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Pathologies of Patriarchy: Death, Suffering, Care and Coping in the Gendered Gaps of  
HIV/AIDS Interventions in Nigeria

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**Abstract**

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In many sub-Saharan African countries, HIV seropositive women intentionally shun life-saving medical technologies like antiretroviral drugs or only engage inconsistently with treatment regimens. These self-destructive patterns of behavior continue in many contexts despite the free provision of drugs and institutional policies that claim to be inclusive of the needs of HIV positive women. Such paradoxical patterns demand urgent attention and this dissertation contributes to research explaining how and why these patterns persist. It does so based on close ethnographic investigation of the social contexts and associated social constraints and inequalities delimiting the ways women access and experience biomedical treatment regimes. This dissertation argues on the basis that orthodox biomedical analyses of interventions fall short insofar as they elide the social realities of vulnerable women with methods that assume too much about these women's experiences of treatment. Using an intersectional framework, the alternative analyses offered here seek to situate women's uptake and adherence to HIV treatment and care across multiple contextual scales from the personal and local up to the global. Across all these scales, the persistence of patriarchal social relations is shown to be a dominant social influence on health outcomes and as such a primary cause of pathology and premature death.

The intersectional approach helps explain how pathology becomes embodied at the intersection of patriarchal social relations and experienced on a very personal level as well as the organizational practices of global and local HIV/AIDS institutions that systematically inhibit and curtail sustainable treatment among HIV positive women in Nigeria. Unsustained HIV treatment access and care among HIV positive women thus occur at the juncture of two seemingly contradictory scales, the individual and institutional.

A major disconnect exists between HIV subjects and intervening HIV/AIDS institutions with the result that women shun treatment when social gaps in treatment are perceived to threaten their physical access to available biomedical resources. Germane to this disconnect is the construction of 'needs' in development discourses and practices mostly articulated as the provision of material or tangible goods and infrastructure, a departure from women's experiences of needs situated at the intersection of self-care and economic empowerment. Women's caring and social responsibilities are practiced in such a hierarchical way that self-care which circumscribes their HIV care is usually subordinated to care for others. In this sense, a simple valorization of care by care ethicists as simply what individuals are wired to do might not necessarily conform to how marginalized HIV positive women experience or practice care in male dominated societies. Such misperceptions of care obscure the social realities that constrain women's access to treatment thereby, taking such bottlenecks off the radar of interventions.

Within a social relations framework and an institutionalized cultural system that reproduce women's over dependencies on oppressive intimate heterosexual relations for social and economic security, this study problematizes the normative constructions of care in patriarchal cultural systems as a relational activity that is neutral or autonomously performed. Conventional construction and practices of 'empowerment' deployed through a needs based development

paradigm are also challenged, complicated and reconstructed to include forms of empowerment that enable the practice of women's self-care and by implication, secure their sustained access and adherence to treatment.

These research findings contribute to the critical genre of HIV/AIDS scholarship through this study's emphasis on the often neglected social dimensions of treatment interventions on multiple scales. It does so by addressing the role of global-local policy transfer in development practice at the intersection of traditional cultural systems and the political economy as they shape HIV seropositive women's treatment access and adherence within a place specific context.

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## **Dedication**

To all the HIV positive women who shared and entrusted their deeply personal experiences with me in the hope that their testimonies will bring the much needed transformative change in the lives of HIV positive women all over the world. I say to you that may your hope that a cure be found never wane, for hope births life.

## **Chapter One**

### **Contextualizing HIV/AIDS: Remapping Illness and Interventions beyond the Biomedical**

#### **Introduction: Organization of the Dissertation and Significance**

The idea of this research was influenced by my various identities and interests. As a woman from Nigeria and as a health geographer, my own gendered experience of local-global relations has definitely given me important perspectives to focus this research. But more than this, my work is also building on and seeking to amplify the outcry in the HIV/AIDS<sup>1</sup> literature about the unmet health needs of women infected with HIV or suffering from AIDS. These needs are unmet either because of the exclusion of gender as a category of concern in interventions, or because of how, even when included, health services fail to address women's needs adequately (Greig, Peacock, Jewkes and Msimang, 2008; Theobald, Simwaka and Klugman, 2006; Seckinelgin, 2005). The body of work on the geographies of health and health care that majorly underpins this study largely problematizes and frames *access* to health services in terms of geographical inequalities or poor health services distribution (Rosenberg and Wilson, 2000). Empirical results from this study nonetheless, challenge this conceptualization of access, adding a feminist geographical perspective to the ways in which space and thus access are simultaneously produced and mediated by gendered inequalities.

Within the global HIV/AIDS scholarship and community, there has been a long standing debate on poor treatment uptake or access and adherence particularly among HIV positive women in different sub-Saharan African country contexts (Smith and Whiteside, 2010; Greig et.al., 2008). An obvious contradiction in these spaces has been the limited, uneven and inconsistent access to treatment of HIV positive women despite the provision of treatment services. Through the

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<sup>1</sup> HIV: Human Immunodeficiency Virus; AIDS: Acquired Immunodeficiency Syndrome

accounts of HIV positive women interviewed for this research, this study foregrounds the need to shift from conceptualizing health access as occurring only within a service provision *availability* framework to underscoring the gendered *nature* of health services as also key to producing disparities in access. In other words, beyond the health service access model, my research underlines the importance of looking closely at how well such services actually address women's health needs in the context of highly gendered socio-geographical relations. This implies that it is key to go beyond biomedical framings of women's health needs to examine the informal contexts in which women as social beings experience and perform the everyday practices of life including health access. Based on the evidence, this study constructs women's health seeking behavior as social.

By investigating why HIV positive women intentionally shun medical technologies like antiretroviral treatment, this study contributes to global health research on HIV treatment. In this regards, this study's authority and value is premised on its foundations in embodied gender research into the socio-geographical complexities of treatment access and adherence (Billo and Hiemstra, 2013; Elmhirst, 2011; Wright, 2010; Haraway, 1998). It is a situated study producing what Donna Haraway has famously described as situated knowledge. A key situation at issue in this respect is that of the household - a space and place that is especially an important site of struggle in gendered power relations. Although the everyday experiences of life's eventualities may differ from body to body within and between households, this research contributes to the wider interdisciplinary work on the social contexts shaping gender health behavior and outcomes at this site and scale of analysis. The more specific contributions this study makes are discussed below based on the key findings from each original chapter.

With the exception of chapter two which describes this study's research design and methods, the four substantive dissertation chapters (chapters three, four, five and six) detail empirical results that have been organized around key findings concerning the complexity and multidimensional nature of treatment access and adherence, as well as the multiple scales in which these are simultaneously experienced. In this regard, chapters three and four address these complexities from women's individual experiences and personal testimonies with chapter five detailing how women negotiate these constraints. Chapter six further explores this complexity from an institutional standpoint while the concluding chapter seven, brings this multiscale analysis together drawing points of connections and departures with existing global feminist perspectives on gender in development, and key recommendations for theory, policy and practice.

In the rest of this first chapter, I frame the subject matter and the broader epistemological and methodological framework that situate this work - health geography, critical development studies, and the political ecologies of health with gender as a cross cutting theme. Through a literature review of the existing scholarship, I demonstrate the need for a feminist intersectional approach to contextualize the subject of gendered HIV treatment. Along this axis, I emphasize the adoption of a multiscale approach to demonstrate that women's experiences of treatment are layered and transcend individual level forces and personal circumstances.

In chapter two, I provide a review on the institutions involved in the provision of HIV treatment and care within the Nigerian HIV/AIDS intervention landscape, and also the political economy and ecologies of the Niger Delta region. The Niger Delta region of Nigeria represents broadly, the study area for this research as well as Erhoike, a local community domiciled in Delta State. Delta State is one of the nine states that constitute the Niger Delta region. I also focus on the actual site of care, the Erhoike Cottage Hospital located in Erhoike community where the cohort

of HIV positive women investigated for this study access treatment. This chapter centralizes the place focus of this study and helps to situate the context in which to understand the relations of social and political power and other social processes that act as broader influences to women's treatment access and adherence. The methods and mode of analysis deployed to investigate this subject matter are also described alongside, the field work process and its nuances as they helped to shape this dissertation and the production of knowledge.

Chapter three which is the first of four empirical chapters addresses a core research question on the individual level barriers and constraints to women seeking HIV treatment and care. The purpose of this chapter is to illuminate our understanding of the complex discursive and material terrain that HIV positive women navigate and negotiate to make treatment decisions to initiate access and to deploy such contextual knowledge to inform local policies. Using both relational and intersectional perspectives, the findings confirm a major proposition of this study that women's treatment experiences are circumscribed within a labyrinth of forces that are material and social in nature yet structural. Empirical evidence points to the fact that women initiate and undergo treatment within a socio-economic risk assessment under the imbrication of religion, culture, gender power and other place relations. The findings also address theoretical shifts and turns in the feminist care ethics and health geography scholarship like the structure-agency debate and the notions of caring and responsibilities as they frame opportunities for women's health outcomes.

Through oppressive patriarchal care relations, HIV positive women feel compelled to neglect their self-care and take on caring roles and responsibilities perceived as their normative gender obligations to their spouses and children. Hence, the evidence shows women's treatment challenges as deeply rooted in the constructions of their feminine identities as wives and

mothers; identities that represent the stereotypical asymmetries of masculinities and femininities firmly expressed in the indigenous traditions of the Niger Delta region. Women's HIV care which circumscribes their treatment access and adherence is undermined by their limited ability to care for themselves first before caring for others. Underlying the intentional shunning of treatment by this cohort of women is therefore, a rationality to protect the social body or self over the medicalized body when the decision to access treatment produces a conflict as the essence of their being is mostly perceived within a socially bounded context.

A major claim this study makes through this chapter is that most marginalized HIV positive women actively construct their bodies as more social than biological; a local construction of self that is in some respects, in conflict with the western biomedical constructions of the body that shape so much of internationally funded interventions in the Nigerian HIV/AIDS landscape. In line with this study's focus of producing situated and place knowledge, this chapter also explores the issues of representational politics in feminist activism on gender equality in Nigeria, and how this equality agenda is understood and pursued among a group of women whose class and social locations shape in significantly profound ways the polarizing discourses of empowerment among local women and corporate feminist actors. Additionally, how place and landscapes of health care although physical have profound social meanings and influence on the patterns and outcomes of HIV positive women's treatment access. The analysis illustrates the need to situate knowledge deployed in gender interventions or feminist movements on gender equality at the level of the subjects while mainstreaming place processes.

Chapter four extends this relational and intersectional analysis to a crucial determinant of women's treatment access and adherence which is HIV status disclosure. Through the personal narratives of HIV positive women, this chapter highlights how gender and material power in

intimate relations shape women's decisions to disclose or not. The chapter examines how women rationalize and negotiate these everyday practicalities in the decisions to disclose or not.

Furthermore, this chapter elaborates on major consequences of disclosure for women which include the disruption of the dynamics of intimate relationships, spousal abandonment through separation or divorce, and other ways spousal abandonment is perpetrated like the lack of economic and psychosocial support within existing relationships as reported. One of the merits of the intersectionality framework is to unearth the nuances of a social phenomenon as experienced not only between but among gender groups to understand how individual women vary in their agencies based on their social and class locations. In this case, it helps us to understand the categories of women most likely not to access or adhere to treatment.

The central finding is that women's disclosure decisions, although constructed at the level of the individual, are embedded within structures of inequalities and marginality. In understanding the process and practice of non-disclosure among HIV positive women therefore, we must move beyond an individualized focus on personal agency, choice and free will to broader socio-spatial structures and contextual forces. Context matters so much because it constitutes the places where diverse structural forces intersect and come to be embedded in particular geographies of personal decision making. Such contextual influence on non-disclosure thus needs to be interpreted as configured by the social, cultural and economic organization of particular spaces. This knowledge of context also helps us to better understand a major implication of women's disclosure which is rejection, abandonment or divorce of infected women by their male partners when their HIV status has been disclosed but not well received. This disruption in intimate relations is fast reconfiguring the structure of the traditional family unit by producing a new typology of the family and female headed households: quasi-widow headed households. Finally,

this chapter demonstrates that economically disadvantaged and uneducated women are mostly impacted by these forces and more likely to delay treatment or care/or not adhere. However, age and marital status as other intersecting factors play a crucial role in how HIV positive women experience and respond to the treatment process.

Chapter five flows logically from the two preceding chapters by addressing how women's bodies already socially disabled with the human immunodeficiency virus, negotiate and cope with the constraints in their path to treatment. This opens the debate on individual agency versus institutional responsibility especially where women struggle to navigate the difficult terrain of HIV treatment access and adherence. This chapter makes a fundamental argument about the ways we understand agency and the practice of negotiation especially by the marginalized; that is if the exercise of agency by vulnerable populations within a limited range of available choices equals claims to power and control. In other words, does the exercise of agency always mean the successful regulation of one's circumstances or can agency be construed as weak or active? Although these questions could not be fully answered based on the available evidence, women's agencies were seen to be largely regulated (and restricted) by broader structural forces.

Women's accounts, however, demonstrate a resistance to treatment barriers through the development of individual coping mechanisms but this varied by access to social and material resources. Most of the HIV positive women did not effectively negotiate or totally subdue the barriers to their access and adherence despite the exercise of what may be conventionally regarded as agency, power or control in attempts to normalize their circumstances. They cope with the barriers rather than actually overcoming them. Hence, their everyday lives are deeply etched with these recurrent or constant struggles to overcome the challenges of treatment. This is especially significant as a finding because of the culture of blame-the-victim that the paradigm of

individualized AIDS research creates by continuing to place the burden of infection on individual behaviors rather than the precursors or underlying push factors that incur risky behaviors. This sort of individualized paradigm works to compel women to assume personal responsibility for their treatment inadequacies while institutions are absolved of their responsibilities, a form of institutional absolution that can culminate in national governments taking an all too laissez-faire and cavalier approach to institutional failures.

Other key findings that also emerge from this chapter are that the HIV/AIDS support group network domiciled in the Erhoike Cottage Hospital is the most critical outlet for coping with the challenges of treatment. As a result, this group largely serves as a site for the accumulation of economic and social capital that are otherwise inaccessible to the HIV positive women in mainstream society and at the level of the household. The support network thus doubles as an alternative care site or enclave of care for disempowered HIV positive women given the nature of services they render which are generally absent from the formal health care space. As HIV/AIDS support groups become symbolic of micro therapeutic spaces and positively transform the larger biomedical HIV/AIDS landscape, this chapter foregrounds the need to formalize this network as an officially funded arm of the Nigerian HIV/AIDS intervention chain.

Additionally, women's perceptions of interventions reflect current debates around more meaningful involvement of HIV subjects in interventions, and on the exceptionalism and normalization of HIV/AIDS. Women experiences of stigma are situated between these two extremes where exceptionalism (channeled through exceptional funding and media attention) and stigma are deemed to be mutually reinforcing; yet damaging to their personal and social welfare because the global hype and media rhetoric around the disease are not appropriately coded to eliminate the stigma it attracts. Through the ways that exceptionalism and normalization are

claimed by women, this chapter argues that the language and definitions of HIV/AIDS exceptionalism are not static but fluid and must integrate spatial and discursive constructions particularly through the voices of specific affected populations and vulnerable groups. Their narratives broaden the scope and scale of this debate while providing context specific or local ideologies and experiences of these concepts in real time.

Chapter six addresses a crucial theme in this dissertation which is the gender equality agenda and how this is mainstreamed into HIV/AIDS interventions if at all, by HIV/AIDS institutions. This chapter interrogates how gender is conceptualized and framed within HIV/AIDS policy discourse and programming, and to understand what constitutes context in gender mainstreaming within the Nigerian HIV/AIDS intervention landscape that can proffer explanations to the current state of this practice. The resulting explanations help us understand the failure of HIV positive women to attain sustained access to treatment from an institutional standpoint despite claims to the contrary of gender equality strategies incorporated in treatment programs. Given the analysis of gender in HIV/AIDS policy documents and the analysis of policy stakeholders' narratives, this chapter makes an overall claim that the failure of HIV positive women to secure sustained access to treatment transcends micro forms of inequalities to include the role of local and transnational HIV/AIDS institutions. It also illuminates the challenges in bridging the chasm between policy and practice.

The ideologies and practices of gender in these organizations through policies and programs further reproduce inequalities and barriers to treatment. These barriers include the role of global health institutional culture and practices; and the lack of coherence in the models and interpretations of gender mainstreaming which produce emergent difficulties in developing a cohesive and clear operational gender equality plan. Given the role of transnational HIV/AIDS

institutions, I argue that the relevance of context is not exclusive to the local but extends to global forces and the ways they mediate the practices of local health institutions around gender. Although conceptualizations of gender have evolved from categorical to more relational notions in Nigerian HIV/AIDS interventions, their deployment in policy and practice reflect more the former giving rise to the proliferation of gender specific interventions that do not wholly address the dynamics of masculinities and male power in undermining women's access to treatment and care.

In consolidating the analyses, the overarching conclusion this study makes is that the resources that accrue through interventions are misaligned with the treatment needs of women living with HIV. Aside other structural explanations, this exemplifies an ideological and substantive disconnect between HIV/AIDS subjects and intervening HIV/AIDS institutions. At base, the ways women with HIV construct and experience interventions differ from institutional perception and policy design. One of the implications is that women shun treatment when these social gaps in treatment are perceived to threaten their physical access to available biomedical resources. Such disconnect also mandates women to make 'irrational' choices in the quest for alternative care routes that maybe detrimental to individual health and counter-productive to public health goals. Yet these choices may in fact be reinterpreted as rational once the limited opportunities of the women are considered more carefully. My study testifies to this disconnect through women's own accounts of their unmet psychosocial and material needs, needs that in turn reflect broader structural inequities. Chapter seven thus proposes a more participatory grassroots approach to engaging the meaningful involvement of HIV positive women in order to determine their own needs and associated outlooks on intervention. My conclusion is that the

need for such meaningful involvement by women in the design and planning of programs should be developed as an alternative to relegating women as just recipients but as active agents.

Both in theory and practice, this dissertation makes a specific contribution to global health interventions on the need to rethink the efficacy of purely biomedical technologies in addressing treatment needs for a disease like AIDS that is intricately tied to the social, political and material dimensions of human life including power and identity politics. Across the three broad scholarships that frame this study; health geography, feminist political ecology, and critical development studies, the reconstruction of scale and the structure-agency debate by human geographers is reinforced in the context of gender and HIV treatment. Through the empirical evidence from this research, I demonstrate that the construction and deployment of scale in traditional geography as distinct levels in which events occur or are experienced to be essentially artificial as these dichotomies are false in reality. The generic ways we construct scale methodologically in distinct operational terms by geography or the level at which specific events occur differs significantly from its experience in the real world. Scale is experienced simultaneously and not as distinct hierarchies of events and also on a very material and social level beyond geographical or spatial boundaries (see Marston, 2000). Chapters three, four and six provide empirical evidence to support this argument. In geographical research therefore, scale should not just function as a concept to denote the level in which we operationalize our study but scale constitutes processes; processes that are social, political, material and inherently interwoven, and individuals can embody all of these layers simultaneously. The evidence reifies current feminist arguments for rethinking and reconceptualizing scale (also see Mitchell, Marston and Katz, 2004).

Within health geography and critical development studies, this study also reifies the importance of the social processes that constitute place in understanding specific gendered patterns in health seeking behavior, and also the reconstruction of ‘needs’ broadly to include empowerment for self-care to achieve health and wellbeing but with specific attention to the voices of intervention subjects in defining their needs. Similarly, in critical development studies, besides making good in practice the long standing claim of alternative development practices that are meaningful and actively engaging of intervention subjects, is the call to attention to specific local and global contexts. Context transcends its conventional usage in gender mainstreaming theory and research as mostly social and cultural resistance by context-specific subjects and local HIV/AIDS institutions to include the role of global institutional power and health governance as they shape local practices of gender.

### **Framing the Study: Gender, HIV/AIDS and Treatment Sustainability**

*“[HIV] treatment programs can ...have dehumanizing effects if the broader social structures that contribute to suffering and impoverishment remain hidden and intact” (Kalofonos, 2010, p. 234).*

Nigeria ranks as a significant contributor to the global burden of HIV infections with 10% of the world’s infected populace. It is also a country where the epidemic is highly feminized insofar as more of the burden of infection is on women and girls at 1.7% relative to 1.3% for men and boys (NACA<sup>2</sup>, 2012; WHO<sup>3</sup>-UNAIDS-UNICEF<sup>4</sup>, 2011). Like most sub-Saharan African countries, gender inequalities, differential access to health services, and many forms of gender based and structural violence predispose women to the risks of HIV/AIDS (NACA, 2010; Oppong and Agyei-Mensah, 2004; Setel, 2000). Yet, interventions have remained gender blind and women

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<sup>2</sup> National Agency for the Control of AIDS

<sup>3</sup> World Health Organization

<sup>4</sup> United Nations AIDS-United Nations International Children Emergency Funds

continue to be constrained in their uptake of treatment (Reuters, 2006). For both men and women, Nigeria's HIV treatment terrain remains an uneven landscape with huge gaps in access.

The National Agency for the Control of AIDS reports an 80% shortfall in HIV treatment among eligible antiretroviral patients in Nigeria (NACA, 2015). While the country is making some effort towards addressing this treatment gap, this study focuses on the 20% of people enrolled in treatment and care. Country assessment reports show treatment access among this percentage of people to be inconsistent (Federal Ministry of Health, Nigeria, 2007). A long standing gap in the country's treatment response has been poor documentation of records and the lack of data on the gendered disparity in treatment access between men and women. Nonetheless, the situation analysis and reports of treatment access and adherence in Nigeria document that greater gender constraints are experienced among women (NACA, 2014; 2010). Beyond the numbers or rates of those accessing treatment, other questions emerge about the pattern and distribution of treatment: namely, whom does treatment target, who benefits or who is marginalized? These remain key questions even in developing countries like Brazil, Thailand, and Mozambique that have actively pursued universal access to treatment (Biehl, 2011; Kalofonos, 2010; Faria, 2008; Rosenberg, 2001). Such studies in turn underline the vital need to assess discrepancies between universalizing policy ambitions and the ground realities of huge inequalities in treatment access and distribution, including inequalities between women and men.

In Central Mozambique for instance, the increasing number of persons entering into antiretroviral therapy (ART) and the plummeting rates of mortality from AIDS belied the day to day experiences of social and economic inequalities confronted by the people living with HIV and how these forces affected treatment uptake in the midst of universal accessibility to treatment. In other words, the progressive statistics of treatment rates do not always reflect the

specific ways that people experience treatment access as fraught with multiple constraints that are largely social in nature. A critical review of ethnographic studies from 2001 to 2012 on HIV/AIDS services in sub-Saharan Africa by Musheke, Ntalasha, Gari, Mckenzie, Bond, Martin-Hilber and Merten (2013) also points out gender inequalities as profound to undermining women's uptake of HIV testing services and by implication, treatment. Such trends have thus provoked lively debates on how to reconfigure gender structures particularly in developing countries health actions (Smith and Whiteside, 2010). One of the suggested pathways has been to deploy a top down structural approach whereby governments mainstream gender sensitive policies into national HIV/AIDS programs. But the problem has been the continued roll out of gender neutral policies and programs or the roll out of supposedly gender sensitive programs which fail to bridge this gender divide (Greig et.al., 2008).

The situation analysis on the epidemic by the National Agency for the Control of AIDS (NACA, 2014; 2010) in Nigeria cites gender and social inequalities as barriers against women's effective access to treatment but no comprehensive theory is proffered to contextualize their unsustainable access. Rather, we get a narrow technical view and an incomprehensive checklist of identified barriers that do not foreground the deeper and hidden structures that underpin these barriers. More than treatment access is adherence to treatment which requires a high compliance to an antiretroviral therapy to suppress the human immunodeficiency virus and rebuild immunity. Reluctance to access treatment or adhere in the midst of drug availability remains one of the many paradoxes in HIV/AIDS interventions whereby the very process that is designed to be life-saving is intentionally shunned by those facing the risk of death. The implication of this paradox is that "[HIV] treatment programs can ...have dehumanizing effects if the broader social

structures that contribute to suffering and impoverishment remain hidden and intact” (Kalofonos, 2010, p. 234).

My research contributes to this critical genre of scholarship on HIV/AIDS by highlighting the often neglected social dimensions of treatment interventions and also addresses the role of global-local policy transfer, and the intersection of traditional cultural systems and political economy within a place specific context; a form of intersectionality that as we will see, becomes embodied in the intricate complexities that inhibit and curtail sustainable treatment among HIV positive women in Nigeria. Grounded theoretical understandings of such local realities from an intersectional and geographical perspective are clearly germane to designing treatment strategies that better enhance access (Posel, Kahn and Walker, 2007).

This need is further underscored by empirical evidence from other studies on HIV/AIDS in sub-Saharan Africa showing that there are different complexities and experiences of the disease mediated by the peculiarities of place (Hunter, 2010). This complicated terrain in which different categories of people experience this disease is also bound to affect how they respond to it whether through their treatment seeking behavior or otherwise. The need for a comprehensive place analysis which produces local episteme around these complex factors cannot be undermined and this is also key to (re)structuring interventions. Within the domain of HIV/AIDS interventions therefore, existing place structures and processes that pose as bottlenecks to effective uptake or access of treatment and care must be challenged through policies and programs that address whether treatment strategies are tailored to reflect local realities. This study thus shifts from popular conceptualizations that frame treatment access and adherence in very individualistic and reductionist terms. Instead, it situates HIV treatment experiences at the

intersection of multiple micro and macro level forces that are intricately intertwined and operating at and across multiple scales.

The fundamental argument that the intimate is always global (Rose, 2001; Mountz and Hyndman, 2006) has never been truer in the individual experiences of this disease which though borders on individual behavior is now argued to be primarily mediated by structural factors operating at a various scales of influence that determine the power of individual choice (see Sparke, 2014; Farmer, 1992). This study connects the intimate to multiple contexts and scales e.g. the social, nation and global by explicating how the uneven practices of intervention in the global-local HIV/AIDS landscape and other structural processes at the regional and national scale materialize into the domestic and personal treatment experiences of women at the household or level of social reproduction (Wright, 2010). These linkages provide a theoretical pathway for understanding women's personal struggles with treatment through a personal and structural lens. In other words, linking HIV positive women's bodies to the public, national or global can be viewed for example, through the diverse connections that Hunter (2010) makes between the political economy and the gendered intimate experiences of everyday life of people in the rise of HIV/AIDS prevalence in South Africa.

This study thus foregrounds the "relationality of scale", that is, the intricate web of social, economic and political relations and forces at the different tiers of human operation that constrain HIV positive women's responses to treatment in patriarchal societies despite so called gender friendly policies (Faria, 2008, p. 42). Although research has created linkages between HIV/AIDS, the political economy and gender, this has been too broadly generalized to the sub-Saharan African context and the specific intricacies of everyday life resulting from these interactions at the individual level and specific place context are less taken into account. To

understand the contemporary discourses of HIV/AIDS in sub-Saharan Africa is to frame HIV/AIDS not only in a broad historical political-economic context but to understand how issues around gender at the level of the body are constituted and enacted under the influence of global-local structural ties and tensions (Hunter, 2010).

Amidst all the intersections analyzed here, gender is crucial in coming to terms with HIV treatment intervention inequalities but the normative framing of gender even by some gender agitators in a purely objective or decontextualized state, “as an uncomplicated modern alternative to backward traditions” without relations to pre-existing social and historical factors could further reproduce inequalities in gendered relationships (Hunter, 2010, p. 130; Kabeer, 1994). This argument speaks to the multiple ways that gender could be deployed and mainstreamed in HIV/AIDS programs and also raises questions around the process and nuances of gender formulation. For example, the positionality of those who formulate these policies or programs, their gender orientation which might be skewed towards a particular gender group, the purpose of gender inclusion or exclusion, and target audience - which gender group is excluded or not. This study thus constructs women’s treatment challenges within this socially bounded and institutional context to explore their constraints at the intersection of these multiple forces - social inequalities, gender and institutional power.

In challenging orthodox biomedical interventions that elide the social realities of vulnerable populations and reductionist methods that oversimplify women’s experience of treatment, this study also adopts a multi-scalar approach using an intersectional framework to situate the multiplicity of all these dimensions - place, institutions and power - as they simultaneously interact to frame women’s uptake and adherence to treatment and care. I situate the analysis of

these intersections within the literature in health geography, feminist political ecology, and critical development studies which I discuss below under the review of related literature.

A feminist political ecology approach is central to this study as it unearths the political-economy and socio-ecological forces that may act as impediments to the effective access to treatment by HIV positive women in the Niger-Delta, the region in which this study is situated. The major proposition that this study makes is that bodies of HIV women are bound up in an intricate web and scale of the sociopolitical which constrains them in myriad ways to framing the right kind of responses to treatment. Broadly, this study argues and demonstrates through evidence that unsustained HIV treatment access among HIV positive women in patriarchal societies occurs at the intersection of two seemingly contradictory scales yet mutually connected and reinforcing.

Based on these approaches, I seek to ask and answer the following questions:

1. How has gender as a distinctive category emerged and shifted over time in official Nigerian HIV treatment policy discourse?
2. What are the proximate and underlying factors of unsustained access to treatment?
3. What are the institutional gaps in national HIV/AIDS policies, and NGO intervention programs that limit and constrain access to treatment by women?
4. How do actual practices of intervention programs create gendered access to treatment, or further rework inequalities and reposition women to be marginalized in new ways?
5. How do women negotiate these processes or inequalities in access to treatment?

### **Synthesis of Related Literature and Theoretical Frameworks**

In this section, I review the works of key scholars in the literature on health geography, critical development studies and political ecology as they intersect with gender. I discuss the important

theoretical tenets that underpin these sub-disciplines, the gaps in the literature and how they frame this study as well as the ways this study contributes to the evolving literature. Key arguments based on the review of the literature center on the intersections of gender, health and place particularly within a HIV treatment and policy-making context.

### ***Geographies of Health and HIV/AIDS***

In 2006, a progress report produced a synopsis of the current state of knowledge in health research and outlined critical areas for future research to include place related investigations that construct place as constitutive of local social processes and geopolitical conditions (Bottorff, Oliffe, Robinson and Carey, 2011; Theobald et.al., 2006). AIDS is archetypical of a disease constitutive of the geo-politics of place, and the spatiality of this disease and disparity in how different groups experience this disease are entrenched in specific place structures and processes within local environmental systems (Craddock, 2004; Opong and Agyei-Mensah, 2004; Alubo, 2002). In most parts of sub-Saharan Africa, the historical legacies of colonialism, corruption, and global political-economic policies like structural adjustment programs (SAPs) not only created conditions of high risk for HIV/AIDS but also diminished available resources to address the bio-social complexities of the disease whether through prevention or treatment strategies (Lurie, Hintzen and Lowe, 2004).

Aniekwu (2002) and Farmer (1999) argue that the vast deal of spatial and temporal variations in this epidemic within sub-Saharan Africa have not occurred randomly, arbitrary, or by chance but are instead shaped by the different sociopolitical relations in specific geographies. While a major commonality of this disease in most parts of sub-Saharan Africa has been linked to social and cultural systems that are mostly oppressive to women, there are specific causalities and correlates of place (Farmer, 2005; Kidder, 2003; Farmer, 1999). For example, the extremely high rates of

HIV/AIDS prevalence in the Niger Delta relative to other regions in Nigeria has been explained by a number of scholars as being largely due to the politicization and marketization of oil resources as well as the concomitant environmental degradation and disruptions (Udoh, 2013; Udonwa, Ekpo, Ekanem, Inem and Etokidem, 2004).

The unique environment of the Niger Delta region and the connections to women's health as demonstrated through the case study description in chapter two illustrates considerably that place is primary in understanding health, including especially the global HIV/AIDS epidemic. To gain a more grounded understanding of the implication of both physical and social environmental change as they produce gender disparities in health is to create location-specific knowledges of such local processes and their complexities (Bryant, 1992). However, Merson, O'Malley, Serwadda and Apisuk (2009) decry the lack of evidence-based place-specific HIV/AIDS research and contextual data on specific populations to guide policy making and informed decisions on interventions despite the huge research investments over time. Understanding place is therefore, fundamental to understanding specific social dynamics and interactions to contextualize the gendered experiences of health particularly in the context of environmental change. Hence, place is a recurrent emphasis in this study.

Place is of course a leading theme in both health and medical geography, even though there has been multiple contestations among scholars in both sub-fields on the ways place is engaged (Meade and Emch, 2010; Mayer, 2010; Kearns and Moon, 2002; Mayer and Meade, 1994).

Medical geographers have engaged 'place' in understanding health and disease outcomes (see Mayer's works on disease and political ecology that foreground place elements and structures in health and disease outcomes), yet health geographers argue for a reorientation in the methodological operationalization of place to move beyond passive constructs to active ways

that foreground socio-ecological models of health (Kearns and Collins, 2010; Opong and Harold, 2010). Health geographers therefore construct place or locality as active from a web of “dynamic social processes” that span multiple scales including the national and global (Hunter, 2010, p. 23; Kearns and Collins, 2010).

Health geographers have continued advocacy to essentialize the complex processes of place for understanding health particularly its social, fluid, relational and discursive dimensions (Kulkarni and Subramanian, 2010; Kearns and Moon, 2002) which cannot be captured using purely biomedical disease models or quantitative research analysis. Health geography thus stresses the study of ‘health’ and health care within broader biosocial models using more interpretive methods. Despite the seeming recognition of the active role of place in shaping health as reflected in the works of geographers like Opong and Kalipeni (2004) and Schoepf (2004), very little attention has been accorded to in-depth bottom up studies that simultaneously analyze health, in particular, HIV/AIDS from a multidimensional and multiscale perspective (but see Hunter, 2010; Merson et.al., 2009; Craddock, 2000).

Increasingly, the proliferation of new HIV/AIDS cases in most of sub-Saharan Africa is empirical evidence that decontextualized understandings of the disease will no longer be adequate for informing the much needed intervention to confront the pandemic (UNAIDS, 2015; Craddock, 2000). Craddock and Mayer (2000, p. 155; 1996) advanced the reasons for “insufficiently complex place-sensitive investigations” as a consequence of health research being increasingly conducted by allied disciplines and western scholars with few geographers and indigenous scholars. Similarly, so called place studies have largely ignored the social constructs of place as shaping health issues; rather, place has been relegated to a level of passivity and only its biological or epidemiological aspects foregrounded (e.g. Pepin, 2013; Wolfe, 2004; Buve,

Bishikwabo-Nzarhaza and Mutangadura, 2002). In addition, authors such as Hunter have also critiqued the overemphasis on uni-dimensional and individual level approaches replete in HIV/AIDS research (2010), approaches which effectively assume place to be some sort of flat or grid-like tabula rasa.

A purely epidemiological model maybe vital to deploying effective biomedical solutions but become inadequate in realms where broader social forces and structural violence strongly mediate individual or group experiences of health like much of the spaces in sub-Saharan Africa (see Farmer, 2005; Akeroyd, 2004; Kidder, 2003). Such violence in turn structures and, as Farmer puts it, ‘strictures’ individual agency, radically limiting the options of vulnerable populations such as women. In these structured and stricturing spaces, health outcomes are rarely products of a singular biological causation, rather an interaction of a multiplicity of macro and micro factors that are socio-economic, political and cultural but intricately interwoven and transcending epidemiological understandings (Oppong and Ghosh, 2004). It is within these gaps in the health geography and HIV/AIDS literature that this study explores the intricate connections of women’s treatment within the nuances of place processes and relations as produced and social transcending an essentialized disease paradigm and biomedical interpretations (Curtis, Riva and Rosenberg, 2010; Kulkarni and Subramanian, 2010).

It is the hope of this study that such interpretive discourses that reflect grassroots experience would help to unseat existing dominant biomedical discourses and improve seemingly well-intentioned intervention models that prioritize technical aspects of ARV provision over the social realities that produce inequities in access. In this sense, in addition to health geography, my models come from other geographers and anthropologists (e.g. Biehl, 2011; Kalofonos, 2010; Faria, 2008). Nonetheless, the analysis of gender in health geography is relatively new, even

though women form part of the marginalized population that is a traditional focus of this field (Brown, McLafferty and Moon, 2010; Dyck, 2010). This is not to undermine the works and contributions of feminist geographers to health (see Dyck, 2010; Dyck and Dossa, 2007; Rosenberg and Wilson, 2000) but gender remains an analytic category within health geography that is still being very actively developed (Leipert and Reuter, 2005).

It is at this juncture that my interests in health intersect with gender and critical development studies by exploring the ways that exclusionary gender interventions are created through highly abstract forms, meanings and representations of gender as well as the hegemonic biomedical narratives that exclude the social aspects of health (Greig et.al., 2008). As hitherto stated, studies that combine both bottom up and top down place analyses of HIV/AIDS in sub-Saharan Africa are lacking. A single focus on either of these directions does present some limitations and as far as the extent of my literature review, studies unifying these two major approaches specifically within a gendered HIV treatment framework do not seem to exist. Aligning with the agenda of health geography, the bottom up aspect of this study provides a voice for marginalized populations to seek for social justice and a more transformative politics. Nonetheless, the top-down structural approach also attracts the benefit of engaging those at the perimeter of power and change, able to give material agency to the articulations of the marginalized (Kabeer, 1994). The varied scales at which my study engages questions around HIV treatment and gender is a timely contribution to the health geography and development scholarship.

The geographies of HIV/AIDS in sub-Saharan Africa mirror spaces of individual and group vulnerabilities to risk. To highlight the intricate details of the HIV/AIDS discourse in particular places is to adopt an epistemology that provides a framework that can represent with more exactness the ways that the local, state and global economies of power become causal

mechanisms that position women in such spaces of risk and vulnerability (Craddock, 2000).

Health geography's attention to place opens up more robust engagements with critical development studies as they relate gender to the political-economy (Kearns and Moon, 2002).

### ***Critical Development Studies: Gender and the NGO Landscape***

Critical development studies evolved directly from critiques of mainstream normative development theories and practices developed within essentialized notions of Euro-modernity, institutionalized and practiced by western bi and multilateral institutions through the construction and use of discourses and language in spaces constructed as the 'third world' (Escobar, 2010; Lawson, 2007; Kabeer, 1994). For example, Jarosz (1992, p. 108) argues that the experiential connections of Africans to their locales have been neglected, with local cultures and 'situated knowledges' excluded in the policy making process and design of intervention programs. Critical development studies thus reflect a diverse array of works that not only advocate a paradigm shift from mainstream development ideologies and practices but advance the creation of alternative development discourses through representations and language unmediated by western premises and ideologies; as well as the development of more pragmatic alternative development practices that provide more salience and inclusion of indigenous people's local knowledge and their cultural realities.

It is from these spaces that the NGO landscape was conceived and further emerged as a viable space and mechanism for 'alternative' development to occur in ways that engender genuine social and transformative change because of their perceived comparative advantage with local populations and place-based knowledge. The role of NGOs in critical development studies has thus garnered increasing attention by critical human geographers and development scholars in contemporary research and for good reasons (Sparke, 2013; Escobar, 2010; Mitlin, Hickey and

Bebbington, 2007; Bebbington, 2004; Mellwaine and Data, 2003; Drabek, 1987). NGOs have continued to assume significance within the alternative development paradigm because as non-state actors and part of civil society, they are largely perceived to be capable of producing more empowering and sustainable forms of intentional development through grounded local knowledges of places and people which is in dissonance with the exclusionary practices of mainstream development actors (Bebbington, 2004). Even more significant, their non-state nature and affiliations with local geographies and grassroots organizations position them to act as counter social movements to normative development projects, able to rework the traditional meanings of interventions in ways that are socially, culturally and politically meaningful and empowering to local populations (Escobar, 2010; Drabek, 1987).

Nonetheless, a schism exists in the development literature between those who applaud and laud NGOs as the “institutional alternative to existing development” practices and those who are critical skeptics and call for more caution about the ability of NGOs to implement a development agenda different from the official norm given their links to colonial actors, and that NGOs could be indirect agents of neo-imperialism (Mitlin et.al., 2007, p. 1700; Bebbington, 2004). Some such skeptics even argue that NGOs have increasingly become the Trojan horses of global neoliberalism (Harvey, 2005; Roy, 2014). Similarly, development scholars like Escobar (2010) have called for the need to develop a recognition and awareness of the politics of so called development expertise manifesting through alliances with non-state actors as they foster new but intricate and complex practices of development. For example, there is evidence that the uneven spatialization of NGOs is serving to “pluralize particular spaces and places at the expense of others” (Bebbington, 2004; Mercer, 2002, p. 13). This is in addition to the growing concern that NGOs are now intricately tied to the very neoliberal agenda that they were designed to critically

engage as alternatives to mainstream development (Mitlin et.al., 2007). The propensity for NGOs to become effective tools for civil society change and transformation is not in debate or in doubt but what is controversial and also highly contested in the literature is their capability to do so because of their connections to broader systems of global policy governance.

Over time therefore, critical questions posed by geographers interested in the analyses of development interventions have cast doubts on this propensity given the increasing professionalization of many NGOs emanating from their dualized nature with simultaneously constitutive relations to transnational forces of aids, the state and neoliberal market on the one hand; and local interests on the other (Nagar and Raju, 2003). Also significant are the specific ways that the immanent development activities of international governance systems, the global political economy, transnational aids networks, and internal organizing structures of NGOs have conditioned the ways that global health interventions are localized and implemented (McGoey, Reiss and Wahlberg, 2011; Yu, 2008; Faria, 2008; Garrett, 2007; Seckinelgin, 2005; De Vogli and Birbeck, 2005; Sparke and Mitchell, 2015). Yet there is a lack of specificity in analyzing the outcomes of NGO interventions as mediated by their nature which is structured by their connection to the broader political economy. Also, the ways in which these complexities have reproduced uneven development or inequalities in specific third world spaces are unclear. It is within this domain that development geographers have made very few contributions. Hence, there have been calls for critical geographic research to move beyond case study based ethnographic studies of NGOs premised on what is presumed to exist or *prima facie* to analyzing NGOs as they actually exist in their true forms which is in connection to these existing global realities (Escobar, 2010; Mitlin et.al., 2007; Bebbington, 2004).

Similarly, a conceptual and methodological limitation of most analyses of NGO interventions in the literature has been the framing of NGOs as a distinct organizational unit possessing clear boundaries divorced from their parent institution and not as a unit subsumed within a larger set of institutions and translocal forces. This typical assumed separation of NGOs and their transnational social structure has had profound empirical and theoretical implications. First, relatively little is known about the deeply embedded social and institutional forces from which many NGO interventions evolve. Second, little is understood about the ideas that underpin their actions. Consequently, less explanation is produced for the ideological premise and trajectory of their interventions which are becoming increasingly distal and exclusive of local populations and their realities (Reid-Henry, 2013; Faubion, Paige and Pearson, 2011; Oppong and Kalipeni, 2007; Yeboah, 2007; Birn, 2005).

It is at this juncture that I seek to interrogate and understand NGO HIV/AIDS interventions as occurring within these relations in terms of the ways they imbricate at the intersection of global and local connections to shape the exclusion or inclusion of gender considerations in treatment plans. In addition, how do the relations between these immanent and intentional development processes as they underpin NGO interventions reproduce uneven development like health inequalities among gender groups? This premise is contingent on an established fact re-iterated throughout the literature of NGOs ability to rework and transform places and livelihoods because of their strong connections to place yet their transnational tendencies may work through specific languages and technologies to produce the exclusion of certain priorities and groups.

Along the aforementioned lines and given the globality of HIV/AIDS, it becomes easy to interpret this disease, formulate and implement interventions around particular languages of international development actors and western understandings. Within a gender context, these

international cognitive intervention maps may lack a contextual understanding of existing gender relations and may ultimately influence and translate to the nature of intervention and outcomes experienced by infected women. But the construction of interventions around particular discourses and languages are not limited to western interventions operationalized through the NGO mechanism.

At the country level, mainstream national policies may also reflect an existing social order like patriarchy and may determine the ways that meanings around gender come to be constituted and thus disconnected from the realities and psychosocial needs of the target population (Oppong and Kalipeni, 2007; Yeboah, 2007; Seckinelgin, 2005; Nagar and Raju, 2003). A classic example is the problematic abstraction of gender in very neutral ways, whether in pure universalistic and west-centric notions occluding local understandings or devoid of any specificity to place and context, mostly do not translate to social change and consequently produce ineffectual gender outcomes (Connell, 2012; Kabeer, 1994). Hence, many studies have called for the study of gender relations and the deconstruction of gender in ways that provide insights into the structural, ideological, cultural entrapments and other constraints of gendered health policies, and particularly framing these within the relations of masculinities to femininities (see Akeroyd, 2004; Hunter, 2010).

Kabeer (1994, p. 280-281) defines 'gender relations' as "specifically referring to those aspects of social relations which create and reproduce systematic differences in the positioning of women and men in relation to institutional processes and outcomes. Gender relations are therefore, interwoven into the broader set of social relations structuring the division of resources and responsibilities, claims and obligations between different social groups of women and men within any given society". However, traditional frameworks of feminist responses to women's

issues have largely focused on rigid categorizations of women as a monolithic group based on biological sex eliding the necessary consideration of other gender categories like class relations, social divisions or other inherent gender markers or issues that exist among women.

Contemporary feminist scholarship has therefore, argued a shift in focus from ‘women’ to ‘gender’ in development studies or policy formulation to foreground power relations between men and women. This was to address the problematic categorizations of gender as an only ‘women’ construct in addressing issues of gender inequalities which obscures the intimate relations and daily experiences that perpetuate such inequalities. But even more problematic is that while these rebranded terms as gender, and gender roles are deployed increasingly, their true imports have not been significantly reworked (McIlwaine and Datta, 2003).

The importance of gender in development practice and policy particularly HIV programming predates contemporary agitations as exemplified in 1992 by Elizabeth Reid, then the Director of UNDP’s HIV and Development program when she stated that “one of the most striking features of the response to the HIV epidemic to date is how few of the policies and programs we have developed relate to women’s life situations” (Greig et.al., 2008, p. 2). This statement provides evidence that the push and call for gender to be actively inserted into development practice is not just a contemporary discourse but has existed over time. Nonetheless, such agitations even in recent times have initiated a reactionary response and necessitated a huge shift in gender studies or feminist approach to development. This shift has included feminist approaches to addressing gender blindness or “male centered conceptualizations of development” in development discourses to now engendering development in ways that juxtapose men and masculinities, women and femininities, women participation and empowerment, diversity and human rights within the development agenda (Connell, 2012; Hunter, 2010; Greig et.al., 2008; McIlwaine and

Data, 2003, p. 369; Brown, 2000). A profound weakness in the analysis of women and/or gender in development therefore, is when the relational dynamics of gender in women's access to resources are neglected. Such deemphasized local knowledges create gender blindness in local interventions and development initiatives for indigenous populations.

Along this axis, critical arguments have also been made for both the intersectional and relational gender approach. An intersectionality approach opens up the possibility for the inclusion of markers of difference or other social dimensions of individual identities within the axes of power like age, wealth that constitute gender relations. The intersectionality theory conceptualizes gender as not static but fluid and contingent on wider inequalities that position a similar category of people experiencing health outcomes differently. Within the gender and health terrain, an intersectionality analysis helps to explicate and further dismantle the complexities of other dimensions of social inequalities as they affect gendered health inequalities particularly within specific gender groups. The intersectional framework not only mainstreams the constellation of individual level differences in the analysis of gender but also links gender to institutions and structural forces. Relational construction of gender means theory and research that conceptualize women's issues not as independent but as relational to include the agency of men because these two gender categories exist in a reciprocal relationship where the dynamics of one affects the other. More succinctly, this framework argues that the theorizations of gender must recognize both social dynamics and the agency of male and female bodies and see them as intricately linked. Relational theory speaks directly to the platform on which transformative and innovative health policies must be circumscribed because this gender approach has been productive in other policy arenas. This framework therefore, embodies positive possibilities to creating an effective

understanding of gender and health issues (Connell, 2012; Hankivsky, 2012; Springer, Hankivsky and Bates, 2012; Cornwall, 2002; Mane and Aggleton, 2001; Lorber, 1994).

Central to the purpose and design of this study therefore, is the mainstreaming of these key emerging arguments from the gender and development scholarship. This demands in turn an understanding of the varied conceptualizations of gender and their implication for policies and development discourses including health. Also significant to these alternative approaches of engendering development is the debate between the needs and rights based model as the appropriate platform of incorporating gender as a visible and active category into development policies particularly HIV/AIDS because of their inherent limitations (Aniekwu, 2002; Farmer 1999; Seidel, 1993; Wisner, 1982). Wisner in a study of development discourses in Africa advocated the relevance not only for a 'need's based approach but a rights based approach (1982). But a review of more recent development literature does not provide clear evidence of a continued advocacy of a collaborative synergy of these two approaches. Instead, advocacy has been limited to mostly a rights based approach to frame women within the development agenda (Springer et.al., 2012; Greig et.al., 2008).

I see this as a problematic gap in the literature and hence, one of the arguments I make through this research is to move past the rights only based approach commonly deployed in HIV/AIDS and gender studies to include a needs based approach but with attention to local culture and traditional practices that shape not only how needs are articulated but how rights are invoked and claimed by less dominant and powerful groups like women in patriarchal societies. Paramount to these arguments therefore is "the need to foreground embedded local practices and the imbrications of local gender relations and ideologies according to place and space... to effect change" (McIlwaine and Datta, 2003, p. 373). But then like rights, Wisner (1982) argues that

certain questions have to be addressed around needs like, ‘who should define needs, the poor or development experts or intervention agencies? What would satisfying a need be? Would it be simply to deliver packages of ‘needs meeting’ services (water pumps, health care, emergency bags of grain) as aid agencies so often do, or must poor people control the resources required to meet their needs? Within the context of Nigeria’s Niger-Delta and the struggles for indigenous resource control and self-determination, a needs-right based approach is relevant to situate an analysis of HIV infected women in the Niger Delta and how their health needs have been articulated and framed by national HIV/AIDS policies and international health agencies through local NGOs. Additionally, to question what ideologies are used to construct the needs of this marginalized population of women in the Delta.

These critical arguments profoundly shape the ways that this study interrogates gender in health interventions as both relational and intersectional and how these may impact the way policies are formulated by planners and engaged by recipients. But despite these theorizations, there is no real comprehensive theory and body of work on the intersectionality of these multiple structures (the global political economy of aids, social and institutional dynamics) and how they mediate the exclusion or inclusion of gender transformative interventions within a HIV treatment context. Also, the specific ways that national intervention policies and NGOs organically set up processes that reproduce inequalities among gender categories and reposition women to be marginalized in new ways with access to treatment as a specific reference point. Critical development studies thus provide the intellectual platform to interrogate these processes especially as they intersect with gender.

### *Political Ecology and the Feminist Agenda*

Political ecology has long been engaged by geographers seeking to establish claims of the role of large scale political and socio-economic processes as key mediators of systemic changes in local social systems and environmental conditions as exemplified by the classic 1985 work of Piers Blaikie and the scholarly contributions of other original works by geographers like Peets and Watts (1996), Bryant (1992), Blaikie and Brookfield (1987). Political ecology approaches environmental changes as both natural and anthropogenic in origin and from small or large scale political-economy forces and the impact of such changes on social systems and human development (Simon, 2008). This field of inquiry has been lauded for its theoretical and methodological configurations which allow a pluralism of methods, critical explanations of the anthropogenic origins of environmental change and impact. It is also acclaimed for its capacity to employ a combination of critical social theories and historical contingencies in the analysis of the intricate multiple connections of the human-environment binary across multiple scales, and within a local context (Elmhirst, 2011; Simon, 2008; Rocheleau, 2008; Muldavin, 2008; Bryant, 1992).

Generally, traditional political ecology research has been mostly confined to the boundaries and rudiments of academic theory. Even so, an emerging significant trend of profound importance has been the extension of traditional political ecology to transformative politics like environmental resource control and management as the practical nature of most political ecology research combined with its critical perspectives demand a pragmatic approach to many of the issues that political ecology addresses (Neumann, 2008; Rocheleau, 2008; Gezon, 1997). This is of particular relevance given the policy perspective of this study. However, the practicality of proactively translating the critique of social and environmental ills to effective policy making in

political ecology research has often been questioned by academics (Walker, 2006). Nonetheless, this field still possesses a great capacity to address pertinent contemporary issues like poverty, social justice, the politicization of environmental degradation and conservation, and the neoliberalization of natural ecologies to produce capital accumulation by dispossession (Elmhirst, 2011).

It is within these analytical and methodological strengths of political ecology to engaging contemporary issues of environmental change on socially marginalized populations that this study is positioned. Engaging political ecology for this study provides an analytical framework to understand the diverse and structural sociopolitical complexities of environmental change in ‘third world’ spaces like the Niger Delta region of Nigeria. As previously established, the place specific nature of HIV/AIDS requires situated and contextual knowledge of local environmental systems. Political ecology bears a direct significance through its increasing engagement with the production of situated and location-specific knowledges (Richmond, Elliot and Elliot, 2005; Craddock, 2000).

This sub-field also provides the conceptual lens to theorize these complexities at different scales both from the ground up and downward. For example, understanding national and transnational forces on third world environment change through the apparatuses of domestic policies and transnational corporations (Global Health Watch, 2008; Bryant, 1992) and how the interaction of these macro power relations come to impact locally on vulnerable bodies of HIV positive women (Wright, 2010). A recurring theme in political ecology therefore, is the need to centralize a phenomenon say health in its broader socio-economic, environmental and political context as subsumed in a variety of scales from the local to the global; also how individual decision making

is intricately connected to external structures that constrain available opportunities to local populations (Meade and Emch, 2010; Donovan and Duncan, 2010; Mayer, 1996).

Political ecology thus emphasizes the intersection of scale and in principle constructs the personal experiences of marginalized groups within a wider matrix of political economy structures, power, and the politics of resource control, distribution and access (Donovan and Duncan, 2009; Faria, 2008; Richmond et.al., 2005; Mayer, 1996). But within the contemporary political ecology literature, scale is now being emphasized to be conceived in varied ways like in social terms that not only connects personal experiences of the environment to macro political economy conditions and social processes, but that which emphasizes a discursive analysis of environmental change (Mauro, 2009). Yet, most of the questions and issues that this study raises around HIV positive women and environmental politics are now increasingly being tackled by feminist environmental scholars as most traditional political ecology analyses do not do justice or give full appraisal to the ecological and social contexts that sustain or impact the lives of women (Peets and Watts, 1996). Given that women maybe particularly vulnerable to adverse environmental change, it is surprising that their role in these complex processes of environmental struggle and change has been largely neglected and the scholarship on traditional political ecology studies is only beginning to recognize this (Rocheleau, Thomas-Slayter, and Wangari, 1996; Bryant, 1992).

