HIV+ MOTHERS FROM SUB-SAHARAN AFRICA: RECOGNIZING RESISTANCE

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RECOGNIZING RESISTANCE

By

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ABSTRACT

This thesis sought to explore the particular experiences of HIV positive mothers living in Toronto, who are refugees and immigrants from Sub-Saharan Africa. The research was based upon a secondary analysis of a data set produced by The Hospital for Sick Children and The Teresa Group for a project in Toronto entitled, <u>Perspectives on Parenting from HIV+ Parents from Sub-Saharan Africa and the Caribbean.</u> This secondary analysis was framed by questions about women's responses to their worry, guilt and loss; it drew on theoretical perspectives that highlight women's work and coping as forms of resistance to adverse social conditions.

The interview transcripts of thirteen members of the original sample of twenty-two formed the basis of the analysis: all thirteen were women originally from countries in Sub-Saharan Africa. A material-discursive approach was employed to explore the women's accounts of their active responses to the challenges they faced.

The findings revealed the odds and difficulties that the women experienced in their daily lives, and the practical and narrative ways in which they managed them. Embedded in their accounts were various forms of work, undertaken to cope with and improve their own situations and the situations of those they cared for. Particular attention was given to the women's understandings of ways in which their self-directed coping could be either sustained or undermined. Their insights have implications for service provision and future research and, more broadly, suggest that attention is needed to the material and institutional structuring of their lives in Canada.

This thesis is dedicated in gratitude
to the thirteen extraordinary mothers who participated in the research;
and to my mom who is an extraordinary mother.

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INTRODUCTION

There is a significant body of research and literature devoted to issues related to

HIV/AIDS, and more specifically to the distinct experience of parents who are HIV

positive (Antle et al., 2001; Faithful., 1997; Hackle et al., 1997). Much of this literature

discusses the stress and challenges that parents struggle with while managing the

responsibility of parenting and their children's needs as well as dealing with their own

health status. Additionally, there is a body of evidence that highlights the difficulties

faced by those seeking refuge from their countries of origin (Lacroix, 2002; George,

2002). However, little is known about the experiences of refugee and immigrant parents

who are HIV positive. This qualitative research seeks to explore the particular

experiences of mothers infected by HIV living in Toronto, who are refugees and

immigrants from Sub-Saharan Africa.

I have a long-standing personal and professional interest in both health related

issues and working with families. These interests led me to become involved with The

Teresa Group, a social service agency in the Toronto area that works exclusively with

children and families affected by HIV and/or AIDS. My volunteer work with the agency

has included facilitating groups for both children and mothers infected by HIV, a majority

of whom were from HIV endemic countries. I was impressed by the sustained courage of

these mothers and children in the face of what appeared to be very challenging

conditions. I was invited by the agency to join an established research team that had

spent the previous year seeking to learn more about the experiences of parents infected

with HIV or AIDS who had come to Canada from the Caribbean or Sub-Saharan Africa (Antle, et al., 2003). With appropriate ethical clearance, the team/principal investigator made available to me the transcripts of the research participants' interviews for the purpose of my thesis research. I eagerly seized the opportunity to explore the character and significance of the courage and challenges that I had witnessed in my practice.

Before a description of the research and its results, the broader backdrop of HIV/AIDS globally and in Canada is briefly set, followed by the introduction of some fundamental theoretical ideas that framed this project.

HIV/AIDS: The Global and Local Context

HIV/AIDS continues to devastate lives throughout the globe. Despite extensive

research and education campaigns, the number of those infected with HIV is on the rise

around the world. Recent statistics from UNAIDS estimate that approximately 39.4

million people throughout the world are infected with Human Immunodeficiency Virus

(UNAIDS Global Summary, 2004). The number of women infected with HIV has

increased dramatically in the last several years (UNAIDS, 2004; Romans, 2000; Sowell et

al., 1997; Mason, 1998). In Canada, adult women represent a growing proportion of the

population who test newly positive for HIV (Health Canada, 2004). In the year 2003,

twenty-five percent of the newly diagnosed cases of HIV infection in the country were

women. This statistic becomes more striking when one considers that women only

represent 10% of the total national HIV infected population. Thus, women are being

infected at a very rapid rate when compared to the rest of the population.

Patterns of HIV transmission are changing. In the past, HIV infections among

men have significantly outnumbered those among women; however this has begun to

shift. Increasingly, unprotected heterosexual contact is the mode of transmission for the

disease and accounts for a majority of the female positive HIV cases (UNAIDS, 2004).

In 1998, 41% of adults living with HIV were women; six years later, the number has risen

to 50% (UNAIDS, 2004). In Health Canada's 2003 surveillance report on HIV/AIDS it

was noted that (between 1985-2003), there were 55,180 people who were known to have

tested positive for HIV in the country (Health Canada, 2004, pg.11). Of that total over

7,500 were women and of those women, more than 3,000 lived in the province of

Ontario. In addition, 75% of these women were considered to be of child-bearing age

(Health Canada, 2004). This is significant since many of the women who have children

and are HIV positive are the sole caregivers for their children. Furthermore, the children

of these women may have no other caregiver in the event of illness or death (Mason,

1998). Women's experience with HIV is arguably different than that of men. Influences

such as poverty, role as primary caregiver, and the social gender expectations placed on

women all work to inform and construct a women's life experiences (Sowell et al., 1997).

It is also important to recognize that women of colour are disproportionately

infected with HIV, both globally and in North America (UNAIDS, 2004; Mason, 1998).

Sowell et al. (1997) wrote that "in contrast to men with HIV/AIDS, women with HIV

infection tend to be poor, non-white and have been infected through heterosexual

contact". In Canada, the number of new cases of HIV infection among white people has

decreased, while the number of Aboriginal and Black people infected has increased

(Health Canada, 2004). In 1993 Black Canadians represented only 8.4% of the reported

HIV/AIDS cases and by 2003 the number had more than doubled to 21.5%. (Health

Canada, 2004, pg.16). Research indicates that African-American men and White women

were more likely to receive social support after the disclosure of their HIV positive status

than African-American women (Clarke et al., 2003). Overall, women of colour who are

infected by HIV are more likely to experience stigma than those who are white, not only

because of their health status but also related to the marginalization of being from a lower socio-economic status and their minority ethnic or racial affiliation (Clarke et al., 2003). In Canada, it is significant that there has been an increase over the past five years in the numbers of persons infected from endemic countries, which are defined as the Caribbean Countries and those in Sub-Saharan Africa (Health Canada, 2004). Women from endemic countries have fifty times greater risk of becoming infected than women from other countries (Health Canada, 2004). Those from Sub-Saharan Africa account for almost half of all reported HIV infected cases that are transmitted by unprotected heterosexual contact in Canada (Health Canada, 2004). In Ontario, immigrants and refugees from endemic countries have grown to be the second largest infected population, with men who have sex with men being the largest group (Health Canada, 2004).

Parents who are HIV positive face particular challenges. They must deal not only with their own reactions to their health status and its life changing implications, but also address the concerns and demands related to the needs of their children (Antle, 2001; Lee, 1999; Faithful, 1997; Kaplan et al, 1997). Parents who are HIV positive often note the primacy for them both of learning to manage their health, and simultaneously caring for and protecting their children. Parents often have to deal with significant issues related to stigma, discrimination, disclosure and secrecy (Hackle et al., 1997; Antle, et al.2001). Many choose not to disclose their HIV/AIDS status to their children. There are a vast number of complex layers that become significant in this decision, including cultural, political and economic implications. Concern for children's emotional and mental well-

being, worry that if they know they may disclose the information to others, fear that they

may reject the parent, concern that knowing will prevent them from having 'normal'

childhoods and fear that they may be rejected by others are just some of the issues

(Scrimshaw and Siegel, 2002). Parents fear that their children, who may already be

marginalized due to socio-economic status, race or ethnicity, will be further marginalized

and rejected as different because of HIV/AIDS being in their family (Antle, 2001;

Scrimshaw and Siegel, 2002). Parents sometimes choose not to disclose their HIV status

as a way of protecting children from negative consequences, however, children are aware

that information is being withheld and that there are 'secrets' in the family (The Teresa

Group, 2002).

In spite of the dramatic rise in HIV infection among women of childbearing age,

and particularly among refugees and immigrants, there has been little research attention to

the experiences of refugees and immigrants mothers who are HIV positive. One study

based in New Zealand considered the needs of HIV positive refugees from Africa and

established a health program specific to the population to address their unique needs

(Worth, et al., 2003). Those from marginalized ethnic and racial communities often face

increased barriers to accessing HIV/AIDS services due to the extensive stigma of the

disease in their families, community, country of origin and country of refuge (Klien,

2000). As noted previously, there has been research on the experiences of parenting

while HIV positive and on such issues as stigma, disclosure, and death. However, a

search of the relevant literature has failed to produce any information on the particular

experiences of refugees who are HIV positive parents and the unique challenges they face and concerns they may have. In light of the apparent absence in research, the increased rate of HIV infection among women who are of childbearing age, and the growing population of individuals from sub-Saharan Africa seeking refuge in Canada who are HIV positive, there is a need to gather further information and insights into the particular needs and concerns of women who are HIV positive refugee parents living in Canada.

This thesis strives to contribute to this endeavour by particularly exploring the experiences of mothers from Sub-Saharan Africa in the larger study of which this is a part. Some central concepts that provided the framework and guided this exploration are introduced below.

