

***ETHERNICHEL*—SWIMMING AGAINST THE FLOW:  
UNDERSTANDING THE UNIQUE NEEDS AND CONCERNS OF  
WIDOWED AND ABANDONED WOMEN IN CHENNAI, INDIA**

by

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Background: The social contexts and roles of women in India, in conjunction with the plight of widows and abandoned women and the stigma and discrimination associated with HIV/AIDS fosters a difficult lived reality for a growing segment of the population. Care and support measures for those infected with HIV are losing priority but are of public health relevance and importance. Therefore, this study aims to understand the perception of quality of life in combination with needs and concerns of HIV positive women in South India. Qualitative research methods were utilized in order to achieve these aims and provide insight to propose recommendations to affect future public health practice.

Methods: Working closely with World Vision India's GRACE Program, an evaluation was completed, and the results were subsequently analyzed for this study. Focus group discussions, participant and non-participant observations along with reflection journals were conducted, recorded and analyzed for emerging themes.

Results: The theoretical frameworks utilized resulted in a conceptual model that combines the constructs of two different theories with the unique identity of participants identified as the triple burden. The triple burden consists of being HIV positive, being a woman and being the new head of household. Needs and concerns related to improving quality of life were identified

surrounding the particularly the need for housing and financial security, with explicit desire for government housing and specialized livelihood training expressed by participants.

Conclusion: Care and support is an important component of combating the HIV/AIDS epidemic.

Widowed and abandoned women in South India are a forgotten population and it is imperative to improve their quality of life in a multi-pronged manner by tailoring microfinance and livelihood training, endorsing the passage of the HIV/AIDS Bill, and continuing promotion and advocacy of education and awareness around HIV/AIDS and the rights of women and widows.

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## PREFACE

This thesis is dedicated to my beloved pattamma, I will always remember the countless nights of porch sitting and multiplication table memorization, instilling in me a passion for learning. You are missed, and I hope this work makes you proud.

To my family— you are beyond wonderful. Mom, Dad and Steven, thank you for loving me unconditionally, and teaching me how to love God and love people. There is no way to fully express how thankful I am for you and for your care for me no matter how near or far.

To my committee— I am immensely grateful for you. Thank you for believing in me when I struggled to believe in myself both as a student and a researcher, pushing me in the midst of my desire to run away from this work, and encouraging me to work hard and look ahead to what is next on this life journey.

To friends that love, uphold, and keep me sane in their own unique ways— I'm keeping you all. My dearest Paige, Tina, Katie, Natalie, Teags, and Mike, there is absolutely no way I would have finished without your presence in my life these last few months.

And finally to the women who shared their lives with me— you have changed my life. I am confident that the rest of my life will be in some way, shape or form be influenced by your trials and joys. Thank you for sharing your lives with me, and showing me how to live life with reckless abandon out of love for others. I am forever indebted to you.

## **1.0 INTRODUCTION**

Prevention, treatment, and care and support for HIV/AIDS have been multifaceted from the beginning of the fight against the infection. As the epidemic has slowly been mitigated throughout the world, particularly in the developing context, the emphasis on care and support has become less of a priority when compared to prevention and treatment. This is indicated by the priorities of various streams of funding and international agreements including the Millennium Development Goal to halt and reverse the epidemic, which fails to include a component on care and support for those already infected. Particular vulnerable populations have been further disproportionately affected by this gradual change in emphasis of concern related to HIV/AIDS—of interest in this study is the forgotten population of HIV positive women who are widowed or abandoned in the context of South India.

India has a very distinct social context that places women, particularly widows and abandoned woman on the lowest rung of the social hierarchy. This milieu in intersection with the stigma and discrimination of HIV/AIDS results in a very difficult lived reality. This population is forgotten in HIV/AIDS care and support, and in light of the changes present in prevention and treatment, it is important that the present context of these women is understood in order to effectively inform intervention and in order to improve the quality of life of this segment of the population.

This thesis will begin with a review of the literature and relevant theories to this study, providing context and background. The research methodology will be described as it aimed to take into account the voices of ‘real’ women and their lived realities as HIV positive individuals in the context of Indian society. Emerging themes established during data analysis will then be presented with a conceptual model, framing the voices of women using the relevant theories and social context. Finally, the findings will be synthesized and public health implications will be addressed with recommendations made for the best way to move forward in regards to intervention and policy.

## **2.0 BACKGROUND**

This section begins with an overview of the trends present in HIV/AIDS globally and in the Indian context. Followed by an account of the social contexts of India, particularly as it is related to women and more specifically widowed and abandoned women. This context helps to provide the framework of how the HIV/AIDS epidemic disproportionately affects women in India. A review of the relevant theoretical constructs of the social ecological model and postcolonial feminism is then completed. And finally an outline of the rationale and specific objectives of this study and paper.

### **2.1 GLOBAL SCOPE OF HIV**

Human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) has changed the landscape of infectious disease, and public health since it was identified in the 1980s and continues to do so today. Resource poor settings and the developing world have been disproportionately affected over the course of the almost 30 years of this pandemic. HIV is transmitted through sexual intercourse in the exchange of vaginal fluid or semen, the exchange of blood products via sharing of needles or mother to child transmission during the birthing process, as well as through breast milk during breastfeeding. HIV transmission can be prevented,

presently there is no cure for the disease once infected, but treatment to prolong life exists via antiretroviral therapy (ART) (CDC, 2010).

Globally, it is estimated that 33.3 million individuals are infected with HIV, with nearly 1.8 million AIDS related deaths total ((UNAIDS), 2010). There has been a great deal of work done in mitigating the effects of the HIV as the spread of the infection has been halted and begun to reverse, in line with the Millennium Development Goals (MDGs). The MDGs are a blueprint agreed upon by the world's countries and leading development organizations with the aim to meet the needs of the world's poor, with the specific HIV/AIDS goal of halting and reversing the spread of HIV/AIDS by 2015. Since the peak of the epidemic in 1999, the number of new infection has dropped by 19% in the last 20 years; this can be attributed to the extensive prevention efforts established worldwide. In addition, over one-third of those requiring treatment in low and middle-income nations have access to treatment (Ibid), indicating the significant gains made in the last 20 years. With the improvement in treatment worldwide and reduction in mortality due to infection and subsequent opportunistic infections, the needs of people living with HIV must be extended.

Approximately 4.9 million people in Asia were living with HIV in 2009, similar to counts five years earlier (Ibid). India has the most number of individuals with HIV/AIDS in the continent, and the third highest count worldwide. Much like other nations in the continent, there are varied patterns in India. For example, in China, five provinces bear the brunt of the burden accounting for over half of all infections (Wang et al., 2009), whereas the incidence has increased in Bangladesh and Philippines between 2001 and 2009 ((UNAIDS), 2010). With the vast differences in the geographical, religious, political and ethnic landscape of India, the HIV/AIDS epidemic is no different as it is changing and evolving.

## 2.2 HIV IN INDIA

India, the second most populous nation in the world, in the midst of the epidemiological transition, has been inundated with learning how to best cope with HIV since it was found among female sex workers in South India. Presently, approximately 2.5 million people aged 15-49 are living with HIV/AIDS in India with a prevalence of 0.5% (UNAIDS, 2007). With the identification of the infection in 1986, the National AIDS Control Programme was launched in 1987 and tasked with surveillance, blood screening and health education. With the increase in the infection rate, in 1992, the National AIDS Control Organization (NACO) was established. NACO was the national level body created to be responsible for policies, prevention work and control programs (NACO, 2007). The primary work of NACO has been to establish the strategic plan, and has produced the National AIDS Control Programme (NACP) I (1992), II (1999), and III (2006) respectively.

NACP-I focused primarily on establishing a national commitment, increasing awareness and addressing blood safety issues. NACP-II aimed to reduce the spread of HIV by promoting behavior change. During this strategic plan, the prevention of mother-to-child (PMTCT) and provision of antiretroviral treatment for free was implemented. NACP-III moved the campaign from the national to state and district levels utilizing the State AIDS Control Societies. Interventions were targeted for high-risk groups and involvement of non-governmental organizations along with different sectors, education, and law enforcement were increased.

The infection has spread from traditional high-risk groups and is becoming cause for concern within the general population. Historically, the HIV epidemic was driven by heterosexual transmission accelerated by the female sex workers; this however is no longer true as the transmission has plateaued in this risk group. The targeted interventions presently the

focus of NACP-III are focused on the needs of the high-risk segments of society. With the number of infections changing in the general population and the number of new infections plateauing, there are new emerging needs that must be addressed by both the various state control societies as well non-governmental organizations working in this field. Presently the focus is on the prevention of new infections, as more than 99% of the population is negative, but with the provision of free antiretroviral medication by the government, the number of people living with HIV is increasing and the care and support for this segment of the population must be a priority.

### **2.3 HIV AND WOMEN**

Women are disproportionately affected by HIV, leading to what has been described as the feminization of the infection. Globally, slightly more than 50% of people living with HIV are women and girls ((UNAIDS), 2010). Though the disparity between men and women is not as pronounced, India is also experiencing the feminizing effect of the HIV pandemic. Women compose 39% of all HIV/AIDS cases (J. Ghosh, Wadhwa, & Kalipeni, 2009). In line with transmission trends throughout the world, 85% of HIV transmission is sexual and dominantly heterosexual in nature. Approximately 90% of people newly infected in India are believed to have acquired it during unprotected sex, though there are still regions such as the northeast where transmission is chiefly through the exchange of contaminated injecting equipment (Organization, 2008). Though there is some variation throughout the nation, women are affected disproportionately.

It has been determined that 75% of women living with HIV/AIDS become positive within the first few years of marriage (S. Solomon, Chakraborty, & Yepthomi, 2004). In addition, the shift from focus on high-risk groups to the general population at large has revealed that the prevalence of HIV is high among women who are married and monogamous and reported no risk factors for HIV other than sex with their husbands, indicating that this is the primary mode of transmission (Chatterjee & Hosain, 2006; Gangakhedkar et al., 1997; Islam, Hossain, Kamal, & Ahsan, 2003; Newmann et al., 2000; Organization, 2005, 2008; Pallikadavath & Stones, 2003) . In one such study, 89% of women reported heterosexual sex as their only risk factor with 88% reporting a history of monogamy (Newmann et al., 2000). Therefore, in order to better understand this unique phenomenon, a discussion of the social contexts surrounding the role of being a woman in Indian is necessary.

