A PHENOMENOLOGICAL INQUIRY OF WOMEN LIVING WITH HIV CARING

FOR FAMILY MEMBERS LIVING WITH HIV IN INDIA: PATHWAYS THROUGH

AUTHORITATIVE KNOWLEDGE AND SELF-EFFICACY TOWARDS

RESILIENCE

By

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ABSTRACT OF THE DISSERTATION

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In this qualitative, phenomenological study, I explore the lived experiences of caregiving women living with HIV (N=33) and how they make meaning of being primary caregivers while ailing themselves. The study is set in north-central India where the socio-cultural context ties women's caregiving roles to their identity as "good women". The following major influences and iterative processes shape women's experiences; Meaning-making of caregiving, Search for authoritative knowledge, (AK), Exercise of self-efficacy, Building of resilience and Social construction of informal caregiving and caregivers in interaction with health workers. Lipsky's street level bureaucratic principles apply to health worker's (N =15) conditions of work. Findings indicate the following: 1) Women make meaning of their caregiving role in primarily positive terms such as wifely duty and being a courageous wife. However, women break away from their care recipients when they make harsh demands of caregiving on them and when women face emotional, verbal, and physical abuse as caregivers.2) Despite the severe burdens of caregiving work and loss of personal health in the process of caring, women search for authoritative knowledge from physicians, community, and family members; they ultimately resort to their own

sense of knowing and often find AK within themselves versus an external source. In the process, women use self-efficacious thoughts, behaviors, and actions to identify what to do and how to do it. 3) Over a period of time, women build resilience through greater self-reliance and supportive relationships with peers and health workers. This study has implications for the development of programs for HIV-positive female caregivers and gender-sensitive programs and policies for women living with HIV in India and abroad.

Acknowledgements

Completing this dissertation has mostly been a joyful journey of learning with a series of delights, surprises and then some really tough times in the past two years. I am glad that I will now join my family's legacy in teaching, research and community service. I am a third-generation doctoral degree holder in my family; a fact that brings me immense joy. It is also because of my family's unwavering belief in me that I kept moving forward even when things got tough. I learnt a lot from my sister's entrepreneurial spirit, my mother's untiring work ethic and my father's lightheartedness and pure intellectual joy. My brother-in-law Chris reminded me that things were always working out for me even when I could not quite see them.

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Table of Contents

List of Figures

List of Tables

Chapter 1. Introduction

Problem Statement

Globally, approximately 36 million people are living with HIV; of these, an

estimated 2.5 million are from India and 40% of them are women (Joint United Nations

Program on HIV/AIDS (UNAIDS), 2016). It is estimated that approximately 63% of

household-dwelling women living with HIV/AIDS in India are married (National Family

Health Survey, 2007). These women often provide informal caregiving to their partners

or other family members living with HIV. Following the global trend of decline in new

HIV infections, India experienced a 32% decline in new infections between 2007 and

2015 (National AIDS Control Organization, 2015). Yet, care and treatment support

remain pressing issues in resource-constrained nations necessitating continuous research

and implementation of innovative interventions.

The majority of HIV/AIDS- related research in India has been conducted with

groups with 'high- risk' behaviors such as sex workers (Sarkar et al., 2008; Vickerman et

al., 2010), intravenous drug users (Panda et al., 2005) and men having sex with men

(Baral, Sifakis, Cleghorn, & Beyrer, 2007; Thomas et al., 2011). Additionally, mobile

populations of migrant workers and truckers, who are primarily men who engage in high-

risk behaviors such as visits to commercial sex workers, act as bridge populations

between the high-risk groups mentioned above and the general population (Abdulkader,

Goswami, Rai, Misra, & Kant, 2015; Sahu et al., 2015; Sastry, 2016). Together, these

groups account for the largest proportion of HIV infection in India and form the primary

focus of HIV/AIDS policy and interventions. While the majority of the epidemic is

concentrated among the high-risk populations, over the past decade, the epidemic is shifting from the high-risk groups to the general population. In addition, the epidemic is decreasing faster among men compared to women (Mitra & Sarkar, 2011; Pradhan & Sundar, 2006; Singh, Karma, & Vishwakarma, 2016). The number of females living with HIV/AIDS (2.02 %) has been lower than that for males (3.23 %) despite the overall progress in the slowing of the rate of new HIV cases. At first glance, this difference seems small, but given the Indian population of more than one billion, it translates into large absolute numbers. The slower decline of HIV prevalence among women is attributed to structural gender inequalities in women's education and employment status as well as poor health literacy and poor access to resources (Mitra & Sarkar, 2011).

Married women are not generally considered to be at high-risk of HIV (Ghosh et al., 2011). These cases may be underreported due to fear of stigma and discrimination in Indian society (Mawar, Sahay, Pandit, & Mahajan, 2005; Steward et al., 2008). Although the Indian National Family Health Survey (2007) estimated that 63% of all HIV-positive women are married, this estimate applies only to 15 to 49-year-old women who live in households.

Further, as is the case globally, HIV prevalence in India is primarily measured through sentinel surveillance at antenatal and sexually transmitted disease clinics; this data collection procedure may under count women (Chandrasekaran et al., 2006), due to excluding women who consider visiting sexually transmitted infections clinics taboo or those who deliver at home and do not access hospital-based prenatal care. These factors contribute to the invisibility of married Indian women who often contract the infection from their husbands (Chandrasekaran et al., 2006).

The purpose of this dissertation study is to explore the lived experiences of married women living with HIV, who are primary informal caregivers to their family members, also living with HIV. Informal caregiving by married women constitutes the focus of inquiry for this study because there is limited knowledge about married women's lives and experiences as they bear the dual burden of being patients and caregivers at the same time. I explore women's everyday engagement in providing care. Additionally, I explore how women's experiences of providing care are shaped by their experience of receiving care from formal sources of care for people living with HIV/AIDS such as hospitals and support agencies (known as care and support centers). I use primary qualitative data collected with married women living with HIV, and from health workers in the northern state of Uttar Pradesh, India.

Significance of the Study

There is limited research conducted with married women living with HIV who are informal caregivers to their partners or other family members who are also living with HIV. Prior research on the theme of caregiving has included married women living with HIV as research participants by chance. Further, extant research on informal HIV caregiving in India has only included women living in India's southern states of Maharashtra, Karnataka, Tamil Nadu and Andhra Pradesh, where the prevalence of HIV is high.

Prevailing research that includes married women is descriptive in nature and focuses on women's emotional, physical, financial and social experiences, often focusing on the barriers to care that they experience. There is vast social and cultural diversity in the Indian subcontinent and geographic variations in culture; women experience varying

levels of autonomy in different regions (Jejeebhoy, & Sathar, 2001). The differences in the intersections of geography, culture and women's autonomy are more pronounced between the northern and southern parts of the nation. Women living in the southern parts of India tend to have higher levels of autonomy than women living in the northern states (Jejeebhoy, & Sathar, 2001) requiring investigation to understand how women living with HIV experience informal caregiving in the northern part of the nation. The state of Uttar Pradesh provides a distinctly gendered sociocultural context in contrast to the southern Indian states. Based on the findings of this study, I propose that married women form an important yet overlooked constituency in the provision of HIV/AIDS care in India because they are primary informal caregivers to their partners or other family members living with HIV, while also living with HIV themselves.

Extant literature on married women living with HIV provides some information about the kind of caregiving roles and responsibilities this population of women provide informally, such as keeping track of scientific developments about the disease, cooking meals, and traveling to hospitals to get medication (D'Cruz, 2008; Kohli, et al., 2012). Through this study I expand the inquiry about women's informal caregiving burden in HIV-affected households towards an exploration of women's motivations to provide everyday care within the sociocultural and familial context of their lives. Further, I examine women's experience receiving formal health care services for HIV/AIDS, both as women living with HIV and as primary caregivers. Extant studies examine caregiving for people living with HIV, by men, women, nurses, physicians and other stakeholders, but generally include married women living with HIV as caregivers by chance (D'Cruz, 2003, 2004, 2008). Thus far, research does not capture the exclusive experiences of

northern Indian married women living with HIV, who often have no self-perceived high-risk behaviors of their own and then take on the role of primary caregivers in their homes.

Specific aims and research questions

The specific aims of the study are to examine: a) the socio-cultural and individual processes by which women living with HIV become primary caregivers, b) the impact of contextual influences in the shaping of women's sense of self and identity as a caregiving woman c) the role of health service provision on women's role and identity as a caregiver, and d) whether and how resources available to health workers shape their service provision to women.

The following research questions are addressed in this study:

1. What are the caregiving experiences of married women living with HIV?

2. What factors influence women in their everyday engagement as caregivers to their HIV-positive husbands and/or children?

3. What are married women's experiences of taking care of themselves and receiving care from formal sources of care?

4. How does women's caregiving experience intersect with service provision for HIV/AIDS affected people in India?

One of my goals in this research is to explore why HIV-positive married women provide every day caregiving despite being ill themselves. I want to understand the socioeconomic, cultural, value-based or other factors that influence them to be caregivers in a challenging life situation. This will allow a critical understanding of the life situations and circumstances of women, what leads them to be informal caregivers while

they are ill themselves, and to make recommendations to policy makers for programs and policies that meet the needs of this population.

Literature Review

Structure of the Review

Here I review interdisciplinary literature that explains aspects of the phenomenon of gendered informal caregiving for people living with HIV. The review is comprised of five interconnected parts. The first section of the review provides an overview of Indian society and how its cultural and institutional features intersect with women's lives. I follow a life trajectory approach, demonstrating gendered cultural traditions, institutions, and their socio-economic impact on women's lives. The second part of the review covers literature specifically about married women. This section outlines factors that make married women vulnerable to HIV, highly relevant for studying the phenomenon of their informal care provision to their husbands and children as they live with HIV. Following this section, I present a review of various definitions of caregiving, the nature of informal care in general and caregiving provision for HIV-affected populations, globally and in India. An overview of the Indian health care system and HIV/AIDS services is provided, barriers to care for women living with HIV are discussed and these are followed by a brief description of the Indian welfare system. In the last section of this review, I discuss a web of theoretical concepts that provide an analytical framework for this study develped post-hoc as the concepts emerged within the data during analysis. As qualitative analysis allows for building on the analysis throughout, it quickly became apparent that concepts of Authoritative Knowledge (AK- Jordan, 1997), self-efficacy (Bandura, 1997), meaning-making and resiliency create a framework for understanding

and interpreting the women's narratives about their caregiving experiences. In addition, Gulliford and Morgan's conceptualization of access to care (2013) and Lipsky's theory of street level bureaucracy (1980/2010) helps explain health worker behaviors and women's interactions with formal health services for people living with HIV.

Cultural Context and Women's Lives in India

Indian culture and context (especially socio-economic, cultural, and institutional features) have direct bearing on the lives of women caregivers. India is one of the oldest civilizations (Feuerstein, Kak, & Frawley, 2005; Maisels, 2001) and one of the most populous countries of the world, after China (Dyson, Cassen, & Visaria, 2005). The texture of Indian society is rich with multiple religions, thousands of languages and dialects, geographic variations, and varying customs and traditions. India has seen rapid economic growth with a fast-growing GDP in the past few decades (Tseng, & Cowen, 2013). Despite this economic growth, poverty and severe economic and social inequalities plague the country. The status of women in India is an issue of major concern at a global level. India has one of the world's worst development indicators for women and is one of the world's worst countries in which to be born a girl (United Nations Department of Economic and Social Affairs, 2015). This section draws attention to the factors that contribute to the accumulation of disadvantages by women living in India over a lifetime, and how some women work to resist the forces of patriarchy in everyday life.

Son preference and the neglect of daughters.

Son preference is pervasive in all regions of India but especially in the northern and northwestern states. The 2011 census of India estimated the child sex ratio at 914

females for every 1000 males (Census of India Report, 2011). Son preference is highest

in the states of Haryana, Punjab, Uttar Pradesh, Rajasthan and Bihar (Mitra, 2014). Sons

are preferred due to their greater social and economic utility. The birth of daughters is an

economic liability for parents due to prevalence of the dowry system or the practice of

the transfer of resources from the bride's to the groom's family. The dowry system is

discussed in-depth in a later section. Dowry, along with the high costs of weddings that

need to be paid by a girl's family at her wedding, make the girl child a financial burden.

Sons are also preferred because they are needed for several important religious rites in

Hindu traditions, including the last rites of parents (Gennep, 2011). The preference for

sons translates into the neglect of daughters and practices of female infanticide to prevent

the birth of daughters in the first place. Laws in India criminalize sex selective abortions

assisted by medical technologies such as ultra-sonography and amniocentesis, but the

practice is prevalent nevertheless. In rural parts of the country where such assistive

medical technologies are unavailable, female infants are sometimes abandoned after birth

(Bhatnagar, & Dube, 2012; Patel, 2013). Son preference also impacts how people plan

their families. The birth of daughters is often quickly followed by the birth of more

children due to the continued desire for a male child. Researchers have found that girls

with older sisters are the most socially undesirable and bear the brunt of maximum

neglect (Arnold, Choe, & Roy, 1998).

Given that the female child is not preferred and is seen as a burden at birth,

investment in her education, nutrition or other aspects of life are additional burdens.

Therefore, girl children are sometimes not educated at all or receive minimal education.

The national literacy rate in India is estimated at approximately 74%; the female literacy

rate is 65% and male literacy rate is 82% (Census of India, 2011). The difference between male and female literacy rates is worse in the northern states, including Uttar Pradesh, and contributes significantly to women's cumulative disadvantages.

The traditional marriage.

The institution of marriage in India is held in extremely high esteem. It is traditionally seen as two families coming together, rather than just two individuals. The Hindu religion, the most predominant in India, holds marriage as a divine union between a man and woman, viewed as irrevocable and permanent (Apte, 1978; Mandelbaum, 1993). Marriages are 'arranged' by families, implying that it is one family that seeks a relationship with another family by way of marrying their son and daughter (Nanda, 2015). When the marrying bride and groom are very young, they have no input into choice of the partner, much less decision-making power. Arranged marriages are a persistent feature of collectivist societies. Collectivist societies prioritize the welfare of families and communities over individuals; this is true for large parts of the world, including South Asia where marriages are arranged by parents rather than by individual choice (Banerjee, 1984; Berreman, 1972; Majupuria, & Majupuria, 1989).

Marriages in the Hindu tradition are performed with elaborate rituals and religious customs, where caste and kinship play an important role in choosing a partner (Menski, 1992). The traditional religious sanctity adhering to marriage makes women the bearers of tradition who are then seen as repositories of the honor placed in marriage. Regularly practiced religious customs reinforce the role of women as channels of men's well-being. For example, in the yearly ritual of 'karvachauth,' married women fast for a whole day. Any consumption of food or water is prohibited, and married women break the fast at

night, praying for the long lives of their husbands (Wadley, 1980). Wadley (1980) describes a multitude of forms of worship such as the worship of the Banyan tree or the worship of the snake God. Women perform most of these rituals for the health, prosperity and well-being of their family members, especially men who may be husbands or brothers. An exploration of women's identity development within the realm of the Hindu household reveals that women, especially those who are home-makers, develop emotional connections with the site of their homes as a means for self-expression and personal reflection (Mazumdar & Mazumdar, 1999; Saegert & Winkel, 1980).