THEORETICAL CONTEXT

Mothers from Sub-Saharan Africa are likely to come into institutional and service

orbits because of a range of challenges and problems related to, for example, their

citizenship status, practical settlement issues and HIV positive health status. In these

environments, central attention is – perhaps inevitably – focussed on their problems and

deficits. In this research, I have sought to balance this pattern of attention by focussing

on women's strengths and achievements – an approach informed by a number of

theoretical perspectives that are introduced below.

From the literature and from my practice experience with them, it is evident that

HIV positive mothers have faced and continue to face enormous challenges in their lives.

It is also evident that they work very hard to meet and deal with the challenges on a day

to day basis. Aptheker's (1989) analysis of women's work as everyday resistance

illuminates the significance of their efforts and was a key conceptual foundation for the

secondary analysis that I undertook here. Aptheker(1989) argues that the strategies and

work of women's everyday resistance is generally overlooked, and that the value of these

daily acts of resistance and their cumulative effects need to be acknowledged, accounted

for and learned from (Aptheker, 1989). She cautions that this is not to minimize the

reality of the social context from within which the women operate:

> To focus on women's resistance as it exists within the parameters of
> their daily lives is not to celebrate the confinement or to romanticize the
> enormity of the damage inflicted. It is to acknowledge the meaning
> women invest in their daily lives, to acknowledge this work on its own
> merits, to acknowledge that many women are indeed activists who have

participated in the shaping of history, and have 'walked purposefully in and out of the front doors of their lives' (Aptheker, 1989. pg 175).

Aptheker also makes the case for reframing the concept of 'coping' as resistance. Rather than understanding coping as an individual or psychological construct, she suggests instead that it can be better understood as a social and political mechanism by which individuals resist the oppressive conditions of their lives (Aptheker, 1989). This reframing more accurately captures the active and innovative nature of the strategies of resistance that women employ, generally unseen, in their daily lives. For the purposes of this thesis, 'coping' and resistance are used interchangeably, with the understanding that 'coping' is more widely defined than its sometimes narrow individual and psychological usage.

Other feminist writers amplify the dimensions and social structuring of women's often overlooked resistance. For example, Schilt (2003) sought to understand the lives of adolescent girls and the ways in which some resist the loss of their voice during their adolescent years (Schilt, 2003). She described both the covert and overt forms of their resistance to dominant perception of teenaged girls (Schilt, 2003). Focussing similarly on how women resist conventional constructions of gender, Hollander (2002) explored the representation of women in violent situation involving men and found that along side the conventional constructions of gender there are alternative discourses that resist these constructions (Hollander, 2002). From this analysis Hollander (2002) posed the following questions:

Under what circumstances do such alternatives arise?
What happens to these alternative ideas?

What forces sustain or undermine this resistance?

Hollander's delineation of forces that sustain and forces that undermine is especially valuable as it directs attention to the external and internal forces that impact upon a woman's ability to resist i.e. to the social structuring of possibilities of resistance. It also identifies areas for change and advocacy that can serve to bolster forces that sustain and mitigate factors that serve to undermine women's efforts.

Just as Aptheker, Schilt, and Hollander draw attention to the work and social structuring of resistance, a related literature highlights the work of mothering and the way women's lives are embedded in the relations of care and responsibility. Maher (2004) argues that there has not been enough attention given to the every day work that mothers do in relation to their children. She suggests that understanding mothering and its work as a trade "focuses attention on the skills and strategies that women use to operate effectively across different spheres of endeavour. It promotes an understanding that "being a mother" is a more complex, pliable and active state than is commonly assumed" (Maher, 2004, pg 14). Similarly, Watler Carney identifies that motherhood is in many ways a disregarded form of management that provides opportunity for skill development that is transferable to other areas of life (Walter Carney, 2004). Both Walter Carney and Maher draw attention to the skills and effort involved in mothering and how these mesh into other work realms outside of being a mother. This perspective lent itself well to the analysis of the experiences shared by the mothers in the research.

These conceptual ideas – resistance and the social and political patterning of coping and mothering, are taken up in some social work perspectives that also inform this

project: Anti-Oppressive Perspective and Strengths Perspective. An anti-oppressive

perspective (AOP) is concerned with understanding and responding to the influence of

institutional structures and unequal power relations on individual's personal experiences,

particularly those who are oppressed (Lee, 2003). The pursuit of social justice with those

who are marginalized by structural forces is central to this perspective and it rests on the

notion that the personal is political – personal troubles are indeed public issues (Lee,

2003). An AOP perspective therefore requires social workers to address and locate

themselves amid the power relations that structure systemic privilege and disadvantage, to

work alongside those who are marginalized, and to challenge the structural and social

frameworks that maintain systems of social injustice (Lee, 2003).

In the research reported here, this approach to analysis and practice is useful in

directing attention to the social structuring of individual experience and to the particular

axes of structural inequality framing study participants' lives, notably: gender, race,

culture, income, immigration and health status. This AOP approach also requires me to

locate myself clearly and consciously in the research. As a white, middle-class, HIV

negative, Canadian-born woman with no children, my social location differs from all of

the women in the study with the exception of gender. I am very much an "outsider" to

their experiences (Narayan, 1994), and it is the women who are the experts and authority

on issues that pertain to their daily lives. Each and every researcher's knowledge is

socially organized and grounded in their personal history and location (Campbell and

Gregor, 2002). Throughout the research of this thesis, I have attempted to be mindful of

the way in which my personal perspective may come into play in the process of research

and to give primacy to the participants' voices. It is my hope that I have listened to their stories the best I can and that the findings from this research will provide further understanding of their circumstances and the forces that shape their experiences and serve as a tool for greater social justice in their lives (Campbell and Gregor, 2002).

The strengths perspective in the social work literature tends to focus at a more micro level but is, arguably, compatible with this analysis as it looks beyond the socially constructed deficits and pathologies which problem-focussed service orientations often emphasize. Rather, a strengths perspective focuses on the resources and strengths of individuals and their collective community and does not assume that hardship inevitably renders a person weaker or needy (Saleebey, 1992). The lens provided by a strengths perspective was significant to this project as it values the personal accounts of individuals, recognizing them, their families and extended community as the experts and determining force behind any work undertaken (Saleebey, 1992). With these guiding theoretical frameworks in mind, I approached the secondary analysis described below.

METHODOLOGY:

This thesis research is a secondary analysis of a data set produced by a project currently underway in Toronto entitled, <u>Perspectives on Parenting from HIV+ Parents from Sub-Saharan Africa and the Caribbean</u> (Antle et al., 2003). The original research project was approved by the Research Ethics Board of The Hospital for Sick Children and an amendment was granted for the secondary analysis for the purpose of this thesis.

The original research project was conducted by The Hospital for Sick Children and The Teresa Group, an agency that offers practical and emotional support to families and children infected or affected by HIV/AIDS. The stated objective of the original project was to "provide insight with respect to their concerns as parents living with HIV/AIDS in a new country and lead to the development of consumer-informed strategies to more effectively meet the unique needs of parents and children from HIV-endemic countries" (Antle et al., 2003). The research questions guiding the original project were as follows:

1. What are the experiences and concerns of parents living with HIV who have emigrated to Ontario from HIV endemic countries with respect to family life and parenting?
   1.1 What role do the beliefs and customs of their home country/community play in their daily routines, family life and parenting practices in Canada?
   1.2 How have these parents handled disclosure of HIV status, particularly with respect to their children? How might service providers more effectively meet the needs of these parents and their children?

The research design employed to explore these questions was qualitative, which was considered ideal by the research team given the limited information known on this topic and the interest in the lived experience of those impacted (Charmaz, 1990). A

theoretical sample of parents from countries considered to be endemic (Sub-Saharan

Africa and the Caribbean) was sought through the agencies involved. Purposive and

theoretical sampling methods were used to recruit a sample made up of nineteen women

and three men; sixteen from African countries and six from the Caribbean and the average

length of time in Canada is four years (Antle et al, 2003). In-depth interviews with these

twenty-two parents were completed using an interview guide (see Appendix A). The

interviews took place over a one-year period at a location selected by the parent.

Participants were provided with an honorarium and child-care if required.

The original project has moved into the second phase of data collection and

researchers are now conducting focus groups. I became a member of the research team

through my involvement as a MSW student volunteering in different practice capacities

with The Teresa Group. When I joined, a majority of the individual interviews had

already been completed and the data analysis was underway. Although the results of the

analysis are not yet published, some core concepts and themes have been identified and

are guiding the on-going work. Specifically, issues of stigma, worry, guilt and loss are

emerging as key foci.

Secondary Analysis: Focussing the Thesis Research:

The literature on secondary analysis identifies some important considerations in

working with existing data sets. For example, Thorne notes that there can be great value

in conducting secondary data analysis, including efficiency and effectiveness in the use of

available data (Thorne, 1994). Secondary data analysis creates the opportunity to make

maximum use of existing research data sets, allowing for the possibility to further an

existing body of knowledge and extend the context of the research findings (Mauthner &

Doucet, 2003; Mauthner et al, 1998; Thorne, 1994). Heaton (1998) notes further that,

secondary analysis permits the utilization of data from particular populations who may be

difficult to access, and lessens the burden on respondents; can provide new understanding

and knowledge in different areas not originally considered; and can provide further

support for already established hypotheses and research (Heaton, J. 1998). Secondary

analysis also, of course, comes with some challenges which are taken up below, most

notably, questions of fit between existing data sets and researchers' theoretical

perspectives and empirical questions (Thorne 1993; Mauther et al, 1998).