## **2.4 SOCIAL CONTEXTS OF INDIA AND THE ROLES OF WOMEN**

The wide gender gaps embedded in the socio-cultural structure of India are particularly of interest to better understand the disproportionate effects of the pandemic on women. India is a patriarchal, patrilocal, and patrilineal society in which the core of the family is dependent on the role of the eldest male (Go et al., 2003). This enforces the notion of the ‘rule of fathers’ with men possessing all power and women possessing subservient and subordinate roles in all realms of family life and society at large. ‘Women are not treated as ends in their own rights, but as instruments of the ends of others—reproducers, caregivers, sexual outlets, and agents of family prosperity’ (Nussbaum, 2000). The patriarchal framework results in distinct roles for men and women that often exaggerate the gender inequalities present from birth throughout the course of

life for women. Different values, for example, are placed on the births of male and female children as the birth of a male child is celebrated whereas the family often sees the birth of a daughter as a burden as they must save for her dowry and marriage. In addition, the opportunities afforded for male children include investment in education and other interests, whereas girls are expected to work in the home and lack educational opportunities (Suniti Solomon, Buck, Chaguturu, Ganesh, & Kumarasamy, 2003).

Women are expected to play very clear and distinct roles whereas there is much more leeway for men. It can be said that there are very strong gender norms that govern everyday behaviors, as demonstrated in one study in a large urban city in south India that interviewed both men and women on their understanding and expectations of gender norms. “As the main provider, men are expected to ensure the family’s social and economic well-being. Although women suggested that men should avoid ‘vices’ such as drinking and visiting sex workers, these guidelines were not socially enforced. In contrast, gender norms guiding women’s behaviors were clear. A woman should be submissive, obedient, and respectful. In her primary role as family caretaker, she is expected to remain deferential and loyal to her husband” (Go et al., 2003). In essence, women are expected to be married, monogamous, mothers.

The differences in gender expectations curtail women’s independence and extend beyond the realms of education and work opportunities outside the home. Gender inequalities are present in the expectations of women as it relates to their reproductive and sexual identity; men are allowed greater sexual freedom, whereas women are held to a strict sexual ethic. Indian women possess low levels of HIV knowledge and risk perception (Chatterjee & Hosain, 2006; Newmann et al., 2000). This is prevalent even among high-risk populations with one study indicating that a fourth of female partners of injecting drug users had not heard of HIV/AIDS (Kumar, Virk,

Chaudhuri, Mittal, & Lewis, 2008). This is primarily because of the expectation of virginity present in Indian society. It is looked down upon when women ask questions related to sexual or reproductive health, as it immediately is assumed that she is promiscuous (Suniti Solomon et al., 2003). The culture of silence of sexuality is rampant in all segments of society for women regardless of socio-economic status and education level.

This culture of silence in addition to the patriarchy present in male-female relationships results in a lack of control or power in verbal, physical and sexual decision-making. This often results in the inability to negotiate safer sex practices (Gupta & Weiss, 1993; Zierler & Krieger, 1997). In addition, even if a woman is aware that her husband is HIV positive, it is the duty of the woman to accommodate the needs of her husband and risks violence, abuse and abandonment if she refuses intercourse, often unprotected, with her husband (Suniti Solomon et al., 2003). The inability to negotiate safe sex practices puts women at greater risk of being STI and HIV infected. These norms however are a result of the sociocultural context of Indian society, which is patriarchal, with built in expectations for females that often make them powerless and continue the culture of silence particularly as it relates to their sexual and reproductive health.

This culture of silence and distinct differences in the role of men and women in the context of relationships, makes women particularly vulnerable to violence; thus there has been an increased interest in the role of intimate partner violence (IPV) and HIV transmission (Newmann et al., 2000; Panda et al., 2000). Violence has been demonstrated to increase risk to HIV/STIs through 1) increased sexual risk taking, 2) forced sex with infected partner and 3) inability to negotiate condom use (Go et al., 2003). This is especially exasperated in the Indian context as the subservience of women makes violence against women, particularly in the context of an

intimate partnership, a social norm. One study indicated that married women face a double jeopardy—when compared to non-abusive husbands, abusive husbands are twice as likely of acquiring HIV outside their marital relationship; and when men are HIV infected and wives are exposed to IPV, their odds of contracting HIV are increased 7-fold (Decker et al., 2009). Therefore, the social context condoning violence in intimate partnerships in turn intensifies the risk of married women contracting HIV.

The social context for women in India brings to the forefront the reasoning for this increase in HIV infections among married, monogamous women. In addition, once infected, both men and women face a great deal of stigma and discrimination. ‘Stigma is rampant in the specific context of HIV, because HIV infection is associated with deviant behavior, religion and immorality, personal responsibility, contagion, and an undesirable form of death’ (Souza, 2010). Considering the social context outlined above however, women are excessively ostracized, often being blamed as the cause and source of the infection/disease/illness that has come upon the family (Mawar, Sahay, Pandit, & Mahajan, 2005; Steward et al., 2008; Thomas, Nyamathi, & Swaminathan, 2009). In addition, the desired identity for women to be wives and mothers is disrupted (Cooper, Harris, Myer, Orner, & Bracken, 2007; Moreno, 2007), and their ‘womanhood’ is called into question when they are found to be HIV positive (Zhou, 2008). Being a woman in Indian society is difficult considering the deeply ingrained social, religious, and economic hierarchy, but when infected with HIV, with its stigma and discrimination, women are further marginalized.

## 2.5 WIDOWED AND ABANDONED HIV POSITIVE WOMEN

Despite the countless attempts legally to ensure the protection and care of widows, widows have a very low status in Indian society. Though *sati*, the burning of a widow along with her deceased husband, has been outlawed, the practice continues in parts of the country, particularly in rural and highly rigid Hindustan communities. In addition, the long held belief that widows must not take part in the pleasures of life is widely practiced and enforced as they are expected to wear white in certain regions and not welcomed at various celebrations or religious events as their presence is considered inauspicious.

In a national survey which covered 2,068 HIV households throughout India, it was found that widows in the sample were young, with nearly 60% being less than 30 years of age and another one-third in the 31-40 age group, only seven percent were older than 40 (Pradhan & Sundar, 2006). Reason for this observation is that often wives are much younger than their husbands, and the husbands were infected long before they were married in turn progressing through the life of the infection at a faster rate, leaving behind young, HIV infected widows who often have young children.

Abandoned women are treated similarly to widowed women in society, as they are often mothers who have left their natal home. Once a woman is married, she is no longer the responsibility of her natal family and she moves to the home of her in-laws. When women are widowed or abandoned however, they are often no longer cared by the in-laws forcing them to return to their natal families or to care for themselves.

This is witnessed in the partition of property and property rights, which is key in providing housing for widows and abandoned women. Indian law affirms that the widow be given the portion due to her deceased husband when partition of assets occurs in a family.

However, in another study in India, almost 80% of widows could not retain the property of their late husbands, leaving them and their families destitute and socially isolated (Pradhan & Sundar, 2006).

The law also indicates that girl children possess equal rights to their father's property as male children. One study among widows in the Indian state of Bihar indicated that,

...both the society and the women themselves saw the widows as having rights to a share of the husband's property, in practice, these rights were limited and restricted. The entire system of widows getting property rights was based on the understanding that they were given property for themselves but to enable them to maintain the patriarchal lineage. That is why it was easier for a widow with sons to get a share of the property. But her rights to this share were, essentially, only usufructuary rights (Misra & Thukral, 2005).

In addition, in practice, property rights for women in their natal home were not present, as the dowry and marriage were to be their portion of the family assets. This was the view at large expressed by the communities in the study, "...even if a widow was unable to support herself, or denied her share of the inheritance in her marital home, the social compulsions being what they were, she would not demand a share as a right in her parental home" (Misra & Thukral, 2005). The onus of care comes to question as each side of the family fails to place care for widows and abandoned women as a priority as witnessed in how property is partitioned, as the housing for widows and abandoned women is not a priority of either the natal or martial families of these women.

Not only must these women deal with the loss of a husband, either by death or abandonment, they must bear the economic repercussions of often becoming the primary provider (Pradhan & Sundar, 2006), deal with the ailing health of both themselves and possibly

their children while facing the stigma and discrimination associated with being a HIV positive woman. Often these women are young, possess no formal skills or education, and lack proper support while being considered of low status in society. They are disadvantaged in every way. Though there are legal measures to ensure that they are cared for, the societal norms are more powerful and therefore dictate a very poor quality of life.

Discrimination against widows and HIV are inter-related in two ways: HIV and AIDS significantly adds to the burden of the already inferior status of widows. At the same time, this economic, social and political inferiority makes women in general more vulnerable to HIV infection. It is a vicious circle of discrimination and poverty (Sleep, 2001).

## **2.6 RELEVANT THEORETICAL PERSPECTIVE**

### **2.6.1 Social Ecological Model**

The Social Ecological Model describes five levels of influence on health behavior including individual, interpersonal, institutional, community, and policy (K. R. McLeroy, Bibeau, Steckler, & Glanz, 1988). It was an innovative synthesis of emerging ideas in the late 1980s in its acknowledgement that behaviors have the ability to shape and be shaped by social environment. The model has been applied to various health behaviors, including HIV prevention aiming to address the unique nature and contexts surrounding factors of behavior as well as its application with high-risk populations including female sex workers (Larios et al., 2009). Each factor of influence is further defined and expounded upon.

The individual/intrapersonal level is related to characteristics that are attributed to an individual and can be demonstrated in knowledge, behavior, skills etc. This also includes all life experiences and development of the individual. Often this has taken the brunt of the focus of health education and the focus of health behavior change. Often lifestyle has been blamed for respective health conditions, but this has not included the broader social environment. Intervention strategies possessing a primarily intrapersonal approach with the aim of changing the individual and not the environment employ strategies such as education programs, mass media, and support groups. This has been integral in changing the knowledge and attitudes affecting condom use in protecting against STIs/HIV.

The interpersonal level of influence refers to the social networks and social support systems, both formal and informal. “Although the influence of interpersonal relationships on the health related behaviors of individuals is widely recognized, health promotion interventions that use interpersonal strategies have typically focused on changing individuals through social influences, rather than changing the norms or social groups to which individuals belong” (K. R. McLeroy et al., 1988). Therefore though the behavior of the individual is the target, intervention will be more focused on the social norms and influences of the target.

The institutional factor of influence includes social institutions that are organized and possess rules and regulations for operation. Individuals spend one-third to one-half of their lives in organizational settings, and it is imperative that they are integral in an ecological approach. Targeting organizations can be key as they provide a medium for supporting behavioral change such as stress reduction interventions to improve worker supervisor relationships (K. McLeroy, Green, Mullen, & Forshee, 1988), as this supports long term change. In addition, organizations are target entities for health promotion by providing services such as adequate day care services,

which help to create a culture supportive to healthy living. Finally organizations serve as influencers in the diffusion of health programs serving as host organizations, playing key and active roles in the adoption, implementation and institutionalization of health promotion.

