interview about how she asserted her agency; by deflecting my questions, refusing to follow her doctor’s advice to tell her children (discussed earlier), and by terminating the interview:

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<sup>72</sup>Rait. A tink dat miebi if de nuu dat den aal fuokus on di bukwerk wud be drap.

<sup>73</sup>A doh no...bikaaz ai fiil laik if ai tel dem, de ar goin tu se it tu dier frenz...

<sup>74</sup>A wori dat miebi am nat gona liv.

<sup>75</sup>Sandra: Hmm...a doh no. Bot wan die a goin aks dem if dey mom az dat wat — ou wud dey riak?—

Gayle: Mhm. Mhm.

Sandra: —fers —

Gayle: And see what they say.

Sandra: — an lish tu wat dey se an if dey se somting bad a doh se eniting.

*Gayle: Sometimes people say they feel like if people know that they would s-support them more.*

*Sandra: Some people might [chuckles]. (Sandra 38–46)<sup>76</sup>*

*Sandra: Yeah, because if I'm getting sick, they will ask me "Did you miss your medication?" Or you know? Well, I guess that's about it. (Sandra 328)<sup>77</sup>.*

Reflecting on the Sandra's interview highlights the importance of researcher reflexivity and of designing and conducting research carefully and sensitively to avoid making assumptions, or manipulating or influencing participants. In research interactions, participants may struggle to articulate the complexities of their daily life to researchers substantially different in their experiences and background. They may simplify their reasons for choosing not to tell their children into easily understood but not entirely accurate concepts, such as: the child is too young, the child wouldn't understand, the child might tell others. As discussed in Chapter 2, all these reasons appear regularly in maternal disclosure research, although they may cast women in a negative light, suggesting that they do not trust their child or are not capable of explaining in an age appropriate way. I suggest these are partial explanations, given by women when asked a complex and hard to explain question by someone whose life experiences, perspective, and even language, may be completely different. This is supported by women giving these reasons, even when children are well into their teens and certainly capable of understanding and secret keeping. Other women say they don't want their children to know or to worry, hinting at the enormous burden of emotion work that would be necessary, on top of existing burdens of both emotional and practical work, in managing and supporting their children to assimilate the information. The interview with Sandra highlights the power dynamic which, though often invisible and unacknowledged, can be a powerful influence on interview interactions and can shape the course of a piece of research. For me, this interview with Sandra illuminated the key issues of emotion work and protective mothering the women identified through their accounts of mothering with HIV, as discussed in Chapters 7–9. The next chapter provides a final discussion of these findings, conclusions and recommendations for future work.

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<sup>76</sup>*Som piipl mait [chuckles]*

<sup>77</sup>*Ye bikaaz if am getin sik de wil aks mi 'yu mis yor medikieshan?' ar – yu no? Wel a ges dats about it.*

## **Chapter 11: Final discussion and conclusions**

### **11.1 Introduction**

My research explored the experiences and views of 15 poor urban Jamaican HIV positive mothers with regard to talking to their seronegative children about maternal HIV. My objectives were to:

- a) Explore how HIV positive mothers make sense of motherhood and living with HIV;
- b) Identify the strategies or approaches that HIV positive mothers use to communicate with or conceal maternal HIV status from their children; and
- c) Make recommendations for policy and practice.

In this final discussion chapter, I address the key issues raised throughout this thesis which have implications for the disclosure of maternal HIV to children. When women disclose to their children, it can be seen as a form of governmentality; when they don't disclose, their mothering is called into question within policy discourses predicated on evidence in the Anglo North. However, there are risks associated with disclosure for women in resource constrained contexts; disclosure may therefore be harmful, rather than beneficial. Additionally, women may partially disclose, may disclose to only some children, or relatives or professionals may disclose to their children. The over-simplistic disclosure/non-disclosure binary fails to consider the emotion work women engage in to manage their health and their mothering identity in the context of their relationships with their children. My research revealed that maternal disclosure of HIV to children involves a spectrum of approaches involving overt and covert disclosures and non-disclosures and is not a binary decision. While disclosure concerns mothers, their priorities include protecting their children, protecting their relationships with their children, and protecting their maternal identity (alongside practical considerations). Mothers carry out this protective mothering through emotion work.

I used Lupton's (2011) concept of responsibilisation as well as Hochschild's (1979, 1983) concept of emotion work and associated ideas of maternal visibility (Garey, 1999; 2011) and reciprocity (Hansen, 2011) to illuminate the themes the women I interviewed identified. I focused on areas of contradiction, and Hochschild's concept of the 'pinch' to identify three key themes: 1) Maternal visibility: providing and protecting; 2) The responsible mother: HIV, mothering at a distance and 'downfallment'; and 3) HIV and reciprocity in mother-child relationships. I now step back from these thematic findings to discuss the more broadly applicable conclusions arising from my research. Through my focus on challenging assumptions, I identify the four key conclusions of this thesis. I then propose a micro-meso-macro framework to help clarify the links between the



thematic findings and wider structural and contextual factors. Finally, I highlight the contributions to knowledge, make recommendations for professionals and researchers working in the field of maternal disclosure and identify potential areas for future work.

## **11.2 Challenging assumptions**

I have explored the experiences of 15 HIV positive Jamaican women with regard to talking to their children about maternal HIV. I extended the IPA methodology to a middle income country setting, incorporating issues of research positioning (*e.g.*, through my discussion of insider/outsider perspectives) and using it alongside a feminist approach (unusual in existing disclosure and IPA literature) and Hochschild's concept of emotion work. I situated mothers' disclosure experiences within the wider Jamaican social, cultural and economic context and challenged existing positivist approaches to disclosure, including disclosure binaries, and assumptions that it is right to disclose. Instead, I argued for recognition of the wide range of experiences of talking to their children about maternal HIV that women describe and the personal and social factors that impact these experiences. My research highlights the importance of preserving a positive maternal identity for HIV positive women, regardless of their position on the disclosure spectrum, and gives examples of their use of emotion work to do this. To improve maternal health outcomes for HIV positive mothers and their families, in addition to existing medical provision, there needs to be additional recognition of the complex and nuanced emotion work HIV positive Jamaican mothers perform to protect their children, their relationship with their children and their maternal identity.

### ***11.2.1 Disclosure is a spectrum not a binary***

My research challenged assumptions that maternal disclosure is a simple binary which is desirable and beneficial to families, and recommendations that all HIV positive mothers require professional support to disclose to their children. Like Allison and Siberry (2015) who propose that disclosure is considered as a continuum, I found that maternal disclosure occurs on a spectrum. I propose that women, recognising the potential risks of disclosure, perform a range of sophisticated emotion work to protect their maternal identity and the physical and emotional health of their children. Using the terms 'disclosure' and 'non-disclosure' can create an artificial binary and cause confusion, implying that disclosure is a formal one-off conversation rather than a long and fluid process. Many families have far more complex realities, and choose a less clearly defined route regarding disclosure, which can be difficult to communicate to researchers, particularly when a disclosure binary is implicit in disclosure policy and much of the existing disclosure literature. Policy developed in Anglo-Northern contexts, premised on developmental theories based on the mother-child dyad and the nuclear family (*e.g.*, Burman *et al.*, 1996) fail to take into account the

diverse familial formations in the Jamaican context. For example, children may be parented at a distance by other family members or parented in multiple households where it may be more complex for a mother to disclose her HIV status to her child as she is not the primary carer. That women don't disclose could be interpreted as failure or lack but I have demonstrated that women engage in complex emotion work in managing their diagnosis and disclosure decisions.

My research reveals that mothers, rather than disclosing or not disclosing, in fact choose a range of disclosure options, including full disclosure, partial disclosure and differential disclosure. The women's experiences of the disclosure spectrum and the factors influencing their decisions are interwoven throughout the thematic findings chapters. Disclosures may be planned or unplanned; mothers must also cope with the repercussions when someone other than they themselves (such as another family member), discloses to their children (see Section 8.2.3). The women made their decisions based on a variety of factors, including an assessment of their own and their children's emotional readiness and need for support, the strength and closeness of their relationship with their children and the impact they think disclosure will have on their children and their relationships. Women's decisions are influenced by their role as their children's 'provider and protector' (see Chapter 7). Thus, these decisions include financial (*e.g.*, fear of loss of employment and hence income as a result of HIV stigma) and practical considerations, as well as their children's long-term physical and mental health, education prospects and the impact on other family relationships (including the children's father, who may be assumed to have brought HIV into the family). Furthermore, women consider the impact on their maternal identity as well as their particular circumstances, such as mothering at a distance or the fear or actuality of 'downfallment' (see Chapter 8). Decisions about whether and how to prepare children for disclosure are also on a spectrum, with some women not preparing children at all, while others undertake preparation activities for months or years before telling them, and still others prepare their children in a general sense for the possibility of anticipated disclosure many years in the future (see Chapter 9).

### ***11.2.2 Maternal disclosure of HIV to children may be beneficial or harmful or both***

Combining a feminist approach with IPA allowed me to challenge policy assumptions that disclosure is necessarily beneficial and to argue that there is no 'one size fits all' solution. The women's accounts clearly articulate that, with regard to disclosure, they have chosen the path they judged best for themselves, their families and their relationships, within the practical, financial and cultural circumstances of their lives. The women discuss and give examples of experiences (their own or those they have witnessed), highlighting the potential risks of disclosure as well as the potential benefits. They describe losing relationships, opportunities, income and social standing, experiences which clearly have a negative impact on the ability of poor families to survive; these

are not well recognised within existing policy. Additionally, women are well aware that families and disclosure are complex and that whilst beneficial for one individual or relationship, may be damaging to others. What is helpful to her children or other family members may not be helpful to the woman herself, or *vice versa*. Women consider the range of personalities, circumstances and relationships surrounding them and recognise that disclosure may be beneficial and harmful simultaneously. I have used emotion work and the concept of the ‘pinch’ to highlight examples, given by the women, of the challenges they faced, whatever their disclosure experience. I argued that challenges arise throughout the disclosure spectrum and that disclosure itself is neither inherently beneficial nor harmful but might depend on individual circumstance and context. I also argued that that medical professionals should be aware of (and disclosure policies should recognise) the complexities of women’s lived experiences so that women can be supported in their choices regarding maternal disclosure to their children.

Some women believed their children not ready to learn of their HIV status and thought they would shun or judge them, or be very distressed. Others felt unprepared to tell their children and deal with the possible emotional repercussions. As Yoo *et al.* (2010) found in their research on cancer disclosure, women who disclosed without reflection often received significant support and were less burdened by the demands of managing others’ emotions. However, this solution, whilst working well for some women, will not work for everyone. I think it is not a coincidence that most women who have freely chosen to tell family members have had positive experiences. Jamaican HIV professionals, well aware of the Jamaican context, tend to believe that Jamaican mothers do not disclose and thus focus their efforts on encouraging disclosure in situations where there is a clear public health risk (*i.e.*, encouraging patients to tell sexual partners and HIV positive children). I suggest this hints at a professional awareness that the WHO (2011) guidance does not provide enough evidence or detail to be useful in guiding professionals in how to work with disclosure issues in the Jamaican context, or in any particular low or middle income country.

### ***11.2.3 HIV + mothers prioritise protective motherhood and achieve this through emotion work***

My research revealed that, although mothers are concerned about issues related to maternal disclosure of HIV to their children, protective mothering is their priority. I define protective mothering as a focus on protecting the child (physically, emotionally, socially, educationally), on protecting the mother-child relationship and on protecting maternal identity in the eyes of the child. Mothers value their relationships with their children and gain strength and support from them regardless of their position on talking to them about their HIV.

My research found that the HIV positive Jamaican mothers I interviewed performed a complex range of emotion work activities to protect their children and their relationships. They used their role as mothers to forge an identity distinct from many of the negative characterisations of HIV positive women and to manage their own and their children's emotions. Although challenging for them, the women worked to present themselves not only as 'good' mothers, but also as 'good' people. They described various strategies used to present themselves as capable mothers within their community, to their children and to themselves. They worked to live up to an idealised concept of motherhood, which expects mothers to be strong, healthy, 'moral', and 'respectable', capable of safeguarding their children's physical, sexual and emotional health, and to visibly carry out mother-appropriate activities. Mothers with HIV, a stigmatised disease, must work harder to overcome practical issues (fatigue, illness, medication side effects, the need to access medical care) as well as the social challenges associated with hiding their condition as they work to be visible in their mothering activities. An HIV diagnosis may strengthen a mother's desire to present an image of herself as a good mother in order to challenge or pre-empt possible judgments.

The women I interviewed described numerous ways they challenged negative characterisations of themselves as HIV positive women, including assumptions of promiscuity or powerlessness. Motherhood is an important element of Caribbean women's identity and the ability to provide for and protect their children is a key element of motherhood. HIV impacts on central elements of maternal identity for many Jamaican/Caribbean women and is problematic because it disrupts support networks women depend on for practical support, childcare (as in the case of mothering at a distance) and emotional wellbeing. Bringing with it the possibility of infecting children perinatally ('downfallment'), HIV affects reproduction and risks judgement of mothering identity (which may be amplified if a child is also HIV positive). Accusations of promiscuity or immorality (including that implied by HIV awareness and sex education programmes in schools) affect mothers' social standing within the community. Beliefs about dirtiness and contamination associated with HIV threaten two key pillars of Jamaican motherhood: cooking food for the family and providing economically for the family (this is particularly true if women's jobs involve cooking/selling food or food products). As discussed in chapters 7–9, illness, medication side effects, fatigue, the logistics of accessing medical care and, often, the pressure of keeping their status secret make mothering and income generation additionally challenging. The ultimate fear associated with HIV—death—literally removes the ability of a woman to mother her children. The women worked to develop collaborative, trusting relationships with their children, to manage and protect these relationships, and to manage disclosure (or preparation for disclosure) conversations with their children. Women seeking access to support whilst simultaneously working to present themselves as capable (which implies no need for support) experience an ongoing tension. I argue

that, rather than being passive recipients of maternal attention, discipline and love, children are, in fact, active agents in supporting their mothers to manage their HIV both practically and emotionally. Furthermore, despite women's wide-ranging experiences along the disclosure spectrum, there is substantial emotional give and take and complexity within the mother-child relationship, as mothers work to manage their own and their children's responses.

#### ***11.2.4 The emotion work performed by HIV + mothers is complex and sophisticated***

I used the concept of emotion work (Hochschild, 1979, 1983) to help identify 'pinches' within the women's accounts, that is, the times where women struggled to align their own views, hopes or needs with the expectations of society. Writers (*e.g.*, Bernstein, 1971) observe that middle class parents are more likely to control feelings or intentions and to do so through appeals to feelings while working class parents are more likely to control behaviour and consequences and to do so through appeals to behaviour. Hochschild applies this concept to emotion work and the commercialisation of feeling:

*The class difference in socialization amounts to different degrees of training for the commoditization of feeling. This is yet another way the class structure reproduces itself. "(Hochschild, 1979:570-1)*

This is an interesting way of looking at how different people respond to particular situations. Assuming that the majority of my participants can be considered 'working-class', one would expect the mothers I interviewed to be more concerned with behaviour than feelings. Research from other LMICs reveals a clear focus from parents on the impact of disclosure on their child's behaviour, usually demonstrated through parental fears of a negative impact on school work. However, concerns about the mother-child relationship and comments about the emotional impact of disclosure are also mentioned. Whilst it may be true that those living in poverty do, by necessity, have a strong focus on practical aspects of daily life, it seems patronising and dismissive to assume that poorer or working class people are not concerned with feelings or intentions, or that their concern with emotions can only be on terms decided by professionals or people from the Global North. For example, according to disclosure policy, engaging in emotion work to prepare, disclose and have ongoing discussions with a child about maternal HIV, would be considered emotion work, but evading questions, calling their illness by another name (*e.g.*, diabetes), or hiding their symptoms to keep their HIV secret and protecting children from anxiety, distress or the possibly negative reactions of others, would not. I argue that this, too, is emotion work, and should not be discounted because it does not align with expectations and definitions created by professionals or the middle class. I challenge Hochschild's assertion that emotion work is more likely to be performed by middle and upper class women (Hochschild, 1983:20) and suggest that, in fact,

women of all social classes perform emotion work and are subject to feeling rules. In fact, those who are poor, black, gay, disabled, unemployed, living with a stigmatised disease or otherwise non-normative may feel more acutely the need to perform emotion work to safeguard or elevate their social standing.