Feminist political ecology evolved from these intellectual tensions. It builds on the mainstream theoretical foundations of political ecology but makes women more visible in the ecological analysis of the environment (Rocheleau, 2008; Hovorka, 2006; Gezon, 1997; Rocheleau, 1996). The reformulation or rethinking of scale has also formed part of an important feminist theoretical shift within political ecology (Dyck, 2010). Recent feminist scholarship in political ecology has

not only reiterated the need to continue to foreground the interconnectivity of scale and spaces concurrent with a traditional political ecology approach, but to emphasize its feminist conceptualizations, and also to understand the formation of the subject of gender as inextricably linked to the political (Truelove, 2011; Nightingale, 2011; Ge, Resurreccion and Elmhirst, 2011; Elmhirst, 2011).

Crucial to this debate are also claims by feminist scholars that ignoring women in political ecology analysis renders them invisible and does not give full appraisal or justice of the ecological and social contexts that sustain or impact their lives. This study annexes with feminist political ecology because it foregrounds the dual relations between the socio-ecological environment of the Niger Delta and women's livelihoods as they mediate the decisions to access and adhere to HIV treatment and care. But an obvious gap in the feminist political ecology framework is that sustainable development in relation to the environment has been mostly thought of in a food, resource management, agrarian and industrial context including the rural-urban binary (see Elmhirst, 2011; Gezon, 1997; Okoko, 1999; Rocheleau et.al., 1996). Although, health consequences as part of environmental processes are broadly featured in some analyses (see Bellows, 1996; Brú-Bistuer, 1996), connections to illness or infectious diseases like HIV/AIDS have not been made within an explicit feminist political ecology framework. It is mostly within traditional political ecology research that disease and health analyses have been featured but without a focus on women (see Robbins, 2012; King, 2010; Mayer, 1996).

Many feminist political ecology studies have focused on activism around the inclusion of women in contemporary environmental debates and issues on resource control, conflicts, social movements and activism (see Rocheleau et.al., 1996 collection of feminist political ecology works and case studies) but less the implication of their exclusion from environmental politics

and resource control. Through this study of the Niger Delta region, this research focuses on how the interplay of market-led environmental decisions, politics of control in resource use and social power may be exclusionary to women as a marginal population in this geography, creating differing sets of life opportunities for gender groups in the context of HIV treatment access. Unpacking such relations of transnational oil corporations especially as they affect gendered rights and responsibilities at the individual level is crucial (Robson, Jarosz and Laurie, 1999).

Given the history of the environment and political economy of oil in the Niger Delta, this disease and its vulnerabilities must not be understood in segregation from the broader context of the political-economy of the nation and state as contextual sources of change to its health and social environment (Bryant, 1992). The role of transnational capitalist policies and investments on the ecological environment and social systems in third world geographies like the Niger Delta as precipitates of negative health outcomes of the local population have been investigated and largely documented in the literature (see Global Health Watch, 2008). What remains unclear is how these deleterious national and transnational policies and marketization of the environment have impacted women's access to HIV treatment or if there are any connections at all. More specifically, there is very little work addressing how the intersection of sociopolitical and ecological relations have produced the situational context that may have disenfranchised women in their access to HIV treatment (e.g. Okoli, 2013; Eregha and Irughe, 2009; Global Health Watch, 2008; Ikelegbe, 2005).

## **Conclusion**

The past and present ecological and political economy environment of the Niger Delta region is a reflection of the complex interaction of these processes and must be accounted for in any intellectual attempt to decipher the factors militating against women's access to HIV treatment in

the region. It is within these cracks and gaps in the literature that this study is situated and consequently, contributes to the literature. The Niger Delta region situated at the heart of the southern part of Nigeria provides an exceptional case study for how feminist-political ecology approach can be deployed to study health narratives in the context of the natural environment. In the next chapter, I provide a detailed description of this region's complexities especially its relation to the wider political-economy of Nigeria. Given that this study problematizes women's treatment within the larger dynamics of private and public HIV/AIDS institutions at the national level, I also provide an overview of the Nigerian HIV/AIDS landscape and its interventions.

## **Chapter Two**

### **Methods: Re-searching Gender in HIV/AIDS Interventions**

#### **Introduction**

This is a qualitative study which adopts an integrated methodology that pays attention to multiple scales of analyses and feminist approaches that engender situated and place knowledge through direct inclusion of the testimonies of women. This hybrid approach addresses inherent gaps in the literature on health geography, feminist political ecology and critical development studies. First, this research is designed using a bottom-up approach that makes for individual level data that reflect the gendered experiences of women and their ‘locally identified needs and priorities’, in combination with a top down approach that includes donor agency interventions and national government policies to draw the benefit of engaging those at the perimeter of power and change.

This multiscale study design is influenced by the emphasis in health and development scholarship on either top or bottom up approaches in addressing issues of gender in policy and interventions and either have been critiqued for their limitations. While a top-down approach provides opportunities for the structural problems of health to be addressed, it is largely insufficient if agency is not provided to the subjects of interventions to effectively articulate their needs in the ways better understood and experienced by them through bottom up studies. Therefore, a combination strategy from a synergy of bottom-up and top-down approaches potentially eliminates the limitations of a single or mono approach.

Second, this study adopts a feminist intersectional lens to include broader forces that transcend individual or group gender dynamics; and also understanding these intersections as simultaneous interactions and not as separate modalities or occurrences. An intersectional lens is deployed to

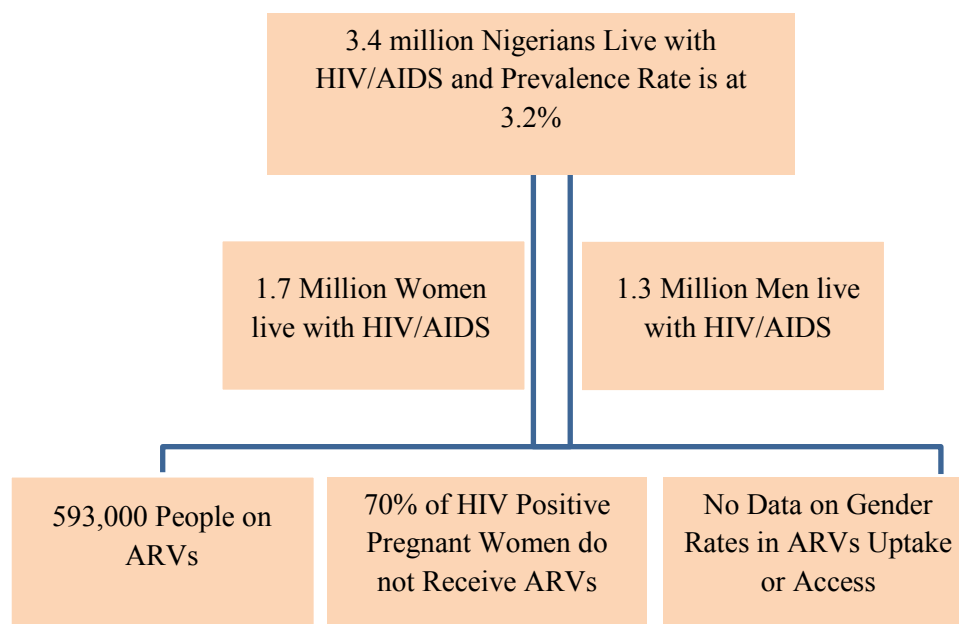
situate HIV treatment access and adherence within the productions of the political economy, environmental processes, culture and other place-based social relations often elided in the attempts to explain HIV positive women's health seeking behavior. In this way, the intersectional approach is not only complementary but reinforces this study's multiscalar design.

The choice of a qualitative methods framework is connected to the nature of this study's inquiry as qualitative methods provide a deep understanding of the historical, social, political and cultural processes of groups of people that may operate within a particular bounded space (Dunn, 2010; Elwood and Martin, 2000). For example, policy makers respond to human drama and experience through qualitative findings which help to explain and contextualize these experiences by describing in poor women's own words the barriers and challenges they face in service access. "Qualitative testimonies can [therefore] be a powerful tool in highlighting gendered disparities in health experiences" (Theobald et.al., 2006, p. 341; Davis and Howden-Chapman, 1996).

In tandem, the sections that follow provide a historical, social and political economy account of the research sites. It begins with an overview of the Nigerian HIV/AIDS landscape which details the emergence of the HIV/AIDS epidemic in Nigeria, the concomitant policy response and how this has shaped the current landscape of intervention. The Niger Delta region in which this study is situated and the specific study site, Erhoike community located in the Delta region are also accounted for to understand the specific environmental, political-economy and place relations that circumscribe women's health behavior as well as the actual site of health care, the Erhoike Cottage Hospital where women access HIV treatment. Finally, I provide a description of the data collection process, methods and analysis. Given practical realities that the data collection process is deeply intertwined and influenced by the researcher's personal location (Billo and Hiemstra,

2013), I briefly reflect on the reciprocity of my positionality and those of the research subjects and how these profoundly shaped the field work process and outcomes, and the ways that I came to understand and interpret the data.

### **Nigeria: An Overview of HIV/AIDS and the Landscape of Intervention**



Source: UNAIDS, 2014 and NACA, 2015

Figure 1: Estimates on adult HIV/AIDS in Nigeria

Nigerian HIV/AIDS interventions can be said to have undergone four phases; the initial phase when the first case of HIV/AIDS in Nigeria was discovered in 1985 (although some of the policy texts document it as 1986) during the era of military dictatorship and political instability in Nigeria. Like many sub-Saharan African countries, Nigeria responded to this disease in disbelief and tagged it as the figment of scientists' imagination. Nonetheless, this discovery created panic within political circles which prompted some interventions like The National AIDS and STIs Control Program (NASCP) set up through the Federal Ministry of Health (FMOH) in 1987. This

was the nation’s first response and it focused on prevention and detection. Given the instability of the military regime at this time, little was done under this era to address the epidemic and established programs were not as effective in curbing transmission rates but more so because there were many unknowns about the epidemic at the time. There was almost a period of hiatus from this time until 1999 when the country transited to its first democratic regime. This period ushered in an active AIDS response which I have designated as phases one to three as indicative of a more strategic policy response to the disease, and also based on each plan of intervention for each phase designed to operate within a five year timeline as indicated in the policy texts. See Figure 2 below for a summary of this timeline and key features in each of the four phases.

**Early Phase of HIV/AIDS discovery in Nigeria, 1985 - 1998**

The era of disbelief, denial and rejection of western scientific evidence of AIDS in sub-Saharan Africa; and initial weak policy response to the disease during the military era which was also a time of political instability. This response was mostly preventative to curb the transmission and spread of the epidemic.

**Phase 1: 1999 – 2004. 1999 ushered in the democratic regime after many years of military dictatorship**

This began an active phase of HIV/AIDS intervention with the establishment of the President’s Committee on AIDS (PCA) and the national AIDS coordinating body, the National Action Committee on AIDS (NACA) with their subsidiaries at the state and local level. The establishment of NACA was characterized by the recognition of a multisectoral response given the intersectionality of the epidemic as cross cutting different issues handled by different sectors. There was still no access to antiretroviral drugs so interventions remained mostly preventative focused on behavior change

**PHASE 2: 2005 – 2009. Active HIV/AIDS response continued and culminated into the adoption of a strategic plan launched by the international AIDS community known as the “Three Ones”.**

The Three Ones strategic plan comprises the HIV/AIDS National Strategic Framework policy plans (the NSFP), One Monitoring and Evaluation System with a single coordinating body,

NACA. Interventions were beginning to be a mix of treatment and prevention as antiretroviral drugs were becoming available at the end of this phase around 2009 but not easily accessible due to physical and economic factors. Gender as an issue of concern was officially launched at this time in policy documents through the concept of gender mainstreaming even though gender was mostly defined in categorical terms excluding relational dynamics.

The National *Action* Committee on AIDS (NACA) was transformed into a full agency, now the National *Agency* for the Control of AIDS (NACA) in 2007 through legislation to further strengthen its coordinating role and overall national response.

**PHASE 3: 2010 – 2015. The most recent phase characterized by increasing availability of antiretroviral drugs and a beginning emphasis on a biosocial model of health alongside existing biomedical interventions.**

The goal here is universal access to treatment and with increasing availability of drugs came issues of non-adherence and focus on the social issues that constrained access like care and support for people living with HIV/AIDS. Gender issues continued to be a focus but with marked variations in terms of its conceptualization as now more relational although not consistently so in all the policy documents.

Figure 2: Timeline and description of Nigerian HIV/AIDS intervention from 1985 - 2015

With a current adult prevalence rate of 3.2% from the initial 5.8% in 2001, Nigeria can be said to have shown remarkable progress in stalling this epidemic over time. However, the country's multisectoral response to the epidemic remains challenged by poor coordination and administration among the different sectors of the polity which has led to the duplicity of efforts at the state and local levels. Although NACA can be said to be a sign of a political commitment to HIV/AIDS response at the national level, the lower level parastatals/committees, SACA and LACA were established as part of the federal government's directives to expand HIV/AIDS response and governance at the state and local levels. However, the political will and

commitment particularly at the local tier have been severely lacking (UNAIDS, 2015; USAID<sup>5</sup>, 2002).

The national response is mostly donor driven and donor dependent but at the state level, private sector contributions remain negligible and untapped. Nonetheless, this over dependence on donors poses as a significant challenge to the long term sustainability of a national response particularly in the face of the current global financial crisis. Other challenges include the weak linkages between various sectors of the economy particularly in development initiatives like poverty reduction programs, social and legal protection services, geographical and gender inequalities in both prevention and treatment efforts (NACA, 2010).

Despite these gains and losses, Nigeria is still on a long road to halt the HIV/AIDS epidemic as critics maintain that the cost of interventions outweigh the achievements documented so far with current prevalence rates showing states in the southern region as most affected (see Figure 3). The Niger Delta, a region popularly tagged “resource cursed” due to its high poverty levels in the midst of plenty oil resources (Global Health Watch, 2008, p. 171) comprises nine states which predominantly constitute the southern states of Nigeria. For example, Rivers State in the Niger Delta region has a very high prevalence rate of 15.2% compared to the national prevalence rate of 3.2% (UNAIDS, 2015; NACA, 2013).

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<sup>5</sup> United States Agency for International Development

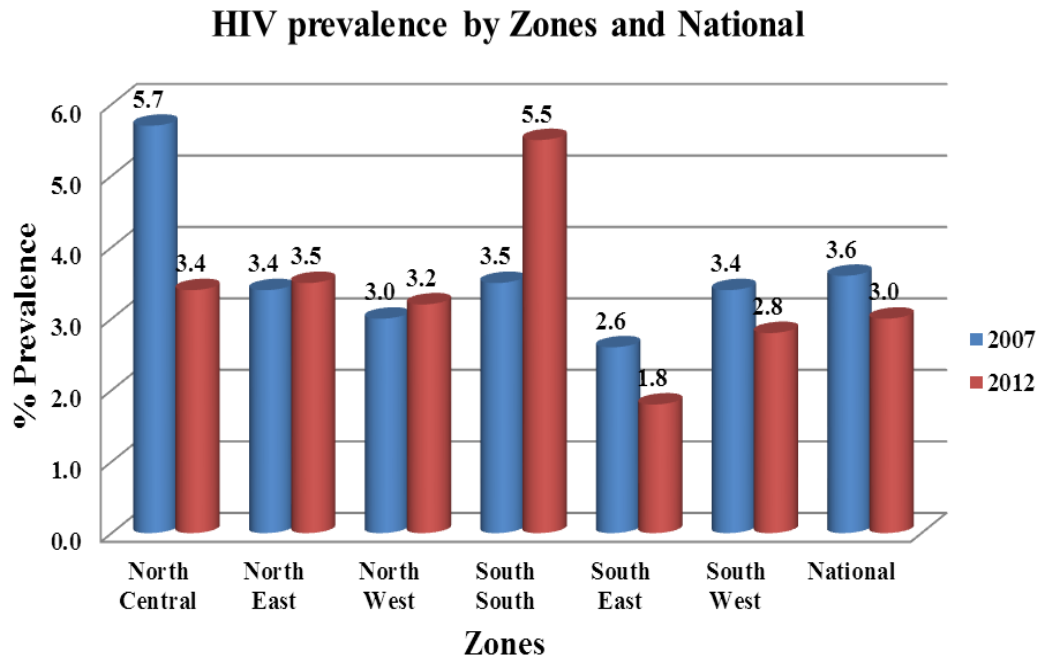


Figure 3: HIV prevalence by geopolitical zones  
 Source: NACA, 2014

In summary, HIV/AIDS is a major public health issue in Nigeria. The inaction and delayed response to the epidemic, the lack of political will to fight the epidemic at the early stage of transmission when the country was under military rule, along with other epidemiologic drivers of the epidemic - heterosexual behavior, presence of STIs, stigmatization and discrimination, gender and other forms of social inequalities, cultural factors and an inadequate health care system combine to make HIV/AIDS a major epidemic in the country (Nasidi and Harry, 2006).

#### **Historical, Political-economy and Socio-ecological Contingencies of the Niger Delta**

The health terrain in the Niger Delta region remains very problematic and needs to be understood through a broad political-economy lens. The exercise of political power and struggles over the control, distribution and allocation of resources between the north and the south are crucial to

understanding health outcomes in this region. The power dynamics in political leadership between the north and south have reduced if not eliminated, concerted efforts to plan national disease specific interventions for this region which is domiciled in the south. The Nigerian policy arena is so much contested that policy formulations and development initiatives for the Niger Delta have met with staunch resistance by the ruling political class in the north and development funds continue to bypass the region by those in the realm of power whose geographical or ethnic interests may not be represented. Hence, a vicious cycle of health inequalities mediated by power and resource control continue to be perpetuated in the Niger Delta States.

Historically and geographically, the Niger Delta is defined as the area that encompasses the natural delta of the Niger River which also produces oil, extending to the east and west. By this definition, the core Niger Delta region comprises originally of three states; Delta, Bayelsa and Rivers which are also the dominant petro states in the country. However, the present day Niger Delta region defined in geopolitical and administrative terms comprises a broader region of nine states (see Figure 4 below). Figure 4 shows the Niger Delta region and its constituent states as broadly and politically defined, and this is the definition deployed in this study (Okoli, 2013; World Bank, 1995).



Figure 4: Nigeria and the states of the Niger Delta region  
Source: Nwankwo and Ogagarue, 2012

The Niger Delta is the ecological nidus of rich biodiversity and natural minerals including crude oil, vast agricultural lands and forested regions, excellent water ways and human resources. Physically, it is the delta of the River Niger to the left which runs through Nigeria to other neighboring West African countries like the Republic of Niger and whose waters drain into the Gulf of Guinea. The Benue River to the right is a major tributary of the River Niger. This makes the Niger Delta region a rich fertile land for diverse agricultural activities (see Figure 5 below).

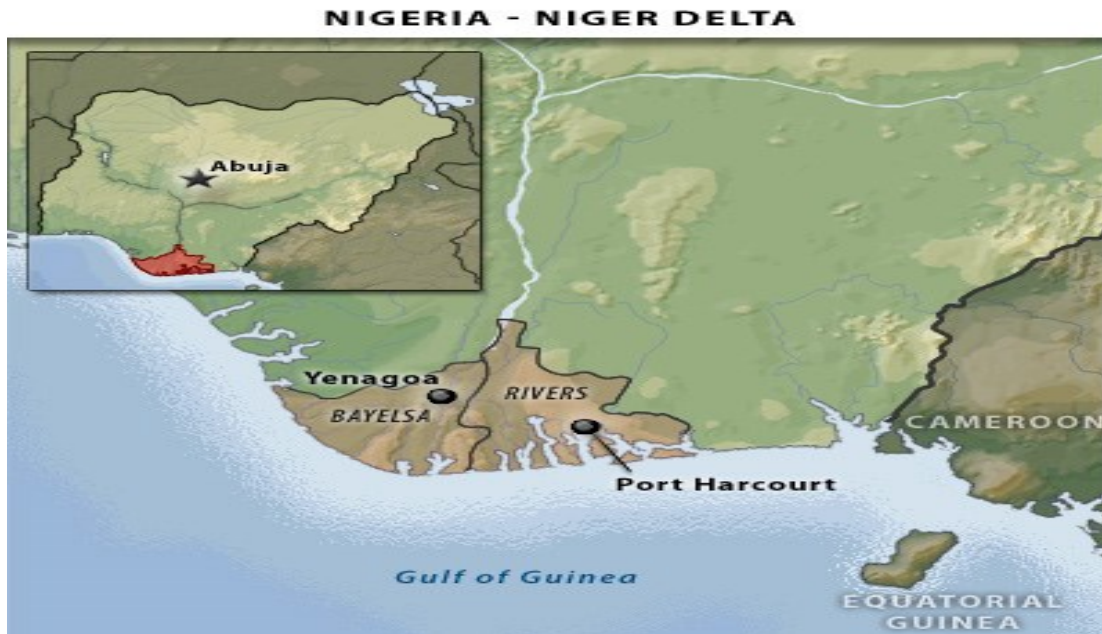


Figure 5: Physical geography of the delta<sup>6</sup>

In Nigeria, the Delta is the region that lays the proverbial golden egg yet paradoxically, it is also a site of social deprivation, abject poverty, squalor, immense political turmoil and social unrest because of marginalization and the massive political struggle over its resources (UNDP<sup>7</sup>, 2006). Another paradox is the underdevelopment of the region which is in stark contrast to its wealth. Expectedly, huge oil explorations are pervasive in the region but accompanied by massive environment degradation. This is despite the fact that a majority of the population especially in rural areas are farmers and fishermen whose livelihood and survival depend on the ecosystem. This region makes Nigeria one of the largest oil producers in the world and makes the most contribution to the country's federal treasury and foreign reserve that is used for developmental projects across the country.

<sup>6</sup> Source: <http://www.electricscotland.com/thomson/images/15.10%20niger-delta.jpg>

<sup>7</sup> United Nations Development Program

However, existing statutory laws centralize the decision making process at the level of the federal government whose physical abode is resident in the north. The decision to allocate and distribute resources is therefore, negotiated at this level irrespective of the indigenous population or its location. Under this legal arrangement, major transnational corporations notably Shell Petroleum Development Company (SPDC) have been given license for exploratory activities to foster the nation's developmental activities. All royalties and rents are paid to the federal government as they reserve sole right over all mineral including oil exploration. However, this political economy of oil and development has imposed a huge health crisis in the Niger Delta. This crisis stems from the large scale environmental deterioration over time with little propensity of a rollback. From historical antecedents in this region, activism on environmental rights and justice for the indigenous population have met with strong political resistance especially by existing powers at the national level who continue to represent their religious, ethnic and self interests under the guise of national development. The execution of Ken Saro-Wiwa (one of such environmental and human rights activist for indigenous resource control) by the military government in 1995 remains a constant reminder of the ways structural violence associated with the oil extraction economy often becomes embodied as personal violence and suffering due to the ongoing struggles over resource control.

Oil spillages and leakages, environmental dumping on lands and water systems have set a chain of ecosystem reaction and social consequences. Loss of biodiversity, arable lands and loss of livelihoods are typical outcomes of these processes (Global Health Watch, 2008). People have been socially and economically displaced with more impact on vulnerable groups like women and children. The monumental neglect by the national government resulting from lack of allocation of economic resources to these areas to counter the effect of such negative

environmental activities have also provoked sets of behaviors and choices among the local population; behaviors of sexual permissiveness that are detrimental to health nevertheless, perceived mostly as logically available choices needed to negotiate these unhealthy circumstances. With high HIV/AIDS prevalence generally linked to extreme poverty, the statistics of HIV/AIDS prevalence in the region are therefore, not surprising given the region's unstable socio-economic and political conditions (UNDP, 2006).

In 2001, five of nine states in the region had the highest HIV/AIDS prevalence rate in the country (Federal Ministry of Health, 2001). Also, seven of these nine states were reported to be among the first eighteen Nigerian states to record higher than the epidemiological threshold prevalence rate of 5%, and of the three states that had the highest prevalence rates, two belonged to this region (Udonwa et.al., 2004). More recently, Rivers State which is one of the three core Niger Delta states has the highest HIV prevalence rate of 15.2%, more than quadruple the estimated national prevalence rate of 3.4% (UNAIDS, 2015; NACA, 2013). These records are not unconnected to the political economy of oil and stark underdevelopment in the region as available evidence from a study conducted by Udoh, Mantell and Sandfort (2009) identified structural factors for the burgeoning rates of HIV infections in this region. This web-based survey by Delphi experts comprising HIV/AIDS research scientists and public health experts identified widespread poverty, lack of social infrastructure including health, and the vulnerability of women due to their economic disempowerment as major structural causes.

The paucity of health resources and services in this region due to large scale structural neglect further compound the situation (Global Health Watch, 2008), and women have been more at the receiving end of this politics of denial. The UNDP (2006) reports the highest HIV/AIDS prevalence in the region to be among women and young people. Many women and young girls in

particular, have been thrown into the sexual economy where sexual relations are negotiated with oil workers or expatriates. Simon's (2010) review of this region also reveals the culture of patriarchy that positions women as victims of circumstances lacking power and opportunities to make informed, safe and healthy decisions as their marginally assigned position disempowers them, renders them voiceless and places them at the mercy of their male counterparts. Other sets of processes that have been initiated by these political economic structures that have shaped negative health outcomes include the conducting of daily life on the existing polluted environment. Simon states that women are most hit as they are traditionally farmers who now have to travel long distances to the interior to find arable lands to cultivate when their only access and means of livelihood and daily sustenance have been cut off.

Similarly, Udonwa et.al., (2004) study also implicates poverty as a determinant of the high rates of HIV/AIDS in the region, and even more problematic is that existing care for people living with HIV is challenged by multiple factors including the availability of health care facilities which leads to poor treatment coverage. Even at the national level, HIV/AIDS initiatives rolled out by the National Agency for the Control of AIDS (NACA) in conjunction with other international agencies like the Global Fund to Fight AIDS do not seem to have combated the generalized HIV/AIDS epidemic in the region (Reuters, 2006). Underdevelopment or the lack of it implies a weak social and health infrastructure. In addition to large scale processes of socio-political control and economic disempowerment as they affect health outcomes, these processes are reproduced locally within communities by local leadership. Civil and social unrests are characteristic of this region emanating from local struggles over resources that are distributed to the local population in the form of environmental compensation from transnational oil

corporations. The infamous Niger Delta militants are also a direct social consequence of these environmental change processes.

It is within this complex conundrum of political economic processes and social structures that I situate local understandings of women's health seeking behavior. Given this broad political economy, environmental and epidemiological scenario of HIV/AIDS in the Niger Delta, a feminist political ecology approach of health becomes fundamental in unpacking the ways these power structures influence how individual women who are HIV positive pursue treatment and care. A feminist political ecology focuses on the place of gender as a key component in the realm of political ecology, that is, the intersection of politics, power, and allocation of resources in relation to the environment and health of women (Hovorka, 2006). This framework also illuminates the role of time and historical forces of the political economy as well as the role of vested interests in the environment not only in the emergence of HIV/AIDS but in understanding how vulnerable populations make choices, and the range of choices available to them in negotiating decisions to access HIV/AIDS care in the region. A feminist political ecology approach foregrounds these multiple forces in ways that help situate and contextualize our understanding of the experiences and health seeking behavior of HIV positive women.

In the section below, I focus specifically on Erhoike, an oil rich producing community in the region which is home to a cottage hospital that delivers HIV treatment and care to the cohort of HIV positive women interviewed for this study. The place narratives presented below are from data analyzed from a focus group discussion of men and youths from Erhoike community, interviews from health workers at the Erhoike Cottage Hospital and observation notes during data collection. In this way, I want to draw attention to the general socio-economic geography, culture and way of life of the people which is somewhat a homogenous representation of the

subculture pervasive in the neighboring communities that are home to these HIV positive women. Consequently, I use Erhoike community as a microcosm of the physical, social, cultural and economic geography of most communities in the Niger Delta region and to detail the relations of place that women's access and adherence are circumscribed. I also provide a detailed description of the Erhoike Cottage Hospital, its emergence, structure, scope of work and daily practices around HIV care and treatment.

### **Erhoike Community as a Landscape of Risk and Despondence**

The first sight that greets one on entering into Erhoike is that of a community that has lost touch with modernity given its poor physical state (hardly motorable roads, see Figure 6) and social conditions (heavy military presence stationed at multiple check points, see Figure 7) in this small and remote town of about 20,000 persons living in close and ironic proximity to a local flow station once owned by the global oil giant Shell (Shell Petroleum Development Company, henceforth SPDC). SPDC is the major transnational oil corporation that exploits oil from oil producing communities spread across the Niger Delta landscape like Erhoike community.



Figure 6: Physical landscape of Erhoike



Figure 7: Military presence, road blocks and check points<sup>8</sup>

The lack of visible development both social and physical infrastructure in this community aptly exemplifies the popular paradox of poverty amidst (oil) wealth. Understandably also, is the resistance of the local population to continuous oil exploitation that has led to the countless civil and social crises and unrests pervasive in this community and many others in the region. The feeling of insecurity and fear is palpable at least for a stranger that was me on my first visit when I got ordered by a military officer at the first military check point to get out of my car. I was questioned on the purpose of my visit to the community and when he was satisfied with his inquiries, ordered me to raise my hands up in an act of surrender and walk past the check point while the driver drove off to go wait for me at some other point. This experience became my ordeal every time I came into the community whether it was rainy or not.

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<sup>8</sup> Source: [http://reformeronline.com/wp-content/uploads/2014/10/IMG\\_20141002\\_133131.jpg](http://reformeronline.com/wp-content/uploads/2014/10/IMG_20141002_133131.jpg)

I share this anecdotal detail to ‘place’ in perspective what may be the recurrent experiences of HIV positive women coming to access treatment in this community and the inherent contradictions as they seek sites of care and wellbeing. The situation is worse so with reports that military personnel prey on already vulnerable women and adolescent girls by soliciting for indiscriminate sexual liaisons as some of the narratives by the health workers indicate; this may further increase HIV transmission rates in the region. These place dynamics and experiences are apt examples of how geopolitical forces and struggles over the control of environmental resources re-structure place processes and the physical landscape of otherwise peaceful communities; and the how these broad forces are directly embodied in both physical and personal ways.

As with many communities in the Delta, there is a visible deterioration of the eco-physical environment evidenced by the sickly crops and plants that dot the physical landscape and consistent air pollution from oil exploitation activities (as we see in Figure 6 above). With a pre-industrial history of mainly agriculture as occupation, the locals have sought alternative livelihoods in artisanship like masonry, carpentry, commercial bike riders among others in the face of massive environmental degradation from oil mining. Socio-economic and cultural life is organized around patriarchy. The practice of polygamy is firmly entrenched in this culture and closely linked to normative constructions of masculinity. Focus group discussion accounts from the natives of this community and the testimonies of health workers place gender relations as highly unequal. Examples of male dominance are revealed through the celebrated births of male offspring and in some cases, child abandonment at the hospital by a family patriarch when a newborn is female. The agency of women and their rights to own or control resources that accrue

from oil is generally channeled through the authority of male adults either as husbands, brothers or as community leaders.

Women's rights according to most of the male participants are limited particularly in public life. For example, women are not decision makers when it comes to oil resources - control, access, allocation and distribution. Communal benefits from oil resources are allocated based on household units and it is at this site that women can access these resources through their spouses. Like in Malawi (see Craddock, 2000), women's rights and resource or empowerment status are circumscribed within men's. Interestingly but not surprisingly, women were always mentioned within spousal relations. Apparently, married women are accorded a high social recognition and importance, perhaps, more than unmarried women with male partners perceived as conduits through which the community's resources can be accessed by women. Men are undoubtedly the decision makers and resource managers in this community. Women are deemed by these male community stakeholders to have little to no social, economic and political power and where they exercise any, it is based on the authority or permission of the man whether in the public or private domain. Unfortunately, this is a more general perception across most communities in the Niger Delta and across the country. Women are generally excluded from the political or governing activities of the community. The male focus group discussants from Erhoike community vehemently invoked rights along religious and traditional lines with the firm belief that male dominance is both the divine and natural order of life as demonstrated below.

*P<sup>9</sup>: yes, the area I want to speak on before is the side of the women. Women usually in this community, from the fundamental days, from the ancestors, women, they have a certain right they have given to women, not everything that women was given to partake. In a matter, issue*

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<sup>9</sup> Stands for "Participant"

*like this affecting the oil side in this community, it is the men usually take decision on the oil and not the women.*

*EB<sup>10</sup>: why?*

*P: why is it so? The women, our elders say that they married the women into this community with their money [another Participant cuts in: our forefathers] so it is when the men, the elders, that is their husbands, when they have [made] decision, money or anything that come into the community concerning oil, it is only the men that governs it and not the women. So is when after they share [and] go home before they can now give to their very wives. If not, concerning the oil, women does not have right on it because they marry them come so if you see women come riot come unfortunately, it means that the men have instigated them to that actions.*

*EB: so it means that it is the men who empower women?*

*Ps: yes!!!*

*EB: so on their own, women do not have any power?*

*Ps: No!!!*

Erhoike community presents the perfect example of “the oil complex” that Watts (2004) so aptly describes as emblematic of the Delta region. Corroborating participants’ responses, a widespread deep seated poverty can be observed on the landscape. Indigenes are stuck in the recurrent cycle of poverty with high rates of unemployment connected to illiteracy and poor infrastructural development. Although, the presence of oil creates a large work force, the community claims that about “95 percent” of the youths are unemployed and not integrated into the oil companies.

*“Yes, the company neglected us in the sense that we have been crying for long but nobody will put ear to our crying, so what do we do? So we continue suffering, as you can see now, everywhere is dirty and the oil still continues running.” – Erhoike community male*

Allegations of neglect have provoked internal protests by the indigenes and consequently, violent crises in the region. The oil complex also involves gender identities and relations around oil politics and local struggle for resource control, internal tussle over power and leadership to

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<sup>10</sup> Name of Principal Investigator and Interviewer: Eloho Basikoro

determine who controls the resources that come into the community with ensuing communal factions and opposition politics. Within this complex, women have been used as pawns by community factions to stage community protests and resistance to opposition politics. From these participants' view point, severity of protests is determined by the gender composition of protesters as we see in the conversation below.

*P: they [community] react to SPDC, those are the people they are seeing, because those are the people they are seeing, when they see what they themselves are to [be] benefiting as well and they are not seeing it, they start reacting. Even one [protest] happened recently that all the women were staging fight to the extent that they close up the flow station for over a week; they were dancing and demonstrating holding vehicles that are passing to ransom*

*EB: just women alone?*

*P: women, they use their women but the men are actually behind it*

*EB: so not that the women on their own have a group that just fights for....*

*P: no no no, they team up together but they [men] now send their women forward to go and do the revolt because they felt that because if they go to together as a team both men and women, people [soldiers] will take it as a high riot and start shooting but you know with women, people hardly react to shooting that's why they send their women forward, actually the men are behind them*

*EB: ...you don't think that women can actually just go forward on their own without seeking permission from the men?*

*P: no no no no, the men were behind them*

*EB: so okay, women were also asked to go in front because they felt women generally are not violent?*

*P: yes, exactly*

*EB: so policemen, security men may not see the women as violent and want to shoot them?*

*R: yes, yes, yes, exactly*

*EB: but if it is the men...*

*P: shooting will come up*

Males usually attract a more violent response from the military security personnel because of perceived association of violence and aggression with masculinities. As a male community member mentioned, the military "do not touch women" as a rule. Women and girls are thus perceived to be more docile, passive and less aggressive or violent. Organized women's movements and protests as I witnessed during the data collection period were engineered by the males given this military rule of engagement which is corroborated by the above conversation. Women have no authority to organize such demonstrations without permission from men. Women also do not voluntarily protest but are organized and compelled to do so with the option of fine on refusal; a fine that most of the women cannot afford. This exemplifies the nature of gender relations in this community but mostly a reflection of the broader gender culture in the region and the social terrain HIV positive women must daily navigate.

### **Erhoike Cottage Hospital: Emergence, Design and Structure**

As the name indicates and also evident in the figure (8) below, Erhoike Cottage Hospital (ECH) is a relatively small health facility located in Erhoike Community. Within the structure of the Nigerian health care system, this hospital is classified as a secondary health facility and in addition to other health services, offers HIV/AIDS services like counselling, testing, treatment, referrals and linkages of advanced AIDS cases to tertiary institutions. In Nigeria, the three tiers of government, the federal, state and local are responsible for the provision and management of health services. Generally, the federal government regulates and coordinates the national health care system through policy guidance, planning and technical assistance among other functionalities and is directly responsible for the management of teaching hospitals which are classified as tertiary health facilities (WHO, 2002).



Figure 8: Erhoike Cottage Hospital

Tertiary health facilities in Nigeria provide advanced and specialized care, in addition to other services like the training of medical students and professionals, and physician residency programs (WHO, 2002). Below this tier are the secondary health facilities and primary health care centers managed by the state and local governments. Secondary health facilities provide some specialized care but make referrals to tertiary hospitals in very advanced cases while primary health care centers provide the first entry points of care usually making referrals to secondary health facilities. Within a HIV/AIDS context, primary health care (PHC) centers provide limited services like counselling, testing and diagnosis while HIV treatment and care are mostly provided by secondary health facilities like the ECH. In substantive terms, comprehensive HIV care in the Erhoike treatment facility is conceptualized in terms of antiretroviral provision and access as well as other psychosocial services by health workers - physicians, nurses and pharmacists. Antiretroviral drugs are free in this facility as with most HIV treatment centers in the country. Cost of access is usually the cost of transportation to treatment

centers and the cost of supplementary HIV drugs like multivitamins and drugs for other opportunistic infections.

Nonetheless, there appears to be more emphasis on the medical side of treatment relative to psychosocial services and support to HIV patients in treatment and care. Where comprehensive psychosocial services are provided, these are mainly channeled through the HIV/AIDS support groups that though are not part of the mainstream health care landscape, are usually annexed to HIV treatment facilities mainly to follow up HIV patients on treatment. This is partly a function of the weak broader health care structure where social services are less foregrounded due to poor health care financing and in the case of this health facility, nurses are burdened with this dual responsibility given the lack of social workers. This ties into the broader argument this study makes about the conceptualization of access in more biomedical terms than social terms within interventions whether at the facility level through the provision of treatment services or in the policy making process. Suffice to mention however, that tensions exist in the conceptualization of treatment access and care among health workers in this facility. That is, access defined in strictly physical terms or as solely geographical access to antiretrovirals on the one hand; and on the other, in terms of the full “ability of the patient to access drugs”; in other words, patient’s access to all that is needed to make access possible which includes the social dimensions of treatment.

Given the ongoing decentralization process and expansion of primary health services in Nigeria, PHCs are relatively easier to access than secondary health facilities like Erhoike Cottage Hospital in terms proximity or distance. As a direct implication, the HIV positive women investigated for this study usually make a travel of about half an hour to one or more from nearby communities and towns to access treatment at this facility. The hospital’s location in a

small rural community and also its specific remote location at the outskirts of the Erhoike community has inadvertently proved to be a strong determining factor for the high influx of patients into the center especially for patients' seeking to protect their HIV status due to fear of stigma and discrimination. The geography of this facility thus attracts HIV patients from more distant locations and cities as well; patients who though may have access to HIV services from more proximate locations choose to undertake such long travels because of the privacy and anonymity this centers offers given its secluded location in the rural hinterland. I expatiate on this in the last section of chapter three. Also, the specific organizational structure and practice in terms of the nature of HIV service delivery has also aided this influx. For example, the hospital's management unique non-segregation policy and strategic operation of not having particular clinic days for HIV patients or a segregated ward for this population have also contributed to expanding this hospital's service area beyond the community and environs to the state and national level.

The Erhoike Cottage Hospital (ECH) emerged out of a tripartite agreement with the transnational oil corporation, SPDC (provided basic infrastructure, administrative services and medical technology and health financing), Erhoike community (provided the land) and the Delta State government (finances health workers' salaries). The ECH was built as a general purpose medical center in 1995 by the Delta State government but became a pilot site for HIV/AIDS comprehensive care including treatment in 2008 under a project called the Niger Delta AIDS Response (NiDAR) sponsored by SPDC which targeted oil producing communities under its jurisdiction as part of its corporate social responsibility program. As part of SPDC's divestment activities ushered in by the incessant but irreconcilable communal aggression against it and vandalization of their oil pipelines, the Nigerian Petroleum Development Company (NPDC), a

public national oil corporation took over the flow station at Erhoike when SPDC relocated its services, the ECH then came under the jurisdiction of NPDC. Aside a few administrative changes under NPDC, the structure of the hospital and its health services remain unchanged under the new administration and NPDC currently performs the hitherto administrative functions of SPDC - obtaining clinical data and general report from the facility, financing support services like payment of stipends to community health workers and medical staff, monitoring and facilitating the drug revolving fund, collaborations with NGOs on health services training for medical staff, as well as provision of medical supplies like blood banks, ambulances and other technical services.

The ECH like other secondary health facilities is mostly state controlled but runs self-sufficiently through a drug revolving fund (a fund set up for the hospital where drugs are sold and the profit re-invested into the fund for the daily administration of the hospital). In addition to NPDC and the state government, the ECH also receives support from local and international NGOs like the Family Health International (FHI) 360, and currently, Institute for Human Virology in Nigeria (IHVN) through their donor funded programs.

### **Data collection and analysis**

The qualitative research for this dissertation was conducted over a four month period between September and December 2014. It involved two broad scales of data collection and analysis - individual and institutional. The focus for the individual level study population was on women living with HIV and accessing treatment at the Erhoike health facility. This level also includes the members of the Erhoike community also referenced as the community level. In turn, the focus at the institutional level is the HIV/AIDS policy making and implementing community in

local and national government (including health facility workers, and national public and private sector HIV/AIDS organizations stakeholders).

At the individual level, I conducted two large semi-structured focus group discussions among twenty two HIV seropositive women accessing treatment on a regular or irregular basis from the cottage hospital at Erhoike community, in addition to two follow up interviews. The women were within the age range of 18 – 60 plus years. In terms of occupation and education, most of the women have agrarian livelihoods; others are petty traders and artisans with minimal to no formal education, with only one participant having a tertiary education degree. The women's marital status ranged from married, separated from their spouses, widowed or in premarital relationships. A central concern in this respect was to examine how HIV treatment experiences varied among the women, and especially how experiences and situations differed between those accessing treatment and care regularly and those women who do not. Following feminist theories of intersectionality, these kinds of comparisons were designed to explore the complexity of embodied experiences at the confluence of multiple social forces and power relations. In turn, the aim was to evaluate how these complexities can help explain variations in adherence and treatment sustainability among the differently situated women in the study. These variations noted, it should also be underlined that the cohort of women understudied all shared some similar social demographics. They come from mostly neighboring communities around Erhoike with a homogenous sub-culture of patriarchal social relations.

The HIV positive women I interviewed all consented to participate in this study after being identified and recruited through snowballing by local health workers at the facility. After the first focus group discussion, the participants voluntarily recruited other HIV positive women who formed a part of the second focus group discussion. The criteria of selection were that the

women were HIV seropositive, were regularly (or irregularly) accessing and adhering to treatment and also willing to participate in the focus group discussions. Copies of the consent form and focus group discussion guides were presented to the health facility for documentation and full disclosure of the research process to the research subjects particularly the HIV positive women as I was not directly responsible for their recruitment. Nonetheless, I personally handled the formal consent procedure of the HIV positive women after they had indicated interest and willingness through the health workers to participate in the research process. This consent procedure was utilized for other research participants with the exception of the snowballing component. The locations and timing of all interviews were at the discretion of the research participants in order to maintain their privacy as well as make them feel safe and comfortable with the research process.

For ease of communication, I conducted focus group discussions and interviews in Pidgin English (with the exception of one follow-up interview) among the HIV positive women, a local parlance that is commonly used in Nigeria. However, there were a couple of women who responded to the questions in Standard English, and others still, who communicated in the local dialect, Urhobo. All non-English responses were directly translated by me and indicated in the quotes presented as evidence in this dissertation. Reflecting on my positionality in the research process, I benefited from having something of an insider's perspective as a researcher who originally grew up in the Delta region. Although I am now a researcher based in the United States, I remain very familiar with the locale and connected to it in a variety of ways (through family, friends and an embodied culture) that helped me to interpret the interviewees' responses in a context-sensitive way.

Although the original research design was to interview both key male and female stakeholders at the community level, I was only able to conduct a focus group discussion among the male adults and youth of the community because of the political and social tension during the period of the data collection. This exigency also produced a limitation in this study given that my inability to interview women from the Erhoike community may not have provided a wholly representative view of gender relations and socio-cultural practices in this community based on primary evidence from community stakeholders as the narratives on these themes highlighted above are from a purely male perspective. Nonetheless, the available primary evidence was triangulated with narratives from the community health workers, HIV positive women and the researcher's knowledge of the study area to provide a grounded place context as much as possible. The focus group responses from these key male informants nonetheless, provide strong insights into the social and political geography of this place in terms of the oil complex, culture and gender relations and the ways they interact to contextualize women's experiences of treatment.

At the level of policy, interviews were conducted among a population of policy makers and practitioners in both public and private HIV/AIDS institutions. Under the policymaker category, I include both stakeholders responsible for formulating policies and practitioners directly executing policies at the level of implementation like the health facility workers at the Erhoike Cottage Hospital. The public HIV/AIDS policy making institutions comprise of the National Agency for the Control of AIDS, and the Federal Ministry of Health, Nigeria, also referred to as NACA and FMOH respectively. NACA is the main HIV/AIDS policy making organization and coordinating body of all public and private HIV/AIDS interventions in Nigeria (see Figure 9 below). NACA also works in conjunction with the FMOH, Nigeria and other private-public stakeholders.



Figure 9: NACA's vision and mission statement<sup>11</sup>

The FMOH is the umbrella body that develops and implements all national health policies and collaborates with other public and private sector stakeholders and parastatals including HIV/AIDS. NGOs like the Institute of Human Virology Nigeria (IHVN) and Action Health Nigeria (AHNi) (an affiliate of Family Health International 360) constitute the private HIV/AIDS sector stakeholders. IHVN and AHNi/FHI 360 are global health non-profit and development organizations geared towards making lasting changes among the vulnerable, poor and marginalized populations. Although these NGOs possess a global outlook, they design and implement country specific programs on HIV/AIDS and other infectious diseases in partnership with national governments and local communities.

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<sup>11</sup> NACA's Vision Statement: To make Nigeria a nation of people with functional knowledge of HIV/AIDS who provide care and support to individuals, families and communities confronted with the epidemic and the Agency solely authorized to facilitate all stakeholder HIV/AIDS activities in the country.

NACA's Mission Statement: To provide an enabling policy environment and stable ongoing facilitation of proactive multisectoral planning, coordination, implementation, monitoring and evaluation of all HIV/AIDS prevention and impact mitigation activities in Nigeria.

Interviews were also conducted among the health workers in the health facility to provide greater context to the micro geographies and individual level dynamics of treatment access and adherence given their direct affiliation with the HIV positive women understudied. Observations on how the facility conducts its everyday affairs with patients were also conducted through regular visits to the hospital, attendance at HIV/AIDS support group meetings, and informal conversations with the support group members and leaders, as well as health workers to gain greater insight into the subject matter.

In summary, a total of 3 focus group discussions were conducted - 2 among HIV positive women and 1 among the men of Erhoike community; 22 interviews were conducted - 5 among health workers at the hospital, 2 follow up interviews with the HIV/AIDS support group leaders who are also among this study's cohort of HIV positive women, and 15 interviews among key government policy makers and NGO representatives. Interviews were conducted until a point of saturation was reached and where further information from the participants did not add any new meaning to the overall framework and there was a diminishing return (Dunn, 2010; Mason, 2010). The choice of the number of interviews conducted at both broad scales (institutional and individual) is also premised on arguments in the literature on qualitative studies that from practical experience, little or nothing new comes out of transcripts after about 20 interviews. While 30-50 interviews is widely accepted in qualitative research as the range for large scale ethnographic studies or studies focused on developing grounded theories, 15 is usually the smallest acceptable sample (Morse, 1994).

I deployed non-probability sampling techniques for this study at both levels of data collection. Purposive sampling technique was deployed to identify and locate key stakeholders occupying significant positions in the HIV/AIDS policy making arena in NACA and FMOH as well as

health workers directly involved with the treatment process; and snowball for the HIV positive women as hitherto stated. Health workers as a broad category ranged from hospital administrators, nurses, medical doctors and pharmacists but for the purpose of anonymity and confidentiality, participants' quotes from policy institutions and health facility are broadly designated as policy stakeholders and health workers respectively and not by the participant's specific job designation. The purposive sampling technique was utilized because given the research questions on HIV/AIDS policy formulation, the answers to these questions could only be sourced from key individuals occupying central positions in the HIV/AIDS domain with a robust understanding of the health system particularly, with specific regards to interventions. Recruitment of participants at this level was through direct physical contact and key informants with knowledge of these organizations after initial email correspondence at the preliminary stage of data collection. For the aforementioned reasons, I also deployed the purposive sampling to identify and recruit key leaders and other stakeholders from the community. Full disclosure of the nature of the research and its procedures like the data collection process and techniques - consent procedure and post data collection - which included how the data will be managed, utilized and presented was provided to all research participants in both written and verbal forms.

In addition to supplementary data from observations and field notes, I also conducted an archival review and discourse analysis of 20 HIV/AIDS policy texts and documents (See appendix 1 for the list of documents and brief description of themes analyzed) to investigate documented institutional processes that may further reproduce gendered inequalities in treatment. The objective is to identify institutional gaps in past and existing HIV/AIDS policies as they frame gender response to treatment either through the exclusion of gender or the ways gender has been included. Ultimately, the aim is to provide a comprehensive explanation of how these gaps

produce the recurrent failure of HIV positive women to secure and sustain treatment access within claims of gender sensitive policies and programs by both local and international HIV/AIDS agencies.

Conducting this study's inquiry using both institutional and individual level data is important to provide explanations to an observed gap in the literature and a long standing problem in health interventions, which is the disconnect between policies/programs and the needs and lived realities of the population whom interventions are designed for. For example, to identify and explain gender and other social dynamics that may inhibit women from accessing treatment even when available that may be elided in interventions policies and programs. Given this, it is pertinent to get women's experiences and their perception of intervention programs to identify these gaps or how such interventions vary from women's identified needs in order to bridge this disconnect. The choice of multiple qualitative techniques is because health research contributes to better transformative change when there is more methodological pluralism as a multiple methods approach is able to adequately capture meanings from different dimensions in ways that are useful in explaining to policy makers and practitioners the varied ways that gender shapes health experiences (Theobald et.al., 2006) Hence, the triangulation of techniques proposed for this study.

Data from observations, interviews and focus group discussions as well as field notes were transcribed verbatim and analyzed thematically. Transcripts were analyzed for themes on the broad variables being observed. The data was analyzed to find meaningful patterns or variations among women's responses that may explain barriers and constraints to treatment, the ways these are negotiated, as well as institutional responses to HIV/AIDS in Nigeria through policies and NGO programs. Other unanticipated sub-themes that emanated from the data that improved

explanations provided by the major themes were also analyzed in addition to pre-planned themes based on the existing body of knowledge. For example, the theme on caregiving discussed in the next chapter (three) was completely unanticipated but resonated strongly throughout women's testimonies and this unavoidably, became a core analytical theme in this study.

### **Reflections on the field work process**

Gender considerations both informed my initial approach to the research and also shaped personal decisions during the field work, influencing the ways I negotiated social relations with research participants and how I collected the data. Given that I grew up in Delta State in the Niger Delta region, my background knowledge of the region also informed the situated production of new knowledge. Throughout the research process, I was personally aware of my positionality as a woman and also the implication of researching gender issues in a male-dominated society. This realization guided the design of my research instruments like deploying particular wordings such that the interview guides excluded associations with the concept of feminism largely perceived as resistance to male power. Rather, I deployed the concept of gender equality as this has become a more acceptable phrase given the wider appeal of the women's rights as human rights advocacy. As my actual field work experience demonstrated, it turned out that I did not entirely succeed in eliminating resistance from some male participants at the institutional level to the gender research theme, and such resistance further illustrates the ongoing struggle for gender equality in the Nigerian society.

The *push back* I received from some of the male participants is also a testament of the timeliness and significance of this research to *push forward* the gender equality agenda. I struggled with having to negotiate my relations with male figures especially those in authority in the ways I talked, dressed or comported myself as I was all too conscious of how I could easily be

objectified, not taken seriously or even disrespected because my gender, notwithstanding my social location or United States university connections, already also imposed marginality on my status. For example, I had a debate with a male policy stakeholder on the issue of gender equality for women which according to him was over rated. Another vehemently questioned my positionality as a female researcher coming from a western institution to research gender issues on local women. My interaction with this particular institutional male figure bordered on verbal abuse and intimidation especially knowing that I required his permission to interview stakeholders within his department. This particular experience was indeed the most emotional for me as this policy stakeholder not only openly challenged my gender identity but also my ethnicity considered as a minority being from the Niger Delta. These dimensions of my identity as he claimed do not place me in a powerful position to challenge the injustices of gender inequality that my research aimed to address.

This particular experience essentially speaks to how we as feminist researchers are confronted with walking the fines lines in pushing the gender equality agenda in a steeply patriarchal society like Nigeria, not only mindful of our multiple identities and social locations but the ways that they inadvertently interact to shape our cause in both positive and negative ways. It was a deeply reflective moment for me as I pondered on the ways that women activists can firmly uphold the egalitarian values and ideals that are desired for women yet address this commonplace male resistance in ways that do not subvert our goals. The section on African feminism and patriarchy is mostly reminiscent of these thoughts.

At the individual level, there were places I felt unsafe to go alone without a male chaperone. One of such places was the Erhoike community and this perception of unsafety became reified during the male focus group discussion with the community stakeholders who became aggressive after

the key contact person left the focus group due to an emergency. Given the internal tension in the community at the time due to warring factions and restive groups within the community over oil resources, it took my husband talking to them *as a man* to mediate the situation, enabling me in turn to reassure them that I was not a press reporter or acting on behalf of the opposing faction. Still, I was warned by this group of males not to return to the community for further data collection as this might spark suspicions from the other warring faction and potentially put me at risk if they perceived I was aligning myself with a particular group. As a consequence, the plans to interview women in the community and other community stakeholders were called off. This experience testifies to the volatility and instability in the region; it also made manifest how the fieldwork process is itself fluid, contested and unstable as many feminist geographers have argued especially when patriarchy is at stake (see Billo and Hiemstra, 2013).

Given the socially-fraught nature of the power relations being examined either due to gender or other positionalities, it was a welcoming surprise that the HIV seropositive women were very accommodating and forthcoming with their personal experiences. I think this was most likely a product in part, of my own identity as a woman from the region and because I was someone able to speak in the local vernacular. I think my background played a vital role in making it possible to gather information quite easily from these women. In both my formal and informal interactions with these women during the interviews, focus group discussions, attendance at the HIV/AIDS support group meeting, and conversations during my visits to the health facility, it was challenging to deal with the wave of undulating emotions that engulfed me as I became entangled in these women's harrowing experiences. Mostly, these feelings were due to my knowledge of the risks and social vulnerabilities that being HIV positive conferred on these already marginalized women but mostly as women whose bodies continue to be governed by the

(in)formal but oppressive laws of patriarchy, narratives that were replete throughout their stories. I was unprepared for how these women's experiences would transform my own understanding of power and privilege not because I was not subject to these same laws but my social and class locations was such that I had some agency to regulate how much these laws could govern me.