Community factors include the established relationships between organizations, institutions and informal networks within a defined boundary. In this approach, communities play important roles as mediating structures, means to connect multiple organizations and effectively exercise power. At its core, the notion of community revolves around relationships helping to affirm the presence of various values, norms, attitudes and behaviors within specific subgroups. Only when these norms and values are taken into account will the community at large be supportive, and therefore result in an effective and successful health related intervention.

Lastly, the local, state and national laws and policies take into account the influence of the outermost factor of public policy. It has been argued that health care professionals can play important roles in policy development, policy advocacy and policy analysis. Through this process of influencing policy, the interceding structures are strengthened resulting in meeting the needs of the population at large. An example of this factor of influence is the 100% condom use mandate in Thailand which has been significantly important in affecting the incidence of HIV from, slowing rate from 1.3% to 0.1% (Punyacharoensin & Viwatwongkasem, 2009).

The social ecological model is key to understanding the complexity of being a HIV positive woman in the Indian context; there are critical elements that affect quality of life in every factor of influence. Linking the factors of influence with the lived realities and perceived challenges of 'real' women can be instrumental in better understanding the realities of their lives. This model provides a framework to think creatively in addressing the needs of this population in a multi-pronged approach that makes use of the different factors of influence. This paper will

aim to understand the lived experiences of women in light of the social ecological model in order to provide insight and recommendations for improvement in quality of life.

### **2.6.2 Postcolonial Feminism**

Feminism has often been understood to be a western construct. However, the deprivations, exploitation and oppression suffered by women are nearly identical throughout the world. Yet there are distinct value system and historical differences which in turn demand that feminism is contextualized in order to be an effective force to improve the lives of women (Bhasin & Khan, 1986; Chitnis, 1988).

Indian society has always been highly hierarchical, and the concept of equality as a correlate of individual freedom is somewhat alien to Indian society (Chitnis, 1988). The feminist movement in India is distinct as it was initiated by men, with long standing legal laws providing for equality, banning practices such as *sati* and women playing a key role in the nationalist movement. The historical context of Indian feminism does not mirror that of traditional western feminism; therefore the criticisms, and feminist arguments along with demands need to be reframed with sensitivity to Indian society (Chitnis, 1988).

In an effort to contextualize feminism to the South Asian context, women gathered together from Bangladesh, India, Nepal, Pakistan and Sri Lanka to establish a broad definition for feminism: ‘An awareness of women’s oppression and exploitation in society, at work and within the family, and conscious action by women and men to change this situation’ (Bhasin & Khan, 1986). Feminists in the India context have moved from working for legal reform and legally equal position in society to working towards the *emancipation* of women. Feminism therefore in the present historical context includes “the struggle against women’s subordination

to the male within the home; against their exploitation by the family; against their continuing low status at work, in society, and in culture and religion of the country; against their double burden in production and reproduction”(Ibid.). Though the definition outlined above is not particular to South Asia, as it does not explicitly state issues related to caste, religion or the historic nationalism connection, it is a basis for beginning the discussions necessary to work towards the emancipation of women.

Of special interest in this paper is to determine how the lived experiences of HIV positive women exemplify certain efforts in this process of emancipation. Connecting the elements of the social context, which clearly establish the exploitation and oppression of women with the voices of the ‘real’ women—this paper will aim to recognize how women are exercising agency in fighting towards emancipation.

## **2.7 RATIONALE AND OBJECTIVES**

The present fight against HIV/AIDS in the arenas of research and project implementation is drastically different from when it was initially identified and studied in the early 1980s. Now that modes of transmission and treatment have been well established throughout the world, there has been a tremendous push to stop the spread of new infections, and provide treatment in order to lengthen the lives for those who are infected. A great deal of research has focused on prevention interventions, many which have been remarkably successful as they often incorporate women’s empowerment and microfinance opportunities along with education and awareness. In regards to case management, the research has focused on ART adherence of different high-risk groups, and mechanisms for dispensing ARTs. Unfortunately, the focus initially placed on quality of life for

those infected by HIV, such as palliative care and care and support programs are becoming more of an anomaly. The face of HIV/AIDS is however continually changing, particularly in low resource contexts throughout the world. Though the incidence rate is significantly slower throughout the world, and ART's are improving the lives of many and allowing them to live drastically longer lives, there are still unmet needs for this population.

Widowed and abandoned women are of particular concern. Due to the social structure discussed in India, this segment of the population has a number of care and support needs. ART and vitamin supplements are readily available from the government, however, in light of longer lives, the needs of caring for children and desire for a good quality of life, it is necessary to understand how this population perceives their needs and concerns, and how they best desire to be supported. Due to the lack of evaluated and evidence based programming on HIV/AIDS care and support, it is difficult to discern and present published work on the role of nongovernmental organizations and networks established by the government in the role of care and support. One such NGO working in this field is World Vision and this study uses the work of this organization as a means to reach this population in order to better understand the needs, challenges, and desired supports of this segment of the population.

World Vision is an international Christian humanitarian non-governmental organization that works to alleviate injustice and poverty. Working in multiple sectors from health and development to emergency response, there are numerous programs, projects and initiatives that are under the jurisdiction of the organization. World Vision India works specifically to meet the needs of people in India with the priorities of: 1) well-being of every boy and girl, 2) sustainable livelihood security, 3) access to water, 4) peace building and reconciliation, and 5) prevent and mitigate HIV/AIDS & TB. The Grassroots Response to AIDS through Care and Education

(GRACE) Programme is one of the projects of World Vision India. The Programme is based in Chennai, in the southern state of Tamil Nadu, and has the overall goal to improve the quality of life of persons affected and infected with HIV/AIDS. This is achieved through a three-pronged approach consisting of: 1) Prevention, 2) Care and Support and 3) Advocacy. Each component includes a number of specific objectives achieved through numerous activities ranging from awareness in schools to counseling services and support groups meetings. Using this organization and established framework, a study was completed aiming to evaluate the program and its work, which was then adapted to complete the following work.

This study will add to the knowledge on the unique needs and challenges experienced by widowed and abandoned HIV positive women in the Indian context with special attention to improving quality of life following diagnosis. Specifically, this study will explore:

- (1) How do HIV positive women perceive their quality of life, what are their unique needs and concerns?
- (2) How do these needs and concerns fit into the theoretical framework of the social ecological model and postcolonial feminism?
- (3) Recommendations to intervene in order to improve quality of life of HIV positive women in South India.

### **3.0 METHODS**

Three focus group discussions (FGDs) were conducted in Chennai, Tamil Nadu, India at the project office of the Grassroots Response to AIDS through Care and Education (GRACE) Programme. FGDs are a form of qualitative research and data collection. They can be instrumental in aiding to build hypothesis, as well as understand beliefs, attitudes and contexts associated with disease outcomes and behaviors. FGDs are unique in their informal nature, which allows for freedom in conversation and extemporaneity. This is witnessed in the comments of one participant triggering another, providing natural conversation rich with qualitative information (Gilmore & Campbell, 2005). Moreover, sometimes FGDs are used to find a consensus among a group of people.

#### **3.1 RECRUITMENT**

Gaining entrée into this community was very important, as it is a highly stigmatized and so building trust is critical in the process of recruitment. For nearly six weeks, I was in the office primarily as an observer. I was introduced to various beneficiaries and would take special interest to interact while they waited to receive various services from the Programme such as counseling services, or were present to pick up monthly food provisions. During this time, I was able to establish my presence in the office, as many would ask about who I was and my purpose

of being at the Programme. In addition, I made multiple field visits to various self-help group meetings, awareness programs and home visits with the community health workers; activities were instrumental in entering the community. The community health workers and staff of the Programme later served as key informants and provided means for beneficiaries to trust me as an individual they would be interested in speaking with and sharing their story. Following the weeks of observation and field visits, recruitment for the FGDs was approved.

The community health workers and volunteers of the GRACE Programme played an active role in the recruitment of focus group participants. The staff initially contacted beneficiaries of the Programme through phone calls and during counseling sessions. Female beneficiaries of the Programme were notified of the dates and times of the three different scheduled focus groups and encouraged participation through follow-up phone calls the day prior to each FGD. The women contacted all received services in a variety of forms from the Programme including but not exclusive to education support for children as well as loans and appropriate materials for income generating activity.

### **3.2 FOCUS GROUPS**

All three focus group discussions (FGDs) were hosted by World Vision, at the GRACE Programme Office located in central Chennai city. The location is known by the community at large as a place for assistance, but specifically caters to the needs of people living with HIV/AIDS. The Programme is well connected with the government hospitals- the locations of Integrated Testing and Counseling Centers, and dispensary of free antiretroviral therapy medication in addition to other non-governmental organizations and multiple networks. This

connectedness results in multiple referrals with many of the beneficiaries receiving services at World Vision aware and connected to services throughout the urban center.

A total of three focus groups were completed in August 2011 during the course of one week. The discussion groups had 4, 5, and 5 participants respectively, resulting in a total of 14 female participants, all of whom were receiving services from the Programme. Of the 14 participants, all 14 were mothers, 12 were HIV+, and 10 were widowed or currently abandoned by their husbands. All of the participants resided in the regions within Chennai city served by the Programme, with two groups recruited from central Chennai region, and one group recruited from the north Chennai region.

The focus groups were completed initially with the purpose of program evaluation. A field guide was developed by researcher and a mentor appropriate for the local sociocultural context. (The field guide consisting of the introduction script and questions are attached in Appendix A and B respectively in both English and Tamil). All FGDs were conducted by researcher in the local language, Tamil, with the assistance of community health worker who served as a note taker.

All participants were compensated for travel costs and were provided with a light snack and refreshments. Travel costs were determined as per the recommendation of the community health workers of the Programme. Each FGD lasted approximately one to two hours and all were conducted in semi-private/secluded area within the office space of the GRACE Programme. All identifying information, including name and home address were not included in the transcripts and were kept confidential. FGDs were audio recorded and transcribed and translated at a later date.

### **3.3 OBSERVATIONS**

Extensive field notes consisting of participant observation and non-participant observation were gathered. Participant observations were completed primarily in the context of the drop-in center, support group meetings, and field visits to homes of beneficiaries and other networks and non-governmental organizations working in this field. Non-participant observations were completed predominantly outside the context of the work and services of World Vision. Observations were recorded systematically, noted twice a week, with notes recorded all field visits. These observations provided insight into general cultural and societal norms and interactions. Special attention was given to perceptions on male-female interaction, as well as role of women particularly outside the home in various locations including but not limited to the marketplace, and communal spaces in slum areas.