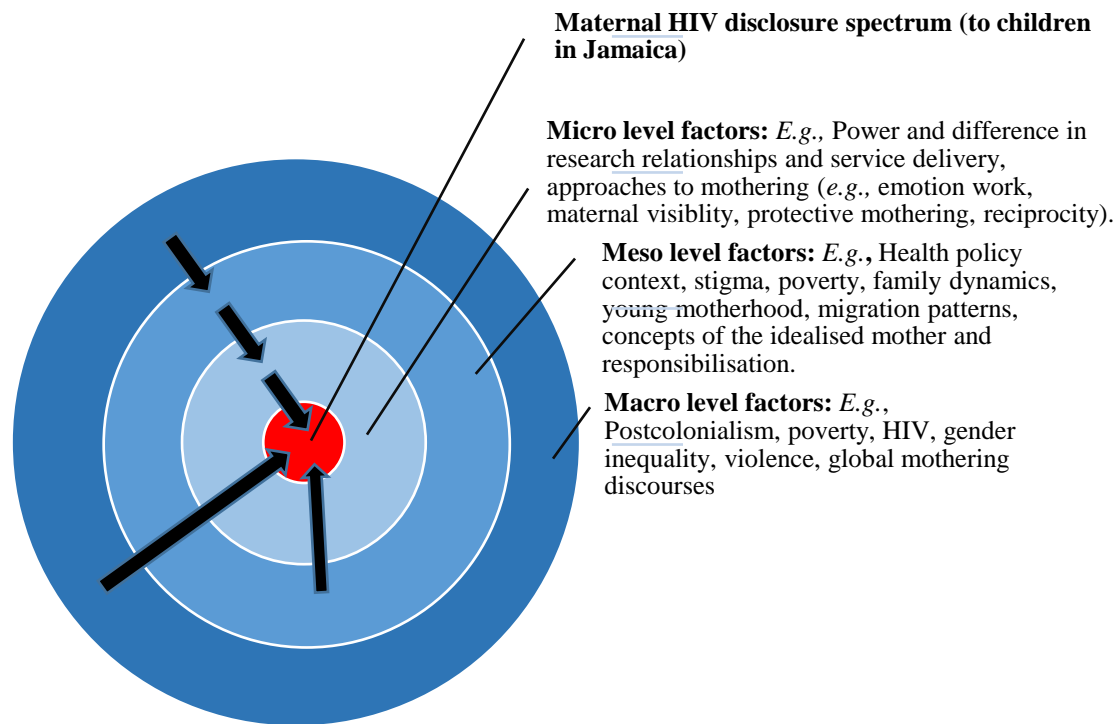
My research demonstrates that Jamaican HIV positive mothers consider a wide range of emotional issues alongside consideration of disclosure to their children, and these emotional factors are given more importance than their disclosure decisions. Women undertake considerable emotion work to develop and protect their maternal identity, to live up to cultural expectations of the mother as protector and provider, to present themselves as responsible mothers and to develop close collaborative relationships with their children. The experience of having HIV, a stigmatised disease, with connotations of immorality and the unfit mother (Alldred, 1996), provides women both with additional challenges and additional impetus to work to protect this identity. Although the focus of women's accounts was on their emotion work, this is not to disregard the backdrop of practical challenges they encounter daily, such as poverty, violence, medication side effects, unemployment, the results of local weather conditions such as annual hurricanes, and endemic diseases such as dengue fever.

### **11.3 Synthesising the findings: A micro-meso-macro framework**

IPA has been criticised for its idiographic approach; I therefore used a feminist approach to IPA to bring into relief the structural and contextual factors that shape women's choices, which I argue are severely constrained by issues such as violence and poverty. I have developed a framework (see Figure 1, below) to synthesise my research findings in relation to women's decisions to disclose, in order to recognise broader social and cultural factors as well as the more individual factors highlighted by the women's interviews. It is also helpful in moving away from the idiographic focus of IPA and recognising that the individual experiences explored here are impacted by wider structural forces. The framework that follows is adapted from Bradley *et al.* (2016), and I have then applied this concept to maternal disclosure of HIV to children in Jamaica. *Macro* can be defined as issues related to nations, governments, health, economics, politics, and structural inequalities. In the case of my research, I use macro to refer to concepts such as postcolonialism, HIV, gender inequality and violence. *Meso* can be defined as issues on a community or neighbourhood level. The factors I refer to which can be categorised as meso, include the health policy context which encourages disclosure, stigma, poverty, and family dynamics (including female-headed households, the prevalence of young motherhood and migration patterns) as well as concepts of idealised motherhood and responsabilisation. Much of this thesis is focused on *micro* factors, which can be defined as individual factors, including those related to research methods and

service delivery, such as power and difference as well as approaches to mothering (*e.g.*, emotion work, mother-child relationships, protective mothering). These factors can be seen in Figure 1, below:

**Figure 1: Macro, Meso and Micro factors associated with maternal disclosure of HIV to children in the Jamaican context**



I propose that these three layers are interconnected and influence one another in complex ways, as well as influencing women's positions regarding HIV disclosure to their children. The findings chapters (Chapters 7–9) provided a detailed exploration of the women's disclosure experiences, illuminating the emotion work undertaken to protect their children and their relationship with them in the context of the contextual factors highlighted in Chapter 3, such as HIV, poverty, violence, young motherhood and migration. The use of feminist IPA as a methodology supports this dual focus on idiographic narratives and their links to the wider contextual factors that impact on individual experience. In this way, my research provides a detailed insight into the experiences of maternal disclosure of HIV to children of women in Kingston, Jamaica, adding to the small existing body of maternal disclosure work in resource constrained settings (see Chapter 2, Section 2.4). My research also speaks to the wider issues impacting on the lives of women in Jamaica, providing the information sought by, for example, Kennedy and colleagues' (2015) review article of HIV disclosure interventions in LMICs, which called for additional research concerning current approaches in resource constrained settings. My research moves beyond existing work by

providing conceptual resources (such as emotion work, maternal visibility and responsabilisation), applied to maternal disclosure experiences, to support a more robust understanding of individual experience as well as situating these experiences within a broader historical, social and economic context.

Disclosure is presented in the literature as a disclosure/non-disclosure binary, as relatively straightforward to achieve, and does not consider the impact of the macro and meso level factors affecting women's lived experiences. Furthermore, there is limited recognition of the sophisticated emotion work women undertake to manage their own and their children's emotions in the context of HIV and other factors. My research provided detail and nuance concerning the women's experiences in order to counter the simplistic and contradictory rhetoric of global policy promoting maternal disclosure and local belief that Jamaican women do not disclose. I have revealed a spectrum of experiences and found that women prioritise relationships and their children's wellbeing over advice to disclose; their decisions balance competing demands on their time and energy and the potential physical, emotional and social risks associated with disclosing. Family dynamics in Jamaica are complex, women's relationships with their children vary according to the child and other factors and are often more reciprocal than is assumed. Thus, the Anglo-Northern idealised nuclear family model is inadequate and inappropriate to the Jamaican context, as well as to many other resource constrained contexts. Women struggled to manage the idealised image of the strong Caribbean mother who protects and provides for her children, alongside the negative stereotypes associated with HIV, poverty, mothers who live apart from their children, and mothers whose babies acquire HIV perinatally. Despite numerous challenges, women demonstrated their power and agency to make decisions they considered to be in their family's best interest.

Women, and to a lesser extent, professionals, are caught between policy based on Anglo-Northern approaches and research conducted in, or extrapolated from, high income countries, and the reality of their lives as low-income mothers with HIV in a middle income country with a very different social and cultural context. Policy promoting disclosure does not consider issues affecting Jamaican mother's lives such as complex family dynamics, poverty, internal migration, stigma and discrimination or cultural attitudes towards motherhood and childhood. However, many Jamaican professionals have a good understanding of these factors and recognise (and sometimes expect) that Jamaican mothers may choose not to disclose their HIV status to their children. HIV positive mothers in Jamaica are thus positioned between pro-disclosure policy and the non-disclosure expectations of many health professionals, whilst simultaneously working to do what they feel is best for their family. Through their narratives, the women showed strong awareness of the meso-level factors which affected their lives, including the impact of stigma, poverty, family dynamics,



young motherhood, migration patterns, concepts of the idealised mother and responsabilisation. Their stories illustrated how they used emotion work, maternal visibility and protective mothering to navigate evolving relationships with their children whilst living with HIV and simultaneously navigating the daily practical and emotional challenges of motherhood and poverty in the Jamaican context.

#### **11.4 Contributions to knowledge and implications for policy and practice**

My contributions to knowledge are threefold. Firstly, my research explores the maternal disclosure experiences of HIV positive women in Kingston, Jamaica. Articles on maternal disclosure in resource constrained settings have increased in recent years, but my research is the first Jamaican study of maternal disclosure, adding to the one existing Caribbean study, in Haiti (Conserve *et al.*, 2014). My research augments our understanding of emotion work in relation to women talking to children about HIV and sexual health issues. I included contextual information in Chapter 3 and throughout the findings chapters to situate my work, my detailed reflections and my methodological considerations so as to address the issues of working as an outsider in a resource constrained setting.

Secondly, my research adds to an emerging body of literature combining a feminist approach with IPA (*e.g.*, Leve, Rubin and Pusic, 2011; Kastrani, Deliyanni-Kouimtzi and Athanasiades, 2015) and is one of a limited number of IPA studies addressing issues relevant to the Global South (*e.g.*, Lorasdagi, (2009) writing about the experiences of students of Turkish origin wearing headscarves in The Netherlands and Spiers *et al.* (2016), writing about Black Africans' experience of HIV in the UK). I challenged simplistic, patronising assumptions about what women 'should' do and exposed the complex, sophisticated strategies mothers develop and use to manage the emotions surrounding mothering with HIV and disclosing maternal HIV to children.

Finally, my research applies Hochschild's concept of emotion work (1979, 1983) as a tool to deepen our understanding of the disclosure experiences of HIV positive mothers. My approach provides an alternative lens with which to explore the reasons given by mothers for their "choices". I conclude that women's views and behaviours are strongly influenced by and interconnected with the emotion work they do to manage and protect their children, their maternal identity and their relationship with their children. Prior research, finding that parents give reasons such as fear of children telling others, the perception that children are too young or will not understand, fear of worrying or distressing children, or not knowing how to tell their children, can be re-examined using the lens of emotion work (Hochschild, 1979; Hochschild, 1983). This lens makes it clear that many of these fears are instead connected to mothers' perceptions of their close relationships with

their children and their desire to protect and strengthen these relationships. Reasons such as not knowing how to tell their children, have led researchers and professionals to propose professional support to ‘teach’ women how to disclose. I suggest that women do not need to be ‘taught’ how to talk to their children or manage relationships within their family; they are already doing this to the best of their ability within the structural and cultural constraints of the society in which they live.

## **11.5 Recommendations**

### ***11.5.1 Maternal disclosure of HIV to children is a spectrum (not a binary)***

A useful first step might be to increase awareness amongst professionals and researchers concerning the complexity of disclosure, the range of disclosure experiences amongst people living with HIV in Jamaica and the factors which influence women’s disclosure choices. The provision of optional professional support might be considered, providing a safe place to explore feelings and recognising that participants may choose never to tell anyone. Despite the supposed taboo on mental health issues in Jamaica, women were very ready to talk to me and also to the student counsellor, so there may be scope for more work in this area, particularly on an individual basis, bearing in mind the desire to keep HIV status private. Women recognised their need to feel confident and comfortable in themselves before being able to address the potential distress expressed by their children upon learning of their mother’s HIV status. To protect the mother-child relationship, it is important that the information comes from the mother herself, whenever possible.

### ***11.5.2 Maternal disclosure of HIV to children poses risks as well as benefits***

Guidance recommending that women tell their children about maternal HIV may fail to recognise the risks in resource constrained countries and therefore could be harmful, and may undermine the professional-patient relationship. Women have shown that despite medical pressure they are prepared to go to great lengths to convince their children they are HIV negative if they do not feel ready to tell them. For example, several women denied their HIV directly when asked by their children and Cupcake ensured that her children believed she had received a negative HIV test result. Throughout the interviews, women demonstrated their agency: to me within the interview and in describing their experiences with medical professionals, friends and family members. I believe that many professionals are already aware of the potential risks to mothers of disclosure and that, despite policy guidelines, disclosure may not always be in their best interests. Women should be supported to fully, partially or not disclose, depending on their particular circumstances and views.

### **11.5.3    *Focus on relationships not disclosure***

My research suggests that guidance such as the WHO 2011 guidelines on disclosure to children, designed to support professionals working with HIV affected families, would benefit from considering factors that women identified as important (*i.e.*, recognising and respecting local concepts of maternal identity and supporting relationship building within the family rather than directly promoting disclosure). Professional understanding and recognition of these issues would be helpful in allowing professionals to support mothers in medically managing their HIV through attention to the issues and challenges important to the women themselves. This subverts common assumptions in professional discourse such as: no one adheres properly to their medication, no one admits when they don't adhere to their medication, and Jamaican women don't disclose to their children. Furthermore, this approach would offer an alternative to programmes which address adherence issues by, for example, testing patients' blood, or promoting disclosure through strong professional 'encouragement' to disclose, thus undermining patient trust in medical professionals. Although this approach is motivated by a desire to support the patient and to achieve positive medical outcomes, in cases where policy and reality do not easily align, professionals are caught in the middle. Recognition of the complexities of women's lives and the tensions involved in talking to children about HIV would respect the reality of women's lives and decisions, strengthen family relationships as well as patient/professional relationships, and ultimately improve patient health. This, of course, is not straightforward, and these issues are interlinked with wider structural issues including gender, violence, migration, and poverty. However, medical professionals' awareness of the importance of relationships to women in supporting their health and the possibility of combining medical care with psychosocial care within clinics will support women's long term health. Interestingly, this focus on psychosocial care was the cornerstone of many early HIV clinics and support services in the 80s and 90s when people were dying of AIDS and little medical treatment was available. As the medical options have increased, the focus on wider psychosocial issues has decreased.

### **11.5.4    *Professionals and researchers need to be aware of their own assumptions and preconceptions and to practice reflexivity.***

Many HIV health professionals in Jamaica experience a contradiction between policy which advises parental disclosure of HIV to children (despite limited or non-existent evidence of the benefits of disclosure in LMICs (WHO, 2011)) and their local knowledge of women's lived experiences. Professionals are often aware of the impact of issues such as poverty, violence, internal migration, family formation and the potential risks of disclosure, which may include loss of work, loss of income, loss of mothering status, loss of practical or emotional support, as well as isolation or violence. My research represents a step towards developing culturally appropriate

policy for Jamaica, as suggested by, for example, Obermeyer, Baijal and Pegurri (2011), Qiao, Li and Stanton (2011) and Rochat *et al.* (2011). This policy would reflect the reality of women's lives and issues which women identify as important (*i.e.*, positive maternal identity, protecting relationships) and would recognise the spectrum of views and experiences. Medical care would be more effectively integrated with social care, mental health services, adherence support and, with patient permission, professionals would be more able to share relevant information. These policies can be supported by carefully designed research which does not impose research agendas on participants and where participants are more likely to feel free to share views and experiences which do not conform to medical recommendations. For example, Giles *et al.* (2009, discussed in Sections 2.4 and 4.8.1) described the 'unique case' of one HIV positive Australian mother within a larger sample, who refused PMtCT interventions for her baby. Far from being an anomaly, a unique viewpoint or an inconvenient divergence from the majority of the data, I suggest that researchers should seek to access, encourage, recognise and include such diversity of experience and highlight the power inequalities which silence experiences that are not obedient, acceptable or convenient according to dominant discourse.

My reflective account of Sandra's interview (Chapter 10), demonstrated how, despite my attempts to be open and non-judgmental, Sandra, over the course of the interview, formed an opinion of what she thought I wanted to hear and altered her answers accordingly. This interview provides an insight into power dynamics at play in an interview situation. As my first interview, it reminded me of the need to be aware of the external factors influencing interactions such as these. I was able to guard against this in subsequent interviews, by, for example, leading into the question of disclosure more slowly and by increasing my tolerance for silence. I think this is crucial to researching sensitive topics to avoid situations such as that presented by the Haitian study (Conserve *et al.*, 2014) which found unanticipated self-reporting of maternal disclosure of HIV to children by a number of research participants partway through the research process. This is reported as a positive research outcome, although in my view this should be treated with extreme caution. Whether these women did in fact disclose to their children or, thinking this was what the researchers wanted to hear, merely reported that they did, there are serious concerns about this situation as an indication of unequal power dynamics (and possibly a lack of recognition of this) and its impact not only on the research, but on the lives of participants. It is well established that disclosure can carry significant risks, particularly for the disadvantaged, and there was no mention within this study of an understanding of this or steps that were taken to mitigate potential harmful consequences to participants.