It was hard to make sense of my emotions at first but, with more introspection, I recognized the main mix of elements in my emotions. It was of guilt, confusion and anger at seeing the real sufferings of my research subjects and the hope they express in my work to produce the much needed transformative change to their situation but my inability to promise that such change was guaranteed even if not now but soon enough. This is a part of ethnographic research that is often understated in formal social science research accounts or descriptions: namely, the profound ways our emotional and social lives become intertwined with those of the subjects that we study. Although, the place of emotions are now beginning to be centralized in ethnographic and field work studies in feminist and emotional geographies (see Schurr and Abdo, 2016); mostly, graduate students are academically untrained and ill-equipped with the requisite skills to channel such feelings of emotion and affects into producing situated knowledge that can be translated back to wider audiences. For example, I struggled with the conflicting emotions, whether to reach out to these women and the ethically appropriate ways to do so that would not violate the ethics and values of the field work process. It was more a conflict alternating between a research process that I desired to be as beneficial to my research subjects who had shared their deep personal lives with me, even as the research was to me.

Although we try to disentangle ourselves emotionally and sometimes physically from activities that might be considered unprofessional or unethical in social science or ethnographic methodologies; practices perceived as getting inappropriately involved or influencing the

research process. I argue that some of these might be missed opportunities in critically engaging with the research subjects in ways that might be transformative given that this is the end goal of most social science research. The question remains on the ways of doing without biasing the research process. This question is really one of research and practice and how as researchers the process of navigating between a traditional extractive research and one that seeks to actively benefit its subjects is usually an afterthought, less planned and often ad hoc in the research design and field work process. The research process also drew me to question if these (un)enacted emotional experiences reveal the shortcomings of ethnographic research, even as they presented opportunities for achieving the real goal of our research, and if these opportunities are being stifled by so called ethical practices in social science research. There are no easy answers but I do think that such field work experiences present us with opportunities to reflect deeply on our work as social science researchers about the ethical dilemmas of our emotions, feelings, and affects in the research process not only in the production of knowledge but in terms of substantive benefits for the research subjects or spaces that we study.

## **Conclusion**

This chapter has provided insights into this study's design and its underpinnings, as well as the choice of study sites and the rationale. It has also provided some insights into the aspects of the research process that is usually hidden yet significant to how we come to pursue the knowledge that we seek to produce, and the ways that our different identities and positionalities help to situate the research process and make meaning of it. While these reflections are in no way a complete picture of my experiences in the field, they do tie into the core themes that this study attempts to explore and address, which is situating women's health seeking behavior through the lens of HIV treatment and adherence within patriarchal gender relations. The next chapter is the

first of two chapters that explores the barriers to women's treatment access and care within this social and gender relations framework. A limitation of this study which is considered for a future study is the need to explore these same gender dimensions in health seeking behavior but from a male perspective as I do with women in this study.

## Chapter Three

### **Dying First: Placing Women's Treatment Access and Adherence in the Context of Patriarchal Care Norms**

*“We women we try to please our men starving ourselves, but in the real sense, we are suffering, like now, we have also found out that at times, if the woman is infected with HIV, and the man is equally infected with HIV at the same time, the woman will die first, and the man is still alive” – Female health worker.*

#### **Introduction**

The arguments made in this chapter bring together critical theories from health geography, development studies, political ecology, and care ethics with gender as a cross-cutting category of analysis. The chapter addresses the research question - *“what are the micro level barriers and constraints to women seeking HIV treatment and care in the Niger Delta region?”* This question emerged from the dearth of place-based multi-scalar analyses to understand the contextual forces that control and limit women's access to health services and healthy living opportunities. This analysis deploys both the relational and intersectional feminist perspectives detailed in chapter one to understand the wider social relations that constrict health access for individual HIV seropositive women. The accounts of HIV positive women here thus assemble contextual knowledge grounded in their personal experiences. The goal is to draw on this situated knowledge through participatory feminist methodologies; hence, the direct inclusion of the testimonies of women as agents of knowledge. This integrated and hybrid methodology holds the potential for the development of a grounded theory of the differentially gendered access to HIV treatment on the study population as well as outlining opportunities for transformative politics at the level of policy. A crucial component of this research is to understand how specific place relations engage HIV seropositive women in their health seeking decisions and behavior. The

relation of place to health is an overarching theme in health geography. That is, health outcomes are contingent on social structures and interactions embodied in place and locality.

The overarching argument this chapter makes is that the complex intersections of care, gender, health and the specificities of how this complex web of relations are experienced and lived out in certain spaces is a reflection of the organization of social, political and economic life at the micro and macro levels of particular places (Thien and Hanlon, 2009). Consequently, policy interventions must be situated within these specific place knowledges. A major claim this chapter makes, and one that is reverberated through personal testimonies of HIV seropositive women in subsequent chapters based on the web of relations of place is that HIV seropositive women in this study's sample population actively construct their bodies as more social than biological. This hierarchical ordering of their bodies is however, structurally mediated; partly because of the existing place practices and cultural discourses of care as always relational, so care of the body is usually subsumed within this construction. Nonetheless, women's accounts do not rule out the existence of a self that can be conceptualized as independent and needing care (self-care) but ultimately, care for others takes precedence over self-care which includes the process of women's treatment access. This study makes this claim within a patriarchal context where caring for others is an intricate part of women's identity and must be performed irrespective of women's personal care needs. In this way, these women construct their 'needs' and what it means to be empowered to sustain treatment access to include the ability to perform self-care within a HIV context.

Under such conditions where women's autonomies are stifled and their commitment to social and gender norms takes precedence over their health and biological needs, their bodies are constructed as hierarchical and take on a social-primary and biological-secondary binary. That is

to say, protection of the self as a social and cultural body takes pre-eminence over protection and care of the biological body. Ironically, interventions construct the body in very biological terms in stark contrast to women's social emphasis of their body. It is within this matrix that health seeking decisions on HIV treatment access are initiated and behaviors of (non)adherence practiced. Access to health services is therefore, intertwined with other rationalities like care and not as actions that women can just simply or voluntarily engage. Just as the biological body has been subjugated to the relational and social body so also caring for the biological body has been subjugated to a social or relational care. How we reconcile this binary through research and policy is of consequence to women's health seeking behavior even outside a HIV/AIDS context as often times, biomedical and policy assumptions about the need for women to make responsible choices too quickly forget the ways responsibility is structured in patriarchal settings to make women care for others before themselves.

Within this main proposition, are three sub-level arguments that each of the three sections of this chapter makes but which reinforce the main argument. The first section explores the constraints to HIV seropositive women's treatment access and adherence within specific caring responsibilities to spouses and children in a patriarchal context. This analysis draws from care ethics theory to understand how women rationalize their decisions to access and adhere to treatment within these feminized notions of care and responsibility as they intersect with constructions of their self and social identities. Primary evidence from HIV seropositive women's testimonials is deployed to illustrate points of connection to and divergence of women's caring experiences from mainstream feminist theories on care. Hence, this analysis argues against universal notions of care but espouses care as understood within specific cultural and spatial contexts. Within the feminist care ethics scholarship, I theorize that patriarchal care

relations are ultimately destabilizing to women's treatment access; and care although framed as mostly relational must also centralize care in relation to the self. Similarly, within local discourses of care giving in patriarchal societies, women's self-care must be reconstructed as a self-rewarding and valuable venture and not only when care is performed in relations to others.

The argument against rigid forms of knowledge besides how we contextualize care is also well illustrated in the second section of this chapter on the practice of African feminism within patriarchal relations and the conflicting discourses of empowerment between elite and local women. For example, in Nagar and Raju (2003), the creation and the training of women by a women-focused NGO in the use of hand pump wells in the drought regions of India created mixed consequences for women in different regions with uneven social shifts locally through the equality agenda the intervention was designed to foster. Similarly, in this study, some of the HIV seropositive women resisted the idea of programs that only built their economic empowerment yet threatened the security of their relations with their male partners. The eminent lesson from these testimonials is that feminist analysis of empowerment, though universal in addressing gender subordination must listen to the voices and interpretations of what local women consider as important or as empowerment. This is the highlight of this section.

As feminist scholars (e.g. Rose, 1997; Kabeer, 1994; Haraway, 1988) have emphasized, knowledge is often constructed in ways in which the location and subjectivities of the producer is significant to the forms that the knowledge takes which could be total or partial. Partial knowledge may not be wholly representative of the subjects and when such knowledge becomes normalized as the common-sense truth, it can become oppressive and exploitative of those around which the production of such knowledge is centered. Therefore, the way knowledge around developments thoughts are constructed and by whom is a premise for the way

development projects are framed, designed and implemented. Hence, "... a different form of knowledge and practice is likely to emerge if it is based on the distinctive experiences associated with women's lives in a gendered social world" (Kabeer, 1994, p. 80). This chapter thus extends the debates of feminist development scholars like Nagar and Raju (2003) and Kabeer (1994) and many others that argue against monolithic forms of feminist knowledge that are disconnected from the realities and psychosocial needs of women targeted through local empowerment programs.

The third section also explores barriers to women's treatment access and adherence due to specific connections of place but within the actual health care landscape and the broader political economy of the Niger Delta. Empirical evidence yet again reinforces the notion that place related knowledge is crucial to understanding individual risk and vulnerability, and other relations of power and place structures as they mediate health and wellbeing.

Throughout this chapter, the crosscutting tensions between structure and agency are also evidenced by the fieldwork data. The research subjects discussed their non-access and weak adherence to treatment due to social and economic barriers, and other relations of power in deeply personal ways; yet these are all structural factors constricting their access to health services and health rights. Connecting constricted personal experiences with social structures in this way ultimately destabilizes notions of individualized risk and agency in traditional HIV/AIDS discourse - notions that depict women as wholly active agents in their own treatment. Instead and most often, women's agencies are shown to be regulated by factors that transcend the provision and availability of antiretroviral drugs, and this in turn helps us to understand HIV treatment constraints in both intersectional and relational terms. At the same time though, these structural barriers to treatment are so hard-wired into the private lives of HIV positive women

such that policy wise, these barriers become regarded as normal in ways that take them off the radar of HIV/AIDS intervention programs.

### **Constructed Identities and Power: (Re)constructing the Notions of Care and Responsibility**

*“We stand together in the shared values of grassroots women caring for their families and communities, but against these roles and contributions being detrimental to the health and well-being of these women”- Statement of the grassroots academy, YWCA International Women’s Summit, Nairobi, Kenya, July 2007 (cited in Robinson, 2012, p. 129).*

The statement of the grassroots academy at the YWCA International Summit, Kenya aptly captures the tone and direction to which the central argument in this section is inclined. The subject of women and care is progressively becoming an established binary particularly in health scholarship because of increasing empirical evidence that frames particular adverse experiences of women’s health within a practice (care) that is socially perceived as intrinsic to women’s being. Care and responsibility are two strong themes that resonated through the discourses of barriers to treatment access and adherence by HIV positive women engaged for this study.

Women’s narratives reveal that particular practices of care and responsibility nested within the intersections of their socially constructed identities and social reproductive activities produce undesirable treatment seeking behavior.

Women’s constructed identities as ‘carers’ or ‘caring’ can be understood and interpreted within the moral philosophies and ethical framework of care but what has been the crux of an ongoing theoretical debate and focus of contemporary moral development scholarship is the gender constitution of morality if at all; that is whether morality is neutral or subjective based on the sexes. Also, whether caring is generic to women due to nature, nurture or simply from cultural and societal values or expectations. Within mainstream moral development philosophies, ‘care’

as a moral consideration is constructed as an activity or practice that occurs in relationships premised on subjective values such as compassion, responsibility, attentiveness and responsiveness that foster meeting the needs of others; and how to conduct the moral self in relation to others. Values that are tacitly implied are more essential to women while men on the other hand, are deemed to be more autonomous, rational and objective hence, are associated with values like justice and fairness (Bowden, 1997; Tronto, 1993).

Within this broad philosophical debate on the morality of care, a care ethic theory departs from the autonomous consideration of humans that mainstream moral development philosophers espouse; it argues that as humans, we are all wired to be empathic, relational and responsive. Care ethics theorists argue that humanity has achieved progressive growth over the years because it has organized moral life around the values of care. Care ethics theorists underscore that care is not only essential to life but something all human beings can engage in through caring relations with others irrespective of gender. The fundamental philosophical principle that underlies care within an ethical care framework is thus the moral ontology of relationality. This is the claim that the thinking and performance of moral actions are done by the self in relation to others with the self conceptualized not as an autonomous, neutral and objective entity but as a product of multiple identities and subjectivities and therefore, relational. This logic and ideology of care thus challenges mainstream universal definitions of morality conceived as rational reasoning based on the rules and principles of rightness that are not premised on any form of subjectivity and one which constructs the self as autonomous, rational and objective (Gilligan, 1993; Tronto, 1993).

The emphasis on care is mostly on mutuality, interconnections, or interdependence which are all in relation to people, animals and conceptual entities like the environment, social justice, equality

but always less self-referent (Lawson, 2007). Central to care ethics therefore, is also social relationality. Hence, relationality is highly centralized as an intrinsic aspect of care, and care ethicists place much value on this interdependence as it connects an individual to others. The conception of care in its ability to remake the individuals involved in it in morally desirable ways and by extension, the wider networks of public relations which includes the social, economic and political domain has produced the notion that care has priority and should be highly valued (Robinson, 2011; Held, 2006).

The normative emphasis on valuing care in care ethics theory makes an important ethical intervention but I argue that within a patriarchal context, a simple valorization of care as what individuals do or are predisposed to do can have the reverse effect of not only devaluing women doing all the care work but the over emphasis on care as always performed within relations to others may re-inscribe the oppressive relations in which such caring in the context of others takes place. I see these dominant discourses of care as always relational, unintentionally coinciding with and reproducing existing patriarchal discourses of care that are socially structured in oppressive and marginalizing ways to women. I take the approach of (McCarthy, 2012) who argues for an understanding of the everyday real implication of such hegemonic discourses even if it is only in terms of the social consequences for the people they address. This approach necessitates a mindfulness of the need to not only theorize social issues from a critical lens as (academic) outsiders but also with attention to the cultural meanings and real conditions in which our theorizations are embedded from an (indigenous) insider's perspective.

Within a patriarchal framework, care can become definitive of gender roles necessitating action, thereby disabling and even dehumanizing for women in so far as its performance is prescribed in essentialist biological terms as the obligatory social prerogative of only the female gender.

Women's caring or caregiving although not inherently bad (Lawson, 2007), thereby ends up being performed under conditions of power imbalances or male domination that can quickly alter the essence of care, making it a site of women's oppression. Care relations that are exploitative, oppressive and abusive to women can also become conflictual, creating polar tensions between women's self-care and caring for the more powerful partner in ways that are detrimental to the health and personal wellbeing of women themselves.

To appropriately situate this argument, I organize my analysis around these conceptual questions: why do women in most patriarchal societies care for others first before themselves, how does care of the self become subordinated to care of the other in both abstract and concrete terms, what conditions influence or shape women's caring practices, and the implication for their health and wellbeing? To answer these questions and particularly how they mediate HIV treatment access and adherence, I draw attention to primary evidence from HIV positive women's experiences to show how they converge and diverge from existing theories on care. I build on how care and responsibilities or the decisions around them evolve from an intricate web of social relations mediated by culture and gender identities, faith based mores, economic inequalities, power relations and social difference.

To be fair, feminist care ethicists have argued against the perception of care as connected to the subordinate status of women in patriarchal societies as inorganic to the kind of care they advocate for. In a 2011 interview, Carol Gilligan mentions that a *feminist ethic* of care is a resistance to patriarchal injustices which inscribe care as a matter of obligation for women in interpersonal relationships. Similarly, Held (2006) a renowned care ethicist argues that the ethics of care do not suggest that humans are solely constitutive of the relations they are in or stuck with them if they are unwholesome. Rather "such persons can and should evaluate and shape

these changing relations autonomously, while recognizing that they are part of who we are. This conception of the person is compatible with the priority of care” (p. 135) but not as the isolated, rational and autonomous individual that is dominant in traditional moral philosophies. In other words, there is a recognition of the autonomous self (not to be conflated with separateness referenced by mainstream moral development theorists) within feminist ethics care theory but one that is still relational yet possesses the ability to act independently or ‘autonomously’ to remake care relations in more desirable ways.

To be sure, Thompson (1993) defines this autonomous self as one that is freely capable of pursuing her own projects. This notion of the individuality of person converges with HIV seropositive women’s care experience in terms of their implicit need to pursue self-care but the point of departure is the assumed “agentic autonomy to pursue their personal wellbeing” outside these oppressive relations (McCarthy, 2012, p. 80) and also if their need for self-care should be prioritized above their relations with spouses and children. These disclaimers by feminist care ethics of the oppressive relations of care recognize the influence of place and context as reconfiguring the essentialized notions of the ethics of care (Tong, 1998). Hence, they underscore that within patriarchy, care can become a *feminine ethic* but care is a *human ethic* within a democratic framework (Gilligan, 2011). Such rationalizations are nonetheless problematic. Their attention to context appears not to be a reflection of the realities of many women in patriarchal societies whose autonomies are circumscribed within their interdependence on these oppressive relations that women are cautioned to extricate themselves from.

An inherent contradiction in Held’s claim which is fundamental to the care ethics theory is the assumption that *all* individuals within such undesirable relations can first, recognize their oppression and evaluate their situation based on this idealized notion of caring. In patriarchal

societies, most women tend to define themselves primarily in the context of their relationships to the men and children in their lives (Skoe and Diessner, 1994). The notions of agentic autonomy therefore, ignore this subliminal conception of the self as sacrificial to interconnections and relationships. Second, it wrongly assumes that post recognition, all individuals possess the agency either to disentangle themselves from their relationships or to shape them *autonomously*.

McCarthy (2012) posits two versions of the human person, one that is universal having a state of mental consciousness and physical form; and one whose formation is culturally contingent and mirrors interpersonal attitudes and a structure of subjectivities. Furthermore, as McCarthy articulates, all cultures include a self that has a sense of will and responsibility that is distinct from the non-self that is dependent on external subjectivities but the extent to which this varies by culture. Hence as the argument continues, in some cultures, the self is seen always according to the roles it plays within a collective group or a community and it becomes difficult to separate the personal from the group's values or actions. Self-identities are therefore, both a product of the independent self as internalized by the individual and by others - a set of external human subjectivities within a social system.

Several studies have investigated how cultural discourses about what it means to be a virtuous or good woman and other prescribed gender behaviors within intimate relations produce mental health issues for women through the ways women cognitively evaluate these relationships within a patriarchal context. Two cognitive schemas are found to be profoundly significant in governing such relations which is care as a sacrificial behavior performed to secure relationships; and a silencing of the self or relegating personal care needs to avoid conflicts and loss of relationships (Thompson, 1993; Jack and Dill, 1992). So while women may perceive such conflict and even

discomfort in their relationships, they many not act because it is usually not perceived as abnormal, rather, their protest to such discomfort is what is considered abnormal.

Through HIV seropositive women's embodied accounts of treatment access, we see this nuanced entity of the 'person' in a relational conflict between a care for the self and a care for others.

Women's narratives implicitly expose the existence of a relational care that is in crisis with self-care because the latter is usually suppressed and not allowed agency as it seeks to conform to expected societal norms by allowing care for others take precedence. Consider the following dialogue with one of the health workers who work directly with women accessing treatment.

*EB: so you talked about nutrition or food as reasons why women do not access treatment all the time*

*P: that can be one of the factors because if you look well, you will know that the men are more fed than the women*

*EB: how?*

*P: I will explain to you. A woman that will cook a pot of food, the best fish inside the pot of food, she will serve it to the man to eat, but she is ready to eat pomo [cow skin which is the least nutritional part] and all sorts of rubbish, all to satisfy the man, and even when you look at PCV of women in the hospital, you will see men having fifty something as PCV, you will hardly have a man having forty something as PCV but while women are having thirty something even though we say that the factor of menstruation is there, but we still observe that men feed well more than women so that factor is actually affecting women*

*EB: is it because they are men, and women are women, so men are actually supposed to eat the bigger portion?*

*P: [laughs] I don't really know but that is what is happening, we women we try to please our men [still laughing] starving ourselves, but in the real sense, we are suffering, like now, we have also found out that at times, if the woman is infected with HIV, and the man is equally infected with HIV at the same time, the woman will die first, and the man is still alive*

*EB: why?*

*P: that is to say that the immune system of the man is higher than that of the woman because the man is eating more, unless on the condition that we find out that the man is a womanizer, if the man is a womanizer, his immune system will drop very fast but if the man is not a womanizer, if he is eating well and holding firm to himself, you will see the man healthy for a long time, nothing will happen, but for the woman, any little thing, the woman drops*

*EB: ... you are saying that most times, the woman dies first?*

*P: first before the man*

*EB: so that means the man is receiving more care than the woman?*

*P: yes exactly, the man is eating more, eating better, good food and is not facing much stress like the woman*

Gendered care in most cultures in Nigeria usually involves women as wives and mothers prioritizing care for male spouses and other immediate family members like children before their self-care. Women identified themselves based on these societal assumptions and expectations of womanhood - marriage and wifedom - and nowhere in my study did these HIV seropositive women indicate or narrate any form of resistance to these care values which was a dominant narrative among these women. Their discourses reveal that these social but gendered values are not only deemed as normal, they are accepted as worthy of their values as women, mothers and wives. Their subtle concern however, was finding ways to manage or juggle these caring roles they consider their responsibility or obligation and yet, be able access and adhere to their treatment regimen. Care for others can thus be deeply dis-enabling for HIV positive women in the Delta. Marriage and motherhood for a woman symbolizes respect, social acceptance and increase in social status. Generally, a woman will sacrifice her wellbeing for the survival of her family even if this might mean using available resources to cater first to others before herself.

These practical experiences of HIV positive women although illuminate care ethicists' idea of the particularism and situatedness of care as unique to specific spatial contexts, it nonetheless

challenges their popular notions that all women can indeed evaluate these relationships, recognize their oppression and act to change it. It calls to question their abstract and universal theorization of women's agency in care relations irrespective of spatiality which makes their understanding or framing of such patriarchal context as partial. The extent to which women in patriarchal societies can recognize their oppression within caring relations may vary by how much these women are immersed within their cultures, and by their level of education and social class. The ability to change their relations depend much more on this recognition but also on their social and economic standing as women may remain stuck in these relations if they perceive they cannot deal with the stigma of being separated or divorced from their spouses (as we will see in the next chapter on disclosure) and if they are also materially dependent on these relations. The feminist care ethics scholarship will therefore, need to pay greater attention to not only geography but also social locations and other axes of difference among women in theorizing the autonomy or agency of women to act within oppressive care relations.

One of the practical implications of the conceptual framing of care as almost always relational as I argue within a patriarchal framework, is that it not only casts all moral actions in the context of 'others', it reinforces this as the norm. Care and responsibility are central to this relational moral model. Caring responsibility as a moral virtue is therefore, centralized in the context of relationships as performing a good is usually conceived in relation to others. It establishes the context for which morality is to be enacted as usually within relations to others outside of the self. Self-care is consequently edged out of this moral realm of responsibility and care actions directed at the self may be perceived as transgressing moral principles or acting in selfish interest although as I previously argue, individual recognition of the need for self-care and the ability to perform it may be circumscribed within a labyrinth of external forces that impede it.

In practice, the concept of self-care is always present as an individual need but may be relegated or even conflict with the moral decision to care for others. Reason is, caring for others over the independent self have been cast as more honorable because of value impressions like altruism, rightness and nobility that it connotes especially in male dominated societies like the Niger Delta. For women, these values represent the essence of womanhood even when such provision of care is at the detriment of their own health and wellbeing. For example, this HIV positive woman depicted in the statement below risks her own health to preserve that of her spouse.

*“Do you know what happened, even our sister here is aware of that case because I was sick that period...I had managed to save money for two months to come collect drugs for my husband... I came to the facility that day and it even rained on me that I caught a cold. I waited here from 8am to around 2pm or 3 pm...I waited until I was tired that day to the extent that my neighbors started calling me that my children had returned from school and they needed to eat. And since my children are not used to eating from other people, I had to leave the drugs to rush back home. The following morning, I got here at 6 am and I started crying because after all the stress yesterday I could not pick up the drugs...If I do not have the mind that I need to do this to save my husband’s life, prolong his life, will I come back the following day?”- (translated) HIV positive woman*

Clearly, the above statement demonstrates the dilemma that HIV positive women go through in the Delta region. Although HIV positive herself, she is expected to juggle taking care of the husband and her kids while relegating her own care and in this case, risking her health. Despite the evidence, self-care is almost overlooked in the theorizations of care or less emphasized; rather the discourses of care are usually focused on placing value on women’s care work. This intersection of care and disease/health is also relatively under studied in health geography but remains a significant frontier to explore in-depth and in various multi-cultural and spatial contexts.

A broader interpretation of the above statement shows that care of the self can be subordinated to care for others in situations of injustice, oppression and social dominance as a function of structural inequities manifesting as unequal power relations and social hierarchies within intimate and household relationships. The disposition of women (as the weaker partner) to care within such relations is marked by dependence, vulnerabilities and the need for security. Women in establishing their emotional, social and economic security within these power packed intimate relations may perform care as an obligation. In this way, care practices at the intimate level for emotional and economic security parallels care framed within discourses of power, needs, vulnerabilities and personal security. For a woman therefore, the household can be a site of security or chaos depending on the choice she makes whether to be subservient or otherwise. She is confronted with a narrow range of options and limited alternatives that epitomize male privilege and female subservience yet elevate the constructed definition of her womanhood before the world. Most often, women may consider adapting to male control or dominance as a more desirable choice because their minds have been socially constrained to think of the self and security within these social boundaries of marriage and constructed feminine identities. Similarly, many women perceive a lack of or limited options for themselves outside marriage or the household.

The following quotes also attest to how women may prefer to endure hardships or other forms of subtle abuse or violence to remain in marriage than to be socially stigmatized as a divorcee or single mother, or relinquish other forms of security. Care thus becomes a form of patriarchal control and health constriction. Limited options can even become no options when women are HIV positive and yet still feel socially obliged to stay as carers in and of deeply damaging relationships with men.

*“...women are very patient especially when they already have children in the marriage, they don't like leaving their children, they like unity homes but men, any small thing, they are ready to marry ten, six, seven wives but the woman is ready to stay in one place and stay by the children, she is not ready to be bearing three, four, five husbands. See where the problem lies? That is it.” - Female health care worker*

*“... I have a friend that the husband maltreats, he will even lock the door of their home against her but because of her condition, she is HIV positive and the man is not, she said that anything that the man tells her to do, she will do because the man can ask her to leave [home or marriage], and if he does that, according to her, it is not easy to get a man so she will have to remain in the marriage and endure.” - (translated) HIV positive woman*

Clearly, interpersonal relationships besides power embody some form of emotional or biological connection like marriage and motherhood. These relationships come with or produce a responsibility or voluntary commitment to care. Women's disposition to care can be said to constantly move between the realms of voluntary compassion to one of mandatory obligation. Care as a value connoting virtue, can quickly take on opposing meanings of power and control especially when the caregiver is disadvantaged in terms of resource ownership and control, and the male partner operating from a vantage position of power and privilege. In other words, the process and terms of care are defined from the standpoint of the powerful. At the private or intimate level, women play the role of caregivers but care practices are produced within a range of processes and activities defined by the terms or nature of that relationship. Care as an activity by the subordinated and less powerful can thus be enacted as an obligatory response to fulfill the needs of the more powerful. To the extent that such relations are unequal and shaped by social and material conditions like gender, class, and economic power; care becomes a burden and challenges women's health outcomes.

In many patriarchal societies like the Niger Delta, this is the norm especially for women whose economic, social and cultural identities depend upon the security of their relations with the opposite gender. Women's care burden therefore, cannot be isolated from patriarchal gender identities and constructions that produce different sets of responsibilities and obligations for the biological sexes. Self identities are both a product of the autonomous self as internalized by the individual and by others as a set of external human subjectivities within a social system. That is, self-identity formed from values and principles internalized by the individual and those acquired from external relations (Garcia and Welter, 2013). By way of extending this logic practically, identities produce roles and expectations. They define the contours for which those assigned such identities are to live by even within unrealistic expectations. Usually, the subject perceives such expectations as natural because they are part of an existing social order, hence considered obligatory and he/she aspires to perform in accordance.

Women see caring as part of their identities, hence obligatory. Nonetheless, they also perceive caring as reciprocal yet as gendered, with caring responsibilities of women perceived as different from men. Masculine forms of love and caring relations are expected to be expressed through financial provision and support or 'provider love' as Mark Hunter (2010) puts it in his account of patriarchy and AIDS in South Africa. Across all levels of stakeholders interviewed for this study, popular male discourses put forward include men as providers, unfaithful, polygamous, dispassionate or "stony hearted" and women were cast in opposite light. This inventory of male identities is congruent with specific male behavior that some of the women claimed they experienced at the household and interpersonal level. People try to act in conformity to societal expectations just as women's relations and 'choices' also confirms.

Women identified themselves based on these expectations. Although the women recognized and articulated their own care needs, they seemed oblivious that the social construction of their womanhood was challenging their ability to care for themselves as well as the health implication of this tension. Hence, this connection was not explicit in their personal accounts. That is, the need for self-care was revealed but this was usually accorded less importance in the face of conflicting needs of children and spouses that were given more priority. This was evident among women whose domestic activities like child care constituted part of their non-adherence to treatment. One can speculate that this is probably because in patriarchal societies, the women have been accorded a second class citizenship status either as girls, women, mothers, sisters and wives. In other words, these social and cultural scripts constantly subordinate women's self-care. This is even more profound in countries like Nigeria where society is socially and politically organized around the core religious principles of Christianity and Islam. Submission by women to male dominance and the association of the virtues of altruism with women are upheld as profound spiritual truths and practices. One can therefore, argue that in male dominated societies, women have been socially and religiously conditioned to accept caring responsibilities and associated virtues of self-sacrifice and altruism as part of their self-identity. Female duties interpersonally and within the larger society are thus performed and rendered within this realm of patriarchal affects and virtues.

Misguided conceptions of femininities and masculinities around care and responsibility not only reinforce the notion of care as an essentialized female enterprise, they obscure the power relations and social tensions wherein care and responsibilities are produced and practiced by women in patriarchal systems. Not surprising, care is very rarely perceived as a burden by and for women traditionally associated with the practice because when care is feminized and

constructed as normative, there is an assumption of power and agency because care is deemed central to their humanity and hence, can pose no challenge in its performance. In the Niger Delta region, children's biosocial ties are usually constructed mostly in terms of the mother. Child care is therefore, deemed as an essential purview of the mother and less the father. It produces "male irresponsibility" (Robinson 2011: 38) and reifies the essentialized notions of maleness that is unconnected to the schema of care and responsibility, relegitimizing unhealthy hegemonic forms of masculinity which forms the basis for action evident in secondary reports of male behavior provided by these women. Not surprising are the increasing rates of single female parenthood or cases of quasi-widowhood (see chapter four) among women participants where mothers automatically (but informally) inherit children in cases of spousal abandonment or separation. This particularism challenges the norms in western societies where shared legal custody is aspired for. Hence, this study reestablishes the need to not understand or interpret care within a collection of universal truths and principles but within specific contexts.

As with the married respondents, young single HIV positive women in intimate relationships though may be less saddled with caring responsibilities than their married counterparts still feel a sense of burden to cater to their partner's needs especially when such relationships hold the promise of securing a life time marital commitment and also delivering on economic security. It is all about the social and emotional security as these vulnerable women act as primary caregivers. In situations of inadequate material resources, this produces a crisis of care for HIV positive women despite the fact that their health status places their care needs as utmost priority. A triaged care situation for HIV positive women is created - as seropositive women needing care, as carers for their male partners or spouses, and as carers for children - in extreme situations of

inadequate material resources and choices will have to be made. Most often, women do not choose themselves.

Ironically, despite women's active role as caregivers at the interpersonal and societal level, they are denied formal care through the ways health policies and other interventions are framed and designed; and in practice, in formal (health) care landscapes as we will see in the last section of this chapter. HIV/AIDS policies and other forms of interventions do not actively take into consideration the role of women as caregivers and how this may constitute a burden and further challenge their wellbeing and access to treatment. This obvious neglect within the policy domain may be attributable to the essentialized constructs of care associated with women, roles that are taken for granted or perceived as natural or as inherent part of women's identities. This may not be unconnected to the conception of care usually associated with the private realm and household as part of the natural responsibilities of women. Therefore, care as practiced by women under dire conditions as a challenge to treatment access and adherence do not make explicit recognition in the domain of HIV/AIDS policy interventions (see chapter six for detailed discussion on policy perspectives). Importantly too is the overemphasis of the concept of care as always relational with less emphasis on self-care that may indirectly continue to inform public and social discourses in patriarchal settings. If we must shift from the globalizing notions of care to theorizing care as contextual as feminist care ethicists espouse, its contextual analysis must not be partial but take full consideration to how it is experienced. That is, the same oppressive relations that women are charged to leave may constrict their ability to recognize these circumstances or act autonomously to change them in some spatial contexts. This argument is further explored in the next section through women's discourses of empowerment where women

demonstrate a desire to be empowered materially but not in ways that challenge the nature of their relationships or the power imbalances within them.

### **African Feminism. Patriarchy and the Conflicting Discourses of Empowerment**

*“The reason for this [non-adherence] is that most of us, we do not have jobs because as we are like this now, most of us we do not have husbands so for us to even be fine is a struggle, we are struggling a lot, it is not easy for us so if the government can even call [employ] us, even if it is just small cleaner job [janitorial] in the hospital or council [county] for us to assist ourselves so we can live our lives progressively just as they have provided free drugs for us, we will also need that.” – (translated) HIV positive woman*

The above statement aptly captures the core of this section which continues to unpack the barriers to treatment uptake or access and non-adherence at the intersection of patriarchy but with a focus on women’s disempowerment and the corresponding local discourses. The term ‘empowerment’ connotes a preexisting state of disempowerment, not equipped with the ability to do something. Gendering empowerment as it relates to women therefore implies that women lack power in whatever forms that it [power] is produced whether material or incorporeal. Males as implied in the quote above are positioned as being generally more empowered which may testify to the little emphasis on male empowerment by most of the research participants but re-empowerment whenever the male gender is considered.

Empowerment discourses also stimulate thoughts to the discursive formations of women’s disempowerment and the context in which it is produced. For example, questions as to why women are not empowered, and who is going to empower them, among others. We therefore, begin to conceptualize empowerment through key universal constructs like position or power, choices or alternatives, actors or recipients, agency and resources; and understanding empowerment in terms of what it is not, vulnerability and powerlessness (Kabeer, 2010). We are

also compelled to think about binaries especially when we construct or deploy gender in relative terms to encompass men and women, femininities and masculinities. In this gendered framework, we think of women and their empowerment as relative to men and vice-versa. If the existing statusquo is one of disparity, naturally, we begin the process of deciphering factors that account for this difference.

Logically, this drives us to think about pre and existing state of structures that foster this condition and whether the existing disparity is peculiar to certain geographies or not. If so, what unique place characteristics may account for spatial differences where some categories of women experience empowerment in particular geographies and otherwise? This speaks to the universalism of this construct yet compels us to ask context specific questions in order to understand its situatedness whether as a function of specific geographies or from more global connections. This is not a sequential order in which the word, empowerment is imagined but this reasoning frames the multilayers and broad dimensions from which I approach empowerment in this discourse.

Women's disempowerment was implicated by all stakeholders as a general determinant in treatment access and adherence. In other words, the most important point of entry towards addressing barriers to women's treatment access and adherence is empowerment. Interestingly though, women talked about empowerment not in terms of being totally liberated from male authority within household relations common with popular western feminist notions of female autonomy, as total liberation from male control or dominance but as a means to financially cater to their own needs within the relationship. This is proof that empowerment is such a loaded concept and multidimensional even more so, the diverse ways it can be referenced and practiced by particular populations. It is also testament that we can never wholly or fully engage all the

dimensions of this concept at once but to use part to theorize or understand a social phenomenon like health.

The term disempowerment, although usually synonymous with marginalized women in patriarchal societies, elite women are mostly involved in the struggles of empowerment for women of lower status. Given this binary and obvious contradiction, it becomes imperative to not only understand how local women as mostly targets and beneficiaries of empowerment programs utilize and appropriate this term but also how this feminist agenda is understood and pushed for by corporate feminist movements or women in power . Existing tensions in the contemporary discourse of feminism involves contestations on globalizing western feminism to all spatial contexts like the third world irrespective of disparities in the historical and modern political, social and religious contexts that shape the relations of gender power in these places (Arndt, 2000; Mikell, 1997). Based on this study's evidence, I contend that the elimination of these global spatial disparities do not in any way produce a feminism that is homogenous within third world spaces or internally within countries. While my focus remains on this feminist representational politics, I argue that such global contentions on diversity and difference are reproduced internally within national and subnational contexts and that class and power privileges are the dimensions implicated at this scale, evident in the disparate ways that local feminism is mapped by different female actors.

I explore the areas of disconnect and convergence in the feminist agenda between women in power and women as subjects of empowerment, and how the intersections of social and class privileges may affect the way the gender equality agenda is pursued by these two groups of women. I also engage other meaningful intellectual questions that emanate from the data and their policy implications. For example, how do women's social and material dis/empowerments

reproduce or rework power differences and unequal gender relations, and consequently access to health resources? How might we practically but effectively engage local discourses of empowerment from indigenous women's standpoint even when these are in conflict with universal notions of empowerment that mostly centralize women? I frame this discourse within the context of patriarchy.

Patriarchy as an anthropological term has been used to denote "families or societies ruled by fathers", a social arrangement that elevates some categories of men over other men (e.g. father over sons) but all men over women in both private and public domain. Over time, it is a word that has come to be solely coded as "men's oppression of women" thereby, losing its original meaning which also connotes oppression for some category of men (Gilligan and Richards, 2009, p. 5 & 22). Patriarchy as a social system however, is borderline with female oppression because its core principles celebrate male dominance and control at every scale of human activity and social relation.

In Nigeria as a patriarchal society, this social organization centralizes a culture and structural arrangement of the socio-political order such that the legitimate existence of women and social acceptance is channeled through male identities as with marriage, kinship and transfer of lineage and inheritance through male biological ties. Women are conceived in this social organization as passive, dependent and subservient to male authority. A characteristic of this system is that unequal power allocation quickly translates to modes of resource control, access and how decisions are made by men, for men and women. This perpetuates sexism and other forms of individual rights violation. Historically and contemporarily, these have been the manifestations of patriarchal practices. Nonetheless, patriarchy is much more than women's oppression and subjugation through systemic bias and discrimination permeated through social and political

institutional structures that operate in both private and public spaces. Its doctrine and ideology form the essence and core of individuals born into this order.

Resistance to such patriarchal dividends and hegemonic masculinities has given birth to the feminist movement across three phases. First wave feminism which occurred in the western world was a push to abolish women suffrage and establish their rights to vote in the late 19<sup>th</sup> to early 20<sup>th</sup> century; second wave feminism in the early 1960s coincided with the civil rights movement in the United States and was a resistance to the patriarchal repression of other forms of sexual love to include gay rights and a call for the expansion of the American constitution and democratic ideals of equality; and third wave feminism which embodies many strands of feminist ideals emerged in the early 1990s as a critique of second wave feminism on the lack of diversity and representation of marginal female identities across the dimensions of race, nationalities, religion and cultural orientations but focused resistance mostly on the re-perpetuation of power relations and male dominance through the use of the media, language and texts (Marie, 2012; Sneider, 2010; Gilligan and Richards, 2009; Kevane, 2004). Much of this resistance have thus been localized to specific place contexts, based on the criticisms of exclusions that formed the third wave feminism giving birth to concepts like African feminism and national feminist movements like the Nigerian Feminist Forum (NFF) in recent times.

The Nigerian Feminist Forum defines patriarchy as a system “of male authority which legitimizes the oppression of women through political, social, economic, legal, cultural, religious and military institutions....Patriarchal ideology enables and legitimizes the structuring of every aspect of our lives by establishing the framework within which society defines and views men and women and constructs male supremacy. Our ideological task as feminists is to understand this system and our political task is to *end* it. Our focus is *fighting* against patriarchy as a system

rather than fighting individual men or women. Therefore, as feminists, we define our work as investing individual and institutional energies in the struggle against all forms of patriarchal oppression and exploitation....With this Charter, we reaffirm our commitment to *dismantling* patriarchy in all its manifestations in Africa” (Madunagu, 2008, p. 670) [Emphases mine].

This statement clearly outlines the mission and objectives of the movement. Patriarchy here as defined is fully charged with popular and ubiquitous sentiments that have always been correlated with this system in social and intellectual discourses especially among feminist scholars and sympathizers of the feminist movement. Any form of social activism towards ending the oppressive practices of patriarchy is laudable and embraced irrespective of the main actors. Nonetheless, the statement of the NFF does bring up fundamental global-local policy issues on best practices for women’s empowerment and the pursuit of gender equality within a patriarchal framework.

Despite its steeped patriarchal nature, Nigeria has a long historical legacy of feminism (Dosekun, 2007; Aniekwu, 2006) from pre-colonial to the colonial era but this existed as a concerted or collective form of women’s actions and was not consciously named or referenced as feminist movements. In the colonial era, these women’s movements were organized as anti-colonial struggles in direct resistance to colonial interventions that centralized men in productive roles in economic and political spaces at the detriment of women. The 1929 Aba Women’s Riots by the Igbo female traders in protest of high British taxation is a clear example of organized women’s movement and female activism in Nigeria among many others. Arguably, gender inequality in Nigeria is said to have been legitimized and institutionalized by colonial powers. This trend progressed into Nigeria as a post colony with a considerable number of social movements that consciously identify and affiliate their interests with women. Corporate feminist activism

however, was formally established in the country in 1983 through the Women in Nigeria (WIN) organization; this pioneer feminist movement opened the pathway for similar movements (Abdul, Adeleke, Adeyeye, Babalola, Eyo, Ibrahim, Ighorodje, and Onose, 2012).

As with WIN, subsequent movements identified as ‘women’s movements’ until 2008 when the NFF was launched as a core ‘feminist’ movement, and as a product of the Pan African Feminist Forum (AFF) that held in Accra, Ghana and became a chapter of the AFF. The NFF is bound by the regional ideologies, principles and values of the AFF (Madunagu, 2008). This does question how much of the NFF’s principles are uniquely Nigerian and if their values truly represent the socio-cultural configuration of the country as many African feminist scholars (e.g. Mbire-Barungi, 1999) have argued that feminist concerns cannot be generalized across the continent even though we can draw commonalities in feminist struggles both regionally and globally. The issues of scale and context in identifying commonalities and differences in gender equality concerns have produced what is known as ‘African feminism’, a concept used to denote its distinctiveness from ‘western feminism’ based on historical, social, political, cultural, religious and tribal nuances that are uniquely African (Kolawole, 2002). Even more than this was the difference in the issues. While western feminism especially in its second and third wave focused on the sexual rights of women, women in Africa were/are still battling with securing fundamental human rights for women; hence the “women’s rights as human rights” became a symbolic slogan following the Beijing International conference for women. African feminism has thus been defined in broad terms as aimed at deconstructing African gender relations and illuminating the ways they produce and constitute problems for the African woman with the transformation of negative gender relations as an end goal (Arndt, 2002).

The NFF is the first women's movement in Nigeria to formally identify with the global feminist movement in form and principle through oral and written texts; and it is also the most recent women's social movement in Nigeria and markedly different from all the other national or local women's movements in principle and philosophy. Hence, it forms a central focus of this analysis to not only illustrate the tensions between western and African feminism but how these tensions are reproduced locally based on other dimensions of difference. Furthermore, the NFF's central tenets embody a model of female activism that I argue may be counterproductive to the goals of gender equality and female empowerment in Nigeria, and I demonstrate this subsequently through the voices of local women.

Women in Nigerian (WIN) and the Nigerian Feminist Forum (NFF) share a rights based approach in confronting issues of gender and social injustices. The cardinal difference is that WIN as with other Nigerian women's movements appears to be more oriented towards African feminism. There is also a politics of language by the WIN movement but contrary to the NFF is engaged in ways that do not directly resist male supremacy but evokes humanitarian attention and sympathy to the plight of women as 'individuals' worthy of equal opportunities. By invoking a rights based approach, these 'women's' groups employ universal ways to claim resources and justice for local women but in ways that suit its contextual dynamics and realities culturally.

Language or words that are apt to provoke male resistance or propositioned as a direct attack on male authority are excluded. An assemblage of words reminiscent of women's suffering and plight - meant to solicit empathy (for transformative policy actions) are in lieu deployed within a socio-legal and human rights framework.

NFF on the contrary, as explicit in Madunagu's publication and the outline of the organization's charter for example, has a clear and direct goal to assert the right to use the term 'feminist' as

African women without apologies judging from the author's tone and inflections. This is symbolic of some sort of existing resistance to this identity, hence, the over emphasis. Implicit in this publication is a subtle acknowledgement that language and text and the discourse they symbolize are very crucial operational tools to the agenda of this movement. Language and text deployed by this group are suffused with politically gendered meanings. For example, the name of the organization legitimizes and formally establishes their agenda; an action laden with political and cultural innuendoes. It is a direct repudiation of male authority or dominance and can be likened to a social and political statement that is in direct resistance with the traditional views associated with the word, "feminism" in Nigeria.

Further analysis of the texts and the use of language also show a direct effort to establish a place of relevance in the Nigerian socio-political environment. I disclaim that this may not be wholly representative of the charter or organization but at the same time, I argue the author's stance to be impressionistic of the fundamental and underlying principles of this movement. This attempt at underscoring the movement's mission through identification with the term, feminism is not surprising. The word, "feminism" in many African countries including Nigeria is foreign not because it is unheard of but that it is literarily associated with foreign or western ideologies that condemn male supremacy with a staunch vision to consciously undermine male authority. Take for example this quote from one of the first renowned Black African women literary figure:

*"Feminism. You know how we feel about that embarrassing western philosophy? The destroyer of homes. Imported mainly from America to ruin nice African homes"- Aidoo, 1989 (cited in Kolawole, 2002, p. 93).*

'Feminism' as a term automatically sparks debates and often provokes a volcano of emotions from men and women at all levels. As a researcher on field work for this study, I experienced

firsthand these push backs from male elites within the policy circle. I had walked into one of the offices of a high ranking male official, the director of a department in the federal ministry of health, Abuja to solicit approval for interviews. This official questioned why I thought I could come from the western world (albeit knowing that I am Nigerian) and come talk about gender issues in Nigeria. My roots did not matter, what mattered was my positionality at that time as a young female academic affiliated with the western world which in his lens, made me seem to automatically identify with western concepts that were in his view in dissonance with our local culture. Sadly, this was not the only case. In a policy dissemination conference on gender equality and gender based violence also held in the federal capital territory, Abuja that I was fortunate to attend, the man who sat beside me had remarked about the excessive focus of gender on women's issues and that men are now beginning to feel marginalized in the scheme of things especially in areas where men need to be "empowered".

The concept of gender equality and even feminism may have gained wider acceptance and reception over time. It is nonetheless, still threatening to men (and women as we see in the quote below) and continues to attract resistance by men (and women) even in so called elite circles especially when used in women specific context without male considerations. It is even more threatening when this resistance is indirectly embodied, perpetuated and institutionalized through social movements like the NFF via their mission statement, goals and objectives. As women whose histories and daily lives are marked with concrete adverse experiences of female subordination, it is easy to be swept in the whirlwind of intense emotions that feminism as a movement may provoke at the risk of losing the core and legitimacy of this cause. To get women to directly resist male authority without simultaneously addressing the structural underpinnings of their current realities is to directly reproduce their inequalities and disempowerment. A

feminism that preaches direct resistance to male authority or leadership is not directly beneficial to indigenous women who constitute a majority of the women population still stuck in the rut of being able to identify with their autonomous self, instead continue to live through male optics. These resistant discourses are rife among local women and one of the health workers gives her experience on this.

*“It is [gender] still an issue, it is still an issue because the issue of gender, the men still want to tell you that they are the big shot, whatever they tell you as the wife, you will take...the public enlightenment most men frown at it that these are foreign culture, they should not bring the foreign culture into Nigeria, if you as a woman, you are buying the gender equality, your husband will start telling you that you are following this foreign culture, you cannot exhibit it in my house, I am an African man, you are supposed to be an African woman, we have our culture, we have to follow our culture, so for the equity to really stand, I think it is common with the educated ones who have really gone out and they have really buy that idea, but I think it’s something that we are still battling in this environment to buy that idea but I don’t really know how soon we will buy it.” - Female health worker*

This statement demonstrates what is believed to be African or a perception of Africanness that is wholly ingrained in the core of both men and women. This woman also opines that it will take a re-orientation and transformation of the mind to buy into the gender equity ideology, and one that can happen mostly as a function of one’s level of education and exposure to an alternative gender culture and gender knowledge. In this statement also, there is a distinct reference to the ways the elite and locals embrace the idea of gender equality with education and class privilege seen as fundamental. This is an assertion that is backed by evidence in the literature on African feminism as more African scholars and women within the elite class are now coming to terms with the concept of feminism. On the one hand, this is partly due to its doctrines becoming re-defined on the terms of African women, now increasingly significant with improving the

situation of the African woman within her fundamental human rights. On the other hand, what I argue as also due to the social and class locations that afford these women the platform to gain this level of understanding and acceptance (Kolawole, 2002). This shifting notion among the elite however, is unrepresentative of African women especially in Nigeria as we will see through the voices of local women who are HIV positive.

The concept of women's empowerment is steeped in complicity with multiple unique interconnections that are peculiar to particular places. This multidimensionality gives birth to varied discourses of empowerment and ideological underpinnings in different place contexts and scales. Locally, women mostly seek forms of empowerment that can translate to economic and financial power in ways that increase their bargaining power and negotiation skills within these relations. A potential benefit of such empowerment as claimed within the social milieu of HIV positive women in this study is the material ability to afford the financial cost of care without having to confront the need to disclose their HIV status or not to partners to incur access. I call this a 'minimized risk and individualized disease management model', that is, while this process is predicated on women's individual economic agency in the absence (real or perceived) of interpersonal psychosocial and economic support within household relations, it may not necessarily eliminate all the barriers of access for some women. Nonetheless, perceived or actual loss of spousal support as consequences of disclosure can be better managed and personally negotiated when women are financially empowered in overcoming economic barriers to treatment access. For example, consider the following statement below by one HIV positive woman but whose central message was common in most of the women's declarations:

*"Because the man is the one in control, it is the man who feeds me. I am a full housewife, he refused me to work, okay and I am accessing drugs. Secretly, just because he is there, fear won't*

*allow me to take my drugs; it is the small money that he gives to me cook, it is from that I will secretly take some money when I want to access my drugs [from the facility]. Maybe he is at home; fear won't allow me to access my drugs that day. He has to leave the house first before I can find a way to secretly go and access the drugs quickly. All these things affect our access and adherence. If as women, men empower us or we are empowered by ourselves, say if I am in my business place my husband will not know where I go and access drugs because I am working and bringing my own money so in that case, I won't have any problem, I will be taking my drugs freely. Even then I can tell him anything I want that these drugs [I am taking] are immune balanced diet drugs that I bought, I will even be swallowing the drugs in his presence but just because I am not working now and I am a full housewife, he will want to dig to the bottom to know the exact nature of the drugs I am swallowing.”- (translated) HIV positive woman*

The above quote provides a strong platform to ask and engage the obvious, whether economic empowerment may negate HIV status disclosure or enable it through empowerment programs directed at HIV positive women. It is a general opinion among women but also policy stakeholders that empowerment can help HIV positive women overcome the challenges of unequal gender and power relations that constrain their access and adherence especially post disclosure. Apparently, such local narratives and discourses of empowerment run contrary to more formalized doctrines. A direct interpretation from the above statement is that women may desire a form of empowerment that gives them financial leverage and economic independence but leaves the prevailing socio-cultural arrangement of their relations with men unchanged as long as it preserves their social and cultural identities.

Within a HIV/AIDS context, this is a form of material empowerment that simultaneously enables access and concealment of seropositive women's HIV status or ability to disclose by choice but not feel compelled to disclose because these women need their partner's financial support in navigating the economic barriers to treatment. This form of empowerment is also perceived to help women confront the real consequences of disclosure like divorce or separation. In cases of

non-disclosure, women desire to be capable of initiating HIV treatment and care independent of partner support or decision fully aware that they can use the excuse of working or going out for their regular business to go access treatment. These women perceive this type of empowerment to elevate their social standing before their male partners and elicit their respect given their relative financial independence. Women can therefore, regain bodily control without a partner invading their private space given that he knows he is not the sole provider in the relationship.

The above quote is also an indication that empowerment helps women regain some level of power and autonomy which enhances their bargaining and negotiating power within intimate relationships. The scenario the quote posits reifies unequal gender structures through male power and control as a significant barrier in women's treatment access and adherence. It is also suggestive of women's need for empowerment and the forms in which women desire this, and also the ways women might deploy their empowerment to navigate the treatment terrain.

Apparently, women do not want their empowerment to directly resist male authority. Although they desire material agency for self-care, they still want to keep their identities as wives and mothers through submission to the authority of their male partners. The reason for the need of such empowerment is that in male-dominated societies, a woman's empowerment is inherently patriarchal as access to resources is generally channeled through men. The following quote attests to this:

*“The reason why these challenges that we have is very serious is that this thing [HIV/AIDS] can happen to anybody but mostly for us who are poor. The majority of us that are infected are very poor because if a woman has no husband, you know something is wrong [there is a problem] except that woman has gone to school [educated] and that she got an education and was a well-paid worker before the husband dies. So because she earns a salary, she can meet up with the*

*challenges but for us local women like this, it is very difficult for us to meet up.” - (translated)  
HIV positive woman*

These are some of the local discourses of empowerment. Although social and gender identities are significant forms of repression for most women, this is further complicated by a lack of education and economic empowerment. The statement above ties a woman's primary source of economic empowerment to intimate connections with men. Secondary female empowerment is considered as that which is channeled directly to the woman through education and consequently, gainful employment. Hence, the profound importance attached to the institution of marriage as it guarantees both social and economic security is a continuous proof that empowerment for most local women are intricately tied to the structures of patriarchy.