### **3.4 DATA ANALYSIS**

The FGDs were audio recorded and uploaded onto the researcher's personal computer as MPEG-2 Audio Layer III (MP3) files. With assistance from Wave Editor, Controller Mate, Quicksilver and the use of a foot pedal, the researcher transcribed each FGD. The recording were translated from Tamil to English and transcribed concurrently.

Following transcription, the data analysis was assisted by the University Center for Social and Urban Research's Qualitative Data Analysis Program (QDAP). The researcher and two technical personnel from QDAP worked to create a codebook following initial readings of the transcripts. Each transcript was coded appropriately making use of ATLAS Ti (Version 6).

Researcher and technical personnel coded each of the transcripts separately. Kappa Statistics were conducted to determine the variability in the coding between researcher and technical personnel. Codebook was modified as necessary, as researcher and technical personnel coded the first transcript. Due to time constraints and other unforeseen difficulties, the last two transcripts were coded solely by the researcher, making use of the codebook created collectively. Kappa Statistics were not conducted for the final two transcripts coded.

Following coding, the transcripts were analyzed for common themes along with similarities and differences between and within all focus group discussions. The data was further viewed under the lens of the social ecological model and post feminism framework in order to better understand the context as well as provide pertinent recommendations for program intervention improvement.

## **4.0 FINDINGS AND RESEARCH CHARACTERISTICS**

This section provides a synthesis of the research characteristics and relevant findings as per the objectives. A conceptual framework was created outlining the intersection of the triple burden with the social ecological model and postcolonial feminism. Finally, the triple burden and needs and concerns of HIV positive Indian woman are further articulated using the stories and voices of real women and their unique lived experience.

### **4.1 FOCUS GROUP DISCUSSIONS**

Three focus group discussions (FGDs) were completed, over the course of one week in August 2011 as a portion of a broader evaluation of the GRACE Program. All the participants were women who were beneficiaries of the GRACE Program. Focus groups were conducted in secure locations and during times of regularly scheduled events at the project office. Demographic information was gathered throughout course of interaction with participants before, during and after FGDs. Below is a table accounting for the demographic information of the participants of the FGDs. Identifying information such as residence location are not included.

**Table 1.** Participant Characteristics

	Age Range	Marital Status		Mothers?	Job Status	
<b>FG.1</b> (4 participants)	23-34	Married		All 4 were mothers with 1-3 children.	Housewife	
		Widowed	4		Work out of home	4
		Abandoned			Unemployed	
<b>FG.2</b> (5 participants)	20-32	Married	2	All 5 were mothers with 1-4 children.	Housewife	2
		Widowed	2		Work out of home	2
		Abandoned	1		Unemployed	1
<b>FG.3</b> (5 participants)	26-38	Married	2	All 5 were mothers with 2-3 children.	Housewife	2
		Widowed	2		Work out of home	2
		Abandoned	1		Unemployed	1

## 4.2 EMERGING THEMES

The concerns and lived realities of the participants were similar across groups, regardless of the age range, marital status and job status. Experiences and stories were often echoed within and across focus groups. A conceptual framework is presented which aims to connect the triple burden with the theoretical framework of the social ecological model and postcolonial feminism. Overarching themes emerged that highlighted burden related to identity, the triple burden; in addition, needs and concerns were expressed, with the specific needs of: 1) *Housing* and 2) *Financial security*.

The Triple Burden is an exploration of the burdens associated with the identities of being a widowed or abandoned HIV positive woman with the distinct new role of being the primary head of household. The lack of education, health concerns and stigma and discrimination highlighted the burden of being HIV positive. The struggle of being a girl, the financial burden

of being a daughter and loss of status due to marital status exemplify the struggle of being a woman. Lastly, the burden of being the new head of household was witnessed in the difficulties of being a widow or abandoned woman, housing concerns and the inability to financially support a family.

As a result of this triple burden, particular needs and concerns were brought to the forefront related to housing and financial security. Housing was a concern as often the participants did not reside in their natal or marital home and failed to possess property rights therefore deeply desiring housing provided by the government. Financial security was a concern as the role of head of household was thrust on the participants unexpectedly and they lacked the skill and education to obtain employment which provided a sufficient salary, therefore there was a desire expressed for provision for means to build financial stability. The items discussed provide the means to better understand the unique lived reality, needs and concerns of this segment of the population.

#### **4.2.1 Conceptual Framework**

Below is a conceptual framework to depict the various components of the triple burden within the framework of the social ecological model shaped by the invisible hierarchy that often times exclude women and marginalizes women.

The external box, and the lens with which this work is being analyzed is the framework provided by post-colonial feminism. Hierarchy as discussed earlier is ingrained in the fabric of Indian society on multiple levels—for the purposes of this paper, the focus will be on HIV positive women who are aiming to improve the quality of their lives. The social ecological model is the primary theoretical outline in use. For each factor of influence—intrapersonal,

interpersonal/family, institution, community/social structure, and policy— there exists the triple burden. To visually depict this relationship, the conceptual model has been created with the triple burden superimposed on the social ecological model.

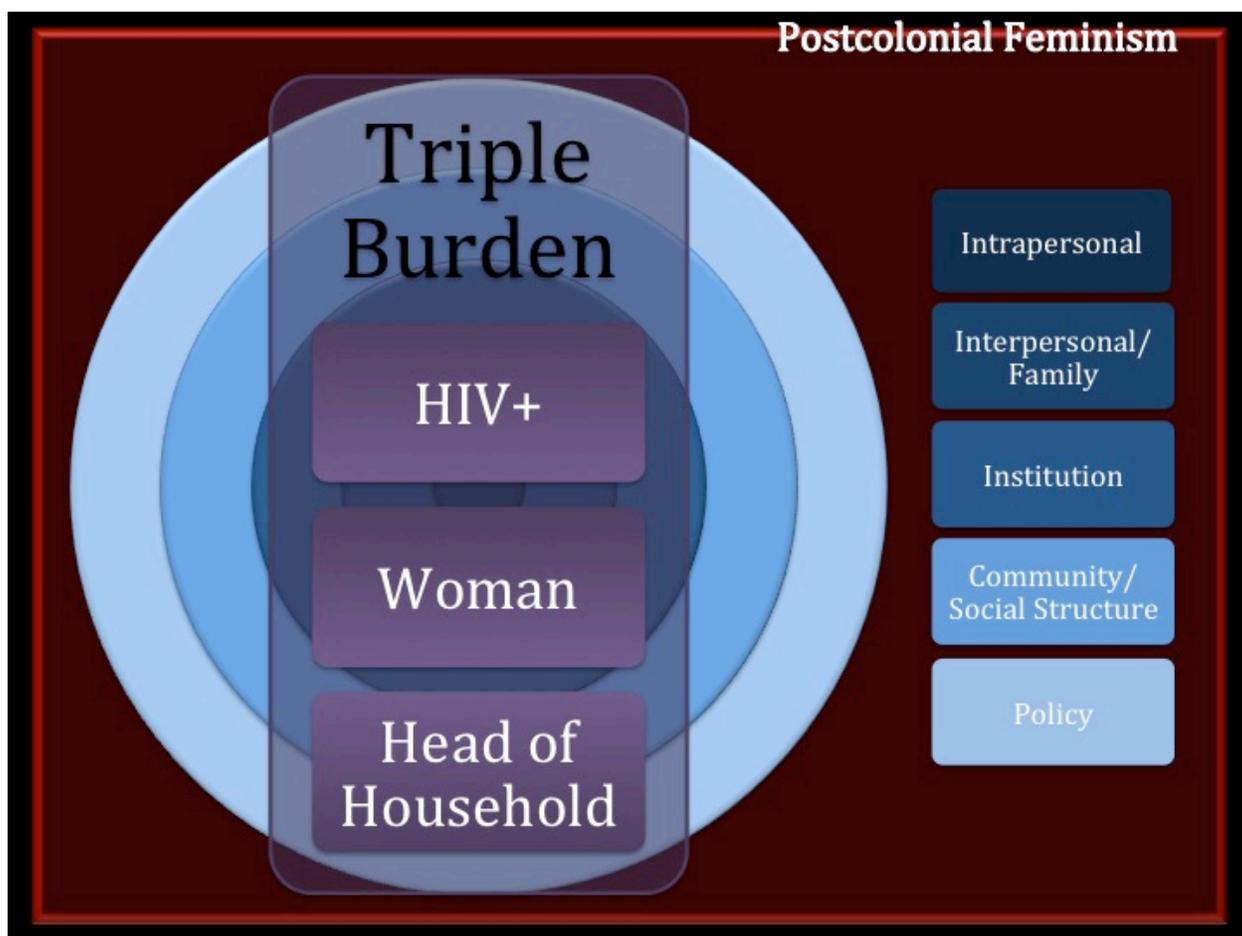


Figure 1. Conceptual Framework

Considering the hierarchy that creates grave gender inequity, there are multiple ways in which the triple burden is actualized in the various factors of the social ecological model. For instance at the interpersonal/family factor of influence are a number of elements which are affected by the triple burden including one's HIV status as women are often blamed as the source of infection, stigma from family which results in a changing relationship and role in the context

of both the natal and marital homes, the change in marital status affects how the woman can interact both within and outside the home as she no longer possess the identity of wife, and finally there is the potential conflict that occurs with the marital family as it relates to property and other assets.

At the community/social structure factor of influence this is manifested in the presence of patriarchy and gender inequity, stigma and discrimination, low socio-economic status, insufficient income due to status and caste constraints of being a widow, the difficulty associated with obtaining housing without the presence of a male the ingrained gender norms surrounding how one is to be the head of household.

Finally, at the policy level of influence, there is a deficiency in anti-discrimination laws and enforcement of gender equity laws, and lastly the constraints of religious law, which prevent land and property from being inherited by women without husbands. The triple burden would be observed by the other factors of influence similarly with the lens of the hierarchy oppressive to women and are identified in the table below.