The secondary analysis reported here focused on a particular subset of thirteen

members of this original sample of twenty-two; specifically on the thirteen women from

Sub-Saharan Africa. The rationale for selection of this sub-sample stems from the

demography of HIV infection among newcomers to Canada. As previously noted, the

rate of infection among women is increasing dramatically. The majority of single parents

with HIV are women. Therefore, the analysis focused specifically on mothers as it is

important to gain further insight into their particular experiences. Further, of those HIV

positive women from the Caribbean and Sub-Saharan Africa emigrating to Canada, there

is a larger proportion from Sub- Saharan Africa compared to the Caribbean.

The sample of thirteen women represented nine countries from Sub-Saharan

Africa and ranged in age from 29-56, with a median age of 37. The number of children in

the mothers' physical care ranged from one to eight. Several women also had more

children who for a variety of reasons reside in Africa. Of the thirteen women, two identified themselves as being single; seven as separated; two as married; one as divorced and one as widowed. At the time of the interviews, four women indicated that they were formally employed in paid work and nine were receiving some form of social assistance. Seven of the women describe attending a post secondary education program of some sort and five of the women completed high school. One woman did not indicate her level of formal education. Immigration/Refugee status among the women varied, as did the number of years that they had been in Canada, the average being four years.

The guiding research question for this secondary data analysis emanates directly from the original project and its central guiding question:

1. What are the experiences and concerns of parents living with HIV who have emigrated to Ontario from HIV endemic countries?

I also posed two more fine-grained questions about women's coping and active responses to their situations:

1.1 How do the mothers from Sub-Saharan Africa describe how they manage and respond to worry, guilt and loss?

1.2 What influences sustain or undermine them in their efforts to cope with their role as a mother in their contextual experience of being HIV positive and a newcomer to Canada?

These questions were not explored directly in the interview guide designed for the original study. However, participants' responses to that guide certainly included material on their work and their coping and enabled me to pursue my analytic focus.

Transcripts from interviews with the sub-sample of thirteen women form the basis

of the findings analysis reported here and were read with these questions in mind. I had

no identifying information for any of the participants and no direct contact with the

participants for the purpose of this research. The analytical approach follows that used by

Ristock (2002): a 'material-discursive approach' similar to that used by Campbell and

Gregor (2002) in their work. The material approach requires that a researcher attend to

the material content of a transcript, or the described story and practical organization of

everyday life of the participant (Ristock, 2002, p.37). The discursive element of the

analysis directs a researcher's attention to the way in which they tell their stories or

experiences and employ words and language to do so (Ristock, 2002, p39). Thus,

transcripts were read multiple times giving special attention and focus to identifying

different stories and themes within the text as described by the participants that may not

have originally been identified or focused upon. This method of analysis allowed for the

stories of the participants of the research to emerge, and provided an opportunity to

consider how the experiences of the participants are articulated and socially constructed

(Ristock, 2002).

This study – the original project and the secondary analysis – aimed to generate

some beginning knowledge about the experiences and positioning of HIV positive

mothers from endemic countries who are now living in Canada. Limits to the

'transferability' of the findings (Lincoln & Guba, 1985) stem from a number of factors:

the limited number of countries from which the women came; the lack of data on some of

their social and demographic characteristics, the fact that they all now reside in only one

Canadian city and the fact that (in order to be recruited to the study) they were all known to health services.   With these qualifications acknowledged, however, the conceptual mapping and preliminary picture generated in this qualitative study can make a useful contribution to this currently under-researched area.

FINDINGS:

As outlined in the introduction, mothers with HIV from Sub-Saharan Africa who have emigrated to Canada face multiple challenges. In contemporary Canadian culture, they are systemically disadvantaged by virtue of their race, lack of citizenship status, health, gender and class. They are likely to come into public view in institutional and service domains that construe them as lacking in some way, e.g. as claimants for refugee/immigration status, or as people in need of settlement services, practical assistance with housing, income or jobs. The research of which this thesis is an extension originated in a health service environment in which women are identified as needing medical and social supports because of their HIV status. Consequently, there is a risk that they predominantly be understood as needy, dependent, passive and sorely challenged by daunting odds. The key themes identified in the data analysis of the main project focused on difficulties that originate in issues of worry, guilt and stigma. The secondary analysis of this project offered an opportunity to delve into the context of those difficulties and to explore how women strove to cope with them.

Worry, guilt and stress were clearly evident in the accounts of study participants and are a seemingly natural response to the daunting odds and confining conditions they face in their lives. However, also present were stories and signals of the ways in which women cope with and actively push back against those odds. Key themes that emerged from my analysis of the interview transcripts concerned the vast amount of work required by the women to cope with their daily lives and the ways they found to manage against

odds that appear insurmountable. First, participants' descriptions of the odds and

difficulties they experienced are described, followed by their accounts of the kind of work

they do in response to them. With this appreciation of their work and their coping, I then

attended to their allusions of the ways in which their coping/resistance was variously

supported and undermined.

Life is not easy': The Challenges in Women's Lives

Appreciating the material context of the women's lives is integral when listening to their stories. The women in the project clearly articulated the difficulties of the daily demands that they face and just how hard it is for them to manage. They spoke of the "toughness" of their circumstances and the toughness it in turn required from them in the process of struggling to resist being overcome by their personal situations. Close attention to how the women described the hardness and toughness of their circumstances permits a deeper comprehension of the magnitude of what it is they must cope with and struggle to manage. One woman described her experience and how she deals with her particular difficulties:

> It's a cultural thing, it's like being tough. About being tough. That's what it is yeah. Yeah you have to be tough. Because everything else around you is tough. If you're not tough you're not going to live. Everything is hard. It's hard to describe it but life is just not easy, everything is about hardship. That's what you know. Life is not easy. So are you going to be crying all the time, or are you going to be complaining all the time? Just whatever happens bury it and move on. No self-pity and things like that. So I think that's what it is. They have to be tough. When there's crying nobody cares. ID105

She identifies toughness as being culturally rooted and necessary to survive life because everything in life is inevitably hard. Life is tough and she must be tough. The image of crying with no one caring and the need to bury things and move on speak to why she may have such a strong belief that one ought to be tough and not complain. Her understanding of reality is that she must cope and manage on her own and just deal with life because it is not going to stop being hard. The words hard and tough were used repeatedly by the women as they narrated their experiences.

A diverse number and combination of factors came together to make each individual mother's experience hard. For some it was the lack of family and community support; for others the inability to find employment, especially in the capacity for which they have already been trained; stigma and disclosure also add to the toughness of managing daily.

> Typical day oh wow, wow, wow. It's like war in here every day. In the morning when I get up I just like jump up it's like another day begins. Just keep going up and down no rest. No time for myself. I can't even remember when I last had a good shower you know. I have to go in the bath and then hurry up and get out of there you know. It's just too hard for me. Too much for one person to do. It's hard like no rest for me. Not even time for me to eat. Take care of myself. It's really hard like no help. Somebody with eight children, there's just too much to do. It's too hard. It's too hard. Every day it's hard. There's no one day easier. Every day is the same. Like when you wake up in the morning you say God help me. Let me go too. It's really tough. Sometimes I feel like I have no life. I ask God why was I born you know, Why do I have to go through this suffering. It's, it's just hard. And I feel like if I had my family here they would help me out. ....I have to take care of the children on my own. Like all day up and down doing this. I have to walk to the mall. Even when it's cold I walk back. Carry heavy bags on my back from the mall. I buy this stuff put them on my back and it's just so much. Then I come home my head is hurting. It's just hard. It's just hard. It's just hard. It's hard. It's tough. Nothing easy here. It's tough. Really tough. ID 86

> It is hard. Yeah. Because what makes it hard is because you don't have jobs. Yeah you don't have jobs that you are trained in that you're qualified in. You have to do jobs like manual work. And sometimes even that manual work is difficult to come by. So it's hard. There are a lot of obstacles that make life very hard for people like myself. ID101

Though there were a variety of 'obstacles' reflected in each woman's life, the theme of hardness and toughness through which they suffer was consistent throughout their interviews.

Another aspect implicated in the hardness the mothers face is the structural factors that are present and consistent for each of the mothers, including race and gender. No specific questions in the study asked about the implications of race and gender on the mothers' experiences. However, illusions to how both race and gender have affected their experiences are found throughout their stories. No direct quotes regarding race or gender are present in the mothers' interviews, yet the participants' experiences are nonetheless embedded in complex and unequal structural relations. Given that participants came from diverse African cultures and traditions, with variable economic and class histories, there is concern to not draw homogenous conclusions or stereotypes. That said, there were many accounts in which it was possible to discern signs of participants' subordination as women in Canada and in their countries of origin. For example, women recounted experiences of being sexually abused by men and spoke of instances where they had been subject to a man's power and authority:

> Women have it rough. Your rights are not equal to those of the
> men no matter what they say. It's the fact and it's not your fault. ID 57

In reading the transcripts I could also discern experiences of marginalization stemming from race. Notably, there were systemic barriers to good jobs because of immigration and employment policies, and an apprehension of official and institutional responses, especially given the added burden and stigma of HIV.

> And my husband was mistreated in the hospital; like he was treated like
> garbage. Even right now if I'm dying I don't want to go in the hospital
> 'cuz I feel like they will treat me like I'm a dirt. They treat my husband
> bad; he was sick, they don't care, they don't give him medicine, they shout
> at him. They do everything to him just because of what his diagnosis is.
> Like what he had, his sickness he had and mostly the colour of his skin. ID 86

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Their experiences as women of colour living with HIV had numerous implications on their ability to cope, manage and resist and are significant forces that work to undermine their efforts. Thus, while impacts of race and gender are made explicit only from time to time in interviews, they are embedded in participants' experiences and worthy of more attention in future research.