## 11.6 Areas of future work

In this research I focused on maternal disclosure from the viewpoint of HIV positive mothers. It would be interesting to carry out research exploring the views of HIV professionals in Jamaica. I have not considered the impact of disclosure on children, which is likely to be significant, particularly where disclosure is a sudden rather than a gradual process. There are anecdotal examples of children in Jamaica being referred to counselling following disclosure of maternal HIV. As noted in Chapter 6, it would be interesting to further examine the relationship between women and their non-biological children, as this is a common feature of Jamaican family structure. My research highlighted the importance of relationships to HIV positive mothers: further research might explore the relationship between HIV positive women and their own mothers (a number of the women I interviewed identified their own mothers as the first person they told and as a key source of support). My research finds that women do talk to their children about protecting their sexual health. This is supported by research in South Africa (Madiba and Matlala, 2012) but contradicts earlier work in Botswana (Nam *et al.*, 2009). More work is needed to investigate different parental and cultural views of childhood and sexual health education in resource constrained settings; for example, the role of relationships with partners, family members and friends could be further explored. It would be illuminating to find out more about the role and experiences of fathers and men regarding HIV disclosure in the family. My research could be extended to explore the potential links between relationships and adherence. My focus was on the experiences of HIV positive women in Kingston, Jamaica; women in more rural areas and women in other Caribbean countries could be interviewed given that, to date, the only published research on maternal disclosure in the Caribbean comes from Haiti (Conserve *et al.*, 2014).

The provision of ARVs has made an enormous difference to the quality and duration of life for HIV positive patients. However, the medical profession is increasingly aware of gaps which are now emerging: patients who do not disclose their HIV to their partners or to their family members, patients who refuse to be tested for HIV or to access ARVs and, after a positive HIV test, patients who do not fully adhere to their medication regime. A range of global, national and local policies exist to address issues acting as barriers to treatment, such as stigma and poverty; these are long term, multidisciplinary goals. These challenges were mentioned by the women I interviewed and are ongoing challenges for them. However, the issue they repeatedly referred to and which ran through all the women's accounts, regardless of any other factor, was the importance to them of their relationships with their children and the work they do to protect their children's physical, sexual and mental health, their educational and career prospects, and their social standing.

Rather than focus on disclosure, my recommendation is to focus instead on the issue which the women in my study identified as crucial to them: relationships. In my research, this is relationships with children, but this could be extended to other supportive relationships patients identify.

Working to strengthen and develop close supportive relationships will, in many cases, enable and support adherence, access and disclosure, which will then improve physical and mental health outcomes for HIV positive women. For the women I interviewed, these relationships are key and closely interlinked with their own mental and physical health (in that their children motivated them to care for themselves). Attention to mother-child relationships is critical to supporting adherence, self-care and disclosure which, in turn, supports increased physical and mental health for these women, and their children.

## APPENDICES

### Appendix I: Searching the literature:

The databases consulted were: Academic Search Complete, CINAHL, EBSCOhostEJS, Gender Studies Database, Health Policy Reference Centre, MEDLINE (includes the West Indian Medical Journal), PsycARTICLES, PsycINFO, SocINDEX, AMED, Global Health, Embase, Social Policy and Practice, and Maternity and Infant Care.

Keywords and combinations of keywords included: Maternal disclosure; maternal disclosure to children; parental disclosure; parental disclosure to children; disclosure; disclosure and children; disclosure and HIV; disclosure and AIDS; disclosure and women; disclosure and mothers; mothers and HIV; children and HIV; parents and HIV; parental disclosure; parents' disclosure to children; women and HIV; HIV disclosure women; Female disclosure; Female HIV, stigma; women, HIV, stigma; mothers, HIV; mothering and HIV; mothering and disclosure, motherhood and HIV; motherhood and disclosure; motherhood, HIV and stigma; motherhood, HIV and discrimination. All articles without a specific focus on issues related to maternal disclosure of their HIV positive serostatus to their (usually negative) children were excluded (for example, articles with a focus on homelessness or intravenous drug use). A search was also conducted by author name (identified through existing work on disclosure) to see what else they may have written, and these articles were included where relevant. Additionally, the bibliographies of existing articles, especially literature review articles, were examined. Keywords can vary in different articles, so I examined articles already obtained in order to identify potential search terms. This helped to ensure that all relevant articles were included, as well as to identify articles which deal with disclosure, but do not have the word 'disclosure' in the title, such as 'Mothers who silence themselves: a concept with clinical implications for mothers living with HIV and their children' (DeMarco, Lynch and Board, 2002).

## Appendix II: Published Article (2013)

*The West Indian Medical Journal*, 62(4), pp. 357–363. doi: 10.7727/wimj.2013.087.

### **What are the benefits and barriers of communicating parental HIV status to seronegative children and the implications for Jamaica?**

#### **A narrative review of the literature in low/middle income countries.**

G Clifford, G Barrow, G M Craig, C McCourt

**Short title:** Communicating parental HIV to children

**Keywords:** HIV/AIDS, parental disclosure, Jamaica

**Synopsis:** This article reviews the literature in low/middle income countries on parental disclosure of HIV status to seronegative children and examines the benefits and barriers to disclosure from the perspective of parents with HIV. Implications for future research in Jamaica are discussed.

#### **Abstract**

##### **Objective**

To examine the benefits/barriers for HIV positive parents of communicating their status to seronegative children in low/middle income countries in order to inform policy and practice in Jamaica.

##### **Methods**

The authors carried out a systematic search of published literature on parental disclosure in low/middle income countries written in the English language between January 1991 and September 2012, identified from databases: Academic Search Complete, CINAHL, EbscohostEJS, Gender Studies Database, Health Policy Reference Centre, Medline (includes the *West Indian Medical Journal*), PsycARTICLES, PsycINFO, SocINDEX, AMED, Global Health, Embase, Social Policy and Practice, Maternity and Infant Care.

The authors also refer to articles on parental disclosure in high-income countries which appeared in peer-reviewed journals and conducted a local search in Jamaica for articles on HIV disclosure in the Caribbean region.

##### **Results**

Global estimates of parental disclosure rates were 20%–97% in high income countries and 11%–44% in resource constrained countries. Mean age of children at disclosure was age 10–18. Mothers were more likely to disclose to older children, female children, and when they had strong support networks. Barriers included fear of stigma/discrimination, not knowing how to tell the child, fear of the child disclosing to others and believing a child was too young to cope. Of the 16 articles identified which met the search criteria, 10 studies and 3 reviews noted positive benefits of disclosure on parental health and the parent-child relationship.

##### **Conclusion**

Significant differences in attitudes and rates of maternal disclosure in low/middle income countries compared to high income countries reflect the impact of cultural, structural, economic and social factors and highlight the need for culturally-specific research. Implications for policy and practice in Jamaica are discussed.



## **Introduction: Disclosure to seronegative children**

Since 1994, strong clinical evidence has prompted the use of highly active antiretroviral therapy (HAART) for the prevention of mother to child transmission (MTCT) (1), resulting in the majority of children being born seronegative to mothers with HIV. In Jamaica, MTCT rates are currently 4.6%, down from 10% in 2005 (2). Although there is considerable research on parental disclosure to seronegative children in high income countries (3–13), little is known about the benefits and challenges for families and communities in resource constrained settings, including Jamaica.

Global estimates of disclosure rates show a contrast between parental disclosure in high income countries (20%–97%) and resource constrained countries (11%–44%) (14); the higher disclosure rates are generally found by studies which include some children known to be HIV positive. Research in high income countries has shown significant mental health benefits for parents, especially mothers, in disclosing to their children (*e.g.*, lower anxiety and depression, higher perceived social support and family cohesion) (7). Several studies identify additional benefits of disclosure including social benefits (*e.g.*, networking), physical benefits (*e.g.*, assistance with housework/caring responsibilities), or emotional benefits (*e.g.*, reduced anxiety) (12,15,16). In resource constrained countries, specific socioeconomic factors, including high levels of ‘felt’ and ‘enacted’ stigma (32) in relation to HIV and the comparatively low levels of professional psychosocial support may help to explain the relatively low levels of parental disclosure to children (14, 17–31).

This narrative review seeks to examine the benefits/barriers for HIV positive parents of communicating their status to seronegative children in low/middle income countries in order to inform policy and practice in Jamaica.

## **Methods**

The authors carried out a systematic search (see Figure 1) of published literature on parental disclosure in low/middle income countries written in the English language between January 1991 and September 2012, identified from databases: Academic Search Complete, CINAHL, EbscohostEJS, Gender Studies Database, Health Policy Reference Centre, Medline (includes the West Indian Medical Journal), PsycARTICLES, PsycINFO, SocINDEX, AMED, Global Health, Embase, Social Policy and Practice, Maternity and Infant Care.

A local search of the University of the West Indies library database yielded no published articles on parental disclosure in the Caribbean. However, 11 Caribbean studies referring to HIV disclosure to partner, family or healthcare professionals were found.

Sixteen of the one hundred and sixty-six studies found met the inclusion criteria: eight from middle income countries, one from a low income country, three looked at African immigrants in Europe, three were global reviews and one was WHO guidance. Methodologies comprised one systematic review, two literature reviews, ten qualitative studies and three cross-sectional surveys. Four papers focussed on mothers, ten on parents and two on caregivers.

To provide a global comparison, the authors also refer to articles on parental disclosure in high income studies (mainly the USA) which appeared in peer-reviewed journals.

In order to examine the experiences and views of parents concerning disclosure of their status to their seronegative children, the authors highlighted and grouped themes identified by the

literature. Three overarching themes emerged: benefits of disclosure (as perceived by parents), barriers to disclosure (as perceived by parents) and the broader implications of particular studies which could be applied to other populations. The benefits and challenges of disclosure for children will not be addressed in this article.

## **Results**

### *Perceived benefits in low/middle income countries*

Studies identified a number of benefits parents attributed to the disclosure of their status to their seronegative children (see Figure 2). In terms of physical health, parents stated that they received practical help from children (*e.g.*, taking on household responsibilities, collecting medication, caring for parents when ill) (19,26,27,28); that they found it easier to take their medication and attend medical appointments (21) and that they had increased energy as they were no longer guarding the secret (18).

Parents also recognised mental health benefits of disclosure. These included direct benefits to the parents, such as: being able to grieve and work through feelings of anger/guilt (19); receiving emotional support from children (18); freedom from worry that the child will guess or find out from someone else (18,19,22,26); reduced stress as parents are able to be open about their status/health issues within the family (and thereby potentially access other support) (28,29,31). Parents also identified indirect mental health benefits as a result of the peace of mind that they obtained from preparing children for adverse events (such as discrimination or parental illness/death) (18,26); and providing children with information to protect themselves from infection through caring for an ill parent, drug use or unprotected sex (19).

Additionally, some parents talked of disclosure prompting a strengthening of the parent- child relationship, particularly when the parent (rather than someone else) tells the child (18,21,30).

### *Perceived barriers in low/middle income countries*

Fear featured prominently as a barrier to disclosure (see Figure 3). Parents were fearful of the potential negative effect of disclosure on the child, especially that the child might feel depressed, anxious, fearful, angry or ashamed; that the child might have social problems at school, their grades might suffer; and that their behaviour might change leading to conflict and disruption at home (18,22,24,27,28,29). Parents feared that disclosure would damage the parent-child relationship and lead to rejection by the child or a loss of respect for the parent (18,26,27).

Parents, especially those in resource constrained settings, may feel unprepared and unsupported in disclosing in an age appropriate way to their child and managing children's reactions over time (14, 25). This may contrast with high income countries which tend to be better resourced in terms of providing emotional and psychological support through counsellors, social workers, and schools. For example, a 1997 study in Scotland found that 72% of HIV-affected families received support from voluntary or statutory agencies (33). Studies of immigrants from low income countries currently residing in high income countries, have found that positive relationships with health care professionals can support PLHIV with disclosure issues (17), suggesting that this model of care could also be effective in resource constrained settings.

Parents feared the reaction of others, specifically that the child or family would experience stigma, discrimination, ostracism, or isolation, and that the child would be excluded from school or by other children (21, 22, 26–31). Implicit in this fear was the assumption that the child would tell others (19, 24, 26, 27, 30). This fear may be of particular importance in resource

constrained settings where families are more likely to rely on family and community networks for practical, material and financial support (23) which may be jeopardised by a negative reaction to HIV disclosure and cause individuals to be less likely to be open about their status.

Other barriers included: a desire to protect the child from distress (22,28), avoid the loss of a carefree childhood (21); a lack of perceived benefits of disclosure to the child (26); a perception that the child was unaware of illness (30), waiting for the child to ask questions (18); uncertainty about what exactly and how much to tell children of different ages, and a feeling that the child was too young/immature (19,27,29,31). However, children can be perceptive, noticing details, overhearing conversations, and constructing their own understanding of events (19). Many children will have been aware of periods of illness experienced by their parents and, if not given implicit or explicit permission by their parents to talk about their illness, may feel unable to raise the topic (18). Despite this, many children will have some knowledge of their parents' illness. In a 2001 American study, 92% of mothers stated that their children knew they were taking medications and of these, 39% believed their children to be anxious about this (7). However, few studies in resource constrained settings acknowledge the potential anxiety and confusion that silence and uncertainty could place on the child, although this is evidenced in the literature from high income countries (34, 35).

Parents also reported uncertainty about the best way of communicating their status, including: uncertainty about how or when to disclose (18,22); a feeling that they lacked skills or guidance (19,26); the need for help from health care providers (27); a belief there was a lack of counselling and support services (27); finding it difficult to talk about sex or death with children (19,21,24,28); and not having enough knowledge about HIV to be able to explain and answer children's questions (30). Some parents felt they had already told their child indirectly (*e.g.*, by sending the child to collect medication or taking the child to HIV-related appointments) (19).

Additionally, a number of studies have identified the emotional needs of parents themselves as they come to terms with their diagnosis as a barrier to disclosure to their children. Some parents are unable to see beyond emotional pain of disclosure (26), fear regret or repercussions (18,24), have difficulty confronting their own mortality (18,28) or are still coming to terms with their own feelings (18).

### **Conclusion: Implications for Jamaica**

Several studies (19, 20, 21, 23, 24) identified that, in resource constrained countries, both the benefits and the risks of disclosure may be heightened. In high-income settings, where families' material needs are more likely to be met, the benefits of disclosure tend to be access to psychological support and relief from keeping a secret; in resource constrained settings, emotional and psychological benefits are often secondary to the potential for increased practical, material and financial support. Obermeyer's (23) review article examined 231 disclosure articles, including 76 from low/middle income countries and reported that both the potential benefits and risks of disclosure were higher in low resource settings where there were limited support services and where

PLHIV look to families and communities for practical, material and financial help, as well as emotional support. The high levels of stigma and discrimination and the additional financial and social challenges, such as the possibility of isolation and ostracism, may discourage families from providing support to PLHIV (23). Disclosure has been found to be higher when people expect to receive help and lower when they expect blame and discrimination, and in many resource constrained countries there is an arguably higher level of stigma and discrimination (or of fear of stigma and discrimination) which may act as a disincentive to disclose (23, 36).