**Table 2. Intersection of Social Ecological Model and The Triple Burden**

<b>Factor of Influence (Social Ecological Model)</b>	<b>Elements affected by The Triple Burden</b>
Intrapersonal	-HIV status -Marital status -Age -Financial role in familial unit
Interpersonal/Family	-HIV status: blamed as cause/source -Stigmatized by family -Changing role within natal/martial families -Marital status -Norms within/outside home -Property conflict
Institution	-Difficulty with women’s collectives and government assistance -NGOs/CBOs failing to incorporate gender inequity in

**Table 2. Continued**

	programming
Community/Social structure	<ul style="list-style-type: none"> <li>-Patriarchy/ gender equity</li> <li>-Stigma &amp; discrimination</li> <li>-Low SES</li> <li>-Insufficient income</li> <li>-Obtaining housing w/o male</li> <li>-Gender norms not primed for HOH role</li> </ul>
Policy	<ul style="list-style-type: none"> <li>-Lack of anti-discrimination laws</li> <li>-Lack of knowledge/ enforcement of gender equality laws</li> <li>-Religious laws denying land, property, rights to women without husbands</li> </ul>

#### **4.2.2 The Triple Burden**

The Triple Burden refers to being HIV positive, a woman, and the head of household. Below are detailed explanations of each of these identities and the manner in which components of every day life are manifested as burdens. It is important to understand this context in order to understand the needs and concerns of this segment of the population.

##### **4.2.2.1 Being HIV Positive**

Participants had known of their HIV status for at least 3 years or longer, with some knowing of their status for nearly 15 years. When participants reflected on the process of accepting their respective health status, many accounted of how they had lacked any awareness of the infection. Many had similar experiences in which their spouses became very ill, and on their deathbed were alerted of their HIV status, thus leading to the women discovering that they were HIV positive as well. A few women also noted that they were alerted of their status when they became pregnant. Nearly none of them had been exposed to any HIV/AIDS education or preventive interventions. This lack of awareness and education often resulted in a very difficult acceptance process. It was

noted that thoughts of suicide and getting an abortion were often the initial response. The emotional toll of accepting one's HIV status was widespread regardless of the circumstances surrounding diagnosis and revelation of status.

The burden of being HIV positive is also manifested in the inability to complete mundane tasks; participants discussed how their own health status presented a burden in their lives in a physical manner:

...it is difficult, my body is in pain, it is hard to clean, to dust, to do things for the children. My daughter's birthday... she asked me to get her new dress, but I did not leave the house, this disease it makes us miss things, and we want to live for our children, but I am sick and not well. If I did not have this disease, I could go to get her dress (crying)... this disease is a curse.

This was one of many stories in which participants said their health status impeded their quality of life.

Participants shared that they had been discovered to have this change in health status in unlikely ways, often lacking any knowledge of HIV/AIDS or methods of prevention prior to diagnosis. The stigma and discrimination associated with being HIV positive was a constant theme through all the focus groups and participant observations. The GRACE Program had no identifying markers that it served HIV positive individuals, with beneficiaries often noting that they had to take multiple buses in order to not be identified on their way to the drop-in center to ensure that others in the community did not know of their connection to the center. Therefore the identity of being an HIV positive individual was something that had come about unknowingly for many of the participants, and though they had been able to get connected to various networks

and the government hospitals providing treatment, they experienced health concerns and viewed HIV as a curse and dealt with constant stigma and discrimination as a result.

#### **4.2.2.2 Being a Woman**

Being a woman in the Indian context as established above proves to result in a difficult lived reality, and the participants spoke with great transparency regarding their identity as woman. The participants had strong notions of what it meant to be a woman. When asked what was unique about their life as a woman, responses included:

...struggle is life. Being born a woman is a struggle itself.

The simple idea that the participants were born of one sex as opposed to the other resulted in the conclusion that their lives by default were a struggle. This was further expounded upon as one of the participants identified what it meant to be born a female:

Being born as a girl is what do they say?... *Ethernice*l.

Though there is no direct translation for the term *ethernice*l, it can be best explained as the notion of ‘swimming against the flow of the river’. In essence, being born a girl instead of a boy is in and of itself against the flow of the river, with struggle being at the core of life and its experiences throughout the course of life. Identifying the essence of being a woman as *ethernice*l, specific items related to the burden of being a woman were identified.

Conversations observed at the drop in center on many occasions surrounded the preference for male children, the difficulties of dowry and marriage and the difficulties that families faced when having to arrange the marriage of multiple girl children. The notion that

having daughters would negatively affect the financial status of the family was repeatedly mentioned as preparing a dowry and saving for a wedding are significant financial concerns.

The financial burden of being a daughter continued into marriage as status in society particularly in the caste based structure of the Indian context. One participant accounted of how her marriage had provided her with status, and now that she was a widow, she no longer possessed any status,

It was a love marriage, but my parents approved... they are Vellalars (caste), but when he died, they (in-laws) told me to leave. Now all of the Vellalars at the temple will not speak to me, only because of him... now that is not there.

Being the wife of a man of a higher caste provided this woman with status in society, but the loss of her husband has resulted in her dismissal. She is no longer viewed with respect, as she fails to possess the identity of wife. Being a woman is a struggle as there are concerns regardless of stage of life, as daughter or wife, it is a constant battle to swim against the flow of the river.

#### **4.2.2.3 Being the New Head of Household**

As a result of losing the male head of household due to death or abandonment, the women spoke of how they were forced to embrace possessing the role of new head of household. Many of the participants noted that there are unique expectations for women who do not have a man as the leader of the home. The role of caretaker is heightened in intensity, as they must continue satisfying the gender norm roles of mother and housekeeper, but are now also must also be responsible for roles often possessed by the male of protection and finances. Many participants also noted that this was a role that they were not in any manner primed to take on. It was mentioned repeatedly that they were not prepared in any way to be young widows; it was

assumed that they would be widowed in old age and at that time be cared for by one of their sons. Therefore, this new role as head of household was unexpected, and many felt ill prepared as they lacked the skills, learned behavior and social support to take on this role.

In light of this context of being a widowed or abandoned woman in this new role, there were distinct burdens mentioned by the woman including difficulty in obtaining housing and financial strain as a result of loans and debt incurred for treatment of husband during end of life. One woman noted that she found it difficult to find a house to rent as house owners often questioned her about not living with her family,

...they (in-laws) told me to leave when my husband died, and my parents live in the village far away, and they won't understand if I tell them I have this disease... but no house owner would let me take room for rent in the city, telling me, 'where is your father? brother?... husband?'

In order to find a location for housing, there was a need to have a male presence in the negotiation process, as other participants noted that they requested a male relative to assist them in the process. Participants also noted that many had to deal with extensive financial concerns following widowhood or abandonment, as they now were responsible for the finances. Many noted that their late husband's health treatments were quite costly and resulted in loss of many assets, and acquisition of loans and debt. As noted earlier, there was a unanimous agreement that there was no preparation to deal with the financial constraints and expectations placed on these women as they assumed this new role as head of household.

As the participants articulated their identity as it related to their health status, and their distinct roles in society, unique needs and concerns were brought to the forefront in their desire to improve the quality of life of both themselves and their respective families. These perceived

needs and concerns are important to understand in the process of program development and policy implementation in order to provide impactful change in order to improve the quality of life of this forgotten population.

### **4.2.3 Needs and Concerns**

The identity of the participants lent itself to be clearly branded burdens. In light of this established context, the participants were asked what they would identify to be their most significant needs and concerns. The needs of housing and financial security were overwhelmingly the most pertinent needs and concerns expressed.

#### **4.2.3.1 Housing**

The patriarchal context of Indian society results in strong social norms that reinforce the notion that there is male head of the family unit, regardless of if it is a nuclear or joint family. For widows and abandoned women, they are the primary leaders of their respective households; this creates a number of problems for them as it relates to housing needs. Many women noted that there is no property or home that is provided to them, as often the land or property owned by their deceased husbands belongs to the in-laws and these women are not provided space in the homes of their in-laws, often all ties with the family of their husbands are severed. It was mentioned repeatedly that they were no longer connected in any way to their marital family and a few noted that they were violently thrown out of their marital homes following the death of their husband or point of diagnosis of HIV status.

Many of the participants voiced that they possessed no property rights and therefore had to rent, but that the social norms associated with relationships between homeowners and renters

without the presence of a male in the negotiation process made it difficult to obtain a home for rent. In addition to the lacking presence of a male, it was reiterated numerous times that if their status was to be revealed, that obtaining housing would be very difficult.

As long as they don't know its ok (our status), but that if they do. If they don't know it is safe, but if they know, that is all, even the house, they won't even give the house for rent... if they know, there is no chance, you won't get a house.

Apart from the difficulty of being thrown out of their marital homes, and then negotiating the process of obtaining a house for rent as a female head of household, many of the participants noted that they perceived housing to be important as they looked towards end of life needs and concerns. Housing was difficult to obtain for a significant number of the participants and the lack of property rights and social support from either the natal or marital families was one of the primary concerns expressed. The problems surrounding renting and the inability to have a definite location to pass away peacefully were matters related to housing that were widespread and specific to the needs of this population.

As a result, there was a widespread expressed need and desire to have government-sponsored housing. This was discussed at length, with participants noting that there was significant portions of land owned by the government which are presently idle and the need to provide housing for those who are of the low socio-economic status. Additionally, it was mentioned that in the last few years the city housing board had provided paperwork to be filled out in order to apply for government housing, but the participants had not heard any further information. Therefore, in light of the concerns surrounding obtaining a home for rent and the lack of property rights as per familial heritage, the participants noted that they desired and needed government-sponsored housing.

#### **4.2.3.2 Financial Security**

Considering the social context, financial security was repeatedly a theme in the focus group discussions as a cause of concern for women who are HIV positive, widowed or abandoned and taking on a new role as head of household. Being primed and trained to work inside the home, the transition to work outside the home is in itself is difficult for most of these women. Due to their place in society, and often the lack of job opportunities afforded them due to their lack of education and skill, the salary is insufficient to care for a family. Many participants alluded to their education level, with many noting that they had not completed secondary school. This in turn resulted in many only having the skill set to work in domestic housework, which fails to provide financial security.

Other than working in domestic housework, a few of the participants had taken up work as peer educators and field workers for the government hospitals and various non-governmental organizations working with people living with HIV. This was one of the only jobs that they could attain considering their education level and skillset. Unfortunately they are struggling to make ends meet in this line of work, as the projects they work on are not stable or secure.

You see, for us, most of us work project wise (as field workers on HIV peer support programs), it you honestly see, there is only five months left. For the next 5 months, there is concern... for January, how will we pay rent? Even if we have the money from December and we pay, after that, who will pay? Like this there are so many problems.

Their inability to generate a sufficient income leads to other problems that are all directly connected to their low socio-economic status.

In light of this financial instability, the participants expressed a distinct desire to be given work or be trained to have jobs that would help them to take care of their families sufficiently.

They do not desire to depend on charity. They desire to be able to work and take care of their own families, and so they expressed the need to be able to gain employment that will allow them to have financial security and care of their families.