'I'm always so busy': Working, Coping, Resisting

In face of the hard conditions expressed, participants described multiple ways in which they worked to deal with and direct the circumstances of their lives. Their work revolved around a number of dimensions and themes: mothering, managing being a newcomer to Canada, managing their health status (on their accounts and in relation to others) and, lastly and only for some, paid employment. Their stories captured the extent to which their role and work as a mother consumed a majority of their time and effort.

Mothering

> Well I wake up in the morning. I have to wake them up. There's only one bathtub so you wake up one person and then when they're finished the other person goes. You have to keep on reminding them to hurry up. Find their clothes, get dressed, do this one, time to go, to have breakfast and everything and when they go to school like everything is quiet. When they come back again you know they're too much running up and down doing stuff. And like on the weekends, when I wake up on the weekends I make them do the housework, do what they have to do and then sometimes we go to church. Sometimes they take out their hair for me to do it up and down. Like children's stuff. Playing. Because I never have time. I'm always so busy so there's no time for me to sit and play with them. Play games with them or take them places but they want me to take them places but I have no time to do that, I wish I had enough time to take them out places. Or sit down, play games with them but I don't have no time so they play among themselves but only I prepare for them to eat. Every day of our lives is busy. ID 86

Unlike paid work, their role as mothers did not always provide them with a measure of their work or a concrete sense of value and worth for what it is they do each day. There was no pay cheque to show the return for their labour, no promotions, no one to praise a job well done.

Because now you have to do everything. It's not so much the work its

just that when you work you get that pay check and that's your sense of worth in a way. You don't realize it until you're not working anymore. When you're at home yes your family appreciates you but you kind of lose a sense of who you are. I don't know how else to explain that. It's very hard. You don't have a measure for your work. You don't really have a return for running around getting the child to daycare doing this that and the other. Your family appreciates it and you're happy but it's difficult it's very difficult. I've gotten used to it but it was extremely difficult in the beginning.   ID 57

Managing Being a Newcomer

In addition to their work mothering, the experience of being a newcomer to

Canada demanded significant amount of time and effort. At times the work of being a

mother and a newcomer blurred together:

The shelter said because I don't have any papers, my kids cannot go to school. So I use....when I came here, I made it my business to read. I used to go, on the internet, and read some more about Canada and the world. I didn't know anything about Canada. And I realized that you know when you're in a country, it's good to know about you know what they are about and I and I realize that in Canada the ...uh the government is a law that there's no child is under sixteen who can be denied entry into a school. So the people in the shelter, they were not very helpful. They were refusing to assist me to get my kids into... into school. And eh...I went to the internet, I found the Toronto Education Board, uh uh phone number. I phoned them and I went to see one director there, eh the Toronto Education Board, and then he gave me a letter... and then I took that letter to Regent Park and in the Jarvis and I put my kids in school, while I was still in the shelter. ID 95

Managing to navigate health, social services and other governmental systems in a

foreign country, with limited support, required a lot of work. Frustrations with the

employment system and the way that it makes finding paid employment challenging,

especially in one's field of interest, are echoed through the research participants' stories.

The women described how being newcomers and trying to also deal with the other factors in their lives, being mothers and HIV positive, was difficult:

> It's worse if you are an immigrant because being an immigrant means you cannot, you cannot like I said you can not get a job without the so called Canadian experience but how can you get that Canadian experience if they don't give you that job to have that experience. Then on top of that so you are still looking for a job, you are still trying to find your feet on the ground and then you have to think of buying medication. You have to think of raising your children.Very hard. ID101

> ...so most of the the problem they are facing is just, they'll tell me once you start working here, Ontario, they're going to cut your drug card. They say once you're going to apply for a job, most of them they have to know you are healthy, problem. So they cannot take your insurance because they know you are sick. You have to buy your own insurance. Yah, which they they think they can go to buy a drug card. So there was one kid, most of them tell me it's difficult to work...Yah. Cause they have to work so hard the end of the day find nothing. You are you you have nothing, you know. Yah. But if ah they can help them just to give, to give that only the drug, continual, continuously. Interview ID 2

The complexity of their circumstances as newcomers was striking. They had work to balance their health needs as people with a chronic illness, with their responsibility as mothers to care and provide for their children, and all within a social system that is often experienced as inhospitable and that demands tremendous effort. The desire of many of the women to have formal paid work was real, but so was the fear of what consequence that could have on their health. The research participants all come from countries where access to needed and life saving medication is not a right but a privilege most do not have. To consider any sort of decision that may jeopordise the guarantee of those medications being available would be an enormous risk. This aspect of management goes beyond the traditional conceptual understanding of daily work and highlights the

multiple ways the mothers in the study work to manage a variety of complicated aspects in their lives and how it will impact their health and survival.

Managing Health: For Self and For Others

The management of their own health, and sometimes that of a child or partner, is another area that women exert a great deal of effort and labour. The informal and emotional work involved in living with HIV is a daily burden that the mothers endure. Their HIV positive status places limitations on the choices that they are able to make and how they cope. One woman described her experience and how her HIV positive status is a constant factor in her life she cannot escape:

> I don't know, it's like being on parole. It like yeah this is how, you're free now as long as you do A, B, C and if you do A, B, C you stay out but if you break the rules you are back in jail so enjoy the freedom because now you are not totally free. You are in a totally different arena. So I know my rules, take your meds, be cheerful you know because that helps your mental well being and that again helps you physically. So follow the rules and you will be ok. ID 57

Even when the women follow 'the rules' they often do not experience freedom from their HIV status. Others in the project have compared living with HIV to being in a dark box or having a shadow that "is not pretty" following you whereever one goes. Coping with the impact of the disease on their bodies and the side effects of medication can also be burdensome.

> So it was a.... it was of course it is a .. it I it's a bit stressful you know... to wake up in the morning, taking many many... the medicine, ah we are taking most of them they giving side effect... you know you take it, it makes you feel dizzy, you take, cause, it it it ah it cures you but It it, it ah

cures it eh eh it give you more side effect again. Yah, diarrhoea, dizziness, headache all the time you know. ID 2

The women manage the day-to-day physical side effects of the medication or health problems and at the same time must continue their work as mothers. Their HIV status and role as mothers are unchangeable. Often their children are not aware of their HIV status and the women went to great lengths to protect them from having knowledge that they feel would be too much for the children to handle. This required finding ways in which to mask the side effects or provide alternative explanations for their physical ailments.

> And you have to think of all these ways to make it easier for you. So
> My husband will ask; have you taken you vitamins. Yes. He always reminds
> me take your vitamins. Oh yeah sure take my vitamins. When you're
> talking about them in public people have vitamins you know you don't
> think anything of it. Versus taken your medications, oh what's wrong.
> You know. And you don't want to have to lie to people so we just find
> other ways of getting around it. ID 57

Similarly, if the mothers are employed or attending a school program they either cannot attend when their health is tenuous and deal with the consequences of their absence or go work and hide the reality of their physical condition.

Managing the Secret, the Mask

An additional aspect of labour involved in managing their health status is the effort that goes into the management of a secret, their HIV status. The work required to ensure their HIV positive status remained undisclosed and undetected by others happens on a daily basis and required both thought and skill. The mothers spoke about their need

to make sure that their health status is kept from others in part to protect those they love

from an unnecessary burden and source of worry, but also to protect themselves and those

they care for from the stigma and feared ostracism that could result if others knew they

were HIV positive.

> So basically the only people who know are my husband and my sister
> and my cousin and that's it. And that's enough. Because back home
> they are still dealing with issues of people accepting the fact that this is
> something that's not your fault. You get cut off from family members.
> Its hard enough dealing with it on your own without having to explain
> to other people and to have to deal with other people's reactions so just
> three people and myself who know and so far it's been enough. I didn't
> want to put anybody else through that. ...of the three of us I took it the
> best. They just cried. They were heart broken. They just cried and my
> sister said but you've always been a good girl. ID 57

> If I tell my son that this is the situation that I'm in, he will be worrying
> everyday. He will think every time I get sick I am going to die. I don't
> want to put that burden on a child who should be left alone to enjoy you
> know his childhood. As long as I am healthy I am ok. ...I feel that it's
> better for me to protect the people that I love and the time will come
> when it's deemed necessary. ID 101

> And eh, I think a child is not capable...to handle that, even that is the reason
> why I have not told my my daughter. She's going to university and I know
> that if I tell her, she's not going to go to university because she's going
> to feel obliged that she has to take care of me. I don't
> have to burden her. She is going through a lot herself. ID 90

Most mothers expressed a strong need to protect their children from learning

about HIV in order to allow them to have a normal life and keep them from worry and the

impacts of the stigma associated with the disease. Mothers spoke of sharing their HIV

status only when it served a specific purpose. When the women have disclosed there is

often further unanticipated work that they must do, including attending to the emotional

needs of family members and ensuring that the information is not shared with others

outside of those to whom they disclose. At times, the women spoke of situations where their HIV status had been disclosed without their consent and they then had to handle various issues that arose. The management of disclosure is another element of the women's daily work.

Paid Employment

Beyond the daily invisible work the mothers accomplished, some of the women also took part in a form of paid labour outside of the home. This work was often not in their area of expertise and did not provide a good wage. Some also attended full time educational programs.

> My diploma, I just got in IT, I was in school and then I met him and married him and then I had all these boys that I had to look after and then I was working full time hours so I had like a whole bunch of things that I was doing all at once you know. I don't even know how I survived it you know but it did survive it and I graduated so. ID 56

The usual work of being formally employed or in school full time is compounded by the uncontrollable and unchangeable factors in the women's lives. As a newcomer the process of finding work of any sort can be gruelling, and there are unanticipated hurdles to overcome.