The form of empowerment that is pushed for by these women where they are materially empowered but keep the existing social statusquo is however, replete with internal contradictions which extenuate the merits of empowerment programs that are transformative to negative gender ideologies. It is as Kabeer (1994) argues, a function of a dimension of gender power that precludes conflict but where the actors, both the dominator and subordinate may lack a consciousness of power hierarchies, or domination and subordination because such practices of inequalities are so deeply entrenched in the prevailing social order that they become perceived as ordained, normative, natural, or that there are no alternative ways of doing things. It is the voices of such women that we need to listen to not because their misconceptions of gender relations should be accepted but because silencing these different voices through elite but combative feminist discourses like the NFF is antithetical to the very transformative gender relations agenda that African feminists seek.

The NFF is a mix of both African and western feminism. There exists the nuance of trying to establish a global connection with the broader third wave western feminist movement evidenced in some core principles of the charter. Their charter is indicative of an organization carving a distinct and clear positionality in the local scheme as African feminists with gender equality at its core. Yet, as third wave western feminists, embrace post-structuralist feminist philosophies. In the Nigerian reality as evidenced in local discourses of empowerment by HIV positive women, this is not a reconcilable ground or shared space as women do not generally think of empowerment from these perspectives. Putting an end to female oppression and according an equal citizenship status to women through better living conditions and welfare was the agenda of the first wave global feminist movement which continued into the second wave of the feminism movement. As western societies moved into a more egalitarian era as products of these movements, the post-feminist era was born.

The Nigerian society has to accomplish the core agenda of the African feminist movement of bringing the living conditions of women to an optimum before pursuing the more abstract and idealistic objectives of western feminism that the NFF currently pushes for. These ideological contradictions and flaws also beg the question of whose interests are actually being represented and which categories of women are included or excluded from empowerment programs that are couched in such feminist ideals. Such unpopular agenda like the NFF's among the locals, imparted or transferred through local empowerment programs may be offensive to the sensibilities of women and men and therefore, garner continued resistance. This becomes a direct reproduction of gender inequalities and power relations among women (between elite and lower caste women) through elitist representation of women's needs, fighting a cause that represents a specific interest group. Yet these elites represent this as a global or national agenda without due

consideration to the needs of local women who are not on the same social and class pedestal or educated and reoriented as such; as feminism is usually a purview of a crop of educated and privileged elite women.

I acknowledge the fact that even individual poor women may try to resist micro level male dominations and inequities especially within household relations but this is done within a comfort zone and with less direct resistance to male authority as we see in the preceding quotes (also see Aniekwu, 2006). It appears that the paths of these two categories of women maybe different but point towards the common goal of improving the situation of the Nigerian woman. Differences in how women conceive of empowerment are therefore, crucial to any movement on the empowerment of women at all levels. Resistance to patriarchal authority that enhances women's autonomy should be a progressive and systematic process that begins with undermining structures of inequities through creating equal social and economic opportunities for women to improve their agency. Blatant resistance of male dominance by women through undiplomatic social activism and acerbic forms of language will meet with equal resistance from men; consequently undermining the most important goal which is equality for all sexes.

This is a more realistic and practical way of addressing the ills and twists of patriarchy as a culture or way of organized social life rather than espousing strategies that are viewed by the indigenous population or subjects of interventions as “foreign”, west-centric or new forms of western cultural imperialism and colonialism. For example, the NFF's mission to ‘abolish’, ‘tear down’ or ‘obliterate’ patriarchy is replete with rhetoric, and is at best idealistic and utopian even on the long term. It conceptualizes the end of a social era and order yet with no concrete conceptualization or structure to the beginning of another. Society is structured, so when a structure is torn down, it should be replaced with another. Perhaps, the target is a “crude reversal

of patriarchy” (Eller, 2000) to usher in egalitarianism. Because patriarchy is synonymous with male authority and leadership, whether the NFF couches their mission as not “fighting individual men” but the oppressive practices permeated through its structure, it will be perceived as such especially when certain languages or texts are deployed. To truly chart a course to ‘dismantle’ something, there is great need to understand that particular entity in all its depth, dimensions and nuances.

Local meanings and understandings of female emancipation differ considerably from western and local elitist appropriations and this is of particular importance in global health interventions that may feature empowerment as an obvious resistance to masculinities. Local discourses of female empowerment is that which empowers this population to make certain independent decisions or better negotiate or manage subordination but still within the realm of male controlled relations. This fact is important because many local women identify and believe in subordination. This may not necessarily be within the realms of oppressive relations but the knowledge that the woman is subject to the authority of the man, thereby subordinate to him in the household decision making process. This proposition is premised on interpretations gleaned from how both men and women in this study’s population appropriated empowerment. Among these groups of women and perhaps men, there is nothing that challenges this reality because of their non-exposure to alternative ideologies or ways of doing. Hence, the general belief that “feminism” within African cultural setting is a foreign discourse and attracts resistance from men and women alike.

Within the domain of HIV/AIDS interventions, it is pertinent to reconcile the existing tensions between cultural knowledges and universal discourses or meanings in terms of not only how they are locally defined and internalized but appropriated and experienced. Unpacking these conflicts

among and within women's social movements as state and non-state instruments in channeling women's empowerment in terms of how empowerment is conceptualized and operationalized is a profound contribution this study makes to understanding why local empowerment programs meet with so much resistance and fail to achieve their intended objectives.

Like the NFF, WIN and other African feminist or women's movements, I argue for an inclusive gender approach geared at the establishment and institutionalization of a more egalitarian society where women like men have equal opportunities and access to resources to attain any level of citizenship and individuality as desired. I argue nonetheless, that it is easier and perhaps more effective to work through the fault lines of a social order in a bid to transform or modify culture but not to tumultuously usurp the existing statusquo as these feminists claim. I am not advocating a double speak or take on the issue. I do not in the least even propose a movement that is complacent and do not critique existing power structures or even suggest that the best strategies at this time should be those that allow women cope with existing inequities. Rather, there is need to have a clear cut systematic and diplomatic strategy that is far more effective in achieving gender equality and women's empowerment without resistance from both men and women.

Furthermore, that the agenda of gender equality is not sabotaged by politicking the agenda of women's movements but that these movement remain true to the core objectives of gender equality with practical but realistic strategies. I propose that empowerment whether economic or otherwise, must begin by targeting women's minds (as well as men) - their thought processes first of all to elicit an awareness or recognition of the more subtle or immanent forms of inequalities and oppressive male behavior that have mutated overtime to become standard norms or acceptable constructions of masculinities and femininities. To the extent that men are oriented and socialized towards inappropriate forms of masculinities, these behaviors can also be

unlearned. With men as leaders and governors in a patriarchal society, it is imperative that they become the first point of change and re-orientation in their disposition towards women and femininities, and towards more appropriate forms and practices of masculinities.

Empowerment should also engender strategies that aim to redirect material resources to women. Women's empowerment has to be multidimensional and adopt a holistic approach as it makes no good to address internalized oppression without material empowerment or vice-versa. Women's empowerment should not be constructed as a western product that is sold to a local population through global health policies and programs. The concept of empowerment is definitely not neutral but subjective so must take into cognizance the multiple subjectivities of the target group which includes religion, culture, social organization and hierarchy to render it effective. These local discourses of empowerment also compel us as researchers and policy makers to rethink and reformulate empowerment as a process, set of doctrines and transformative actions that can be incurred through empowerment programs. Women's empowerment should therefore, not always take the form of a tangible or material product as it is often touted and practiced in policy circles and NGO programming.

### **The Geography of Health Care as Landscapes of Risk and (In)-security**

The concept of 'place' though pluralistic in definition is a foremost theme in the new geography of health. A range of geographic research into health has produced place related knowledge that shows an eclectic use of the concept of place. This methodological pluralism range from the operationalization of place as the particularities of a physical location or research site, place as landscapes of meaning, as well as the positivist tradition of empirically capturing place through multilevel modelling. Arguably, studies that have made the most effective contribution to spatial research are those that have deployed physical geographies metaphorically and in non-literal

terms. Interpretive landscapes represent places as a complex layering of meaning and history, but also as intersections of culture, social processes and the political economy in particular localities. Its centrality and terms of reference in the health geography scholarship underscore that both the experiences of health and health care are shaped by the peculiarities of specific places. Post medical geographers therefore, argue against the medicalized framing of ‘place’ as a “passive container in which things are simply recorded”, or place as a static concept (Dyck, 2010; Kearns and Moon, 2002, p. 587) which arguably (see Mayer and Meade, 1994) is how place is constructed and operationalized in the traditional parent sub-discipline of medical geography. Health geographers frame ‘place’ as a living construct that matters, as active and relational, wielding interactive power to structure individual health experience and outcomes (Hunter, 2010, p. 23; Kearns and Collins, 2010).

In particular, health geography foregrounds health care systems and health service delivery as significant to the healing process and wellbeing of patients. It considers as important not only the location of the health facility in relation to access but the actual sites of care and the mode of service delivery (Rosenberg and Wilson, 2000). To Kearns (1991), the activities that transpire within a health care facility have as much profound effect on individual wellbeing. In other words, health care landscapes can become therapeutic spaces or constitute spaces of risk and vulnerability for health subjects although health care landscapes can also simultaneously embody both. As a consequence, the geography of health and health care is becoming increasingly grounded in acknowledging the voices and experiences of people who access health services in particular sites. The inclusivity of their voices act as significant components of health landscapes as they add new meanings to these sites of care through personal experiences (also see Gesler, 1993). Dyck confirms that the cultural turn in geography has opened up the frontiers for health

geography to make a shift from the medicalization to the socialization of health and health care systems such that issues that border on experiences of diseases and other social dimensions of the health care experience are mainstreamed through consumer self-reports of health care provision (2010).

Similarly, the deployment of place and landscape by health geography provides a direct theoretical and methodological interface with political ecology as both sub-fields show a commitment to the construction of place related experience of health as a function of social processes unique to specific contexts. The varied accounts of studies in political ecology demonstrate that health and disease are inextricably bound to spatial and social systems in which they are experienced. That is, individual health risks and vulnerabilities are not only socially produced but are structurally conditioned by large scale political-economic decisions which transform the natural environment and shape the emergence of diseases (King, 2010).

A general objective of this study is to understand human health-environment relations as products of the complex interactions of market-led environmental decisions and resource use. Also, to utilize evidence to shift the normative coding of HIV subjects as individualized risky subjects to understanding their risks and health behavior in more structural terms. That is to say, individualized health risks and risky behaviors are usually products of more invisible structural factors. Situating this analysis within the health geography and political ecology framework, I demonstrate the social activism and fluidity of place. In other words, I illustrate the ways that the geography of health care in the Delta has been transformed through socio-political and economic production to become landscapes of fear, risk and insecurity for women living with HIV. Through empirical evidence, I make the argument that place matters in understanding the challenges of treatment access and adherence by HIV positive women in the Niger Delta region;

and that particular features of the physical and social landscape may interact with women to birth behaviors that may exacerbate their poor health status, in dissonance to healthy outcomes and wellbeing.

Since the 1956 discovery of oil in the Niger Delta, most communities within it have become sites of power, struggle and resistance to global and national capitalist forces in the determination of the fate of the environment and corporate destiny of the lives of the local population. Watts (2004) speaks of this space of resistance as inextricably bound to the intricacies of the presence of oil resources, what he popularly labeled as the 'oil complex'. Chaotic restiveness and violence are the social hallmarks of these communities and are almost permanently inscribed in the local culture as the native population keeps fighting to procure the needed development in their respective localities. This is in spite of the situatedness of crude oil in the region, the nation's main resource and economic mainstay. Erhoike community as with other oil communities in its environs is a site of marginality with the production of a persistent state of insecurity through criminality, internal or communal resource conflicts and militarism. The fight over oil resources has led to environmental insecurity and a militarized response by the state and national security forces set to secure the oil resources as they become the target of conflict. As evident in the community and its environs, the physical landscape is dotted with military roadblocks and check points at almost every turn reminiscent of the volatility of the region. Armed military security personnel have become part of the social landscape to protect the environment and secure peace, yet their presence as agents of security is contradictory in many ways. Accounts of military activities recounted by health workers and HIV positive women accessing treatment at the Erhoike Cottage Hospital establish that the military personnel deployed to restore peace and

security in the region can be counter-productive as they pose as threat to human lives and social security.

In the wake of a recent community crisis and attendant militarization of the community and environs, patients' access to treatment was abruptly halted. Access to treatment and adherence was negatively impacted as patients living in the community and proximate locations to the health facility had to relocate to safer places. For some, continuity of treatment was impossible especially if they had to travel longer distances and incur a higher transportation cost to access alternative HIV care only available through secondary or tertiary health care facilities that maybe few and far in between. Restricted mobility produced a temporary cessation of their antiretroviral therapy which caused many of the patients to relapse and consequently, resulted to death for many. Patients who survived were usually those who could seek other health care options and others who relied on the benevolence of those with continued access (from other treatment facilities) willing to share their drugs. As hitherto mentioned (see chapter two), the organization and geography of HIV treatment and care in Nigeria is such that while primary health care facilities may be easier to access, they only act as sites for counselling, testing, diagnosis and referral. It is the secondary health facilities like the Erhoike Cottage Hospital that administer treatment and these are few and sometimes, may require some travel time. HIV positive women have thus often been challenged with mobility and long wait times at the facilities when commuting from distant places especially when their appointment times conflict with their social reproductive duties. For example, women have reported up to six to seven hours wait time to access their drugs (see quote on page 82).

Likewise, health care workers at the Erhoike Cottage Hospital reported personal experiences of physical harassment and molestation, violence and death threats by the armed military security

agents as they made their way to the health facilities to assume their official duties in the heat of the crisis because of perceived suspicions that the health workers were on the side of the individuals in the community involved in the protests against oil activities and government forces. Military stops and routine checks of personal items of all individuals entering the community, being asked to step down from one's vehicle, raise hands as an act of surrender as one walk's past the military check points constitute other forms of harassment detrimental to the access of HIV treatment and care as reported by some of the health workers and patients. Other times, rumors of war, crime and conflict scare patients away from regularly accessing their treatment and these affect their access and adherence. In cases of ongoing communal crisis and protests, patients have been advised by the facility's health workers to take a different but longer route to the health facility to access their treatment. For some of these women as reported, the implication is that more money needs to be budgeted for transportation which is mostly unaffordable. Although this is not a regular occurrence, social unrests, communal violence and rumors of unrests are fairly common in this locality and environs and both health workers and patients themselves have reported gaps in treatment access and consequently, adherence in such situations as many patients are lost in adherence monitoring and follow-up. In HIV treatment landscapes where there are recurrent risks of social disruption like the Delta area in general, alternative care strategies for HIV positive women are called for. These strategies should transcend mapping of secondary routes designed to enable geographical access as these may yet endanger lives or even prove unaffordable by women who are already burdened with the usual cost of mobility to health care facilities. Other forms of risky behavior reportedly perpetrated by these so called security agents have been the proliferation of risky sexual behavior by engaging with vulnerable adolescent females and women. Such behavior is bound to recycle the vicious

process of HIV transmission in the region which is already in motion due to the political economy of oil and environmental processes perpetrated through transnational oil corporations.

Germane to this geography of health care is also the differentials in health service locations; the rural-urban binary as it determines access to health services among African women. For example, Wisner's (1989) study of Kenya's health care system showed a flow of movement of poor women from rural areas to urban centers in the quest for health services. The location of the Erhoike Cottage Hospital is not only rural, situated in the hinterland; it is also remotely located in the community. These location attributes do not only structure access, they create a unique demography of patients influx to the center such that there appears to be a reversed mobility as rich women periodically migrate from urban to rural areas like Erhoike to access treatment. This facility serves as a beehive for the elite and upper caste of the society relative to other treatment centers that are centrally located. Patients from the northern part of the country and other regions undertake about half to a day's journey to access treatment in their bid to avoid or limit social stigma that is considered highly probable in bigger treatment centers.



Figure 10: Remote location of the Erhoike Cottage Hospital

Besides its remote or secluded location in countering the effects of stigma, this HIV treatment center also holds a huge attraction for many seropositive individuals including women from lower social and economic strata because of the facility's non-segregation policy. This means that infected HIV individuals are attended to at the health facility like every other patient with no special ward designated for HIV patients that may become a source of stigma. In many studies (e.g. Herek, Mitnick, Burris, Chesney, Devine, Fullilove, Fullilove, Gunther, Levi, Michaels, Norvick, Pryor, Snyder and Sweeney, 1998), sources of stigma for HIV positive individuals (and also confirmed by women in this study) include the health facility as a function of how particular spaces within service centers are designated only for HIV patients. On the contrary, the evidence from the narratives of HIV seropositive women suggest that the Erhoike Cottage Hospital did not constitute any form of social stigma through the physical organization of its treatment space except in rare occasions when there were familiar or known faces among the health workers or direct stigmatizing behavior by health workers. In addition to the way the treatment space is organized, another aspect of the non-segregation policy is a no-ART clinic day. In other words, HIV patients did not need to converge as a group on a particular day to access treatment. Rather, each individual HIV patient is given an appointment day and could walk in anonymously like other patients to receive treatment.

It is worth mentioning at this point that the organization's practice of allowing individual HIV patients access their drugs at different times is not a common practice among health facilities across the country as confirmed by the hospital administrator and other health staff . According to these health workers, the reverse is mostly the case in other facilities. The health workers state that a common appointment day for HIV patients to access treatment services is a source of facility based stigma from non-HIV patients accessing other types of care at health facilities as it

becomes easy to identify HIV patients when they converge together at the same time and place to seek treatment and care. The Erhoike hospital's administration cited this practice as an organizational policy that originated from the current Medical Director when he assumed office at the facility as part of strategies to increase the influx of ART patients and improve adherence rates. However, this practice has met with some resistance by the NGOs collaborating with the facility because it does not have provision within the treatment national guidelines. But the hospital administration had stuck to what has been a successful practice in enabling access to treatment and mitigating facility based stigma. This practice illustrates the need for implementation strategies that are specific to context and needs of the target subjects, and also underscores the need for flexibility in HIV/AIDS programming in adapting best practices.

The physical treatment arena - the hospital wards - is therefore, designed as a common space for all patients except for the wards where tuberculosis patients are quarantined and treated. This re-organization of space to accommodate the social needs of already vulnerable patients greatly minimizes the risk of stigma especially for poor women who because of their economic status are constrained, with limited ability to choose to access treatment services from more distant health facilities in the bid to avoid known faces and consequently, stigma. It also provides an insight into how specific health care landscapes that are by default risky and potential sources of stigma can be re-organized to be more therapeutic and safer for health subjects. This is a positive departure from popular representations of HIV related stigma based on the physical geography of health facilities. It also serves to illustrate that the actual sites of care have meanings and are interactive in nature in ways that can both be therapeutic and enable the wellbeing of patients, or as spaces of risk and vulnerability as Kearns (1991) and other health geographers have continuously espoused.

Health workers also constitute part of the treatment landscape and social space of this facility. Their behaviors can either pose as a source of emotional and psychological instability to patients or promote their wellbeing. Most of the women reported dissatisfaction with health workers attitudes towards them and other general inefficiencies in the administration of treatment. As an example, a research participant narrated an incidence where improperly prescribed medications almost cost her life. Another narrated multiple incidences where health workers have wrongly counselled newly diagnosed HIV positive women instilling fear and hopelessness in the patients; and other reported experiences of non-consensual disclosure of patient's status and stigmatization. Based on women's accounts, I sum up below the attitudes of victimization by health workers. Victimization is used here to mean behaviors research participants perceived and reported as unfair treatment or actions towards them, and types include:

*Shouting/yelling*

*Delay in attendance to patients*

*Refusal to attend to patients or administer drugs*

*Rudeness or talking down at patients*

*Refusal to negotiate conditions of access with patients or reach a safe compromise*

*Insensitive nature of health workers to the plight of patients in respect to pick up of medications*

*Insensitive comments or statements*

*Stigma*

*Unsolicited and unethical disclosure of patients' HIV status*

A politics of access through unequal treatment of patients by health workers was very emphasized and recurrent in all the interviews and focus group discussions conducted among the HIV positive women. The women described discriminatory attitudes by health workers and the provision of preferential treatment to women with material means. Less privileged women had longer wait times, were unfairly delayed when they show up to access treatment on their due

dates, sometimes denied treatment and inhumanely treated when they miss their appointments and show up on later dates. Women attributed this differential treatment to the fact that the rich are able and willing to pay bribes or make informal compensation to health workers to be attended to and on time irrespective of when they show up for treatment. The administration of health care at this site and antiretroviral drugs which are cost-free are somewhat akin to commercial products offered first to those who can afford them but usually in violation of the legitimate institutional practice of administering treatment on a first come, first serve basis.

Participants' claim that a different set of rules applies to them than patients of higher socio-economic class creating the use of the terms "us or we" and "them" as the women narrated their experiences. Women reported cases of people who do not come to the facility because they had made special arrangements with the health workers to convey their drugs to them. This behavior was perceived to be unfair especially when health workers became insensitive to the plight of poor patients who were financially stranded or for other justifiable reasons were unable to make their appointments. For these less privileged patients who are unable to come pick up their drugs at the required time, requests made to the health workers for alternative arrangements or to allow friends and families help them pick up their drugs were often turned down. While some of the research participants argued against the practice of health workers insisting on patients self-picking their medications because of the inconvenience, this appears to be a standard national ART treatment guideline and practice across facilities in the country. This practice is designed to create the opportunity for health workers to physically evaluate patients' conditions and their treatment progress when they visit the health facility to pick up their medications.

The practice is however, constantly violated when it comes to members of the elite class as reported by the women. This provoked a strong argument among the women on the justification

or rationality of the practice especially for poorer patients. Some of the women argued that whatever good reason this practice was institutionalized, its implementation negates the original purpose because it is selectively practiced. Research participants claimed the elite called for their drugs without being physically present as required of some of the poorer folks. Furthermore, they claimed that the actual practice of checking for vital signs and other evaluative health procedure when physically present is hardly practiced by the health workers which is also in contradiction to the ART national treatment guideline. The few occasions this has been practiced, it is usually not for the benefits of patients as participants claim, instead it is implemented as a very rudimentary process to meet up with the report and documentation demands of collaborating NGOs.

Health workers attitudes thus disrupt the physical process of access, and also impact patients psychologically and emotionally by negatively challenging the motivation for continued access to treatment which affects their adherence. Psychosocial and emotional impacts from health workers behavior were reported by women. This has the potential to compromise the recovery process and overall wellbeing of poor women already burdened with the physical, emotional and material impact of the disease. The persistent inequalities perpetrated in these health care landscapes not only recreate class differences but reproduce the inequities that structure women's vulnerabilities outside the household and intimate relations. Health workers as agents of care can thus become counter-productive to the life-saving ideals and values that they represent and act as countervailing forces to the palliative and curative effects of the HIV treatment that they administer. At a miniscule level, practices and attitudes of health care workers mirror and expose gaps in general HIV/AIDS interventions around poor service delivery. Weak or inadequate training of health workers on service delivery, poor care ethics or the lack of professionalization

in the delivery of health care, as well as health workers ignorance of the disease which culminates into stigma are some examples of a weak health care system and HIV/AIDS service delivery.

To effectively understand HIV positive women's poor health outcomes despite the physical availability of treatment is to grasp the complex web of social and environmental risks that they have to individually navigate daily in their quest to seek health care. Construction of treatment constraints as individualized precludes systemic factors on multiple scales and renders them invisible. Such personalized constructions also pose the danger of situating women as active and sole agents in their treatment uptake once treatment has been made available. The path to health and wellbeing of HIV positive women in at risk communities in the Niger Delta region must consequently be understood inwardly and contextually. Experiences of treatment access by environmentally challenged HIV positive women in the Delta area cannot be homogenized and addressed as with women who come from more secure spaces. How much of place related risks are factored into health interventions is unknown at this time. Sites of health care may not only embody risks and vulnerabilities but hold undesirable meanings and representations of health. Within the geography of health and health care, women's self-reports and experiences of health systems help us to view with critical lens, so called formal landscapes of (health) care to unravel the hidden and alternative meanings they hold for users and what these symbolize for their health and wellbeing. Such situated and relational knowledge - from providers and users - offer significant utility to researchers and policy makers to reposition and transform local health systems.

## **Conclusion**

The empirical evidence presented throughout this chapter pose a multiplicity of implications for HIV/AIDS policy and research. The evidence also enables this study to safely make certain claims on the geography of HIV treatment and care especially in relation to women. Given the ethnographic nature of this study, I acknowledge the limitations and the extent to which these findings can be generalized to a larger population. Still, we are able to draw compelling insights and knowledge around the very personal ways that treatment is constructed, rationalized and engaged by women in patriarchal settings. This is in spite of how generalized HIV treatment and care have been constructed and operationalized in the domain of policy. The plethora of evidence here addresses theoretical shifts and turns in feminist and health geographies like the structure-agency debate and how such evidence frames opportunities for women's health outcomes. The evidence also addresses the varied ways we can apply scale; for example, the theorization of the body and place as social and not just in biological and physical terms respectively. Hopefully, the evidence also re-informs how we theorize a feminist ethic of care within the care ethics scholarship.

Theoretically but with practical relevance is also how we understand knowledge in terms of the methods of production and the scales at which knowledge should be produced whether personal, household or macro. Hegemonic knowledge can be deeply contested and redefined as we move through different spaces and scales hence, the scale and the methods of knowledge production are significant as we observe through this study. Some of the findings re-echo existing assumptions in the literature at the same time dispel others. Better still, they signify that such propositions do not hold true in all spatial contexts hence, all knowledge must be situated and grounded within specific place context.

This argument is continued in the next chapter which emphasizes the knowledge of HIV treatment challenges as not only situated within relational inequalities between men and women but also other forms of inequalities and disparities within a gender group that has been mostly conceived as homogenous. Chapter four provides other dimensions to the barriers of treatment and access to extend the debates of women's access not only as occurring in relations to men but also as intersectional with other axes of social difference within the female gender group. The chapter delves more deeply into the relational and intersectional theories using specific place evidence to reify these concepts.

## **Chapter Four**

### **Situating Women's Treatment Access and Adherence at the Intersection of Non-disclosure and Social Difference**

*"I will not disclose even if I am dying here, if it is what is killing me, I will not disclose. And if at all I remarry, I will never disclose my status."- HIV positive woman*

#### **Introduction**

This chapter is a sequence to addressing the question of unsustained treatment access and adherence among women addressed in chapter three. It also continues to ground the knowledge of non-treatment access/adherence in the voices and experiences of HIV positive women. As the preceding analysis demonstrates, issues of treatment and adherence among seropositive women in the Delta may appear as micro forms of inequalities; in actuality, they are underpinned by structural forces. As such, we see a recurring tension between structure and agency in the decisions and choices women make around uptake of treatment and its adherence. It becomes imperative to always relate and situate our knowledge of these issues within a place context but more than that, as they intersect with other social forces given evidence from this study that women's bodies are in constant interaction with macro level forces within particular places.

The argument against rigid forms of knowledge made in the preceding chapter is also well illustrated in this chapter's analysis through the unique stories of HIV positive women. This chapter continues to use an intersectional lens to understand how women's decisions to initiate and sustain treatment uptake are situated within a constellation of co-constructing forces that influence this decision making process. The chapter reinforces the argument made in the previous that the barriers to women's treatment access and adherence are not linear but circumscribed within a labyrinth of forces that are social and material in nature. Through the

evidence, the chapter also continues to demonstrate that the ability of women to respond positively to treatment in terms of consistent uptake is contingent on place structures and contextual forces. More importantly, the evidence helps to shift the discourses of HIV treatment non-access and non-adherence beyond a model of individual irresponsibility to other scales of influence. Consequently, a significant contribution that this chapter makes is reifying new notions and feminist constructions of scale as both gendered and embodied. Scale as demonstrated through the evidence is experienced simultaneously and not as distinct hierarchies of events, and also on a very material and social level beyond geographical or traditional physical boundaries.

Scale as experienced simultaneously and not as distinct hierarchies of events is demonstrated through the evidence in the section on HIV/AIDS non-disclosure which suggests that women's refusal to initiate treatment is based on household level and interpersonal power dynamics but with women at a weak bargaining end because of their marginal status wrought by structural inequalities. Scale constitutes processes; processes that are social, political and material but inherently interwoven and individuals can embody all of these layers at once. These expressions of scale are also reified through the narratives of women in the section on the intersectionality of treatment where women lament their embodied experiences of treatment constraints due to limited wage work and the lack of alternative livelihoods to farm labor. An intersectional lens helps us to understand how these forces occur in reality within multiple scales of influence, whether as individual level social differences among women as they create disparities in their access or as contextual forces that reflect broader place processes and structures. This is a core focus in this chapter as the analysis deploys women's testimonies to directly illustrate the theory of intersectionality, and its twin, the gender relational theory.

The relational framework argues that the theorizations of gender must recognize both the social dynamics and the agencies of male and female bodies and see them as intricately linked. A major principle of the relational theory is that femininities and masculinities are intimately linked and forged in relation to each other. In effect, both the relational and intersectional theories promote diversity and dynamism in understanding gender relations and categories, challenge conventional gender and health research that ignore the interactional effects of social locations, power and other forms of inequities, yet do so by linking different scales of power (Hankivsky, 2012; Tolhurst et.al., 2012, Springer, et.al., 2012).

This chapter's analysis begins with the section on HIV/AIDS non-disclosure and the findings demonstrate that disclosure or non-disclosure is more than a linear event or practice; it is a deeply complicated process for many HIV positive women. With the fast increasing spread of HIV/AIDS across sub-Saharan Africa, the sharing of the knowledge of a HIV seropositive status by infected individuals to partners and those at immediate risk of infection is increasingly emphasized to aid preventative efforts and so that individuals can get the support they need from family and other social support systems to initiate and sustain treatment. This is what HIV/AIDS disclosure means. Explanations of HIV status non-disclosure repeatedly attribute the unwillingness of women to disclose their seropositivity due to stigma. Unfortunately, this focus on stigma as the main causal factor obscures other underlying influences.

Using an intersectional approach, this study argues that beyond stigma are other hidden social processes that are often ignored when non-disclosure is explained solely in terms of stigma. Through the embodied accounts of HIV positive women, the practical conditions of everyday life beyond stigma that shape and often constrain women's decisions to disclose particularly within intimate relations are highlighted. How women rationalize these everyday practicalities and

negotiate decision-making around disclosing or not are also examined. The central finding is that women's decisions to disclose although constructed at the level of the individual are deeply regulated by external forces. Non-disclosure among HIV positive women is not always performed as a matter of choice and free will but under restrictive conditions. The decision to disclose or not is contingent on the expected or real behavior of the male partner whether good or bad and further complicated by the marginal conditions of women. This perception or reality thus defines the decision making process and space for treatment access and adherence.

As an interesting paradox, the presence of husbands or relations with male partners inhibits access and adherence especially on non-disclosure when women fear they might lose their relationships. In other instances as we see in the second section on how HIV/AIDS is reconfiguring the traditional family structure, women who have been abandoned by their spouses due to their status cited the absence of their husband's economic support as a major barrier to access and adherence. Important is the knowledge that husbands or male partners are symbols of social and economic securities; women's circumstances are thus inordinately regulated by the presence or absence of a male partner. This connection between absentee husbands and treatment limitations are linked to gender roles and identities where the expectations of men are as providers and women as financial dependents. The analysis thus highlights a major consequence of HIV/AIDS disclosure on women which is spousal abandonment and how this is breeding a new form of female headed households. A finding that underscores the need for an appropriate socio-legal framework to better manage the process of disclosure and its negative outcomes especially by health service providers who are mostly primary initiators of this process in health care settings.

This chapter's substantive analysis ends with the section on the relationality and intersectionality of treatment access and adherence. A major finding is that beyond these prevailing forces against women as aforementioned, there are individual level markers of difference that reproduce intragender inequalities among HIV positive women which shape the nature of individual access and adherence. The finding proffers valuable insight into the categories of women likely to access and adhere to treatment or not and such knowledge is particularly important for planning treatment interventions. The different challenges of treatment and negotiating patterns among this cohort of HIV positive women also demonstrate gender as a fluid identifier because its experience is contingent on its interaction with other axes of social difference which diversifies the ways women experience health inequalities. Consequently, I argue that while gender is a key analytic variable through which we can view health disparities between and among gender groups, it must be situated within the intersection of other social variables that shape how gender is lived and experienced in real time and space.

Following, the reciprocal nature of social relations which is that men and women both shape the dynamics of gender relations is heavily underscored in the relational theory. Within the health domain, evidence here presents a subtle departure from this dialectic. Health decisions and behaviors by women as mediated by gender power with negative implications for women are observed to be mostly driven by male power. Although it is premature to draw a conclusion based on the available evidence that this is a mostly unidimensional impact given that male seropositive individuals were not investigated for this study; there is overwhelming evidence of male power as a dominant social force in mediating female health behavior especially in male controlled heterosexual relationships. Centralizing men in interventions must therefore, be

considered a permanent fixture of treatment interventions in producing positive health outcomes for HIV positive women, and even in matters of general female empowerment.

**‘It is the Fear’: Contextualizing the Politics of HIV/AIDS Non-disclosure at the Intersection of Place, Culture, and Gender Power Relations**

*“What about me, how do I get married? I am afraid...this is the reason why I won’t tell him because the first man, he already knew my situation and that is why he ran away from me. It is the fear that if I tell my current boyfriend that he will leave me just as the previous one, which is why there is no need to tell him.”- HIV positive woman*

The beneficial effects of HIV status disclosure on access to treatment and adherence both as a policy and practice have been strongly established in the public health literature but as the above quote poignantly demonstrates, most of the HIV positive women understudied seem to have a different experience, a departure from the universalistic and normative conceptions of the positive impacts of disclosure. Disclosure affects not only decisions to initiate antiretroviral therapy but also consistent uptake of treatment (Moyer, Igonya, Both, Cherutich and Hardon, 2013; Winchester, McGrath, Kaawa-Mafigiri, Namutiibwa, Ssendegye, Nalwoga, Kyarikunda, Birungi, Kisakye, Ayebazibwe, Walakira and Rwabukwali, 2013). Nonetheless, despite the clear rationale for partner disclosure and its common use in serodiscordant couples counselling, this practice has yet to become a customary behavior among HIV/AIDS diagnosed individuals in intimate relationships. Likewise, within the policy arena and in practice, HIV/AIDS non-disclosure remains a contentious issue because of the tensions and ethical dilemmas between the obligations to protect the rights and privacy of infected individuals who refuse to disclose versus public health interests; social and gender complexities around who is disclosing and to whom; and complications created by health care workers in the process of enabling disclosure across diverse health care settings (Greary, Parker, Rogers, Haney, Njihia, Haile and Walakira, 2014;

Nnamuchi and Nwabueze, 2013).

With sub-Saharan Africa having the highest rates of HIV/AIDS prevalence in the world; for example, Swaziland with up to 27.7% and Nigeria currently at 3.4% (UNAIDS 2015; 2014), the importance of HIV/AIDS status disclosure in Africa, particularly between sexual partners, cannot be over-emphasized. Partner disclosure empowers individual to seek counselling, testing and diagnosis; and consequently, to initiate access to treatment and care when seropositive (Neuman and Obermeyer, 2013). More than the initial uptake of treatment, adherence to treatment can also be enhanced due to partner and familial support in cases of disclosure. Despite the benefits, disclosure always remains challenging for infected individuals.

Among HIV positive women in Nigeria and other sub-Saharan African countries, a plethora of reasons have been put forward to explain why women do not disclose. Fears of rejection, partner abandonment, and social alienation are reported consequences of disclosure as well as different forms of gender based violence that have been widely experienced by HIV positive women (Okareh, Akpa, Okunlola and Okoror, 2015). While the benefits of disclosure are well documented and the public health risks of non-disclosure are also well known, there remains a challenging and complex social and economic terrain that infected women navigate as they make decisions on whether or not to disclose, a terrain that is less underscored in the discourse of non-disclosure. This section represents an attempt to map this terrain in relation to place, power and gender relations using the evidence from infected women's testimonies. In doing so, it seeks to complicate the most common explanation of non-disclosure identified in the public health literature: namely, stigma.

The central arguments are that foremost, non-disclosure is not always related to stigma and that the practice of disclosure is loaded with other hidden social processes and phenomena that are further obliterated when disclosure is only explained through a single concept and association as with stigma. Stigma is one of the most commonly associated factor and barrier to non-disclosure because it produces discrimination and social isolation of infected individuals, and consequently inhibits their disclosure (Paudel and Baral, 2015; Deribe, Woldemichael, Njau, Yakob, Biadgilign and Amberbir, 2010). Stigma is usually produced from the misperceptions of HIV transmission associated with heterosexual activities. This construction produces moral judgements around infected women who are perceived to have indulged in wanton behaviors often in conflict with expected or acceptable cultural and religious norms. Knowledge of one's HIV status is therefore, usually shrouded in secrecy due to fear of societal rejection from exposure. But while non-disclosure is almost always associated with stigma, such an explanation is too reductionist. It does not do justice to the much more complex dimensions of non-disclosure and other co-occurring factors that shape the terrain of gendered non-disclosure. While perceptions of stigma are certainly linked to non-disclosure, the underlying social structures of particular places that underpin stigma are not always as well documented as they should be (Anglewicz and Chintsanya, 2011; Frye, Fortin, Mackenzie, Purcell, Edwards, Mitchell, Valverde, Garfein, Metsch and Latka, 2009; Yang, Li, Stanton, Fang, Lin and Naar-King, 2006). This study therefore makes a shift from the stigma based theory of non-disclosure by illustrating some of the complex context-contingent conditions that shape disclosure and non-disclosure and where patriarchal gender relations are notably dominant.

The other main argument is that disclosure is both a relational and intersectional process, situated within the relations of gender power and at the intersection of other structural forces. That is, the

will to disclose or not to disclose is not an objective or neutral process as it is sometimes conceived in theory and practiced by health care or social workers who mostly facilitate the disclosure process among infected individuals in ways that cast disclosure as a simple and homogenous process with uniform outcomes especially for women. The forces delimiting women's disclosure embody structural forces of violence unique to place. Coming to terms with such structural violence destabilizes conventional notions of individual agency and choice that are common in traditional HIV/AIDS discourse wherein women are positioned as freely capable of making the decision to disclose or not. These normative forces work in complex ways through the private lives of women such that they are rarely addressed in mainstream interventions and implementation research. Consequently, (non)disclosure has to be understood in relation to their embedded spatiality. By spatiality, I mean the character of particular places configured by socio-political and economic structures. The (non)disclosure decisions of HIV positive women are profoundly contingent on place and the ways in which places embody social relations and interactions. As the evidence from this study also shows, non-disclosure decisions are imbricated within spaces linking constructions of self and social identities. The ways women rationalize their decisions to disclose or not to disclose within these complex contexts are illuminated through the politics of everyday life within and outside intimate partner relations.

In the analysis that follows, I discuss the social and material conditions that transcend stigma which shape women's decisions to not disclose their status to their partners. I draw comparisons between the nuances of partner and group disclosure by illuminating the conditions that motivate women to not disclose their status to partners in private yet do so publicly to a larger group of individuals. Finally, I draw attention to the inherent contradictions in the act of HIV disclosure.

Here, I demonstrate how the practice of disclosure can be empowering for public health goals yet inimical to women's welfare.

Non-disclosure among HIV positive women although intricately linked to stigma, is also profoundly configured by identity, social hierarchy, power, ownership and control of resources particularly in intimate relationships. As a precursor to women's disclosure, identity works in two ways. First, the discursive framings of the disease which socially criminalizes infected women through popular representations of its causal pathways as mostly through sexual promiscuity. Second, women's social and cultural citizenship are defined within the bounds of marriage and motherhood, and HIV is perceived to reduce the opportunities for acquiring such status. These are expatiated on below.

The socially and culturally accepted identities of women, married ones in particular are 'faithful and monogamous'. HIV potentially disrupts these identities with its associated sexual stigma conferring upon women a status that is socially unacceptable, as women with 'spoiled identities' (Goffman, 1963). These women feared that disclosure might produce new but undesirable identities about them in the psyche of their partners with potential negative implications for their relationships. This is the association that stigma has with HIV status disclosure within an identity framework. Women thus find it relatively hard to disclose to male spouses or partners, and consequently delay initiation and consistent uptake of treatment. The translated conversation below among some of the women in one of the focus group discussions captures this well, showing how identifying with this infection not only transforms their self-image but also their public identity which conflicts with the social and moral expectations of womanhood.

*P1: What is there to take pride in? [Referring to HIV/AIDS]*

*P2: You can't talk about it in public*

*P1: As a woman who has honor, who has honor, you can't take pride in it because it is dirty*

*P2: You can't talk about it.*

*P3: Even people will run away from you.*

*P2: Not everybody says it is caused through using needles, they will say you were having indiscriminate sexual relations and a woman that has indiscriminate sexual relations, what do they call her? They say she is a prostitute. So that is why people not infected do not understand because though you see people who disclose, me, I can't talk about it because the popular opinion is that it is through sexual intercourse as people say and mostly women, women who are illiterate [about HIV], they will not understand*

*P4: prostitution, they would say it is sleeping around with other men*

*P2: that's why we hide it....we keep it secret because it is not a good name, it is not a good name.*

This conversation shows how the disclosure of HIV seropositivity implies the affirmation of behavior and identity that are negative and undesired. HIV not only disrupts identity, it challenges the infected individual's self-concept of what it is to be 'normal' or a non-deviant individual (Frye et al., 2009). What is apparent is that women contest and resist these new identities and struggle to stay with the more desirable old identities. It begins to show how individual ability to disclose is embedded within enduring social structures. While studies have alluded to the profound influence of drug availability in the reduction of stigma (Brown, Trujillo and Macintyre, 2001) as diseases take on an unexceptional status and potentially become curable, there is a reversed reality with AIDS. The availability of HIV treatment has not necessarily reduced the social stigma; instead and paradoxically, stigma inhibits the uptake of treatment. This speaks to the exceptional nature of this disease. Though it does not visibly bear identifiable markers of physical deformity like diseases such as leprosy, it carries with it

unparalleled stigma because its etiology criss-crosses socio-cultural lines, moral and gender identities in many spatial contexts including the Delta.

Disclosure is also embedded in the inequalities of gender power and resource control permeated through the personal politics of everyday life in interpersonal and social relations. The decision to disclose or not although enacted through a personal cognitive process, reflects larger structural inequalities that women have limited control of. In the translated dialogue below, the participant is a young unmarried woman in an intimate relationship and the youngest in this cohort of women. She speaks about her fears and insecurities in securing a partner for marriage due to her status.

*P: What about me, how do I get married? I am afraid.*

*EB: But you are in a relationship, so why don't you disclose your status to your partner and educate him about the disease that it does not necessarily kill so that you both can get married at some point?*

*P: this is the reason why I won't tell him because the first man, he already knew my situation and that is why he ran away from me. It is the fear that if I tell my current boyfriend that he will leave me just as the previous one, which is why there is no need to tell him [continues] why do I not take my drugs? It is because I am living with my boyfriend so the day he is at home, I won't take it that day. When he goes to work, I will take the drugs. I do not want to disclose to him, if I do.... Another participant cuts in: if you tell him will he abandon you?*

*P: the previous boyfriend, the one who infected me when he knew that I was now aware of the disease...because I was always seeing the drugs in his bag and then I didn't know what it was*

*EB: did he not disclose his status to you?*

*P: he did not*

*EB: and he was accessing treatment?*

*P: Yes. He did not tell me and he was accessing treatment before I came to know that he was infected. I later told him that I know why you are taking these drugs. After the day I told him, he*

*did not call me again. So I decided that I do not want this present relationship to break up the way the previous one did hence I am afraid to disclose.*

*EB: you are afraid?*

*P: yes*

*EB: if he leaves you can't you be by yourself...or is it that he is assisting you financially?*

*P: yes*

This dialogue not only reveals the social dilemma women face in treatment uptake and adherence but also the economic rationalization and material aspects of disclosure. Psychosocially, the process of disclosure involves a cognitive evaluation of the status of personal relationships, where women assess if their male partner loves them enough to accept their status or not. This is performed in the context of the potential risks associated with the process of disclosure, whether or not their partners will accord them the stereotypes associated with this disease, blame or even outrightly reject them. So there is a perceived level of trust and love in intimate relations that would either determine or motivate women to disclose or not. Men fear to disclose as well as the dialogue reveals, and secondary evidence from the women and health workers' narratives also show this to be true but for a different set of reasons. However, men are not the current focus of this study so that dimension will not be delved into but considered as a future study. In another example, a participant narrates her ordeal of how her she was abandoned by her husband and left to cater to the kids after the husband learned of her status even though he refused testing to know his status when he was asked to.

*“He asked me to pack my things and leave. Since I refused to pack, he now packed and left me. So the children and I remained in the house, later on he said he will not pay for the house rent so I had to pack and leave the house to a cheaper place. It is in this cheap place that I and the children are living now. He does not even care for the children. I am the only who does, it is the farming that I do that I use in taking care of these children, to pay their school fees...the man I*

*had children for abandoned me when I disclosed to him let alone another person. I will not disclose even if I am dying here, if it is what is killing me, I will not disclose. And if at all I remarry, I will never disclose my status.” - (translated) HIV positive woman*

These narratives establish that women who had experienced stigma through spousal abandonment or rejection from intimate partners after disclosure in previous relationships are less poised to disclose to partners in new relationships. There are other similar narratives like the conversation below with another HIV positive woman, one of the leaders in the HIV/AIDS support group at the health facility. She cites the experiences of some women she had worked with.

*P: there was the case of a lady, she is the second wife of the husband and the husband came to her because the wife at home can't produce a child, she was the one doing the production of kids for the man [Case 1]*

*EB: and she is positive?*

*P: she is positive. So when I asked her to disclose, she said she won't try it that the husband is going to run away and abandon the kids for her but we still encouraged her to still try and access her drugs and if she discovers the husband is going down [getting sick], she should bring the husband in so that they can run a test, she accepted doing that and we encouraged her to start accessing her drugs...there is another case of a lady [Case 2]that is positive but the husband is negative and the husband did not know she was positive and she being scared and she does not want to lose her marriage, she does not come to access her drugs. She is on her own because she does not access her drugs*

These conversations proffer profound insights into the power dynamics, socio-economic conditions and cultural complexities that shape women's disposition to disclose or otherwise, and consequently, their uptake and adherence to treatment. Women's refusal to disclose aligns with perceived and actual risks based on a self and social assessment of the potential outcomes of disclosure, and/or prior negative outcomes of disclosure experienced personally or by others.

Clearly, the women who perceive themselves as having a lower status or as the weaker partner in such relationships are less likely to disclose to the more powerful male partner/spouse when they test positive. This perceived status quo creates certain dynamics around access and adherence to treatment but further complicated by the structure of the relationship whether monogamous or polygamous. In a conventional monogamous relationship where a couple lives together, women are less likely to have the privacy of accessing or adhering to treatment without giving out the knowledge of their status when they have not disclosed to their live-in male partner or spouse. The contrary is the case in a polygamous relationship where though married, the woman may not share the same living space with her spouse as exemplified by Case 1 in the third narrative, where the woman might still be able to access and adhere to treatment even on non-disclosure. This is quite contrary to the experience of the second woman in Case 2 involved a monogamous relationship, who refused to access treatment for fear it would expose her status to the spouse. Women generally feel that because of their marginalized social status relative to their male spouses, it is easier for them to lose their relationships and their identities as married women or women in relationships when they disclose to men. As with the woman in Case 1, she would not use condoms because the basis of the relationship is her fertility and reproduction and she needs this bio-social tie to secure her social status and material position with her partner. I provide a context to these sorts of narratives.

In male dominated communities in Nigeria, women's identities and notions of self are deeply structured by patriarchal conventions, tied to their associations with men and conditioned by both religious and cultural laws (Para-Mallam, 2007; Aniekwu, 2002). Marriage and motherhood for many Nigerian women particularly in the Niger Delta, symbolize respect, social acceptance and an increase in social status. For a HIV positive woman therefore, the household can be a site of

security or chaos depending on the choice she makes to disclose or not. She is however, confronted with a narrow range of options due to norms of male privilege and female subservience. In the social optics of society, these options define her womanhood. Most often, the choice to not disclose and retain her married status is more desirable because most women have been constrained to think of self and security within these social boundaries and worse so, if they are materially dependent on these relationships. The following quotes attest that women will prefer to endure hardships or other forms of subtle abuse or violence to remain in a marriage than to be socially outcast as a divorcee or single mother, or relinquish other forms of security. These unfavorable living conditions can sometimes become the only option when women are tested positive to HIV as the following reports from two participants confirm.

*“...women are very patient especially when they already have children in the marriage, they don't like leaving their children, they like unity homes but men, any small thing, they are ready to marry ten, six, seven wives but the woman is ready to stay in one place and stay by the children, she is not ready to be bearing three, four, five husbands. See where the problem lies? That is it.”- Female health worker*

*“... I have a friend that the husband maltreats, he will even lock the door of their home against her but because of her condition, she is HIV positive and the man is not, she said that anything that the man tells her to do, she will do because the man can ask her to leave and if he does that, according to her, it is not easy to get a man so she will have to remain in the marriage and endure.”- HIV positive woman*

Uninfected female spouses as mothers are reluctant to raise their children without fathers. They desire to raise their children within the traditional domain of marriage and conventional idea of family so will stick to an infected male partner. When the woman is the one infected, she remains still because there is nowhere to go so either way, the choices are less for her. This speaks to the tradition of bride price payment in many patriarchal African societies. A woman is

assumed as no more a part of her immediate family once the bride price has been paid so she is no longer welcome home. As long as the bride price remains, she is a property of the man and his family and bound by her marital ties. In the event that she flouts this tie and decides to leave, there is literally nowhere to go especially when she is economically disempowered and cannot fend for herself or children. Fear of loss of marriage, fear of not being able to attract a potential spouse, fear of spousal abandonment and rejection especially where kids are involved, and fear of the threat of domestic violence were the commonly cited reasons for non-disclosure. These social and cultural implications are constitutive of some of the contextual forces in which non-disclosure among HIV positive women in the Delta are negotiated.

Partner non-disclosure is therefore, linked to perceived or anticipated risk, or real risk based on the individual's prior experiences of disclosure or knowledge of the experiences of others.

Women personally evaluate the nature of their relationship vis a vis their partners as part of a risk assessment and benefit analysis where the social and economic risks are weighed against the gains of disclosure. Power distribution between partners, social insecurities, who controls the decision making process, and economic factors like resource ownership and control within intimate relationships are crucial in rationalizing the decision to disclose and this directly or indirectly shapes treatment uptake and adherence. I argue that these individualized assessments of risks though deeply embody individual power relations and identities are a microcosm of the broader social and political-economy structure in most patriarchal and resource limited societies. These macro structures adversely interact with women at a very personal level in ways that render them powerless. This is a dimension of non-disclosure that is obscured in the HIV/AIDS discourse.

Women's socio-economic rationalization within intimate relationships as well as their personal choices and decisions are made within a gamut of available opportunities that are structurally underpinned. With these underlying structural issues unaddressed like the issues of resource access and control by women, and traditional gender structures that undermine women's power and autonomy through the burden of certain social identities that women are compelled to live by, it is not surprising that individual level interventions aimed at improving disclosure have failed. The way the body behaves and the decision it makes on a personal level is usually in consonance with these broader forces. These structural conditions are in constant conflict with women's agency in most developing world spaces (Farmer, 2005; 1999) and this includes the agency to disclose their HIV status to partners without fear of violence in any ramification. Structural violence creates limited to no choices that are not only related to social behavior associated with the rise of HIV/AIDS but also the socially manifested health seeking behavior of affected individuals like the decision to disclose which may determine treatment initiation and adherence. This fact reinforces the relationality of scale which understands women's social behavior through connections to prevailing macro economies and social systems (Faria, 2008).

As with similar observations in other studies (Gillett and Parr, 2010), the HIV/AIDS support network at the Erhoike Cottage Hospital functions as a site of care and support for this cohort of women not only for the psychosocial succor but for access to economic resources. On a gender scale, the disparity in membership with more women than men may be symbolic of more structural underpinnings like socio-economic inequalities that affect more women in the Niger Delta. These inequalities act as push factors for women to join the HIV/AIDS support network. Similarly, membership constitutes mostly uneducated infected women that are less socially and economically privileged. For most of these HIV positive women, the case of HIV/AIDS support

groups as informal financial ports is not in doubt. While incentives to join the group may vary, the HIV/AIDS support group is generally considered as a form of social and economic leverage for many women as the following conversation with one of the group's leaders depicts.

*P: some is to benefit but some, they just want to be part of the family so that they can move on with their lives.*

*EB: so what kind of benefit would that be?*

*P: benefits in terms of what they can have*

*EB: like*

*P: in terms of money...because there are some monies that are supposed to be for the members*

Invariably, existing structural inequalities are transforming HIV/AIDS support groups to emerging therapeutic enclaves within the larger health care domain. These sorts of survival acts by HIV positive women corroborate the accounts of a new form of citizenship espoused by Vinh-Kim Nguyen within the social triage of AIDS care; a therapeutic citizenship where HIV seropositivity is used to claim psychosocial and material resources from HIV/AIDS programs (2010). Given that disclosure is a mandatory parameter for participation in support groups, the gender make up of this group is also indicative of the dynamics involved in group disclosure or 'coming out'. Like partner disclosure, women are not as predisposed to group disclosure and a similar set of risk factors apply but these play out in very distinct ways with differing outcomes. As prior evidence shows, women find individual disclosure to spouses or partners difficult due to the fear of real or anticipated consequences around their social and economic security. When assessed risks of disclosure outweigh perceived benefits, women do not disclose. In group disclosure, women also conduct these same risks assessments yet may feel compelled to publicly disclose to the support group even when they have failed to disclose to their partners in order to gain access to social and financial incentives. Thus, women may find it relatively easier to

disclose in non-private spaces when they do not fear retribution from powerful male partners, loss of identity and social security. From the evidence, it is clear that gendered poverty is also a structural driver and motivation to disclose or not to disclose (see chapter four for a detailed analysis on HIV/AIDS support networks).

Disclosure comes with trust and feelings of personal security and women claim that their perception of the degree of love of a partner towards them also guides the disclosure decision making process. Individual personalities as well as nature of relationships also matter as some of the women claimed. The common practice within health care settings in Nigeria to engender HIV status disclosure post diagnosis thus emphasizes counselling aimed at reworking the fears and insecurities of the disclosing individual. A safe space for disclosure is oftentimes considered as emotionally and psychologically working on couples through partner counselling to elicit a positive reaction from the uninfected partner in the event of disclosure. The positive impact of this practice is acknowledged but this is yet another individual level strategy that subordinates women's fate to the whims and decisions of their male partners as seen from the aforementioned cases where women with no economic power and social leverage suffer a twin tragedy - rejection or abandonment in addition to their seropositivity. They lose their relationships, social identities as faithful married women as well as the economic security that comes with such relationships.

The reported abuse women suffer from their male partners on disclosure calls to question existing program strategies on handling the negative outcomes of disclosure among this already vulnerable and marginalized population. How these women are assisted to move forward and psychologically re-oriented to enable future disclosure despite previous negative experiences such that continued HIV transmission can be halted should form a crucial component of HIV/AIDS programming. As existing HIV/AIDS program implementation by the mainstream

health workers at the Erhoike health facility shows, disclosure strategies are more directed at actual disclosure but less on addressing potential and actual social, emotional and psychological outcomes that confront women when this process goes awry. The following quotes are evidence.