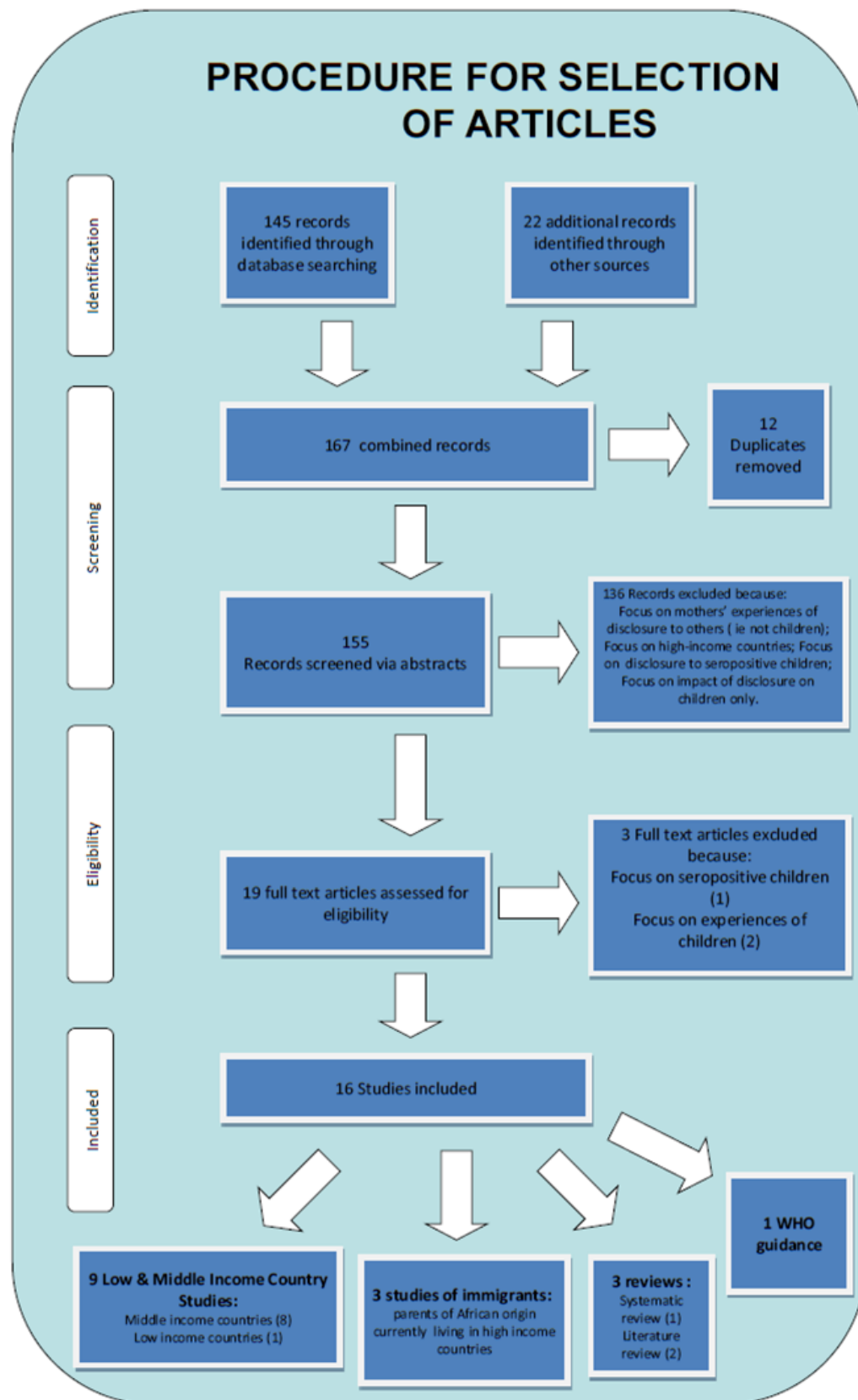
The enormous stigma attached to HIV in Jamaica has an impact on the health-seeking behaviours of HIV patients, delaying entry into treatment, care and support (37). In addition, up to 20% of women and 5% of HIV exposed infants do not receive treatment through the current MTCT prevention programme, due to late presentation to antenatal care, failure to disclose HIV status when presenting to care (36) or by avoiding the healthcare system entirely. It is not uncommon for HIV infected mothers to refuse replacement formula feeds, fearing that failing to breastfeed may be seen as evidence of their HIV status (36).

The issues identified by existing studies of disclosure in low/middle income countries with potential implications for Jamaica fall into two broad categories: the need for professional support and the need for social support. Studies have identified a need for enhanced intervention programmes which are culturally sensitive and adaptable to local contexts (18,27), addressing parenting, family support and social networking (20). Programmes would include practical guidance on age-appropriate disclosure to children (14,25), managing parental fears and children's responses (21), planning for the future (21), using tools such as story books and memory books (26), and balancing advantages and disadvantages in specific family contexts (22).

Parental disclosure is an important issue because of the far-reaching impact it can have on the health and well-being of families as well as the broader implications for public health and community cohesion. There is a lack of research into maternal disclosure in the Caribbean, where specific cultural and economic factors affect the choices that parents make. The importance of particular psychosocial factors (including family involvement and communication, planning for the future, providing peer support, and reducing stigma and discrimination) in supporting families affected by HIV across the world, are well documented (19,21,22,23,24,28,29,30). Jamaica has a strong track record of reducing MTCT (2) and providing effective medical treatment to PLHIV (37). The gaps in providing psychosocial support to families (including supporting parental disclosure to seronegative children) could be addressed by adapting successful global programmes to the Jamaican context.

## Diagrams and Tables

Figure 1



Source: Moher *et al.*, The PRISMA Group 2009 (38)

**Figure 2**

**Comments from parents on the benefits of disclosing their status to their children**

*“I wanted them to get it from me directly...it makes me feel good that I told them instead of knowing it from someone else.”*

38 year old mother of five children aged 8 to 24, Uganda (26).

*“I love it when my kids remind me of the medication...she will just run to the bedroom and give me a glass of water.”*

38 year old single mother two children aged 14 and 16, Botswana (21).

*“I’ve told my kids. Because they had to take care of me—they have to be aware, when I was very sick and I didn’t want to put them at risk.”*

38 year old single mother of two children aged 12 and 16, Botswana (21).

*“We are closer and more concerned about each other.”*

Thai mother comments on her relationship with her daughter after disclosure (18).

**Figure 3**

**Comments from parents on the barriers to disclosing their status to their children**

*“How can I? Where do I begin? The old one or the young one? What if they ask how I got it?”*

43 year old father of thirteen children aged 4 to 23, Uganda (26).

*“There are children of different natures, some withdrawn and quiet. It is better not to tell them.” “Some children are aggressive. It is better a counsellor deals with disclosure issues.”* Mothers, Southern India (27).

*“I feel so sad about it and I know they would be sadder, cry and do all those heart-breaking things that I am not ready for.”*

39 year old mother of six children aged 9 to 22, Uganda (26).

*“If we tell him [the child], he may tell other kids in our village. He knows nothing about the seriousness of it. Sometimes gossip is very unpleasant and offensive.”*

Mother, China (30).

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## Appendix III: Tables of participants and key findings of parental HIV disclosure studies in LMICs in the Caribbean and Africa.

**Table 1: Description of participants, disclosure rates and key findings of parental HIV disclosure studies in LMICs in the Caribbean and Africa.**

Authors	Title	Participants	Participants' children Number Age HIV status	Rate of disclosure as reported As a percentage	Main findings
<b>CARIBBEAN LOW INCOME</b>					
Conserve <i>et al.</i> Haiti 2014	Disclosure and Impact of Maternal HIV+ Serostatus on Mothers and Children in Rural Haiti	Mothers (25) and children (26)	26 ages 10–17  HIV - and HIV +	Brief disclosure ( 16/25) <b>64%</b> Explicit disclosure (9/25) <b>36%</b>	Reasons for disclosure: HIV-related stigma in the community, encouragement from health care workers in this intervention, need for social support. Researchers suggest need for support and education programmes for children of MLWHs in Haiti, for children at risk of acquiring HIV, and children who have lost a parent/s HIV/AIDS; also need for programmes to combat the stigma of HIV. Children felt sad, worried, wanted to care for parents. Disclosure provides opportunities for reassurance which non-disclosure does not. Suggests post-test counselling sessions as opportunities to discuss approaches to disclosure methods that parents can use with their children. Need for interventions in the Caribbean to improve communication and socio-economic support.
<b>AFRICA MIDDLE INCOME</b>					
Geiselhart, <i>et al.</i> Botswana 2008	Children, Adolescents and the HIV and AIDS Pandemic: Changing Inter-Generational Relationships and Intra-Family Communication Patterns in Botswana	Mothers (36), fathers (14), young people (10), households (11) and professionals (16)	Not stated Not stated, but article assumes age 6/7 suitable for disclosure. HIV +, HIV- & unknown	20/50 told their children <b>40%</b>	Evidence that comprehensive, open, inter-generational communication about issues of HIV children would benefit children. Suggests more research into impact of secrecy/openness on children in order to improve communication strategies for different age groups to help with prevention and treatment.
Nam <i>et al.</i> Botswana 2009	Discussing matters of sexual health with children: what issues relating to disclosure of parental HIV status reveal	Mothers (12) and fathers (9)	24 children ages 5–18 HIV - and HIV +	4/21 had disclosed (2M, 2F) <b>19%</b>	HIV-positive parents on ART found it difficult to discuss their HIV status or sexual health in general with their children. More likely to disclose to older (median age 14 years), rather than younger (median age 11 years) children or if health worsened. Reasons not to disclose: wanting children to have a carefree childhood, children being too young, not wanting to worry older children and not wanting children to be hurt by the reaction of others. Suggests that secrecy and family instability may be more disruptive than the distress parents fear may be caused by disclosure. Finds that cultural norms (respect for elders, sexual matters inappropriate for children) act as a barrier. Focus on intergenerational communication ( <i>e.g.</i> , grandparents and grandchildren) and developing lifeskills and resiliency in children, including info on how to protect themselves from HIV.

					Providers of support need to be aware of Botswanan context ( <i>e.g.</i> , changing family roles, typical intergenerational modes of communication, prevalence of orphans).
Palin <i>et al.</i> South Africa 2009	Disclosure of Maternal HIV Infection in South Africa: Description and Relationship to Child Functioning	mothers (103) (primary caregiver not necessarily the biological mother)	Not stated, 103 mothers aged 29–49, who are the primary caregiver aged 11–16 Women with more than one child reported on the oldest child in the age range. Not stated	<b>44%</b> of mothers had disclosed	First quantitative S African study on the relationship between disclosure and child functioning in a sample of South African mothers and their adolescents. Similarities and differences with previous US research. South African mothers have numerous concerns about the impact of disclosure on their child's welfare. Family process variables are more important than maternal disclosure decisions with respect to child functioning. Strong mother–child relationships and mother–co–caregiver relationships are protective for children regardless of disclosure. So disclosure interventions should also work to strengthen the parent–child and parent–co–caregiver relationships.
Rochat <i>et al.</i> South Africa 2013	Maternal HIV Disclosure to HIV uninfected children in rural South Africa: A pilot study of a family-based intervention	24 mothers	24 families with at least one child in this age range 6–9 years HIV -	PILOT INTERVENTION By end of project 11/24 fully disclosed ( <b>46%</b> ) and 13/24 partially disclosed ( <b>54%</b> )	Intervention where lay counsellors delivered the six sessions over a six to eight week period, intended to increase maternal disclosure, health promotion and custody planning. 11/24 mothers disclosed fully using the word "HIV"; while 13/24 disclosed partially using the word "virus". The study finds that complex therapeutic processes can be transformed into practical, structured, step-by-step activities allowing for experiential learning and reflective practice, and leading to health behaviour change within families. Family centred with story and play based activities. Focus on relationships and parenting.
Rochat <i>et al.</i> South Africa 2014	Maternal HIV disclosure to young HIV-uninfected children: an evaluation of a family-centred intervention in South Africa	281 mothers	281 women with an HIV-negative child aged 6–10 HIV -	INTERVENTION By end of project: One hundred and seventy-one ( <b>61%</b> ) women 'fully' disclosed and 110 ( <b>39%</b> ) women 'partially' disclosed their HIV status to their child.	Finds that mothers are able to disclose 'fully' to children as young as 6 and 7 years, and that children respond with emotions and questions which demonstrate their ability to understand the information. Discussion about issues such as maternal death are difficult for children and parents but helpful for custody and care planning, and provides practical and psychological benefits for children. Children are persistent in their questions about parental health, highlighting importance of communication. No evidence of age or sex predicting disclosure. Mothers with current partners to whom they had disclosed significantly increased likelihood of mother disclosing to her children. Suggests need to integrate partner disclosure support within broader child and family disclosure programmes. Unsure if improvements in child mental health were as a result of disclosure or of improved mother child relationship.
Rochat <i>et al.</i> South Africa 2015	Maternal and child psychological outcomes of HIV disclosure to young children in rural South Africa: the Amagugu intervention	281 mothers	281 women with an HIV-negative child aged 6–10 HIV -	FOLLOW UP TO 2014 INTERVENTION <b>61%</b> women had 'fully' disclosed <b>39%</b> Women had 'partially' disclosed their HIV status to their child during their participation in the Amagugu intervention	This intervention resulted in many women disclosing to their children and in significant decreases in maternal and child psychological morbidity and parenting stress. Link between avoidant coping and nonadherence has been noted: improved mental health is likely to lead to improved adherence. Children of highly anxious parents show higher levels of behavioural and other problems. Almost no existing research involving primary school aged HIV affected children in LMIC – this intervention demonstrates significant positive psychological effects on children of this age. Study results suggest that as well as maternal disclosure children's psychological wellbeing is improved by other aspects of the intervention, such as improved family relationships and communication.

					This project is low-intensity, uses lay counsellors which could be scaled-up in low-resource settings, to increase disclosure, family communication and mental health.
Rochat <i>et al.</i> South Africa 2016	The Amagugu Intervention: a conceptual framework for increasing HIV disclosure and parent-led communication about health among HIV-infected parents with HIV-uninfected primary school-aged children	281 mothers	281 women with an HIV-negative child aged 6–10 HIV -	<b>61%</b> women had ‘fully’ disclosed <b>39%</b> Women had ‘partially’ disclosed their HIV status to their child during their participation in the Amagugu intervention	Post intervention evaluation found that the intervention was acceptable to participants and effective at increasing maternal disclosure to children. The intervention improved maternal and child health, improved health care engagement and custody planning; the intervention demonstrates the possibilities of disclosure to primary age children. The model includes elements to support parenting skills and capacity, encourage disclosure, strengthen parent-child communication and provide health education, including sexual health education and improve parental capacity for custody planning. 71% of participants stated that they enjoyed all aspects of the intervention and 42% said that they went on to involve other family members post disclosure. 90% said they felt they could help other mothers to disclose, suggesting increased confidence around disclosure issues.
Rochat et al South Africa 2017	Communication about HIV and death: Maternal reports of primary school-aged children's questions after maternal HIV disclosure in rural South Africa	281 mothers	281 women with an HIV-negative child aged 6–10 HIV -	<b>61%</b> women had ‘fully’ disclosed <b>39%</b> Women had ‘partially’ disclosed their HIV status to their child during their participation in the Amagugu intervention	Found that about a third of children who are disclosed to ask questions about death, depending on child response to disclosure and financial and social stability within the family. Mothers did not report short term negative consequences for children in talking about death. Finds that children affected by HIV have similar informational needs to children affected by other parental illness or death. Recommends that providing information to HIV affected children as a public health priority. Authors suggest that more information could increase child resilience.
Madiba, South Africa 2013	The impact of fear, secrecy and stigma on parental disclosure of HIV status to children- A qualitative exploration with HIV positive parents attending an ART clinic in South Africa	26 nondisclosed biological parents	60 children 7–18 years HIV - (implied, not stated)	26/44 <b>59%</b>	Reasons for non-disclosure: fear of stigma, discrimination, and gossip, also lacked disclosure skills and needed support from health care providers to disclose. Suggests need for health service practices to protect HIV positive people taking ART from stigma and discrimination. Benefits of ART should be emphasized so that communities perceive taking ART more positively. High fear of death and dying possibly because of initial portrayal of HIV and AIDS as debilitating, frightening and fatal disease (despite current availability of ART). This fear made non-disclosure more likely. Healthcare providers should challenge negative perceptions of HIV with educational programs portraying HIV as a chronic disease that is well controlled with ART. Need disclosure guidelines to assist parents to disclose their HIV status to children and help children cope with parental HIV infection; also important for HIV positive children.
Madiba & Matlala South Africa 2012	Disclosure of Parental HIV Positive Status: What, Why, When, and How Parents Tell Their Children in the Era of HAART in South Africa	21 disclosed HIV positive parents aged 20–50 years, with 1–3 children	39 children 7–18 years. One child was HIV +.	16 parents told all children about parental HIV; 5 told only some. (33/39 children told; 6/39 children not told).	Most parents: anxious and fearful of rejection by children, disclosure to children unplanned and emotive. Living in context of HIV stigma, discrimination, and fear of death from HIV/ AIDS. Differential disclosure: older children in same family more likely to be told (more mature and able to keep secrets). Found that once decided to disclose, disclosure was generally full and open, though depended on age of child. Focus of disclosure varied depending on if the reason was to receive support or to encourage children to protect themselves. Unlike Nam et al., found that some parents discussed sexual health and protection from HIV with their children and combined this with disclosure into an ongoing discussion. Despite adhering to HAART, many parents disclosed in order to prepare children for their