> And they were telling us, that you know, you have to go through the system, you cannot us...just go and look for a job, no one will hire you. Interview ID 95

Learning how the employment system operates and the process that newcomers who desire to work must complete impacts on their ability to find formal employment.

Once employment has been found, the mothers then begin to consider the impact of their

health status on their ability to maintain their paid work.

> Yah, I worry inside that us, I mean if I get a job and I keep getting this
> good day, bad day, good day, you know, who's gonna employ you when
> you are like that? ID 90

FORCES THAT SUSTAINED AND FORCES THAT UNDERMINDED WOMEN'S COPING

Participants' accounts of their work and coping revealed that they experienced forces and events that, variously, sustained and undermined their coping and efforts to take charge of their lives.

Forces and Processes that Sustained

"It's the faith that helps me"

That is that I am by being positive. I am focusing on God. That is where I draw my strength and my inspiration. I just pray. When I pray I believe that what I am praying for, God is going to deliver. ... Yeah so it's the faith that helps me.

The women singled out either their faith or God as being essential to their daily survival or the ability to deal with and accept their circumstances. Many of the women spoke of their faith being the source of courage and strength that allowed them to live and manage on a day-to-day basis. Their faith was also a significant factor in coming to terms with their HIV positive status. As one woman said:

> I just I've willed myself just by praying and talking to God. That's how I accept. ID101

Acceptance of their HIV positive status had been significant to many of the women in the process of establishing control in their lives. As they began to accept their status they were better able to make positive choices, which in turn had an impact on their sense of power they held in their lives. The women spoke of how faith and prayer can impact their strength both physically and emotionally even when they are sad or low.

> Yeah but for me, I was sad and I'm stronger. Maybe it's because of the faith that I have in God. That makes me strong. I think

about Him a lot. I pray a lot. I pray with other women. So that
helps me to stay focused. And to stay healthy. Yeah. That make
me, that makes me emotionally strong because I know that He God
I have is very, very, He's an amazing God. And I have seen a lot of
things that have happened. I have prayed for so many things and it
works so that helps me. ID101

So when I came to Canada as a grown woman you know I always kept
the faith you know and believed in what my father taught me because
ummm for me ummm being in this condition I believe the only answer
I have got right now is God. That's the closest I can get to him because
right now I don't know what my future is. I don't know my destiny so
umm I give everything to God you know to give me the answers and to
give me the strength to carry on. So every time you know when I'm at my
lowest you know I will just go and say my prayers and you know that
would give me the strength you know you know to move on you know so
my faith it keeps me going. That's actually where I draw most of my
strength; prayer. That's the only thing and when I pray, go down and pray
and say that prayer you know, I get up you know my courage, you know
my strength back you know to move on. ID 56

Faith is a source from which the women draw the strength they need to "keep

going" and "move on". Similar to the way in which one of the women described

children, another woman indicated that her faith and prayers gives her "the strength to

carry on". It was sources of strength, such as one's personal faith, that worked to sustain

the women and impact on their sense of hope.

Being Blessed: "Living with Positive Hopes"

Regardless of the hardships the women may endure many expressed a spirit of

gratefulness. Without dismissing the difficulty of their personal situations, women

identified reasons they had to be thankful and that there were those who were worse off

then themselves. This attitude of gratefulness and idea that there are 'those less fortunate'

than themselves served to enable the women to recognize the positive hope in their own

lives. The reasons for their gratefulness differed. One woman spoke about how the

knowledge of being HIV positive was something for which she was thankful:

> I thank God that I'm positive and I know I'm positive. Some
> people are walking on the streets, they're infected and they
> don't know yet. ID 90

One would assume that knowing you are HIV positive would not elicit a sense of

thankfulness for most individuals; however, she saw having this information as important

and believed that those who are positive and not aware of their status are at a

disadvantage in comparison.

It was a common occurrence for the mothers to be informed of their HIV positive

status either after having children or while pregnant. This in turn led to concern that their

children or unborn child may either already be or become infected in utero. Most of their

children were negative for HIV, but of the 13 mothers, three had one or more children

that were HIV positive. The mothers whose children tested HIV negative described being

thankful that their children are healthy and uninfected.

> Then this person told me the results and I just knelt down and I just prayed
> and I thanked God that my children were okay. So when it came back that
> they were negative. I was so so happy. So we are truly blessed that our
> children are ok. ID101

> I think what made me think that I'm not maybe so removed from this
> experience right now is that when I had my child and he was not infected
> that I got relieved, that's just like, it's like I didn't care after that because
> that was my biggest worry. ID105

> Just knowing about, knowing all I can kind of gives me a simple joy. I
> can't control the virus but if I know about it at least I feel on top of it.
> I count my blessing and that also helps me. I look at I think at how it
> could have gone. I could have found out too late. Had a child. And what
> made us think of having a physical? We could have found out late and then
> the child would have been positive. Which would have been totally awful.

So I think in terms of what could have happened you know this could have gone totally differently and been in a worse position. Interview 57

For these women, the peace of knowing their children were not positive served to make their own positive status more manageable.

There were also those women who expressed appreciation for simply being alive every day. All the women in the sample had come from Sub-Saharan Africa where the diagnosis of HIV is often equated with a quick and lonely death. In comparative terms the access to medication and nutrition available in Canada had offered them a chance of a longer life expectancy with HIV.

> The first thing I wake in the morning I thank God that I alive.
> I alive to you know to keep on going you know. Yeah we thank
> God for every day. We happy. ID 86

> Well the fact that um...I'm HIV doesn't mean that it's
> the end of the world... and um, thank God I'm eating
> healthy. Like in Africa people don't have food and that's
> what makes them even more sick ..they don't have
> medication.. I have medication and that keeps me going to.
> So in a way I really thank God that I'm here. You know for
> the food for the medication for the shelter and all this research
> that is going on. I really thank God for that. ID 90

> Coming to Canada to me it was like a God sent you know its like
> you know God saved me, delivered me because maybe I would be
> dead right now if I was in Kenya. You know my cousin just died
> about two years ago from the disease (emotionally upset) I can't be
> thankful enough for this country you know. You know I'm happy
> I'm here, I don't know who else has those diseases back home. I
> don't know which of the relatives I have, have them but I know people
> pretty much suffering a lot and people are dying every time because
> they don't have access to medication so. ID 56

There was awareness among the women in the study of the reality that many in their country of origin did not have access to the same basic necessities of life that they themselves were receiving in Canada. By Canadian standards, many of the women were living below the poverty line but they believed themselves fortunate in many ways. Their sense of good fortune generated a sense of responsibility for the plight of those in their countries of origin and Africa in general. Flowing from a sense of gratitude, the women articulated a need to give back in return for the positive hope and sense of faith they identified.

"Giving rather than getting"

Participants' understanding that, despite their difficulties, there were others less fortunate than themselves, generated in many a belief that they had a responsibility to the larger community who are affected by HIV, both locally and globally.

> It think um... I think I should help other people who maybe are ... in a in a box...closed in a box and they feel that HIV means death. I think I've really benefited from uh uh many many social supports in Canada. I've really appreciated it and I've really benefited , but uh...I think I should, if there's someone uh whom I can talk to and let them know that it's not the end of the world...I think I should be giving rather than getting. Because I think...if it was that time I was telling you about, yes, I would have told you, I need I need help, but now I think up I I think I've been able to deal with this and accept it. ID 95

Concern for Africa, and the plight of those 'back home', was a familiar echo in the transcripts.

> Well maybe it helps in the sense that I feel my life has been prolonged by my desire to help those people back home. My desire my wish is if one day I had a good job, even if I could help just one pregnant woman, buy her medications throughout her pregnancy. If I can just help one woman give birth to a healthy child who is HIV negative I would be very happy. So

hopefully. ID101

The desire of the mothers to help those back home in Africa, particularly women and children, gave them a purpose and meaning that served as a desire to live, as did their concern for their children.

"For the sake of my children"
... if any of it's not for me at least for the sake of my children you know. I just need to pick myself up and just carry on you know. That's the best I can do."

All the women in the research were mothers of at least one child. Though one of the significant sources of stress and worry that they were managing in their lives is related to their role as mothers and the practical care their children required; they also identify their children as a source of strength and motivation. Their children provided them with needed purpose and gave a tangible reason to stay strong.

> Knowing that my kids need me. It also gave me strength to want
> to do something about you know what was happening in my life. ID 95

The mothers identified their children as a reason to live and a source of motivation that they might have been without had they been HIV positive and childless:

> Because my son, I want to live, I want to work, I have him, you know but
> otherwise I don't give any sense to live with HIV if I don't have any kids.
> Just living and dying and that you know. But I have reason now. I have
> reason to live. He needs mom. He needs to have even someone else. He
> can raise him only but not like mom. Mom is different for the child. So
> that's big reason for me to. And God thank he give me the same times child
> and forces work myself you know. I am forcing my everything because I
> have reason for my son. If for only alone I don't care. I can live, live and die,
> die. Yeah. Big reason. ID 49

The mothers communicated a need to stay strong to ensure that they could provide the best life possible for their children and allow them opportunities that they themselves may not have had:

> I have two boys you know that I have very great, you know
> high expectations for them so the best I can do for them is
> just to remain strong and healthy and see them through college
> you know. That is the best I can do. They give me the strength
> to carry on everyday. Interview ID 56

Children were a significant source of strength for the mothers and provided reason to resist the potential desire to give up. There was a sense of purpose for the women behind any personal hardships they may endure if in the end it would mean that their children are better off. Children supplied their mothers with the needed inspiration to manage and keep going:

> Like I'm saying he is my only joy right now. He keeps
> me going. ID 93

> Take your medications and let the baby develop and every thing will
> be okay and that's how I managed to block of my mind you know to
> the past and stop blaming myself and move on so I think my baby
> gave me a lot of strength too you know. Because I was like you
> know just for this baby you know this is my angel, God gave him to
> me so let me just concentrate on that and you know worry about the
> baby coming. So I think the baby also gave me a lot of strength.
> ID56

Many of the mothers single out children as a source of strength in the daily struggle to cope with their circumstances.