In that way, standard, if there is a job, that is enough. We ourselves will see everything. That one – job, second from that we should earn enough to run our family, that sort of salary we should get... is we only get Rs. 3,000, with that you cannot do anything. In this Chennai city, if you want to run a family, a salary, an amount, a job like that. We don't want help; we will run our own families.

The concerns expressed by this population are deeply connected to the triple burdened identity of being HIV positive women who have taken on the new role of head of household. Considering the hierarchy, which excludes and marginalizes them, it is important not to be overwhelmed and debilitated by this lived reality, but rather be insistent to find a way forward in order to improve the quality of life of this segment of the population.

## 5.0 SYNTHESIS AND REFLECTIONS

The combination of being a women in a patriarchal society (Go et al., 2003), managing stigma and discrimination due to health status (Yamba, 2007), lacking male support and thereby losing fundamental status in society, in addition to having the responsibility to care for often times multiple children (UNAIDS, 2002) has been documented through the world (Luginaah, Elkins, Maticka-Tyndale, Landry, & Mathui, 2005; Oluwagbemiga, 2007; Oosterhoff, Anh, Yen, Wright, & Hardon, 2009) as this is the reality of a growing segment of the population. The multiple burdens and challenges present in the lives of Indian women are however unique, and often these factors have been addressed in reference to ART adherence (Nyamanthi et al., 2011; Shet et al., 2011), and affected creation and implementation of prevention programming (Chakrapani et al., 2011; P. Ghosh et al., 2011). Regardless the elements of the triple burden—being HIV positive, being a woman, and being the new head of household have all been identified in a number of different studies, therefore affirming the congruence of this work with many others.

In addition, the unique needs related to housing and financial security have also been identified in previous work (Luginaah et al., 2005; Nyamanthi et al., 2011; Oosterhoff et al., 2009; Pradhan & Sundar, 2006; Suniti Solomon et al., 2003; Souza, 2010; Thomas et al., 2009) as it pertains to the needs of women infected and affected by HIV/AIDS. Therefore the results of this work are in congruence with previous studies and reports, affirming both the multiple

identities of women infected with HIV as well the unique needs that are present for this segment of the population.

A significant point of interest however is the idea of palliative care and its association with the need of housing. Palliative care was a hallmark of the care and support associated with HIV/AIDS programs early in the process of combating the epidemic. Since that time, there has been a shift away from palliative care and focus on end of life concerns. For young widows, there is a concern that they will not have anyone to take care of them during the this end of life period, as their children will not be old enough to care for them, and they are disconnected from familial support. One participant noted that there was concern that anyone would be willing to touch and care for them at this stage in life, and that having a home would result in a peaceful passing:

...if something happens, and our bodies, we cannot do anything, who will carry? we are like this. Will they touch us? There is this fear in our minds. How (will this happen) if we live in house for rent...when we cannot do anything and are sick, our relative(s), will they see (take care)? Will they touch and carry? If for us there is a place, we can peacefully die. There is that thought.

When asked if palliative care was what they desired, there was a unanimous notion that they would rather pass away in the context of their own homes. They did not want an institutional form of care at the end of life, but desired to create a space that was comfortable for this period of life. Therefore, there must be new and innovative ideas regarding palliative care for such a highly stigmatized health status. This idea is not articulated in the present literature, and there is need for more research and work to understand the usefulness and best way forward when thinking of improving end of life services for this population, so that there is grace and dignity

provided in this time of life. Finally, the results of this work also help to shed some light on the interplay of perceived needs and concerns, the strict oppressive hierarchy and the desire to express agency and be emancipated from this societal structure.

The needs and concerns expressed were directly connected to the new role of head of household. The desire to have a stable home and financial security were connected to the identity of being the primary head of the home, as there is an overwhelming notion that the women were ill-prepared to take on this identity and role. In addition, the social context makes it difficult to take on this identity that is often forced upon these women. Though the burden of being HIV positive, a woman, and head of household was well established, the needs and concerns did not encapsulate the three components of burden, as they were directly connected to the new role of head of household. It can be therefore argued that, perhaps, there is an acceptance of the hierarchy that oppresses, marginalizes and excludes women, but there are glimpses of a desire to express agency and fight for emancipation from this ingrained social structure.

Despite the difficulties associated with the identities as expressed by the participants, the women spoke with great resilience in their desire to work, provide and care for their children. For instance, there is a great deal of pride in the fact that though the participants must be responsible for an extensively demanding schedule, that they are in fact accomplishing the numerous items on their 'to-do' list.

If you look, from morning till evening, finishing everything and then at night laying down and thinking about we wen all these places today, did all this work... I myself will be very surprised. This great distance I have walked, this much work I have completed, this many buses I have gotten up and down, this many problem I have solved. And so, I am surprised and think—and I can work even more.

This desire to continue to work speaks to the emancipation that these women are experiencing, as they are on a daily basis accomplishing tasks that perhaps are outside what society deems to be appropriate. In addition, the desire to change the reality for future generations particularly as it relates to gender norms and roles was shared by multiple participants as they discussed what they hoped for in reference to their children:

They (referring to 2 daughters) must study, and I will do as much as I can do to help, take debt to pay tuition if need be. But they should be strong, not be dependent on a man when they are older, be able to work and earn for themselves. That is what I say to God, 'I did not study, but my children should study'. They should be big people... I want them to do well.

The participants though they have the identity of being HIV positive woman who are unattached as widows or abandoned women possessing the new role of head of household and the burdens associated with this unique identity, these women greatly desire the ability to express agency.

Therefore, there is this internal struggle present—to accept the societal hierarchy of being subjected to these roles of daughter, wife and mother with the burden of being HIV positive, a woman and a new head of household or to change the tide which so gravely bounds them and be part of creating a society that no longer imposes these burdens of identity but be able to see a different future for generations to come. The identification of needs and concerns highlights only one burden, the one burden that does not fight the notions of what it means to be HIV positive or be a woman, but there is a desire to express agency and begin to change the notions of what it means to be HIV positive, and be a woman. These are not changes that will occur immediately, but the desire to change the status quo and these small changes of working outside the home, and fighting for property rights along with strongly fighting for a difference in the hierarchy for

future generations are steps towards eliminating the triple burden, and allowing those titles of HIV positive, woman and head of household to simply be ways in which there is identity but not burden.

## **5.1 RECOMMENDATIONS AND PUBLIC HEALTH IMPLICATIONS**

The public health implications in light of the findings above are further expounded upon in this section. Considering the complexity of the context of the lives of these women and their overarching needs, it is imperative that any program or initiative aiming to provide care and support must be multi-pronged and be brought to fruition under the framework of the social ecological model. It is essential that the next steps make use of the voices of women and the triple burden that they face in order to positively affect their quality of life. In order to achieve this goal, there are numerous points of possible intervention and improvement; however the following are the most suitable recommendations on the best way to move forward considering the specific needs and concerns of this population as expressed in this work.

### **5.1.1 Recommendations**

#### ***Tailoring microcredit schemes and livelihoods training to meet the need of financial insecurity of HIV positive women in India.***

Programs supporting income generation and microfinance have been well established in the aim to target the intersection of poverty and gender inequity in HIV/AIDS (Dworkin & Blaneknship, 2009). It is important to further tailor these initiatives to meet the contextual needs of women

experiencing the triple burden. The participants were interested in creating community based business endeavors and working with others in the HIV positive community. Therefore, it is integral for success that these programs are community based and make use of the networks connecting positive individuals and ultimately increase the financial stability of the participants and provide a sufficient income in order to be effective heads of households.

***To pass the HIV/AIDS Bill.***

The passing of the HIV/AIDS Bill would be a policy level change that among its many provisions would prohibit discrimination of persons with HIV in regards to employment, education and housing (Collective, 2007). The HIV/AIDS Bill was drafted and presented to the Health Ministry in 2006, but failed to move to Parliament till March 2010 (Shalini, 2011). Despite protests in November of 2011 prior to the winter session of Parliament, as of March 2012, the bill has yet to be passed and is currently pending with the Health Ministry.

It is imperative that this Bill is passed in Parliament. The Bill provides specific provisions related to housing that are vital to be established at the national level, in order that more pressure maybe applied at the state level in order to attain the official government housing that is desired by women experiencing the triple burden. In addition to housing, the bill would provide the enforcement power of law to the many right-based approaches supported by the government and is vital in changing the quality of life of persons living with HIV/AIDS.

***Promote and advocate for increased awareness and education around HIV/AIDS and rights of widows and women.***

The hierarchy that excludes and marginalizes women is deeply ingrained in the fabric of Indian society and daily life. In addition, stigma and discrimination are rampant, as seen in the constant fear of HIV status being revealed in any sector of life. Though there have been significant movements to increase awareness and education including the Red Ribbon Express and women's collectives pushing the feminist agenda at the local and national level— stigma and discrimination along with low social status of women are perpetuated in all segments of life. Therefore, it is important that awareness and education continue to play a significant role in breaking down these barriers that continue to impose the triple burden.

**5.1.2 Public Health Implications**

The recommendations presented aim to address the needs and concerns identified by the participants, taking into account the voices of real women experiencing the hierarchy of Indian society and aiming to live a quality life despite their difficult lived reality. It is important to take into account the implications of these recommendations as are there are important items to note in the desire to find a way forward.

***Implication of tailored schemes to improve financial security.***

Microfinance and income generating programs aimed at providing livelihood training and seed money directly work to improve financial stability, with many having a specific focus on woman and making use of their particular skills. It is important to contextualize these efforts so that they

have the best potential to succeed. It is important to gain community input as this work has done in order to gain the appropriate knowledge to contextualize these initiatives.

Unfortunately, the women gave examples of how past initiatives to help generate income have failed. There is need for specialized programming and training that takes into account deeply ingrained cultural and social norms. For example, one of the participants has attempted to set up a food stand at a large bus terminal. She noted that she had an affinity for cooking, and was well supported by her family in the profitable endeavor. However, she experienced various problems due to the inappropriate interaction on the part of men at the bus terminal—men would cross physical boundaries of personal space that are important in public contexts outside the home among men and women who are not relatives and speak in profane ways with this participant. Being a woman without the presence of a male in this profitable endeavor posed countless problems and the participant was forced to close the food stand. There were many more accounts presented by the participants as they shared the difficulties with the income generating projects that they had been involved in; often they were closely tied to the role of women working outside the home in a capacity outside the realm of domestic housework. Therefore, it is important that the livelihood training and microfinance funds are not specific for endeavors that potentially do not have the ability to succeed considering the social context and hierarchy.