					illness or death or to receive support when ill. Children sometimes pre-empted disclosure by suspecting due to <i>e.g.</i> , weight loss and expressing fear of parental death. The research suggests professional support to help parents and children through the disclosure process, including decisions about when, how and the pros and cons of both disclosure and non-disclosure.
Gachanja, <i>et al.</i> Kenya 2014a	HIV-positive parents, HIV-positive children, and HIV-negative children's perspectives on disclosure of a parent's and child's illness in Kenya	16 HIV positive parents (aged 30–54, 11 were women, 5 were men) with 1–6 children, including one married couple Plus, 7 HIV + children, 5 HIV – children aged 8–17 years	7 HIV + children, 5 HIV- children aged 8–17 years HIV – and HIV +	9/16 fully disclosed (to at least 1 child) <b>56%</b> 5/16 partially disclosed/disclosed child's illness but not parents' <b>31%</b> 2/16 not disclosed <b>13%</b>	Provides an overview of disclosure from the point of view of HIV-positive parents and disclosure reception from the viewpoint of HIV-positive and negative children. Focus on resource-poor nations with high HIV prevalence. Participants recommend considering parents'/ children's state of health status, children's understanding and maturity level, important life events ( <i>e.g.</i> , school exams), and who best to perform disclosure.
Gachanja, <i>et al.</i> Kenya 2014b	HIV-Positive Parents' Accounts on Disclosure Preparation Activities in Kenya	16 HIV positive parents (aged 30–54, 11 were women, 5 were men) with 1–6 children, including one married couple Plus . 7 HIV + children, 5 HIV – Children aged 8–17 years	7 HIV + children, 5 HIV- children children aged 8–17 years HIV – and HIV +	9/16 fully disclosed (to at least 1 child) <b>56%</b> 5/16 partially disclosed/disclosed child's illness but not parents' <b>31%</b> 2/16 not disclosed <b>13%</b>	Found that parents find full disclosure challenging. Four main phases: secrecy, exploration, readiness, and finally full disclosure. May take years. May be child by child, not all children together. Conflicting advice from healthcare professionals can delay disclosure. Healthcare professionals need disclosure training including: info on the four disclosure phases, Tasker's (1992) research. They should consider: parent and child health statuses, relationships within the family, child's age of sexual debut, and when to refer on to <i>e.g.</i> , counselling or support groups.
Gachanja Kenya 2015B	A Couple's Marital Disharmony and its Psychological Effects on Their Children during the HIV Disclosure Process in Kenya	An HIV positive couple (parents of 5 children:	5 (same family) 25 M, 24M, 22F and 20F and 15M) HIV- & unknown	4/5 children ( one family) So had disclosed to at least one child <b>100%</b>	HIV positive married couples may not agree if, when, and how to fully disclose to their children and this may delay disclosure and cause conflict within the family. However, children may prefer to receive disclosure of their parents' illnesses from both parents at the same time. Recommendations: Parents need programmes to help them accept their HIV and the guilt they may feel, and to guide them through the steps of fully disclosing to all children; children need programmes to help them accept their parents' HIV (especially if related to parental marital infidelity). Urgent need for programmes to improve harmony, resiliency, relationships, and communication patterns among HIV-affected family members before, during, and after full disclosure.
Gachanja,& Burkholder Kenya 2016	A model for HIV disclosure of a parent's and/or a child's illness	16 HIV positive parents (aged 30–54, 11 F, 5 M) with 1–6 children, including one married couple Plus 7 HIV + children, 5 HIV – children aged 8–17 years	7 HIV + children, 5 HIV- children children aged 8–17 years HIV – and HIV +	9/16 fully disclosed (to at least 1 child) <b>56%</b> 5/16 partially disclosed/disclosed child's illness but not parents' <b>31%</b> 2/16 not disclosed <b>13%</b>	Disclosure of parents' or children's HIV status is challenging for healthcare professionals, parents and children (positive, negative or untested) This is a model to support disclosure in Kenyan or similar contexts. It includes the following six themes, identified from the research and found to interact with each other, impeding or facilitating the disclosure process: HIV testing, living with HIV, evolution of disclosure, questions, emotions, benefits, and consequences of disclosure.

Raphael Avornyo, John Amoah.  Ghana 2014.	Disclosing Parental Human Immunodeficiency Virus (HIV) Status to Children in Ghana: Reasons for and against Disclosure and Effects of Decision.	26 parents (18 mothers, 8 fathers) aged 20–50+	21 children Aged 2–20's Majority HIV negative	18/26 parents (2/8 fathers, 16/18 mothers) had not disclosed their status.	Reasons for non-disclosure included: fear of stigmatization and discrimination; children being too young; not wanting the children to worry; and children thinking their parents would die. Those who had disclosed tended to be younger. Children responded initially with sadness and later learned more about HIV and supported their parents. Researchers believe significant psychological, social and physical benefits of disclosure for parents and children; suggests need to develop programmes to counteract stigma and discrimination and interventions to equip parents with skills and knowledge to disclose to their children.
<b>AFRICA LOW INCOME</b>					
Rwemisisi, <i>et al.</i> Uganda 2008	‘What if they ask how I got it?’ Dilemmas of disclosing parental HIV status and testing children for HIV in Uganda.	Interviews with 10 parents, plus interviews about counselling policy with directors and counsellors from 5 counselling institutions.	51 4 to 36 years HIV +, HIV- & unknown	Half of parents interviewed had disclosed to all or some children, aged 8+. <b>50%</b>	Need for more research on parental disclosure of HIV in Africa (and other areas with high rates of vertical transmission) which includes viewpoints of children and caregivers. Acknowledges the tensions between honesty and risk. This study raises the new possibility of a link between child testing and parental disclosure which would mean that parental disclosure is a child health issue. Uganda MoH finds that infected children are not accessing treatment and support in the numbers that they anticipated. Counsellors report giving contradictory and improvised advice because of lack of appropriate guidance. Parents wanted to be the ones to tell their children, suggesting programmes should equip parents with the necessary skills and for health professional input to be via parents. Support needs to be context specific and sensitively delivered, not transplanted from high income settings.
Kyaddondo <i>et al.</i> Uganda 2013	Disclosure of HIV status between parents and children in Uganda in the context of greater access to treatment	12 in-depth interviews (6 adults over 32 yrs 3F, 3M); 4 unmarried young people aged 18–24; heterosexual infection; 2 aged 19–20, perinatal infection. Also 2 single sex focus groups discussions of 8 people each, one males, one female. And open-ended survey questions (100 women, 48 men)	Not clear Children's ages not specified HIV – and HIV +	Not stated	Highlights challenges and complexities of disclosing HIV status in family settings, especially to children. Disclosure is a moral, relational, and practical decision ( <i>e.g.</i> , Need for care and support, and to plan for the future). Disclosure may be pragmatic and in response to circumstances or be a long process of weighing up potential risks and rewards. Also involves interpersonal relations and management of guilt, blame, and shame. Local cultural norms which inhibit discussing sexual matters with children make disclosure more challenging. Perinatally acquired HIV is especially challenging and parents may delay testing until after children become ill. Health care demands may force disclosure. PLWHIV seek to protect their image as a ‘good’ parent or child, until they become very ill and the need for support becomes paramount. Possible need for counsellor to help “objectively evaluate and determine to whom, when, and how to disclose”. The use of intermediaries for sensitive issues is already culturally acceptable. Most participants experienced positive reactions to disclosure, but it is a long complex process which could be supported by trained counsellors, for PLWHIV and family to help work through issues, identify support and devise coping strategies.
Osingada <i>et al.</i> Uganda 2016	Prevalence, barriers and factors associated with parental disclosure of their HIV positive status to children: a cross-	344 HIV positive parents	Not stated Aged over 5 years Not stated.	37 % had told at least one of their children that they were HIV positive.	Barriers to Disclosure: Fear children may tell others, desire not to worry or upset children; believe that children will not understand. Older parents, Pentecostal parents and parents who had agreed a guardian for their children were more likely to tell their children; parents with tertiary education were less likely to tell their children.

	sectional study in an urban clinic in Kampala, Uganda				
De Baets <i>et al.</i> Zimbabwe 2008	HIV disclosure and discussions about grief with Shona children: A comparison between health care workers and community members in Eastern Zimbabwe	64 health care workers 131 community members	64 health care workers & 131 community members Not specified-questions were hypothetical Not stated-hypothetical	Hypothetical: participants asked what they think people should do not what they have actually done <b>Hypothetically 89% to child age 14+</b> The participants suggested partial disclosure from the age of 10.8 years and full disclosure from the age of 14.4 years.	Questions assumptions: rural people/adults don't want to disclose HIV status to children, Western counselling models are applicable and acceptable for southern African families, and current training models pay sufficient attention to variant southern African family structures. Findings: Identified a need and desire for open communication about HIV in the family and issues of grief and death with children; desire and practice may differ; disclosure practice may also differ between biological and foster children. Challenge to design a useful guideline for HIV disclosure for children of various ages. Mothers may want to disclose but not be considered to have the authority within the family so may need to involve wider family. Compared to community members, health care workers were significantly more open to full disclosure and disclosure at a younger age but were slightly less open to discussing grief.
Tiendrebeogo <i>et al.</i> Burkina Faso 2013	Parental HIV disclosure in Burkina Faso: Experiences and challenges in the era of HAART	mothers (37), fathers (26)	37 women (59%) and 26 men (41%) with at least one child 7 to 30 years of age. HIV + and HIV - (Five women had children who tested positive, not clear how many children this is)	<b>47.6 %</b> of parents had disclosed	This research suggests reintegrating basic counselling principles into HIV disclosure, finding that current counselling is bureaucratic and focuses on prevention and enabling access and adherence to treatment. Counselling should include issues such as supporting disclosure to children. Counselling approach should be reflexive and focus on social interactions and family relationships (not standardized and informative approaches with public-health objectives). Parents describe relief in disclosing to children. Despite parents fears of blame, stigma, and inability to keep the secret or cope with the information, all children who were disclosed to became an important and positive source of support. However this can be challenging for parents without support and children may need support to process the information.
Muparamoto & Chiweshe Zimbabwe 2015	"Managing identities" and parental disclosure of HIV sero-status in Zimbabwe	12 mothers, 7 fathers	Not stated Most had at least 1 child aged over 15. HIV - (implied, not stated)	5/14 had disclosed <b>36%</b>	Found that disclosure is a challenge for parents and that parents use strategies to control the information and create a desired identity. Draws on Goffman's work on spoiled identity. Finds that parents fear spoiling their identity in the eyes of their children and are uncomfortable discussing sex with children. Suggests increased awareness amongst health professionals promoting disclosure of social context and social norms especially stigma and sex, as well as parents' desire to protect their children from judgement.
Moore <i>et al.</i> Togo 2008	To disclose or not to disclose?: Lower class parents living with HIV/AIDS in Lomé, Togo	151 men and women living with HIV in Lomé, Togo. Average age 35, 59% had children	Average age of children was 12. Only two participants reported having an HIV positive child.	16 % had disclosed to children.	Low disclosure rates to family (12 % had disclosed to mothers and 16 % to children.) Reasons given for non-disclosure to children: child too young, don't want to traumatize child, no point in disclosing. Researcher interpretation: regulated nature of parent-child interactions in Africa (children should be seen, not heard). Non-disclosure means that PLWHIV cannot benefit from social, economic, and psychological support from close family.

**Table 2: Table of upper and lower age limits of children of participants in research on parental disclosure of HIV to children in LMICs Africa and the Caribbean.**

Article ( Author and date)	Lower age limit	Upper age limit
Avornyo and Amoah , 2014	2 years	Over 18 years
Rochat, Mkwanaazi and Bland, 2013 Rochat <i>et al.</i> , 2014, 2015, 2016 and 2017	4–6 years	17 or 18 years
Rwemisisi <i>et al.</i> , 2008	4–6 years	Over 18 years
Osingada <i>et al.</i> , 2016	4–6 years	17 or 18 years
Nam <i>et al.</i> , 2009	4–6 years	17 or 18 years
Conserve <i>et al.</i> , 2014	7–11 years	17 or 18 years
Palin <i>et al.</i> , 2009	7–11 years	17 or 18 years
Madiba, 2013; Madiba and Matlala, 2012	7–11 years	17 or 18 years
Gachanja, Burkholder and Ferraro 2014a, 2014b; Gachanja and Burkholder, 2016	7–11 years	17 or 18 years
Gachanja, 2015	7–11 years	Over 18 years
Tiendrebeogo <i>et al.</i> , 2013	7–11 years	Over 18 years
Muparamoto and Chiweshe, 2015	15	17 or 18 years
Geiselhart, Gwebu and Kruger, 2008	Age of children not stated	
Moore <i>et al.</i> , 2008	Age of children not stated	
De Baets <i>et al.</i> , 2008	Age of children not stated	
Kyaddondo <i>et al.</i> , 2013	Age of children not stated	



## **Appendix IV: Example participant information leaflet**

### **HIV and Mothers in Kingston, Jamaica:**

#### **Telling the children: Issues of maternal disclosure**

#### **Interviews with mothers: Information sheet**

Hello, my name is Gayle Clifford. I am a PhD student with City University in London, England. At the moment, I live in Kingston and I am carrying out some research here. I am asking you to consider taking part in this research. Before you decide if you want to take part or not, I want to tell you why the research is being done, and what you can expect if you do take part. Please ask if you have any questions. Talk about it with friends, relatives or project staff if you wish.

#### ***What is the purpose of the study?***

The purpose of this study is to gain an insight into the lived experiences of HIV positive mothers in Kingston, Jamaica, with regard to their experiences of disclosure/non-disclosure of their HIV status to their own child(ren).

I am carrying out one to one interviews with women to find out how they feel about disclosure. The study will:

- Examine mothers' attitudes towards disclosure to their seronegative children;
- Examine the factors which influence mothers' disclosure decisions;
- Explore the impact of disclosure or non-disclosure on the family;
- Examine the attitudes of service providers towards disclosure, including their understanding of the advantages and disadvantages
- Use findings to inform the development of disclosure protocols for health & social care workers

The findings from this research may help agencies to better understand the needs and concerns of women about disclosure issues and may help other women who are thinking about disclosing their status to their children.

This research is being conducted in order to fulfil thesis requirements. Findings will be published in a report, on the internet and presented at conferences. You will not be identified in any of the publications.

I will send you a summary of the research findings if you would like to see them.

Here are some questions people often ask about research, and my answers. If you have any other questions, please don't hesitate to contact me on [REDACTED]

#### ***1. Who has given ethics approval for the study?***

City University, London's Research Ethics Committee and UWI Ethics Committee have reviewed the study and given it ethical approval.

**2. *Why have I been invited to take part?***

You have been invited to take part because you are a mother aged over 18, who is HIV positive with at least one seronegative child, and you have been aware of your status for at least one year. You do not have to agree to take part.

**3. *What would be involved in taking part?***

I would like to invite you to a face-to-face interview. I will ask you about your experiences of motherhood, HIV diagnosis and your thoughts and concerns about disclosure, especially to your children. The interview will also allow you to talk about any issues regarding your status that are important to you. The interview will last approximately 30–60 minutes. Interviews will be audiotaped and will be held at the HIV Clinic or NGO offices, immediately after your appointment or at a time that is convenient to you.

**4. *Will I be paid for taking part?***

You will not be paid for taking part in this study. I will cover the cost of bus fare within Kingston and provide a small snack during the interview.

**5. *What if I change my mind?***

You can withdraw from the study at any time without giving a reason and you can end the interview at any point. This will not impact any future care or services that you or your relatives may receive.

**6. *Will taking part be of any benefit to me?***

There may be no individual benefit. However, I hope you will find it beneficial to explore your views and experiences with me. I will give you written feedback about the findings of the study.

**7. *Are there any disadvantages to taking part?***

There should be no disadvantage to taking part. However, I appreciate that for some people, talking about their status and disclosure issues may be distressing. I will provide you with the details of NGOs in Kingston who work to support people living with HIV. I appreciate that participating will take up some of your time, but I will do my best to ensure I fit the interview around your own commitments.

**8. *Will what I say be anonymous?***

Yes. Nothing you say will be revealed to anyone in a way that could identify you. You do not have to tell me your real name. Recordings of interviews will be stored securely and made accessible only to research team members. They will be destroyed at an appropriate period from the end of the study, or lodged in an anonymised form with an appropriate research archive. It will not be possible to identify you in any reports or other publications.

**9. *What if I have any concerns?***

You can contact me on [REDACTED] I will be very happy to discuss your concerns and/or put you in touch with someone who will be able to help.