'What they do for us': Formal Services

For some participants', formal services of various kinds had been experienced as

helpful and sustaining. They discussed both the practical and emotional support that they

had received from various social services and professionals as newcomers and as people

infected with HIV.

> A place like the Teresa Group which is not, it's not therapy, but you are just
> friends, you are people who are just willing to listen an you know let you
> cry, give me coffee and cookies …it makes a difference…just makes you
> feel loved, makes you feel like there's someone who cares. ID 95

Participants had also received practical support such as financial assistance, daily

support, and the opportunity to connect with other individuals in similar circumstances to

themselves through contact with these helping professionals and agencies:

> …other agencies do have like the African Help, African Help services like
> they are sometimes financially I think they helped me twice…The Teresa
> Group help like counselling all those stuff and sometimes like I say once a
> year we get the gift certificate   Interview 86

> The only thing I can say is that I am so grateful. Very grateful to the Teresa
> group and what they've done for our children. I don't know what I could
> have done without the Teresa Group's help. The formula and diapers.
> Especially the formula. For some times I go without coming to them to
> get diapers but the formula I don't leave. You know. That was really,
> really helping with our children. ID101

The women indicated how some of their contact with different services had

assisted them in their efforts to cope with the demands on their life and provided support,

acceptance and a potential community to which they could turn when they are in need,

especially in the absence of family and friends.

Forces that Undermine

Just as there were processes and forces that enabled women to better manage the demands of their daily work, there were also factors that work to undermined and jeopardized their efforts to cope and resist.

Work: Its excess and its absence

As previously described, the sheer amount of daily labour in which participants engaged in and of itself created a huge challenge and drain on their energy. The copious demands that came from being a mother, a newcomer, a woman, a person of colour and a person living with HIV/AIDS could become overwhelming and effectively undermine their ability to get by.

Despite their hard work, both paid and unpaid, finances and the absence of good or suitable paid jobs were a worry to many. They worried that they would not be able to provide for their families' basic needs, had concerns for their children's educational futures and wondered how, if they die, their children would be provided for financially. Many participants communicated not only the material importance of finding formal paid work, but also its symbolic importance to them: it provides needed finances and also gives them as sense of self worth and public purpose.

> Right now ... actually, my main worry's a job. You know when you're
> out there doing something, it's better than sitting at home doing nothing.
> And that keeps you thinking too. You know like how is my life is ... is not
> just going to be like this forever no... you know I need a job to keep me
> away from thinking. To make me feel that I still have a chance to live you
> know. ID 90

The women conveyed that they had experienced difficulty finding employment for multiple reasons. This not only impacted the women financially, but also impacted their identity and sense of value. In a society that places importance on having a career, cultivating independence and self-advancement, being seen as unsuccessful could become demoralizing. It was not enough for the women in the study to just find any available job but one for which they had been educated and trained.

> Here I am doing something that I am not even trained in… well I do customer service. That is not what I am supposed to do so that is for me… I consider that that is not very normal. Because I am supposed to do what I am trained in. You know. I feel that I would be happy if I did that. You know like. Not doing …what I'm doing…I'm doing this just for survival because of the children that we have to do what we have to do. So that is it is like a step backwards. Going backwards instead of going forward. ID101

The women discussed the lack of paid work as a key source of worry in their lives and suggested that one of the areas in which they could use assistance is finding jobs, specifically in their areas of expertise. To secure formal work would create an opportunity to provide for themselves without the reliance on social assistance, which undermined their ability to provide care to their families and emphasised their perceived deficits. The lack of formal employment and financial uncertainty were compounded, for some, by a lack of working identity. Not to have an income was a reminder of their status as a newcomer and person infected with HIV and had a negative impact on their image of themselves. The women's ability to manage was also undermined by their experiences of emotional and mental distress.

Distress and Self Blame

The reality of living with HIV/AIDS is something that the mothers from the study could not escape or control. Most women articulated going through a difficult period after diagnoses before they came to a place that they were able to begin to manage the truth of their situation.

> So they did it again and it still came back positive so... it was
> heart breaking for me. ID 90

In the narratives shared by the women, there was a consistent theme of 'feeling dead' for a period of time - believing their death was imminent and unavoidable - and that they would be better off to die as soon as possible. Several expressed thoughts of suicidal ideation.

> I was just waiting, I was thinking, when I wake up in the morning,
> I would say, I think I was going to die today. ID 95

> I felt like you know I should put my head in a bag and kill myself,
> you know. ID 86

Some women spoke of becoming 'depressed', but at the time not necessarily knowing what they were experiencing because in their country of origin 'depression' did not exist. This experience of depression, and other forms of distress, impacted on their perception of themselves, their daily functioning and their ability to parent.

> Before I was very depressed and didn't want to do anything and I would
> I would not get out of bed. I will not eat. I will not feel hungry. I would
> spend....seven days in my bedroom. And my kids would be asking me to
> wake up or they will make tea for me..my daughter will be telling me,
> "Mommy, let's get a shower". "Mommy come and watch TV," and I I
> didn't want to do anything. I didn't want to do anything and then...I ..I
> don't know...I was...I don't know what was happening to me but I didn't
> have interest in anything. ID 95

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> I didn't even want to cook for my children no more. I feel like if I cook for
> them they gonna get the HIV, like. Like everything, like I even I use to
> wash my clothes different. And it was really hard, it was like I was dead
> already. I cried every day like, I couldn't eat a lot, I was so worried. I feel
> like I was nothing to my children. I didn't want to cook for them I didn't
> want to wash for, I didn't want to touch anything that the youngsters did
> because I felt like you know the ones that didn't have it, I felt like I was give
> them the virus. ID 86

It is understandable when one considers the magnitude of what she was coping

with that this mother struggled with 'depression'. The stressors in her life went beyond

being HIV positive. This particular mother had been sexually and physically violated,

fled a country due to political strife, left behind one of her children and a community of

support, moved to a different climate and culture, struggled to deal with the governmental

systems in a new country on her own, and was unable to find paid work. This was all in

addition to learning that both she and her youngest child were HIV positive and coping

with the secrecy and stigma associated with their health status.

The few mothers with children who were peri-natally infected with HIV during

pregnancy also expressed struggling with blaming themselves for the situation their

children are in. Coming to terms with their role in their child having a chronic illness had

an impact on their state of mind and contributed to their experiences of mental and

emotional distress. They carried an emotional burden of responsibility.

> And I blame myself a lot, I blame myself. Looking they are innocent
> children, they didn't do anything, you know. I live my life before,
> normal life, and I'm old now so I don't worry about that but I want my
> children to have normal life too like everybody else, be treated like
> everybody else. And I see them not having the same life as everybody else.
> It worry me a lot and I know that they didn't deserve anything. I blame
> myself for not knowing earlier to prevent it, you know. ID 86

There were whole hosts of reasons why the women in the study struggled with distress and self blame. Regardless of the cause, the state of their emotional and mental well-being had considerable implications for their ability to handle the day-to-day work that they strove to manage. The mechanisms by which the mothers cope are impeded by mental health issues, such as depression, and undermined their ability to resist as they would otherwise.

Lack of Familial/Cultural Support

The experience of being a newcomer to Canada with limited community or family supports impacted on the mothers' emotional well-being and was another area that had the possibility of jeopardising the mothers efforts to cope. The women in the study spoke of adjustment to a new country, a new culture, a new climate and the isolation that many experienced leaving countries where they had a wide network of community and family support that, regardless of any downfalls, they had been able to rely upon. To go from being immersed in a culture that is interconnected and interdependent to a western society where emphasis is placed on the individual and independence was a difficult transition:

> Being alone, yah, mmm my first year was really hard. Because I was on my own and of course the weather and all those things, so ..but now I got use to it. ID 90

> You don't get a chance to gently kind of merge into the society because you have no mechanism for doing so. Ummm and then came winter which was... I wasn't used to that cold and it was just miserable. It was a combination of all those things and it was just miserable. ID 57

In the midst of dealing with the change of a new country, climate and culture, the absence of the community and family support made the adjustment that much more

difficult. Many of the mothers highlighted the absence of their family and the way that

they had previously been able to depend on them to step in and help in times of need.

The women described the contrast from living in community with their extended family,

to being alone:

> ...you know we only talk on the phone so and part of my traditions back
> home is you know you live together, all of you in the same house and eat
> together, do everything together and then when you live here you're alone,
> and that's a big change. ID 90

The mothers expressed worry regarding who would care for their children when

their health deteriorates or in the event of their death given the absence of their extended

family.

> I have nobody to look after my children. If my sister was here she'd be
> looking after my children. And that makes me to cry more.....That's all I
> worry about every day, every day. I don't want my children to go to
> Children's Aid, I don't want my children to be separated; I want my children
> to be together. If I have my family members here, my sister or somebody I
> know that they can take care of my children. ID 86

Dislocation and lack of family and communities were not only produced by

geographical distance but also by fear that someone may learn of their HIV status in their

cultural community. They had concerns regarding the impact of this stigma and ways they

may be ostracised and also for how it may impact on family members still living in Africa

if people in their country of origin learn that they are HIV positive. This in turn further

isolated the women from potential sources of support that could assist them in managing

with their daily work. The internal and external impact of stigma were far reaching in the

lives of the families affected by HIV/AIDS.