Women must always behave in ways that maintain the social order and the honor of both the parental and husband's families. Marriage is also seen as the ultimate safe institution for a woman. Once a girl is married, she is the responsibility of her husband and his family, maintaining loose ties with her natal family. She must then invest her whole physical and emotional self in maintaining the new social bonds defined by her marriage.

The institution of dowry.

The institution of dowry in India includes a transfer of money, commodities, and services from the bride's family to the groom's family, upon the initiation of marriage and as an ongoing practice during the marriage. The flow of goods and services from the bride's family to the groom's family can be traced back to the 14th or 15th century in India. Dowry practice began as a way for women to generate personal wealth called "Stridhan" or "wealth of the woman" (Miller, 1980) because women did not have inheritance rights from their natal family. Women rarely, however, individually

controlled this wealth because it became a part of the husband's family resources (Miller, 1980). The widespread prevalence and compulsory nature of dowry in India requires people to sell assets or borrow money to arrange for the costs of their daughter's wedding. This economic burden of dowry on the girl's family reinforces son preference over girls (Das Gupta et al., 2003; Diamond-Smith, Luke, & McGarvey, 2008). Because large sums of money or valuable goods such as gold jewelry or land are transferred during marriage, it can leave the girl's family destitute.

Dowry practices often continue after the initial rituals and customs of marriage, sometimes even over a lifetime. This leads to great pressure on the bride's family to maintain the support of the marriage of their daughter. Dowry grants power and control of the groom's family over the bride's family. Dowry practices have often led to demands for more dowry with violence towards the married woman and even bride burning when demands are not met (Jutla, & Heimbach, 2004; Stone, & James, 1995).

The Dowry Prohibition Act of India (Willegen & Channa, 1999) criminalizes the institution of dowry in marriage, yet it continues as a social custom. Despite its legal prohibition, over time, dowry has emerged as a mechanism for equalizing the individual differences of the bride and the groom and their families, as a way of paying for an equal match (Dalmia, & Lawrence, 2005). The understanding of paying for an equal match has maintained dowry as a part of social customs and practices despite anti-dowry laws. The large investments on behalf of women's parents in the woman's husband's family as part of dowry make it even more difficult for women to leave their marriages, even when there are emotional, financial, and other forms of abuse.

Cultural meanings of conjugal love.

Traditionally, anthropological and sociological accounts of marriage have addressed the differences between arranged and love marriages in relationship with the differences between collectivistic and individualistic societies (Dion & Dion, 1993). The meanings of 'love' in arranged marriages in collectivist societies like India are to be understood differently from the meanings of love in individualistic societies like the United States. Individualism and collectivism structure the relations between the individual and the group across various areas of social functioning (Hofstede, 1984). Individualism has been defined as "the subordination of the goals of the collectivities to individual goals," while collectivism represents "the subordination of individual goals to the goals of a collective" (Hui, & Triandis, 1986, pp. 244-245).

Love in collectivist societies typically is defined by respect for traditional norms in arranged marriages and is demonstrated by following the norms of the collectivist household, which is usually a joint family arrangement where married couples live with the groom's parents and his family. Duty towards the household, appropriate management of financial assets, the rearing of children, and the care of elderly parents are more important in traditional Indian marriage in contrast to individual passionate love towards the spouse (Dion & Dion, 1993; Dion & Dion, 1996). Women express their love by fulfilling their duty as a caregiver towards family members, ensuring that every detail of the family's everyday needs are met. Anthropological accounts capture the norms and behaviors expected from newly married couples. For example, they must not acknowledge each other in public but wait to talk, and women must cover their heads or faces, especially in the presence of older men in the family (Chowdhry, 1993). Other

studies have challenged the dichotomy of arranged and love marriages and assert that individualistic motives in finding a mate, pre-dated modern and westernized societies (De Munck, 1998). More recent studies in mate selection support this view. For example, Netting (2010) interviewed male and female unmarried professionals in Gujarat in India and found that couples creatively used a combination of individualistic and collectivist ideals in mate selection and focused on achieving personal goals in a conjugal relationship such as equality, friendship, and supporting the bride's transition into the groom's family. Such personal goals and the hybrid use of both individualistic romantic love and collective norms in marriage is perhaps more common among professional and educated groups. Individual romantic love predominantly remains a counter-narrative in popular culture, expressed in paintings, songs and movies (Orsini, 2006).

The status of widows.

An estimated half of all women above the age of sixty, and approximately 12% of women in the age group of 35–39, are widowed in India (Chen, 2000; Jensen, 2005). The most common experience shared by all widows across class, caste and kinship groups is a decline in social and economic status. Religious customs and traditions further accord widows a lower social status by not permitting them to participate in religious ceremonies or celebrations. Practices of what is permitted and not permitted tend to differ by caste and social group, where elderly widows suffer fewer restrictions than younger widows who are seen as unfortunate or ill-omened women. The most severe constraints have hitorically been placed on widows in north India, where widowhood was often institutionalised, and religious practices required widows to shave off their hair, wear only white clothing, and live in a temple rather than mingle with their family and

community members (Ghosh, 2000; Ranjan, 2001). The historical practice of 'Sati,' which was abolished in 1861, required women to burn themselves to death with their husband, upon his funeral pyre (Hawley, 1994; Mani, 1998). Although the practice of Sati is no longer prevalent, the historical treatment of widows in Indian society still reverberates through the poor social and economic treatment meted out to widows, particularly where there are limited existing safety nets for the elderly (Bhat, & Dhruvarajan, 2001; Rajan, Miśra, & Sarma, 1999).

A small proportion of widows end up remarrying. This is partly because older women can find it harder to find a match in the Indian social milieu. Women with sons may have their sons support them financially, making remarriage unnecessary. Other women may fear ill treatment for themselves and their children from an earlier marriage in a second marriage. These factors make remarriage among widows uncommon, especially among older widows. Although most literature about widows in India concentrates on elderly widows who comprise the vast majority of widows, widows in this study typically were much younger, generally aged 20 to 40 years.

Every-day forms of resistance.

Patriarchal values in north India place constraints on women's everyday lives and choices including women's mobility and personal preferences, such as dress, schedule and food preferences. Because many of the constraints women experience have roots in how women's roles have been defined in the religious texts of the Hindus (Harlan & Courtright, 1995; Wadley, 1977), some of the most powerful narratives of women's dissent are also found in alternative religious traditions that broke away from mainstream

Hindu practices, yet redefined themselves within the larger Hindu religion. The tradition of Meera's 'bhakti' or 'devotion' movement is one such example dating back to 13th century India. The songs and poems in Meera's tradition reflect powerful dissent from Rajput (a clan in western north India) patriarchy and particularly the practice of female infanticide. Women in various parts of the country sing Meera's songs even today (Bhatnagar, Dube, & Dube, 2004; Futehally, 2003). Meera herself embodied dissent by refusing to marry and instead finding a divine lover in Lord Krishna (a popular God in Hinduism) (Bhatnagar et al., 2004).

In contemporary Indian popular culture, women's every day forms of resistance are reflected most through female characters who take pleasure in exploration of the self, of life and the world through travel, sexuality, reading and other activities traditionally denied to women (Bhaumik, 2016; Bose, 1998; Gupta, 2015; Uberoi, 1998). Expressions of women's dissent are also found in books, art, paintings and songs. For example, in a culture that emphasizes the need for women to fast for the well-being of the male family members, the predominantly poor potter women of north-east Uttar Pradesh sing the story of the 'Phuhari' or the 'disorderly woman' who overeats and is rewarded for violating the Gods with her wild and outrageous behaviors (Caughran, 1998). A more recent study focuses on understanding forms of resistance in arranged marriages among middle and upper-class professional women in Delhi (Chawla, 2007), finding that women sought material comfort for themselves in arranged marriages as a way of 'owning a marital story' (Chawla, 2007). Accounts of participants in Chawla's study (2007) demonstrate that women speak up for their personal choices even when in-laws (especially the mother-in-law) have rigid expectations of the woman. She may be asked

to dress in a specific way, limit her travel or spend long hours in the kitchen. Women tailor their resistance to their own situation; their methods may include speaking up, fasting as a form of protest, distancing from the in-laws, or keeping silent at all times.

In addition to dissent expressed in popular culture and everyday life, in the past decade, patterns of marriage and intimate relationships have seen slight changes in some parts of the country. Changes in marriage patterns in urban areas include the initiation of cohabiting and living-in relationships (Yadav, 2012). The 1991 census of India estimated the divorce rate at 1% nationally, this is now estimated to have increased to 5-7% in the intervening decade (Nambi, 2005). This increase in divorce rate is limited to urban areas of the country,where traditional and rigid gender roles are gradually declining and companionate marriages are preferred among some groups, especially the educated middle classes (Yadav, 2012). Despite this gradual change in the pattern of divorce and the essence of marital relationships, up to 70% of India still resides in rural areas where marriages continue to be performed with an understanding that they are irrevocable and for life.

This section offered glimpses into the texture of Indian society for women. Despite incremental policy shifts that are expected to enhance the status of women, women's experience of everyday life in India is heavily bound by restrictive gender norms that limit life choices. In the following section, factors that contribute to married women's vulnerability to HIV are discussed.

Gendered vulnerability to HIV among married women

The HIV/AIDS epidemic in India has followed the global trend of slowing down more rapidly among men than women (Mitra, & Sarkar, 2011; Quinn & Overbaugh,

2005). This trend is especially true in developing nations where women face more severe barriers to accessing reproductive health information and HIV related care and treatment options (Quinn, & Overbaugh, 2005). Marriage is believed to be safe for a sexual relationship in traditional societies like India (Santhya, & Jejeebhoy, 2007), yet a large proportion of HIV-positive women are married women who believe that they are in monogamous relationships with their husbands. Globally, it is estimated that four-fifths of new HIV infections among women occur within marriage or long- term relationships (United Nations Population Fund (UNFPA), 2005) and married women often believe that their husbands are in sexually monogamous relationships with them when their husbands actually have other intimate partners or visit brothels.

In a recent study in a district of rural north India, researchers found higher prevalence of HIV among wives of migrant workers than wives among the general population, only a small proportion of these wives (approximately 15%) had any knowledge about HIV (Ranjan, Bhatnagar, Babu, & Detels, 2017). In another study in Chennai in south India, Newmann and colleagues (2000) found that 81% of all women living with HIV were housewives; 95% were previously or currently married and 89% reported heterosexual sex as their only HIV risk factor while 88% reported a history of monogamy. Even though these studies were conducted in single districts in the north and south of India, they highlight how heterosexual sex with husbands is often women's only risk behavior. Most women were unaware that they were at risk because they were unaware of their husbands' engagement in activities such as visiting brothels, having sex with men, or using intravenous drugs. Factors that increase married women's vulnerability to HIV are discussed below.

Marriage at a young age.

More than 40% of the world's child marriages take place in India (UNICEF, 2012). Although child marriage (below the age of 18 years) for girls is against the law (Child Marriage Prohibition Act, 2006), about 45% of women ages 20-24 were married by age 18 (Santhya, & Jeejebhoy, 2007). Married young women engage in unprotected sex because they are having sex exclusively with their husbands whom they believe to be sexually monogamous. Further, they feel a sense of urgency from family members to prove their fertility, and they have poor knowledge about condom use (Santhya, & Jeejebhoy, 2007) increasing their risk of being infected by their husbands. This association between women's age at marriage and risk of contracting sexually transmitted infections including HIV has been corroborated by studies in other developing nations of the world. For instance, Clark, Bruce, and Dude (2006) examined factors that increase risk of HIV transmission among young women using health information from 29 countries in Africa and Latin America. They found that over 80% of young women under the age of 19 who had unprotected sex were married. In addition, poor access to educational and media
information about HIV put young married women at greater risk of HIV (Clark, 2004; Clark et al., 2006). In several developing nations of the world including India, marriage at a young age puts women at risk of contracting HIV as they often have limited economic independence, comprehensive knowledge about sexual health and have poor access to sexual and reproductive health information. Therefore, young women often have little skill or power within their relationships to negotiate condom use and safe sex practices.

Non-disclosure of risk behaviors and HIV status by husbands.

Married women's risk of contracting HIV increases when their husbands do not disclose their own high-risk sexual behaviors outside of marriage. These may include having male intimate partners or visits to female commercial sex workers (Steinbrook, 2007). Despite gay men's high-risk of contracting HIV/AIDS, there is little information available on the prevalence of same sex sexual activities in developing nations including India (Cáceres, Konda, Pecheny, Chatterjee, & Lyerla, 2006). However, epidemiological studies in India indicate that up to 60% of Indian men who report having sex with men are married (Go et al., 2004; Gupta et al., 2006). Married men who engage in sex with other men often do not disclose their sexual behaviors to their wives due to pressure to follow conventional family patterns and conceive children. They fear stigma and discrimination from their family and community members (Solomon, Mehta, Latimore, Srikrishnana, & Celentano, 2010). Husbands' non-disclosure of extramarital sex or HIV-positive health status puts wives at further risk of contracting HIV.

Physical and sexual intimate partner violence.

Domestic and sexual violence against married women by their husbands increases women's vulnerability to HIV. Studies in South Asia as well as the United States have found increased rates of women's self-reported sexually transmitted infection symptoms based on experiences of intimate partner violence. Researchers found that intimate partner violence against female partners signifies and often facilitates sexual transmission of HIV to women in India (Go et al., 2003; Stephenson, 2007) and elsewhere (Martin, & Curtis, 2004; World Health Organization (WHO), 2004). A study of married women, using nationally representative data from the National Family Health Survey in India,

found that slightly more than one third of women in the sample (35.49%) experienced physical intimate partner violence and/ or sexual violence from their husbands (Silverman, Decker, Saggurti, Balaiah, & Raj, 2008).

Approximately 28% of women reported experiencing physical intimate partner violence without sexual violence. Married women experiencing both physical and sexual intimate partner violence had over twice the rate of HIV infection compared to women who did not experience any intimate partner violence (0.73% vs 0.19%) (Silverman et al., 2008). Similar results were found in another study (Decker et al., 2009) that used a nationally representative sample of Indian married couples from the Indian National Family Health Survey to test if the risk of wives' HIV infection based on husbands' HIV infection differed due to their exposure to interpersonal violence. Results indicated that abusive husbands had higher odds of acquiring HIV outside the marital relationship compared to non-abusive husbands. Risk of acquiring HIV increased seven-fold in abusive relationships (versus non-abusive relationships). A husband's extramarital sex, multiple sex partners, inconsistent condom use and forced unprotected sex increase a woman's vulnerability to contracting HIV from her husband. Finally, women have higher biological vulnerability to HIV than men due to hormonal changes, vaginal microbial ecology and general physiology (Higgins, Hoffman, & Dwarkin, 2010; Quinn, & Overbaugh, 2005). From the studies discussed above, we can conclude that the experience of intimate partner violence puts women at higher risk of contracting HIV.