For independent advice on your rights as a research participant please contact Professor Archibald McDonald, Dean, Faculty of Medical Sciences, University of the West Indies, Mona, Kgn 7. Tel:

[REDACTED]

If you would like to complain about any aspect of the study, City University London has established a complaints procedure via the Secretary to Senate Research Ethics Committee. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary of the Senate Research Ethics Committee and inform them that the name of the project is: HIV and Mothers in Kingston, Jamaica: Telling the children: Issues of maternal disclosure.



## Appendix V: Sample participant consent form



CITY UNIVERSITY  
LONDON

### INFORMED CONSENT FORM FOR INTERVIEW PARTICIPANTS

**Title of the Study:**

HIV and Mothers in Kingston, Jamaica: Telling the children: Issues of maternal disclosure

**Purpose and description:**

The purpose of this study is to find out more about what HIV positive mothers in Kingston, Jamaica, think about the issue of telling their HIV negative children about their status. I will do this by talking to HIV positive mothers about motherhood and HIV.

This research is being carried out for a PhD course at City University. Findings will be published in a report, on the internet and presented at conferences. You will not be identified in any of the publications.

**Procedures:**

I would like to invite you to talk to me about your experiences as an HIV positive mother in a face-to-face interview. The interview will last approximately 30–60 minutes.

I will ask you about your experiences of being a mother, about your HIV diagnosis and about your views and experiences of telling people about your HIV status, especially your children. You can talk about any issues regarding your status that are important to you. Interviews will be audiotaped and will be held at the HIV clinic or NGO offices after your appointment or at a time that is convenient to you.

**Risks:**

There should be no disadvantage to taking part. However, I realise that for some people, talking about their status and disclosure issues may be upsetting. If you would like to talk to someone, please let me or a member of staff know.

**Benefits:**

There may be no individual benefit to participating. However, I hope you will find it helpful to talk about your experiences with me. I will give you written feedback about the findings of the study.

The findings from this research may help agencies to better understand how women feel about telling their children that they have HIV. It may also help other women who are thinking about disclosing their status to their children.

**Right to withdraw or refusal to participate:**

You can choose whether or not you want to talk to me. You do not have to talk to me. You can stop participating at any time without giving a reason and you can end the interview at any point. This will not affect any future services that you or your relatives may receive at [organisation] or elsewhere.

**Confidentiality:**

I will not tell anyone or write anything that you say to me in a way that will let other people know that it was you who said it. You do not have to tell me your real name.

I will store the recordings of the interviews securely and only my academic supervisors will be able to access them. They will be destroyed at an appropriate period after the study is finished. It will not be possible to identify you in any reports or other publications.

**Compensation:**

You will not be paid for taking part in this study. I will cover the cost of bus fare within Kingston and provide a small snack during the interview.

**Contact Details for Researcher/Principal Investigator**

If you have any questions regarding the research project, you may contact me, the principal investigator:

[REDACTED]

I will be very happy to discuss your concerns and/or put you in touch with someone who will be able to help.

**Rights as a Research Participant:**

For independent advice on your rights as a research participant, please contact Prof. Owen Morgan, Chairman, Advisory Panel on Rights and Medico-Legal affairs, Ministry of Health, Oceana Complex, 2–4 King Street, Kingston, Jamaica. Tel: [REDACTED]

If you would like to complain about any aspect of the study, City University London has established a complaints procedure via the Secretary to Senate Research Ethics Committee. To complain about the study, you need to phone [REDACTED] You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: HIV and Mothers in Kingston, Jamaica: Telling the children: Issues of maternal disclosure.

You could also write to the Secretary at: Anna Ramberg  
Secretary to Senate Research Ethics Committee  
City University London, Northampton Square  
London EC1V 0HB  
Email: [REDACTED]

Alternatively, you can contact Dr Geoffrey Barrow at CHARES and he will pass your complaint on to City University:

Telephone: [REDACTED]

Email: [REDACTED]

Address: Dr. Geoffrey Barrow, Clinical Coordinator,  
The Centre for HIV/AIDS Research, Education and Services  
University Hospital of the West Indies  
Mona, Jamaica

**Statement of declaration:**

**1. I have read the informed consent form, or that it has been read to me, and I understand it. I know that I will be given a copy. My signature below shows that I agree to participate in this study.**

**2. I have had time to think about whether or not I want to participate.**

Name of Respondent: .....

Signature of Respondent: .....

DATE: .....

Name of Researcher: .....

Signature of Researcher: .....

DATE: .....

Name of Independent Witness: .....

Signature of Independent Witness: .....

DATE: .....

## Appendix VI: Ethical approval letters



**School of Health Sciences**  
Research Office  
Northampton Square  
London EC1V 0HB

Ref: PhD/11-12/10

Tel: +44 (0) 20 7040 5704

[www.city.ac.uk](http://www.city.ac.uk)

12 September 2012

Dear Gayle, Gill and Chris

**Re: A qualitative investigation of HIV positive mothers' experiences of and views on disclosure of their own status to their seronegative children; Kingston, Jamaica**

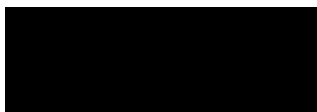
Thank you for forwarding amendments and clarifications regarding your project. These have now been reviewed **and approved** by the Chair of the School Research Ethics Committee.

Please find attached, details of the full indemnity cover for your study.

Under the School Research Governance guidelines you are requested to contact myself once the project has been completed, and may be asked to complete a brief progress report six months after registering the project with the School.

If you have any queries please do not hesitate to contact me as below.

Yours sincerely



Alison Welton  
Research Governance Officer





# THE UNIVERSITY OF THE WEST INDIES

MONA CAMPUS  
Faculty of Medical Sciences  
Office of the Dean

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Dean: Horace Fletcher, MB, BS, DM (O&G), FRCOG, FACOG  
Professor of Obstetrics and Gynaecology

September 6, 2012

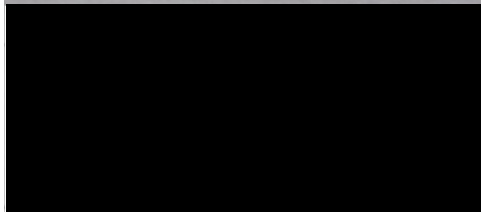
Dr. Geoffrey Barrow  
Clinical Coordinator, CHARES  
Department of Medicine  
The University of the West Indies  
Mona, Kingston 7

Dear Dr. Barrow:

**Re: Gayle Clifford's research proposal entitled- HIV and mothers in Kingston, Jamaica: Telling the children-issues of maternal disclosure. ECP 154, 11/12**

Thank you for submitting the above mentioned proposal for review by the UHWI/UWI/FMS Ethics Committee.

The proposal was reviewed and approved, having met the required ethical standards.



Professor Horace Fletcher  
Chairman UHWI/UWI/FMS Ethics Committee





**MINISTRY OF HEALTH**  
**STANDARDS & REGULATION DIVISION**  
OCEANA COMPLEX, 2-4 KING STREET, KINGSTON, JAMAICA  
TEL: (876) 967-1100/3/5/7; 948-4106 FAX: (876)-967 1629  
WEBSITE: [www.moh.gov.jm](http://www.moh.gov.jm) EMAIL: [osboumcp@moh.gov.jm](mailto:osboumcp@moh.gov.jm)

ANY REPLY TO THIS COMMUNICATION  
SHOULD BE ADDRESSED TO THE  
PERMANENT SECRETARY AND THE  
FOLLOWING REFERENCE QUOTED:

Reference: No. S&R/ERP/7

October 16, 2013

Ms. Gayle Clifford  
2 Trafalgar Mews  
Trafalgar Road  
British High Commission  
Kingston 10

Dear Ms. Clifford

**Approval of Project: HIV & Mothers in Kingston, Jamaica: Telling the  
Children – Issues of Maternal Disclosure**

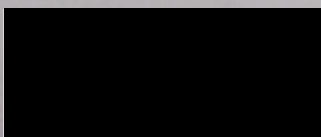
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This serves to inform you that the Advisory Panel on Ethics and Medico-Legal Affairs in the Ministry of Health has reviewed and approved the above-mentioned Study. The Study has been assigned the number **2013/08**.

Please keep the Ministry updated regarding the progress and submit a summary or the results and conclusions at the end of the Study.

We wish you every success in this endeavour.

Yours sincerely



Prof. Owen Morgan  
**Chairman**  
Advisory Panel on Ethics & Medico-Legal Affairs

## Appendix VII: Interview Guide

My interviews were intended to be unstructured in order to allow the participants to explore the issues of relevance to them. I hoped that interviews would flow after one or two initial questions:

‘How do you feel about talking to your children about your HIV status?’

‘What has your experience of this been?’

I planned to follow up with prompts as needed *e.g.*:

Silence....

‘Mmmm....’

‘Can you tell me more about that?’

‘Can you describe it to me?’

‘How do you feel about that?’

‘Could you give an example?’

‘And then what happened?’

‘And then what did you/he/she do/say?’

‘What do you think/feel about that now?’

However, I was aware that for a variety of reasons, participants might require more encouragement and prompting. Additionally, ethics committees required more detailed information on the kinds of questions I might ask. Below is the information that was supplied with my ethics applications, indicating possible questions. In the interviews I was guided by participants, questions did not follow any particular order and not all questions were asked to all participants.

### PART 1: LIFE HISTORY

#### Background

What is your name? (that we use for the interview, does not have to be real name).

Can you tell be a little bit about your life before you received a diagnosis? Where did you live?

What were your living arrangements (family/partner friend *etc.*)?

(Establish age, number of children, current partner, child(ren)’s father(s) *etc.*)

What are the important events of that time that you remember? (births, deaths, marriages, important achievements/disappointments— personal or professional).

### **Becoming HIV positive**

When did you find out you were HIV positive? How did you find out?

What made you decide to get tested?

What were your concerns before testing?

What were your concerns after testing?

Do you know how/when you became HIV positive? Can you tell me what happened?

### **Key Relationships**

Family (parents, siblings); Friends; ‘Babyfather’(s); Other sexual partner(s); Own child(ren); Support staff.

Have you disclosed your status to your family/partner/friends? (explore the differences between these 3 and the reasons for the differences)

If so, how has it affected your relationships? What were your concerns before telling them?

How do you feel about having told them?

If not, what are your concerns about telling them? Do you plan to tell them in the future? Do you want to?

If you have disclosed to some people and not others: what is your experience of this/ Is it difficult to maintain different identities? Are you afraid that those you have told, will tell others?

Is the fact that you have not disclosed to your partner/family a factor in your decision not to disclose to your child?

### **Living with HIV**

Have you been treated differently as a result of your status? Please give details. In what way?

What about your children? Has your status affected them? In what way? Can you give examples?

Have you ever been treated unfavourably? Can you give examples? Have your children?

NB: If participant uses the words 'stigma' or 'discrimination' I will ask for more detail, what do they mean by these terms, what has happened, what examples/contexts *etc.* Also about their children's experiences.

## **PART 2: REFLECTING ON EXPERIENCES AND ATTRIBUTING MEANING**

### **Gender**

In what way has being a woman affected your experiences of being HIV positive?

Has it made it easier in any way? For example to access services

Has it made it harder in any way? Eg ?

### **Becoming a mother**

In what way did becoming a mother impact on/change your feelings about being positive?

Did you expect to feel that way?

Do you feel that your relationship with your child(ren) is different as a result of your status?

Positive/negative effects?

### **Disclosing your status**

#### **If disclosed**

Pre disclosure (Reconciling concerns, prioritising issues/goals)

What concerns did you have about telling your children (before you told them?)

How did you resolve these concerns? What issues did you decide were more important (with regard to disclosure) and why? What events led up to your decision to disclose? How did you come to the decision to disclose? What influenced you?

#### **Disclosure**

How did you tell your children? What did you say? Who was there/ Where were you? How did they react? What did they say/do? How has their reaction changed over time?

What are the positive and negative results of them being aware of your status (school, home family, medication, behaviour, relationship).

#### **After disclosure**

What are your concerns?

How do you feel now about having told them? What influenced you? How do you feel about your decision at the moment? How have your feelings changed over time? Do you have any regrets? What are they? What advice would you have for other women thinking of disclosing?

### **If not disclosed**

What might the positive and negative results of them being aware of your status be?(school, home family, medication, behaviour, relationship).

What are your concerns?

Would any of this change if you told them, do you think?

Do you intend to tell them at a later date? When/How/Why?

How do you think they will react? Do you think that they have any idea of your HIV status?

### **Support**

What support do you think would help you in disclosing to your child (if this is what you want to do)?

What support do you think would be needed once you disclose?

What support do you think your child would need/currently needs?

### **Pressure to disclose**

Have you ever felt pressured into disclosing your status? What happened?

Have you ever said that you had disclosed your status to your partner/friends/family when in fact you had not? Tell me more about this.

Do you think that women sometimes feel pressured in this way?

What do you think about this?

### **The Future**

Feelings, plans and aspirations for self and for child(ren);

## Appendix VIII: Living arrangements of participants

**Table 3: Living arrangements of participants**

Name	Lives alone	Lives with one or more of own children	Lives with partner/husband	Lives with own mother	Lives with siblings	Lives with other
Sandra		X	X	X		Stepfather, husband's daughter
Susie	X					
Laura		X	X			
Winnie					X	
Patrice		X	X			
Jay		X				
Tina		X				
Maria		X				
Cupcake		X			X	
Margaret		X			X	sister's niece.
Anna		X				
Johnnett		X	X			
Tracy		X		X	X	
Sarah		X	X			
Nora		X	X (sometimes)	X	X	

## Appendix IX: Family dynamics of participants

**Table 4: Family dynamics of participants**

Name	Number of children	Non biological children	Child/ren brought up by	Babyfathers	Relationship
Sandra	3	husband's daughter	First by 1st babyfather /babyfather's family (overseas); 2nd and 3rd by mother and 2nd babyfather	2	Married to second babyfather
Susie	1		Maternal grandmother	1	Single
Laura	2		Maternal grandmother	1 (implied)	Now lives with new partner
Winnie	1		Mother	1	Single: Left partner (not babyfather) after diagnosis
Patrice	1		Both parents	1 or 2 (not clear)	Married to babyfather of fourth child (and possibly all children)
Jay	4		Mother	2–4 (not clear)	New partner
Tina	4		First three by respective babyfathers/family; fourth by mother	3	single
Maria	3		First by babyfather (overseas), 2nd and 3rd by mother	2	single
Cupcake	3		Mother	3	single
Margaret	2	sister's niece.	Mother	1	Widowed (partner died of AIDS)
Anna	3		Mother	2	2 <sup>nd</sup> babyfather died of AIDS
Johnnett	3		First two by maternal grandmother, third by mother	3	New partner
Tracy	3		Mother	3	single
Sarah	4		First 3 by mother, fourth by mother & babyfather	2	Current fiancé: 4 <sup>th</sup> child's father
Nora	4		Mother	2	Visiting relationship (1 <sup>st</sup> babyfather died of AIDS)

## Appendix X: Extract of analysis process for interview with Cupcake

Table 5 illustrates the initial analysis of a short part of the interview with Cupcake:

**Table 5: Extract from Cupcake's interview**

Text ID	Interview dialogue	Exploratory and linguistic comments	Initial/emerging themes
129	Gayle: Ok. So talk to me – talk to me a little bit about your sons. Tell me about them.		
130	Cupcake: Ok – well my three kids – di bigger one? he's – he's – I really don't have a very great relationship with him? because you know he is big – he is sixteen? but the baby, we have a very good relationship and sometimes? I – they know I have a sickness but they don't know it's HIV. Because a have to take the meds and because sometimes when mi take di medication? it will like block me out for a likl while? so what I do I tell dem a – a - a just trick ma son and tell him dat because di burst a have in my head, a sick wit ma head. So they think it's just ma <b>head</b> . So each time that I am sick a just tell that it is because a mi <b>head</b> . So now –	<p>Difficult relationship with her oldest son 16yo, teenage years? She stops and starts- difficult to express?</p> <p>Very good relationship with the 11yo. Refers to him as 'the baby'. No details about middle child.</p> <p>They know she has a sickness, but not that it is HIV: partial honesty/disclosure.</p> <p>Sometimes when she takes her meds, it 'blocks' her out for a little while: this has meant that she needed to tell them something. So she tells them, 'tricks' him, by saying it is just her head (it seems she had a previous illness, a 'burst' in her head) and that is why she needs the medication.</p>	<p>Difficult relationship with oldest son</p> <p>Close relationship with younger son</p> <p>Sons aware she is sick: partial disclosure</p> <p>Dishonesty about illness ('tricks')</p>
131	Gayle: What happened to your head?		
132	Cupcake: No, I had a bers in dier –		
133	Gayle: Mhm.		