Stigma

The stigma associated with HIV/AIDS is un-paralleled with any other disease or infection, which the wider study of this data elaborates upon. It is impossible for a person affected by the disease to escape the influence of stigma and its potential power to devastate lives. The women in the study did not elude the impact of stigma on their lives. When speaking about HIV/AIDS many of the women made a point of indicating that they were "good girls" and had not become infected because of anything "bad" they had done. Societal attitudes towards the disease have affected the women's lives in profound ways. Though there were no specific questions regarding stigma in the interview guide, the women still discussed the need to keep the information of their HIV positive status secret from almost everyone in their world and indicated they experience great hesitation and fear regarding any decisions that required disclosure. Accessing services that could offer assistance and support became a challenge because of the fear.

> So it's almost a catch 22 at certain point because sometimes you don't
> get the help you desire or you need because you are afraid. ID 57

Some of the women discussed how asking for help and sharing personal information is not typical for them culturally. Not bringing shame to your family for some is seen as more important than your basic human needs. When coupled together, the stigmatization of HIV/AIDS and different cultural understandings, such as withholding information, created situations where the women found themselves having to manage isolated on their own.

> It's just the fact that my personal circumstances or my personal, my
> family, the idea was so you didn't eat nobody needs to know that.
> It's a family problem you keep it in the family. You don't go washing

your dirty laundry in public. You know. So you only have one dress
well we wash it tonight and hang it out. And iron it in the morning
so you look neat. So you don't have two cents nobody needs to know
that. You know. That's just how we were brought up and that's how
my cousins have been brought up so it's typical of the region where
I'm from. So if you're hungry you can't afford anything and people say
well lets go and eat this; I'm not hungry. Even though your stomach is
growling. It's just a pride thing. Keeping things. That's more important
than your needs. You don't shame the family, you don't shame the clan.
And that's why many African people can not talk about their status
because...then you bring shame. ID 57

Many of the women spoke of times when they have disclosed their HIV positive

status to family and friends and had unfavourable reactions. One woman shared how her

partner used the information against her:

So it was constant fighting you know constant fighting and even after
my condition you know you know it became worse and he started using it
as a weapon to me. It was like a weapon you know. He had this weapon
against me so I was always in constant fear you know oh my who is he going to
tell next you know. ....I was always looking over my shoulder because I didn't
know what to expect of him you know. ID 56

Her own partner used the knowledge of her HIV status as a weapon of control and

fear in her life. Stigma and societal perception related to HIV/AIDS worked on

innumerable levels to weaken the women in the study and their resolve to resist on a daily

basis.

Formal Services that Diminish and Disrespect

Unfortunately it is not only the reactions of the general population and family and

friends of the participants that marginalized and stigmatized the women. There were

many instances in the narratives of the women when professionals and community

services providers had said or done things that had the potential to impede the women's

efforts to manage from day to day. At times it was advising the women with inaccurate information about HIV/AIDS:

> Because I remember her (a nurse) saying that my tears, I should be careful of my tears. That they could give HIV to the baby. They should not touch the baby's skin otherwise he is going to get my sickness from my tears. ID 93

It is not surprising that comments such as this further intensified the women's experiences of stigma and impact the process by which stigma then can become internalized and maintained in their lives. The comment of one nurse resonated with this particular mother and had a profound impact on her perception of herself and interactions with her child.

As well, several mothers discussed occasions when health professionals disclosed their HIV positive status to others without consent:

> But the only thing is that like my area people knows, but you know because when my husband please I have a neighbour here so don't mention anything about my husband's HIV virus. And then while I was in the room with the doctor a nurse came outside and told my neighbour, "Do you know what, are you related to them? Are you a relative" and my neighbour said "No, they are just a friend". And she said, "Oh well let me tell you so you can protect yourself. Her husband died from AIDS". So she told my neighbour. So my neighbour knows. Because if I say, I told my neighbour "no" but she don't believe me, she said she believe the nurse because the nurse told her in the hospital. So, she knows. So other people were talking about it to other people. People tease my children outside. ID 86

The impact of this nurse's disclosure to the neighbour had far reaching consequences on the family, especially on the mother who was a lone parent raising her children. The emotional burden and work from the experience was staggering: dealing with the neighbourhood and the stigma/persecution she and the children were subjected to with the knowledge of HIV being a part of the family, while also supporting her children

in the situations they must now learn to struggle with because of the disclosure. The mother had no control over the decision to disclose or the how the reaction was managed. Many of the other mothers were hesitant to trust professionals and social services agencies because of experiences where that trust has been damaged.

Various service providers also lessen the women's sense of control and authority in the skills or manner of service delivery they use. The sometimes bureaucratic and un-listening response of professionals was raised by the women. One spoke of the need for professionals to put down their pens and stop writing and instead listen to what they were saying and respond with authenticity:

> What I mean is they should be more open and just put down the pen and paper...because they they all that all that they they're think is we're doing our job....we come from different countries, we come from different countries, we're we have we're a different culture, we deal with things differently than people here in Canada. ID

Others also discussed the ways that service providers were not sensitive to cultural differences and the need to approach issues, such as asking if they require help, in such a way that clients will feel that they can accept the help. Several mothers spoke about how difficult it was culturally for them to ask for help or say they are in need and felt that professionals could do a better job in this area:

> When you ask somebody if they need something especially if they come from Africa, most of us are going to say no. Keep at it. Find different ways to ask people or to offer people without making them feel less than they actually are. Not that it's done that way it's just the way we perceive it. Nobody ever wants to feel like they are begging or that they are being trouble. Just find different mechanisms of asking the same thing without saying what can I give you or what can I get you or what do you need. Because some of those they are very, your interest is to say nothing. It's a pride thing also and I think Africans are very proud. ID 57

Additionally, the women in the study spoke of their desire for services that allowed for them to contribute to how things are run.

> Not just every time they get together and then you have somebody that's like an organized social worker or community group person facilitating it but sometimes you just don't want to be facilitated. You know, we have someone telling us what to speak and what not, like we are being run. I don't like that. The person whose doing it because they have a good heart. Nice, the nice person right, good thing to do but at the same time they don't really know what it's like to be you. You just don't want it to be run. ID105

At times the programs run by professionals acted as a disservice to the women and their desire to take charge of themselves. Regardless of the good intentions of the social worker, this mother did not feel she was being given the opportunity to speak or for her voice to be heard authentically.

Whether providing mis-information, disclosing without consent, or structuring programs that do not effectively meet client needs, professionals involved in the mother's lives had the ability to undermine the women's efforts and diminish their sense of ability and worth in the process.

DISCUSSION

Summary of Findings:

The women who participated in this research and those I have met through my practice experience illuminate the daily work and resistance of newcomer mothers from Sub-Saharan Africa who are HIV positive. The secondary analysis reported here revealed the work involved in the women's everyday lives, and the ways in which they manage the challenges they face. In general, there has been little attention given to understanding women's daily resistance as a form of work which requires laborious effort, or its value in enabling women to direct, moderate and improve the conditions of their own lives and the lives of those for whom they care and feel responsible (Aptheker, 1989). This research sought to explore what women said about these themes and, in doing so, acknowledge and make visible their efforts and resourcefulness in managing the difficult circumstances of their lives.

Much of the work done by the mothers in the study was invisible and uncounted. The forms of their work varied. The work of any mother requires a great amount of time and effort and the women in the research were no different. Some of the participants also managed the work that comes from having formal paid jobs outside of the home and the difficulty of balancing them with their other responsibilities. In addition, these mothers engaged in work that would not typically be considered a part of a woman or mother's everyday life. Some of it related to the management of a secret - their HIV status - and

the required physical, mental and emotional effort invested into ensuring that the secret is not disclosed. The participants' HIV status led to other, unrecognized forms of work: protecting children from stigma and potential marginalization; the management of their own physical health and in some cases, that of an HIV positive child or partner; and seeking services and support in the community. Being a newcomer also made demands: navigating the system and services of Canada with limited family or community support generated mentally and emotionally demanding work. These aspects of women's daily work are generally invisible and, as such, not counted as aspects of their worth and value.

Despite the invisibility of their efforts, research participants were tenacious and found ways to push back and manage their lives regardless of the evident personal and structural disadvantages that threatened their control and agency. They found ways to establish some control, to author their own stories and create meanings that ran counter to dominant depictions of them as only needy and depleted.

Understanding what supported and what undermined their self-directed efforts was a key focus of the analysis as it could offer suggestions for future practices and research with this population of women. In her study of the resistance strategies of African American women and how they cope with racism and sexism, Shorter-Gooden (2004) generated a conceptual distinction that proved useful for understanding the work and resistance of the women studied here. She distinguished between internal resources (resting on women's faith, depending on their culture and heritage and valuing themselves) and external resources (social supports) that women relied upon to cope with their experiences. In parallel, in this study the women's personal faith and assertions of a

positive attitude both functioned as important internal sources of resistance: narratives

with which they constructed identities of strength and survival. On the other hand,

distress and self blame operated as internal forces that undermined the women's sense of

themselves and diminished their ability to cope with their burdens. External supports

took the form of social services offered in acceptable ways, and family and community

when available and not stigmatizing. Unsurprisingly, lack of available familial and

cultural supports, along with negative experiences with formal services weakened study

participants' efforts to manage on a day to day basis. Paradoxically, some of the internal

and external resources that sustained participants also had the potential to undermine and

constrain them and it is to such complexities that we turn next.