Although married women may have reduced vulnerability to HIV if they do not have any high-risk behaviors of their own (are sexually monogamous and their partners practice sexual monogamy as well, this is not always the case. In addition to contracting

HIV, married women then must provide care for their husbands and children. This requires that they cope with a complex life situation while also ailing themselves. This study explores factors that influence this population of women to be caregivers in their particular life situation.

Caregiving: Defining Caregiving

The word "care" has more than one meaning; it can refer to physical caring activities like fetching water or cooking meals and to the expression of caring feelings, such as worry or endearment on the part of a caregiver (Folbre, & Nelson, 2000). It is often assumed that the caring feelings of the caregiver provide a motivation for doing caregiving activities, and assure the effectiveness of the care received (Folbre, & Nelson, 2000). According to Folbre and Nelson (2000), "the care recipient is expected to feel cared for, nurtured, recognized and valued as an individual, emotionally supported, empathetically connected, or in shorthand, loved" (p. 129).

An informal caregiver has been defined as a person who helps another person with physical care or coping with disease without being paid for it (Hileman, Lackey, & Hassanein, 1992). Other caregiving definitions conceptualize care as providing help and assistance within the family or community without expecting or demanding any form of payment or as a result of government regulation (Bennett, 2005). Caregiving is also defined as providing attention and response to the needs of another person in a close relationship (Fisher, & Tronto, 1990). Further, in health economics literature, informal caregiving has been defined as "a quasi-market composite commodity consisting of heterogeneous parts produced (paid or unpaid) by one or more members of the social environment of the care recipient as a result of the care demands of the care recipient"

(Berg, Brouwer, Exel & Koopmanschap, 2005, p. 1). This definition seems to include some forms of paid caregiving work as informal, but that may be a reference to informal markets, unregulated by the government. Bennett's definition (2005) most closely captures the situation of married caregiving HIV-positive women in India because caregiving provided among family members was always unpaid. Caregiving includes, but is not limited to, providing personal care, doing housework and meals, running errands, escorting the person to a hospital, financial support, medical assistance, and legal aid, as well as providing emotional and social support (Bennett, 2005).

Gender Norms and the Costs of Women's Caring Labor

Gender roles all over the world tend to dictate women's responsibility for care (Folbre, & Bittman, 2004; Meyer, & Jepperson, 2000; Ryn et al., 2011) in a variety of contexts. Evidence from different parts of the world suggests that women account for the majority of informal as well as formal caregivers. Evidence from studies in developed nations (Folbre, 2004; Ryn et al., 2011) and also from developing and underdeveloped nations (Chadiha, Adams, Biegel, Auslander, & Gutierrez, 2004; Prince, 2004; Shaji, Smitha, Lal, & Prince, 2003) support the thesis that women are the predominant informal caregivers in all kinds of life situations and contexts.

Literature focusing on women's caring labor demonstrates how women's household labor is unaccounted for in national economies and undervalued in the familial context of the women who perform acts of caregiving (Berg et al., 2005; England & Folbre, 2002; Folbre, & Bittman, 2004). Measuring the value of informal care has been difficult and several frameworks have been suggested such as the well-being valuation method, opportunity cost method, the proxy good method and the contingent valuation

method, which is said to be more sensitive to the preferences of caregivers (Berg et al., 2005; Berg, & Ferrer-i-Carbonell, 2007). It follows that because women's informal caring labor goes unreported and unpaid, it often leaves them income-poor. In addition, caregiving women are often 'resource poor' and 'service poor' due to their own poor health, the burden of caring for other family members, financial stresses, and the time and energy it requires to get connected with services (Barnett, & Whiteside, 2002). For delivering such caring labor to their children, elderly or other members of the family, women pay a penalty in terms of life-time loss of wages (Folbre, & Bittman, 2004). These penalties are compounded by the potential loss of personal health, time to rest, and wages; these additional burdens accrue faster when the care provider is sick herself especially in resource constrained environments.

The majority of caregivers for people living with HIV are women who risk exposure to HIV in providing such services (Akintola, 2006; Barnett, & Whiteside, 2002; Heyzer, 2001; Russel, & Schneider, 2000). While risk of exposure to HIV as a caregiver is minimal, contact with bodily fluids, primarily blood, is always a possibility, particularly in settings where paying for gloves and gown may be impossible; this makes caregiving itself a hazard in poorly resourced areas like Uttar Pradesh. Most studies on informal caregiving for HIV/AIDS have been conducted on the African continent and found that approximately two thirds of primary caregivers in HIV- affected households are female (Kipp, Nkosi, Laing, & Jhangri, 2006; Steinberg, Johnson, Schierhout, & Ndwga, 2002). Qualitative studies in South Africa (Orner, 2006), Malawi (Chimwaza, & Watkins, 2004) and Botswana (Lindsey, Hirschfeld, & Tlou, 2003) found that the vast majority of informal caregivers for individuals with HIV are women who operate within

rigid gendered division of labor in the household where men rarely participate in caregiving activities. In addition, women experience financial, physical and emotional strain and are found to be at an increased risk of being infected with HIV and tuberculosis (Akintola, 2006). Even though the caregiving impact on women has been most documented in Africa, there is evidence for this trend across the developing world. Warwick and colleagues (1998) found that in Dominican Republic, Mexico, India, Tanzania and Thailand, women performed all kinds of caregiving activities. Description of activities included cooking meals, taking care of the medicine schedule, cleaning, buying and administering drugs, providing nutrition, and toilet assistance and/ or supplementing nursing care (Warwick et al., 1998). Even though it has been almost two decades since Warwick' study, more recent studies in other developing nations show similar findings. For example, in Thailand, mothers provide care to more than half of the people living with HIV (Knodel, & Saengtienchai, 2005). There is evidence from all over the world that informal caregiving is a gendered phenomenon in which women form the majority of primary informal caregivers regardless of their own or their family's health status.

The situation in India

In India, families constitute the largest proportion of caregivers for all chronic illnesses including HIV/AIDS (Bharat, 1999; D'Cruz, 2003; Nymathi et al., 2016). Household members' level of involvement of was found to be important in the way caregiving was experienced by HIV- positive people in the 1990s (Warwick et al., 1998) and in more recent times (D'Cruz, 2003; 2008; Nyamathi, 2016). Women's experiences as caregivers to husbands or children living with HIV are expected to be influenced by

the context of living with the disease themselves as well as the texture of relationships between men and women in specific families and in their immediate societal context.

In one of the few studies including women caregivers, D'Cruz (2003) describes experiences of wives in seven HIV/ AIDS-affected nuclear households in Mumbai from the moment they discover their own and their spouse's HIV-positive status. D'Cruz uses "moments of truth" as a metaphor to describe turning points in the lives of these women. Seven couples were interviewed for D'Cruz's study (2003). Five of the husbands in the study acknowledged their high- risk behaviors (visiting commercial sex workers, unprotected sex, and multiple-partner sex) while two denied any risky sexual behaviors. D'Cruz (2003) describes becoming a caregiver as one of the "moments of truth" in the women's lives where many women felt that they had no choice other than to take on the caregiving tasks, while others received caregiving support from their natal families. However, the researcher did not explore reasons for caregiving or potential caregiving options, and three of the women participants in this study were HIV negative.

D'Cruz (2008) also explores informal caregiving in the context of HIV/AIDS in southern India. The researcher interviewed 17 participants, of whom seven were male care recipients, two male and three female seronegative caregivers, and five female seropositive caregivers. D'Cruz found that caregivers' interactions with the formal health care system were mostly negative interactions such as violations of confidentiality while getting their care recipient tested for HIV. Care recipients experienced loss of autonomy and feelings of having no control over their lives, while caregivers reported struggling to prolong the lives of the care recipients. Although D'Cruz (2008) sheds some light on informal caregiving experiences for HIV, she does not focus exclusively on married

women with HIV as caregivers and the study does not explore factors that influence women to be caregivers while they are ill themselves. Kohli and colleagues (2012) used qualitative focus groups to understand issues of HIV- related home- based care in two urban centers in Maharashtra in southern India. Their findings indicated that people living with HIV/AIDS perceived home-based care as an economically viable option (Kohli et al., 2012). Women provided the majority of the informal caregiving tasks giving unconditional support to men. Kohli and colleague's study (2012) provides insights into general caregiving experiences but does not focus on the experiences of married women living with HIV and providing care to their HIV-positive family members.

When multiple members of a household live with HIV, women tend to pay a high opportunity cost when undertaking caregiving responsibilities for their families, decreasing their capacity for income generation, education, and skill building. Given the nature of informal care and the difficulty of measuring it, this care work tends to go unaccounted in national economies. D' Cruz (2008) and Kohli and colleagues (2012) provide insight into the experiences of caregivers of people living with HIV, such as the nature of tasks caregivers perform and the challenges they face, but these studies do not focus exclusively on the caregiving experiences of married women living with HIV who often have no self-reported or self-perceived, high-risk behaviors of their own. Moreover, most of the studies focus on barriers to care and none of these studies has used theoretical lenses to analyze the experiences of caregivers. These are gaps in our knowledge about the experiences of women living with HIV while also providing informal caregiving. I will address these gaps in this study. The following sections

discuss caregiver strain and gain as useful concepts to explore positive and negative aspects of the caregiving experience in varied contexts.

Caregiving: A Strain or Gain?

Caregiver strain is understood as a problem one experiences due to a caregiver role or status that exerts several simultaneously occurring demands on an individual (Pearlin, Mullan, Semple, & Skaff, 1990). Studies exploring caregiving with different groups of care recipients such as the elderly, children or people living with dementia, HIV/AIDS, or stroke indicate that caregiving tends to impose physical and emotional forms of stress on the caregiver (Schulz et al., 2012; Schulz, & Sherwood, 2008; Vitaliano, Zhang, & Scanlan, 2003). Caregiving has multiple characteristics of a chronic stress experience (Schulz, & Sherwood, 2008) including increasing risk for mortality (Shulz, & Beach, 1999).

A study by the Australian Bureau with women caregivers found that nearly three quarters of the caregivers felt dissatisfied with their caregiving roles, 29% felt that their physical and emotional wellbeing was adversely affected due to their caregiving responsibilities, and almost half of the caregivers reported that their sleep was frequently interrupted (Australian Bureau of Statistics, 2003). Pinquart and Sorensen (2007) conducted a meta-analysis on 229 studies from all over the world; they explored differences by gender in the psychological and physical health of caregivers, caregiving stressors, and social resources. Results were similar to those of individual studies discussed above; researchers found that women caregivers experienced higher levels of caregiver burden and depression, and lower levels of emotional well-being and physical health (Pinquart & Sorensen, 2007). The meta-analysis reported that carerecipients'

physical and cognitive impairments and behavioral problems were sources of stress for

the caregivers. In contrast to men, women provided more caregiving hours and helped

with more caregiving tasks even though there were no differences by gender in the use of

informal and formal support (Pinquart & Sorensen, 2007).

Despite the negative effects of caregiving on the caregiver's physical and

psychological health, there are positive outcomes of caregiving as well, which include the

psycho-emotional benefits of providing care. Caregiver satisfaction or gain has been

defined as "the extent to which the caregiving role is appraised to enhance an individual's

life space and be enriching" (Kramer, 1997, p. 240). Some studies on caregiving

outcomes have indicated that caregivers have a lower risk of mortality compared to those

who never had a caregiving role (Brown et al., 2009; O'Reilly, Connolly, Rosato, &

Patterson, 2008). A longitudinal study (O'Reilly et al., 2008) examined the health of

caregivers in a nationally representative sample from the 2001 Northern Ireland Census

examining the subsequent mortality of caregivers over the following four years.

Researchers found that those providing fewer hours of care were relatively more affluent

than those providing care at greater intensities, and caregivers had lower mortality risks

compared to those who did not provide any caregiving. Effects were more prominent for

women, older people, and those reporting poorer health at the start of the study.

Mackenzie and Greenwood (2012) reviewed nine quantitative and qualitative studies

from various databases from 1999 to 2009 and found that stroke patients' caregivers'

positive feelings were associated with the care recipients' progress. Other positive aspects

of the caregiver experience included strengthened relationships with the stroke patients

they were caring for, feeling appreciated, and increased self-esteem (Mackenzie & Greenwood, 2012).

For Alzheimer's caregiving, Sanders (2005) explored both caregiver strains and gains in a sample of eighty-five diverse caregivers of Alzheimer's patients in an urban setting. The majority of the respondents were women with an average age of 60 years; one third of the women participants were wives of the patients. Participants came from Caucasian, African American, Hispanic and Asian backgrounds. Eighty-one percent of the caregivers reported both strains and gains, while nineteen percent of the caregivers reported only experiencing strains. Caregivers experienced strains due to worries and uncertainties, balancing multiple demands, and feeling overwhelmed. Caregivers experienced gain through spiritual and personal growth and feelings of mastery as a caregiver (Sanders, 2005).

Few studies of caregiver gain or strain have been conducted in India. Gupta, Rowe and Pillai (2009) explored psychosocial factors associated with perceived caregiving burden in a sample of 263 primary caregivers to the elderly in Allahabad, Uttar Pradesh, in northern India. The dependent variable was perceived caregiver burden measured with a 31- item ordinal scale adapted from Stommel, Given and Given (1990). Role overload, adherence to Asian cultural norms, and gender of the caregiver were independent variables. Role overload was measured through a four-item role overload scale developed by Pearlin, Mullan, Semple, and Skaff (1990). The items in the scale measured the level of fatigue experienced by the caregiver in carrying out chores in addition to providing care for an elderly person. A twenty-two-item filial piety scale adapted from Ho and Lee (1974) indicated identification with Asian cultural norms.

Researchers found that the odds of men feeling a high level of caregiver burden depended

only on role overload. Feelings of caregiver burden increased for men with an increase in

role overload until role overload reached a threshold level and then such feelings

decreased even when role overload continued to increase. For women, there was a

positive interaction between the adherence to Asian cultural norms and role overload in

determining the odds of feeling burdened (Gupta et al., 2009). Another study assessing

burden among caregivers of stroke patients in an urban community in India (Das et al.,

2010) found that a large proportion of the caregivers experienced increased workload,

related anxiety, depression, sleep disturbance and financial worry. Financial stress was

more prominent among the socioeconomically disadvantaged participants in this study

(Das et al., 2010).