*“We try to counsel them, that is what we do, we try to counsel them and we leave them to their fate.”- Female health worker*

*“I encourage them [women to disclose] ...because when the virus gets serious and you fall very sick, that man that you are hiding your status from, you won't even know when you will disclose to him when things get worse so the best thing is to open up to him now so that he just knows, and if he wants to abandon you, let him abandon you provided you have opened up.”-*

*(translated) Female HIV/AIDS support group leader*

In a society where women are more likely to remain in abusive relationships because of fear of losing social and economic protection, partner counselling as the only strategy to enable safe disclosure leaves women with fewer choices to deal with negative outcomes. While it may seem empowering for women to disclose their status, the outcomes may be disempowering for them yet through the mandatory counselling process by health workers, they might feel pressured to disclose. The will and responsibility to disclose at the individual level can either complement or challenge public health goals.

As demonstrated, women's non-disclosure is contingent on perceived loss of resources from a relationship that they are not socially positioned to receive outside of such relations because of their marginal status. In some instances, disclosure provides access to resources as we see in HIV/AIDS support group disclosure. In others, non-disclosure is perceived as the only means to achieve this end as we see between couples. Therefore, that an individual discloses does not mean this was wholly voluntary if the power of choice to disclose is based on considerations outside their immediate control. Yet disclosure may have to be done to access certain resources

that their citizenship rights should have guaranteed but nonetheless, are non-existent for them. This also calls to question the standard international guidelines of disclosure that stipulates voluntary and consensual (non)disclosure within a legal-ethical framework as deployed in medical and health circles.

International guidelines on disclosure encourage beneficial disclosure of HIV status, which is

*“Disclosure that is voluntary; respects the autonomy and dignity of the affected individuals; maintains confidentiality as appropriate; leads to beneficial results for the individual...and meets ethical imperatives so as to maximize good for both the uninfected and the infected”- (UNAIDS and WHO, 2000, p.6).*

*“Provider-initiated HIV testing and counseling efforts must be made to ensure that a supportive social, policy and legal framework is in place to maximize positive outcomes and minimize potential harms to patients. Adaptation of this guidance at country level will require an assessment of the of the local epidemiology as well as the risks and benefits of provided-initiated HIV testing and counselling, including an appraisal of available resources, prevailing standards of HIV prevention, treatment, care and support, and the adequacy of social and legal protections available...service providers should always aim to do what is best in the best interests of the individual patient. Endorsements of provider initiated HIV testing and counselling by WHO and UNAIDS is not an endorsement of coercive or mandatory HIV testing. WHO and UNAIDS do not support mandatory or compulsory testing of individuals on public health grounds”- (UNAIDS and WHO, 2007, p. 6).*

Sometimes, not all of these conditions are present during the process of disclosure initiated by health service providers especially a socio-legal framework to act as a buffer to the harmful outcomes of disclosure. This is where to “persuade” partner notification by health service providers as espoused by the WHO and UNAIDS (2000, p. 21) can potentially become a double edged sword in particular spatial contexts where less attention is paid to the conditions in which disclosure takes place or what is actually in the “best interests of the individual”. Rather, in many

health care settings, focus appears to be more on the mandate to persuade with less concern on anticipated outcomes. Also within the framework of the above stated guidelines by the WHO and UNAIDS, I draw attention to the difference in the ways medical doctors and other health workers initiate the process of disclosure from the period of counselling, testing and diagnosis.

The reports from participating health workers in this study show that medical doctors advocate for privacy and confidentiality throughout this process citing the Hippocrates oath which is binding on their medical practice to substantiate their claims. On the other hand, nurses and other health staff appear to be less concerned about these nuances and more on the act of disclosure itself but the available evidence does not proffer any explanation to this discrepancy. In the steps preceding disclosure like testing, there are reported instances of pregnant women seeking antenatal care who were tested for HIV but were not pre-informed and neither were their consent sought for fear that most women will refuse to be tested. Among this group of health workers, the rationale is to protect incoming generations from this disease irrespective of patients' informed consent. There is a need to resolve these discrepancies and raise awareness about them.

There is thus a fine line between voluntary and obligatory disclosure and sometimes, this line is crossed with negative outcomes for women. While protecting the right to individual privacy and confidentiality is advocated for in international guidelines, the ethics of disclosure in practice violate the original goal of voluntary consent. Besides the role of health care providers in this regard, the everyday social spaces inhabited by HIV positive women in patriarchal societies compel a form of disclosure that is ostensibly involuntary given the marginal conditions in which such decisions are made. 'Voluntary' disclosure and even non-disclosure motivated by structural inequalities can thus be obligatory when either of these decisions becomes an essential pathway for women to access or retain their economic and social security. These realities necessitate

attention to the process and choices available to HIV positive women in making their decisions to disclose especially in the face of expected risks or threat of violence. The next section expatiates on one of such expected or actual risks of disclosure that is most feared and reported by the women, which is spousal abandonment or divorce, and one that is gradually changing the traditional family structure in the Niger Delta area.

### **HIV/AIDS and the Changing Family Structure: Quasi-widowhood**

The phenomenon of female headed households in Nigeria became observable and common in Nigeria following the adverse effects of the Structural Adjustment Programs (SAPs) as more women were compelled to join the formal economy to meet the material needs of their family. A 1991 census survey on the impact of SAPs on creating female headed households confirmed this trend and shows Delta State to be astronomically high with 32.5% while other states had figures ranging from 4% to 15.7% (Oyekanmi, 2005). Comparatively, Delta State, the site of this study had more than twice the rate of female headed households than the second highest state. While there were no contextual sources explaining these variations at that time, post SAPs explanations for this growing national trend have been attributed to the social and political-economic structures that are now more enabling to female education, with corollary effects on women's increasing visibility in the economic and political space. This is said to account for the increasing numbers of females who aspire to fulfil their own self-destinies irrespective of men (Oyekanmi, 2005). While these reasons proffer a general insight into the broad commonality of the rise of female headed households across the national polity, new data that have emerged from this research as with other place studies may proffer new and further insights into this trend. The data also underscore the fact that these insufficient explanations belie other contributing factors to this

developing trend, distorting some of the negative underpinnings of this shift especially at the micro level.

At the crux of the political ecologies of health and health geography epistemologies is that a critical social analysis of a population's health experience must properly integrate the specificities of place and scale to wholly understand a social phenomenon. Hence, feminist political ecologists emphasize the interconnections of scale and its conceptualization in social and feminist terms to understand how the lived intimate and very private experiences of the feminine body are subjective and political. An example of such interconnection is inferred from Okoko's (1999) study of Ibeno, an oil rich community in the Niger Delta region which details male outmigration and the creation of female headed households as some of the social responses to the negative environmental changes wrought by oil exploitation and gas flaring in the region. Iyang and Udong (2013) analysis of the social impacts of oil degradation in the region also implicates the untold hardship of abandoned wives and mothers who are not only compelled to join the formal economy but have to diversify or take on dual means of livelihood as survival strategies to make ends meet. In both cases, men have been forced out of their communities in search of greener pastures and alternative means of livelihood following the destruction of their ecological environment and traditional means of occupation, leaving behind wives and children. Likewise, high mortality from HIV/AIDS with its rapid spread as a by-product of increased commercial sex work with foreign oil workers is also reconfiguring the structure of the traditional family model where male heads of households have been lost (Udoh, 2013; Udoh et.al., 2009). AIDS mortality and environmental degradation as indirect and direct impacts of the Niger Delta oil complex may proffer additional but also contextual explanations to the high

number of female headed households in the study area as observed in the 1999 national census statistics.

This section also attempts to contribute to existing explanations of female headed households within these broad relations but through the lens of a new and emerging form of female headed households, one that is also linked to HIV/AIDS but rarely addressed in the literature. The obscurity of this typology of female headed households may be due to its place specific nature given its contingencies as well on the oil complex. Data from this study confirms the growing trend of single female parent headed households not only from AIDS mortality but from partner disclosure. I refer to this category of women as quasi-widows because they do not rigidly fit into the more traditional meanings of widowhood but socially experience and cope with the impacts of the disease like conventional widows. Quasi-widows are women who have been physically, socially and emotionally abandoned by their spouses for multiple reasons, and in this case because of their HIV status. They are the products of absentee or run away husbands. Absentee husbands also include men who are physically present with their wives but have socially, emotionally and economically checked out of their spousal and paternal duties and obligations. Quasi-widows may therefore, physically live on their own as divorcees or separated, or live with their spouses as married but still receive no support from them.

In this study, many HIV positive women lamented the absence of husbands either through mortality to AIDS or abandonment due to disclosure of their HIV status. As an interesting paradox, the absence of husbands was cited as one of the major barriers to their access and adherence to treatment when in some instances, it is the presence of husbands or male partners that inhibit access and adherence especially on non-disclosure when women fear they might lose their relationships. The connection between absentee husbands and treatment limitations can be

linked to gender roles and cultural identities where the expectations of men are as providers, and women as domesticated and financial dependents. Undoubtedly as previously analyzed, HIV/AIDS disclosure embodies dire and unwanted consequences for less powerful individuals who are socially and economically disempowered to individually tackle the effect of this disease. And women disproportionately fall within this category.

This analysis elaborates on a major consequence of disclosure for women, which is the disruption of the dynamics of intimate relationships through spousal abandonment, separation or divorce, and other ways this is perpetrated like the lack of economic and psychosocial support within existing relationships as reported. From a policy and development standpoint, I look at how quasi-widows may become vulnerable subjects that are overlooked in interventions through the rigid official designations and categorizations of beneficiaries, and how these conceptualizations through formal texts and languages can become powerful mechanisms for their exclusion or inclusion. Furthermore, I draw attention to the ways in which the individual is theorized as a unit or scale of intervention and their practical implications within the discourse of HIV treatment access and adherence.

The psychosocial implications of HIV/AIDS in the literature include the reconfiguration of the family system and the changing gender roles within it (Bor, Miller and Goldman, 1993). In past studies, changes in family structures were mostly conceived in terms of household composition, shifts in gender roles and dependency burden contingent on the affected family member (Nyambedha, Wandibba and Aagaard-Hansen, 2003, Ntozi and Zirimenya, 1999; Bor et.al., 1993). If the male spouse usually the dominant partner and head of the home is the one affected by the disease, his bodily incapacitation may necessitate the female partner to take on a headship role especially from an economic productivity view point, if she has the ability. The provider

status is swapped as the woman doubles as the provider and caregiver. The decision making structure and process as in most interpersonal relations is thus reconfigured. Economic power can translate to social power vested with some decision making power and privilege. These are the classic documentation in HIV/AIDS scholarship of the disease's impact on the restructuration of the conventional nuclear family unit. Thus mortality or change in provider status of the traditional male heads can culminate in the production of female heads or single parent household formations.

The impact of HIV status disclosure on marital and social arrangements though well documented is less addressed as a problematic development to the broad structure of conventional familial institutions and social systems. I am yet to find any documentation linking HIV/AIDS disclosure to the creation or rise of female and single parent headed households, or what this study has designated as quasi-widowhood. A common form of quasi-widowhood in the Delta is where a woman is legally married into a polygamous union but lives alone and bears most if not all of the financial responsibilities for her immediate family. The 'husband' may show up at will and make financial contributions by his choice. Although this type of quasi-widowhood has implications for disclosure and treatment uptake (as we see in the preceding section of this chapter), it is not always a function of spousal abandonment from HIV/AIDS status disclosure. Under this cultural arrangement, a man can claim paternity to his children at will whether or not he performed his paternal duties. Patriarchal customs automatically confer progeny and lineage descent to the male parent irrespective of the mother's role in being largely responsible for the upbringing of the children. Societal constructions of gender and roles discipline women to assume filial roles. On the other hand, men are provided sort of a pass or an allowance when they shun their spousal or paternal duties yet can claim legal and traditional rights or ownership over children at will.

Filial responsibilities are culturally designated as the purview of women because of their biological anatomies or reproductive nature, and the essentialized notions of care as feminized. While men are culturally ascribed the status of a provider, the social ethos in most patriarchal societies not only engender oppressive conditions of women, these values also foster irresponsibility among men who are not educated or oriented into appropriate forms of masculinity. In this case, such ambivalence in societal standards breeds a crop of men who care less to live up to their provider status. While such male behavior is generally condemnable, it is more tolerated than when women are the perpetrators of such irresponsibility.

There are HIV positive women from monogamous unions who operate as single parents while still legally married but living alone because they have been abandoned or separated from their spouses. In other instances, these women have been rejected and divorced. In both cases, these women are quasi-widows as a result of their HIV status post partner disclosure. Cultural expectations and gender roles in these societies position women as vulnerable subjects, and HIV/AIDS compounds these vulnerabilities. With women's economic security tied to male identities and associations, women who test positive to the HIV exist in more precarious conditions as victims of spousal abandonment. Thus many of the HIV positive women lamented the absence of their husbands as a major reason for the lack of access and adherence to treatment. The following statement by one of the HIV/AIDS support group leaders presents a practical scenario of how HIV quasi-widows experience treatment challenges due to spousal abandonment.

*“Most of them that you are seeing stopped to take their treatment due to not being able to provide for themselves in terms of their husbands running away after [the women] disclosing their status. So they have not been able to provide for themselves in terms of how to care for their own personal needs and there is no way they can take the drugs like that without something*

*to eat and no work for them to do. They don't have work to do, they don't even know how to go about most of their own personal activities and some, [these are] some of the problems we encounter here as the executives of the support group [and] you see some, they complain to you in terms of their home rentage, how to pay their rent, they don't really have that, they don't have it. Then some, after losing their husbands, they don't even know how to go about anything anymore." - Female support group leader*

Quasi-widowhood also exists in marital relationships or the traditional family structure where both spouses are living together in the same physical space. But despite the physical availability and presence of the male spouse in the home, he abandons his provider status and other social responsibilities. The woman is thus conditioned to take on both the financial and filial responsibilities that include the husband and the kids (in addition to her personal care which is mostly relegated in the scheme of things) in a struggle to outwardly keep the traditional family unit together. This arrangement enables her to maintain her marital identity and retain a father figure for the children, even if it means a fatherhood that lacks substance and materiality.

Consider the following dialogue in my interview with one of the women.

*EB: so what about those still with their husbands, do you think that gender issues or relations, say the way men and women relate to each other will make women face more challenges? [This question has been cut short for brevity]*

*P: I will say yes*

*EB: in what ways?*

*P: I will use myself as an example. Even though it was my husband that infected me and he is supposed to feel sorry, he still doesn't feel sorry, he still has the full belief that even if I leave today, someone else [another woman] will come in, you understand? And my kids, I can't say I am a single parent because I don't just want to accept it but most of the responsibilities fall back to me*

*EB: but you people are still married?*

*P: yes*

*EB: but he does not take care of all that?*

*P: he does not, it is only when he maybe, how will I put it? When I get really pissed off and I try to leave the house for some time, that is when he knows he will understand, that is when he knows that he has a responsibility to do. But immediately after that, if I return back to the house, he still does the same thing, so they [the society] will tell you, “na you born the pikin” [this is in pidgin English but directly translated as “you are the one who gave birth to the children”] so it is your responsibility to take good care of them and make sure they are comfortable and you know, every woman, there is no woman that will say after having your baby, you can’t even provide what that woman [you] wants for him or her, you know, you will want to do everything to make your kids comfortable and even without the man’s help because you cannot abandon your own children*

*EB: is this something relating to maternal instincts or women as caregivers as opposed to men who feel that the responsibility of taking care of children is actually the women’s?*

*P: yes, yes*

*EB: so how does this conflict with your accessing treatment?*

*P: like my husband will not even give me money to come pick up his [HIV] drugs, even transport [fare] he won’t do it. I am the one that does that and I am the one that ought to pick up his drugs, the only thing he will tell me is, thank you, that is just it.*

*EB: and not that you have so much [money]?*

*P: no [but] I will have to, it is a must, I will have to do it because I will want him to still stay alive for the kids.*

This dialogue aptly and holistically captures the extra burden placed on HIV positive women who are already by default vulnerable because of harmful patriarchal customs and cultural misconceptions of care and responsibilities. HIV positive women are conferred with a dual socio-economic burden; acting as providers to their families in the absence of male responsibility while navigating their health challenges. With women’s disclosure of a positive HIV status, the household or family becomes a contested site of power and negotiations, transforming the family dynamics such that existing hierarchies are reproduced in ways that a subservient partner

becomes even more powerless. The family system maintains an external traditional structure yet inwardly embodies new forms of intra-household dependence and familial relations.

Women may exist as heads of their households but usually, this does not shift the balance of power towards them but may push them further down the ladder of vulnerability. While their provider status may equip them with some bargaining power in some instances, they remain trapped by local customs. They must remain submissive to male authority to maintain their identities and home. In patriarchal societies where the public and economic space is mostly regarded as an enterprise of men, HIV positive women as heads of households are doubly challenged with having to source for resources to meet their new financial responsibilities.

The social dislocation of the family structure transcends the couple to constitute a triad impact as children become pawns within such spaces. Sometimes, the offspring of such families share breadwinning responsibilities when their mothers are unable meet up with financial obligations. Children thus become products of the conflicts and tensions that disclosure brings positioning them in a space of risk and vulnerability. By extension, these versions of the family system expand the vulnerable population of HIV incompetent individuals. These types of vulnerable subjects within this reconfigured family structure - usually women (and children) are often outside the radar of interventions as they do not neatly fall within the traditional definitions of widows. Nonetheless, they experience the social and economic burden of the disease in relative ways and sometimes more. These are infected adults who need care for themselves yet burdened with providing care for their spouses and children while grappling with impoverished and austere conditions.

Usually, HIV/AIDS interventions focus on social welfare programs for conventional widows because this category of women falls within the official definition of widowhood. Not aptly defined, the operationalization of the term, “widows” by the UN Women and other international organizations (see Thomas, Park, Ellingen, Ellison, Menanteau and Young, 2011; UN Women, 2001) show conventional forms of usage. Quasi-widows, who can claim legal marital identities, yet suffer multiple vulnerabilities fall through the cracks of such interventions because the marriage space and formal associations with a male partner as perceived conditions for social and economic security veil their true conditions. These women within the intervention paradigm are placed in a space of limbo because they do not clearly cut the picture of widows or similar classifications of vulnerable HIV adults. Their vulnerabilities are further obscured within the discourse and practice of HIV/AIDS interventions as adult vulnerability is usually conceptualized in terms of risk of transmission and not in treatment as a challenge (see Onwuliri and Jolayemi, 2006). At the country and possibly at the global level, the needs of HIV quasi-widows are excluded from interventions since most program and funding decisions are derived from official designations of programmatic areas.

This knowledge underscores the need to target HIV/AIDS programs at the family unit as a social system and not isolate programs at the level of the affected individual only. Presently, HIV/AIDS interventions target the community as a social system through awareness campaigns and other stigma related programs. Where the scale of intervention is the family unit, it is mostly in the practice of counselling sero-discordant couples prior to testing, diagnosis and disclosure and not the long-term undesirable social effects of the impact of disclosure on the family’s dynamics. Couple’s counselling is evidence of the growing recognition of the family especially the nuclear

unit as an important scale of intervention. Still, couples therapies need to be holistic to include all other psychosocial and material aspects of the family.

Clearly, these findings present another gap in HIV/AIDS interventions which is the lack of social workers and psychotherapists as integral part of the biosocial model of intervention that this study advocates. Women do not only deal with the material conditions of their status, they also have to deal with the emotional and psychosocial impacts especially in situations where their disclosure disrupts their normal social functioning and intimate networks. But there is little around coping strategies for women to reduce these social stressors whether as conventional widows or quasi-widows within and outside of marital relationships. Many of these women had expressed a range of emotions from regret, self-pity, anger, hate and bitterness given their situation. A common characteristic of these women is that most do not have any form of psychosocial support because most of them are isolated emotionally within and outside their marriages. To facilitate HIV women's access and adherence to treatment, micro level interventions must be restructured to focus on the family whether through theoretical research of a psychosocial nature or through policies that focus on the personal and intimate forces that may affect care. It begins by reconceptualizing a HIV positive woman in treatment, first as a social being, and second, as a unit that transcends her autonomous being but as part of a larger constituency. Women's narratives of the barriers to treatment are proofs that addressing negative intra-households shifts and dynamism will greatly enhance uptake and adherence to treatment.

### **The Intersectionality and Relationality of Treatment Access and Adherence**

Throughout this chapter and the preceding one, HIV positive women's personal experiences have revealed that the vulnerabilities that confront their access and adherence to treatment are multi-dimensional and relational in nature. Women's multiple vulnerabilities have been

evidently linked with relations to other social bodies, structures and other forms of institutional power, thus challenging orthodox notions of gender as an independent phenomenon. This is the crux of the relationality and intersectional approaches which prescribe alternative analytical gender models that are able to link bodies and institutions, and other forms of social production that can explain the complex experiences of gendered health (see Connell, 2012; Hankvisky, 2012; Springer et.al., 2012; Cornwall, 2002). This is the overarching theoretical lens that women's access and adherence to treatment is approached from by this study.

Specifically, the intersectional approach eliminates the limitation of using gender as a single category of analysis in constructing the differential experiences of health between the sexes. It opens up possibilities for the consideration of other social dimensions and axes of individual identities that can explain gendered health patterns; for example, the axes of social power, age, and wealth. In this section, I put this framework to use to re-demonstrate and reinforce the need to depart from monolithic understandings and expressions of women in policy and health research. Utilizing knowledge produced from HIV positive women, this section emphasizes that among a seemingly homogeneous gender group, individual expressions of women can be as varied as the number of women. Similarly, individual women possess socio-demographic markers that produce differentials in their pattern of access. This section considers how class, socio-economic hierarchy, age, marital status, occupation and religion can reproduce wider social and health inequalities even among a 'similar' group of women accessing same intervention resources. I limit analysis to these demographics because they are what emerged from the data. I also discuss the implications of the evidence for policy and theory.

Though much of the evidence on women's poor access to treatment and care mostly implicates systemic forces, there are non-systemic and micro level factors that may extenuate access. These

are individual level identities, though intrinsic to one's being are lived and experienced in social ways. For example, age which qualifies our biological cycles can become significant to one's 'life course' - a sequence of social events that individuals perform through time - and can greatly shape the optics through which we view and perform life. In health interventions, particularly access to HIV/AIDS resources, age may shape how individuals negotiate decisions in respect to their uptake e.g. antiretroviral drugs. Within this cohort of HIV seropositive women, younger women seemed likely to initiate early onset of treatment after testing and diagnosis; they reported more access; and are also more likely adhere to treatment than older women.

In the two focus group discussions conducted which are: women living with HIV accessing treatment/adhering, and women with irregular access and adherence to treatment, the demographics of women in the first group were favorably inclined towards younger women. All the older women participants featured in the second focus group. This pattern was also confirmed from health workers' interviews and the responses of the older women themselves who claimed they had "lived their lives" and closer to their graves, so there was not much compulsion to initiate and regularly access treatment or adhere. The older women expressed sympathy for the younger women who they perceived were compelled to access treatment and maintain adherence because they had their whole lives ahead of them as these women had only just begun their life's course. These claims were confirmed in the first focus group with women that have better access and adherence, women that also happened to be much younger. The younger women tied their struggles to access and adhere to treatment despite the prevailing obstacles to the need to live long to fulfil their dreams which includes getting married for the single ones, and staying alive to cater to their children for the married mothers.

Age as a demographic factor also co-occurs with other social identifiers like economic occupation that mediates individual access and adherence to treatment. Farming was co-constructed with non-adherence to treatment. Women especially the older ones considered farming as a means of livelihood not sustainable with access as it does not bring enough remuneration to afford consistent access; and adherence because of the strong side effects of the drugs on the body. Yet for some of the women whether young or old, farming represents the only income generating source and means of accessing HIV treatment and care, and we see this connection in the quote below. An elderly woman speaks in my native dialect, Urhobo. This is a direct translation.

*“The thing that prevents me from taking this medicine, is it still not the issue of money? Money is still the issue we are talking about. You can work and work so hard in addition to the sickness, plus the fact that there is no husband. The husband died and left me with children, the children they go to school and I can’t leave them to stay at home, then came this sickness and the husband has died and left me with these children. And I work so hard doing this farm work and I have even complained to the doctor that this farm work is too hard for me and I am tired of it and it’s not as if one even sees the money. And the doctor asked me if the farm work is the only thing I do and I say yes and that the farm work is the only thing I do as I do not yet have money to begin a trade and it’s now even making me lean (lose weight). If the government can give us other jobs and even with little salary because the farm work is too stressful and hard.”- HIV positive woman*

Another elderly woman again speaks in Urhobo dialect and this is also directly translated.

*P: It is what she is saying [referring to the previous participant above] that I will still say because it is still money that makes me not to come access my treatment. And sometimes, it is hunger. I don’t see money to buy food and my body does not want any strong work or hard labor but it is still the farm work that I do.*

*EB: but is that hard labor?*

*P: Yes, when I do small farm work like planting and uprooting cassava to make food available to eat, but I don't have the strength to continue working so I sold my farm so I don't see money for transportation [to come pick up drugs].*

For elderly HIV positive women especially those widowed with no financial support, they are confronted with a twin crisis of having to fend for themselves and children, and maintain an agrarian livelihood that is no longer sustainable with their age and current health status. These women barely make enough to eat and survive despite the hard farm labor because the lands have also been degraded. This is a two way relationship; the virus weakens the body and the body is no longer able to biologically function to be economically productive. Nonetheless, to be healthy and economically productive they need to take the drugs but can only do so by engaging their weak, impoverished and food-deprived bodies in a form of economic production that is no longer compatible with their present biological status. The situation is further compounded with food insecurity and lack of nutritive diet. With no food, even with the drugs, they are not strong enough to continue to engage in a livelihood that will enable them sustain uptake and adherence. This is a complicated narrative and emblematic of the nature of health as a phenomenon. That is to say, the categories of intersecting forces that mediate individual health outcomes are not stable but fluid and nuanced. The above narratives also evidently demonstrate the biosocial nature of disease and the need to construct health through a biosocial lens. They also underscore the importance of understanding the biological body as ultimately unstable because it is in constant interaction and tension with social forces.

These testimonials also call for careful and special consideration in HIV/AIDS intervention programs that feature empowerment schemes and skills acquisition for local women. The agrarian lifestyle generically associated with rural women in the Delta is not always a thing of choice especially in the contemporary political economy of oil. Sometimes, local women are

constrained to seek alternative livelihood strategies in other places due to the difficulty of relocation especially with child care, thus are restricted to making choices from a limited range of labor opportunities. Both women in question expressed a lack of agency in shifting to or creating other forms of livelihoods more suited to their current health needs. As with most nature-society studies that feature the rural-urban dichotomy, women are usually more economically disenfranchised because they have fewer means of livelihood and sustenance depending basically on agricultural production which given the current oil and environmental climate in the Delta, is under performing. Some other means of livelihoods, for example, hairdressing was also considered risky and a potential pathway of HIV transmission by women in this skilled profession because of the tools involved like needles. For one of the participants who had acquired hairdressing skills through professional training, she had to quit this line of occupation to search for more viable options. In other words, there is limited wage work and issues around sustainable livelihoods that affect treatment uptake and adherence which are not always visible, and therefore, not systematically addressed.

Other individual level forces or social demographics that can also create disparities in HIV treatment access and adherence include marital and partner status, religion or faith, and class hierarchies have been featured in earlier analyses in this chapter and the preceding one. To reiterate, similar patterns of differential access and adherence to treatment were shown to exist among women living with their partners; and among women without partners or with partners but not living in the same household. In other words, women who had failed to disclose to partners but living with them showed lesser chances of access and adherence. Also, previous analysis in chapter three highlighted the discriminatory patterns of access between poor HIV positive women and those perceived to be of higher social standing and economic means. For

example, we now know that among HIV positive women, social relations are experienced differently at the public scale as we see in health workers positive treatment of seropositive women with class privileges and vice versa; and also poor experience of treatment access and adherence in intimate relations for less privileged women.

At the intimate level, local discourses of empowerment by women are indicators that with improved socio-economic standing of HIV positive women, the relational dynamics in the household space can be positively impacted even though gender inequalities may still be present. This study has shown that although gender and social identities may negatively impact many women in patriarchal societies, the degree and extent to which these inequalities are experienced are contingent on the class locations of individual women.

The evidence reworks the often conventional assumptions of health research that hold other social factors constant while rendering gender as the only analytic category for understanding health variabilities. The intersectionality perspective transcends gender as a single concept or explanatory variable of health inequalities. Instead, gender is only one lens through which we can view health relations. These other identified social forces however, do not completely displace gender as a central category as some intersectional studies have emphasized (see Doyal, 2009). Rather, a deeper and critical analysis of these factors - age, livelihood, marital and partner status, and socio-economic status - not only indicate connections to gender but show gender as a very active influence on how these variables work. In other words, gender as an analytic variable sometimes works through these categories to produce difference just as these forces also work through gender. Among some women, for example, gender as variable might be active or appear redundant in producing health inequalities, while other social factors like race take primacy.

Nonetheless, gender relations and its affiliation with the social and cultural still remains a critical point of entry to understanding how women in patriarchal societies experience treatment.

Power in patriarchal societies is usually permeated through culture and social structures; a gender lens remains crucial in the ways we understand these relations given the evidence from this study that women's bodies continue to remain a site of marginality and power because the very essence of patriarchal inequalities gain material expressions through feminine bodies.

Recognizing this reciprocal relationship between gender and other categories of analysis therefore, informs our perspective on how we design studies on gender health. To gain a comprehensive knowledge of how HIV positive women negotiate the treatment terrain is to understand the collective and interactive effects of gender and other intersecting social forces.

## **Conclusion**

The analysis presented here constructs the concept of health needs as very diverse but also nuanced and tied to the unique social identities of the subject of interventions. It eliminates the general assumptions about the generic nature of women that are sometimes invoked in interventions; women as a monolithic and often rigid body. It suggests that the framing of women's health needs must represent the social diversity of the particular population besides gender. It is also a direct contradiction to policy assumptions that the provision and availability of health technologies e.g. antiretroviral treatment guarantees effective or uniform access especially among a gender population that appears to be homogenous. The subjects' social positioning matter in defining agency and access to treatment. By relating evidence to policy therefore, this type of gendered knowledge helps to pinpoint and locate the finer lines of intervention.

Translating theory into practice is one of the hardest aspects of action research. I acknowledge the challenges in attempting to mainstream a diverse range of individual level socio-demographic factors of recipients when designing interventions. Yet, such specialized knowledge can be beneficial as a guide to policy planners and programmers. Insights of this nature enrich and diversify knowledge and policies, at the same time help to retain the local and context specific themes that can be effectively utilized at all scales of intervention. The findings here thus accentuate the importance of utilizing both the relational and intersectional perspective within a place specific context; yet emphasize the need to understand specific details or the peculiarities of the individuals within it. The next chapter illustrates the many ways women negotiate the barriers to treatment access and adherence that have been highlighted in this chapter and the previous.

## Chapter Five

### Negotiating Support: On the Challenges of Realigning Interventions with the Needs and Coping Strategies of Women Living with HIV

#### Introduction

The meeting place of the Courage HIV/AIDS support group although located in a remote corner on the grounds of the Erhoike Cottage Hospital, occupies a central place in the lives of the HIV seropositive women investigated for this study. This place exemplifies many things but more than anything, it embodies hope and survival for the many who have turned to it; mostly women.



Figure 11: The Courage HIV/AIDS support group, in Erhoike Cottage Hospital

As I sat in one of the meetings held by this group, it was a deeply emotional experience for me as I saw a diversity of people about twenty in number whose only similarity may lie in the infection that they shared yet forging a common cause of survival, hope and fortitude. I struggled between my emotions as an individual and my positionality as a researcher; it was hard to strike such a balance and maintain a good composure at that meeting. This was a moment of reflexivity as I began to be aware of my feelings and position of power, and how they could potentially bias the

production of knowledge which I wanted to be grounded in the voices of these women, and not my feelings of what I think their circumstances or lives should be or could have been. On the other hand, I was confronted with thoughts on the ways I could channel these emotions in positively ethical ways that could be beneficial not only to the research process but these subjects I was studying.

In that moment of critical reflection and emotional negotiation, I was also deeply aware of my positionality as an insider privileged to share in the feelings and experiences of these women who for most, did not choose their present circumstance but as an outsider because I could not share in that major bond that brought and held them together, their seropositivity. Yet, our lives were intersected as women who embody the same history, place, and social processes that privilege male power and which this research has come to challenge. While this seemed a weak moment for me as my academic training and prior professional experience had not got me prepared with the skills to effectively navigate this uncomfortable terrain, it was also a powerful one as I observed the strong psychosocial and emotional support that members of the support group rendered to each other.

From the testimonies shared by members at the meeting who were mostly women (only two males), it was obvious that these patients relied on each other for strength and psychosocial support especially through personal stories of how they navigate the daily challenges of life that their seropositive status presented them. These stories were motivational for others to remain strong. There was also a poignant and palpable feeling of hope, personal resilience and strength, and a belief that things will surely get better with them. There was also, a lot of mention of God, faith and miracles (Christian faith to be precise) and those who believed that they could be cured

someday and those who held on to faith and hope in God that they will make it through their current predicament despite the challenges that they were daily faced with.

A health talk was given by the two leaders of the group (also HIV seropositive women) and then feedback was elicited from members' on their health and welfare. Some members complained of drug side effects, the drudgery of taking drugs for the rest of their lives, issues of disclosure and financial challenges around coping with the virus and other reasons for non-adherence. Members were counselled on these issues and encouraged by the leaders to stay in good health by adhering to treatment. For many women, this is what the Courage HIV/AIDS support group embodies for them, an informal alternative resource and care space within the official HIV/AIDS intervention landscape. It is the reason this group has become the major pathway for many women to negotiate the challenges of living with HIV which include the constraints of treatment.

Chapter three and four already described in detail, the barriers facing women's access to treatment and the associated challenges to adherence. This chapter addresses the ways women negotiate them, if they do. In making sense of the ways that HIV/AIDS support groups have become critical alternative care circuits within the HIV/AIDS landscape, the weaknesses and limitations of current HIV/AIDS interventions are exposed. The push-pull factors to the HIV/AIDS support group are not only reflective of the unmet treatment needs of women living with HIV; they reveal the absence of resources from the formal health care space to meet these needs. The weaknesses of current HIV/AIDS programs are also illuminated by women's own perceptions of treatment and care within mainstream interventions, and their conceptualizations of access. Overall, an overarching argument this chapter makes is that interventions are often out of sync with the needs of women living with HIV with three notable kinds of disconnect - structural, ideological and substantive. In other words, current interventions do not really mirror

the realities of women that are underpinned by structural factors. Similarly, the ideologies or conceptualization of interventions like needs, access, the exceptionalism of HIV/AIDS interventions and what it means for women, and the implication for health service access at the grassroots are not always in sync with institutional framings. Consequently, actual tangible resources that accrue from these interventions do not always address the needs of these women.

Such disconnects mandate women to make ‘irrational’ choices detrimental to their individual health and counter-productive to public health goals in the quest for alternative care and resources. Yet these choices become rational within a framework of limited or restricted opportunities. The evidence demonstrates that women do attempt to negotiate these barriers but most of these attempts are not sustainable on the long term as they are more individualized rather than structural or systemic changes. Although women resist the challenges in multiple ways, it is important to note that their abilities vary according to their particular social and material conditions. The coping mechanisms outlined in what follows are therefore, not universally applicable to all women living with HIV. This chapter also foregrounds the heterogeneity of coping strategies and the varied ways that they are deployed to negotiate the barriers to treatment and the uneven social and material conditions that shape their selection. This chapter proposes a more participatory grassroots framework and meaningful involvement of HIV subjects to determine their own interventions.

This chapter begins with an in-depth analysis of the Courage HIV/AIDS support group, an informal arm of the HIV/AIDS intervention network as the most significant coping outlet for the HIV positive women understudied. Although underfunded and not adequately empowered to tackle the weight of social and health responsibilities that it has come to assume, the Courage HIV/AIDS support group has borne these responsibilities because of the criticality of the needs

of women they support and manage. The operative scope of this network has undergone an informal expansion and transformation, unintentionally reshaped by the nature of the needs of HIV positive women. Given the emergence of HIV/AIDS support networks to originally provide follow up services to patients to ensure strict compliance with treatment protocols, I draw attention to their reconstitution by broader social and material forces, their mutually constitutive relationships with the women they support and the broader treatment landscape. The evidence provides the basis for the argument that the nature of HIV/AIDS support groups in patriarchal settings are essentialized and deeply rooted within discursive productions and broader structural imbalances of the society against women. In other words, besides the prevailing social structure of the larger society that has reshaped the practices and kinds of services offered by this organization, its internal dynamics are also shaped by cultural discourses around how femininities and masculinities are understood and practiced, and other class based inequalities.

HIV/AIDS support groups can thus be considered informal institutionalization of the care needs of HIV positive women that are affective, social, and materially expressed but less underscored within the mainstream intervention system. Ironically, while these women are burdened with the responsibility to care for others due to traditional social institutions and mostly unspoken gender expectations, their care needs are not formally centralized within institutionalized health care systems. Due to the transformative power that this organization wields which transcends the medical lives of HIV positive women to positively building more competent HIV/AIDS communities, it is recommended that HIV/AIDS support networks be better integrated and formally institutionalized as an officially funded component of the Nigerian HIV/AIDS intervention network.

In addition to support group networks, the sections on “individualized pathways and coping strategies”; and “the culture of blame” also delineate other identified pathways for negotiating the barriers to HIV treatment access and adherence but underscore institutional irresponsibility and a culture of individualizing health responsibility as significant to the choices women make in attempting to cope with these barriers. Religion is identified as the second most important coping pathway for women living with HIV. Hence, the intersection of faith and HIV/AIDS is underscored in this analysis as well as the implication for individual and population health. Based on the narratives of the women, a fundamental argument is made that the negotiation of access and adherence should not be conflated with being empowered and a successful self-management of the situation. These women are not utility maximizing economic agents or the fully responsabilized biocitizens imagined in accounts of neoliberal and advanced liberal health citizenship (e.g. Rose, 2001).

These women do not operate from a vantage position of power, control and choice. Rather, they contest the challenges they face from a position of vulnerability and within an all too limited range of choices. They develop resilience to survive especially unfavorable conditions. This lack of recognition implicit in health workers narratives and sometimes policy stakeholders as discussed in these sections, I argue mis-conceptualizes and oversimplifies the terrain and conditions these women navigate to cope with these challenges, and erroneously over exaggerates their agency. To explain why this critique matters, I explore how the concepts of institutional responsibility and individual agency function as a relay of the blame-the-victim culture associated with HIV/AIDS. This is a culture that places the fault of infection at the level of the individual. This social misconstruction of individualized infection not only obscures the

structural underpinnings of the disease, it also absolves institutional obligation while transferring the burden of care to sufferers deeply exacerbating their vulnerabilities.

In the following section, attention is drawn to women's perception of HIV/AIDS programs and how their assessments and articulations of the weaknesses and strengths of interventions provide profound insights about the nature and utility of HIV/AIDS intervention resources from a user perspective. They proffer alternative ways to strategically rethink health service provisions in locally appropriate ways. Alongside women's critiques of the limited social resources from interventions, they also implicate the exclusionary practices of state and non-state actors. They blame their unaddressed needs on the disconnect between them and donor agencies, between the nature of their needs and donor priorities. They argue for a more inclusive and active involvement as well as direct access to policy stakeholders.

The need to foster a participatory approach and a more meaningful involvement of women living with HIV is also reinforced through the narratives of women on the paradox of HIV/AIDS exceptionalism in this chapter's final substantive section. Common global policy-making definitions of exceptionalism are normally directed at the disease specific response to AIDS and the overwhelming focus of research and funding this pandemic has experienced over time relative to other diseases. In a sharp contrast, women's accounts demonstrate that exceptionalism does not only lie in the abstract, it is a lived experience in how their bodies have been socially marked and treated differently because of how HIV/AIDS continue to gain media exceptionalism through negative media rhetoric considered to foster fear and stigma around victims.

HIV/AIDS exceptionalism, although a global construct is therefore experienced in deeply personal ways. It signals the relevance of scale and the discursive dimensions to elitist debates on

exceptionalism and normalization and the need to marry both local and global discourses around them for policy decisions. HIV positive women's experiences and interpretations of these concepts add to existing evidence that exceptionalism is not a static concept but fluid and spatially contingent. As a result, the current debates on exceptionalism must be embedded within spatial contexts to include local responses and impacts which may not all be positive but not as a unilateral global enterprise as it currently exists. In each of these sections, the lessons learned for policy and scholarship are highlighted.

### **HIV/AIDS Support Networks as Emerging Spaces of Therapeutic Citizenship**

In previous chapters, women's experiential accounts of treatment had established that the convolution of barriers that challenge their access and adherence are best understood within a non-biomedical and structural framework. Analyzing and interpreting individual risks within a structural framework may preclude the assumption of individualized coping strategies or negotiations around these barriers. On the contrary, women's testimonies demonstrate a quest, acquisition and development of survival strategies albeit within a narrow range of choices and opportunities. A crucial survival mechanism identified by these women is finding support through social groups and supportive HIV/AIDS networks, and entering a space of belonging with people of shared interests and other commonalities. A significant push factor to the HIV/AIDS support group as an alternative health recourse was reported as dissatisfaction with the nature of current services both medical and social procured through the main health facility. First, women strongly critiqued the overemphasis on drugs at the detriment of other social and economic considerations that challenged their uptake. Secondly, social services like counselling are deemed to be sub-optimal within the main health facility; a space also perceived as hostile,

unsupportive and unwelcoming to patients due to health workers attitudes. Secondary provision of some of these services was credited to the HIV/AIDS support group.

Women living with HIV and even policy stakeholders branded HIV/AIDS support networks as the most significant channels or media for negotiating treatment access particularly adherence at the facility level but a deeper analysis reveals other less visible motivations and forces that are non-facility based but complicit in a larger socio-economic framework. With most participants lamenting existing interventions as impersonal and unsatisfactory because of the poor attitude of health workers and unmet psychosocial and economic needs respectively, HIV/AIDS support groups have become bastions of alternative care providing more than social support to HIV positive women. Invariably, the existing gaps in what has become the standardized model of health care transform support groups to alternative care enclaves within the larger health care domain.

From personal observations and reports from HIV positive women, the support group designed as an informal and miniscule entity within the larger official HIV/AIDS intervention framework is in actuality very multifaceted in its operations because of the broader forces that have come to shape its form. Although having a semblance of simplicity in the services they render, this group is a formation of a myriad of complexities that range from the nature of/and motivation for membership to issues of social identity, gender and class dynamics. A critical appraisal of this network's activities, funding and organizational structure is pertinent to further advance our knowledge on their role and importance in the formal HIV/AIDS intervention space despite being officially external to it. In tandem, this section also elucidates the different ways this group transforms the lives of 'unhealthy' subjects and positively alters the present health landscape. We also see how this network provides the missing but important nexus between the gendered bodies

of HIV subjects as both biological and social within the framework of HIV/AIDS interventions. Reported positive impacts of this group which are documented below intensify the need to strengthen their capacity and service delivery, in addition to expanding and officially institutionalizing the network's coverage at the grassroots.

Although a formally recognized network with a non-profit structure, HIV/AIDS support groups are an 'unofficial arm' of the Nigerian HIV/AIDS intervention chain. As such, there is no mandated and official funding plan for this network through conventional state or non-state funding systems and sources. At best, more established support networks usually at the national level are able to independently attract funds from donor agencies to help coordinate their activities and assist local support groups registered with them to achieve prevention, comprehensive care and support for people living with HIV/AIDS (NEPWHAN, 2013). In contrast, most grassroots support groups are unable to attract such mainstream funding except as secondary beneficiaries of donor resources channeled from NGO programs to them as domiciliaries of health facilities. As a case in study, the Courage HIV/AIDS support group domiciled in the Erhoike Cottage Hospital (ECH) is on the verge of extinction because of such financial challenges. The consequence of this will mostly be felt by women whose access and adherence to treatment are contingent on the support they receive from this group. Given the performativity of this support group and the social resources they generate for the underserved HIV positive population, it is safe to argue that the group's exclusion from the central HIV/AIDS funding structure is a huge omission and a flaw in the HIV/AIDS intervention framework in the Nigerian context. Reason is, these networks over compensate for the overly biomedical paradigm of most HIV/AIDS programs as the evidence subsequently reveals. HIV/AIDS support groups

complete the intervention chain in remarkable ways by taking on a more holistic and comprehensive approach to health service delivery, in particular, treatment access and adherence.

By default, these networks operate the biosocial model of health (NEPWHAN, 2013) that critical health theorists have long agitated for. While there appears to be a general recognition of the importance of social support to people in HIV treatment and AIDS care by the mainstream Nigerian HIV/AIDS intervention as expressed through the presence of these networks in most treatment facilities, this importance is undermined by the lackluster approach to the networks that provide these services. For example, the Courage support group mostly independently incurs the economic cost of the social health services they provide with the group's leaders (all HIV positive women) bearing the burden to provide forms of care that extend beyond their original jurisdiction and mandate because they have become personally invested in the lives of the people they support over time. As this case study reveals, services rendered by this group which can be broadly categorized as both tangible and intangible are mostly acts of expedience in response to the unaddressed needs of HIV patients procuring mainstream health service through the health care facility. With depleting funds from the parent health facility where they are domiciled and from existing donor sponsored NGO programs, the support group leaders have sometimes been compelled to personally bear the financial cost of supporting their distressed members.

The Courage HIV/AIDS support group by original design was established to follow up HIV patients already in the line of treatment, offer counselling services to newly diagnosed patients, follow up on treatment adherence, conduct community based awareness programs through which testing, diagnosis and referral are target goals. While most of these services are treatment based (as an end goal), the reality and magnitude of members' challenges have inadvertently broadened the scope and depth of their outreach and services to the provision of more social services. As an

example, the HIV positive women contrasted and characterized the quality of services received from health workers and support group leaders as dispassionate and empathetic respectively. More so that dissatisfied patients always sought the counsel of support group leaders after being attended to by health workers. The general level of mistrust between patients and health care workers compels the support group leaders to function as liaisons or middlemen between patients and the health facility. In other words they act to bridge the “us and them” gap that the women referenced - what Hodgson refers to as “social distance” (2006, p. 286) between health challenged subjects and the more powerful health workers. In essence, the prevailing nature of interventions has caused a fragmentation in health care delivery such that women access mostly medical services from health facilities but access care and social support from the support groups, and sometimes medical services too.

On an interpersonal scale, this group works to create a space of belonging and unconditional acceptance for patients who feel particularly vulnerable and out cast from mainstream social and interactive spaces because of their biological connections to HIV/AIDS. The Courage support group acts as a route for HIV patients to be socially normalized or re-orientated into the broader society through the impartation of psychosocial skills and coping strategies. This group also serves as a pathway for women to rediscover a self that has been emotionally traumatized by public opinions and moral discourses around the infection and disease. The group helps women re-acquire their lost self-esteem and identity so as to be able to tackle the challenges of their new biosocial status which include treatment as reflected in the statement below.

*“Yes, the women I have seen that do come to access drugs in this hospital, they prefer coming to us, wanting us to attend to them...like since we started working here, most of them, when they discover we are here, they have been able to gather that courage of feeling at home and being*

*more comfortable with themselves in terms of accessing the drugs and they have been able to move on with their lives. They are happy about it.”- Female support group leader*

From the services they provide, support group leaders double as social and biological risk managers. As part of the extended scope of their services, they provide medical support - assisting members with their prescriptions and dealing with the side or interactive effects of drugs. Materially, they support women with funds for transportation to collect the main antiretroviral drugs from the health facility and also pay for supplementary drugs like multivitamins. The group has also provided financial support to new mothers and members in bereavement who may have lost a spouse or family member. It is noteworthy to mention here that the support group usually received funds from NGOs and other non-state actors channeled through the health facility to conduct these expenses but when these monies stopped coming in, the leaders sometimes felt compelled to help women financially from their personal purse but based on their own volition.

Psychosocially, the group helps women in the social and self-management of the disease, aids members to redress issues of (non)disclosure and negative outcomes, empowers women to fight stigma through health education and awareness, inspires the growth and development of self-confidence, and to finding social acceptance within and outside the group. There is no direct evidence from the HIV positive women interviewed for this study who have disclosed their status to their partners and families that this support group aided their disclosure as is the trend in some other studies (e.g. Paudel and Baral, 2015; Neuman and Obermeyer, 2013; Gillett and Parr, 2010) but there are reports of women who were supported to effectively negotiate the negative outcomes of disclosure like rejection and spousal abandonment.

For some women, their marriages and homes have been salvaged through the interventions of the support group. For some others, they learned and acquired coping skills and strategies in dealing with their day to day struggles. A majority of women reportedly gained emotional and psychological stability, self- confidence and a broadened knowledge of the infection and disease through this group as the statement below indicates.

*“I enjoy the support group because when I just came into this hospital to begin accessing my drugs and I was told that there is a support group that helps people access and adhere to their drugs, I decided that I would like to join. It was when I joined the meeting that I rebuilt my self-confidence. Before now, even after the doctors and health workers have counselled me, when I get home I still think about my situation and I sometimes I will be thinking that is this the way I will just continue to take drugs until I die? But since I began attending the meeting, I started seeing people who are fat because I used to think that it was this sickness that made me to be slim but when I started seeing people who are taking these drugs and yet looking fat and robust, I knew that my slimness was just my own normal body. When I started this meeting I said to myself, if these people that are on these medications look like this and they live their lives freely and they don't think about this HIV, I said to myself that I would also be taking the medications consistently and also attending the meeting...The meetings have really helped me a lot, even my husband comes now because he knows the meetings help me a lot. I don't think anymore, I am okay now. I gave birth to a baby and when the baby was HIV free, it helped to strengthen my mind a lot and that was when my husband said that this meeting that you are attending that has helped you overcome your moodiness and psychological distress, I also want to attend so that I can learn new things and that is why anytime I come for the meeting, he joins me, we come together.” - (translated) HIV positive woman and support group leader*

Despite these gains, the support group as an alternative care space does not hold true for all HIV infected persons. Not all HIV positive women or men benefit from this organization. From members' demography, we gain insights into the material and social conditions that designate the support group as a safe space and by whom. The demographic character of the support group

shows gender and class based identities as strong factors and motivations for membership, and these elements shape the operative space, scope and the material nature of the support group. At the ECH, every HIV patient is expected to be a member of the Courage HIV/AIDS support group as the poster on the image below indicates. Yet, the demographic characteristics of members indicate a homogenous membership pattern with men and middle to upper class educated women mostly absent from this group.



Figure 12: Courage HIV/AIDS Support Group

From personal observations and confirmed by the group's leaders, membership constitutes more women that are less educated and also in the lower social and economic cadre. Given the knowledge of the range of services and resources available through this group, its membership structure provides insights about the categories of people most likely to value and engage this network as an alternative space to accumulate social, moral and economic capital outside the household and other productive spaces. Likewise, the heavy presence of women in the group

may be affirmative of structural underpinnings like the general socio-economic disparities between men and women in this geography.

The case of the support group as an informal financial port especially for women who may have few options for a viable and sustainable livelihood is not in doubt. As women's accounts demonstrate, less materially empowered women were willing to invest time and even obtain credits to attend the group's meetings as long as there was the assurance of financial remuneration, and more than they had borrowed. Attendance at the group's monthly meeting has visibly thinned out as reported by a group leader. At one such meeting that I attended, I was told the turnout was less than the regular attendance compared to previous attendance when the group made funds available to assist members with lunch and cost of transportation to the meetings.

*"Yes, even yesterday when I called members to tell them that there is a meeting and that they should attend, they were asking me, is there money? They said they did not have transportation and if there is no money, they would not be able to come...but if there is money, you will see more than fifty people here but since there is no money, we only have few membership attendance but as I still do encourage them to come for meetings whether there is money or not."*  
- (translated) Female support group leader

While the lack of funds for transportation may seem to constrain attendance to meeting, the real issue is not in the inability to get to the venue but that they may not be reimbursed by the group as usual with amounts that are more than the actual cost of transportation. This was confirmed during my call for participation for focus group discussions as most of the women had 'logically' asked if their transportation cost would be compensated. As the leaders confided to me, these recruited participants wanted to know the exact amount of compensation to ascertain if there would be some extra monies left after their transportation expense to the focus group discussion. In contrast, intentions for participation in the network among leaders appear to be mostly

altruistic demonstrated by their decision to continue to offer their services to the group (inspiring members to live positively) even after all financial remunerations to them from their sponsors ceased. For these leaders who have publicly disclosed their HIV status, their commitment is borne more out of a sense of self and purpose to encourage other women to live positively with the infection and achieve their full potentials as the quote below reveals:

*“As an executive, it is a voluntary work so I don’t expect to gain from what I am doing; I expect to give out the little I have and to see people get well. Those that are living with the virus, I really want to see them happy, at least I really want to see them better and not die like that.” - Female support group leader*

For such leaders, the concern is more with accumulating and making resources available for members’ needs even if it means taking personal financial and social responsibility. This is not the standard practice in other support groups as one of the support group leader cited instances where leaders in other groups have only taken up the role of leadership as a means of livelihood with the monthly stipend received from their health facilities. While incentives to join the group may vary across members and leaders, the support group is generally considered as a form of economic and social leverage for many. With already identified challenges by HIV positive women, and the categories of women who patronize the group’s services as well as testimonials, gendered poverty is one major driver and motivation for support group participation.

Given that disclosure is a mandatory parameter for membership in support groups, the gendered membership may also be indicative of the gender dynamics involved in public disclosure or “coming out”. It appears that men relative to women are more unlikely to publicly disclose their status as indirect or secondary reports by the health workers and other study participants claim. While women are also not very predisposed to public disclosure, a different set of reasons apply

to both. Similar to the reasons women disclose to partners at an interpersonal level as previous analysis show (see chapter three), they are also compelled to publicly disclose to gain access to social and financial incentives unavailable to them at the household or mainstream society. The evidence suggests that women find individual disclosure to spouses or partners difficult because of power differences and the fear of real or anticipated consequences. Yet, they may find it relatively easier to socially disclose even in spaces considered public but where their individual and social security are guaranteed. For example, women who felt stigmatized and refused to disclose their status to families and partners in private, are members of the support group who convene publicly within the hospital facility after group disclosure. There is a relative level of comfortability disclosing to a larger group of strangers with like minds than to a close individual (whether a spouse or partner) with an unshared seropositivity status.