134	Cupcake: — so a just tell him dat is – that’s the reason I have to be on the medication –		
135	Gayle: Ok.		
136	Cupcake: — because I take the medication out of the bokl, keep them in something else? and they would give it to me every night before I go to my bed. That’s their duty because I will forget to do it. So they was – they are always ‘mumi yu tek yu medikieshan?’ but they don’t know what it is for. I don’t tell them.	<p>She puts the medication in a different container so they won’t guess from the label. Hides the fact that she has HIV but not that she is unwell.</p> <p>It is her sons’ job, their ‘duty’ to give her the meds every night, so that she doesn’t forget. Children’s role/responsibility</p> <p>They always check, but they do not know what it is for.</p>	<p>Partial disclosure. Careful about what they know.</p> <p>Giving her medication is her sons ‘duty’/responsibility</p>
137	Gayle: Ok.		
138	Cupcake: I don’t.		
139	Gayle: And um...so what did you – so when you first – so you just told them that it was a – but did they ask you or did xxx [one or two words; speaking overlaps]?		
140	Cupcake: Ye – no I <b>tell</b> them that is because a my head that I take – but they hear – they hear about it – they hear like – because I used to do a very good business?	<p>She told them it is because of her head.</p> <p>But they heard about the HIV, she used have a good business.</p>	<p>Sons have heard gossip that Cupcake has HIV</p> <p>Community: fear of stigma?</p>
141	Gayle: Mhm.		
142	Cupcake: — um, two years ago? very – very good business in – in the country and I came to di clinic one day and somebody came here and saw me. And like she went back? and den she told somebody else and den spread it and it was discrimina — you know? And I was like ‘no’. A we — a went down dier to see somebody and all a dat? but everybody you know? sometimes dem still talk about it. People still talking about me having HIV but a don’t really watch what dem se a	<p>2 years ago, a very good business, in the country.</p> <p>She came to the clinic one day and somebody saw her and went back, told someone and it was spread around. Discrimination. She denied it, went and talked to somebody about</p>	<p>Gossip destroyed her business 2 years ago. Loss. Discrimination</p> <p>Let them talk: sadness and defiance</p> <p>She looks good, confidence, defiance, determination. Hiding HIV.</p>

	jos gwaan du ma ting bikaaz mi stil luk gud az yu kyan si. So it doh obvious, it's not showing –	it, but they are still talking. She moves into Patois at this point: upset?  She doesn't worry about it, she just does her thing, she still looks good (as you can see), so it's not obvious, there's no sign.	
143	Gayle: Mhm.		
144	Cupcake: — so dem stil afi tink it twais. De bin talking dis for how many years? And dem don't see no difference –	They still have to think twice. They've been talking about it for years, but there's still no difference.	Let them talk No visible sign/she looks good
145	Gayle: Mhm.		
146	Cupcake: — so mi no really watch dem. So a went on now to a ada country and doing ma likl ting dier.	So she doesn't worry about it. She has gone to a different area and she does her little thing there. But it affected her business.	Let them talk Moved her business elsewhere. Moving on
147	Gayle: And so do you think your sons heard when –		
148	Cupcake: Ye they hear about it but de don't believe. De are always saying dat – because me and dem did come and do di – di result? and den di lady told us about di negative part of it? –	Her sons heard, but they don't believe it.  When they came to the clinic to do the HIV test, she let them believe that the	Sons don't believe she has HIV  Dishonesty: Cupcake allowed them to believe that the negative HIV test was for the whole family, including her.  Active steps. Protecting children.
148	Gayle: Mhm.		
149	Cupcake: — they thought dat it was for <b>everybody</b> .	Negative result was for all of them, including Cupcake.	Dishonesty- Cupcake allowed them to believe that the negative HIV test was for the whole family, including her
150	Gayle: Mhm.		
151	Cupcake: So...they don't know. They still saying –		
152	Gayle: So how old were they when they got tested?		

153	Cupcake: Just last year.	She got her sons tested last year.	Fear of sons having HIV? Or to counter rumours?
154	Gayle: So you did – they weren't tested as babies –		
155	Cupcake: No.	Not tested as babies	Fear of sons having HIV?
156	Gayle: - no. So did you – what made you decide –		
157	Cupcake: Because um, the reason why I decide to test dem because de always having a skin problem.	She wanted to get them tested because they were having skin problems.	Fear of sons having HIV? Potential signs of HIV. Worry
158	Gayle: Mhm.		
160	Cupcake: Like sometimes if they play in the dirt and so de would have a likl, you know? But dem – dem very um, we yu se now? Dem chi – dem av di badi an evriting. Not xxx [two or three words]. A would always have it in di back a mi head?	They seemed healthy, no real signs, but she always had it in the back of her head, especially the youngest	She wanted to get them tested because they were having skin problems.
161	Gayle: Mhm.		
162	Cupcake: — that the baby is HIV.		
163	Gayle: Mhm.		
164	Cupcake: But he wasn't. He did the test two times.	But he wasn't, he did the test twice	Fear of sons having HIV. Anxiety
165	Gayle: Mhm. And so why – why did you have it in your head?		
166	Cupcake: Why I have it? Because I know I am HIV and I have it – I have them –	She was worried because she has HIV	Fear of sons having HIV. Anxiety
167	Gayle: And you just wanted to be sure.		
168	Cupcake: Ye. I have them so they – you know?		
169	Gayle: Mhm.		
170	Cupcake: So that's why I'm always thinking that dem HIV positive. A always have it in di bak a mi head. But after I did di test and evriting now? Mi feel happy about dat.	Always thinking about it, always in the back of her head. Now she feels happy	Fear of sons having HIV. Worry Relief sons are negative

I then went through the initial themes from the entire interview and loosely grouped them, according to themes I felt recurred throughout the interview. I used colour coding, as shown below, retaining the text identifiers so I could easily retrace my steps. The themes I identified were: Denial & loss, Secrecy and protection, Living with fear, Self care, Talking/thinking about HIV. A short extract of this for Cupcake's interview is shown below (Table 6):

**Table 6**

Text ID	Initial/emerging themes
129	
130	<p>Difficult relationship with oldest son</p> <p>Close relationship with younger son</p> <p>Sons aware she is sick- partial disclosure</p> <p>Dishonesty about illness ('tricks')</p>
131	
132	
133	
134	
135	
136	<p>Partial disclosure. Careful about what they know.</p> <p>Giving her medication is her sons 'duty'/responsibility</p>
137	
138	
139	
140	<p>Sons have heard gossip that Cupcake has HIV</p> <p>Community- fear of stigma?</p>
141	
142	<p>Gossip destroyed her business 2 years ago, Loss, Discrimination</p> <p>Let them talk: sadness and defiance</p> <p>She looks good, confidence, defiance, determination, Hiding HIV.</p>
143	
144	<p>Let them talk</p> <p>No visible sign/she looks good</p>
145	
146	<p>Let them talk</p> <p>Moved her business elsewhere. Moving on</p>

147	
148	<p>Sons don't believe she has HIV</p> <p>Dishonesty/protection Cupcake allowed them to believe that the negative HIV test was for the whole family, including her.</p> <p>Active steps. Protecting children.</p>
148	
149	Dishonesty/protection Cupcake allowed them to believe that the negative HIV test was for the whole family, including her
150	
151	
152	
153	Fear of sons having HIV? Or to counter rumours?
154	
155	Fear of sons having HIV?
156	
157	Fear of sons having HIV? Potential signs of HIV. Worry
158	
160	She wanted to get them tested because they were having skin problems.
161	
162	
163	
164	Fear of sons having HIV. Anxiety
165	
166	Fear of sons having HIV. Anxiety
167	
168	
169	
170	<p>Fear of sons having HIV. Worry</p> <p>Relief sons are negative</p>

I then created a list of emerging themes and subthemes for the entirety of Cupcake's interview:

### **Draft themes and subthemes: Cupcake**

#### **Denial & loss**

- Denying HIV and treatment
- Loss of US opportunity
- Loss of father and siblings
- Loss of business
- Loss of future

- Loss of identity: I am HIV

#### Keeping HIV secret

- Maintaining silence
- Invisible HIV
- Protecting her sons: breastfeeding, secrecy, safe sex education, self-blame
- Telling her sons they are all negative
- Telling sons HIV meds are for another condition

#### Living with fear

- Fearing her sons have HIV
- Fearing telling her sons about her HIV
- Fearing loss of new business
- Fearing the 'sickness time' & death
- Preparing for sickness and death
- Fighting for life, hanging on

#### Self care and 'taking it into reality'

- The shock of illness
- Taking it into reality
- Coping & distraction strategies
- Depression & isolation

#### Talking about HIV, reflecting on HIV

- Telling her sister
- Help from her father
- Her friend who died of HIV
- Opportunities through HIV
- HIV limits your life
- Thanking God

## Appendix XI: Themes from all interviews

The letter and number after each theme indicate the interview, so, for example, S1 is Sandra, Interview 1 and C9 is Cupcake, Interview 9. By returning to the analysis for each interview, I was able to find the text identifiers and obtain the original quotation from the participant, in order to illustrate the themes throughout my findings chapters.

**Table 6: Themes from all interviews**

<b>1. NEGATIVE EMOTIONAL RESPONSES TO HIV</b>	
SHOCK	The shock of diagnosis (W4) Son's HIV a shock (S14) Eventual double (triple) diagnosis (S14) The shock of illness (C9) Shock of diagnosis (T13) (J12)
LOSS	Loss of US opportunity, father and siblings (C9) Loss of business (C9) Loss of identity: I am HIV (C9) Shattered dreams: Restrictions of HIV (T13) HIV as loss of opportunities (S1) In sickness you lose friends (M10) Lack of control: Others disclose on her behalf (S1) Loss of control (L3)
ANGER/ SADNESS/ GUILT	Anger that daughter's HIV should have been preventable (T13) Guilt at aunty's death (T13) Depression & isolation (C9) A sense of failure: broken dreams (T7)
DENIAL	I want to get rid of it (M10) Why me? (W4) Avoidance (L3) Do I really have HIV? : Doubting and denying HIV (T13) Physical and emotional paralysis (L3)
FEAR	Fear of medication (J6) Fear & dread of HIV / physical expression (M8) Fear of death as motivation to tell mother (M8) Fear, gossip and her relationship with her sister (P5) Fear and discrimination in the community (P5) Fears for of future losses due to HIV (M10) Shame and fear of meeting people she knows at the clinic (J12) Fearing loss of new business (C9) Fearing the 'sickness time' & death (C9) Fears: who will care for my children? (N15)
A JOURNEY/ BATTLE/HARD ROAD	It is not easy (M10) HIV as a rocky road (W4) Prospect of Fighting a series of stages as HIV progresses (S2) Fighting for life, hanging on (C9) Identity, sees self as a fighter (J6) I am a fighter (A11) HIV as a journey (S14) HIV as a journey, a rough road (A11)
DESTROYING/	'Mash-up' of relationship (W4)

WEAKENING RELATIONSHIP WITH PARTNER/OTHERS	HIV divided her and her babyfather's families (A11) Being judged by others (work colleagues) – buy it in the shop (M10) Negative family reactions (T13) Experiences of Stigma and discrimination (A11) Enacted stigma/Felt stigma (S14)
<b>2. POSITIVE EMOTIONAL RESPONSES TO HIV</b>	
DIAGNOSIS NOT A SHOCK	Diagnosis not a shock (J6) Premonition of HIV (M8) Being proactive: Looking for a diagnosis (P5) Chasing a diagnosis (S2)
SELFCARE: PHYSICAL HEALTH	HIV better than cancer, own cancer risk (A11) Multiple complex health issues, past and present (A11) Visible and painful symptoms (A11) In good physical health (M10) Staying physically well (J12) Starting medication: fear & uncertainty (S2) Physical challenges of taking medication with unpleasant side effects (T7) Following doctor's orders (S14) Controlling symptoms herself using bush medicine (A11) Conventional and bush medicine: combined or exclusive? (A11) Self-care (S14) (C9) (L3) Self-care and 'taking it into reality' (C9) Coping strategies: Physical health (N15) Taking care of herself and her daughter (T13)
MENTAL HEALTH	Managing mental health: not fretting (A11) Avoiding/seeking counselling (M10) Emotional health – forgetting HIV (J12) Distraction strategies (M10) Coping strategies: Emotional/social health (N15) Coping strategies: Mental health (N15) Family Helping her to forget (S1) Doing OK: a journey of understanding (T13) Acceptance, being positive (S14) Making choices (S14) Forgetting HIV (W4) Worrying & fear of worrying (N15) Coping & distraction strategies (C9) The benefits of counselling (N15) Understatement as protective mechanism (T7) Emotional distance: understatement as protective mechanism (N15) Comfort during interview (P5)
DOING GOOD	Acceptance & education: protecting others (W4) Being kind, accepting, positive (P5) Challenging discrimination (P5) Telling her story in public, felt stigma (A11) Being responsible (S14) Doing good: informal and anonymous advocacy (N15)
MOVING ON/ HOPE FOR THE FUTURE	Positive thoughts (S14) Getting over it (W4) Stages of acceptance (J6) Helping herself (A11) Respectable, independent & intelligent (L3) Regaining control (L3)



	<p>Moving on (L3)</p> <p>Living as if not sick (L3)</p> <p>Actions not words (L3)</p> <p>Trying to better herself (T7)</p> <p>Desire for financial independence (N15)</p> <p>Taking action, power of the mind (M8)</p> <p>Hope for the future, regaining control (M8)</p> <p>Seeing the positives (M8)</p> <p>Working to overcome the shame (M8)</p> <p>Hoping for a better future (T13)</p> <p>Strength &amp; a second chance (T13)</p> <p>Trying again (T13)</p> <p>An opportunity in becoming a grandmother? (N15)</p> <p>Defiance in the face of community reactions (C9). Also A11</p> <p>Wants a second chance to 'mother' as a grandmother (S2)</p>
<b>3. STRENGTHENED RELATIONSHIPS AND SOURCES OF SUPPORT</b>	
MAINTAINING/ STRENGTHENING RELATIONSHIP WITH PARTNER	<p>Caring for partner (S14)</p> <p>Being a good wife Caring for husband (S1)</p> <p>Not blaming, maintaining the relationship (S14)</p> <p>Strong relationship with babyfather/ keeping HIV private (S14)</p> <p>Husband's support (P5)</p>
MAINTAINING/ STRENGTHENING RELATIONSHIP WITH OTHERS	<p>Comfort &amp; hope: improved relationship with mother &amp; sisters overseas (M8)</p> <p>Relationship with her mother: Physical distance; desire for closeness (M8)</p> <p>Close bonds with siblings and mother (J12)</p> <p>Improved relationship with her sister (C9)</p> <p>Being mothered, Mother pre-empting death (L3)</p> <p>Grandmothering/role of grandmother (L3)</p> <p>Positive family reactions (L3)</p> <p>Support and blame of own mother (M10)</p> <p>Friend/family/babyfather's co-worker's support (A11)</p> <p>Supportive friends (S2)</p> <p>Family support (W4)</p> <p>Support from cousin who is a doctor (P5)</p> <p>Practical, emotional support from family (S1)</p> <p>Support &amp; solidarity: family &amp; NGO (T7)</p> <p>Family uses TV to educate selves about HIV (S1)</p> <p>Other Support: organisations, friends, family (C9)</p> <p>Practical and emotional support: friend, family, 2<sup>nd</sup> babyfather (of 3) (T13)</p> <p>Family treats her the same (J12)</p>
PROFESSIONAL SUPPORT	<p>Support group (P5)</p> <p>NGO Support (A11)</p> <p>Influence of NGO involvement: support &amp; pressure? (T7)</p> <p>Support &amp; solidarity: family &amp; NGO (T7)</p> <p>Seeking medical, emotional, spiritual reassurance (M8)</p> <p>Medical support (P5) (A11)</p> <p>Receiving medical reassurance (S2)</p> <p>Support from medical staff (S14)</p> <p>Other Support: organisations, friends, family (C9)</p>
STRENGTH FROM GOD	<p>Faith in God (S14)</p> <p>Strength from God (W4) (J6) (S2) (J12)</p> <p>God has a plan (S1)</p> <p>Thanking God (C9)</p>