Literature on caregiver strain and gain provides us insight into the possible nature

of positive and negative experiences associated with informal caregiving. While there

are several studies that explore the home-based caregiving experiences of women caring

for people with HIV/AIDS in African countries (Akintola, 2006; Barnett, & Whiteside

2002; Heyzer, 2001; Russel, & Schneider, 2000), few such thorough accounts are found

in the Indian context. Studies that have investigated the population of informal HIV

caregivers in India (D'Cruz, 2003; 2008; Kohli et al., 2012; Pandit, & Vishnuvardhan,

2013) are all concentrated in Southern India and do not explore the caregiving

experiences of HIV-positive married women exclusively. Because one of the purposes of

this dissertation is to explore how HIV- positive women's informal experiences of

caregiving intersect with their experiences of receiving care for their own health from

formal and institutional sources of care, the following section provides a brief overview of the Indian health care system and HIV/AIDS services in India.

An Overview of the Indian Health Care System and HIV/AIDS Services

The Indian health system is organized to include both private and public health care services. In recent times, the private sector has assumed the predominant provider role. As many as 70% of urban households and 63% of rural households use the private health care sector as the main source of health care. Households in the upper quintile of the wealth index are more likely to use hospitals and doctors from the private medical sector in contrast to households in the lower quintiles of the wealth index (National Family Health Survey, 2007). People often prefer not to use government health facilities due to poor quality of care, long distances to public health clinics, and long waiting periods (National Family Health Survey, 2007). Despite a variety of private health insurance schemes and the Central Government Health Scheme, only 5% of households reported that they have any kind of health insurance for at least one member of the household (National Family Health Survey, 2007). India currently spends 1.2% of its GDP on publicly funded health care, which is drastically lower than other nations with similar development indices (Gill & Taylor, 2013). Further, India is the third largest medicine producer in the world and low-cost Indian medicines have played a critical role in the extension of treatment to other parts of the world. However, these medicines are often not easily available to Indians themselves, partly due to costs and accessibility (Gill, & Taylor, 2013).

The National AIDS Control Organization in India is the central public agency for management of the epidemic (NACO, 2014). This agency operates through a

decentralized model with State AIDS Societies that connect people living with HIV/ AIDS to various counseling, care, support and treatment services. State AIDS Societies approve new policy initiatives, oversee annual plans and budgets, appoint statutory auditors and accept annual audit reports (National AIDS Control Organization, 2009). State AIDS Societies' services are provided through the Antiretroviral Therapy (ART) Centers, Voluntary Counseling and Test Centers (VCTC), Prevention of Parent to Child Transmission (PPTCT) Centers, Sexually Transmitted Diseases Centers and the Family Planning Centers. Some of these services are provided through primary health care centers in districts.

From 2007-13 along with hospital-based care, community care centers (CCCs) were set up for people living with HIV/AIDS to function as a bridge between hospital and home-based care and to provide inpatient care for at least five days (National AIDS Control Organization, 2007; Sogarwal, & Bachani, 2011). The community-care centers connected people living with HIV to various services described above including counseling for home- based care. However, there are no studies assessing the quality of such counseling and its effectiveness for informal caregivers. Every community-care center had only ten beds and could provide inpatient care to ten patients at a time (National AIDS Control Organization, 2007) resulting in serious competition for in-patient care. In addition to the serious shortage of space within the community-care centers, they were located in areas of high HIV incidence and in urban locations, further depriving rural populations and people with HIV living in low incidence areas of needed care and support.

A national level process evaluation study (Sogarwal, & Bachani, 2011) of 197 community health care centers revealed important insights into problems associated with health care delivery for people living with HIV/AIDS. Important issues affecting care and treatment services included the large number of clients, poor coordination with antiretroviral therapy centers, shortage of medicines for treatment of opportunistic infections, and the need for further training of counselors for drug addiction. Issues of education regarding infant feeding and prevention of HIV infection between discordant couples also required attention (Sogarwal, & Bachani, 2011). Other factors that were found to hinder care delivery included long distances that clients need to travel for care, incorrect addresses, client migration, and resistance to home visits by outreach workers due to fear of stigma and risk of disclosure of HIV status (Sogarwal & Bachani, 2011). Other studies have also identified the need for better identification of the needs of people with HIV in India (Claeson, & Alexander, 2008) and the need for coordinated programming among community care centers and other programs including tuberculosis and maternity care (Bhatia, & Anand, 2009; Larmar, & James, 2013).

Since 2014, the CCCs have been replaced with Care and Support Centers (CSCs) all over India for greater integration of HIV services with the general health system. CSCs are co-located within a few miles of the antiretroviral therapy centers, which are located in public hospitals. CSCs offer psychosocial services and connect people living with HIV with welfare benefits. Unlike the CCCs, CSCs do not offer accommodation or in-patient care. Clients are expected to collect a monthly quota of ART medications from the ART center and then travel to the CSC for psychosocial services (NACO, 2013a).

Availability and Access to Antiretroviral Therapy (ART)

In the last decade, several competing Indian manufacturers supplied about 80% of antiretroviral therapy drugs bought by donors for use in developing nations (Médecins Sans Frontières (MSF), 2011a). Competition amongst pharmaceutical manufacturers in India is critical in reducing the cost of ARTs worldwide (MSF, 2011b). ART was made available free of cost in India through public health care services in 2004 with the aim of establishing 250 ART centers by 2011 to treat adults and children infected with HIV (NACO, 2004). Medecins Sans Frontieres (2011b) suggests that these aims have been exceeded with a reported 293 established ART centers. Antiretroviral treatment for HIV has become increasingly available in India, yet there is a limited supply of HIV drugs with respect to the growing need. Further, the costs of the ART medications were a major barrier to ART adherence among patients at least till 2005 (Kumarasamy et al., 2005). Freedberg and colleagues (2007) estimated the lifetime cost of the ART regimen using an HIV- disease simulation model with data of natural history, treatment efficacy and costs of care from India to be approximately US $5430 per person in 2004. Highly active antiretroviral therapy, a separate category of antiretroviral therapy has been available using generic drugs since 1999 and these prices have decreased substantially over the past several years. Despite the decrease in ART cost and increase in availability, only approximately 50% of eligible HIV-positive patients in India were actually receiving ART in 2012 (WHO, 2013).

Barriers to care for HIV-positive women in India.

Stigma and discrimination against people living with HIV/AIDS forms a significant barrier in accessing care and treatment services, especially for women in India

(Bhatia, & Anand, 2009; Bharat, Aggleton, & Tyrer, 2001). Women living with HIV face discrimination not only in their homes but also in health care settings, especially with gynecologists in maternity clinics (Bharat et al., 2001). For women, HIV/ AIDS-related discrimination replicates and reinforces pre-existing gendered economic, educational, cultural, and social inequalities; it also hampers equitable access to HIV treatment and services (Parker, & Aggleton, 2003; Pradhan, & Sundar, 2006). Women in rural parts of India face more severe barriers to accessing care. A study in rural parts of Chennai (Nyamathi et al., 2011) in southern India explored barriers to care for women living with AIDS in rural areas and investigated alternative delivery models to increase women's adherence to antiretroviral therapy. Researchers found that the most common barriers to treatment adherence were illness, psychological stress, and financial issues with childcare, distance and transportation to the site. Discussions with physicians and nurses suggested a paucity of trained health care workers at the primary health care centers and lack of expert services (Nyamathi et al., 2011).

Welfare provision for people living with HIV/AIDS.

In this section I provide a brief overview of India's welfare system as it intersects with provision of welfare services for people living with HIV. In the Federal Polity of India, provision of social protection is enshrined in Articles 38 (securing a social order for the promotion of welfare of the people), 39 (certain principles of policy), 41 (right to work, education and public assistance in certain cases), 42 (just and human conditions of work and maternity relief) and 43 (living wage) of the Indian Constitution as a part of the Directive Principles of State Policy. This implies that the Indian State will strive, within the limits of its economic capacity, to make provision for securing the right to work,

education and public assistance in cases of unemployment, old age, sickness, disablement, and in other cases of undeserved needs of people (Tayal, & Jacob 2005).

India's wide and complex welfare system is located in two distinct domains of the formal and informal economy. Approximately 96% of India's economy lies in the informal sector, unregulated by the government or government owned enterprises (Basile, 2013; Bremen, 2013). While employees working for the government or government owned enterprises are covered through strong social protection (Goswami & Karunarathne, 2002), those belonging to the informal economy are provided welfare services through a patchwork of government schemes, implemented through state and local governments; schemes include benefits in cash or kind (Dreze & Sen, 1989; Kapur & Nangia, 2015).

Extant literature does not account specifically for the experiences of people living with HIV/AIDS in accessing available welfare services. This is of particular importance because there are no schemes targeted specifically at people living with HIV. Nevertheless, there are a few programs that may be temporarily rolled out through the State AIDS Societies. Predominantly, schemes accessible to the general population are also provided to people living with HIV/AIDS. The government aims to connect people living with HIV to welfare schemes through a network of public-private partnerships aimed at building an HIV-sensitive social protection in India (National AIDS Control Organization & Ministry of Family Welfare, 2012; UNDP, 2014).

There are numerous welfare schemes operating at both the central government and state levels that address a wide range of concerns including food, health, housing, pension, disability, employment generation, skills development, and education.

Together, these schemes cover the two interrelated aspects of social security in social protection and social promotion. Protection-oriented welfare is directed at the primarily conservative objective of "preventing a decline in living standards" of the vulnerable sections of the population, especially during times of crisis such as economic recession and production failures. Promotion entails a more comprehensive effort at addressing the endemic deprivation in the society through a multipronged strategy spanning the core developmental concerns in areas such as employment generation, health care, sanitation, and education that would contribute towards the long-term goals of "enhancement of general living standards and to the expansion of basic capabilities of the population" (Dreze & Sen, 1989). In this study, I will explore women's experiences of getting connected with welfare provision and health workers' efforts at connecting women with welfare schemes.

Theoretical and Conceptual Framework: Key Definitions

In this section, I define key concepts as they emerged from the analysis of data in the findings chapters. Several themes in women's narratives were found to be consistent with pre-existing concepts, discussed here. The conceptual lenses form an analytical web that assist in understanding the phenomenon of informal care provision by ailing women.

Authoritative knowledge.

The idea of 'authoritative knowledge' has its roots in anthropological, sociological, and feminist literature. Jordan (1997) first conceptualized Authoritative Knowledge (AK) in two primary ways. First, AK is knowledge that is attached to an individual in a position of authority, for example, a physician who specializes in the treatment of a particular disease or a teacher in the classroom, or a manager in a

leadership position, and second, AK is the knowledge base on which decisions are made in any given setting, by a community or social group. AK is embedded in power relationships where the power of AK is "not that it is correct, but that it counts" (p.58). The question of what constitutes AK in various social situations, in whom or where it lies and what components constitute AK, are questions relevant to how people make decisions in various situations. Authoritative knowledge was first applied by Jordan (1997) to study childbirth in various cultures where AK may lie in a single person such as a physician, or may be jointly constituted by women in communities who have varying experiences of childbirth. Jordan acknowledges that in some social situations, multiple kinds of knowledge sources are present by virtue of the varying backgrounds, resources and experiences that multiple members bring to the situation. The production of AK has been studied across cultures, especially in the context of childbirth. Examples include the role of fetal ultrasound imaging in Greece in the production of AK (Browner, & Press, 1997), the role of prenatal medical technologies in the constitution of AK for decisions regarding the termination of pregnancies affected by fetal anomalies in the United States (McCoyd, 2010), the role of intuition as AK in midwifery and birth at home (Davis-Floyd, & Davis, 1996), and randomized controlled trials as constitutive of AK for midwives in North America (Johnson, 1997). Of particular importance is a study by Root and van Wyngaard (2011) who explored the role of church run home based caregivers in Swaziland in a high HIV prevalence area. Researchers found that religious ethos and practices played an important role in the development of caregiver's authoritative knowledge about caregiving, but their AK was also complicated by their sense of moral

religious superiority. In this study, the concept of AK is used to understand women's search for certain and authoritative information about HIV and informal caregiving.

Self-efficacy and Resilience.

The concept of self-efficacy refers to people's understanding of their influence and control over tasks and events in their lives. Self-efficacy is peoples' beliefs in their ability to impact events and circumstances, and it plays an important role in determining the extent to which people persevere in the face of difficulties (Bandura, 1994). Bandura (1994) describes four central sources of self-efficacy. First, experiences of success or 'mastery' enhance a person's belief in their ability to accomplish a task; second, 'vicarious experiences' through observation of role models can be a source of self-efficacy. Third, 'verbal persuasions' are used as a source of self-efficacy when others remind people of their ability to accomplish a task. Fourth, people also use their own emotional states as cues of the measure of their abilities, where stress is interpreted as a sign of diminished abilities and positive mood is perceived as enhancing self-efficacy.

Self-efficacy plays a critical role in HIV prevention and early connection to care because individual's perception and abilities to perform self-protective behaviors, such as the practice of safe sexual behaviors (Brafford, & Beck, 1991; Jemmott, Jemmott, Spears, Hewitt, & Cruz-Collins, 1992) and timely HIV testing, is dependent on their perception that they can positively impact their life situations (Bandura, 1990). However, a few studies have found that self-efficacy may not be significantly associated with safe sexual behaviors. For example, in a study with college students, Crowell and Emmers-Sommer (2000) found that even when students reported high self-efficacy about condom use, it did not necessarily translate into actual condom usage.

In addition to HIV prevention, in contemporary HIV literature, greater self-efficacy has been associated with higher rates of condom use and greater ability to disclose HIV status to the partner, (especially among men), and lower emotional distress (Kalicman, & Nachimson, 1999; Simon et al., 2008). Other studies have found that greater ART adherence among people living with HIV is associated not only with greater levels of literacy and knowledge, but higher practiced self-efficacious behaviors (Barclay et al., 2007; Wolf et al., 2007).

Self-efficacy is positively associated with the concept of 'resilience' (Milioni et al., 2015). Resilience is peoples' capacity to spring back from adverse life circumstances and situations and continue on the path of their individual development in any life domain, despite obstacles and setbacks. Resilience, then, is a personality characteristic that can be developed but whether one is resilient or not can only be known in the face of unfavorable life circumstances (Garmazy, 1990). Resilient people demonstrate stability in the face of adversity, different from 'recovery,' which involves a trajectory of arriving at the level of well-being prior to the adverse event (Bonnano, 2004). In this study, resilience has been used to understand women's consistent positive behaviors towards their health and well-being, in the face of being of HIV-positive themselves while caring for their family members living with HIV.

Meaning-making, constructivism, and dialogue.

The meaning-making framework used in this study is central to phenomenological inquiry. Meaning-making is understood as the process by which individuals make connections among events, circumstances, and complex interaction with other factors. Meaning-making assists people in making sense of their world and life.