In addition, it was repeatedly mentioned that participants would like to work with others from the HIV positive community. This is one of the strengths of this group, harnessing this sense of solidarity and desire to uplift one another towards collective financial stability and gain should be used in the self help groups and further in possibly creatively thinking of new opportunities for income generation. This recommendation has the potential to affect the triple

burden at both the intrapersonal level of financial input as well as at the community level in combating low socio-economic status and insufficient income.

***Implication of passing HIV/AIDS Bill.***

The passing of the HIV/AIDS Bill into law would be a tremendous step forward in improving the lives of those living with HIV/AIDS in India. If the bill is to be passed, success and effectiveness are contingent on the emphasis of enforcement on all levels. In the Indian context, equality laws have been in place from the independence of the nation, but the feminist movement has been working hard to educate the public about its rights and pushing for strict implementation. It is important that along with the passing of the bill that community based groups would be key in the process of education and police and the necessary agencies and levels be briefed in order that implementation occurs.

For instance, Indian women have equal political rights to men. In addition, they are recognized as a portion of the 'weaker sections' of the population akin to untouchable castes and tribal groups, and therefore under the constitution should be specially assisted to function as equals (Chitnis, 1988). Unfortunately these legal and political rights afforded woman are not utilized, therefore it is important that woman are educated regarding their rights as this will enable them to make use of the provisions provided for them in the constitution. Awareness of rights alone will not result in change of the societal norms, but it is vital that legal services are extended to women who are in need of them. In addition, it is important that this bill, if passed, does not remain simply a part of law, but one that begins to change the lived realities of those with HIV/AIDS.

In regards to housing, this law would be vital in ensuring that woman are not thrown out of their homes, and remain a part of a household:

Every protected person who is a woman or who is a person below the age of 18 years shall have the right to reside in the shared household, the right not to be excluded from the shared household or any part of it and the right to enjoy and use the facilities of such shared household in a non discriminatory manner (Collective, 2007).

In addition, this federal law could provide the necessary means to begin placing pressure on the state level government to provide official housing that is non-discriminatory, therefore making sure that those who are HIV positive are not secluded or separated from society at large by way of separate housing. This recommendation has the potential to affect the triple burden at the interpersonal and policy level. Discrimination based on status and refusal of shelter are legitimate concerns, and this law has the potential to make large policy changes which can significantly improve the quality of life of those living with HIV/AIDS.

### ***Implication of increased education and awareness.***

Awareness and education have been at the cornerstone of the response to the HIV/AIDS epidemic for numerous years. In India, there have been multiple initiatives nationally, at the state level and in local communities via the Red Ribbon Express and street plays and media campaigns. These initiatives have helped to increase awareness and educate the public on transmission, but there are still gaps in knowledge as the National Family Health Survey revealed that 43% of married woman had never have never heard of AIDS and only 35% know that consistent condom use is a means of HIV prevention (NFHS, 2007). The lack of knowledge

is directly connected to the high level of stigma and discrimination present in Indian society. In addition, the rights of women and widows present in the legal framework are unknown to the population at large, and it is important that there is increased education and awareness of these rights both for women and the general population.

Many participants cited that they had no knowledge of HIV/AIDS or its transmission until they were notified of their HIV status, and that many feared that sharing this knowledge with others would be misconstrued as promiscuity in this culture of silence. In addition, it was noted that the lack of knowledge resulted in stigma and discrimination, often resulted in assumptions regarding who was to blame in the partnership for bringing the infection into the relationship. Participants believed that the street plays and media campaigns had helped to open conversations regarding HIV, domestic violence and gender relations, but they believe that more work needs to be completed in order to reduce the stigma and discrimination that they experience on a daily basis. The lack of knowledge surrounding women's rights also continues to perpetuate the low status of women, particularly widows in society. Awareness and education are key to breaking down the stigma and discrimination surrounding HIV/AIDS as well as help improve the status of women. These changes will be slow as are they are ingrained, but it is important that the aim to educate and raise awareness continues to be part of this gradual change.

## **5.2 LIMITATIONS AND STRENGTHS**

There are a number of limitations and strengths present in the study. The results of the focus group discussions solely reflect the thoughts, needs and challenges of the respective participants, and are therefore not generalizable to all HIV positive widows, or HIV positive women in

Chennai, India. In addition, the sample size (n=15) for the analysis was considerably small, highlighting the inability to generalize. The unique lived experiences captured in this work however are of a forgotten segment of the population, and provides insight into their specific and distinctive needs and the small sample size was considered sufficient considering this great insight provided by the participants.

In addition, recruitment only included the beneficiaries of World Vision's GRACE Project. Therefore, the results particularly as they relate to the income generating activities are only indicative of the initiatives of this specific program and may miss a significant number of positive and sustainable projects presently being conducted in order to improve the quality of life of this segment of the population. The concerns expressed in the focus groups however maybe helpful in understanding the failure involved with other initiatives, and would be greatly beneficial in future intervention development and implementation. In addition, the participants were well connected to other networks and non-governmental organizations (NGOs) serving the HIV positive community and were welcomed to speak to all of their experiences.

Another limitation connected to the partnership with World Vision was that the organization was experiencing significant funding cuts and shortages during the time of work conducted by researcher thereby creating an abnormal circumstance for program evaluation, and perhaps skewing the responses of the participants. Funding however is always a fluid commodity in the work of NGOs and funding difficulty is a reality; therefore it is important to note that this is key when considering care and support programming and initiatives conducted by these institutions.

## 6.0 CONCLUSION

Needs and concerns related to quality of life following diagnosis of HIV status for women in India is a significant public health concern, and therefore the focus of this thesis. This study explored the unique experience of HIV positive women. Participants from focus group discussions were invited to share about this unique identity, their perceived needs and concerns and desired changes in order to improve their quality of life. The theoretical framework and constructs of the social ecological model and postcolonial feminism were used in order to better understand and articulate the social context and lived experiences shared by the participants.

The experiences shared by the participants alluded to a triple burden resulting from their identity of being widowed or abandoned HIV positive women who had taken on the new role of head of household. As a result of this particular set of burdens, specific needs and concerns related to housing and financial security were brought to the forefront. Participants expressed desire for government issued housing, and a permanent home for end of life concerns. In addition, the desire to be able to be financially secure, by way of secure employment and income in order to care for their respective families was a firmly held thought among all participants.

Often a forgotten segment of the population, it is imperative that the needs and concerns of widowed and abandoned women are taken into account in the care and support of all HIV positive individuals. The movement towards prevention and treatment via extensive campaigns and provision of ARTs is very important in improving the lives of many, but elements of care

and support related to quality of life of individuals post diagnosis of HIV status must not be forgotten in this transition. Specialized microfinance and livelihood training initiatives are important in order to improve employment stability and income generation, with special interest placed on community based endeavors that make use of HIV positive networks. The need for legislation that provides anti-discrimination rights of employment, status, property and housing by way of the HIV/AIDS Bill is vital to move forward in changing the lived realities of this population. Non-governmental organizations and other institution level factors must be involved in the push to make this Bill and subsequent legislation into law in order to have a platform to make structural changes that will have lasting effect. Lastly, stigma and discrimination, and the low status of women are deeply ingrained in the fabric of Indian society; awareness and education must continue to break these barriers, as this is crucial for long term change and providing a different social context that has the potential to exponentially improve the lives of HIV positive widowed and abandoned women.

There is a desire for a different future, a future that will result in a life not lived purely out of an identity of burden and need, but it is imperative that widowed and abandoned HIV positive women taking on the role of head of household are not forgotten in care and support so that this new reality of a satisfying life be actualized. During a time of observation at the drop-in center, a newly widowed woman with a 5-year-old daughter shared a few thoughts,

...I don't want to depend on anyone. I must now become faster in life, take more work, make my children learn, progress and come up in life. I didn't have a goal before, but now I must... people say, 'oh look at her, how sad', but we must change things, not only say, 'how sad,' but say, 'what can we do so that life is not a waste, we must stop talking and do something'.

## **APPENDIX A: FGD INTRODUCTION**

### **FOCUS GROUP DISCUSSION INTRODUCTION**

#### **A.1 ENGLISH**

Good Afternoon. Thank you for coming today to be a part of this focus group discussion. The aim of this discussion is to better understand your thoughts on how you can best be supported as women. It is important to have places and locations where one is comfortable; these places can be created or better tailored to meet your needs so that you feel supported. The information gathered today will be gathered and shared with organizations like World Vision who are involved in supporting and caring for women such as yourselves. To make sure that there is accuracy in the recollection of this conversation, this discussion is being audio recorded. If anyone is uncomfortable with that you may leave at this time.

This focus group is being done to gather information. You, as the participants are the experts and your thoughts, and beliefs on what we will be talking about today are incredibly valuable. With that being said, all of you have different experiences, and come from various backgrounds, resulting in differences of opinion. Please don't feel like there is only one answer to the questions, there is no wrong or right. Please realize that the differences of opinion are very valuable, and it is helpful to hear for the benefit of the group. Please respect the breath of opinions stated. This discussion will last approximately an hour.

I am Sharon, and I will be the facilitator this afternoon. I will be asking the questions and wanting to better understand you and your experiences. I can help to clarify terms, and verify information. But remember that I don't have the answers; you are the experts after all. I am also charged with keeping track of time and helping us to complete the discussion.

Behind us, you see \_\_\_\_\_ (Recorder's name). S/He will be taking notes today. S/He will not be a part of the discussion today.

Here are some ground rules that we will abide by during the course of our time together this afternoon. Please speak one at a time, taking turns, being respectful of one another. It is okay to

disagree with one another, just remember to be respectful throughout the process. The content of the discussion is to remain private, everything said here is confidential information. Please respect each other and please keep what is said during the discussion to yourself. Your privacy is importance to us; none of your names will be divulged. All of the information provided will only speak of the group at large; with no individuals will be mentioned. Following transcription, the audiotape will be destroyed. Our desire is to make this a safe-space where there can be open discussion, without fear of judgment and risk of being identified. Finally, you are allowed to leave at any time, and there is no need to justify your reasoning.

Are there any question or concerns that you may have?

All right, lets get started...