From the evidence, we can argue that social security matters in disclosure more than the scale or the platform which it occurs whether private or public. But in public disclosure, women demonstrate that there are hierarchies in which disclosure can happen at this scale. That is, actual disclosure to a small public circle of like minds within the health facility that are sworn to secrecy by their own status versus publicly claiming a HIV seropositive status through external activities like awareness programs and public speaking at the community level. This hierarchy is what distinguishes the ordinary members of the support group from the leaders as the latter category of women have *come out* or publicly disclosed. It is reasonable to assert that there is a threshold or scale where public disclosure for some is perceived to be risky especially where perceived risks outweigh perceived gains. For such women who usually fall within the members' category, the motivation to disclose is not to bring broader societal awareness to the experiences of People Living with HIV/AIDS (PLWHA), or disseminate experiential knowledge to help the

larger community of HIV patients like the support group leaders do. Instead, it is for perceived personal gains that range from the psychosocial, material, and economical. The demographic characteristics of most support group members usually low income earners and uneducated women doubly prove and solidify prior analysis that for most poor women, security in varied forms is an important motivation for disclosure. This point provides an important segue into the next argument.

The demography of a more female support group membership strengthens the evidence that challenges to women's access and adherence to treatment are significantly gendered, social and class based and not for the lack of biomedical technologies especially with free antiretroviral drugs. These challenges by nature reflect the lived realities of women within household and communal spaces as a function of patriarchy. These constraints also present valuable insights into the primary reason the HIV/AIDS support group represents a safe and alternative space not only for economic reasons but also for psychosocial capital. This is because these provisions are inherently lacking in the private sphere. Perhaps, the sense of safety that women feel in these enclaves is also a reflection of the absence of male power or dominant male relationships in this space given that leadership is by women and membership is predominantly female. It is not clear from the data or observation if having a support group system where males are as active and dominant as women will change the dynamics and sense of safety that most women have come to associate with this network. Hence, I theorize with caution that this space may represent autonomy from male power and authority which makes it more enabling for women to accumulate these sorts of informal capital where access in the general society has failed due to male privilege. It cannot also be ascertained through the available evidence if the prevailing social ethos and gender prejudices evident in the larger society will be injected into this space

with more men or if members' shared HIV status will eliminate such biases. Nonetheless, the evidence calls for strategic thinking and careful consideration of the role of gender in shaping how people who are infected or live with the disease benefit from the HIV/AIDS support group network particularly in future establishments.

Class, social and gender locations constitute an identity framework that mediate individual experience of HIV/AIDS and consequently, include or exclude the entry of people who can collectively form and benefit from such HIV/AIDS therapeutic spaces. This is not to propose that women of high socio-economic class do not offer active membership in support groups particularly in more urban spaces. For most elite women, they might be able to independently negotiate the social and economic challenges of living with HIV without a collective identification for support as informal conversations with the support group leaders reveal. The support group may thus lack meaning for them as they are able to seek and purchase psychosocial respite through more sophisticated therapeutic spaces and individualized therapy. General studies on HIV/AIDS support networks and how they shape the HIV/AIDS community particularly in the Nigerian context are very scarce. Consequently, we do not know how and if these social markers impact differently and shape the nature and structure of support groups in this spatial context and even other geographies. What can be argued is that membership in the Courage HIV/AIDS support group is a deliberate and strategic decision influenced by shared identities, a coalition of common minds, a shared bio-social experience of the infection, and perceived psychosocial and material security.

It is acknowledged that existing cultural discourses around masculinities and femininities could also explain the gendered nature of this support group even though this was not directly evident in the findings. Nonetheless, allusions (by the support group leaders) were made to certain

masculine identities as reasons why men may shy away from identification with and active involvement in the support group. This raises critical issues for policy around the role of gender constructs in decision making in the uptake of health services. It stimulates the need for critical thoughts on how local perceptions of gender may influence who can access or who is disconnected from certain resources produced from health interventions. It also necessitates the need for better and strategic planning for more male involvement in HIV/AIDS programs.

What then are the broader implications of the above narratives? Women's testimonies do not only reveal the centrality of social care and welfarism as significant points of entry into their healing, it symbolizes their omission from their current health care package. The emphasis on support groups as the most significant coping outlet by HIV positive women makes it apparently clear that these networks provide a range of services that are absent in other spaces within and outside the health system. Better still, services or resources that are beyond the reach of the women who turn to the network for provision. It is also indicative of the linearity and limitations of existing HIV/AIDS interventions, and suggestive of the support group space as not only safe but as a site for seeking care and affective relationships that the main health workers do not provide in treatment.

HIV/AIDS support networks have become symbolic of micro therapeutic spaces with a positive transformation on the larger HIV/AIDS landscape. They exemplify the weak or missing link between pure treatment landscapes and landscapes of care for HIV/AIDS sufferers; they form an important ideological intersection between the medical and social constructs of health care in health scholarship. For health scholars, the practical knowledge of these support groups offers some specificity into the comprehensive model of health care that we often tout as ideal. For policy and planning purposes, support group spaces could act as micro health models and present

us with ways that social health care can be integrated into the mainstream. Overall, the identity structure of membership re-legitimizes existing notions of health as experienced not only on a gender scale but in terms of class and social differences. By making visible the role and nature of HIV/AIDS support networks, we can make careful assertions about the categories of women that stand to benefit from the resources available through this network in patriarchal settings, although this may vary spatially. Finally, we can also make modest claims that the dynamics of support groups may reflect the structural inequities in the larger social space in that the prevailing structure of the larger society is generic to its nature. On the other hand, the group wields transformative power that transcends the medical community to this broader social space.

### **Institutional Responsibility versus Individual Agency: Coping Strategies**

In addition to the HIV/AIDS support group (which is more an institutional based outlet than an individual strategy) as an outlet for coping with treatment challenges, individual based strategies were also cited. The implication of some of these strategies for both individual and population health, and the multiple ways they affect the overall goals of HIV/AIDS interventions are also discussed. This study disclaims that these strategies are the standard or acceptable negotiation practices. Rather, the argument is made that as an essentialized trait of the human nature, distressed subjects including HIV positive women under conditions of structural neglect will eke out survival mechanisms to address their immediate sufferings. These choices may not represent logical decisions that might be assimilated under ideal circumstances but they become rationalized for individuals operating within a realm of restricted resources and scarce opportunities. Again, these strategies are exhibitiv of the structural deformities in present interventions as they mandate individual level coping mechanisms and multiply the insecurities of already vulnerable HIV positive women.

The main proposition is that frequently, less privileged HIV positive women do not effectively negotiate or totally subdue the barriers to their access and adherence; hence their everyday lives are characterized with these constant struggles. Sometimes, the outcomes of their choices for negotiation are positive, other times outcomes endanger their health and the general population, and consequently undermine general intervention efforts. This is not because of intentional individual decisions but that certain irrational behavior becomes rational in a context of survival where there are limited alternatives. A common ‘illogical’ behavior as a technique to negotiate the challenges of the disease is the commercialization of sex by infected individuals to solicit for material gains to meet the cost of living including treatment. Testing positive to HIV does not stop indiscriminate sexual activities but may reinforce it as infected women now have an added financial burden to care for their health. This is the voice of one such woman who as a single parent with four children and no sustainable means of livelihood opted for what she considered her best course of action given her available opportunities.

*“For me the truth is before I met this man who wanted to marry me, I had three to four boyfriends that paid me so much money. I did not use condom and I could not use condom because they are rich men. And even if I had told them [I had HIV] they would not have believed me until last year when I met this man that promised me marriage. The kind of man that I had really prayed for, God brought him so because of this man, I had to quit from all those people and concentrate on him.” - (translated) HIV positive woman.*

As a cultural trend in Nigeria, some men have abhorrence for condom and would pay extra to sex workers to have unprotected sex. This was also confirmed at the support group meeting I attended at the ECH when a male positive HIV support group member stated the same preference for the lack of condom use during sexual intercourse. In other words, improperly designed HIV treatment schemes that do not comprehensively cater to the needs of the target population can act as catalysts for individual social behavior that undermine population health.

The non-consideration of treatment outcomes beyond biological or curative ends produces specific processes and outcomes that countervail mitigation and eradication efforts.

Studies like Liamputtong, Haritavorn and Kiatying-Angsulee (2009) have positioned infected women as active agents in their response to the social challenges of the disease because of their ability to develop individual coping mechanisms but the testimonies of women in this study compel me to take a slightly different approach and perspective to this argument. I take issues with this sort of generalization because it flattens out individual experiences and extenuates the arduous conditions less privileged and under empowered women navigate to cope given the notion that women act in their own agency to redress these challenges. It also unintentionally absolves institutional responsibility and designates solutions as always possible within individual agencies and boundaries.

Agency can be assumed to have been enacted when women possess complete authority and free will to control and self-determine their destinies through actions that are not structurally mediated by an oppressive system. In other words, complete agency is expressed when women do not act under constraining conditions but able to *effectively* change their circumstances through unrestricted options. A question always to be considered is the subjectivity of women's choices. Will a particular choice be made if there were better or more options or will this choice remain constant under improved personal conditions? If no, then we may not actively construct this as an expression of full agency and mis-conceptualizing the subjects of structural violence as having the power to control their choices in desirable ways just because they survived. As evidence, implicit in women's accounts was an astute sense that the strategies reportedly deployed may be contradictory to their choices if they had better alternatives. For example, the woman in the aforementioned quote had gone on to quit her multiple sexual relations when she

chanced upon a better opportunity, the alternative of a monogamous relationship with the promise of marriage that would secure her financial and social needs.

Consolidating our knowledge of the diversity of ways women address these challenges makes it easier to conceptualize their positioning and deep vulnerabilities within the broader intercourse of institutional responsibility and individual agency. Through these personal choices, we are also able to assess the level of control women have to produce their desired health outcomes, and the degree to which women extemporize solutions to their predicament also enables us to assess the need for more structurally placed solutions. The broad implication of the provision of treatment without wrap around services is that the responsibility to negotiate challenges is vested on the individual already burdened with the infection or disease's vulnerabilities, sometimes; such responsibilities are transferred to non-state formal organizations like faith based organizations (FBOs).

Second to HIV/AIDS support group, the internalized beliefs in a supreme being that grants grace and internal strength to overcome circumstances beyond the control of individuals was cited as an important coping mechanism by HIV positive women. Common myths associated with HIV/AIDS are still prevalent among these seropositive women. Some common HIV/AIDS narratives are: HIV/AIDS brings bad luck, HIV/AIDS is a wicked spirit, it is a spiritual problem, and it is a death sentence. With such supernatural affiliations with the disease, it is no wonder that infected individuals seek spiritual pathways to their treatment and cure. Deep religious beliefs define the core of the Nigerian society. Surveys conducted such as the BBC (2004) show that Nigerians are the most engaged society in religious activities relative to other countries. Other studies (Olarinmoye, 2010; Oluduro, 2010) have also confirmed this intersection of faith and HIV/AIDS established in women's narratives. In this particular health facility, there were

multiple reports of deaths among AIDS patients due to faith based messages by religious leaders that declared deliverance and healing from the affliction of HIV/AIDS. Many lives have been lost because these individuals adhering to such faith based messages exercised faith that they have been healed, and consequently, discontinued antiretroviral therapy. Below is one such narrative.

*“... little balancing means [little ‘help’ or ‘support’] in the sense that they can afford money to move, they can eat well and they are little more exposed [enlightened], there are no religious characteristics behind it. Some people, religious characteristics are affecting them. They will take it that God will heal me, and at the end when their situation has started deteriorating so much, they will come out again to say, treat me but that time, water has already passed garri [the last phrase is a local slang which means that ‘it is already too late’ and death occurs], that is it.”- Female health care worker*

The statement above, one of many accounts of deaths from religious beliefs, depicts two categories of women; the first refers to a category of infected women who need little adjustment after diagnosis to manage their HIV positive status because they are socially and economically empowered to do so. For this group of women, religion plays a lesser role because they do not need to rely on a supernatural power to control a situation that they can handle by mobilizing the relevant resources. For the other category of women, they rely on spiritual healing in the absence of real or tangible alternatives. The nature of coping strategies consistently reveals differences among women’s choices and re-establishes the need for policy and programs to target women as a heterogeneous group with disparate needs. It also reveals that women enact different levels of agency in coping or negotiating the challenges of treatment access and adherence. Hence, there is a need for caution, not to make generalization of agency to all HIV seropositive women based on those who are able to effectively cope with the associated challenges as yet again, we see social demographics among women impact individual experiences.

Although the aforementioned situation makes apparent how religious messaging can be counterproductive to treatment efforts, religious sites do act as spaces for poor infected women to mobilize and accumulate psychosocial and material resources as evident in the quote below.

*“We do not want to die now, life is sweet to us so we will struggle, we will struggle. It is by God’s grace, may be church. Like me, my church knows my status. For me, I opened up, my children, everybody knows. So if I do not even have money, I say Daddy [referring to and means ‘the church head or pastor’], I want to go and pick up my drugs. I even use my situation as an avenue to collect money from the church and my family because I am important to them. And because I have been good to them, when this kind of thing happened to me, they cannot abandon me.”- (translated) HIV positive woman*

There is no gainsaying that there is a needed collaboration between faith based organizations (FBOs) and secular actors involved in HIV/AIDS intervention efforts in Nigeria. FBOs in Nigeria have a long history of collaboration with HIV/AIDS coordinating and implementing partners (Ucheaga and Hartwig, 2010; Aguwa, 2010; Okereke, 2009) but most of their participation have been inclined towards preventive efforts. Only recently is HIV/AIDS research beginning to recognize the indirect role of FBOs in sabotaging treatment efforts due to their faith messaging (WHO, 2007). It is pertinent therefore, not to designate FBOs as just collaborators in HIV/AIDS preventive programs but their partnership should make for more meaningful involvement to include treatment.

Just as religion defines the value and social existence of many Nigerians, it is bound to define health seeking behavior or how individuals seek solution to their health challenges. Studies in other sub-Saharan African contexts reveal similar trends and the WHO (2007) confirms the need for more research into this area as the intersection between religion, culture and health is still underexplored particularly in HIV/AIDS research. Within the HIV/AIDS landscape, as with

support groups, religious groups possess strong potentials to serve as therapeutic spaces and sites of solace for some HIV positive women. Religion has been determined to be a strong commonality among a majority of Nigerians and this study has established that HIV positive women need a shared interest and common space of belonging to address their challenges. HIV positive women can thus organize around this shared religious element to bond, pool resources, and expand their social networks. It is significant therefore, to expand ongoing dialogues with FBOs and the need to develop their capacity to deliver such informal care within the context of HIV/AIDS.

Disclosure is a strategy mostly perceived by stakeholders (health workers and policy stakeholders) as a significant way of negotiating the barriers to treatment access and adherence because it directly elicits partner or familial support which aids infected individual's treatment initiation and adherence. However, the many downsides of disclosure do not make this a viable first or regular alternative among these HIV positive women as they rationalize their decisions within a continuum of economic risk and social consequences. Disclosure for those who can voluntarily do so represents the most effective strategy for mediating barriers to access and adherence as it enables the individual to solicit both psychosocial and financial support especially from family and loved ones. In some instances, it might eliminate social barriers to treatment adherence especially if the individual has a strong support system whether from the household or community. Disclosure is usually touted by support group leaders and health workers as a precursor to initiating treatment and a pre-requisite for maintaining adherence. Nonetheless, the support group is ill equipped with the skills and resources to address ill-fated disclosures because this process can be a double edged sword as outcomes can swing either way.

As earlier analysis demonstrates, disclosure is not always ‘voluntary’ but a rational choice in the face of limited options for many women.

For women who cannot/do not disclose, they engage a range of other strategies to include deceptive tactics. For example, some women lie to their spouses about taking trips to the market while actually visiting the health facility to pick up their drugs. In some instances, they may need to bribe the health workers so that they can be quickly attended to when they visit the health facility. Other coping strategies deployed by women that emerge from non-disclosure include covertly redistributing and utilizing funds allocated to them by their partners for household expenses to procure treatment especially to cover the cost of transportation.

Quick fix behavioral strategies or other forms of extemporized coping mechanisms cannot function in lieu of structural mechanisms to address the challenges of HIV positive women. Individualized coping strategies imply that infected women must take personal responsibility for their care in the absence of structural solutions. However, deploying personal strategies for structural problems are not sustainable on the long haul as most of these strategies are contingent and temporary solutions, in that they take the form of everyday exigencies and are quickly deployed to provide immediate respite. Since most treatment challenges are structural, individualized and non-structural solutions may not provide a permanent fix. The implication is that survival tactics become entrenched in the everyday lives of women as they are continuously recycled to negotiate these challenges on a regular basis; thereby, launching women into an endless and vicious circle of health and social tragedy.

In the next section, I discuss the ideological constructions that promote the overrating of HIV patients’ agency for health change and how they confer undue burden on women to assume

power for change while diminishing institutional power and control. This is the blame-the victim culture, a mindset that cast infected individuals as the architect of their misfortune rather than as victims of structural violence.

### **Institutional Responsibility versus Individual Agency: The Culture of Blame**

An over estimation of the agency of HIV positive women to manage their disease status can be linked to their own self perceptions and societal blame. Given the major transmission pathway of this virus by heterosexual relations in most sub-Saharan African countries, HIV/AIDS affected individuals are constructed as responsible for their infection. Consequently, they must assume responsibility in the management of the infection or disease whether or not they are capable. This is somewhat the narrative among HIV positive women and other stakeholders interviewed for this study. While there were no direct or explicit blame on patients by themselves and others, some of the narratives by health workers and even the women themselves revealed this tension.

A majority of women mentioned the issue of user fee in accessing the mandatory supplementary multivitamins and other drugs for HIV opportunistic infections as a huge challenge in their access and adherence. They claim it is hard enough sourcing for funds for transportation but even worse so, when they have to pay additional monies for these side drugs. See the exchange below.

*P1: ...it affects. Sometimes, you can finish your drugs and you don't have the money for transportation to come pick up another set, let alone have the small money you need to drop [at the hospital] ...it makes one to skip taking the drugs sometimes.*

*EB: which small money are you referring to?*

*P2: the one we are asked to pay*

*P3: yes, maybe like when they [we] fall sick, maybe you are having like typhoid or malaria, they [we] will have to buy drugs, once they [we] don't have the money to buy the drugs and you know, we living with this virus, we are easily affected with any kind of illness because*

*our immune system is no longer as strong as it used to be so some can't even afford those drugs the doctor has written for them so it is really difficult for them [us] to get the drugs since the money is not there. And even some of these multivitamins that we do buy from the hospital, not everybody [can afford it], some are pre-ART patients and these pre-ART patients, they don't take the real HIV drugs, what they take is just these multivitamins [like] septrin and there is a blood capsule, that is what they take because their CD4 is still very high so they will have to buy their drugs [the multivitamins which are not free like the antiretrovirals]*

*EB: so they will have to buy those ones?*

*P3: yes, they are buying their drugs*

*EB: and those ones because of money too, not everyone is able?*

*P3: yes, not everyone has money to buy it and even we that are on ART, we still have to buy those same drugs also.*

Women's responses do validate existing research evidence that any additional user fee for health can act as a barrier to health service access especially for the very poor (see Odeyemi and Nixon, 2013). In contrast, the responses of some of the facility workers indicate women as having complete power and control over their access. One of such health workers (see the quotes below) states that the charge of user fees for supplementary drugs or other requirements of treatment like nutrition should not at all be a challenge or barrier to them because it is the least women can do to show some form of responsibility in their treatment after they have been provided free antiretroviral drugs by the government.

*“Well, government from what I can say, they have tried, the NGOs have tried, it is not easy to provide those drugs because if you say you [patients] are going to buy those drugs, Nigeria go die finish [means ‘most poor HIV positive Nigerians will perish’], the drugs are expensive so that is why may be. If they [relevant institutions] can provide drugs, they [women] should be able to feed themselves to take the drugs.”- Female health worker*

*EB: So these challenges, how do you think women, women that you attend to here in this hospital, how do they overcome these challenges, how do they solve these problems or don't they solve these problems at all?*

*P: We try to counsel them, that is what we do, we try to counsel them and we leave them to their fate*

The above narratives depict a flawed program implementation where women are empowered with information to manage treatment challenges but left without the material agency to translate this knowledge to alter their situation. It also underscores the ways institutional stakeholders construct women's responsibility and agency in the management of their own bodies and health. While the argument of a shared responsibility may sound very reasonable and logical, it precludes an objective assessment of women's capability to redress these barriers on their own.

We can theorize possible reasons why undue responsibility is conferred on infected victims. Most infected women claimed their infection was outside their control and traced their infection to their male spouses or partners absolving themselves of all moral guilt. On the other hand, women are not likely regarded as the victims that they are by health workers but as active perpetrators in their own infections which sometimes, may provoke a lack of sympathy or empathy from these health workers. This is evident from health workers attitudes and reported facility based stigma towards women (chapter three outlines these behaviors) from which we may infer that health workers construct a more narrow disease transmission mapping and moral compass that place infection directly at the level of the individual. In this way, we see two polar moral perspectives of transmission but one culminates into blame on women. Such moral judgements around women as responsible for their own infection produce widespread institutional and societal beliefs that emphasize a notion of personal responsibility in women's health management. This notion of individual responsibility is captured in the figure below. It is

an HIV/AIDS advert pasted on the wall of the HIV/AIDS support group building at the Erhoike Cottage Hospital.



Figure 13: Poster transmitting a message of individual responsibility

This is a typical HIV message across Nigeria where women are told to take responsibility for their future. Like Faria's (2008) study in Ghana, individual blame and responsibility for the disease within the HIV/AIDS and secular landscape usually bears the face of a woman. It is remarkable that this image and its message have the endorsement of global health agencies as evident in the poster. Whether intentional or not, as a subsequent section on the paradox of HIV/AIDS exceptionalism details, such images and rhetoric are perceived by HIV positive women as reinforcing HIV/AIDS stereotypes and stigma through their literal and figurative meanings.

Interestingly, women are beginning to view themselves in the light of these existing discourses of blame and individual responsibility which nullify the exercise of their rights to claim institutional obligation towards their health citizenship. We see a pattern where these women are

stuck between the need to claim personal responsibility for these issues thus hesitant to claim full entitlement from the government on what is supposed to be their civic and human right. Yet, at the same time, they levy blame on institutional actors for the paucity of programs, and the lack of a comprehensive treatment package that do not eliminate these barriers.

*“To me and other people, their weakness, they [referring to NGOs and other program bodies] just come and talk, they do not do what they say, that is the truth. they don’t do what they say, they just come, talk so long as they are able to get their agenda [which is] the minutes of whatever meeting they hold [and] photographs because they have their report to submit to whoever they collected that money from. So as long as they have their reports, they are okay, they don’t do what they say and it is not right. I would say [it is] because we are the ones suffering it, although they are not the ones that put us in this condition.”- Female support group leader*

This is an obvious example of how HIV positive women acquit institutional powers of blame and civic duties to them to accepting interventions as a form of privilege and not as a right owed them. Not surprisingly, some of the women conflated their rights to comprehensive treatment as a privilege. The above quote on the one hand, indicts NGOs as uncaring through the ways they execute their programs as only based on their own agenda. At the same time, the NGOs are absolved of responsibility through claims that they are not the cause of their infection so should not be wholly held accountable for treatment challenges or failures in meeting women’s needs.

The voices of women and other stakeholders reveal a tension between institutional and individual responsibility within the business of HIV treatment. An undue emphasis on women’s agency to mediate treatment challenges while excusing corporate inaction elides the structural dynamics of inequality and gendered poverty that hitherto positioned these women at a place of risk and vulnerability to the infection. It is irrational to assume that individuals who could not

protect themselves from being infected or diseased because of their marginal and vulnerable positions can suddenly confront the challenges of their new health status under the same conditions. Such ideological constructions among institutional actors promote a laissez faire attitude and corporate irresponsibility, and make institutions not fully accountable to their citizens especially the vulnerable groups. These responses yet again invoke and reinforce the individualized disease paradigm which holds infected individuals liable for their condition and management without recourse to broader structural factors. The next section details the perceived weaknesses and flaws of these institutional actors based on existing interventions from the viewpoint of HIV positive women.

### **Perception of HIV/AIDS Policies and Programs**

It is pertinent to state that the propositions made in this study are not against the use of biomedical solutions to addressing public health problems; in lieu, biomedical solutions should not be constructed as singular and universal especially in local contexts where the use of such solutions alone will not suffice. This study supports the deployment of biomedical technologies but argues that it should not replace other alternatives as needed. Perceptions of treatment programs by HIV positive women reveal mixed reviews. A perceived reported weakness is the overly biomedical nature of the programs. Still, they showed a deep appreciation particularly for the provision of free antiretroviral drugs while agitating for more comprehensive interventions mostly through empowerment schemes that would foster their access and adherence.

Generally, women's negative perception of interventions bordered around issues of representation, conflicting donor priorities, the lack of participatory approaches and meaningful involvement of people living with HIV. Specific narratives include patients' marginalization and exclusion from active involvement in a process that determined their health, NGOs over concern

about reports and statistics and less about a representative evaluation of the efficacy of intervention outcomes on patients, NGOs and government's insensitivity to the needs of patients because the infection and disease affect a vast poor majority, distrusts of NGOs real motives for example, the use of patient's statistics to meet funders requirements, NGOs not doing the talk or keeping their promises but using patients to fulfil their agenda in respect to funding or donor requirements, non-payment of salaries to HIV/AIDS support group workers or leaders, and inadequate government provision for training of health workers for effective job performance. Women linked the poor attitude and discriminatory behavior of health workers to their lack of skills and training to perform. Positive evaluations of programs include the provision of jobs to HIV positive people as adherence counsellors through the HIV/AIDS support network and free ARVs as previously cited even though many wished the supplementary drugs were also free.

A vast majority of the women spoke of a disjuncture between the nature of resources supplied and their needs. This was the most cited weakness by HIV positive women and many perceived this to be from the difference in NGO's priorities vis a vis women's real needs. While most of the women voiced their grievances against the government, the support group leaders voiced theirs against the NGOs. This may be because NGOs are the more visible intervention body in the general geography of HIV/AIDS relative to government agencies. In addition, they are more accessible to the support group particularly the group's leaders. NGOs were framed as 'uncaring' but were generally perceived to be better than government agencies. Women particularly the support group leaders perceived NGOs to be exploitative, using patients to meet donor requirements not minding patients reported needs. Women perceived their needs to be less relevant in the wider scheme of things and this has engendered distrust with HIV/AIDS institutions.

Relatedly, is the medium and ways through which women's needs are reportedly channeled to policy stakeholders. A participant among these HIV positive women claimed that the needs of women may not be known to relevant government agencies. This was cited as a function of current exclusionary practices of programs that do not enable patients' direct formal access to policy planners and relevant stakeholders except through facility workers who may or may not accurately convey patients' needs. Here again, the voices of these women provide evidence to this argument.

*P1: we do not know those people at the top that we need to meet, that is my own problem. If we know those people we need to speak to [P2 cuts in: our NGOs], those in government not NGOs, let the government call a meeting. Then two, they should bring us in contact with the government, if they can bring us in contact with them, we can tell them our problems, let them hear from the horse's mouth and see if they can proffer solution to the problem because if they don't, many people will still go about transmitting HIV even though they know they are positive (translated)*

*P2: we don't want them to send anybody, we want to talk to them, face to face because the ones they are sending, it is what is on their mind, that is what they are doing, just for their own pocket [referring to a third party representative] because I have gone for a seminar like that, it is for the man's own pocket. Even for everything I said, I have not heard anything so we want to talk to them one on one.*

*P3: let's sit down and talk to them one on one, with [mentions name of NGO, NGO A] told them they presented the matter to state government...we have not heard anything till now but if we talk to them on our own, tell them, this is our situation - Voices of women living with HIV*

Better policy access is perceived as better platforms like organized forums where women can directly engage state and non-state actors on the broader HIV issues facing them. HIV positive women generally hold the belief that during such stakeholder forums, their needs can be effectively communicated to policy and program planners when their population is represented

by one of their own. As opposed to the current practice of being represented by the health workers who may not self-identify with the women's health status and needs or empathize with their situation. It is important to mention here that some of the women have access to NGOs especially during periods of monitoring and evaluation when the NGOs visit the health facility. But this is perceived as rudimentary and not productive because NGOs priorities are donor oriented and will only respond to women's reported needs when it aligns with their program requirements.

The underlying narrative here is that HIV positive women are rarely called for participation in HIV/AIDS program seminars that discuss and evaluate their response to treatment. In lieu, such health reports are channeled to the relevant policy stakeholders in these forums through the health workers. Nonetheless, the facility's administration has hitherto taken important steps for better inclusion and visibility of patients in the intervention process. The hospital's management is reportedly responsible for the current structure of the HIV/AIDS support group where the leadership constitutes women living with HIV instead of the regular health workers as facilitators and organizers of the support group as it originally existed. However, there is still room for greater inclusion for HIV positive women in HIV/AIDS governance at scales beyond the facility in order to establish a more equitable intervention environment. To be sure, women continue to assert the need for more active inclusion despite their engagement through the support network as HIV and adherence counsellors. They desire a more representative participation, one that shifts the present dynamics of patients' representation in policy forums directly to them. In the next section, the issue of representational politics is also explored but on a much more global scale and argues for inclusion and engagement of the voices and experiences of women in the global debates on the business of HIV/AIDS.

## **HIV/AIDS Exceptionalism: The ‘Other’ Side**

The lethality of HIV/AIDS and threat to global biosecurity has culminated overtime in an intense and expanded global-local response through funding, research and scholarship (Oppenheimer and Bayer, 2009). This exceptional response and privileging of AIDS funding relative to other communicable diseases is popularly referenced in texts as AIDS exceptionalism. Whiteside and Smith (2009) describe two types of AIDS exceptionalism: one in the early phase of the disease defined by western response to containing an impending viral epidemic; secondly and more currently, is the overwhelming global response through huge financial public health disease-specific allocations that has produced an outcry from public health practitioners in other communicable infections, and led a critical global debate on AIDS normalization. This tension was re-enacted in women’s narratives as they inadvertently weighed in on the justification or not for AIDS exceptionalism through their responses to questions on perception and personal experience of HIV/AIDS interventions. The goal here is not to recapitulate the essence of this debate or to pick a side but to draw attention to alternative framings of exceptionalism from the standpoint of the population most impacted by this controversy, framings that are based on how women personally experience the exceptionalism of HIV/AIDS in everyday life. Also, to possibly view the multiple ways these local perspectives can help redefine this debate to shape future policy considerations and actions.

The language of exceptionalism is deployed in a slightly different way among women living with HIV. AIDS exceptionalism among HIV positive women is interpreted in terms of specific social outcomes and local response to the disease, not in the rigid disease-specific focus or funding framework that intellectual and policy actors mostly reference. Women’s narratives reintroduced discussions on the globalism of the disease in respect to the massive global attention it has

received. At the same time, they were critical of the outcomes of such global response in the form of a proliferation of local interventions whose impact they considered incommensurate to effort mostly because the disease has yet to be demystified and normalized through a cure. A major critique is that such huge focus has created extensive local publicity that has climaxed into a fear and stigma around the infection and disease rather than the opposite. One of the specific but substantive channels they argue by which HIV/AIDS has gained exceptionalism is through the negative messaging and reinforcement by the electronic and print media. The women believe that the huge public awareness campaigns supposed to improve knowledge about the infection and disease have only heightened fear and stigma because some of these have been poorly coded often with wrong or haphazard media messaging about the pathology of the virus. Ultimately, such misinformation has only produced high rates of stigma discouraging testing, identification of new cases and disclosure as the conversations below confirm. Women thus demanded for a rethinking of publicity strategies that destabilize the negative dimensions of HIV/AIDS exceptionalism locally. The statements below demonstrate this paradox which is that there is so much publicity around the virus yet so much unawareness about it remains due to the ways HIV/AIDS has been publicized. This exceptionalism also makes AIDS not as normalized as other infectious diseases like malaria.

*“Just as everybody in the world knows what malaria is and what it is not, if I have malaria, I can go to my husband and say, honey, I went to the doctor today and I was told I have malaria, it is very easy, he will not be angry but...once someone just hears the mention of HIV/AIDS, they will move away from you because of lack of awareness. If they place posters of the disease all over the place, everywhere, on the news, television, and talk about it, men are hearing about it, including children, everybody will know about it. Who does not know PDP in Nigeria? [Nigeria’s ruling political party] Everybody knows. If people know that HIV does not kill as long as you take your drugs, and that you and your husband can be together, if you tell your husband*

*that see what I was told [HIV diagnosis], he will not be angry. It is because people are not aware that is why there are very afraid when you tell them.”- (translated) HIV positive woman*

*“Another is that, there is a place in Warri...they placed this big signboard, “HIV kills” so that is bad publicity that people give to HIV, that is why people are still running away from us but if you can provide the correct information, everybody will know the real nature of HIV. People should be sensitized from community to community, radio, television, newspapers, books, just make sure that the information is spread the way the virus spreads so that if we just spread the information like that, we will see that this discrimination will be reduced. That big signboard of HIV kills, it scares people away.”- HIV positive woman*

In other words, AIDS exceptionalism is defined by paradoxes. Women in their own voices have experienced the impacts of HIV exceptionalism but in social ways, not as a function of a lack of publicity but of negative publicity through negative messaging and rhetoric. For them, AIDS exceptionalism is socially experienced through stigma and discrimination due to the overwhelming response to the disease both globally and locally.

Different pathways to the normalization of diseases are documented in the literature, and significant among them is treatment or the availability of drugs. Too often, these recommendations are based on western premises (Rosenbrock, Dubois-Arber, Moers, Pinell, Schaeffer and Setbon, 2000) eliding social and cultural prejudices around this disease that may make normalization impossible in particular places. These HIV positive women assigned meanings to the concepts of exceptionalism and normalizations through their direct experiences of the virus within a spatially bounded context. Their interpretations are localized and embedded within their place experience. This is a slight departure from the more global meanings of exceptionalism in the sense that the elements of the lethality and globality of the disease are retained in women’s interpretations as the cause of AIDS exceptionalism but these combined

tendencies also produce a unique local response that is contingent on their socio-cultural geography. From women's viewpoints, we can claim that the meaning and interpretation of exceptionalism are not static but fluid and must integrate their varied spatial and locally assigned meanings particularly through the voices of specific at risk populations and vulnerable HIV groups like women.

Media programs and other HIV/AIDS awareness outlets can act to produce both positive and deleterious effects in how HIV/AIDS messages are coded and transmitted. These can produce major consequences and become counterproductive to the positive response this disease has received on the global scale (Liamputtong et.al., 2009; Faria 2008). On the one hand, there are those at this level that have called for a normalization of the disease through redistribution of funds from HIV/AIDS to other diseases. Locally, HIV positive women argue for normalization but not in these conventional terms of less focus or funding but that these resources be properly channeled and utilized at the level of the general population to eliminate the negative constructions of cause and effects associated with the virus. A state of normalcy for HIV positive women is when HIV/AIDS is less stigmatized and no longer perceived as a death threat or sufferers socially criminalized.

It is important that the different spatial and ideological notions by HIV/AIDS actors especially the infected population be reconciled and integrated into the ongoing debates of exceptionalism and resolutions for HIV/AIDS normalization. Local demands should serve to guide future decisions and planning. Women's narratives should re-awaken our stream of consciousness to continue to make sense of universal health concepts from local perspectives.

## **Conclusion**

Broadly, the analysis has focused on the gendered response to treatment challenges and women's perception of existing treatment programs. A strong theme that has emerged in this chapter's analysis is the perceived disconnect between women and the provision of resources available to them through interventions. This disconnect reveals identified needs that are yet to be addressed by relevant stakeholders. In women's own voices, they have clearly articulated the need and utility for a more meaningful involvement in the intervention process by people living with HIV not just as recipients but as active agents in the design and planning of programs. A significant step in bridging this gap is the inclusion of more grassroots involvement of HIV positive women in policy processes as opposed to the current practice where active involvement is mostly at the national level. It is therefore, pertinent to address the issue of scale in the expansion of meaningful involvement to involve the local context. Currently, in Nigerian HIV/AIDS interventions, involvement of people living with HIV appears to have been incorporated at a more upscale level through the national level HIV/AIDS support groups. At the grassroots mostly confronted with these challenges, the evidence is contrary. This accentuates the need for local populations to be better co-opted into the process in mainstream interventions.

Both spatial and gender representation are key to ensure that marginalized and vulnerable groups like women are integrated as core participants. This is a significant step in identifying user needs and providing resources on their terms. As part of proposing more holistic recommendations for integration to bridge the ideological and substantive gap between self-reported needs and resources provided by institutional policies and programs, a more participatory but meaningful approach is called for.

Part of the proposed resolutions to meet women at the point of their reality include creating structural buffers to address women's challenges to treatment and adherence as individualized coping mechanisms for challenges that are structural are largely unsustainable. The identified lapses in HIV/AIDS interventions have exposed a gap in the provision of social and care services for women in treatment. It is also reiterated here that existing biomedical components of interventions are good but should not double as mainstream while social aspects are relegated as alternatives to be individually incurred by intervention subjects. This study argues and proposes an intervention model that not only formally incorporates social and wrap around services in interventions but legitimizes them as part of the mainstream.

Finally, the justification of AIDS exceptionalism or the proposed transition to normalization remains a contestation in academic and policy spaces (Forman, 2011; Morfit, 2011; Fisher, Kohut and Fisher, 2009; Lazzarini, 2001). Women's narratives have helped to broaden the scope and scale of this debate through their local experiences of these concepts in real time. More importantly, their framings of the paradoxes of AIDS exceptionalism steer us to contextual sources of thinking and explanations as to why heavily funded HIV/AIDS programs like enlightenment fail to meet their target outcomes due to local and cultural prejudices, as opposed to proffering universal explanations or globalizing debates on issues that occur at local scales and disparate spaces.

The preceding chapters, three and four have explored the barriers to women's treatment access and adherence from a micro level perspective even though it is argued that these individual level barriers are really the product of structural forces. This chapter therefore, explored the ways that women negotiate these barriers and the role institutions play in assisting or not seropositive women in coping with these challenges. Given the multiscalar nature of this study, the next

chapter focuses on the role of HIV/AIDS institutions in both the private and public health sector and how they inadvertently shape the experiences of treatment access and adherence at the individual level. It investigates the role of institutions mainly through the concept of gender mainstreaming to argue and explain how the conceptualization and practice of gender within a health development framework can have local influence whether positively or negatively on the ways women experience treatment.

## Chapter Six

### **Ma(i)nstreaming Gender: How Abstract Commitments to Equal Treatment Access for Women with HIV can Reproduce Gendered Inequalities**

#### **Introduction**

The goal of ‘gender mainstreaming’ evolved from concerns about the need to create equal opportunities for women by incorporating gender considerations into every aspect of policy. Established at the Fourth United Nations World Conference on Women in Beijing in 1995, gender mainstreaming was designed as a global strategy to promote gender equality when existing gender specific (i.e. women only) strategies previously launched through the 1975 World Conference of the International Women’s Year in Mexico were judged to have failed to provide equality for women. In 1997, the UN’s Economic and Social Council (ECOSOC) established a resolution on the core principles of gender mainstreaming which is that the integration of gender must be ensured in all aspects of organizational and development work (UN, 2002), with the following statement:

*“The Council encourages the General Assembly to direct all of its committees and bodies and draw the attention of other bodies of the United Nations system to the need to mainstream a gender perspective systematically into all areas of their work, in particular in such areas as macroeconomic questions, operational activities for development, poverty eradication, human rights, humanitarian assistance, budgeting, disarmament, peace and security, and legal and political matters, taking full advantage of the outcome of the work of the Commission on the Status of Women” - United Nations ECOSOC (1997, p. 3).*

The aim of this shift from a narrow to a generalized approach to gender is to challenge existing gender specific policies that may unintentionally reproduce inequalities among the sexes in terms of opportunities and resources mobilized through policy. By mainstreaming gender

considerations into all aspects of policies and programs, the anticipated outcome is to restructure processes and systemic relations that reproduce gender inequalities. Hence, the approach of ‘mainstreaming’ is seen as key to institutionalizing and forwarding structural shifts towards achieving gender equality within institutions and all spheres social life (Bock, 2015; Greig et.al., 2008). However, persistent inequities around access to treatment among HIV seropositive women in the Niger Delta region despite institutional claims to gender mainstreaming expected to address these barriers, call for investigation into this practice in Nigeria’s HIV/AIDS interventions, in particular, treatment.

Such investigation is even more pertinent given evidence of failings of gender mainstreaming in other spatial contexts due to multiple challenges that constrain what the mainstreaming of gender can achieve (see Alston, 2009; Moser, 1989). These challenges include not least of all, a lack of political will and funding as powerful constraints. Others are organizational and cultural resistance. However, a strong determining factor is the weak framing of gender mainstreaming that complicates the ways it is practiced through programs, in a manner not consistent with its original ideology of integrating the relational dynamics between men and women (Giles, 2015; UN Women, 2014). These contexts underpin the investigative focus of this chapter, which is to interrogate how gender (and its mainstreaming) is conceptualized and framed within the Nigerian HIV/AIDS discourse among policy stakeholders and implemented in practice, as well as other contextual factors that can help us understand the treatment challenges of HIV positive women from an institutional standpoint. Based on the findings, this chapter makes the following major arguments that gender mainstreaming in Nigerian HIV/AIDS interventions:

1. Has run into the massive roadblocks of entrenched patriarchy in Nigeria with both organizational and cultural resistance as attendant consequences. Overall, activities designed

for gender mainstreaming do not match up in terms of rigor and practicality to the heavy ideological theorizing and analysis of gender outlined in policy documents due to the existing political structure, culture, gender and representational politics.

2. It is situationally re-interpreted in a range of ways that sometimes assume gender means that women should be treated the same as men, and other times that women need special treatment in order to come closer to equality with men. Consequently, producing conflicting gender narratives and programs that are sometimes inclusive of men, and other times, very specific to women.
3. It is complicated in practice in the ways it is performed to get performance based funding due to donor requirements. Therefore, it is fragmented and not really practiced systematically across the landscape of HIV/AIDS intervention including treatment
4. It acts as a kind of prism that reveals the ways in which global health interventions and their institutionalized culture and practices fragment and split up developing countries national health systems and any related systemic goal like gender mainstreaming.

Overall, this chapter makes the claim that the inability of HIV positive women to secure sustained access to treatment locally transcends individual level inequalities to the role of local and transnational HIV/AIDS institutions. A constellation of factors ranging from the ideologies and practices of gender in private and public sector HIV/AIDS organizations through the ways policies are formulated and implemented reproduce inequalities and barriers to treatment. To arrive at this conclusion, this chapter is divided into four major sections including the introduction and conclusion. The chapter transitions from specific contextual analysis and findings on gender mainstreaming based on policy stakeholders' narratives in section two to findings from the discourse analysis of Nigerian HIV/AIDS policy texts to situate gender and

treatment gaps in section three, while section four draws broad conclusions and recommendations based on the overall findings. In this chapter and generally too, I deploy the term policy stakeholders to include policy makers and practitioners across the public and private HIV/AIDS sector. Policy makers are those who formulate policies and the practitioners are those who execute policy guidelines, for example, the health workers at Erhoike Cottage Hospital. NGOs double as both policy makers and practitioners but for the sake of clarity, in this study, they are categorized as policy makers even though they act as local implementing partners to international donor funding agencies.

Following the introduction, section two explores within the Nigerian context, barriers that subvert the effective translation of *gender sensitive policies* into practice beyond the universal rhetoric of gender mainstreaming as producing transformative change and equality for women. The bottlenecks against the smooth implementation of gender mainstreaming are explored from two seemingly asymmetrical scales yet interwoven in reality which is the global-local binary of HIV/AIDS institutions through their specific gender ideologies and practices. Specific tensions between the policy and practice of gender mainstreaming include gender knowledge gaps within organizations and among institutional stakeholders, conflicting models of gender mainstreaming and interpretation underpinned by gender and cultural politics, and the entrenched culture and practices of global health organizations that are inimical to local gender policies.

The narratives of policy makers on HIV/AIDS and gender mainstreaming extending across public and private sector health domain contextualize the schism between policy and practice but do so in ways that concretize the existence of the multi-complex challenges that produce these seemingly oppositional domains. To understand and grasp the constitution of this unproductive interface between the theory and effective practice of gender within the health development

praxis broadly, this chapter argues for context to be framed not only its relations to the particularities of place and culture but also the invisible connections to the global. In other words, local institutional practices may create unproductive forms of conflict between gender policies and its implementation but sometimes, these practices are indirectly regulated by the not so visible hands of global health institutions. This argument is underpinned by the characterization of context in gender mainstreaming as mostly within the discursive conditions of places that breed cultural bottlenecks to the effective actualization of gender mainstreaming strategies (Alston, 2009).

In the Nigerian context for example, variabilities in the ideology of gender mainstreaming among state and non-state policy actors reveal strong cultural and institutional politics which determine how men or women are included or excluded, or allocated into categories of privilege and disempowerment through intervention resources. Even at the local level, cultural politics is still very much rife as previous analysis show how gender based identities and social expectations are key to how much women may be receptive to interventions. Nonetheless, bilateral and multilateral agencies also exert a powerful influence and significant control on the ways that gender as a policy component and practice are taken up at the local level. Yet, their role is less underscored in the literature. In situations when the role of international development agencies is analyzed, it is usually referenced in terms of the glocalized nature of NGOs and how their embeddedness in transnational aids networks or their neoliberal market connections indirectly shape local health landscapes (e.g. Galway, Corbett and Zeng, 2012; Mercer, 2002). It is less the ideological role that international health agencies play in recreating bottlenecks around the materialization of gender mainstreaming or how the presence of these institutions on the local landscape and their attendant material practices directly shape and alter the gendering of HIV/AIDS interventions in

Nigeria. For example, specific practices like performance-contingent evaluations based on numerical gender targets achieved through sex disaggregated data significantly fail to rework the conditions of HIV positive women seeking treatment and retention in care. This is in addition to the uneven gender considerations among donors that undermine the systematic mainstreaming of gender into treatment programs across public and private sectors within the Nigerian AIDS intervention landscape.

Section three provides an overview of the nature of the Nigerian HIV/AIDS intervention using the results of a gender review and discourse analysis conducted on HIV/AIDS policy and gender texts. Discourse is deployed here as a system of texts with interactive ability, existing in a multidimensional relationship with other texts - intertextuality. According to Seidel, discourse analysis “shows how social and institutional values or ideologies may be constructed and circulated”. Discourse analysis is concerned with the “politics of meaning, with language as a political object, a political resource, or as a control, identify[ing] the ways in which the linguistic and the political have been connected” (1993, p. 175).

Following Foucault’s scholarship on discourse, Seidel seeks to understand the aspects of discourses which show how subjects become embedded in a web of politics and power relations. Studies or discussions on discourse seek to expose how language through discourse has been used to construct, oppress and disempower minority, powerless and marginal groups. Therefore, central to the focus of discourse in this analysis is how power permeates institutional discourses on gender and HIV/AIDS to shape local access and adherence to treatment. To understand the HIV/AIDS intervention landscape in Nigeria, I examine the phases of HIV/AIDS intervention from history to recent times, the models of interventions, the various discourses including gender and treatment and how these have evolved, the underpinnings and rationale, strengths and

weaknesses. Furthermore, I situate the emerging discourses on gender and treatment from this analysis within contemporary feminist discourses on gender in development to examine their implication for local HIV positive women in treatment and care.

A major finding is that the discourse of gender mainstreaming gets better in documentation/policy texts but without a commensurate change in its implementation and practice among relevant stakeholders. However, similar to the findings from policy stakeholders' accounts, the discourse analysis shows some lack of coherence and inconsistencies in the ways gender is framed in policies (sometimes as relational, other times as categorical) and these produce emergent difficulties in developing concrete and clear operational gender equality strategies. In the scholarship and field of practice, this has motivated calls for the development of universal gender mainstreaming methodologies (Glynis, 2007). It is not clear if these proposed methodologies are to be developed universally or localized to context. However, some sort of universalistic methodological guideline may be promising in terms of clear organizational directives or principles but prescribed methods also stand the risk of being interpreted as rigid and monolithic gender formula. This might negate attention to context and inhibit the fluidity of gender mainstreaming which makes it adaptable in diverse spatial contexts.

Additionally, such standard methodology may recreate power relations in global health governance with yet again the third world perceived as being educated by the west on how to locally engender feminist ideologies of equality that suit their particular contexts. This is a paradox in the sense that it is this fluidity of gender mainstreaming that also makes gender mainstreaming difficult to implement. As apparent in the Nigerian case, this fluidity produces both conceptual and methodological ambiguity. Still, this section argues that the fundamentals of gender mainstreaming may not be totally weak given that scholars like Alston (2009), and Moser

and Moser (2005) have argued that it seems a little idealistic and very simplistic in terms of the weight of structure and deeply entrenched cultural and sociopolitical scripts it has to trouble. As we see in the Nigerian example instead, it is the existing sociopolitical structure that gender mainstreaming is meant to undermine that challenges its success.

In the final analysis, section four concludes this chapter with recommendations. Gender mainstreaming in Nigerian HIV/AIDS interventions is relatively new and not yet institutionalized as a norm or standard of operation but organizations are moving towards this albeit some taking the wrong approach. The adoption of a multisectoral approach to the HIV/AIDS epidemic in Nigeria is applaudable and creates for greater inter-organizational and intersectoral collaboration but if the issue of variability in gender knowledge, interpretation and response is not addressed, this can be counterproductive. The lack of a clear or explicit framework for gender analysis creates conflicting implementation plans especially among implementation partners for which this serves as a guideline. There needs to be clarity of language deployed in gender policy documents and efforts to create a unified gender response. This can begin from addressing knowledge gaps and all forms of cultural resistance by integrating the gender mainstreaming ideology into organizations' core vision, mission and all aspects of internal organizational structure such that the gender mission is binding on all staff and proposed programs. Gender trainings that are sensitive to these constraints can be a great starting point for integrating and strengthening gender equality agenda into organizations. Gender mainstreaming is an iterative process and needs conscious effort, planning and detail with attention to scale to be effective.

Global health organizations also need to be included in this gender awareness plan. The change must begin from them given the nature of their unequal relations and partnership with local

HIV/AIDS institutions. They must be deeply cognizant of their role in the local HIV/AIDS landscape through their intentional and immanent development practices and consciously move away from the practices that complicate the local gender landscape. For us to achieve the goals of interventions through gender mainstreaming, global and local HIV/AIDS organizations also need to shirk the danger of statistics which measures performance based on female-male ratios or program targets; rather, we need to view deeply and inward the ways that both women and men are impacted by HIV/AIDS programs. This is a cautionary tale lest we reverse the impact of the epidemic in subtle ways. Political will at the international and national level remains an important index for effective and successful gender mainstreaming but the funds required to engender gender sensitive development in the HIV/AIDS domain remain farfetched. This nonetheless, reinforces the need for a transformative approach in ways that ideological constraints to the political will to act are also addressed.

### **Two Sides of a Coin? The (Un)productive Tension between Policy and Practice**

*“In theory, there is no difference between theory and practice. But in practice, there is.” - Jan L.A. van de Snepscheut<sup>12</sup>*

For those committed to effecting social change through research, a major challenge and continuous point of tension in positively transforming the lives of the subjects or spaces that we so enthusiastically study is the translation of theory into practice. Much of abstracting becomes inadequate over time when we realize that outside the production of knowledge which much of philosophical theorizing is inclined, there is an innate need and personal longing for knowledge production to transcend the transformation of conceptual spaces and positively altering the lives

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<sup>12</sup> Cited in “Doug Rosenberg and Matt Stephens (2007) *Use Case Driven Object Modeling with UML Theory and Practice* p. xxvii; Quote is also cited without attribution in Doug Rosenberg and Kendall Scott (2001) *Applying Use Case Driven Object Modeling With UML*, p. 1”

of people and actual spaces around which we produce knowledge in practical terms. It is at this point where we leap beyond the boundaries of theory that we face the multifaceted real world complexities that drive a wedge between theory and practice. The realities of ongoing tension between theory and practice is no different from that experienced within development spaces where translating policy into action seems to be a fundamental challenge in spite of strong policy blueprints. For example, gender mainstreaming. This section responds to the central issue that frames this chapter which is an attempt to move the theory of gender mainstreaming beyond the rhetoric of a transformative ideology to actual engendering of social justice and progressive change for women through effective practices. Secondly, to contribute to ongoing discourses around the not so successful implementation of gender policies particularly in third world spaces (Mannell, 2014; Gruskin et.al., 2013).

The objective of this section is therefore, two pronged. First, by examining the narratives of gender by policy stakeholders, I demonstrate the forces that drive the tensions between the theory and practice of gender mainstreaming within the Nigerian context. These forces include the lack of gender knowledge or its awareness, conflicting models of gender knowledge and interpretations which produce ambiguity in translating the knowledge of gender into practice, the power of global health institutions and practices, as well as other contextual issues like cultural resistance and lack of political will. In exploring these barriers, I draw attention to the problematic and somewhat reductionist conceptualization of context which although rightly foregrounds the situatedness and localization of place, understates the hidden but complex assemblage of broader structural connections that the local makes with the global. Significant to this argument are the specific ways that immanent development activities of international governance systems, the global political economy and transnational aids networks through the

NGO mechanism and bi/multilateral arrangements condition the ways that global health interventions are localized and implemented. NGOs connections to transnational funding networks not only drive their local agenda, they structure the forms of knowledge integrated into interventions including gender. As a consequence, their generic capabilities to streamline local context into development strategies and rework mainstream interventions in socially, culturally and politically appropriate ways are stymied despite recurrent notions of NGOs being grounded in local knowledge.

Second, is the contradiction in the ideology and adoption of the gender equity agenda among the different bilateral and multilateral agencies that privilege or under privilege gender in their interventions on HIV/AIDS. To be specific, the United Nations Entity for Gender Equality and the Empowerment of Women also known as UN Women is the single most significant global driver of gender equality in the Nigerian development landscape. Yet, the reported inconsistencies between their conceptualization of gender as relational and their local practice of gender as mostly exclusive to women through gender specific programs may produce cultural resistance, and consequently recreate gendered inequalities with unhealthy outcomes mostly for women. Similarly, the adoption of the gender equality concept as a priority agenda is not uniform across donor organizations within the global HIV/AIDS community. Through multiple vertical funding relationships with indigenous development practitioners, these inconsistencies are reproduced on the local HIV/AIDS landscape and create micro tensions between the policy and practice of gender mainstreaming among policy makers and implementing partners alike. Below, empirical evidence is provided to substantiate these claims and arguments.

### *The Gender Knowledge Gap*

In the analysis of policy makers' narratives, a distinct tension between the theory and practice of gender mainstreaming is the knowledge gap or the general lack of awareness of this concept.

Gender mainstreaming illiteracy constrains the seamless transition of gender theory into practice.

In the organizations studied, the lack of gender awareness is not mutually exclusive but deeply rooted in the internal organizational structure of NGOs within the private HIV/AIDS sector, and also the multisectoral nature of public sector HIV/AIDS organizations which compartmentalizes gender response according to different program areas and sectors respectively. Across board, in both NGOs and public sector national HIV/AIDS organizations, gender mainstreaming knowledge is mostly concentrated among a few policy actors whose focal program areas visibly intersect or crisscross the gendered aspects of the HIV/AIDS epidemic.