In this study, meaning-making is used to understand phenomenon in two distinct ways. First, I explore how women who are HIV-positive caregivers make meaning of their caregiving role in the context of their socialization and the worldviews that they have accumulated over a lifetime. Second, I explore how women make sense of their caregiving role and their own health, in dialogues with health care providers in formal systems of care for people living with HIV. Some examples of meaning-making where people utilize their world views include assigning positive meanings to an event and one's role in it in an attempt to finding purpose in the midst of stressful life circumstances (Affleck, Tennen, & Gershman, 1985), finding spiritual meaning in one's life circumstances and events (Johnson, 2003; Lips-Wiersma, 2002), and accepting one's life situation as a form of coping (Davis, & Morgan, 2008).

Because social meanings of phenomenon are constructed in social spaces through interaction and the processes of meaning-making, dialogues between actors in a social situation play an important role in the construction of the social meanings of phenomena. Collectively developed and repeated dialogues assign the validity of truth to social events, circumstances or phenomena under consideration in a given socio-historical context (Berger, & Luckmann, 1966; McNamee, & Gergen, 1999). Merleau-Ponty (1962) and Levinas (1969) bring together the perspectives and philosophical traditions of constructivism and phenomenology to draw attention to the meanings of human existence and human experience as it emerges in collective dialogue. In Merleau-Ponty's philosophy, social meanings are created through interactive and interdependent actors and situations. In this philosophical perspective, there are no autonomous beings, individuals are but a part of the meaning-making process in which no singular actor

individually exercises influence in the outcomes of the meaning-making process.

Merleau-Ponty (1962) aptly described the dialogic co-constitution of meaning:

> There is constituted between the other person and myself a common ground; my thought and his are interwoven into single fabric, my words and those of my interlocutor are called forth by the state of the discussion, and they are inserted into a shared operation of which neither of us is the creator. (pp. 354)

Therefore, following from Merleau-Ponty's definition of dialogic processes, the onus of the construction of meanings then does not lie with any singular person but meanings are essentially co-created through acceptance, discussion, argument, questioning, inquiring, resistance and other modes of conversation. For the purposes of this dissertation, the meanings of informal caregiving are explored through dynamic and collective social interactions; collective sense is made of informal care and women's health through dialogues between health care workers and caregivers living with HIV.

Lipsky's theory of street-level bureaucrats.

In the 1980s, Lipsky theorized the critical role of frontline workers in all spheres of public services such as schools, welfare offices, courts, police and hospitals. Frontline workers, according to Lipsky (1980/2010), play a critical role in defining and shaping policies because they have immense discretionary power in the dispensation of goods and services directly to the beneficiaries. Frontline workers, then, are the face of the policy with which the beneficiaries are interacting. Lipsky argues in his seminal work 'Street-Level Bureaucracy, Dilemmas of the Individual in Public Service,' that the decisions frontline workers make, the mechanisms they employ to cope with work pressures, and the management of limited resources ultimately become the policies they implement.

Lipsky offers a broad net of concepts which assist in understanding the working conditions, constraints, action orientations and decision-making orientations of frontline workers or 'street level bureaucrats' (SLBs). The theory proposes several assumptions about the role of SLBs; the most important facets of the theory for the purposes of this study are described here: 1) Street level bureaucrats work in resource-constrained environments that are almost always overworked, understaffed and suffer paucity of material resources, 2) SLBs individual actions contribute to and create the actions of the agency in which they work, 3) Because SLBs interact directly with clients, their views about clients and decisions for clients contribute towards a collective view of groups of clients and even change the client's behaviors and views. 4) SLBs cope with the pressures of their demanding jobs by working to limit demands, optimize the use available resources, and develop procedures to gain compliance from clients. To achieve this, SLBs use strategies such as grouping clients into categories of who can be helped first or last (Triage).5) Finally, SLBs have maximum influence on the poorest clients. In this study, I use Lipsky's theory to uncover the challenges of health workers while serving people living with HIV, and I examine the discourses and action-oriented strategies they develop to deal with the difficulties of serving women clients who are themselves living with HIV while providing care to their HIV-positive family members.

Summary

In this review, I have described the context of gender and the experience of women living in India generally, followed by a description of married women's vulnerabilities to HIV. This was followed by definitions of caregiving work, its effects on caregivers, and descriptions of specific policies affecting health and welfare in India.

The final section covered theoretical concepts used for analysis, which include authoritative knowledge, self-efficacy, resilience, meaning-making, constructivism and dialogue and Lipsky's theory of street level bureaucrats. In the following chapter I describe the design and methodology of this study.

Chapter 2: Methodology and Design

The subject of informal caregiving is complex and diverse and most appropriately studied using qualitative approaches. This study uses a phenomenological qualitative approach to the production of knowledge. Phenomenology, as a segment of the philosophy of the mind, developed in two simultaneous traditions in European philosophy and in the Austro-Anglo-American traditions (Smith, 2004; 2013). While there are variations in what is accepted as phenomenology in different traditions, it is unanimously understood as a method of inquiry that concentrates on the details of respondents' conscious experience and the analysis of mental experience rather than observing an individual's behavior (Creswell, 2003; Smith, 2013). Central to phenomenology is the structure of conscious experience from the first-person point of view and the conditions of that experience, including thoughts, emotions, perceptions, self-awareness, memory, imagination, and the use of language (Smith, 2013).

The earliest formal uses of phenomenology can be traced to the 20th century works of Husserl, Heidegger, Sartre, and Merleau-Ponty, among others. The phenomenology of Heidegger and Merleau-Ponty differed from Husserl. For Heidegger and Merleau-Ponty, phenomenological reduction or bracketing (by which the researcher is expected to suspend his or her ideas about how the world is or should be), is impossible to achieve because we are all products of our contexts at a deeper subconscious level (Smith, 2013). Husserl, on the other hand, believed that bracketing or a suspension of the researcher's beliefs and worldviews is necessary to the research process. Further, classical phenomenological traditions differed in their methods, focusing on either the pure description of the lived experience, interpretation of the experience through a study

of its contextual factors, or the analysis of the form of a type of experience such as an art form or aesthetics (Smith, 2013; Bratu & Marculescu, 1979).

However, in the past few decades, phenomenological methods have ramified from the classical traditions. As Smith (2013) describes, the modern ramifications include a logico-semantic model of phenomenology where the "satisfaction conditions for a type of intention" are specified (Smith, 2013, p. 6), implying that the flow and directedness of intentions towards a particular subject is of prime importance, before the actions flow towards the subject. Another example of modern ramifications is the neurophenomenological model, which assumes that conscious experiences are grounded in neural activity. Further, these models differ in how they define conscious awareness, with logico-semantic phenomenology asserting that it explores a higher-level thinking about thinking and neurophenomenology exploring an inner perception of an activity (Smith, 2013).

Phenomenology in This Study

In considering any particular method of inquiry there should be an alignment between the research question and the branch of philosophical enquiry (Maggs-Rapport, 2001). The overarching question of this study is- *What is the lived experience of HIV-positive, caregiving, married women in Uttar Pradesh, India?* This question is best suited to the phenomenological method of enquiry.

For the purposes of this study, a reflective, hermeneutic phenomenological approach, originally traced back to Heidegger (1927/1996) is appropriate. This allows exploration of the lived experience of HIV-positive married women as caregivers, as well as an exploration of their experience of action in concrete situations and contexts such as

the ART-CSC centers (where ART centers are located within government hospitals and the care and support centers are located within 2.5 kms from the hospital). The term 'hermeneutics' broadly refers to the comprehension and interpretation of both linguistic and non-linguistic expressions (Bleicher & Bleicher, 1980; Ramberg, Bjorn, Gjesdal & Kristin, 2013). I adopted this approach because it focuses on the individual experience and at the same time provides the scope to analyze the impact of contextual factors; it allows me to interpret how women came to understand their world and take action in their varied life situations.

Hermeneutic phenomenology emphasizes the importance of meaning-making as an integral part of being human. All meanings are embedded in culture, time, history and the individual's other life circumstances, factors that Heidegger referred to as the person's "historicality" within their existence (Creswell, 2003). Therefore, I interpret participating women's experiences as caregivers within the context of Indian culture and predominant north Indian values, especially those that are particularly applicable to women. Further, I interpret women's experiences within the context of the state of Uttar Pradesh where they live and the system of formal care services to which they have access. I use phenomenology to understand women's lived experience and I use health workers' narratives more descriptively for triangulation as a tool for completeness.

The phenomenological method provides the researcher with narratives, which are as close as they can be to the actual experience itself (Creswell, 2003; Moran, 2002). It is the "world of action that represents the highest level of human engagement, especially when it emerges in joint co-operative undertakings and in discussion" (Moran, 2002, p. 312). In alignment with Heideggerian phenomenology, this approach allows the

researcher to be engaged in the research process as her own person and does not require distance or the suspension of the researcher's worldview all together in the process of data collection or analysis. Therefore, this process of inquiry allows the researcher to listen closely, question, reflect, recheck and interpret important dimensions that emerge from the narratives of the participant's experiences (Creswell, 2003; Patton, 2002).

Data Collection Procedures

Sample.

A purposeful sampling method was used for this study. The primary sample was of women caregivers. In addition, I had a sample of health workers who worked with the caregiving women. I used the two samples to develop an understanding of the system of care the women experienced. I selected respondents according to their experience of the subject of study. There are no well-defined rules for sample size in qualitative research but sampling in studies using qualitative methods tend to rely on small numbers to study depth and detail (Patton 2002; Tuckett, 2004). Qualitative research seeks richness of data about a particular phenomenon; in this case, the phenomenon of interest is women who are HIV-positive and married, and who provide informal caregiving to their partners and/or other family members who are also living with HIV.

Qualitative sampling is reasonably flexible such that sampling criteria may change as the study unfolds in order to allow deeper exploration of a new aspect of the phenomenon (Tuckett, 2004). In this study, sampling criteria did not change because I continued to have access to women with the predefined eligibility criterion. Five health workers were living with HIV themselves which did not change predefined criterion for interviewing health workers but added another dimension to the sample group.

In addition, sampling continued until I recognized that no new data were forthcoming, and a point of data redundancy or saturation was reached (Guba & Lincoln, 1994).

Sample sizes in previous studies exploring informal caregiving experiences have ranged from twelve to twenty-five participants. Although initially I had expected to interview approximately 25 women and 12 health workers, I interviewed 33 women and 15 health workers. The larger sample size and rich data accommodated for saturation of themes. Some respondents who agreed to be interviewed had already traveled for a day before arriving at the ART-CSC center and the Care and Support Centers where they were interviewed. Due to travel fatigue, some respondents needed to return home as soon as possible. This resulted in some interviews being shorter than expected, necessitating a slightly larger sample size.

Inclusion criteria.

Women respondents.

Respondents in this study were 18 years old or above, were currently married or had been married in the past three years, and identified themselves as HIV- positive. Further, they were currently living with, or had lived with, an HIV-positive member in their household, such as a partner or child, in the last three years. Participating women were or had been caregivers in their homes to other family members living with HIV. All women who were approached agreed to participate and gave informed consent to all parts of the study, including being audio-recorded in order to be included. There were women who wanted to be interviewed, but I was not able to interview them because they did not meet sampling criterion.

When I initially approached women for interviews, I explained to them the purpose of the study. If they were willing to talk further, I asked them if they had been caregivers to their HIV-positive partners or other family members. Depending on their answers and their willingness to participate, they were included in the study. Three respondents were accompanied by their husbands during their visit to the Care and Support Centers and another two were accompanied by their mothers. There were no separate protocols that I followed except extending my time of observation and consulting with a health care worker before I approached the woman. I interviewed the women alone.

Each participant was presented with a saree of minimal value (approximately $5 or Rs 300) after the interview, as a token of appreciation for her time and willingness to participate. At the start or the end of the interview, I collected demographic information about the participant on a separate sheet. All interview guides and demographic information sheet were translated into Hindi. Although I am fluent in Hindi, there were words in women's narratives that I did not understand due to the variety of Hindi dialects spoken outside of Lucknow city. I consulted health workers about the meanings of those words without mention of respondents who had used those words. Sample characteristics are described in Table 1 below followed by a description of sample characteristics of health workers.

Table 1. Demographic information about women respondents

Demographic characteristics of women respondents

Variable	Frequency N=33	Percent
Marital Status		
Currently married	22	66
Widowed within 1-3 years	11	33
Has child(ren) living with HIV	7	21
Age at marriage		
Below 18	20	60
19 -25 years	13	40
Self-reported approximate age		
18-30	30 (1 respondent at 19yrs)	91
x>30	3 (1 respondent at 50)	9
Estimated time spent as caregiver		
6 months-2 years	12	36
2-5 years	18	54
6-7 years	3	9
Geographical area of residence		
Lucknow	16	48
Outskirts of Lucknow	17	52
Type of household		
Nuclear family (A husband and wife with their children)	10	30
Joint family (Two or more generations of the family living together)	23	70
Education		
Standard 8th and below	20	61
High-school	4	12
Undergraduate	4	12
Diploma or vocational training	5	15
Monthly Family Income		
Rs 10,000 –Rs 15,000($150-$224)	7	21
Rs 5,000 – Rs 10,000 ($75-$150)	23	70
Income < Rs 5000 ($75)	3	9

Health professionals.

Health professionals were interviewed for triangulation of data for 'completeness' and not for confirmation or verification of women's interviews. This is critical because phenomenology relies on the authenticity of participant accounts. The health workers were viewed as a separate population with their own perspectives and challenges as care providers who could provide insider information about how the care and support services were ideally to be delivered. Health professionals who were interviewed had at least one year of experience working with married women living with HIV and they were 18 years of age or older.

Health workers included eight medical and peer counselors, two project coordinators, and five outreach workers. Five health workers were living with HIV themselves and had disclosed their HIV-positive status at work. Six were female and nine were male and all had at least a high-school education. All health workers spoke Hindi and all gave their consent to be interviewed and audio-recorded.

Institutional review and informed consent procedures.

The study protocol was approved by the ethics review committee at the Institutional Review Board at Rutgers University, New Jersey in the United States. In India, the Uttar Pradesh Welfare for People Living with HIV/AIDS (UPNP Plus) was consulted to ensure the cultural appropriateness of the study protocols, interview schedules, and consent forms. I am fluent in both spoken and written Hindi and English. Translations of consent forms from English into Hindi were also reviewed and approved by UPNP Plus.

I collected data over six months in the spring and summer of 2015. I approached women when they visited the Care and Support Centers, administered by non-profit agencies to meet with the case manager for counseling. In seeking a woman's consent, I used the "teach to goal method" where after I explained the study information to her, each woman was asked to explain her understanding of the study. I repeated this sequence until I was satisfied that the woman had sufficient understanding of the study to give informed consent. This technique has been effective in research with vulnerable populations where literacy skills are limited, to ensure truly informed consent (Tamariz, Palacio, Robert, & Marcus, 2013).