	<p>Coping strategies: Spiritual health (N15)</p> <p>Seeking medical, emotional, spiritual reassurance (M8)</p>
<b>4. PROTECTIVE MOTHERING IN THE CONTEXT OF HIV</b>	
PROTECTING CHILDREN BY TELLING/NOT TELLING	<p>Protecting by telling (N15) (L3)</p> <p>Protecting by not telling (L3)</p> <p>Protecting her sons (C9)</p> <p>A triple secret: protecting her son (S14)</p> <p>Protecting by not telling (N15)</p> <p>Protecting by telling (N15)</p> <p>Family secrets: daughters don't know about mothers HIV or that father died of AIDS (M10)</p> <p>Told her sons to protect the relationship (A11)</p> <p>Reasons to tell children 1.: Protecting themselves (T7)</p> <p>Reasons to tell children 2.: Demonstrates a close bond (T7)</p> <p>Reasons to tell children 3. Teaching them not to 'stigmatise' (T7)</p> <p>Disclosure advice for other mothers: take your time, make your own decision, but hard if children hear it from others (P5)</p>
GUILT AND ANXIETY: HIV+ CHILDREN	<p>Her sons health: anxiety and pride/relief (S14)</p> <p>Daughter's 'Downfall': Guilt (T13)</p> <p>Son's 'downfallment' (S14)</p> <p>Shattered dreams: HIV restricts her daughter's opportunities (T13)</p> <p>Makes it difficult to have another daughter (T13)</p> <p>Testing her sons for HIV (C9)</p> <p>Putting to rest concerns about children and HIV (J12)</p> <p>Anxiety about her sons and HIV (A11)</p> <p>Testing sons for HIV (L3)</p>
<b>5. CHALLENGES OF DISCLOSING HIV TO CHILDREN/OTHERS</b>	
DISCLOSURE TO FAMILY AND FRIENDS	<p>Keeping HIV a family secret (P5)</p> <p>Selective disclosure (W4)</p> <p>Telling her family (A11)</p> <p>Choosing to tell/not tell (J6)</p> <p>Telling adults first (J6)</p> <p>Telling but not telling: her twin sister (S2)</p> <p>Maintaining silence about HIV (C9)</p> <p>Feeling alone and wanting to reach out (S2)</p> <p>Preserving the secret from the community (T7)</p> <p>Other family members: telling some but not all (M10)</p> <p>Protect yourself (tell partners you have HIV or they will kill you) (A11)</p> <p>Fear of other people gossiping (W4)</p> <p>Wanting to tell but afraid (W4)</p> <p>Fears people knowing her son's status/their statuses intertwined (S14)</p> <p>Family guards the secret within chosen members (J12)</p> <p>Privacy &amp; confidentiality within the family unit (J6)</p> <p>A whole-family disclosure fantasy (S2)</p> <p>Protecting (excluding?) her own mother (S2)</p> <p>Discrimination by proxy: Hears people discriminating on the street, makes her want to keep the secret (N15)</p>
PREPARING TO TELL CHILDREN	<p>Desire to be strong enough to 'repair' children (M10)</p> <p>Uncertainties and half-truths: talking to her younger son (J12)</p> <p>Considering telling (L3)</p> <p>Preparing to tell (S1)</p> <p>Finding time &amp; space (J6)</p> <p>Exploring ways to tell her children (P5)</p>

	Thoughtful, considered parenting: creative preparation to tell son (P5)
DISCLOSURE AND DISTANCE: PHYSICAL/ EMOTIONAL	<p>Relationship with older children disrupted by distance (J12)</p> <p>Distance from children (T7)</p> <p>Sense of responsibility for daughter (though brought up by her mother/ sister) (S2)</p> <p>Own relationship with oldest daughter in USA: distance (M8)</p> <p>Lack of bond with daughter, feeling excluded (S2)</p> <p>Telling some children, wanting to tell other children, overcoming distance (T7)</p> <p>Responsible for telling child about HIV (betrayed by own mother) (L3)</p> <p>Mothering at a distance (L3)</p>
NOT WANTING TO TELL CHILDREN	<p>Defying medical pressure to tell her daughter (T13)</p> <p>Paralysis I just don't want them to know (S1)</p> <p>Choosing not to tell (S1)</p> <p>Keeping HIV 'enclosed'(S1)</p> <p>Denying HIV and treatment (C9)</p> <p>Not telling youngest child: beliefs about childhood (T7)</p> <p>Not talking about it (L3)</p> <p>Deceiving her sons about her own HIV (C9)</p>
FEARS/ CHALLENGES OF TELLING CHILDREN ABOUT HIV	<p>Fear of scorn (S1)</p> <p>Fear of damage to parent –child relationship (S1)</p> <p>Fear of causing distress (S1)</p> <p>Fears and uncertainty about telling children (S14)</p> <p>Worry, uncertainty &amp; fear about telling her children, especially youngest (past tense) (P5)</p> <p>Worrying about how to tell children (past tense) (M8)</p> <p>Fearing telling her sons about her HIV (C9)</p> <p>Fears about telling her daughter (T13)</p> <p>Fears about telling her sons (T13)</p> <p>Fear &amp; uncertainty about telling children (M10)</p> <p>Fear of being judged by daughter &amp; sister (S2)</p> <p>Role of school HIV education: not helpful (M10)</p> <p>Disclosure as a one off event, not a process (J12)</p> <p>Veiled indirect communication, children try to express concern, support (J12)</p> <p>Struggling to tell 3<sup>rd</sup> child: a multi-step process (complex situation) (T7)</p> <p>Hardest to tell her daughter, emotional, both crying (J12)</p> <p>Childhood: sons as independent, responsible for own knowledge (L3)</p>
<b>6. Positive aspects of mothering with HIV</b>	
SUPPORT FROM CHILDREN (MEDICATION/ PRACTICAL/ EMOTIONAL)	<p>Accepting medication from son (L3)</p> <p>Child helping with medication (S1)</p> <p>Medication as focal point of disclosure to children (J6)</p> <p>Support from sons – practical, financial (A11)</p> <p>Practical assistance from children (J6)</p> <p>A stronger relationship, daughters helping her (M8)</p> <p>Importance of children's emotional &amp; other support for her own health (P5)</p> <p>Desire to tell: Shift to receiving support from children, a more honest and open relationship (M10)</p> <p>Children as inspiration/motivation to live (J6)</p> <p>Motivation to persevere with taking medication (T7)</p> <p>Children as hope (T13)</p>
COLLABORATIVE MOTHERING:A	<p>Collaborative approach to parenting (J6)</p> <p>Knowledge as positive (J6)</p>

SHARED JOURNEY/ DISCLOSURE INDICATIVE OF CLOSE BOND	<p>Empowerment through knowledge (J6)</p> <p>A stronger relationship: protecting &amp; reassuring daughters (M8)</p> <p>Children's questions &amp; reassuring them (J6)</p> <p>Close affectionate supportive relationship with children (P5)</p> <p>What goes around comes around: collaborative parenting (P5)</p> <p>Good relationship with children (S14)</p> <p>A journey of learning together (M8)</p> <p>A stronger relationship: feeling closer (M8)</p> <p>Benefits to her and her daughter: a comforting ritual (W4)</p> <p>Disclosing as a learning journey (J6)</p> <p>Confronting HIV: gaining strength through telling (M8)</p> <p>Telling her daughter: supportive(W4)</p> <p>Her sons don't scorn her: acceptance (A11)</p> <p>Deciding to tell her sons (A11)</p>
<b>7. WIDER CONTEXTUAL FACTORS</b>	
MORALITY/ SOCIAL EXPECTATIONS AND HIV	<p>HIV as judgement (A11)</p> <p>Denial of HIV is weak, murderous (W4)</p> <p>I didn't know I had it (S14)</p> <p>Cheating, relationships and HIV (S14)</p> <p>Lack of trust (S14)</p> <p>Gender norms: women as faithful (W4)</p> <p>Gender norms: women as passive (W4)</p> <p>Identity in the context of HIV: passive? (J12)</p> <p>Incorporating HIV into her life story: choice &amp; lack of blame (S2)</p> <p>It is not my fault – betrayal by babyfather (A11)</p> <p>HIV as disruption of identity, result of r/ship with violent older man (M8)</p>
POVERTY	<p>Lifelong poverty (J12)</p> <p>Poverty &amp; limited choice (T7)</p> <p>Multiple challenges: violence, homelessness, health issues, bereavement, premature baby (T7)</p> <p>Juggling priorities and negotiating practical challenges (S14)</p> <p>Financial support: who to turn to for help? (J12)</p>
CHALLENGES OF BEING A MOTHER	<p>Mothering &amp; pregnancy with HIV (N15)</p> <p>Mothering a child with challenging behaviour (N15)</p> <p>Mothering three young children and a pregnant teenager (N15)</p> <p>Aspirations for children (N15)</p> <p>Teaching children manners (N15)</p> <p>Being a 'good mother' protecting her identity (S1)</p> <p>Being a 'good mother' putting children's needs first (S1)</p> <p>Being a 'good mother' teaching children to protect themselves (S1)</p> <p>Supporting children financially (T7)</p> <p>Supporting children emotionally (T7)</p> <p>Burden of parenting alone, sense of betrayal by partner (M10)</p> <p>Responsibility for care of child (L3)</p> <p>Being a selfless mother: protecting children, supporting school, career <i>etc.</i> (M10)</p>

## Appendix XII: Excluded themes

These are themes which I identified during the analysis process but subsequently excluded as they are not directly related to my research question. The codes are the first letter of the participant's first name (pseudonym) and the number of the interview. For example the first interview was with Sandra, so her interview code is S1.

**Table 7: Excluded themes**

MAKING SENSE OF LIVING WITH HIV: THE EXPERIENCES OF JAMAICAN MOTHERS	
Shock/not a shock	<p>The shock of diagnosis (W4) (J12) (T13)</p> <p>Son's HIV a shock (S14)</p> <p>Eventual double (triple) diagnosis (S14)</p> <p>The shock of illness (C9)</p> <p>Diagnosis not a shock (J6)</p> <p>Premonition of HIV (M8)</p> <p>Being proactive: Looking for a diagnosis (P5)</p> <p>Chasing a diagnosis (S2)</p>
Loss	<p>Loss of US opportunity, father and siblings (C9)</p> <p>Loss of business (C9)</p> <p>Loss of identity: I am HIV (C9)</p> <p>Shattered dreams: Restrictions of HIV (T13)</p> <p>HIV as loss of opportunities (S1)</p> <p>In sickness you lose friends. (M10)</p> <p>Lack of control: others disclose on her behalf (S1)</p> <p>Loss of control (L3)</p> <p>'Mash-up' of relationship (W4)</p> <p>HIV divided her and her babyfather's families (A11)</p> <p>Being judged by others (work colleagues) – buy it in the shop (M10)</p> <p>Negative family reactions (T13)</p> <p>Experiences of Stigma and discrimination (A11)</p> <p>Enacted stigma/Felt stigma (S14)</p>
Distress	<p>Anger: daughter's HIV should have been preventable (T13)</p> <p>Guilt at aunty's death (T13)</p> <p>Depression &amp; isolation (C9)</p> <p>A sense of failure: broken dreams (T7)</p> <p>I want to get rid of it (M10)</p> <p>Why me? (W4)</p> <p>Avoidance (L3)</p> <p>Do I really have HIV? : Doubting and denying HIV (T13)</p> <p>Physical and emotional paralysis (L3)</p>
Fear	<p>Fear &amp; dread of HIV / physical expression (M8)</p> <p>Fear of death as motivation to tell mother (M8)</p> <p>Fear, gossip and her relationship with her sister (P5)</p> <p>Fear and discrimination in the community (P5)</p> <p>Fears for of future losses due to HIV (M10)</p> <p>Shame &amp; fear of meeting people she knows at clinic (J12)</p> <p>Fearing loss of new business (C9)</p>
BEING PROACTIVE: CARING FOR THE SELF AND SOURCES OF SUPPORT	
Self care: physical health	<p>HIV better than cancer, own cancer risk (A11)</p> <p>Multiple complex health issues, past and present (A11)</p> <p>Visible and painful symptoms (A11)</p> <p>In good physical health (M10)</p> <p>Staying physically well (J12)</p> <p>Starting medication: fear &amp; uncertainty (S2)</p>

	<p>Physical challenges of taking medication with unpleasant side effects (T7)</p> <p>Following doctor's orders (S14)</p> <p>Controlling symptoms herself using bush medicine (A11)</p> <p>Conventional &amp; bush medicine: combined or exclusive? (A11)</p> <p>Self-care (S14) (C9) (L3)</p> <p>Self-care and 'taking it into reality' (C9)</p> <p>Coping strategies: Physical health (N15)</p>
Self care- mental health: Avoiding 'fretnation'	<p>Managing mental health: not fretting (A11)</p> <p>Avoiding/seeking counselling (M10)</p> <p>Emotional health – forgetting HIV (J12)</p> <p>Distraction strategies (M10)</p> <p>Coping strategies: Emotional/social health (N15)</p> <p>Coping strategies: Mental health (N15)</p> <p>Family: Helping her to forget (S1)</p> <p>Doing OK: a journey of understanding (T13)</p> <p>Acceptance, being positive (S14)</p> <p>Making choices (S14)</p> <p>Forgetting HIV (W4)</p> <p>Worrying &amp; fear of worrying (N15)</p> <p>Coping &amp; distraction strategies (C9)</p> <p>The benefits of counselling (N15)</p> <p>Understatement as protective mechanism (T7)</p> <p>Emotional distance: understatement as protective mechanism (N15)</p> <p>Comfort during interview (P5)</p>
Maintaining/strengthening relationship with partner	<p>Caring for partner (S14)</p> <p>Being a good wife, caring for husband (S1)</p> <p>Not blaming, maintaining the relationship (S14)</p> <p>Strong relationship with babyfather/ keeping HIV private (S14)</p> <p>Husband's support (P5)</p>
Maintaining/strengthening relationship with others	<p>Comfort &amp; hope: improved relationship with mother &amp; sisters overseas (M8)</p> <p>Relationship with her mother: Physical distance and desire for closeness (M8)</p> <p>Close bonds with siblings and mother (J12)</p> <p>Improved relationship with her sister (C9)</p> <p>Being mothered, Mother pre-empting death. (L3)</p> <p>Grandmothering/role of grandmother (L3)</p> <p>Positive family reactions (L3)</p> <p>Support and blame of own mother (M10)</p> <p>Friend/family/babyfather's co-worker's support (A11)</p> <p>Supportive friends (S2)</p> <p>Family support (W4)</p> <p>Support from cousin who is a doctor (P5)</p> <p>Practical, emotional support from family (S1)</p> <p>Support &amp; solidarity: family &amp; NGO (T7)</p> <p>Family uses TV to educate selves about HIV (S1)</p> <p>Other Support: organisations, friends, family (C9)</p> <p>Practical and emotional support: friend, family, 2<sup>nd</sup> babyfather (of 3) (T13)</p> <p>Family treats her the same (J12)</p>
Disclosure to family and friends	<p>Keeping HIV a family secret (P5)</p> <p>Selective disclosure (W4)</p> <p>Telling her family (A11)</p> <p>Choosing to tell/not tell (J6)</p> <p>Telling adults first (J6)</p> <p>Telling but not telling: her twin sister (S2)</p> <p>Maintaining silence about HIV (C9)</p>

	<p>Feeling alone and wanting to reach out (S2)</p> <p>Preserving the secret from the community (T7)</p> <p>Other family members: telling some but not all (M10)</p> <p>Protect yourself (tell partners you have HIV or they will kill you) (A11)</p> <p>Fear of other people gossiping (W4)</p> <p>Wanting to tell but afraid (W4)</p> <p>Family guards the secret within chosen members (J12)</p> <p>Privacy &amp; confidentiality within the family unit (J6)</p> <p>A whole-family disclosure fantasy (S2)</p> <p>Protecting (excluding?) her own mother (S2)</p> <p>Discrimination by proxy: Hears people discriminating on the street, makes her want to keep the secret (N15)</p>
Professional support	<p>Support group (P5)</p> <p>NGO Support (A11)</p> <p>Influence of NGO involvement: support &amp; pressure? (T7)</p> <p>Support &amp; solidarity: family &amp; NGO (T7)</p> <p>Seeking medical, emotional, spiritual reassurance (M8)</p> <p>Medical support (P5) (A11)</p> <p>Receiving medical reassurance (S2)</p> <p>Support from medical staff (S14)</p> <p>Other Support: organisations, friends, family (C9)</p>
Strength from God	<p>Faith in god (S14)</p> <p>Strength from God (J6) (W4) (J12) (S2)</p> <p>God has a plan (S1)</p> <p>Thanking God (C9)</p> <p>Coping strategies: Spiritual health (N15)</p> <p>Seeking medical, emotional, spiritual reassurance (M8)</p>

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