The Paradoxes, Contradictions and Tension:

    Two particular paradoxes were evident in the participants' narratives and

produced tensions that merit discussion before considering the implications of the

findings for future practice and research. First, excess work and responsibility depleted

and burdened the women even as, at the same time, the care that was required of them

also gave purpose, meaning and identity. For example, they spoke of their children both

as a sustaining source of strength and as a source of demand and responsibility that

strained their capacities to cope. Women's complex, relational work as mothers rested on

their moral commitments to care and echoed Gilligan's articulation of the ethic of

responsibility and care that characterizes women's lives (1982). Women who participated

in her research defined themselves in relation to others and acted and identified

themselves primarily in terms of a moral disposition to care for their personal

relationships, but also the larger community (Gilligan, 1982). In this research,

participants spoke similarly of their care and responsibility both for their children and

families, and for the wider communities to which they belonged: those at home in Africa

and other individuals who are HIV positive. Echoing Gilligan, Schalge's highlighted the

ethic of care and responsibility of poor women living in Tanzania who are caring for their

children and grandchildren, and concluded that the role of motherhood is conditioned by

the political, social and economic context a woman operates within (Schalge, 2004,

p.151). "What women as mothers do, how they do it and how they define themselves are

complex issues that must be untangled and investigated, rather than assumed"(Schalge,

2004, p.152). The women in Schalge's research were driven by knowledge that they

were being depended upon and saw their primary responsibility to care for their children

and ensure that they succeeded (Schalge, 2004). Though the mothers in this research

clearly identified the vast amount of work that they were managing on a daily basis, and

the toll it took emotionally and physically, they also had a corresponding desire to act

upon what they believe is their responsibility to care for those beyond themselves. Other

research elaborates this disposition and points to the possibilities for collective identity

and action that it generates. For example, Connolly (2004) studied a group of mothers

who gave leadership to a neighbourhood initiative, noting that they acted out of their

relationship to their children and the connectedness to the people in their community and

the desire to provide care and foster these relationships. Their ethic of care and

responsibility flowed "out of their roles as mothers" (Connolly, 2004, pg55).

Another paradox apparent in study participants' interviews was that they

described both how 'tough' their lives were and how lucky and positive they were: how

fortunate, blessed and lucky and yet also needy of practical and emotional support.

This apparent contradiction may stem from the juxtaposition of the worlds they

know. When comparing themselves with those still residing in their countries of origin,

the mothers recognized that they were living a relatively privileged life and were grateful

that they had been blessed with so much. However, here in Canada, they are still in need,

and in this context, struggling and marginalized. While acknowledging the personal

meaning and implications of this comparison for women like those studied here, their

relative sense of good fortune should not be understood in the Canadian context in a way

that excuses or permits denying them resources. Further, acknowledging the success and

achievements of the mothers to manage their daily work and resistance does not mean

that the contextual barriers and needs that they experience can be ignored. Rather, health

and social programs of all kinds and the service providers within them are challenged to

fashion responses with an understanding of this apparent contradiction: to *both*

acknowledge and see women's strengths and hard-earned senses of themselves *and* offer

support and resources in ways that respect and sustain them.   This raises important

questions for service organizations, practice and research.

Implications for Service Providers:

From analysis of the women's narratives several implications for service providers

can be identified. Service responses are required that assist women in a manner that does

not reduce, weaken or diminish them but, instead, affirms their value, and their resistant and self-directed identities. Some specific aspects of such responses are directly suggested by this study. For example, participants spoke of a desire for professionals to become more attuned to the cultural needs of the communities they serve, seeing it as essential if they are to offer help in a way that affirms who clients are.

Attention to the language used by professionals working with newcomers and those with different cultural backgrounds is also a key element of this important process of education and attunement – one illustrated by the confusion found in the study with respect to 'depression'. As noted earlier, 'depression' proved to be a problematic term for the women studied here and resonates with Doyal's analysis of the social significance of mental distress (1995, p.45), and her cautions about the damage done by ignoring it. Western medicine's conceptualization of depression tends to individualize its origin and its treatment, diverting attention from contextual/structural origins and remedies. The women studied here saw that the circumstances of their lives 'boxed' them in and became at times overwhelming, impacting upon their mental and emotional well-being. However the label of depression did little to assist them in escaping from the confinement of the box. Different cultures and contexts will have specific understandings and responses to distress (Doyal, 1995, p.45). The women in this research spoke of not knowing what depression was and did not believe it existed in their countries of origin. They indicated that they are different culturally and, therefore, deal with things in a different manner than people from Canada.

Traditional methods of providing service should be flexible to the needs of the client. The women in the research highlighted their negative experiences with some western practices and assumptions. For example, the women indicated that they did not want to be 'run' in groups. They articulated the importance of attending a group that is organized democratically that fosters equality and community rather than being facilitated by an outsider positioned as an expert on their lives. The women also suggested that practitioners should 'put down the pen and paper' and listen instead of responding in a bureaucratic fashion that was alienating to them as clients.

The importance of finding ways to offer services in a manner that allows clients to accept assistance with their needs was also highlighted in the research. Participants spoke of the need for professionals to learn to ask if they require assistance in different ways that do not diminish their personal pride or value. It is paramount for professionals and service providers working from an anti-oppressive framework to ensure that it is the women themselves who have the space and opportunity to articulate their needs and how they feel that these needs can be best met. The mothers' knowledge and authority as experts on issues and needs related to their lives must guide service's responses to ensure that they are effective as a sustaining force in their worlds.

Implications for Future Research:

The secondary analysis undertaken here proved to be a valuable opportunity for exploring the data set in pursuit of particular questions about women's work and capacities to cope. The secondary analysis was also fitting in practical terms; it enabled

me to pursue these questions in a time-frame that corresponded with the limits of my

thesis and graduate program.

In closing, it is important to return to the issue introduced earlier about the

challenges of secondary analysis and, in particular, the degree of 'fit' between the

framing of available data and the secondary analyst's questions (Thorne, 1994, p.270).

There certainly was enough material in interview transcripts to permit examination of

participants' work and of how they made sense of their situations i.e. to pursue both

material and discursive elements of their experiences (Ristock, 2002). However, as noted

earlier, some dimensions of their lives of interest to me were not actively pursued in the

interviews and suggest valuable directions for future research.

Specifically, the original study did ask questions related to culture and its role in

the participants' lives, but did not explore questions related to race and its implications

and impacts on their personal experiences in Canada. In addition, the original study

sought to look at the experience of parents, both mothers and fathers, and did not

specifically target issues related to gender. It was possible to make various inferences

about the impacts of gender and race on the experiences of the mothers, however future

research could explore them more directly.

The secondary analysis of the data focussed on the presence of work, resistance

and coping in the mother's lives. These themes were ever present in the women's

transcripts, though no explicit questions were asked as they were not the focus of the

original research. Future research could address these areas in more depth. Explicitly

framing questions with an emphasis of this sort would shift attention from considering

only their needs and deficits, and would affirm and communicate an assumption of their strength and hard work. It is, perhaps, inevitable that women's HIV status is treated as their dominant identity in a health care context. In the contexts of their own lives, however, it may not be so or, at least, may be a health problem embedded in the complex layering of equally challenging social experiences (emigrating, immigrating, settling, low income, discrimination based on race, gender etc.).

The strength, resourcefulness and spirit of resistance found in the narratives of the women studied, co-existed alongside the struggles and challenges that characterised their lives. The literature and attention surrounding newcomers to Canada infected and those infected by HIV has neglected to capture this element of their narratives or provide space for the strengths of their stories and voices to be heard. The inattention of the dominant discourse to these dimensions of their experience does not negate the reality that they do indeed exist. As much as the women in the study dealt with significant stress, worry, and guilt, their responses to their individual circumstances illuminated some of the ways in which they can and have resisted.

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<u>APPENDIX A</u>

Proposed Interview Guide – (The focus group guide will be developed following the analysis of the individual interviews)

1. What brought you and your family to Canada?
    1.1. Potential Probes:
    -   What were the ups & downs, problems, challenges?
    -   Did HIV/AIDS play a role in your move?
2. Can you describe an average day for you and your family here?
    2.1. Potential Probes:
    -   What about your children, what is a typical day like for them?
3. Can you talk about the differences that stand out for you between living back home vs living in Canada, particularly as a family living with HIV/AIDS?
    3.1. Potential Probes:
    -   have you experienced any negative reactions (discrimination & stigmatization) back home or here around HIV/AIDS
    -   having lived in both places where would you rather be?
4. Can you tell us who knows about the HIV/AIDS status in your family?
    4.1. Potential Probes:
    -   What sorts of things did you take into consideration when telling others?
    -   Were there any accidental disclosures?
    -   What kinds of reactions did you receive from those you told?
    -
5. What about your kids, have you disclosed to them?

No	Yes
Can you talk about why not?	How did you tell them?
At any point do you plan	What was their *reaction?*
to tell them?	How long have they known, and have you seen changes over time?

6. How are your kids doing in?
    6.1. Potential Probes:
    -   school
    -   with friends
    -   with you
    -   what sorts of things do you think they worry about?
7. How does your life back home (beliefs, customs, family values, religion) guide you and your family now?
    7.1. Potential Probes
    -   Raising your kids (What is the role children play in your community back home)
    -   What are the main concerns you have regarding your role as a parent?
8. Where do you turn for support? How do they help you?
    8.1. Potential Probes:
    -   Faith community, Friends, Family
    -   AIDS Service Organizations, Support Groups, Counseling
    -   Hospitals, Doctors, Nurses
9. What other supports, kind of help do you & your children need?