Informed consent was sought from the health professionals who were interviewed. All health professionals belonged to the agencies from where women respondents were recruited. They also offered additional audio-recorded consent as health workers living with HIV.

Recruitment, site for data collection and fieldwork.

I identified two nonprofit agencies in Lucknow in the state of Uttar Pradesh to gain access to married women living with HIV who were primary caregivers in their households. In contrast to other states with high rates of HIV prevalence (states such as Maharashtra, Tamilnadu, Andhra Pradesh, and Karnataka), Uttar Pradesh has a low HIV prevalence rate of 0.07% among women with 40,728 women living with HIV/AIDS in 2010 (Uttar Pradesh State AIDS Society, 2011). Uttar Pradesh is a good site for data collection for this project for four reasons. First, this study is not concerned with the numbers of HIV-positive women but with the experiences of these women. Women's experiences are best understood through their personal opinions and perspectives as well

as the sociocultural background of the area where they live which contributes to shaping their experiences.

Second, the state of Uttar Pradesh has one of the poorest development and health indicators in India, especially concerning women's health (Bloom, Tsui, Plotkin, & Bassett, 2000; Stephenson, & Tsui, 2002) providing a unique context for this study. Research studies on women's health in Uttar Pradesh have found that women have unmet needs for family planning and related information (Speizer, Nanda, Achyut, Pillai, & Guilkey, 2012). Women living in Uttar Pradesh face high levels of domestic violence compared to the southern states of India (Jejeebhoy & Sathar, 2001; Koenig, Stephenson, Ahmed, Jejeebhoy, & Campbell, 2006). There is poor literacy for girl children in Uttar Pradesh (McDougall, 2000) and acceptance of justification for domestic violence in this region is further associated with decreased chances of seeking any form of health care (Sudha, & Morrison, 2011). Despite its low prevalence of HIV, the state of Uttar Pradesh is a good site for data collection for this study due to its socioeconomic and cultural context for women, which is expected to influence and shape women's life decisions including their decision to be caregivers while they are sick themselves.

Third, the state of Uttar Pradesh has a peculiar pattern of HIV transmission, which is different from the southern high incidence states. Unlike the southern states where HIV prevalence is connected with intravenous drug use and commercial sex work (Vickerman et al., 2010), the prevalence of HIV in Uttar Pradesh is connected with the pattern of male migration from this state to other states in India. A majority of the migrants from Uttar Pradesh travel to the central and southern Indian states, which have moderate to high HIV prevalence areas, and often return to their home state infected with

the virus, eventually passing it on to their wives (Mukhopadhyay, Nath, Gulati, &

Mohapatra, 2001; Steinbrook, 2007). Of all inter-state migration in India, approximately

one quarter of the migrants are from Uttar Pradesh. Migrants from rural areas in Uttar

Pradesh who travel to high prevalence cities have higher HIV incidence rates than non-

migrants in the state (Uttar Pradesh State AIDS Society, 2011).

Finally, given the importance of context in phenomenological studies, the state of

Uttar Pradesh provides an unusual context for this research because of the extremely poor

health indicators for women as well its distinctive pattern of HIV transmission. Thus,

this study reveals the experiences of resource-poor, married women with low literacy

who live with HIV in an Indian state with low HIV incidence and where there are high

expectations to be good caregivers.

Phenomenological interviewing.

According to Seidman (2012), the purpose of phenomenological interviewing is

to deeply understand the lived experiences of people and the meanings they attach to their

experiences. For this research project, semi-structured interviews of 30 to 120 minutes in

duration were conducted in a private space at the Care and Support Centers from which

the respondents were recruited. All interviews were finished in one sitting. Although I

had initially planned on conducting two rounds of interviews, there were days when it

was not feasible for the agencies to have me at the CSC due to excessive workload. In

addition, once women who I interviewed had their ART medications for themselves and

other family members, they did not return to the CSC for months. This made it almost

impossible to conduct repeat interviews.

According to Seidman's framework, phenomenological interviewing involves an understanding of the temporal and transitory nature of human experiences while trying to understand the meanings people give to them. Seidman (2012) believes that language is central to the construction of the lived experience and this explains the centrality of the transcript to the research process. Finally, a phenomenological approach to interviewing puts emphasis on the importance of what the experience means to the participant (Seidman, 2012). "By asking participants to reconstruct their experience, and then reflect on its meaning, interviewers encourage participants to engage in that act of attention, that then allows them to consider the meaning of a lived experience" (Seidman, 2012, p 19).

I conducted two pilot interviews and modified the phrasing for a few questions. However, strategies and techniques of interviewing evolved throughout the interview process. For example, women's narratives often described relationships including incidents of physical, verbal, financial or emotional abuse at one point during the interview, and simultaneously described feelings of love for their spouse at another point. To explore this more deeply, I had to gently identify what I perceived as inconsistencies in their narrative as I sought to understand them. Another example of change in my questioning technique involved how women care for themselves. During the initial interviews, I assumed that women would understand what it felt like to take care of themelves. However, after not receiving any responses in the initial interviews, I gave them a few examples of what taking care of themselves would look like, including physical exercise, prayer, or similar activities which they may personally consider to be good for them. Although western notions of "self-care" are not what I was exploring, I

did want to explore women's attempts to care for themselves while also providing care to others.

All interviews were audio-recorded although respondents had the option to ask for the audio-recorder to be switched off during discussions of sensitive topics. Three respondents asked for the audiotape to be switched off for parts of their interviews. In all three cases, women were describing instances of physical intimate-partner abuse during which I chose to suspend all writing. Women who recounted incidents of physical abuse were currently widowed, separated or seeking formal divorce.

The interview guide was used loosely to ensure that all important areas for discussion were covered. Interviewing as part of the phenomenological approach is understood to be different from other interviewing techniques as it includes not only dialogue, but also reflection on the part of both the researcher, and the researched (Munhall, & Boyd, 1993). This reflectiveness in the interview process tends to accept the importance of the role of the researcher in the research process (Wimpenny & Gass, 2000). As part of the phenomenological interviewing process, I had to allow for long pauses and for women to sob in order to create space for them to reflect on their story. A few interviews lasted much longer than anticipated. Women deeply appreciated the space to talk about their lives and every day struggles, about which they perhaps rarely spoke. Especially notable is the fact that they had almost never spoken about their caregiving burden in an experiential way. Health workers had always spoken with women about caregiving in task-oriented ways, such as about how they were managing the nutrition or cleanliness of their homes, rather than in an experiential way to encompass women's emotional journeys as a caregiver while ill themselves.

Challenges during fieldwork: The problem of too much assistance.

One of the problems I faced in the field was being offered too much assistance in the research process. Many health workers wanted to be interviewed and offered their time to me, perceiving it as a help to me, even when they did not meet respondent criterion. Initially, this meant refusing a few health workers and explaining why I was not interviewing them. Overtime, when this became my repeated experience, I took the opportunity to broach the subject during a lunch session: I was invited to share lunch and I casually spoke about how much I loved talking to each one of them, but that my formal interviews would need to be conducted according to sample criteria.

Another time, I was offered help with interviews in the form of being taken to women's homes during health worker's home visits. Project managers thought that it would save me time and assist in finding women with eligibility criterion if I accompanied outreach workers rather than waiting at the Care and Support Centers every day for appropriate participants to show up. Given that there were several days when I was a guest without a purpose at the agencies, they began to repeatedly make this offer to me, at which point I had to again intervene systematically. Although I had earlier explained research protocols to agency heads, I felt the need to explain research design constraints with clarity to all staff members. I communicated the research protocols to all members through a conversation with one female staff member who was a natural leader in the team, well connected with everyone and who was supportive of my research endeavors. She willingly acted as a channel of communication about research protocols to all staff members.

Initially I viewed such communication as a strategic requirement of my fieldwork, but repeated communication about research protocols with staff members helped me build relationships that generated understanding for me, respect for my work, and stronger engagement from staff members when I needed it. I also ended up hearing a lot of stories about previous researchers who had approached the community in ways that were not deemed culturally appropriate in comparison with my research treatment of respondents.

Data Organization, Analysis, and Interpretation

Transcription and translation.

I translated and transcribed the audiotapes at the same time from Hindi to English. The translated English script was treated as the official transcript because the final study is in English. Translated scripts had additional notes on the setting in which an interview was conducted or any unique observations I made about it. I also included Hindi words during the transcription to allow for more accuracy in the coding process. All respondents were allotted pseudonyms in the transcripts to maintain confidentiality.

Translation of audio-recorded interviews certainly had an impact on the findings of the study. This is because languages develop in specific cultures and therefore translation of findings from one language to the other requires proficiency in languages and a deep cultural understanding of the context from where the data are collected (Larkin, Casterle, & Schotsman, 2007). While translating findings, I looked for English words that most closely transferred the meanings and ideas intended in Hindi. However, there were several words and metaphors that have no approximate parallels in English; they are culturally specific and their translation dilutes their impact and power. I have

explained metaphors or the exact cultural phenomenon or specific cultural trait to which they refer within parenthesis within quote extracts.

Coding and categorizing.

Qualitative coding was conducted in ATLAS.ti (version 1.0.31) qualitative software as part of the practice of capturing the essential elements of the participants' experiences. The initial codes were clustered for similarity and led to a pattern and facilitated the development of categories following an analysis of their connections (Saldana, 2012). During the coding process in ATLAS.ti, code names emerged from the data, to name and condense the social or individual process, behavior, personal or cultural values, thoughts or feelings of the respondents.

Following this, a focused coding was conducted, where similar codes were assigned to categories. In the final round of coding (Axial coding), I looked for relationships among the categories. Axial coding assisted in exploring the conditions of the participants' lives, the context and interactions of any strategies employed by the participants, and consequences that follow (Saldana, 2012). Following this, I explored relationships between each informant's earlier experiences and the current situation to understand patterns in life trajectories. I organized data thematically for each chapter according to the emergent conceptual network of relationships that became evident.

Although the process of coding assisted in understanding the themes and patterns in data, I repeatedly read transcripts in their entirety to make sense of the phenomenon as a whole. Final interpretations in this study have been made keeping in mind the broadest trends that truly reflect the phenomenon of informal caregiving by ailing women.

Verbatim quotes from respondents have been used to demonstrate the authenticity of the final interpretations and their true reflection as the voices of the respondents.

Analytical approach.

Data analysis and interpretation followed the interpretive, reflective phenomenological approach. Heidegger, in 'Being and Time" (1927/1996), explained that in order to conduct a phenomenological inquiry successfully, one must understand the foundations of the hermeneutic circle and that in which it is grounded (Plager, 1994). Therefore, to understand the circle, a threefold fore-structure is utilized. Plager explains Heideggerian thinking:

> A *fore-having*: we come to a situation with a practical familiarity, that is, with background practices from our world that make an interpretation possible. A *fore-sight*: because of our background we have a point of view from which we make an interpretation and a *fore-conception:* because of our background we have some expectations of what we might anticipate in an interpretation. (Plager, 1994, p. 72).

According to Plager (1994), for the project to have credibility, the researcher "lays out preconceptions, biases, past experiences, and even hypotheses that make the project significant for the investigator and that may affect how the interpretation takes shape" (p. 72). My reflexivity statement can be found in a later section on credibility and dependability.

Dissemination.

Preliminary findings were shared with some women and the staff at the CSC where data were collected. Presentations and reports will also be given to the two

agencies from which the respondents were recruited. I hope they can use relevant

information from the findings to assist them in developing individual or community

based interventions to alleviate the plight of HIV-positive married women. With the

CSC's support, I will further disseminate the findings to other local nonprofit agencies

and the Uttar Pradesh, State AIDS Society. Further, I have begun to disseminate the

findings through presentations at national and international conferences and through

journal articles. These steps assist in following the interpretive process as systematically

as possible to streamline and clarify the interpretations. Interpretations submitted through

a rigorous process of analysis can then broaden possibilities for social work interventions,

policymaking and research.

Rigor

Rigor in qualitative research is understood through the constructs of credibility,

transferability, dependability and confirmability (Shenton, 2004). Qualitative research

depends heavily on the insights and conceptual capabilities of the researcher, unlike

quantitative methods where reliability and validity of research depends on the protocols,

design and instruments of research. Thus, the qualitative researcher bears the

responsibility for following processes that enhance the rigor of their work and managing

threats to the credibility and transferability of research. The credibility of qualitative

research broadly depends on three related areas. These involve rigorous methods for

doing fieldwork that include, prior training and experience of the researcher, define the

researcher's philosophical beliefs about the nature of qualitative inquiry and ultimately

provide the researcher with rich data for analysis (Shenton, 2004). Techniques that have

been followed in this research study to enhance credibility of the research are discussed below.

Triangulation.

Triangulation refers to the process of combining methods, documents or using several observers to observe the same phenomenon in order to overcome biases and limitations attached with any single methodology, document, observer or site (Patton, 2002). In this study, triangulation has been used for completeness and not to confirm or verify women's experiences (Adami, & Kiger, 2005). Interviews with health professionals have contributed to a more thorough understanding of the context in which women receive formal sources of care and contribute to our understanding of the phenomenon itself rather than confirm or negate women's experiences. Patton (2002) asserts that the question really is about what each analysis contributes to our understanding. In this study, triangulation of data via interviews with both women caregivers and health care providers was an important technique for understanding how informal caregiving is made invisible by interactions between women and health professionals and the discourses they develop mutually about women's health.

In chapter 6 of this dissertation study, I use Lipsky's framework to reanalyze descriptive data from health workers. This approach assists in understanding how women and health workers make-meanings and co-create discourses about women's health. Phenomenology continues to provide an overarching philosophy and methodology for understanding the full scope of women's experiences, where their interactions with health workers contribute substantially to both positive and negative aspects of women's experience of overall well-being. The use of phenomenology brings

a more holistic approach to understand women's experiences (not in isolation) but while acknowledging their interactions with actors who contribute to shaping women's experience.

I acknowledge that 'completely' understanding women's experiences may require a more expansive research approach such as understanding the perceptions of their HIV-positive husbands as they also shape women's experiences of informal caregiving (a limitation I note in the dissertation). Phenomenology in this study, may then be re-interpreted to include any major and close influences on respondents who are shaping women's core lived experience, how they make meanings of their life situations and behave with self-efficacy and resilience. The influence of health workers on women's experience and meaning-making is especially true in this case because health workers are perceived to hold 'authoritative knowledge' by women.

Phenomenology depends on the authenticity of respondents' experiences. In this study, I have used triangulation as a technique for completeness and to fully understand women's experiences. Neither women's nor health workers' narratives are scrutinized for counter-evidence. My approach in the final chapter where I use Lipsky's theory assists in explaining how women's role as informal caregivers are 'socially constructed' in interactions with health workers. This expands our understanding of phenomenology to include the idea that 'experiences are not created in isolation', nor are they just 'socially constructed' with an element of definitiveness but experiences are 'influenced by and shaped with' other actors.