At the NGO level for example, a lack of gender awareness can be attributed to the ways programs of interventions are structured as distinct from each other. In NGO A, there appears to be no collaborative or integrative effort to mainstream the issues of gender into all program areas as a matter of how the organization is structured. One of the policy participants from this organization mentions that he is not wholly immersed into gender issues neither does he possess a knowledge of gender mainstreaming because gender as a unit is distinct from his unit (ironically, the HIV treatment and care unit). On my explanation of this term however, he claims that some form of gender mainstreaming does take place because of the gender issues that typically evolve around treatment uptake which the treatment unit does try to address.

The practice of gender mainstreaming thus appears to be ad hoc and driven by real life contingencies that potentially challenge donor goals of meeting treatment targets during program implementation. Gender considerations are considered an afterthought and implemented as a

contingency plan driven by field logistics and expediencies but not necessarily that gender is consciously planned for and mainstreamed into treatment programs to rework inequalities or transform the social processes that create barriers among recipients. The quote below demonstrates this.

*P: so our gender unit works with children, works with other community and faith based organizations that do gender in respect to our programs so we engage these organizations and try to get them to buy into our programs so far that is what they do but I have not really had time to really ask them the details about what they do with gender but I think that is what they do*  
*EB: So before you go out to the field, you do have your program design, so when you design your programs, you don't have the gender unit coming into to the treatment unit saying...*

*P: no no no, most times it will be after the initiation of treatment that the gender unit comes in not at the beginning*

This treatment of gender issues as the purview of a distinct gender unit counteracts the whole idea of a seamless mainstreaming and constitutes a gap in implementation. The lack of gender awareness by implementing NGO partners and the deployment of gender as distinct from treatment and care maybe a direct testament to the gender challenges explicit in the accounts of HIV positive women at the Erhoike Cottage Hospital, a facility that is managed by NGO A. This assertion is illustrated below.

*"Okay, so because we have a gender unit that is very separate from the treatment unit, I am speaking to you for [sic] someone coming from the treatment unit, I am not really aware what the gender unit, what they have prepared for their gender program but from the treatment unit, from what we see, we usually encourage the community health officers when they go on outreach to make a case for gender participation."- Male NGO practitioner.*

*"If [gender] is not fully integrated as you have explained it now and program design implementation is unit based, you understand, so the treatment unit may design a program and implement it and then the gender unit may just do the gender component of it but we don't sit*

*down together to prepare our work plan and then go out to the field together.” - Male NGO practitioner*

Knowledge of gender mainstreaming is underpinned by organizational structure and unit divisions at the NGO level as the above quotes demonstrate. However, it is also driven by personal interests and the perceived relevance of this concept to specific programmatic areas. An example is the argument below made by a technician at NGO B of the irrelevance of a gender equality perspective in the HIV laboratory and testing unit.

*EB: so what is your understanding of gender mainstreaming?*

*P: oh dear, we had an orientation on gender mainstreaming but because it doesn't feature so much in lab, but my personal understanding of gender mainstreaming is just having women reached, having men reached but I know that [tape unclear] because I am not really interested in gender mainstreaming as such*

*EB: can you please say that again*

*P: I said that first of all, personally, it is not an area of interest for me so I don't know much about it but when the gender component started coming up within the organization, there was orientation on it and my personal reading was just a little reading just to have an idea of what the gender was all about but I knew that it was not all about sex as in male female but it goes beyond to the perception about roles and responsibilities of health issues, community issues but to be frank I know little*

This NGO stakeholder's position however, raises the question of the compatibility of gender mainstreaming with all programmatic areas particularly in HIV/AIDS interventions, which also calls to question the methodological strength of this concept in terms of practice. *How easily applicable is the concept of gender mainstreaming in HIV/AIDS intervention particularly in program areas that are deemed essentially biomedical?* In other words, it may appear that the mostly biomedical nature of current HIV/AIDS interventions may have a diminishing impact on how much a gender perspective can be easily mainstreamed into them given the qualitative

nature of this concept. It thus begs the question if gender as a development agenda can be seamlessly mainstreamed into all areas of HIV/AIDS intervention. Nonetheless, is this perceived incompatibility counterintuitive to *mainstreaming* especially its feasibility in practice? While it is not within the purview of this dissertation to address these questions in depth, they raise important points for debates on the practicability of the theory of gender mainstreaming in all aspects and types of development work, and how we might further understand the failures of gender policies and programs to significantly improve treatment conditions for women despite institutional commitment. This perceived incompatibility may demonstrate the limitations of the ‘mainstreaming’ aspect of gender which is to seamlessly integrate gender considerations into *all* aspects of development interventions as defined in 2001 by the Economic and Social Council (ECOSOC) resolution section 41 (United Nations, 2002). The perception among policy makers and practitioners that gender is not compatible with all program areas thus undermines the seamless incorporation of gender into aspects of HIV/AIDS interventions that appear not to possess an apparent need for it. Consequently, such policy stakeholders disconnect themselves and their programs from this movement.

In the public HIV/AIDS sector, the impression of gender as a distinct entity is also prevalent although this perception is not shared among those directly responsible for managing the national gender response to the epidemic which is the Gender Technical Committee (GTC). Within the public sector national HIV/AIDS intervention domain, gender mainstreaming is designated mainly as the purview of the Gender Technical Committee (involving a cross section of partners from multiple sectors, global and national organizations like the UN Women, UNFPA<sup>13</sup>,

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<sup>13</sup> United Nations Population Fund

UNICEF<sup>14</sup>, Women Affairs, NACA<sup>15</sup>, Agriculture Ministry, among others) rather than horizontal across all sectors, policy makers and practitioners. Among the GTC and others knowledgeable in gender issues, there is a deep recognition of the intersectionality of the disease hence, the multisectoral approach that is nationally deployed. This multisectoral approach requires cross sectoral collaboration among different ministries from Education, Women Affairs, Agriculture, and Transportation among others to address the different dimensions of the disease; the national GTC places gender at the core of this response. Nonetheless, the intersectionality that drives this multisectoral response and collaboration is what also undermines the smooth incorporation of gender into policy plans. For example, we see a situation where the ministry of health is grounded and unable to effectively tackle gender issues because some groundwork that was supposed to be provided by other ministries is undone. Furthermore, the ministries are structured as independent sectors with separate financing, budgets, programs etc., and this actually inhibits a smooth coalition of gender programs across the different relevant ministries and parastatals. Consequently, there is actually very little effective multisectoral collaboration going on as this female policy stakeholder poignantly explains.

*P: I will cite an example for you, you have NACA and you have NASCP<sup>16</sup>, the HIV division [in the Federal Ministry of Health-FMoH], then you have malaria and then you have tuberculosis, and malaria is a program that you have a national malaria program but you don't have an agency that controls malaria, so malaria is like one program body, tuberculosis is like one program body [but] we have HIV/AIDS division [in the FMoH] and NACA [as a separate HIV/AIDS body], so why don't we have them as one division so that they can plan very well? For instance, NACA has meeting today, HIV/AIDS division [FMoH] we [will] have the same meeting that NACA just had tomorrow, so now we are doing duplicate of many things while we are under*

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<sup>14</sup> United Nations International Children's Emergency Fund

<sup>15</sup> National Agency for the Control of AIDS (NACA) is the country's national coordinating body on all multisectoral work on HIV/AIDS across both the public and private sectors.

<sup>16</sup> National AIDS/STD Control Programme (NASCP)

*one umbrella and we are talking about gender mainstreaming. So if like malaria is going to Ebonyi state, everybody goes to Ebonyi state not the one that people will go to Niger, [other] people will go to Ebonyi so if you are talking gender mainstreaming, you are going to bring all these programs under one umbrella because believe it or not, we still have monitoring and evaluation department, we still have adult ARV<sup>17</sup> NACA<sup>18</sup>, we still have the PMTCT<sup>19</sup> unit in NACA so they are still repeating the same thing and all of us are still trying to cover the same population in quote while we are doing the same thing. So what I am saying is that, putting all these programs under gender mainstreaming can help you monitor what you are doing. This is one program, only one head, we can't have two directors general for one program so that you will now design your work plan to know where and where you want to do one program or the other*

*EB: so in essence what you are saying is that there is really no collaboration between NACA and NACSP?*

*P: there is no collaboration, we are supposed to be working, NACA is supposed to be multisectoral response to HIV, while NASCP<sup>20</sup>, [HIV/AIDS division] for the Federal Ministry of Health response but NACA is doing the work of NASCP and even doing more because they have more funding than NASCP because most funding of HIV goes to NACA so making NASCP people almost like redundant. Now adult ART<sup>21</sup>, pediatric ART, PMTCT and covering aspects of gender, then you have a program that can design like gender mainstreaming that can bring all these programs that are scattered into one umbrella, I believe it is going to work and it is going to be monitored appropriately, that is how I see it*

As the quotes depict, plans on HIV/AIDS are formulated as distinct and independent and not as integrated despite the intersectional nature of programs. As some of the participants argue and also confirmed by existing national policy documents on NASCP, the Federal Ministry of Health formulates policies and action plans on HIV/AIDS separate from the country's national coordinating body on HIV/AIDS which is NACA. Most times, policy plans are not in sync with

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<sup>17</sup> Antiretroviral (ARV)

<sup>18</sup> National Agency for the Control of AIDS (NACA)

<sup>19</sup> Prevention of Mother to Child Transmission (PMTCT)

<sup>20</sup> National AIDS/STD Control Programme (NASCP) run by the Federal Ministry of Health

<sup>21</sup> Antiretroviral Therapy

each other particularly, gender. The independent structure and setting of ministries thus act as barriers to a seamless adoption and practice of gender mainstreaming. In a much wider application however, these quotes draw out two important points. On the one hand, gender mainstreaming as a systems wide focus and concern serves to illustrate the problems with verticalized<sup>22</sup> or disease-specific intervention approaches which include a fragmentation of the health system, separate accounting systems, dual reporting structure to both national stakeholders and international donors, and limited intersectoral collaboration and communication which enable the duplication of program efforts and wastage of scarce funding resources among others. On the other, gender mainstreaming not only foregrounds the type of broader health structure that is disabling to its successful implementation, it reveals the needed integrated and systems wide approach it requires to thrive. As in the Nigerian context, effective gender mainstreaming is weakened by the prevailing vertical approach to programs and the funding structure of its national health system which in large part, is influenced by donor partners vertical funding activities.

Policy responses (corroborated by the discourse analysis of gender documents) also reveal that the evolution, awareness and adoption of gender mainstreaming across these public sector health ministries through time were not simultaneous. The national public HIV/AIDS sector is therefore, an undulating gender terrain as across ministries, there are marked variations in the knowledge and receptivity of gender which also shape gender interest, funding priorities and gender budget allocations. The quotes below from another participant also corroborate this assertion.

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<sup>22</sup> Vertical programs are disease focused interventions that are deemed to be cost effective but with critics arguing against its “health exceptionalism” approach which undermines an integrative or systems wide approach to addressing diseases across a broader spectrum.

*“It should start with gender, if we can change their orientation, that would be the first step in the right direction, then if we can fund gender mainstreaming in ministry of health because in that NASCP<sup>23</sup>, many people don’t know what they say about gender. When I was doing gender, when I go to their office to ask about what are the gender issues in this your component, what do we do, how do we go about it, I was going round then, all of them just said they are not interested, they just don’t understand, and to make them understand, you spend time, talk talk talk, they don’t understand anything despite the fact that they are literates but for gender issues, they are real illiterates.” - Female policy stakeholder*

*“ [the] challenges, just like I told you before, the gender desk could not be established, when I ceased to be the gender focus person, ... many other persons did not want to reckon with [gender] to the extent that I was asked to make some proposals so as to fund gender, many other things will go, gender will not go. So from the onset, they were not really interested in gender, that is one of the challenges. People are the helm of affairs, they feel gender is not one of their [problems] although the GTC [Gender Technical Committee) see it that it is an issue and they are the ones pursuing the issue of gender in the country.” - Female policy stakeholder*

Evidently, gender mainstreaming knowledge is centralized amongst a few entities particularly the Gender Technical Committee as hitherto referenced, and NACA<sup>24</sup> as the evidence from the analysis also reveals. Gender knowledge is yet to be diffused across all sectoral platforms including NASCP<sup>25</sup> which operates under the Federal Ministry of Health. A dire implication of this knowledge gap or variation in the level of awareness among policy stakeholders is that it produces a relative level of prioritizing in terms of what is important to be funded. The lack of political will by decision makers has therefore, remained a significant index for unsuccessful gender mainstreaming in the Nigerian AIDS context as funds to engender gender sensitive interventions remain farfetched. The same female policy stakeholder above affirms that when "gender is not one of their problems", gender proposals do not receive funding approval relative

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<sup>23</sup> National AIDS/STD Control Programme (NASCP)

<sup>24</sup> National Agency for the Control of AIDS

<sup>25</sup> National AIDS/STD Control Programme

to other issues when presented to the ministry given the perception of program priorities among the decision makers. In the case of this participant's organization, when the policy official who appointed her as a gender desk person left, the replacement was not interested in gender issues for an extended period from 2005 - 2013. Consequently, all gender activities on HIV/AIDS in that unit were halted. As at 2013 when she left the HIV/AIDS unit in that particular ministry, there has not been a gender desk person.

This evidence reinforces the need for a transformative approach that is integrative and able to destabilize the ideological constraints against gender mainstreaming and consequently, the political will to act. Across public and private HIV/AIDS policy organizations in Nigeria, it can be claimed that there is a general low level of awareness of gender mainstreaming which strongly influences how gender is prioritized in HIV/AIDS interventions. Within these organizations, existing gender units where present act distinctly and do not mainstream their activities across board. Across public sector HIV/AIDS organizations, there is also little intersectoral collaboration on gender issues despite claims to the contrary in policy documents. This differentiated gender knowledge or level of awareness, perception of the relevance of gender considerations and varying degree of application influence the degree to which gender mainstreaming is integrated and operationalized and by extension, its success and efficacy.

Gender knowledge gaps also have direct impact on policy practitioners responsible for translating policy plans into actions. By practitioners, I mean those directly at the implementation level responsible for executing defined gender strategies into concrete activities that impact the targets of interventions. For example, out of the five health workers interviewed at the level of the health facility, only one (female) was familiar with this concept and gave a correct interpretation of this term. The lack of gender consciousness at this level ultimately

produces the implementation of treatment interventions devoid of active gender considerations. In principle however, these policy practitioners recognize the need for gender equity in treatment interventions due to the prevailing gender power dynamics that disadvantage women within the HIV/AIDS context. However, the translation of equity into practice to tangibly improve the lives of women appears to be undermined by their conceptual limitation of the actual principles of gender mainstreaming. This evidence would seem to confirm the arguments of Alston (2009) and Kabeer (1994) that knowledge is the major prerequisite for translating gender into practice. However, narratives by policy makers somewhat contradict this assertion and provide proof that knowledge of gender policies may be essential but not wholly adequate to produce effectual gender policies especially when such knowledge is in contestation with mainstream traditional gender knowledge predicated by the forces of culture and gender politics. This ties into another complexity of gender mainstreaming which is the conflicting interpretative gender framework deployed among the knowledgeable or avowed gender conscious policy makers.

### ***Conflicting Models of Gender Mainstreaming and Interpretation***

Policy narratives may include “stories about social problems and how they need to be solved” (Mannell 2014, p. 456) based on constructs that maybe mostly rooted and framed within a personalized lens and informal knowledge frames of how the world operates, as well as formal information from more sophisticated knowledge regimes. This argument is mostly premised on the notion that knowledge is socially situated and contingent on known realities including representations of gender, class, and other social hierarchies (Schoepf, 2004). Consequently, an individual’s inherent beliefs and ways of knowing and doing are usually shaped by personal, social and religious values and convictions, and also on relationships and identities forged overtime from social relations. For example, policy makers as men and women are daily engaged

in social relations whether at an intimate or formal level with the kinds of people that they design and formulate policies about. By implication, it is inevitably natural that these relations are not only intentionally or inadvertently transferred to the work space but that they may form the basis for which the generality of gender needs and policies are constructed and formulated (Kabeer, 1994).

Ultimately, it becomes potentially difficult to challenge such individualistic and lopsided policies based on these internalized personal convictions even with alternative knowledge that is ostensibly superior and more rational. At best, both knowledge regimes are adopted and coexist along each other. The outcome is a conflict in ideologies that in principle negate each other and their translation counteractive at the level of implementation. This is the current state of the Nigerian HIV/AIDS policy landscape where the analysis of policy makers' narratives (and gender policy documents as we will see in subsequent sections) reveal divergent interpretive gender models underpinned by a clash of culture, science and gender politics. Also complicating this narrative is the mandate on policy makers to adopt the principles of gender equality through transnational health partnerships or internationally donor sponsored programs.

Another distinct tension between the theory and practice of gender mainstreaming therefore, is the multiple knowledge orientations or gender interpretations among institutional actors.

Through the analysis of policy makers' responses, the findings demonstrate how this tension is not only implicated in the practice of gender but its failure in shrinking the gender gap. I also draw attention to context specific factors that underlie these diverse institutional gender maps and the practical outcomes that are direct products of these different gender codes.

Alston (2009) and Glynis (2007) reference three interpretive models of gender equity with potentially different outcomes - similarity (wherein women aspire to same equality as men; that is, equality for women means to assume sameness with men); difference (recognizing the socially constructed differences between men and women which also place unequal value on the productivities of men and women); and transformative (creating a more generalized gender change from an integrated perspective by transforming gender relations; this requires attention to social and cultural context). While policy makers did not consciously articulate or label a distinct model of framing gender mainstreaming, an analysis of their narratives and gender policy documents reveal the adoption of multiple competing gender frames. From the analysis, it is evident that policy makers recognize the existing disparities (difference) and inequalities between men and women. Consequently, gender specific programs that empower women to bring them to equality and wielding equal power as men (similarity) are framed as solutions to bridge this gap. At the same time, policy makers invoke a sustainable gender equity framework through integrative and transformative approaches that target both men and women; yet, without attention to the challenges these multiple frames pose at the level of implementation. Culling from the responses of policy makers, the quotes below demonstrate with evidence how these multiple frames are deployed albeit with equity as a central focus.

Policy makers deploy the similarity framework of gender mainstreaming as "*more like a concept where we focus on women and men and not having any gender disparity*". In this instance, although gender is considered as all "*inclusive*" and "*unbiased*" "*integration*" of men or women in consideration to how development policies affect these populations (which may seem integrative), it is based on the recognition of existing *disparities* or *differences* which for the most part are considered harmful. It is this idea of unwholesome difference that invokes the logic

of the similarity model. Policy makers although aware of the universal principle of gender mainstreaming as relational posit that current gendered interventions are skewed towards women because they have been long marginalized and for "fairness", "justice", and "equity", women need to be privileged over men. The rationale is to inspire women to sameness and similarity with men through women focused programs as this participant reiterates, *"you know, the issue like I said, a lot of work is already done, a lot of gender work is being done because we have a lot of focus on women particularly in this department, we have a lot of focus on women. I just gave you an example, although it has expanded but when you talk of focus on antenatal care for instance, your antenatal relates to women so of course, that is a gender dimension to that."*

In this context, the gender similarity model is mostly equated with gender equality in the sense that the goal is to position both men and women on the same pedestal of power and privilege. While in principle, adopting multiple frames might make sense given women's situational context, the inherent contradictions in these different paradigms are manifest in the pluralism of gender programs that countervail each other in terms of outcomes. For example, the difference and similarity models which Mannell (2014) refers to as the recognition-redistribution model will produce gender specific programs that address the recognized inequalities between men and women and thus attempt to redistribute resources along this continuum to erase these differences. However, this is not sustainable because it simplifies the complexity of structures that produce these inequalities (and leaves them untouched) with the assumption that solely designing programs exclusively for women will bridge the gender inequality gap. In other words, the *integrationist* approach to mainstreaming gender in interventions may be popular among stakeholders; it is not always matched in practice particularly in terms of the number of programs that are truly gender inclusive and reworking the underlying forces that marginalize women.

In addition to the conflicting agenda that the adoption of multiple frames of gender interpretation poses to its success as a practice are also the factors that underpin their selection by policy makers. Continuous reference was made by policy makers to the social dimensions of the HIV/AIDS epidemic as the primary motivation for gender mainstreaming, a fact that is evidence driven based on the feminized impact of the HIV/AIDS epidemic. Another motivation is the broader feminist and global agitations for gender equity strategies in development, particularly the Millennium Development Goals (MDGs), the Beijing and CEDAW projects which stakeholders perceive lines up with the situational context of women in Nigeria. As a policy stakeholder remarks:

*“Well, the whole thing is that you trust Nigeria, when there is a global call, they usually respond positively no matter how difficult it is, if you look at the child rights act for instance, it’s had a lot of issues, I will just use that because it’s one of the issues we deal with through Women Affairs [ministry], when you talk about child labor, you know with us in Africa, even parents in the local communities, they carry things on their heads, so it had issues at the AU<sup>26</sup> level, the regional level, the African Union when they met, so people were saying that are you saying that if I can fetch firewood, and I carry firewood, my child will not carry firewood and you will say that is child labor when the size she is carrying is commensurate to her size? So there were a lot of issues, a lot of people hawk things after school, and you say no hawking, that is what they are using to feed, it had a whole lot of issues, I am just using that as an example to say that even though it was difficult, they still considered it and they still signed, Nigeria signed and many states have signed, but many have not because of these issues I am saying because they don’t know how to pass it into law that after school a child, after school, we are not saying during school, after school, I am selling tomatoes in the market, after school my child will go home because of child right act, no way, it’s not going to happen, I am just trying to be practical, those are some of the issues that even though it’s difficult, Nigeria always signed and so when it came to gender mainstreaming, of course. Look at the issues, whatever happens to a woman*

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<sup>26</sup> African Union

*negatively, there are health implications, psychological, mental, whether she is battered, whether she has to fetch water and she has to fetch firewood and come back and do all the house work, it will affect one thing, her health so we are going to be solving a lot of problems if those things were in place, it was going to lessen the burden on the health sector so you find that it wasn't so difficult for us to buy in. remember that there was an ICPD<sup>27</sup> in 1994 I don't know, which pushed for a whole lot of reproductive health needs for women, her rights to family planning, this same woman is still going to have eleven children, she will miscarry some, some will die so it was so easy for us to buy into.”- Female policy stakeholder*

In the Nigerian policy space, gender mainstreaming is mostly rationalized within the universal articulations of gender as relational to capture the essence of global feminist constructs.

However, practical solutions are premised on the local situations of women driven by the stark inequalities between women and men. Hence, programs by design are categorical to women as a gender group accompanied with strong justifications to upgrade women's status or bring them at par with men. This reasoning connotes a semblance of logic or common sense and even a necessity especially when confronted with the patterns of gender inequality in the HIV/AIDS epidemic whether in transmission or treatment challenges as mostly impacting women. While this reasoning pays attention to context in that the needs of the most vulnerable and at risk subjects are centralized, the inherent paradox is that it obscures other aspects of context. The patriarchal structures that position women as risky and needy subjects are elided and unaddressed and these same structures will act as bottlenecks in the accessibility of resources redistributed by such gender specific programs. It is the recognition of these hidden paradoxes by feminist development scholars and practitioners that prompted the enunciation of the gender mainstreaming concept in the 1995 Beijing meeting when existing women focused policies

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<sup>27</sup> International Conference on Population and Development

formerly launched through the World Conference of the International Women's Year in Mexico in 1975 did little to advance the transformation of women's rights globally.

Despite the conflict between local realities and universal debates on the need to feminize development strategies through an integrative gender framework that is inclusive, this chapter also makes the case that the fluidity of gender as a concept (Hunter, 2010) which lends itself to multiple applications in diverse contexts is also fundamental to the conflicting models of gender interpretation. As a consequence, affiliated discourses rooted in this concept like gender mainstreaming become amenable to multiple interpretations and methodological pluralism across and within diverse spatial contexts. In spaces where gender is intricately tied to culture and social identities, the ideology and practice of gender mainstreaming as Glynis (2007) asserts, turns into a site of cultural struggle as it intersects not only with the social identities of the actors but that of the recipients. Fortunately, these underlying discursive conditions and gender politics as they help to perpetuate these divergent gender views are not completely unrecognized among gender literate policy makers as the participants below point out but it does not stop the pursuit of a gender agenda that may seem to be serving only a particular gender group:

*"I remember the first meeting, the first year we had a plan, a gender mainstreaming work plan or something like that for HIV and AIDS and I chaired that although I was having problems with the gender committee because it's like 95% women and I happened to be the only person [male] there was a time they were threatening me that I was not gender sensitive [laughs] because I was defending the interests of men and all of them were defending the interest of women [laughs] although we know gender goes beyond men and women... even though we seem to have the theoretical meaning of gender, we seemed to understand the theoretical meaning of gender, when it comes to practicing it, people have different orientation as to how to really practice gender...I find out that even though I have the statistics, I present the statistics most of the time about women but women are seeing gender as more of sex, female female female, male male*

*male but gender should be about dynamics about relationship between the two and how this relationship predispose or make people vulnerable and how do we do this, it's not just about male male, what can I do to make sure that males are represented or males have services but we need to look at the dynamics the relationship and how this relationship has become a serious factor in the epidemic... that is what happens in reality when you come to practice but when you define it, people will have correct definition but when it comes to implementation, people are divided.” - Male policy stakeholder and former chair of the Gender Technical Committee.*

*“The people making the policies are men, it is going to be skewed towards men so if I am setting up a company right now, whatever I am going to write down there is going to be skewed towards women depending on my mindset and whoever is going to come in is going to fall behind the policy so that is why the board of directors, whoever is making the policy like in NACA when it was instituted, the men will do it to suit them, close the gaps so that women don't come up that rapidly so who decides who takes over a unit or a department, it's the board of directors.” - Female gender consultant*

*“To a large extent there are still many men in policy making, in decision making positions that are still not gender sensitive, there are many, and it's not about education, it's more about your upbringing, about your orientation about everything because you can be educated, you can even be a sociologists specializing in gender but if your upbringing, your perception, your orientation as to male female issues is not gender balanced you will still be thinking of [word not clear].” - Male policy stakeholder*

And another:

*"Yea of course, you cannot say everybody is going to be on the same page when you talk about [gender] implementation. Of course, when you go to organizations that are more women, they are talking about our rights you know, speaking the voice of women. When you go to organizations that are men, they say these women are at it again, do you understand? In this country when you say gender everybody is talking about men and women not because of HIV but because of other social aspects of life that women are marginalized so the cry for women is more, democracy you know, so when you are talking about diseases now, in fact when we talk of HIV, we now say HIV has the face of a woman because she carries the burden of the virus and*

*she should be given more attention than the man so we do. A lot of partners concentrate more on women especially the UN agencies. This one was supported by UNDP<sup>28</sup>, they have gender as part of their responsibility, the UN Women are also for women, even UNICEF are talking about a little bit of women." - Female policy stakeholder*

The above quotes are strong indicators of gender and cultural politics in HIV/AIDS interventions and these continue to be re-established as some of the female participants argue that to achieve gender mainstreaming or equality especially at the institutional level, women have to deploy personal and institutional diplomacy. One of these participants states that women have to be able to "lobby" men, "negotiate", "play ball", "play around men", "make friends with the men", and in essence not act in isolation from men which might be interpreted as soliciting male involvement in gender plans. This perspective is also evidence of the tension and conflict among institutional actors on how to achieve gender equality for women with views that are sometimes inclusive of men, and other times exclusive.

Recognition of these multiple knowledge regimes is one thing but reconciling them is the real challenge. The real danger is that gender mainstreaming as a universally identified panacea to gender inequalities may become an avenue through which particular relations of power among policy actors and also the lay public are re-perpetuated because of how scientific evidence interwoven with culture and gender politics reconfigure its meanings and practical applications as the quotes above reveal. This may offer partial explanations for weak gender mainstreaming in Nigeria where the distrust and division among men and women interest groups influence how and where resources should be directed. It also provides some explanations as to why women empowerment programs at the grassroots are not necessarily meeting stated objectives due to this disconnect and lack of institutional harmony on the pathways to achieving equality for women.

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<sup>28</sup> United Nations Development Program

Besides the obvious contradictions in gender mainstreaming and the corresponding weak gender programs that these sorts of institutional tensions incur, what is very striking is that there is a growing recognition of gender rights at the level of policy institutions despite claims in the literature to the contrary (see Kabeer, 1994). Likewise, an initial assumption of this study was that because the policy arena is male dominated, this may potentially weaken the insertion of gender or women in development. The voices above demonstrate that female policy makers are beginning to coalesce, find their voices and be more assertive in challenging male dominance in policy decisions as it affects women, thereby, reconfiguring the gender and power structure of policy institutions.

As the above quotes also depict, the stream of thought, gender as synonymous with women because of particular local realities has become hegemonic and defined the dominant discourses of gender mainstreaming in both the institutional and social landscape even among international agencies like the UN women with presence on the local intervention landscape. To reiterate the quote from the female policy stakeholder above, *“a lot of partners concentrate more on women especially the UN agencies. This one was supported by UNDP<sup>29</sup>, they have gender as part of their responsibility, the UN Women are also for women, even UNICEF are talking about a little bit of women”*. The UN agencies perceived as connoisseurs of knowledge speak of gender but focus solely on women. Consequently, within male policy circles or male dominated organizations, the mention of gender may come off as empowering women over men and thus meet with resistance. Hence, men even as institutional policy actors are not all receptive to gender mainstreaming because of these sorts of narratives that seem to conflate gender with women among national and transnational organizations and ultimately transcend to social circles

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<sup>29</sup> United Nations Development Program

as the statements below confirm. Also of importance is the language used to frame equity which has also become synonymous with women. A case in point cited by a policy maker is the establishment of the coordinating national ministry on gender in Nigeria which is the “Federal Ministry of Women Affairs”, one that resulted in a public outcry among men who felt neglected and outside the loop of gender focus reiterates how institutions can embody and reproduce spaces of resistance albeit unintentionally.

*“You see, for our society, you find that the woman is actually disadvantaged in 99.9... I don’t know I am not quoting anybody but I am just saying because if you look at everything, the woman is always more disadvantaged so you find that programs have to focus more on women, that is why there was a Ministry of Women Affairs created but overtime they said, “ah, you women”, you know this mentality, women “Beijing platform, they like talking about themselves” and you find out that you need to reprogram to carry along men as much as possible because they too have issues, their own issues...”- Female policy stakeholder*

*“That’s what I am saying, that is always the thing, when we started distributing insecticide treated nets to pregnant women and children, and they [men] were like eh heh, mosquitoes don’t bite us? Automatically they look at it and say, even at the national level, the national hospital was said, Women and Children’s Hospital and they [men] kicked and kicked and kicked, finally the name has been changed to National Hospital because they were saying so you people [women] want best treatment and the place is so glamorous when it first started you will even want to fall sick just to be there and it was like, at that level, they didn’t understand the issues, of course they said that men too can go there but they [men] will say but you said it’s for women and children so but now it’s national, so now they don’t feel marginalized and they too can go there and all that, so that is just what generally is the trend now, you know [men say] “women, ah, they are coming up.” – Female policy stakeholder*

This institutional resistance is also reproduced among the lay population and general public where gender equity strategies are generally equated with women empowerment or gender

specific programs that privilege women over men, usurp men's authority or threaten their positions as the dominant gender. An explanation cited for this resistance is *"because gender is a new concept around here, not many people know what it is, in fact if you ask people what they understand by gender they will tell you that you want [women] to challenge their husbands so that is the kind of understanding people have, they feel that women are looking for power, they don't want to be women again, they don't want to cook, so that is the understanding of gender among the lay people."* - Female health worker, Erhoike Cottage Hospital.

As the quotes above depict, there is some cultural resistance to programs that are framed purely for women even within a gender equity framework as it clashes with existing notions of male superiority and female subordination both at the institutional level and grassroots. This speaks to the issue of language and framing gender issues as women's issues only and the need to come up with gender constructions that also resonate with men and are perceived as inclusive.

Misconceived notions of gender equity strategies perceived as threat and resistance to male authority are not peculiar to men but women imbibe same because the language of gender mainstreaming or equity is increasingly feminized due to data driven evidence from the epidemic with local feminists leveraging on this to advance the emancipation and rights of women. The evidence strengthens earlier claims made in chapter three of this dissertation that material empowerment of women from gender specific programs may produce resistance and unacceptance by women and men alike if such programs are not juxtaposed with strategies geared to rework current traditional constructions of gender within the existing social order of patriarchy. While it may seem counter intuitive to incorporate masculinities or not trying overtly to subvert male dominance in order to achieve equity for women, if that is the context that needs

to be addressed to achieve women's emancipation, might feminists and policy makers not take that route?

An ideological shift in gender mapping and orientation is needed and should be centralized in policy interventions. Otherwise, gender specific policies will at best provide a temporary safety net or solution for women without long term traction as patriarchal structures remain untroubled. This may explain the failure of so called gender sensitive programs because the challenges that women face daily as a result of gender and social power relations are rooted in hegemonic male discourses wherein inequitable and unjust gender practices are embedded. This chapter therefore, argues that an effective way to mainstream gender is also to engage men even when programs are women focused. Male involvement must also be centralized in empowerment programs for women. Similarly, men need to be addressed as to the importance of such programs for women so that they can form meaningful partnerships with their spouses/partners in engendering the success of such programs without feelings of marginalization. As one of the policy makers rightly posits, male involvement does not have to be material, it can be informative. It is also not enough to invoke a relational gender framework, this has to be consciously and practically mainstreamed into all aspects of interventions.

A relational approach does not negate gender specific programs but mainstreams mechanisms that address the gender dynamics between the sexes and one way to accomplish this is to involve men. In information empowerment programs for women for example, men should also be targets considering that empowering women with information without re-empowering men with the same may provide limitations to how well such information is put to use particularly if such information is intended to address negative masculine behaviors that impact women. A relational

approach pays attention to context and in this particular context of patriarchy, gender specific focus programs for women must include male involvement.

This is even more significant because if it is seemingly difficult for women as victims of traditional gender norms to challenge or resist the structures that hitherto de-emancipated them, it is only commonsense or conventional wisdom to achieve a social or structural shift in power from the source, by designing sound and carefully thought out gender reorientation strategies that are not visibly resistant to male power yet resets the social order. Through policy narratives (and gender policy documents) however, male involvement do not seem to have gained such prominence to the degree or magnitude it deserves given its proven significance in reworking structural inequities and power relations (Hawkes and Buse, 2013). For the most part, it is documented as strategies in policy documents, in particular, prevention of mother to child transmission (PMTCT) programs but less across other aspects of HIV/AIDS interventions like treatment. There is thus almost a double speak on the issue of male involvement sometimes articulated as important, yet is peripheral and almost sidelined in program designs and implementation.

The goal of analysis here is not to advance any one gender mainstreaming model over another but to problematize their inherent tensions in terms of actual policy outcomes; in other words, the possible practical implication of deploying multiple but incongruous gender frameworks. The paradigmatic principles of these different models will conflict in terms of operational strategies and produce distinctively gender outcomes, if clear or conscious thoughts are not given to their pre-existing tensions and differences with the aim to reconcile these contestations and make gender equality a reality. Perhaps, this is a testament of the complex realities or unclear methodological strategies of gender mainstreaming as a universal concept that Glynis (2007)

references, and the recognition that it is easier to theorize but harder to translate these articulations into concrete and feasible activities. In the Nigerian situation, in both policy discourses and programs that articulate a transformative approach to gender mainstreaming, there are no clear or explicit guidelines as to how this would be achieved. Most policy makers point to the difficulties of implementation as a critical bottleneck to gender mainstreaming because of the contextual realities that stifle its smooth translation into practice. See for example:

*“The capacity to implement like I told you earlier that there is still a lack of understanding of the concept of gender and so capacity is lacking because not many people understand the concept, implementing it becomes a difficulty...although there a few people who understand it but implementing it means everyone understands the concept and they are ready to run with it but we are not yet there, capacity is still being built and it will take a while for everybody to be on the same page.” - Female policy stakeholder*

These operational difficulties even when there is a clear understanding of the concept is what makes critics argue that gender mainstreaming is potentially an “empty signifier” (Bock, 2015; Alston, 2009, p. 150) if the theory of it offers more than can be feasibly or effectively practiced (Moser, 2005). These contextual realities include the variabilities in gender knowledge and interpretations which as one moves across different spatial contexts, gender mainstreaming becomes a contested concept and practice. Even when there is understanding of this concept as the evidence from this analysis reveals, its fluid nature which may relate to the shifting contexts of gender produces multiple interpretations based on individual subjectivities and biases.

Individual or particular group agenda for gender equity sometimes trumps universal considerations and institutional goals. These unaddressed contextual forces and ideological ambiguities potentially strip gender mainstreaming of its potency or power for transformative

change as intentions and practical solutions are not always in sync. The subsequent section addresses other aspects of this context and the broader influences.

### ***Institutional Power, Gender Mainstreaming and Global Health Institutions***

The argument of authors like Bock (2015) and Glynis (2007) that a cultural and place specific context is indeed important to not only how we understand gender mainstreaming but its effectiveness is confirmed by the narratives of policy makers in the preceding analysis.

Nonetheless, the relevance of context is not exclusive to the local but extends to global forces and the ways it mediates the practices of local health institutions. Attention to context as a major recommendation of gender mainstreaming proponents must include the role of institutional power enacted through funding relations and the ways this shapes health governance at the local level. This role of global health organizations as contributive to the contextual forces against gender mainstreaming is demonstrated in two ways. First, the conflict in interest and commitment to gender issues among global health organizations manifest through their funding priorities. Second, the ways established institutional norms and entrenched global health culture indirectly misinform local understandings and the practice of this concept.

Issues of donor priorities and funding as major limitations against the effective practice of gender mainstreaming are evidenced in the accounts of NGO practitioners in the Nigerian HIV/AIDS intervention landscape. These issues speak to the general skepticism around the complex but unequal relationship that exists between NGOs as civil society organizations and the corporate world of donor agencies cum the global political economy of development aids, and the ways they structure the forms of developmental activities that NGOs undertake. This indirect but strong influence on NGOs conceptualization of social problems at the grassroots and strategies for change, Garret (2007) aptly labels as stovepiping. Stovepiping describes the nature of donor

funded interventions as mostly a reflection of the interest and concerns of the sponsors and not the recipients. This is not to say or argue that NGOs do not have their own local agenda that are rooted in their commitments to the needs of the population they serve but their generic non-state or for non-profit nature usually means they have to rely on external sources for funds to implement their agenda.

Given the discourses of corruption and mismanagement of funds around public health sector institutions, NGOs as non-state agents are considered viable alternatives to mainstream development by bi/multilateral organizations and private corporate philanthropists that seek active engagement in the international development space. NGOs have thus been coopted into this transnational development space through funding as a tool and what often initially appears to be an alignment of development goals and commitment to domestic priorities. Often times, this is a catch twenty two situation where these alliances are not always compatible with specific mission and goals of particular NGOs. On the other hand, much of the intentional development by NGOs is only possible because of these aid relations. It is within this conundrum of paradoxes and contradictions that NGOs operate and must choose whose agenda to implement, and whether to make good or not their commitment to grassroots issues. In these kinds of situations, what do NGOs do?

Dominant discourses among NGO stakeholders reveal that NGOs choose their interventions based on the rules guiding the access and allocation of funding resources. Doing the contrary precariously places them in a situation where they are faced with the threat and possibility of exclusion and ultimately extinction from the development landscape as this participant confirms.

*"The way I see it is this, if it is an environment where NGOs, there is an easy access to funds for NGOs, I will say NGOs will be more independent to pursue the original mission and vision. You check most NGOs, they have their own mission and vision but they have to immediately forget that mission and vision when they are sourcing for funds and align straight with the mission and vision of their funders so that is what is going on. Most NGOs are living from palm to hands and they have staff, so commitment is there, and they have offices they have to pay for, so when the rubber meets the ground the story changes immediately." - Male NGO stakeholder.*

This statement echoes earlier arguments made in chapter one of this dissertation that despite having strong civil society roots and grassroots affiliations, the inherent structure of NGOs is such that performativity of these civic duties according to local prescriptions or realities largely depend on the strength of NGOs financial ties. Most times, these financial ties are to aid networks that may be opposed to specific domestic priorities like gender mainstreaming. As sites for alternative or critical development, NGOs are therefore, often positioned at a social and political crossroad through their mandates (Glynis, 2007) to cater to locally identified gender needs and the desire to pacify donor agencies for continued access to funds. Development activities therefore, continue to be more rooted in the mandates of transnational development organizations than the population they were originally instituted to serve. Not surprising therefore, funding was recurrently implicated across all HIV/AIDS organizations understudied but mostly among NGOs, as a dire challenge to the practice of gender mainstreaming in Nigerian HIV/AIDS interventions.

Funds direct the nature of interventions or what components are planned for and implemented. As confirmed by the above NGO stakeholder, NGOs may have good intentions that mirror the needs of the grassroots population or subjects of interventions but often times have to change their mission and vision statement to reflect the needs or agenda of funders. Realigning the

organization's mission to funder's objectives is considered by NGOs as the major way they can access funds from donors and to keep their organization afloat in respect to their financial and operative costs. In more ways than one, this confirms the debates in the literature of NGOs as not been autonomous but linked to global political economy forces of immanent development, recreating a form of mainstream development which may nullify the agenda and civic nature of NGOs (Mitlin et.al., 2007; Seckinelgin, 2005; Bebbington, 2004; Nagar and Raju, 2003). Furthermore as this chapter argues, NGOs dependency on global or international funders may reflect new forms of development imperialism channeled through funding bodies outwardly perceived as anti-imperialists or agents of alternative development. In this way, indigenous NGOs have been launched into the formal global capitalist economy redirecting the production of health services towards the direction of capital flow as captured by the evidence below:

*"...it is not very common you find an NGO designing a program completely by themselves because every NGO packages their programs to suit what the funder is willing to fund so most NGOs actually respond to what the funder is asking for and by that, it is now an issue for what is Funder A capturing as its package of care, what is Funder B capturing as its package of care so where you find a major funder saying that this particular fund has to do with outreaches to men group, of course, the NGO will respond immediately because they know that once you don't write within that context you will not be entitled to the funding. So with the understanding that there are different players on the table, NGOs respond to what the funders dictate, I know USAID is one of those that I have heard that will say okay come with your idea, then we will now look at and see if it's something that is an innovation but most funders will already tell you that this is how you should package so it's a funder directed thing, it's a funder guided thing because you as the NGO you will know if even if you have the best intention but it is not captured in your funders books." - Male NGO stakeholder*

In addition to the performance based funding structure of NGOs which sometimes undermine commitment to programs that are gender based, it is important to note however, that NGOs

allude to some form of gender mainstreaming in their programs but this is to the extent that they do not deviate from funder's directives. For example, within a particular component of their interventions as approved by the funder, there is some level of freedom of implementation in ways that are adaptable to the needs and contextual realities of the community. The impression is that actual strategies of implementation may not be over regulated by funders but this must be within the broad framework of the funded program area whether as it relates to gender or otherwise. It is within this allowable limit that this organization (NGO A) is able to target issues of gender mainstreaming as part of its program design and implementation strategies but frequently, this is not holistic.

The implication is that there is some form of ad hoc gender mainstreaming going on which is not well integrated as a staple component of intervention. An example of this is seed grants provided to the recipients of interventions as part of empowerment initiatives to the extent that funders approve. Once again, funding and donor priority are issues in situations where these do not align very well with local needs. A significant question that is implicit throughout the evidence however is; how can NGOs as non-profit outfits regain and maintain their autonomy to act in the interests of the people they are supposed to represent and serve rather than the needs of the sponsoring organization? While I am still pondering the answer to this one million naira or dollar question, the current argument and evidence call for the need to develop a recognition and awareness of the politics of international development organizations that is manifest through financial alliances with non-state actors as they foster new but intricate and complex practices of development (Escobar, 2010).

Even more paradoxical is that the notion of gender mainstreaming originated from international development organizations (UN Women, 2014; UN, 2002); yet, it is not prioritized by global

health institutions in the conduct of transnational health business. Their commitment or not to gender issues and other social aspects of treatment is reflected through the nature of programs they prioritize and fund. For example, NGO A which manages the Erhoike Cottage Hospital cited dwindling and fluctuating funding as responsible for their ad hoc commitment to gender and social issues of treatment. This particular narrative is corroborated by testimonies of the health workers and women living with HIV at the facility. These participants had hitherto mentioned that an empowerment component managed by NGO A which had women allocated some seed money to enable their transportation to access treatment was cut off due to lack of funds. This was also the case with the HIV/AIDS support group leaders whose salaries were halted due to shortage of donor funds. Confirming this narrative, one of the stakeholders in NGO A stated that the resources for this particular intervention component were redirected to cover the funder's mandate when the organization experienced funding shortfalls from the donor. See evidence:

*“The funding comes from PEPFAR and Global Fund.... first of all, he who pays the piper dictates the tune right, so if you are going to be using United States funds for our programs in as much as we will try to key along the rules of the country we are working with, we will also have to uphold the rules of the United States Government as well, so issues that has to do with terrorism, race, gender and all that are well addressed in our letter of agreement with our funders, but when it comes to gender, our funding doesn't have any room specifically for gender issues or gender needs and all that...”- Male NGO stakeholder*

The above evidence also reveals that gender mainstreaming may not be a widely accepted theory or common agenda among the donor community on international health. The major point demonstrated here is that local commitment and prioritization of gender mainstreaming in HIV/AIDS programs are partly a reflection of the inconsistencies in commitment to a gender

priority in the global health community. A fact also reiterated by a policy maker in the public HIV/AIDS sector who states that while most international development bodies are invested in gender issues, the United States government through PEPFAR is less emphatic about gender.

*“Well, the NGOs may not but as a country we are a signatory to most arrangements or this world grants and you must report on gender as a country for instance, as a country we have a report that we present every year called Global AIDS Response report and gender issues must be reported and that is to both UNAIDS, WHO and other UN group, UNDP even for UK Group, the DFID<sup>30</sup> program, gender is emphasized, I think the only organization that may not be emphasizing gender is probably US, the PEPFAR group because most of their indicators may not [interruption] US government, I have looked at all their indicators they are not as very strong in terms of gender, unlike the UN system, UN system and UK, they emphasize gender, in fact, at times they support special evaluation, that you must include a gender consultant in your evaluation team but I think the US has not being too emphatic about it.”- Male policy stakeholder*

These inconsistencies at the global level are transferred to the national HIV/AIDS intervention landscape through local programs or interventions as exemplified in the disordered national gender intervention landscape: from a no gender plan or limited gender plan to a comprehensive gender plan as one moves across public and private HIV/AIDS institutions. At the NGO level, the lack luster gender approach particularly by NGO A directly affiliated with the United States government through PEPFAR funding bears testament as we see in the previous quotes.

However, donor influences or regulations appear to vary by sector. For the public sector national HIV/AIDS coordinating body like NACA, it is usually an equal signatory or partner to most of its unilateral and bilateral agreements as it operates directly under the auspices of the country as a national partner. While this might still be an unequal partnership to some extent even at the country level, NACA may be less regulated by donor rules in terms of how funds should be

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<sup>30</sup> The Department of international Development (in the United Kingdom)

disbursed whether to gender issues or otherwise. However, it appears that donor agencies are now beginning to realize the importance of gender mainstreaming but interest and commitment are mostly contingent on how naturalized these organizations are. That is, if they have a strong local presence that positions them to access firsthand knowledge of local gender issues and their significance, as this quote demonstrates.

*“So I will say it’s on a spectrum, if you have multinational organizations like UNFPA and has had office in Nigeria for years it gets a major grant, gender grant [they] adapt to it to local issues [and] start sourcing for NGOs, you have alignment but [if] you have an NGO just entering Nigeria today [and] has a mandate from the funder, deliver on this this this, if the gender issues is not so prominent on it, they just run with what the funder says they should run with so it’s a spectrum for major organizations, maybe not even multilateral, just organization that have been in country for a long time and they have drank and eaten our issues and they know where we are at, they will still develop an intervention that is close to reality...” - Male NGO practitioner*

Also significant to the ways the international health community impacts the local gender landscape is the transfer of specific standard global health norms and practices that inform how national and local HIV/AIDS institutions frame and practice gender. Most global health institutions have increasingly adopted a scientific approach to interventions emphasizing effectiveness and performance of interventions on “scientifically based measures of evaluation” while neglecting basic fundamental logics of tailoring intervention programs to specific needs, unique “practices and rationalities” of the recipient countries (Biehl, 2011, p. 106). For example, global health programs often treat populations as homogenous entities when they frame and measure intervention impacts through purely quantitative measures or overly preoccupied with statistics like the reduction of AIDS mortality rates or increasing numbers of people with access to treatment and not the specific ways individuals experience these interventions.

Reports of programmatic evaluation through monitoring and assessment indicators that underscore sex segregated data is a core requirement of donor sponsored HIV/AIDS programs. Little attention is given to other intersecting demographic characteristics like social and economic class, marital status and age which differentiate groups of people or provide information on the specific parts of the population actually having access to treatment. Given the evidence from this study's population of HIV seropositive women, we know that poor uneducated women are less likely to initiate treatment or drop out of treatment after initial uptake, and this is further complicated by age and marital status with older women less accessible or adherent to treatment than younger married women. Often times therefore, national or global statistics and figures belie the huge inequalities existing on the ground and other social factors that limit access within and between gender groups. Nonetheless, statistics in numbers disaggregated by sex remain the evaluative criteria set by global health institutions to measure the impact of development programs including HIV/AIDS. For example, all the institutions understudied deploy sex disaggregated data by number of males and females reached to monitor and measure program impact.

*"...though the tools, the registers are disaggregated by sex...so if from the indicators [it is] lacking...if you want visibility and clarity you should be able to say the number of boys and girls, in your brain you know that when you go out there you will be looking out for those components boys, girls, women and men so when you are getting your components and you are writing your report you should be able to write it clearly so that those policy makers, project managers will be able to program or write their budget for women say okay these are the things that are really affecting the girls or the boys because [if] you just lump them, people living with HIV, okay you just say people but when you start dissecting them..." - Gender consultant*

This international development convention of conducting impact assessment through numeric measures of sex disaggregated target goals I argue negates the core principle of gender

mainstreaming which is assessing the *implication* of particular development actions on men and women. The conventions and terms of monitoring and evaluation deployed by international health organizations are fundamentally weak and reductionist in achieving comprehensive assessment of gender impact programs. For example, the commonly used term, *impact indicator* as a health assessment metric can be understood to connote something more than a numeric change to include a more comprehensive or qualitative change particularly for certain programs that target transformative social change like gender. Yet, it is measured numerically. Is the rationality for statistics the fact that numbers can produce an overwhelming effect or even beguiling in the absence of quality in the impact of programs? Or does this speak to a similar argument by Davis and Howden-Chapman (1996) of the need to deploy policy language strategically in ways that appeal to multiple policy audiences. For example, numbers as statistically significant or ethnographic findings that are emotive and responsive to human drama if health research is to gain traction with policy makers? Among institutional health actors, gender dynamics appear to underpin the preference for quantitative versus qualitative measures in assessing the impact of HIV/AIDS programs. See the statements of a policy maker below:

*“Men are more especially men that are educated...are gender sensitive, they have [gender] at the back of their mind especially when the program is driven by statistics, you try to look at how it affects the various groups and you try to be objective.”- Male policy stakeholder*

*“I think in positions where I have actually served or where I have acted I find out that most of the time women may be more selfish than men because men are driven by statistics...Irrespective of who is affected men will go a long way to fight that cause...”- Male policy stakeholder*

Although this participant does appear to be unbiased in terms of personal gender orientation as the major driver of male predisposition to mainstreaming gender in HIV/AIDS interventions, he implicates women as more likely to be influenced by such subjectivities. In his own opinion,

male interests in gender focused interventions are driven more by statistics and the burden of disease. In other words, male policy actors exercise objectivity and rational reasoning in their commitment to gender ( which ties into the feelings of justice on moral issues as espoused by moral development theorists like Lawrence Kohlberg) issues driven by the hard facts of science and empirical evidence while women are more driven by context, emotions and their personal subjectivities. This oppositional construct of a gendered morality between men and women is a core argument and point of contestation between moral philosophers and feminist care ethicists (see Tronto, 1993; Gilligan, 1993). Undoubtedly, understanding this binary in the sense of morality as it shapes the enactment of equity and gender justice among male and female policy makers might help health researchers design their research in ways that elicit a more comprehensive gender commitment to HIV/AIDS issues in third world spaces. Considering the strong male presence within the global health domain, it is no wonder that global health interventions may have emerged as a hard science (implementation science), and institutional and program evaluation metrics driven by statistics and numbers.

Going back to the earlier argument however, the nature of gender mainstreaming does lend itself to alternative ways of monitoring and assessment through qualitative measures. Hence, this chapter argues that traditional monitoring and evaluation measures do not suffice to capture the essence of gender program impact on populations. Therefore, more methodological rigor that includes qualitative data techniques should be embraced. In the review and assessment of Nigeria's gender response to the HIV/AIDS epidemic conducted by NACA in 2013, more rigorous data collection techniques like focus group discussions although more time consuming and cost intensive were deployed as a gender assessment tool one time. Nonetheless, it produced a rich analysis and assessment of the national gender situation in respect to HIV/AIDS. It

assisted in unraveling where the national gender response is making substantive impact or otherwise. Statistical counts may therefore, be less rigorous and cost saving but negate the goal of the impact approach; the *how* in gender mainstreaming which targets the ways that women and men receive or are impacted by development programs and strategies. Hence, there is need for more comprehensive and effective evaluative measures.

In the final analysis of the role of global health institutions in gender mainstreaming within the Nigerian context, this chapter also draws attention to how power loaded transnational relations shape local orientations of gender through the transfer of knowledge from the globalizing spaces of the global north to the global south. This is actualized through capacity building programs like workshop trainings and seminars with the content of training manuals designed around western notions of development or program implementation. Sometimes, trainers or mentors are foreign development actors or indigenous development practitioners that are passing on information and knowledge accumulated directly or indirectly from these western institutions. These capacity building programs have become customary and a staple component of local institutional health governance with NGOs especially mandated to continue this tradition as they implement donor funded programs at the grassroots. Here again, training or capacity building programs are evaluated based on sex disaggregated statistical data. Therefore, beyond the methodological reductionism through monitoring and evaluation techniques as previously argued, is the categorical notion of gender that is unintentionally reproduced by these deeply entrenched global health practices and how they reify the notion that gender equality means *gender balancing* by the numbers.