## A.2 TAMIL

விவாதக் குழு அறிமுக அறிக்கை - ேவரல்டு விஷன, இந்தியா

இந்தக் கலந்தாய்வில் கலந்து ொகாண்டிருக்கும் உங்கள் அனைவருக்கும் வணக்கம் மற்றும் நன்றி. இக்கலந்தாய்வின் முக்கிய ேநாக்கம், ொபெண்களாகிய நாம் ொபெண்களின் முனைனைற்றத்தில் எத்தகைய கருத்துகளைக் ொகாண்டிருக்கிறோம் எனபெதை புரிந்து ொகாள்ள. ொபெண்களாகிய நாம், கூடி விவாதிப்பதற்கும் நமக்கு பொதுகாப்பொனை அல்லது வசதியானை இடங்களைக் ொகாண்டிருப்பது முக்கியம். இத்தகைய இடங்களை ஒருங்கமைப்பெதோ உருவாக்குவேதா நமது முக்கிய கடைம. இக்கலந்தாய்வில் நாம் ேசகரிக்கும் தகவல்களை ொபெண்கள் முனைனைற்றத்திற்காகவும், அவர்கள் பொதுகாப்பிற்காகவும் ொசயல்பெடும் அமைப்புகளானை ேவரல்ட் விஷன (world vision) ேபொனற அமைப்புகளாடு பெகிர்ந்து ொகாள்ளப்பெடும். இக்கலந்துரை யாடல மீள் ஆய்வுக்கு உட்பெடுத்தும் ேபொது, இதன துல்லியத்தை உணர்த்த இது பெதிவு ொசய்யப்பெடுகிறது. பெதிவு ொசய்தைல விரும்பொதவர்கள், இக்கட்டத்திலேய இக்கலந்தாய்விலிருந்து விலகிக் ொகாள்ளலாம்.

இங்கிருக்கும் நீங்களைனைவரும் ஏற்கனைவே இத்தகைய குழுக்களாடு ொதாடர்புடையவர்கள், குழு விவதாங்களில் திறனுடையவர்கள், அதனனால், உங்களுடைய சிந்தனைகளுடம், கருத்துகளுடம் இந்த விவாதத்திற்கு மிகவும் இன்றியமையாதது. அதனனால், உங்கள் கருத்துகளை முடிந்தவைரை

துல்லியமாகவும் உண்மையாகவும் பெதிவு ொசய்யுங்கள். இங்கிருக்கும் பெலரும் ொவவ்வேவறு பினனைனியிலிருந்து வந்திருப்பதாலும், ொவவ்வேவறு அனுடபெவங்கையும் ொகாண்டிருப்பதாலும் இங்கு நம்மிடைய பெலவிதமானை கருத்து ேவறுபொடுகள் நிலவும். எல்லாக் ேகள்விக்கும் ேரை பெதில்தான இருக்க ேவண்டு ொமனற கட்டாயம் இல்லை, இது சரி, இது தவறு எனற ேபெதங்களுடம் இல்லை. இத்தைகய கலந்தாய்வுகளில் கருத்து ேவறுபொடுகள் முக்கியமானைவை, விவாதங்களை முனொனைடுத்துச் ொசல்ல இவை முக்கியமானைவையும் கூட. பிறருடைய கருத்துகளுடக்கு மதிப்பெளித்து இக்கலந்தாய்வை நாம் நடத்திச் ொசல்வோம். இது ேதாரையமாக ஒரு மணி ேநரைம் வைரை நீடிக்கும்.

நான, ஷா ேரான. இந்நிகழ்வைவ இப்பொது நடத்திச் ொசல்லும் ொபொறுப்பு எனனுடையது, எனனுடைய பெணி விதிமுறைகளை விளக்கி, தகவல்களை உறுதிப்படுத்துவேதாடு நிகழ்வைவ ஒருங்கிணைத்துச் ொசல்வதும், ேநரைத்தை நிர்வகித்து, வைரையைற ொசய்யப்பெட்ட ேநரைத்தில் கலந்தாய்வை நிறைவாக முடிப்பெதும் ஆகும். ேதசமயம், விவாதத்தினுடைய ேகள்விகளுடக்கு எனனிடம் பெதிலில்லை, நீங்கள்தான விவாதத்தின நாயகிகள், நீங்களே விடைகளைக் கண்டையுங்கள்.

நமக்குப் பினனைால், இங்கு அமர்ந்திருக்கும் \_\_\_\_\_ (கலந்தாய்வை பெதிவு ொசய்யபெவர்). அவர் இந்நிகழ்வைவ குறிப்பொபெடுக்கும் பெணியை ேமற் ொகாள்வார், விவாதத்தில் அவர் பெங்கு ொபெற மாட்டார்.

இந்நிகழ்வை முழுவதற்கும் நமக்கு சில விதிமுறைகள் உள்ளனை, நிகழ்வை முடியும் வைரை இந்த விதிகளை நாம் பினபெற்று ேவாம்.

- ஒரு ேநரைத்தில் ஒருவர் மட்டு ே ேபெச ேவனடும். உங்களுடைய முறைக்காக காத்திருங்கள், ஒருவர் ேபெசும் ேபொது இடையில் தைலயிட ேவண்டாம். ஒருவருடைய கருத்தை நீங்கள் ஏற்க மறுக்கலாம், மறுப்பு ொதரிவிக்கலாம், நிகழ்வை முழுவதும் இதை ஒழுக்க விதியாக கைடபிடிக்க ேவண்டும்.
- இந்நிகழ்வைவில் விவாதிக்கப்பெடும் விவாதப் ொபொருட்கள் அனைத்தும் ரைகசியமாய் காக்கப்பெடும். நீங்கள் ொதரிவிக்கும் கருத்துகளையும், பிறர் ொதரிவிக்கும் கருத்துகளையும் ொவளியே கசிய விடுதல் கூடாது.
- இந்நிகழ்வைவில் கலந்து ொகாள்ளுடம் ஒவ்வொவாருவரின ரைகசியமும் பொதுகாக்கப்பெடும், யாருடைய ொபெயரும் ொவளியிடப்பெடாது.
- இந்நிகழ்வைவில் ொவளியிடப்பெடும் ஒவ்வொவாரு உண்மைத் தகவைலையும்

நாங்கள் மதிக்கிறோம். இங்கு விவாதிக்கப்பெட்டு திரைட்டப்பெடும் கருத்துகள் ஒட்டுொமாத்த குழுவினுடைய கருத்தாகேவ பெதிவு ொசய்யப்பெடும், தனி நபெரின

கருத்தாக பெதிவு ொசய்யப்பெடாது. இவ்வவிவாதத்தின எழுத்துவடிவ அறிக்கையும், ஒலிப்பெதிவும் அழிக்கப்பெட்டுவிடும்.

- ஒரு முழுமையான மனைந்திறந்த விவாதமாகேவ இந்நிகழ்வைவ நாங்கள் நடத்த விரும்புகிறோம். எந்த விதமான தயக்கேமா, அச்சேமாயினறி இவ்வவிவாதத்தில் நீங்கள் கலந்து ொகாள்ளலாம்.
- எந்த ேநரைத்திலும் நீங்கள் இந்நிகழ்வைவ விட்டு ொவளியேறலாம், அதற்கான காரணத்தை நீங்கள் ொதளிவுபெடுத்த ேவண்டும் என்ற அவசியம் இல்லை.
- இக்கலந்தாய்வில் நீங்கள் பெங்குொபெறுவதால் நீங்கள் ேவர்டு விஷேனைடு ொகானடுள்ள எந்த உறவுகளிலும் பொதிப்பெற்பெடாது. உங்களுடக்கு விதிகள் ொதாடர்பொக எதாவது சந்தேகங்கள், ேகள்விகள் இருந்தால் ேகட்கலாம். சரி. இப்பொது விவாதத்தைத் ொதாடங்குேவாம்...

## APPENDIX B: FGD QUESTION GUIDE

### FOCUS GROUP DISCUSSION QUESTION GUIDE

#### B.1 ENGLISH

1. A Tell me about your typical day like as a woman?  
*-What do you do?*  
*-Feel free to mention things from the morning till evening.*  
*-What is unique to your day because you are a woman?*
2. What types of challenges do you face?  
*-This can be any difficulty.*  
*-Health? Children? Spouse? Extended family? Finances? Housework?*  
*Religious/spiritual obligations? Stigma? Gender?*
3. How do you go about dealing with these challenges?  
*-Mundane activities?*  
*-Is this how it is? Or do you want something different?*  
*-Individual concerns or community concerns?*
4. What ways are you supported?  
*-Do you feel supported?*
5. What ways can you better be supported?  
*-Thinking about your challenges, what would help to alleviate the burden?*  
*-Programs? Initiatives? Networks?*

## B.2 TAMIL

### ேரு 2 (ேபாராட்டங்கேள்)

- ெண்ணாகே உங்கேளுடைய வழக்கேமான வாழ்க்கைகே எப்படி இருக்கிறது? - நீங்கேள் எனன ெசெய்கிறீர்களே? -கோலை முதல் மாலை வைர நீங்கேள் ெசெய்யும் பணிகேளை எந்த வித தயக்கேமும் இல்லாமல் ெவளிப்படுத்தங்கேள். -ெபண் எனபதால், உங்கேளுடைய தினசெரி வாழ்க்கையில் தனித்தனைம வாய்ந்த ெசெயல் எனன?
- எனன வைகேயான ெபாராட்டங்கேளை நீங்கேள் செந்திக்கிறீர்களே? - எந்த விதமான ெபாராட்டங்கேளாகேவும் அவைவ இருக்கேலாம்? - ஆரேராக்கியம் சொர்ந்தைவயாகே இருக்கேலாம், குழந்தைகேள் சொர்ந்தைவயாகே இருக்கேலாம், தைணவர் சொர்ந்தைவயாகே இருக்கேலாம், குடும்பம் மற்றும் இல்லைற பணிகேள் சொர்ந்தைவயாகே இருக்கேலாம், ெபாருளாதார, பாலின, மத/கேடவுள் வழிபாடு சொர்ந்தைவயாகே இருக்கேலாம், அவங்கீகோரம் சொர்ந்தைவயாகே இருக்கேலாம்?
- இந்த செவால்கேளை நீங்கேள் எப்படி செமாளிக்கிறீர்களே?
  - உங்கேளுடக்கு ஈடுபாடு இல்லாத ெசெயல்கேள் உள்ளனவா?
  - அவைவ எப்படிப் பட்டைவ? நீங்கேள் ஏதாவத வித்தியாசெமானவற்றை விரும்புகிறீர்களேளா?
  - தனி நபர் சொர்ந்ததா? அவல்லைத குழு சொர்ந்தைவயா?
- நீங்கேள் எனன வழிகேளில் உதவி ெபறுகிறீர்களே? - நீங்கேள் உதவி ெசெய்யப்பட்டதாகே உணர்கிறீர்களேளா?
- ெவறு எந்த சிறப்பான வழிகேளில் ெமலும் உதவி ெசெய்யப்படலாம்? - உங்கேளுடைய செவால்கேள் பற்ற. உங்கேள் செவால்கேள் எப்படி குறைக்கேப்படலாம் என எண்ணுகிறீர்களே? - ெசெயல்பாடுகேள்? குழு நடவடிக்கைகே?

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