Reflexivity.

Reflexivity is an active acknowledgement by the researcher that his or her own beliefs, decisions and position (for example- socio-economic, religious or professional position) in society will inevitably impact upon the meaning and context of the experience under investigation. Reflexivity involves the researcher going through a process of personal introspection to deconstruct one's identity and understand ways in which our biases, predispositions, cultural lenses of the world, beliefs and experiences can have a potential impact on the ways in which we attribute meaning. The researcher is responsible for an in-depth understanding of the ways in which these personal factors are similar to, or different from, the participants we engage with during the research process (Jootun, McGhee, & Marland, 2009).

Insider, outsider, or just on their side?

I believe that the dichotomy of the insider/outsider often used in phenomenological and other qualitative inquiries serves limited purpose in actual research. I had used this dichotomy to explore my position while writing the proposal for this research project and sorted factors of interest about myself that could make me an insider or an outsider to my participants.

I grew up in the city and state where data were collected and have experienced the texture of patriarchy in that part of the world. I thought that would be a substantial ground for connection with my respondents. As a young girl, I had access to everything I needed and yet I could not walk down the street outside of my house after dark, due to my parents' worry that a passerby would make lewd remarks at me. While growing up in Lucknow, I was hyper-aware of all forms of restrictions on my perceived freedom; my surroundings imposed limitations upon me and there were gender-related restrictions I

faced during my school years in Lucknow. I usually resisted them in action but not in word because they were everywhere, in the details of the norms of my family, their beliefs about what girls can or need not do, in school, everywhere. Also, I now remember that putting forward resistance to any gendered restrictions just felt like it would lead to more resistance and bring me limelight that I did not want. I was quietly looking forward to moving on, on my own path in life. Reflecting back, what may be seen as restrictions had their own advantages. While I could not drive and girls rarely played sports in playgrounds overcrowded with boys, it meant that I spent a lot of time reading - fictional and real adventures, elegant spy thrillers, books that ignited my imagination and taught me to think and write.

At the time of this research, I had found my way to things that make me feel free and had almost forgotten everything about the limitations I had felt in the past. Like most healthy human beings, I work my selective memory in my favor and indulge in feeling the freedom of today rather than reflecting on the restrictions of the past. In addition, the forms that my lack of freedom took in the past such as certain restrictions on mobility, a given framework for partnership and predefined pathways for educational choices, have now become almost irrelevant to my larger being and the purposefulness of my life. My childhood environment was not one that offered choices to girls; I had to create them to the best of my abilities and sensibilities and have enjoyed the process very much. In addition to my long stay in Lucknow before college, I had also believed that shared language would be a great bridge between my respondents and me.

The expected bases of connections held true during my data collection process. My prior stay in Lucknow and common language was a tremendous help and in fact I

cannot imagine researchers conducting phenomenological research with strong emotional dimensions in the respondents' lived experience with linguistic dissimilarities between the researcher and the research participants. Respondents talked of me as a sister and someone to whom they could open their hearts. During data collection, I took this as a huge success and as an indicator of the authenticity of my data and my research processes.

However, despite the similarities that did assist data collection, in the phase of writing and interpreting, at first, I was subconsciously more aware of my vantage point of the past few years, of my education and exposure to life. Combine my vantage point with my selective memory of my troubled feelings as a girl child growing up in Lucknow (that I now remember) and I could only look upon the disadvantages of my respondents. There was therefore a considerable amount of remembering and forgetting that happened for me as a researcher and as a woman during the research process. My forgetfulness of my past has been purposeful. It does not empower me and it does not assist me in realizing who I really am. I truly believe that 'now' is all I have and live by the '*Power of Now,'* I learned from one of my favorite philosophers Eckhart Tolle. However, that forgetfulness overshadowed my work temporarily during this research process and brought me to a point where I was overly focused on the disadvantages of the participating women. This was reflected in the earliest drafts of this dissertation. Conversations with my dissertation advisor and committee members assisted in some remembering of my past experiences, and my journey to who I have now become.

Eventually, I remembered that I had found moments of freedom, moments of tremendous empowerment and joy even in the constraints that I experienced as a young

girl growing up in Lucknow. I remembered that in this city, I had been a somewhat restrained teenager, questioning everything in my mind but not really knowing what to do with all that questioning. Yet, I had also had breakthrough moments that had carved out my future steps. When I remembered those moments, it was as if I had allowed sunlight through a window and I could see my respondents again as everyday women who made choices even where few existed. They were working to find their purposefulness and their identity within whatever framework was available to them. Since then, I found myself not as an outsider with higher education, or HIV-negative health status, or an insider knowing their city and language but as a woman who is on their side. I realized we shared the experience of being women- this allowed me to learn, to teach, to be and to see the strength and light in them. Viewing my participants in this new light led to understanding their challenges from their point of view such as their search for authoritative knowledge on the subject of HIV/AIDS and what they would and would not tolerate within the gendered framework of life available to them.

How would this study be different if it was not me?

There are varied ways this study would be a different study if it was carried out by another researcher. For example, other researchers may be more interested in understanding family economics and women's role in the division of resources as it pertains to their caregiving labor. I see this as a probable line of inquiry because women in the west have found professional space as workers in the market economies. Therefore, they may make greater financial contributions to their families and consequentially may have greater decision-making power in the distribution of family resources, including the allocation of resources (food, time for rest and entertainment) for

themselves while women in developing parts of world are still working their way towards employment opportunities. Quantitative and medical researchers may be more interested in teasing out the exact relationship between hours and types of caregiving labor performed and the variety of effects on the ailing woman's health. For example, women who are merely action takers in their caregiving role may have better mental health compared to women who are deeply affected by stigma and discrimination and who worry for their HIV-positive partners and children. In short, my insider and outsider status combined, rather than separated, create a position for me to interpret my data in ways it is likely few would be able to use- a position that may allow new perspectives to reach the western research literature while making recommendations for new policy in India.

Audit trail.

An audit trail was used as a tool for rigor in the study. This included a description of all steps involved in the research process. The audit trail manages threats to trustworthiness by detailing the research process and making explicit every minor or major decision made by the researcher during the research process (Shenton, 2004). This makes it possible for another researcher to replicate a similar study. An audit trail was conducted by maintaining a journal in which all research-related and fieldwork decisions were documented along with the justifications for making those decisions. These were shared with my dissertation supervisor and I received consistent feedback on my fieldwork processes.

Peer debriefing and member checking.

Peer debriefing involves engaging in dialogue with peers and colleagues outside of the research project on which one is working. Ideally, these colleagues would have experience in the methods, substantive area under focus or the target population. The strongest peer debriefing was offered by my dissertation supervisor who questioned and challenged my assumptions and analysis. Conversations with other committee members were insightful in broadening my understanding. They assisted me in looking at aspects of the phenomenon under study that I was missing. Conversations with my peers in the doctoral program and audiences at national presentations of aspects of the study also assisted in honing my analysis.

Member checking.

Member checking refers to respondent validation**,** which allows participants to review findings from the data analysis in order to confirm or challenge the accuracy of the findings. It helps determine if the findings as presented by the researchers are actually representative of the participants' views and experience of the phenomenon under study. Towards the end of data collection, I was able to meet again with three women respondents and two health workers (approximately 10% of the respondents) for member checking of my analysis at that point. I shared a few verbatim summaries of the transcript and interpretations and asked the participants if they found my reflections to be consistent. Women agreed with my analysis, but also added more to it; for example, they reminded me that they experienced consistent pressure from family members, particularly in-laws, and that those pressures contributed to their actions as caregivers.

Women added that while they believed that people discriminated against them based on their HIV-positive status, they believed that internalized stigma and women's

personal decision to not share their HIV status played a more crucial role in the way they experienced stigmatization. Participants in the member checking brought an additional dimension to understanding stigma and discrimination by emphasizing the role of self-stigmatization. Women agreed and corroborated the various factors that propelled them into their caregiving role were not stand-alone factors but worked together (such as love, responsibility and gendered socialization), which strengthened my analysis.

Chapter 3.
The search for authoritative knowledge and self-efficacy: Women's caregiving trajectory

Overview

This chapter presents a theorized trajectory of the experiences of wives living with HIV, as caregivers in Uttar Pradesh. Tracing the circumstances and the chronological stages of caregiving, this trajectory is synthesized from intensive interviews with women where they identified the specific challenges faced at each stage of their husband's illness. The use of 'stages' for the organization of themes fits with phenomenological emphasis on examining events as temporal and contextual. I use Jordan's concept (1997) of 'authoritative knowledge (AK)' and Bandura's (1997) concept of 'self-efficacy' to explore women's everyday experiences as they move through the chronology and severity of their own and their husband's illness.

The concept of authoritative knowledge pertains to decisive and trustworthy information as it rests in a person in a position of authority or as a knowledge base on which decisions can be made (Browner, & Press 1996; Davis-Floyd, & Sargent 1997; Jordan 1997; Whitley, 2009). Jordan describes AK as "rules that carry more weight than others either because they explain the state of the world better for the purposes at hand ('efficacy') or because they are associated with a stronger power base (structural superiority), and usually both" (Jordan, 1993, p. 158). AK is also situational and rooted in local communities and cultures. In this chapter, I examine women's hopes, needs and search for authoritative knowledge as caregivers.

The second concept of self-efficacy implies one's understanding of one's own influence and control over tasks and events in one's life. Self-efficacy refers to peoples'

beliefs in their ability to impact events and circumstances and it plays an important role in determining the extent to which people persevere in the face of difficulties (Bandura, 1997). Bandura (1994) describes four central sources of self-efficacy. First, experiences of success or 'mastery' that enhance a person's belief in themselves to accomplish a task; second, 'vicarious experiences' through observation of role models; third, 'verbal persuasions' where people may be reminded of their ability to accomplish a task by others; and fourth, people also use their own emotional states as cues of the measure of their abilities, where stress is interpreted as a sign of diminished abilities and positive mood is perceived as enhancing self-efficacy.

From the women's narratives, I identified three major stages of caregiving, along with their sub-themes. The first stage of caregiving is represented by the theme of 'Walking in the dark.' This theme represents women's initial struggles before they themselves and their spouses were accurately diagnosed with HIV. This theme provides the background on women's information levels, initial perceptions about HIV, prior knowledge about health services and their experience with health providers before the HIV diagnosis was made. This theme includes the following subthemes- Mayhem, and the Pain of Not Knowing. The second stage of caregiving is represented by 'Caring every day' (with subthemes of 1) worrying and doing, 2) caregiver's dilemmas and solutions, 3) husbands as caregivers, and 4) unrequited care. This stage of caregiving represents the everyday challenges faced by women in caring for their HIV-positive husbands and children, and identifies the emotions associated with receiving or not receiving care from their husbands, the primary care recipients. The third stage of caregiving is represented by the theme 'Losing the labor of care' when women were

faced with caring for their dying husbands. These three stages and the subthemes represent the nuances of the lived experience as a caregiver over time.

Walking in the Dark

In this section I uncover the themes of 'Mayhem' and the 'Pain of not knowing' that together comprise the experience of 'Walking in the dark.' 'Mayhem' represents women's confusion and distress when they had to visit various health care providers, make sense of what they were being told by the health providers, and make sense of their own and their husband's physical symptoms of disease. The 'pain of not knowing' describes women's lack of information about HIV and their emotional burden as they took personal responsibility for not having access to information about HIV.

Mayhem.

Some of the most vivid memories women had of their caregiving tasks are from the initial phase, before the couple was diagnosed with HIV. In most cases, the husbands were first to show symptoms that were often initially ignored until their condition worsened. At the worsening of the husband's health, women were alarmed and visited multiple hospitals with their husbands, searching for answers to their ill health. For most respondents, their husband's and their own diagnoses were delayed, even after they were experiencing severe symptoms. *Mayhem* represents a phase of confusion and distress when either one or both partners were experiencing physical symptoms of ill health such as regular fever, chills, severe fatigue, or body aches. Women traveled among health care providers hoping to find answers to their questions about the couple's health and to find relief. In this phase, women's concern as caregivers was related to finding out what it was that had happened to their husband and getting him connected with appropriate

health care. Individuals generally tend to use a combination of publicly available information on a topic, and more personal resources of information such as information gained from informal support networks including family and community members, as they explore subjects of importance to them (Kaye, 1995). Respondents in this study had almost no access to any web-based information, although they had access to television as a source of information. Access to information on a subject that is directly affecting an individual's life, such as being HIV-affected, is desirable for the human purpose of having control and impact over their life circumstances. In this stage, women are already searching for information that is legitimate, enduring, and trustworthy or "authoritative" (Jordan, 1997). Uma, who is now widowed, recalls her early days prior to being diagnosed;

> In the beginning, we did not know that we have this disease so when
> my husband fell very sick, he became very serious. Then private hospital
> and Mission hospital and all these big big hospitals …I got tired of showing
> him around and getting medicines for him.

For some women, the fatigue of repeated visits to the hospitals and health care centers worsened when some of the health care providers were unresponsive. Women met with health care providers who did not want to consider the husband or couple for treatment, either because they were ill equipped for HIV treatment or because they expected a positive diagnosis of HIV and therefore did not want to see those patients. In this phase, women felt helpless because they had little understanding of HIV and did not understand why they were being met with health provider's resistance. The sense of 'mayhem' was exacerbated through experiences with health care providers who provided inaccurate diagnosis or treated women poorly. Sonam recalled her experiences and

described how she felt when some doctors would not attend to her husband and insisted on referring him to other clinics.

> I felt very bad but what could I do? … He was very serious so I took him to Sultanpur and then to Faizabad… The doctors there did not look at him… They did not see him… He did not get better… Then we went to Faizabad and he got admitted in the district hospital… He was very sick… The doctor told me to take him to Ram Manohar Lohia... There he will get medicines… Then I got him here.

As women hustled among health care providers, they often had little support from parents, in-laws or other family members in the process. Rakhi recalls taking her two young daughters with her to all the hospitals and clinics she visited, because her in-laws would not assist her with childcare or other aspects of her situation. She remembers

> I would take him (her husband) to Merath for treatment. For some time, he was very very sick. He had tuberculosis and he was very weak. …I would have a bag with me and the two children. No one in my in-laws' family ever helped me. I would take both my children and my husband out in the sun...I did everything I could… Every moment I helped him. Every month he would get money from my parent's house and me.

In addition to accompanying their husbands to various hospitals and clinics, at this stage women also begin to make financial arrangements to afford the various health care costs. Apart from the physical labor of visiting hospitals and clinics and trying to understand what was going on with their body and health, most women faced financial distress in this phase. Some of them sold off their gold jewelry, a traditional form of women's wealth in India, usually gifted to them at their weddings. Alternatively, they

borrowed money from their parents. Those who did not have this support, borrowed

money from a friend or other relative with the promise of returning it as soon as possible,

personally going into debt to afford the costs of treatment. Here we see the first glimpses

of women's self-efficacious behaviors when they make decisions for their family's well-

being and health in order to affect the situation. Women were in charge of their family's

health and took decisive action to sell personal items such as gold jewelry to afford the

costs associated with visiting multiple health providers. Such actions were sacrificial,

and came at the cost of personal depletion of resources.