*“...we are not yet there in terms of ensuring equity because of several factors; several factors militate against ensuring that we have a gender balance response. For instance, when you go to*

*some facilities you have to ask to train equal numbers of males and females...if you want to do trainings let's say you want to train equal numbers of males and females and there are no females in the place, since you cannot manufacture them, you will end up training what you find but whereas your intention is to have a balanced group of participants both males and females so that each gender will be [equally] represented but sometimes, it won't work out the way you plan, that is for capacity building but for other aspects we try as much as possible to involve as many men and women in the activities.”- Female NGO stakeholder*

In what Rogers (1980, cited in Kabeer, 1994) describes as western feminist notions of inequality or equality, this sort of false and artificial division may produce unintentional bias or discrimination in the sense that third world women's issues go beyond bringing parity between the sexes in terms of program reach if the deeper structural processes that induce such disparities are unaddressed. At the level of implementation, these superficial impact measures create a dichotomy between men and women, obscure the relational power of gender and belie the struggle against poverty, subordination and other forms of oppression that women daily grapple within their micro geographies. Ideologically, this notion of equality challenges the effective practice of gender mainstreaming as gleaned from the analysis of policy responses. The conflicting notions of gender mainstreaming have been hitherto cited where policy makers articulate this concept in terms of reaching equal number of men and women but less the impact or how particular development strategies may disadvantage a particular gender group.

An underlying issue however, is that most health programs by default are set up based on categorical gender constructs from institutionalized global health tradition and practices. This culture according to one of the policy stakeholder stifles the practice or even the ability to sell the ideology of a “*core gender mainstreaming program*”. This core gender mainstreaming is a more conscious and systemic integration of gender considerations in interventions which include

gender analysis, gender budgeting, gender auditing, and gender consultancy. By default, gender mainstreaming is approached in two ways: core gender mainstreaming is driven by a more thought out consideration of the gendered implications of certain programs; while the other evolves from pure considerations to empirical data or statistical evidence that appear to be representative of men and women by numbers without a deeper impact analysis. Although both are geared towards equality, the processes and outcomes are remarkably different.

Gender mainstreaming in HIV/AIDS interventions some policy stakeholders argue, is already being done because their programs are focused on women. To corroborate, one of the participants states that gender is a “*broken down concept*” because people in different program areas perceive themselves as doing gender because by default, programs are designed for women and men. Sometimes, this is misconstrued as being gender sensitive. This is an important piece of knowledge which demonstrates institutional misconceptions about gender but also the source of such local misconceptions which is not always directly visible. Consequently, gender is not consciously mainstreamed by design into programs and by implication, not practiced with conscious considerations to the much needed transformative change.

Apparently, there is a difference between just focusing on women’s issues or men for that matter because of identified empirical gaps in observational data and consciously doing this to ensure sustainable equity outcomes for both women and men. Less emphasis is therefore on process and transforming structures and more on coverage by numbers of men and/or women reached. Yet, it is in this conscious deliberation and attention to (social) processes that the inequalities around women living with HIV are reworked such that resources that accrue from interventions do not bypass them. Instead, through inbuilt equity mechanisms in interventions, HIV positive women are positioned to benefit from resources that are meant to redress their treatment challenges.

While this analysis has demonstrated the discourse of HIV/AIDS interventions among policy stakeholders, the next section details the textual discourse of HIV/AIDS interventions based on existing policy documents.

### **Gender in HIV Treatment Interventions: A Discourse Analysis**

Gender considerations in official Nigerian HIV/AIDS policy documents do provide the semblance of a national commitment to a gender response. However, the challenges among grassroots HIV positive women on treatment in the Niger Delta because of gender inequalities contradict this commitment. As feminist scholars like Kabeer (1994) argue, gender visibility in policies and programs does not necessarily translate to improvement in the lives of women if unaccompanied with the political power and material agency to transform unequal structures. Furthermore, attention must be paid to critical questions on process - how gender is inserted into interventions to challenge and rework exclusionary development practices. This is the main focus of this section. This attention entails the deployment of gender theories that address aspects of social and/or gender relations and their intersectionality with other factors of influence, as well as the use of participatory methodologies among women to mainstream their voices in development. In other words, questions around the appropriate conceptualization of gender must be asked and critical attention paid to the methods deployed to provide functionality to gender in development. For example,

- Is gender framed as relational or as essentialized categories of men and women?
- Is gender constructed as intersectional with class and other axes of power and difference?  
Class relations and social disparities (e.g. religion, education, income, ethnicity or culture) can differentiate how a particular gender group like women negotiate inequalities in health
- How is gender claimed within development, as a right, a need or both?

- Are the methods of inserting women top-down exclusive or bottom up and participatory?

Contemporary feminist theories on development are centralized around these themes (McIlwaine and Datta, 2003; Kabeer, 1994; Connell, 2012; Springer et.al., 2012); therefore, these questions underpin and influence the direction of this discourse on gender in HIV/AIDS interventions.

Central to the focus of this analysis is also to illustrate the ways power maybe permeated through institutional discourses in unintentional ways that oppress and disempower minority, powerless and marginal groups like (HIV) women. This thesis was originally based on the premise in the literature that effective gender outcomes are contingent on how gender is framed and conceptualized (Connell, 2012; Hunter, 2010). Policy stakeholders' narratives from this study show that while this is true, it takes more than the correct framing of gender to be effective if contextual forces like gender and cultural politics and other institutionalized practices are unaddressed. Although significant, the correct framing of gender does not always mean that its practice or implementation will be correspondent. Institutional and local context are key to effective gender practice as findings from this discourse analysis of policy texts again solidify this position, given that the discourse gets better in policy but not the practice.

The propositions made in this section are based on the results of a policy review and discourse analysis of HIV/AIDS and gender policy documents on the national multisectoral and strategic response to the disease, documented implementation frameworks and action plans between 2000 - 2015. The policy documents, all HIV/AIDS and gender related were sourced from different public sector national and international HIV/AIDS organizations<sup>31</sup>. The empirical evidence presented here is limited to the body of texts analyzed for this purpose so caution is deployed as to the generalizability of this analysis to all policy response on the epidemic. This analysis

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<sup>31</sup> See the appendix for an inventory of the documents.

touches on several themes in this study with gender barriers in HIV treatment interventions as central. This discourse centralizes treatment and gender through attention to language, ideology and meanings using a textual analysis. Like Seidel (1993), this study treats discourse as an intertextuality or interaction of texts. Hence, a discourse as deployed here is not treated as a distinct separate unit but as a coalition of languages and ideologies conveyed through texts and how the production of this intersection - their combined meanings - impacts or explains institutional barriers to women's sustained access and adherence to treatment and care. Silences and exclusions in these policy texts and their meanings and implications for women living with HIV are also examined and foregrounded.

Presenting this analysis, this section is divided into six short sub sections according to topical issues within the Nigerian HIV/AIDS intervention landscape. The first sub section is an overview of Nigerian HIV treatment interventions from inception to the current. The second sub section examines the major approach deployed in the response to the HIV/AIDS epidemic which is multisectoral and identifies representational politics and poor coordination among the different administrative tiers or bodies responsible for HIV/AIDS programming in the country as major gaps. The third sub section briefly explores the paradigms of HIV/AIDS interventions through time - the changing discourse from preventative approaches to treatment or biomedical focus and recently, more biosocial considerations - and their underpinnings or rationale. The fourth sub section narrows down into the policy discourse of treatment and care and how HIV positive women are centralized within this. The fifth section details the changing discourses of gender through time with the history of a conscious gender mainstreaming in official HIV/AIDS interventions in Nigeria only about a decade old. Sub section six provides a synopsis of the discourse analysis and concludes that while the discourse of HIV/AIDS treatment from a gender

and social perspective in policies has improved over time, its practice has not been commensurate. Gender conceptualizations in HIV/AIDS policies are still flawed and like policy stakeholders, are not consistent throughout and implementation is far from the level of theorization that exists in these policy texts.

### ***Overview of Nigerian HIV/AIDS Interventions***

Like many sub-Saharan African countries affected by HIV/AIDS, Nigeria has experienced different phases of response to the epidemic. Nigeria made a first active response to the epidemic in 1999 through the establishment of the Presidential Commission on AIDS (PCA) in the first democratic regime post military era. Since then, the country has moved through different phases of interventions reflected through its tripartite policy documents: the *HIV/AIDS Strategic Framework and Implementation Plan*, the *National Response Assessment*, and *Monitoring and Evaluation Plan*. The structure of these documents - each with a 5 year plan - shows that Nigeria has undergone three distinct but connected phases of HIV/AIDS interventions from 1999/2000 - 2004; 2005 - 2009; and 2010 - 2015 besides the very early HIV/AIDS response that is not actively considered as an intervention phase. In the context of this study, I refer to these as the first or early phase, middle phase, and third or most recent phase respectively. With increasing knowledge of the epidemic and the need to strengthen the country's response, other supplementary policy plans particularly gender were launched and established subsequently, overlapping with some phases of intervention. I had the opportunity to be present in one of such gender policy dissemination meetings in December 2014 during my field work where the document on the National Plan of Action addressing Gender Based Violence (GBV) and HIV/AIDS Intersections for 2015-2017 and other gender instruments were launched. These

gender documents were also analyzed, in addition to the three broad document types aforementioned.

### *The Multisectoral Response*

As part of a national emerging HIV/AIDS intervention landscape, Nigeria adopted a multisectoral approach in response to the intersectional nature of the epidemic and in response to the “Three Ones” principle launched by the international HIV/AIDS community to promote a universal coordination in the fight against HIV/AIDS (WHO, 2015; UNAIDS, 2004). The “Three Ones” mandate the national response of developing countries to operate under One HIV/AIDS coordinating agency<sup>32</sup>, One strategic plan (National Strategic Framework) and One monitoring and evaluation system<sup>33</sup>. A multisectoral response involves a coalition of relevant public and private sector agencies and a multifaceted program intervention that simultaneously targets multiple areas like prevention, treatment, care and support and more recently, gender. As with any syndicated enterprise, there have been significant challenges particularly in terms of administration and coordination of the national response between and across private and public HIV/AIDS sectors, among the different ministries and sectors, as well as the different tiers of program administration - national, state and local across sectors or ministries as the following quote depicts:

*“The present multisectoral approach still lacks a legal and institutional framework through which to operate and the sectoral roles of the various implementers are yet to be well defined. This has led to poor coordination, multiplicity of effort and an inability to fully maximize*

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<sup>32</sup> In Nigeria’s case, it is the National Agency for the Control of AIDS, NACA

<sup>33</sup> In Nigeria, these two last principles have produced two corresponding policy documents (mentioned in the preceding section), in addition to the national response assessment document. These form the tripartite policy documents through which the country makes its response to the epidemic; in addition to other supplementary policy documents and guidelines like gender.

*investments in the actualization of...objectives” - Policy document: National Policy on HIV/AIDS (NACA, 2003, p. 7).*

The outcome has been duplicity and replication of efforts, a problem that has persisted from the early phase of interventions to recent times. While NACA could be said to be a sign of a political commitment to HIV/AIDS response at the national level, the lower level parastatals like SACA<sup>34</sup> and LACA<sup>35</sup> at the state and local levels respectively were established as part of the federal government’s directives to expand the HIV/AIDS response and governance. However, political will and commitment at these lower levels are severely lacking, underfunded and consequently, less functional. In particular, the local arm of the HIV/AIDS intervention network (LACA) which is supposed to directly oversee implementation activities at the grassroots. The quotes below corroborate this assertion (and also confirm stakeholders’ responses).

*“...the State Action Committees on AIDS (SACAs<sup>36</sup>) and the Local Government Action Committees on AIDS (LACAs) were mainly the result of the Federal Government’s directives. There is little evidence of true commitment in many state and local governments as shown by initiatives undertaken proactively to control the epidemic in the various states” - Policy document: National Policy on HIV/AIDS (NACA, 2003, p. 7).*

*“There are critical shortfalls in technical and managerial capacities in most SACAs and all LACAs. Poor funding of SACAs remains a pernicious and recurring issue. Political interference in coordination structures distorts relationships and linkages of institutions at several levels” - Policy document: National Strategic Framework for Action 2010-2015 (NACA, 2010, p. 22).*

These weaknesses create fundamental gaps in the intervention chain (including on gender issues) because the lower tiers particularly LACA which serves as a direct representation of the grassroots population highly underperforms. Even though a bottom up approach is deployed in

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<sup>34</sup> State Agency for the Control of AIDS

<sup>35</sup> Local Agency for the Control of AIDS

<sup>36</sup> So called before it was changed to State Agency for the Control of AIDS

gender HIV/AIDS interventions as stated in policy documents, it is weak in the sense that the mechanism to effect or enable interventions that is grounded from the bottom or local context is undermined by the underperformance of these lower tiers. A fact that was confirmed at the Erhoike Cottage Hospital where the representatives of the HIV/AIDS support group decried the non-access to government HIV/AIDS agencies and their weak participation in local interventions.

This also raises the questions of difference and representation of the voices of local HIV positive women at the national level. Nonetheless, most of the national documents claim a participatory approach and meaningful engagement of people living with HIV/AIDS (PLWHA) and other relevant stakeholders in gender consultations by gender experts in order to mainstream local gender concerns but women's responses declare otherwise. Logically, this calls for the need to address issues on social and class locations around the way needs or interests may be represented, if national programs are indeed representative of all categories of women like those understudied.

### ***Paradigms of Interventions***

Dominant paradigms of interventions in the country's HIV/AIDS response over time as inferred from policy documents have been both biomedical and biosocial. Human rights, social justice and equity are hegemonic discourses that resonate throughout the policy texts from the early phases of interventions and these constitute the biosocial paradigm. At the early to middle stage however, rights were deployed not in terms of challenging the existing structural statusquo that violated the rights of marginalized populations like women and predisposed them to the risk of infection from HIV. Rather, rights were invoked against the discriminatory attitude which prevented voluntary confidential counselling, testing and diagnosis by individuals with the sole

purpose of addressing underreporting and other barriers to preventive efforts. In other words, although rights were invoked as a human entitlement, it was done more as a public health measure to curtail the epidemic and not necessarily to preserve the rights of individuals to be free from the structures that exposed them to the risk of transmission. Although the focus on rights was well within a social medicine framework, it was more a preventative bias of public health agencies given the context of the epidemic especially in the absence of treatment, rather than a deliberate and conscious adoption of the biosocial model as an appropriate response to the epidemic. Thus this biosocial approach was more based on the contingencies of the epidemic at that time.

As expected at this period (at the early to middle phase), public health emphasis was on prevention and control and less treatment, and preventative discourses were centered on behavioral change and not strongly on structural models. In the latter stages of interventions, rights became more people centered although outcomes appear not to have translated into much substantive improvement in the lives of infected individuals. Some of the policy documents did acknowledge this challenge inherent in the weak power of rights to protect PLWHA<sup>37</sup> because policies in Nigeria do not yet have the power of laws. Furthermore, there are no explicit laws on HIV/AIDS even now except reference to general human right laws that prohibit discrimination of any kind. It is the same way that the existing weak legal framework is unable to protect the rights of HIV positive women.

*“The challenges for effective HIV/AIDS-related policies include weak links between community experiences and policy designs, slow pace of development, lack of legal backing and limited awareness of existing policies among potential users. There is an urgent need to revise legal*

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<sup>37</sup> People Living with HIV/AIDS

*instruments to ensure they are gender-sensitive and in sync and harmony with other existing policies”- Policy document: National Strategic Framework for Action 2005-2009 (NACA, 2005, p. 27).*

*“The problem is that, at the moment, there are no HIV/AIDS specific laws on the statutes. As legal reforms have been notoriously slow in coming and without the backing of the law, government policy documents can only be inspirational in wishing for an effective national HIV/AIDS response that respects the rights of PLHIV [People Living with HIV] and PABA [People Affected by AIDS)....The absence of explicit laws leaves PLHIV extremely vulnerable to the violation of their rights...” - Policy document: National HIV/AIDS Response Review (NACA and UNDP, 2009, p. 14).*

As at 2005 in the middle phase of intervention, there was still no mention of antiretroviral (ARV) access in policy documents so it seemed treatment was still generally elusive at this time and only available to a few. Hence, access as an issue was foregrounded but defined based on considerations like ARV unavailability and inequalities in access but with emphasis on actual treatment goals and less the social processes that surround treatment. Equity was defined in economic (affordability) and physical terms and not from a gender relations perspective because geographic and economic access were the most visible constraints to treatment at the time. Social services in treatment were not central or mainstream and neither was gender. The concern was purely treatment - availability, quality and delivery of antiretroviral drugs to the general population. When women were focused on, it was to ensure their access as a high risk group to reduce transmission rates either through vertical transmissions to children or horizontal transmission through commercial sex work.

However, with increasing access to treatment over time, the need for social and support services in particular, to poor infected individuals and other marginal groups with poor access segued into the launch of other policy documents that focused solely on care and support in treatment to

enable better and sustained access to treatment in the recent phase of interventions (2010-2015). With Nigeria's commitment to universal access to health and in line with the Millennium Development Goals (MDGs), universal access to treatment appears to have come into being towards the end of the second phase of intervention around 2009/2010. Even at this phase and with social dimensions consciously mainstreamed into general HIV/AIDS policies, treatment still lacked a clear gender perspective and the social aspects of treatment were weakly framed.

### ***Treatment, Care and Support as a Discourse***

Although there were still gaps in physical treatment access despite the year 2010 targeted for universal access to treatment, with increasing access to ARVs at this time, other forms of inequalities that inhibited access to treatment like gender and the need for care and support services for people living with HIV/AIDS (PLWHA) emerged. HIV/AIDS support groups and other forms of social support are cited as factors that can improve adherence in the policy documents. However, care in these documents is mostly conceived as care needed to be rendered to PLWHA and less in terms of the caregiving activities that PLWHA engage in that could alter their access and adherence. Care burden was not addressed specifically in terms of the women affected by HIV and burdened with the responsibility to care for others but referenced in terms of the family unit and health workers as caregivers to PLWHA. Support for the caregiver is thus acknowledged but it is not explicit if caregivers are referenced as those infected by HIV, whether as women or just other family caregivers at the household or community level who provide care to PLWHA. Ironically, among HIV positive women interviewed for this study, there is a reversed reality as these women are the ones actually burdened with caregiving responsibilities to their families (see chapter three); an observation that appears to be absent in the policy documents that focus on the thematic areas of treatment, care and support. There is a dire need to

not only recognize that women living with HIV face care burden but intervention plans should be targeted as such.

### ***A Gender Analysis***

Earlier policy documents in the first phase of interventions 2000 - 2004 did not show an explicit consideration to gender (see USAID, 2002; HEAP, 2001, and Situation Assessment of HIV/AIDS in Nigeria by Family Health International policy document). Initial stage interventions on gender were weak because of the many unknowns about the epidemic and efforts were mostly geared towards disease control. At best, the deployment of gender signified a focus on women because the feminized nature of the epidemic gave way to the silent constructions of women and their bodies as risky subjects which fostered critical national attention to maternal health and other reproductive issues as women's bodies especially pregnant women were considered as obvious transmission routes with such discourses as we see below.

*“...an increasing number of children are being infected with the virus, through mother to child transmissions...by all indications, the HIV/AIDS epidemic has continued to grow largely... through mother to child transmission...”- Policy document: National Policy on HIV/AIDS (NACA, 2003, p. 2).*

*“Nigeria shall place the highest possible priority on ensuring nationwide access to antiretroviral medication for all pregnant women with HIV and treatment provided at delivery to prevent vertical transmission”- Policy document: National Policy on HIV/AIDS (NACA, 2003, p. 14).*

An active gender plan began in 2005 and gender mainstreaming as a formal concept and strategy was officially launched through the five year National Strategic Framework policy document (NSF) for the period 2005-2009. This confirms that gender mainstreaming is a relatively new concept in Nigerian HIV/AIDS intervention which partly explains the multiple challenges the

country is presently navigating as previously detailed. In the National Strategic Framework policy document during the middle phase, gender is articulated but still mostly in reference to a specific category, pregnant women through the prevention of mother to child transmission (PMTCT) programs as with the earlier phase. In this middle phase, gender considerations were vague and very broad based. For example, the use of the term “gender sensitive” programs with little to no specifics in details, in terms of identified gender strategies. Male involvement is also referenced but mostly in terms of PMTCT and also lacks details to its implementation.

Gender discourses began to significantly change and better articulated in the third and most recent intervention phase (2010-15) as gender mainstreaming became relatively more centralized. Women began to receive focus in HIV/AIDS policies for their self-worth and value as women and not solely for their biological role in reducing transmission and mortality rates in the general population as we see in the policy statement below:

*“In most African societies, women are the homemakers and they play a central role in stabilizing families and maintaining its health. There is evident need to keep women healthy and safe for the sake of their health and the stability of the family” - Policy document: National Guidelines on HIV/AIDS Care and Support (NACA, 2014, p. 15).*

Nonetheless, some of these latest policy documents still reveal an antithesis as gender is defined in relational terms but proposed strategies are deployed in gender specific terms to include only women and girls. In another document on gender based violence and HIV/AIDS intersection launched by the Federal Ministry of Women Affairs in collaboration with other partners, gender is used to refer to men and women categories and even in an intersectional sense. It does seem that there is some inconsistency in the way that gender is appropriated sometimes as intersectional depending on the organization framing gender; other times the relationality and

intersectionality of gender is almost obscured or elided. For example, the policy statement above which states that women as homemakers need better access to care because of the central role they play in stabilizing their families and maintaining health does not specify which categories of women (whether HIV positive or not, or the social demographics of women being referenced) need this most because rich educated women can afford to pay for domestic help at the household level and may not be affected by such family dynamics. Within a scarce resource situation, it becomes pertinent to specifically mobilize resources to a target population in the most need and not over generalizing needs to a gender group.

Sometimes, the issue of male involvement is centralized; in some other documents, it is silenced or when deployed, it is in a very specific sense of PMTCT and less in general adult antiretroviral treatment access which covers the generality of women. As a result, there are a lot of gender discourses that focus on pregnant HIV positive women through PMTCT programs compared to other categories of women in the most recent intervention phase. Some of the policy texts do not consider specific barriers to treatment and adherence but generalize to the infected HIV/AIDS population. Gender barriers are thus acknowledged generally but in the thematic area that focuses on treatment and health related problems, male involvement is also absent. Male involvement is mentioned in some of the activities designed for thematic areas in prevention like Behavioral Change and Prevention of New Infections but not in treatment as also a preventative effort.

There should be an explicit and strong male involvement component in treatment interventions so that women can get the required male support they need to adhere to treatment. Other policy documents like the NSF 2005-09 from NACA addresses general gender issues in treatment albeit superficially. This is to say that the level of awareness and depth of gender knowledge among

institutions are different; hence, the inconsistency in framing gender and gender issues in treatment. This may also imply that institutions may not be collaborating as much given the country's multisectoral response particularly in the aspect of formulating a cohesive gender plan across institutions that addresses same issues of treatment. In general, while the discourse on gender has improved through time, it is still flawed in many ways in how it is framed and deployed.

### *Synopsis*

Although replete with flaws and gaps, a fine policy blueprint on HIV/AIDS and gender response has emerged over time but implementation does not match up. The narratives of gender and other social barriers to treatment by HIV positive women at the Erhoike Cottage Hospital are a testament to this disconnect. Generally, policy plans appear to acknowledge the problems than a practical and effective plan to address the issues. There is also ambiguity in conceptualizing gender and the lack of clear and explicit gender strategies across gender policy documents but this varies across documents depending on the institution responsible for such policy plans. Gender documents reveal inconsistencies in the ways gender is deployed sometimes as relational as involving men (albeit and usually in the context of maternal and reproductive health through the PMTCT program), other times as intersectional or categorical. This observation reveals inconsistencies among institutions, disparity in gender awareness and conflict in strategies in mainstreaming gender plans into policy guidelines. These inconsistencies also mirror a state of disorganized gender ideology and response among relevant policy institutions; a fact that is confirmed through the narratives of policy makers as we see in the preceding major section and draws attention to the need for a unified gender response. The lack of a unified and cohesive gender response can cause programmatic confusion among implementation partners (IPs) or

policy practitioners that deploy these conflicting policy guidelines at the level of execution. For example, definitions of programmatic concepts like gender mainstreaming are not strong or as explicit; they are vague and ambiguous at best. Consequently, implementation partners at the local level who may not be very gender aware may not have full understanding of how to implement or carry out gender mainstreaming activities and continue to think of this concept in terms of male and female disaggregated data which is the default gender interpretation and norm across most local HIV/AIDS institutions in Nigeria.

In the most recent policy documents on gender mainstreaming, there are none that specifically or explicitly provides guidelines on mainstreaming gender into treatment. The general HIV/AIDS documents are great in that they provide deep knowledge of gender inequities around the disease but for a more effective response, these gender strategies also need to be designed in specific reference to treatment access and adherence so that IPs can have a clear programmatic guideline on how to specifically mainstream and implement gender sensitive strategies in treatment interventions. Other gaps or silences in these policy documents include the exclusion of the activities of the private sector e.g. NGOs as they promote or impede the national HIV/AIDS and gender agenda. Existing HIV/AIDS policies are mostly based on public sector activities and on public sector HIV/AIDS institutions without (explicit) reference to the NGO sector and their activities which are a strong component of the Nigerian HIV/AIDS intervention landscape.

## **Conclusion**

This chapter aimed to expose the barriers to effective gender mainstreaming practice and to problematize this within the context of institutional (local and transnational) power relations. Consequently, I unpacked the relations of institutional power on multiple scales and underscore the specific ways they frame gender and the equality agenda and re-perpetuate the inequalities

that these institutions are ostensibly committed to redress. I conclude that failure to promote gender equity in development policies cannot be attributed solely to a gender irrationality among local health planners and practitioners (Kabeer, 1994). Reason is, among the not so visible forces are the institutionalized machineries of transnational governance that re-perpetuate both conceptual and methodological ambiguity in the effective incorporation of gender into HIV/AIDS policies and interventions.

I also demonstrate that context in third world spaces is an imbrication of the local and the global where local health practices are mostly shaped by the global health and aids economy. Therefore, attention to local context in the policy and practice of gender mainstreaming cannot be divorced from these invisible yet powerful global connections. These connections must include the role of NGOs as vehicles of transnational health governance but most importantly foreground the intentional developmental activities of transnational health actors themselves and ways they reproduce local gendered health inequalities despite an equity agenda that speaks to the contrary. In this way, I have shown that attention to local context should not preclude global connections and the ways that their particular practices contribute to local gender gaps and failure to significantly rework the conditions of HIV positive women seeking treatment and retention in care.

The next chapter concludes this argument and the analyses from previous chapters with a major recommendation to reconcile the gaps between institutional gender practices in HIV/AIDS interventions given the disconnect between what HIV positive women need to sustain their access and the nature of resources that accrue from interventions.

## **Chapter Seven**

### **Reconciling the Local with the Global: Conclusions about Unending Work**

This research has investigated how gender shapes women's HIV treatment access in Nigeria's Niger Delta region and how these gendered inequalities in treatment access become reworked locally through both public national level HIV/AIDS policy interventions and the interventions of global-local NGOs. As a recap, chapters three and four focused on women's subjective experiences of treatment which are shown to be co-occurring with a complex set of social and material conditions but within a wider matrix of the political economy, patriarchal power relations and the environment. Chapter five addressed issues on women's agencies versus the role of institutions in enabling women to effectively negotiate the barriers to treatment. Chapter six demonstrated using policy and critical discourse analysis how institutionalized discourses on health and gender through policy ideologies, texts or language of interventions act to disempower women's ability to sustain treatment access. These analyses were situated within the historical and contemporary political economy of oil and other place relations in Nigeria's Niger Delta as they shape the present physical and social landscape as well as produce institutional barriers to HIV treatment.

While the evidence offers valuable insights into the proximate conditions in which women's unsustainable treatment access occur as mostly social but disconnected from the constructions and implementation of treatment interventions, the privileging of biomedical technologies over biosocial models of health are also challenged and destabilized. Knowledge gained from women's experiences of HIV treatment and self reports on their perception of HIV/AIDS interventions are therefore, significant to this research thesis and overall rationale which is to understand the constructions of health from the standpoint of those whom interventions are

designed for. More significantly, this situated knowledge makes a profound contribution to the health geography scholarship which broadly frames this dissertation; a scholarship that centralizes health and wellbeing and constructs these as intricately interwoven with social processes as a departure from a pure disease model that isolates the activism of place processes and relations.

From theorizations in the literature to empirical observations from this study, a conclusion that has emerged is that health is situated at the intersection of social and material forces that are actively constructed by place. Given this intersectionality, health and wellbeing can only be realistically achieved through equal and adequate attention not only to the biological but also the social conditions that produce their emergence. The debates of disease and treatment versus health and wellbeing that are replete in the health/medical geography and global health literature are re-enacted through these women's experiences. Personally observable practices of interventions during this study in addition to women's accounts not only reestablish this binary, they validate this as the statusquo in Nigeria, at the risk of overgeneralizing.

This inadequacy of the biomedical model of care in producing healthy outcomes has led leading geographers like Kulkaranian and Subramanian (2010), Kearns and Collins (2010), Hunter (2010) and more to emphasize health and wellbeing over a monopoly of a strict treatment or curative approaches. In this way, women's accounts re-echo the voices of health geographers of the need to emphasize the human and behavioral aspects of medicine. The empirical evidence also reinstates the need to move towards more interpretive methodologies in understanding the situated and local constructions of health concepts like needs and effective access. Hopefully, such continued emphasis will undermine and displace the long history and legacy of biomedical explanations in understanding and proffering comprehensive solutions to the multifaceted

dimensions of population health and institutionalize the need for more social aspects of medicine.

In practice, the evidence is established from users own voices that a comprehensive gender sensitive HIV/AIDS care model that emphasizes health and wellbeing is less centralized in interventions. Rather, focus has been more on physical access to drugs and maintaining adherence for curative purposes aimed at reducing prevalence or incidence rates but not much in terms of the challenges that confront treatment reception by the target population. Outcomes of needs met are usually not measured in terms of improvement in the quality of life but in the numbers of people receiving delivered goods and services of supposed treatment. Such an intervention premise will continue to be detrimental to the goals of interventions and importantly, the lives of millions of people particularly women currently accessing treatment.

This fact therefore, brings to the fore problematic representations of women and or gender needs designed from global and national spaces far divorced from patients' needs at the grassroots.

Local knowledge of health and wellbeing from the perspectives of the users help to challenge the popular politics of interpretation and needs assessment within intervention circles. In preceding chapters, HIV positive women have strongly articulated and recommended a more meaningful participatory process where they can adequately vocalize their needs. Hence, one of the recommendations by this study (in addition to others made within each substantive chapter) to effectively engage women in the intervention process is to integrate the Basic Needs Approach (BNA) into health interventions (Kabeer, 1994).

The BNA model operates on the principle that the subjects of interventions be responsible for the articulation and reflexive identification of needs and resources through collective action. In other

words, there is a need to adopt an alternative development model where the marginalized and the poor locally organize and control their own need system. Specifically, this model was designed as a more effective alternative to inserting women/gender into development in such a way that their inequities are reworked to improve the situation of women but a rights based approach has received increased advocacy to mainstream gender in development and health interventions (e.g. Farmer, 1999). In making recommendations for a more meaningful participatory gender approach in health interventions and one that ensures compliance with the specific needs of women legitimized through the invocation of rights, I provide a cautionary tale that the intrinsic values of a needs and rights based framework should not be taken *prima facie* as devoid of problems especially when practiced within specific spatial contexts. In other words, given the ways that both the needs and rights based approach to claiming gender in health have been touted as hegemonic solutions in both local and global discourses of development and even within the Nigerian HIV/AIDS interventions, I clarify the specific ways I recommend these as solutions for a more participatory gender framework.

Like the Nigerian HIV/AIDS interventions, a needs-rights based approach is the hegemonic discourse that underpins its gender mainstreaming yet as the evidence shows, this has not adequately functioned to address the barriers to HIV seropositive women's treatment access and adherence. In the next sections, I explore this current discourse within the framework of past and contemporary global feminist theories on development to extend this gender in development debate using evidence from the discourse analysis findings. To effectively operationalize participatory gender methodologies in health is also the need to centralize male involvement in interventions by consciously designing interventions to address the gender relational power dynamics that undermine women's health service access to antiretroviral treatment.

## **Claiming Gender in Health Using a Needs-Right Based Perspective**

One of the notable concepts that is cross cutting in the feminist literature is ‘rights’. According to McIlwaine and Datta (2003), the push for women’s emancipation has increasingly centered on the issue of ‘rights’. Similar to this is the equality approach that advocates for power redistribution between women and men regarded as a fundamental human right (see Chant and Gutmann, 2000). The principal needs or interests being advocated for on behalf of women fall within this universal human rights framework which provides a legal ground to claim such ‘needs’. In this human rights framework, equality among all humans is paramount as well as equality in access to resources and life’s opportunities. Rights foreground equality and its exercise or claim to entitlement. Equality and rights may thus transform women’s ‘needs’ to something that can be legally claimed. This is more so that women’s needs and interests have long been relegated in a male dominated world given the ill- conceived notions of male superiority.

Within the Nigerian context, equality, social justice and rights are the dominant narratives that situate women’s emancipation particularly within the HIV/AIDS policy discourse. However, a basic needs approach (BNA) is also deployed to identify the needs of the subjects of interventions through a participatory process that includes women living with HIV and consultations from gender experts as the discourse analysis on the country’s gender response reveals. Central to a needs based approach therefore, are representation and participation. This basic needs approach (BNA) according to Stewart (1985, in Wisner, 1989, p. 25) “is one which gives priority to meeting the basic needs of *all* the people” and takes the satisfaction of needs as a universal priority. The BNA however, empowers or provides agency to this approach of meeting *all* basic human needs by framing needs and its fulfillment as a universal right within

the UN's Universal Declaration of Human Rights (Article 21). It states the right of everyone to commodities and services required to attain a basic standard of living for an individual's health and well-being, including her/his family.

But how representative are poorer women in this model of needs and participation especially considering that the local arm of HIV/AIDS interventions (in Nigeria) is weak and this creates a disconnect between the elites or the gender experts and the grassroots women whom are mostly affected. As the empirical evidence from this study shows, indigenous discourses on female empowerment are remarkably different from elitist constructions which mostly favor gender specific interventions that do not integrate men. Although the Nigerian HIV/AIDS, gender and needs model engage women living with HIV in their policy process at the national level as the policy documents reveal, it is silent as to social demographics if these represent the diverse categories of HIV positive women particularly at the lower socio-economic hierarchy.

Arguably, there might be great commonalities and shared interests in the needs of all women living with HIV. Nonetheless, gender needs are particularly fluid and changing when other categories or axes of difference like location, age, marital status, income, education and class among others are inserted into the equation. Similar to this argument is the nature of 'experts' or 'gender consultants' that are solicited for this process. While the basic needs model subordinates 'experts' judgment on the definition of needs to that of the group and makes the former secondary, my contention is that this model does not make clear the nature of the 'expert' organization whether foreign or localized. This may have implication for the kind of aid rendered to women if there is disconnect between perceived needs by experts and actual local needs.

In the Nigerian case, although the policies do not as well state the demographics of the gender experts consulted, there are clear indications that these are both local and foreign gender experts but all elite albeit some with local gender knowledge. I had the opportunity of interviewing one of them. Although this gender expert highly emphasized the need for gender specific programs or that HIV/AIDS intervention programs should be “*skewed*” towards women, she also underscored the need for male involvement. Her responses reveal a vast knowledge of gender issues on HIV/AIDS within the Nigerian context being a local gender expert. However, like so many other institutional actors, she levies undue agency and power for change upon the Nigerian woman to be able to “*prove herself, double it*” as she says in the fight against male dominance and inequality. This I find contradictory to her stance on male involvement if the onus is more on the woman to change systemic forces that antagonize her through doubling her effort to prove herself as equal to men. A response that does not mirror the situation of HIV positive women at the Erhoike Cottage Hospital whom for many, it appeared that they would like to challenge such injustices and power relations against their access and adherence. Nonetheless, their marginal status positions them weakly to fight against a system that is dominated by the men whom they feel bound to economically, socially and emotionally; men who might want to retain their gender privilege. While I do understand the need for women to transit from a status of being passive ‘victims’ to active agents of change, there is also a need to be deeply aware of systemic constraints and be balanced in the realistic expectations, in particular of poor women as such change agents. In other words, the social positioning of experts does matter in addition to their knowledge of local gender issues.

These sorts of tensions around representation and definition of ‘needs’ like questions or contestations around who articulates needs, and how the subjects of needs are positioned within

this framework, whether as activists or as passive recipients (Wisner, 1989) are part of what makes the needs approach a basically flawed singular model of intervention. This tension has come to delineate what is now termed the strong/radical basic needs approach and the weak basic needs approach. The former is conceived as that which frames the deprived as activists and the latter model frames them as recipients. The radical BNA is articulated not only as a participatory process but one which helps to challenge the “politics of needs interpretation” (Kabeer, 1994, p. 230). This approach operates under the principle that the subjects of interventions be responsible for the reflexive identification and articulation of their own needs, control over their own lives and resources through their collective action aided by support and action groups.

Although studies like Seidel (1993) and many others have argued for a participatory approach for women living with HIV in the policy process, this study argues for a model of participation that is truly representative of the social demographics of HIV subjects. This study proposes for the Nigerian situation, a needs model that moves beyond a *basic* participatory approach which engages women living with HIV and/or gender experts to a more *meaningful* engagement. A model where gender experts are in *direct* consultation with the subjects of interventions at all levels such that categories of HIV positive women whom are most affected are also engaged and actively positioned within this framework through a collective action and participatory process guided by gender experts to determine their needs.

One of the fundamental principles of human rights is non-discrimination and inclusion in the claim and ownership to rights and liberties but how does this inform public health policy on HIV/AIDS? Like Wisner (1989), Seidel (1993) posits that there is an interrelation between human rights and HIV/AIDS in health development but he provides a tenuous link at best between these two concepts save for the importance of a rights based perspective in public health

policy to protect vulnerable subjects in HIV/AIDS research and vaccine trials. Nonetheless, there is a strong connection between the needs of women living with HIV in terms of treatment access (access viewed in a holistic sense) and a human rights perspective as hitherto argued. Most of the basic vulnerabilities to HIV transmission are produced from structural inequalities like gendered poverty, oppression and exploitation of women through social, cultural and economic institutions that violate individual human rights as evidence from this study demonstrates.

The United Nations (UN) convention on rights recognizes this fundamental need to protect such minority groups and populations and this is where the advocacy for gender rights originates particularly for women's health. The discourses on HIV/AIDS in relation to rights derive primarily from the United Nations Universal Declaration of Human Rights (1948) which is part of the International Bill of Rights. This declaration is comprised further of three UN texts: 'The International Covenant of Economic, Social and Cultural Rights,' 'The International Covenant on Civil and Political Rights,' and its 'Optional Protocol' (Seidel, 1993). These are significant because they emerge from the international code of conduct in relation to universal human rights, have moral weight and part of the customary international law. These have set the basis for other sub-laws at the international, regional and national level like the 'Convention of All Forms of Discriminations against Women' (CEDAW) and the African Charter of Human Rights. It is within this international legal framework that the claim for gender equity in the Nigerian HIV/AIDS response is made (for example, see policy document: the Gender Policy Handbook by NAFDAC, 2014). Within the country's HIV/AIDS and gender policy plan, the human rights and legal framework is thus very centralized. Yet, only minimal progress has been made in addressing the legal and human rights issues around the epidemic. A number of reasons can be deduced.

Foremost is that in Nigeria, policies do not automatically translate to law and cannot be enforced in the courts of law. Evidently, institutional policy actors attribute the weakness or failure to achieve an effective HIV/AIDS response to non-legal backing of policies; hence, a strong emphasis on rights and laws as the pathway to an effective response. While these sorts of narratives are not only common place in the policy discourse in Nigeria and in the HIV/AIDS literature, I argue that making policies into laws is not an end to a more effective response if the legal environment in which these policies are to be embedded are weak or faulty. I share the opinion that when HIV/AIDS policies do not constitute law or embody the force and power of the law, it can render them weak and ineffective because it is not legally binding on implementing institutions or individuals to make recourse to these guidelines. The deployment of these guidelines is therefore left at the choice and will of implementing partners and individuals which may result to the selective and convenient application of policies given the lack of legal penalties as implied in the following policy statement:

*“[HIV]AIDS policies are merely administrative tools and guidelines that provide direction for governmental action. However, these policy documents can and may elaborate and specify the goals, values, and standards to which existing laws aspire and may be useful in interpreting the latter as well as guiding programmatic interventions by the government. The problem is that, at the moment, there are no HIV/AIDS specific laws on the statutes. As legal reforms have been notoriously slow in coming and without the backing of the law, government policy documents can only be inspirational in wishing for an effective national HIV/AIDS response that respects the rights of PLHIV and PABA [People Affected by AIDS]. Currently, the 1999 Nigerian constitution and international treaties ratified by the country have provided the major sources of human rights for PLHIV and PABA in the country. However, as none of these treaties or the constitution specifically addresses the situation of PLHIV and PABA, the case of their applicability often has to be made through advocacy and lobbying. Thus, although PLHIV have human rights to be respected and protected, it is the tendency of the society to have pervasive*

*prejudices and to overtly and covertly stigmatize and discriminate against PLHIV and PABA. A constitutional provision that does not speak HIV/AIDS contexts specifically does not do much to help the situation of the rights of PLHIV. And the protection of the rights of PLHIV and PABA are not on the priority radar screen of law enforcement agencies. The absence of explicit laws leaves PLHIV extremely vulnerable to the violation of their rights...” - Policy document: National HIV/AIDS Response Review 2005-2009 (NACA and UNDP, 2009, p. 14, 15, 65 & 67).*

But what I do contend is that even when policies on HIV/AIDS are ratified and invoked within a human rights perspective, they can also be contested or challenged by the individuals that these laws are even meant to govern. Rights emanate and are contextualized from people’s experiences (Brown, 2000). As the African Charter of Human and People’s Rights posits, “how human rights should be implemented and respected is a question of beliefs, values, solidarity, organization strategies” (Seidel, 1993, p. 181). This clause in the contextual application of human rights produce conflicting notions of rights as policy actors usually claim universal notions of rights but the African jurisprudence of law which Nigeria is part of articulates a rights approach that is reflective of local contexts, values and beliefs.

In Nigeria, this conflict is obvious in the dual legal framework and constitution - the Common law and the Sharia law - whose prescriptions sometimes differ from international conventions on human rights like the Convention of All Forms of Discriminations against Women (CEDAW) which prohibits all forms of trafficking of women, exploitation of women and girls and general gender based violence. Yet, under the Sharia law, a female less than 18 years old is considered an adult when married; a law that exposes young adolescent women to intergenerational sex, power and male control which are a prerequisite for HIV transmission and even access to treatment on the long term. Similarly, under both the common and sharia law, the penal and criminal code prescribe that a husband cannot be guilty of the offence of rape of his wife. The

reason is that in Section 6 of the Criminal Code, unlawful carnal knowledge is defined as that which takes place otherwise than between a husband and wife and women who seek redress for such acts are subject to the judgement of their character (Ekhtator, 2015). Demonstrably, human rights in the Nigerian context are intricately tied to patriarchy and existing gender structures from traditional and religious mores. Even among the local women and men studied for this research, the prescription of rights was invoked within these religious and cultural scripts especially in the focus group discussion conducted among men in Erhoike community. Women's rights as human rights at the local level are mostly framed within religious and cultural values and not within the universal concepts of rights even though the latter is what is invoked in Nigerian HIV/AIDS policies.

Similarly, Nigerian HIV/AIDS policy documents reference actual instances of the violation of rights to privacy through mandatory counselling in the form of pre-marriage HIV testing required by some religious institutions mostly churches as a basis for marriage or employment in their organizations. In a society like Nigeria where religious institutions and leaders are considered as bastions of power and authority, it is challenging to get people to be responsive against such religious principles especially as this study demonstrates that religion and faith are strong avenues for HIV positive women to negotiate their challenges. It is within this disordered and conflicting state of the law and indigenous human rights discourses that a legal framework for HIV/AIDS policy plans in Nigeria has been proposed, pushed for and practiced.

The over emphasis placed on a human rights framework to achieving gender equity leads to my second argument that claiming the equality of HIV positive women within a human rights approach will not necessarily translate to their agency or redistribute power or resources if the anomalies in the legal constitution itself are not challenged, redressed and rewritten to equally

favor women. Establishing rights is never the same as enacting or realizing them and the achievement of rights for certain minority populations may only remain a utopic ideal at best. This reifies a general criticism of scholars who propose a caution to invoking the ideal of rights as the key to resisting all inequalities. Hence, there are studies that though advocate for a right based approach, also beckon on structural changes (e.g. Greig et.al., 2008). However, these studies do not point to pathways for alternative development given that mainstream development agencies and institutions may embody deeply entrenched rules that reproduce policies and programs of exclusion and marginalization.

What I claim here is the paradoxes, the difficulties and the dilemmas of the concept of rights as antithetical; rights as a concept is powerful yet weak in some contexts and its application. While we may be quick to claim rights as the obvious legitimate path or route to stall and address these forms of subordination of HIV positive women, is rights itself enough to deliver the promises of freedom, liberation and equality that it is said to embody (also, see a similar argument by Brown 2000)? If rights do not necessarily translate or transform our situation as women, why do we still make claims to rights as the sine qua non to women's freedom globally? It is because "rights function to articulate a need, a condition of lack or injury..."(Brown, 2000, p. 239) that may not have the potential to be even addressed at all if that need is or was not articulated or framed within a 'rights' context. In other words, a rights framework provides the legal basis for which certain needs or wants can be claimed. A rights based approach may help to fundamentally articulate the principal needs or interests of marginalized groups like women within the universal human rights framework and to provide a legal ground for such "needs" channeled through participatory methodologies (Akeroyd, 2004) with agency to women's voices. The strength of invoking the human rights framework is that it provides a platform for 'needs' or justice to be

legally claimed even though pragmatically, this is highly contested (Hunter, 2010; Craddock, 2000; Seidel, 1993). This is what a rights based approach in gender and development studies may possibly offer when it comes to arguing for women's needs or using a combination of a needs and rights based approaches.

More specifically, Marx's analogous argument in Brown (2000, p. 239) articulates this more poignantly that "political emancipation certainly represents a great progress...not the final form of human emancipation...but [could be] the final form ...within the framework of the prevailing social order". Again, this speaks to the duality of a rights based approach in that it can be effective but it all depends on the spatial context which most times go unrecognized in studies that canvas heavily for this framework. Rights can be invoked and their presence through laws can serve as a protective force or barrier against social inequities and injustice. However, rights do not automatically empower women or even vulnerable populations if those enacting the laws (usually males in positions of authority) are not favorably disposed to making the law provide redress for those who seek it. As in the cases of domestic and gender based violence as they intersect with HIV/AIDS, social power especially within intimate relationships and the pressure to conform to certain societal rules wield more power over the victims and aggressors than the protective force of the law. As an example, a Nigerian woman who would seek redress from the law against her husband is mostly seen by her peers and local community and sometimes even by her own family and religious community as a betrayer. This is because socially and religiously, she has been conditioned and expected to endure such violence as part of sacrifice for her home and children at her own detriment.

What then are some practical and realizable solutions in articulating gender using a needs-right based approach? As previously stated, a needs based approach must be mindful of the politics of

representation and the conception of needs that are deployed in interventions. Like rights, the concept of ‘need’ is also very subjective and can quickly replicate inequalities if needs are not representative of the subjects of interventions. Gender policies can also be translated into laws within a rights-based framework but it is also imperative to establish an enabling socio-legal environment for rights to be effectively claimed by the marginalized. Social education and male involvement in seeking redress for women’s rights remain key weapons in troubling institutional or traditional mores and should be centralized more in HIV/AIDS policies. This point transitions smoothly into another significant feminist shift in claiming women’s equality within a development framework which is the relational gender approach.

### **A Relational Gender Approach**

A fundamental shift in the conceptualization of gender within a development framework has been to incorporate men and masculinities as both a focus of gender. Most feminist scholars have argued that “... genuine transformation of gender inequalities is impossible without the participation of men (McIlwaine and Datta, 2003, p. 375). Achieving gender equality entails eliminating discriminatory bottlenecks that constrain equal opportunities for women and men and this includes the transformation of the social and economic structures that produce such inequalities. The need for this shift emerged from the insertion of women as a category into development plans and other sectors of the economy in previous models of gender development but more as a symbol of inclusion and visibility without the political will and materialism to give this agency (Kabeer, 1994). This speaks to earlier arguments made in this dissertation that the insertion of women in development plans or policies does not necessarily translate to social change. This does provide significant hypothesis or assumptions as to why much of ‘gender

sensitive' HIV/AIDS programs and interventions may not have been very successful at improving the lives of HIV positive women in treatment.

The evidence from the Nigerian HIV/AIDS discourse shows that mainstreaming women under the category of gender in development discourses or policies should include meaningful representation and engagement not only in the process of formulating policies but needs identification. Female or women empowerment has become a common catch phrase in the Nigerian HIV/AIDS and gender policy discourse especially in the plans to destabilize men's controlling power and establish female autonomy. This calls for a more extended and rigorous discussion of male involvement that is weakly referenced in the national strategic action plans within the Nigerian HIV/AIDS intervention landscape. Throughout this study, I emphasize the need for a relational approach to gender in HIV/AIDS research. That is, studying issues of women's health not as independent of men because these two categories exist in a reciprocal relationship where the dynamics of one affect the other but with men's relations having a more considerable impact on women than the reverse as previous analysis shows.

Policies, interventions and health development projects that claim to be gender sensitive must address these gender dynamics in ways that seek to modify existing gender and power relations that marginalize and suppress women. Considering that at the core of gendered relations is power and access to and control of resources, interventions must seek to redistribute power and resources and balance control. Most importantly in patriarchal settings, interventions must seek ways to integrate the men who are at the heart of controlling, allocating and distributing these resources. It is now increasingly acknowledged that gender inequities can mostly be surmounted when men's responsibility for women's unprivileged positions is unveiled and where men are persuaded of the need to rectify this imbalance (Grieg et al., 2008).

## **Final notes**

To begin with, at the individual level, knowledge from this study mandates a dire need for context specific interventions and to understand the convoluted personal politics and social terrain that women uniquely navigate in their decisions to undergo or initiate treatment. The process is not at all linear as intervention maps and design exemplify. This study claims that women who will initiate and engage in treatment and consistently adhere are those who have devised the means to secure their primary needs and interests, needs that are mostly socio-economic and cultural in nature. In other words, the availability of free treatment may not be the primary motivator for access and adherence. This demonstrates the need for a health service access model to transcend the *availability* of health care resources to underscoring the *nature* or type of health services provided as strong determinants of access.

At the institutional level, gender ideologies determine how men or women are included or excluded, and allocated into categories of privilege and disempowerment. The most effective way to rework gender inequalities is to challenge existing gender ideologies and constructs and to re-empower the gendered mind to construct gender relations differently. Empirical evidence suggests that it is possible to challenge negative attitudes and increase positive behaviors especially among men towards women's reproductive health issues (Berg, Brittain, Mercer, Peacock, Stintson, Janson and Dubula, 2015; Barker and Ricardo, 2005). One way this can be achieved is by replacing existing but powerful traditional gender messages and codes with superior ideologies of gender in ways that uproot and replace the old with new and appropriate gender knowledge through the power of information - peer education, school curriculum, informal social marketing of equitable gender relations and male involvement. The Family Life and HIV/AIDS Education (FLHE) program that is proposed in the Nigerian HIV/AIDS and

gender policy guidelines and already being implemented in some states is a good start. Nevertheless, there needs to be a more aggressive and revolutionary approach to include sensitization of both males and females at every sphere of public and private life.

I do not entertain utopian thoughts or ambitions that this study can erase all inequalities around treatment among HIV positive women. Rather, I have attempted to expose the unequal conditions that consume their daily lives and how these may create risky but avoidable vulnerabilities in HIV treatment and consequently, produce unhealthy outcomes. The aim is to draw conscious attention to these social inequities in the hope that they can be at least addressed at the individual level through institutionalized policy instruments that effectively mainstream women's ornate social realities.

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## Appendix

### Inventory of HIV/AIDS Policy Texts<sup>38</sup>

S/N	Title of Policy Text	Main Agency Responsible	Date
1.	HIV/AIDS in Nigeria, A USAID Brief	United States AIDS	2002
2.	National Policy on HIV/AIDS	National Agency for the Control of AIDS	2003
3.	HIV/AIDS Emergency Action Plan 2001-2003/2004	National Agency for the Control of AIDS	2001
4.	HIV/AIDS National Strategic Framework for Action 2005-2009	National Agency for the Control of AIDS	2005
5.	National Guidelines for HIV and AIDS Treatment and Care in Adolescents and Adults by Federal Ministry of Health Abuja, Nigeria	Federal Ministry of Health	2007
6.	National Policy on HIV/AIDS	National Agency for the Control of AIDS	2009
7.	National HIV/AIDS Response Review 2005-2009	National Agency for the Control of AIDS	2009
8.	HIV/AIDS National Strategic Framework for Action 2010-2015	National Agency for the Control of AIDS	2010
9.	National Guidelines for HIV and AIDS Treatment and Care in Adolescents and Adults by Federal Ministry of Health Abuja	Federal Ministry of Health	2010

<sup>38</sup> Two categories of policy related documents were analyzed: gender documents that ranged from gender policies on HIV/AIDS to intersections with gender based violence and other gender health related documents; and another set of documents on the national response to HIV/AIDS through policy plans and strategic and implementation framework. The documents were analyzed for the ways gender is defined and conceptualized whether as relational/intersectional or categorical; for exclusions and inclusions; or silences and the ways the language of gender is used if it somewhat re-perpetuates inequalities. The documents were also analyzed for discourses on empowerment, needs and rights and the conceptualization of treatment, access, adherence as well as the general framing of interventions whether as biomedical or biosocial and how these have evolved through time.

10.	Women, Girls, Gender Equality and HIV. Five Year Strategic Plan and Program Implementation Framework 2011 – 2015	National Agency for the Control of AIDS	2011
11.	Global AIDS Response Country Progress Report	National Agency for the Control of AIDS	2012
12.	Gender Assessment of the National Response to HIV/AIDS in Nigeria	National Agency for the Control of AIDS	2013
13.	Nigeria Operational Plan Report	United States President's Emergency Plan for AIDS Relief	2013
14.	National Guidelines on HIV/AIDS Care and Support	National Agency for the Control of AIDS	2014
15.	National Plan of Action: Addressing Gender Based Violence and HIV/AIDS (GBV/HIV/AIDS) Intersections 2015-2017	Federal Ministry of Women Affairs and Social Development	2014
16.	Gender Based Violence in Nigeria. National Guidelines and Referral Standards	Federal Ministry of Women Affairs and Social	2014
17.	Mapping of Laws, Policies and Services on Gender Based Violence and its Intersections with HIV in Nigeria	National Agency for the Control of AIDS and United Nations Development Program	2014
18.	Gender Policy Handbook	National Agency for Food and Drug Administration and Control	2014
19.	Global AIDS Response Country Progress Report	National Agency for the Control of AIDS	2015
20.	The Violence against Personals (Prohibition) Bill: An analysis	Choice for Life	N/A