In addition to financial distress, several women had difficulty understanding the

doctor's prescriptions, hospital rules, and disease related information. Rani, now an older

widow, recalls "I went to Barabanki… All kinds of hospitals… I am not even educated,

so (it was) difficult to understand what is going on." Women's lack of information and

literacy exacerbated their feelings of being overwhelmed and helpless. Most respondents

in this study had low levels of general literacy and approximately one third of the

respondents lived in rural areas or townships with poor access to information and

education about HIV. Studies in India and other parts of the developing world indicate

that poor health outcomes are often associated with poor general literacy and education,

and poor health literacy (D'Cruz, & Shankar, 2013; Harrison, 1997). Women were

distressed about their inability to find answers to their own and their husband's ill health.

When this was accompanied with financial difficulties affording health care, health

provider's ill treatment, and inability to comprehend health information, the experience

together comprised 'Mayhem' in the phase prior to accurate diagnosis of HIV.

The pain of not knowing.

In resource-constrained environments such as Uttar Pradesh, women's access to information is often limited by their low levels of educational attainment and little exposure outside the home (Basu, 1992). The gender gap in literacy levels is large in Uttar Pradesh (McDougal, 2000) and lack of access to health information and general health awareness among women, is much worse than for men (Stephenson, & Tsui, 2002). Although this study is conducted in north India, evidence from Southern states in India suggests that women, especially women living in rural areas, have worse levels of general literacy and health literacy (Navaneetham & Dharmalingam, 2002; Pallikadavath, Sanneh, Mcwhirter, & Stones, 2005) as compared to women living in urban areas or men. Even when women have heard about HIV, they do not always accurately process the information about channels of transmission or precautions for HIV prevention (Pallikadavath et al., 2005). Several respondents in this study had never heard of HIV/AIDS before they were tested themselves. Women who had heard about the disease knew that having the disease came with serious negative connotations. For example, women associated HIV/AIDS with a blanket understanding that it happens to 'bad people' who have 'bad behaviors.'

When Manju found out that she is HIV-positive, she felt confused and scared. Although she confessed not knowing much about the disease, she knew that it is 'terrible,' which usually implied non-normative sexual behaviors such as extra-marital relationships or non-heterosexual relationships. Women vaguely knew that being HIV-positive meant something that led to serious social implications, beyond her physical health. Manju related: "I felt nervous, I felt very nervous…I had never known about it. I felt that, from where this terrible disease has come to me?" Part of the reason for the

distress women experienced was associated with not clearly understanding the symptoms or the channels of transmission for the disease. Women attributed the lack of their knowledge about HIV to different factors associated with their life situations. The language women used demonstrates a sense of personal responsibility for not having HIV information. Neelam attributes her lack of knowledge about HIV to being a housewife who spends most of her time at home. She thinks that if she worked outside she would have known better.

> Because I am a home maker… I did not go out of home. When I will experience
> the world then I will realize … If I keep sitting at home then nothing will happen.
> I did not have any information when the situation was upon me.

Kaniya thinks that she did not have information about HIV because she lives in a village. Because she was tested in a district hospital, she believes that if she lived in the district or township area, she would have had information about the disease. Kaniya shares,

> I did not know what is HIV positive. In village, there is so much we do not know.
> There are Asha sisters (community health workers for maternal and neonatal
> care), so when I got to know when I got myself tested at the ICTC (Integrated
> Counseling and Test Center) in the district hospital, then it came out that I am
> HIV-positive.

Some women were tested very late for HIV. Sakeena's husband was tested for various diseases but not for HIV in the district hospital where he was seeking treatment. His health deteriorated rapidly and he was found to be HIV-positive a few months before his demise. Sakeena was pregnant with her son at the time and she did not receive

adequate prevention from mother to child medications, due to a non-institutional

delivery. Sakeena explained:

> At Akona, he got his blood tested… No major disease came out… We did not get
>
> information for a while that he has this disease…I was pregnant with my younger
>
> son that time, he had this disease. He (the child) died and one year later my
>
> husband also died.

> Respondents in this study felt a deep sense of regret in not having access to the

right information at the right time. They perceived the rapid deterioration in their

husband's health or his demise to be a result of the lack of information, to which they

should have, somehow, had access. This deep sense of personal responsibility for 'not

knowing' resonates in Usha's words as well. She is now widowed and toiled to ensure

her husband's well-being while he was alive. During the interview, she recollected

> I took very good care of him… I even used to help him in the toilet all the time.
>
> He used to lie in the bed all the time…. I did not have any information. He was
>
> not taken to the right place at all from where he could have got help to get better.
>
> When I should have taken him to Lohia, I took him to Balrampur hospital. Having
>
> no information, that is why all this happened.

> Another woman, Noorjahan shared
>
> I felt that… I wished that he had got his medicines and I had got the medicines on
>
> time… I wish I had some information. The behaviors that were supposed to be
>
> enacted were not enacted.

Before getting diagnosed, 'the pain of not knowing' was exacerbated by feelings

of personal responsibility. Uma recalls "I did not know…. He felt that he has some

disease but I did not have any information." Women felt that it was their duty to have the right information and they felt responsible that they had not been connected to the appropriate services, early on, at the onset of symptoms. They expected themselves to know, despite the fact that much of the literature on health awareness in India, and especially rural India, indicates that women have little access to health care information (Banerjee, Andersen, Warvadekar, Aich, Rawat, & Upadhyay, 2015; Das, & Sarkar, 2014).

Women were essentially walking in the dark, with little sense of what the physical symptoms of the disease meant or which health provider they should visit. In this phase, women's lack of information translated into women's inability to exert control over their situation and circumstances. That, in turn, led to the accumulation of negative emotions in the form of general gloominess and anxiety or extended periods of sadness. In addition to experiencing negative emotions, women simultaneously felt a deep personal sense of responsibility for their husband's and children's health, despite living in family and community environments where HIV related information was not available to them. Women's personal sense of responsibility resonates with their human need to want to exert positive control over their own and their spouse's life situation and the desire for self-efficacious behaviors. Women's sense of wanting to exert positive control over their spouse's health as a wife and caregiver was also societally expected to allot women honor and worthiness for being able to care for their husbands, contribute positively to their partner's health, or save his life.

Caring Every Day

The second stage of caregiving 'Caring every day' refers to the everyday practices, dilemmas, and emotional states of women as they transitioned into daily caregiving. The themes of 'worrying and doing,' 'caregiver's dilemmas,' 'husbands as caregivers,' and 'caregiver's regrets' together form the broader experience of caring every day.

Once couples were connected with the appropriate health care provider and had an accurate diagnosis, they returned to their routine life, knowing that adherence to their medication regime and visiting the Anti-Retroviral Therapy (ART) center and the Care and Support center (CSC) were now an integral part of their lives. Women returned to their everyday lives, sometimes needing to tolerate the side effects, commonly experienced at the beginning of the ART regimen. For some women, the side effects from the ART regimen became a consistent part of their lives. In this phase women were responsible for caring for themselves, but their role performance as caregivers gained prominence due to the priority they placed on their partner's or child's health.

Once the accurate HIV diagnosis had been made and the couples were connected with appropriate health care services, women started to feel some sense of their ability to exert control over their circumstances in their homes. Perhaps, women's experience of getting connected to the appropriate health care provider and getting an accurate diagnosis of their own and their husband's health status constituted an experience of mastery (Bandura, 1997) for them as a wife and caregiver. This sense of success perhaps enhanced women's sense of self-efficacy. Mastery constitutes the experience of achievement in an arena towards which one has been making an endeavor (Bandura,

1997). With one experience of mastery behind them, women now seem to exert more

control over their environment in three important ways that include an emotional

response, an

 action-oriented response and an intellectual response to their life situation.

        First, their feelings shift from feeling a general sense of helplessness and

anxiety to feeling worry about the well-being of their family. Women used worrying

about their family as an emotional response that put them in a position of being in charge

of their family's health. Worrying is used by women as a way of being the emotional

leader of caregiving in their homes. Women's emotions in supportive relationships

shifted to feelings of less concern and greater stability. However, in almost all cases,

women

exerted emotional control over the situation by becoming a worrier- someone who is in

charge of her family's health. The second phase is an action-oriented response where

women take concrete actions to ensure the well-being of their family members and begin

to manage the care recipient's daily schedule of medicines and visits to the physician.

The sub-theme of 'Worrying and doing' represents the first two responses. The theme of

'Caregiver's dilemmas' represents women's intellectual response while identifying

 problems and generating solutions while defining their boundaries as caregivers. The

final sub-theme of 'Husbands as caregivers' pertains to women's experience of receiving

or not receiving care from their care recipient and women's thoughts and feelings about

their relationship with their care recipient.

        Worrying and doing.

Many women found themselves engulfed by a chronic sense of worry, focusing on their husband's and their children's health. Neelam recalls times when her husband was very sick and she could hardly eat or sleep because she was so worried about him. Even though doctors had explained to her that the couple must have their medicines regularly in order to survive, she imagined that there must be someone who could offer a complete cure for the disease and thought about how she could connect her husband with this entity.

> When he was sick, then I could not think about myself. I would eat in 3-4 days… I couldn't eat food… I used to be so worried… I would think 'where I should take him for cure forever'… I could not think of me, I only thought of him.

Worrying emerged as women's way of exerting emotional control in their role as caregivers. Rakhi recalled during the interview,

> I started having medicines since the birth of my second daughter… My CD4 came down a lot and I was having tension about him. Living in tension… I would not eat much so then my CD4 went down.

Neelam makes it a priority to ensure that her husband gets his medicines on time. She explains and consoles him from time to time about the importance of the ART medication, about which she has learnt from a counselor at the ART center. Along with becoming emotional worriers for the health of their husbands and families, women began to define and reinforce their roles as caregivers by taking action-oriented control over their husband's health. Women monitored their partner's ART adherence and managed their nutritional and other health needs. It appears that women's sense of personal responsibility was now extended towards achieving perfection as a caregiver.

Neelam describes how she cares for her husband.

> I do not have to eat medicines yet, but I give him medicines, when it is time for him to eat medicine, I remind him... CD4 count tests we get, when he comes back from home I ask him to rest… If you do not rest you will fall sick … I tell him…

Neelam is very particular about her husband taking his medicines on time and attends to his nutrition, she explains:

> If medicine is left for 4 days also I coax him to go and get medicine… I coax him, I follow up with him to go and get it done… With myself, I also get it done for him… CD4 test every 6 months… I remind him… CD4 test date is written (shows me the book) … When to get test and when to get medicine… And when we go to the ART center, it is written there what his weight is... So, I get to know how his health is… I get to know by weight… If his weight has fallen then I know his health has fallen… I keep thinking what should I feed him so his health improves.

Neelam keeps an extremely vigilant eye on her husband's food, nutrition and his weight. She stresses over every detail to monitor his health, while she lives with HIV herself.

Women used worrying as a caregiver and their actions geared towards perfecting prescribed gender role as an exemplary female caregiver. In the phase of 'caring every day,' women begin to exert control by caring in a disciplined way for their husbands and children, ensuring timely medications or regular visits to the doctors. Even in circumstances where women received assistance from their partners, they saw themselves as the emotional leaders of caregiving by worrying or managing caregiving practices. As

the data demonstrate, at first, women use their new situation in life as a spouse to an ill husband as an opportunity to consolidate their role as a caregiver.

Caregiver's dilemmas and solutions.

Although most respondents' demonstrated worry for their husband's health, they sometimes felt torn between taking the time off to rest or caring for their husbands and children. This feeling of being torn led to a moment of reflection, when women pondered over their own health in the midst of caring for their family members. Nevertheless, most women overwhelmingly made the decision to ignore their symptoms and need for rest and continued with their caregiving schedules. Some of the respondents had to continue providing caregiving tasks for the entire family, including in-laws or other family members, despite challenges of their own health. Swagati is currently married and she has to care for her husband and her son, who are both HIV-positive. Her previous husband also had AIDS related health complications. Now, in her new family, she continues to be the primary caregiver. She has a lively demeanor in the beginning of the interview but gradually she opens up her feelings of sadness to me.

> But everyone's caregiving… Cooking and feeding the children and doing things
>
> for them... All this work… But when I am sick I do not have the strength to do
>
> anything… Then I have this dilemma… What to do... I will take some painkillers
>
> and start working again.

This dilemma that women shared provides insights into the tensions they felt on an everyday basis, as they had an awareness of their own need for rest and care. An important shift emerges in women's trajectory as caregivers when, despite feeling the 'pain of not knowing' and an awareness of not having access to HIV information, women

begin individually to define their boundaries and practices as a caregiver as a way of consolidating their caregiver role. This process of defining their caregiving actions begins with them feeling a dilemma about what to do and not do as an HIV caregiver and leads them to find solutions by building individual boundaries as caregivers. Women have two types of myths or perceptions about HIV. First, women fear that proximity and physical contact with the care recipient can lead to a worsening of their own health. Second, women believe that HIV is something that happens to bad people with bad behaviors and that society punishes them with ill treatment. Women view the above-mentioned perceptions as problems they have as a caregiver and cope with these problems in two distinctive ways. Solutions to both problems are used as opportunities to define and consolidate their role a caregiver.

Women wondered about the appropriate amount of physical contact and the mixing of bodily fluids or food, with their husbands. In most cases, women had already been diagnosed with HIV but since their husbands had more severe symptoms, they were often perplexed about how they could nurse their husbands while keeping themselves safe. Each one defined their boundaries differently, including what they would and would not do. For example, Kaniya is now widowed, but she explains that she was truly in love with her husband who loved her back ardently and yet she followed some rules while caring for him.

> I would not give him my food… And not eat from his… I would sit next to him, feed him, take care of him… I did everything but his food I did not eat... Rest everything I would do… Bathe him, clean him, take care of him, change his beds... Only I did not eat from his food.

Rajvati lives in a village, a few hundred kilometers from the ART clinic in Lucknow. Rajvati has two HIV-positive children, aged 5 and 10. She is a farmer with a tough disposition towards life and spends hours working on the field every day to provide for her children. She shares with me that she feels extremely angry at her husband for ruining her children's lives and her life, along with his own. Although she takes good care of her husband, she feels emotionally distanced from him and sounds resigned about her situation. She prefers to maintain physical distance from her husband for fear of worsening her own health. This sense of resignation mixed with anger was present in quite a few of my respondents. 'Caregiver's dilemmas and solutions' represent a shift when women begin to create their own caregiving identity by defining the terms of their caregiving role through an examination of the appropriateness of contact they should or should not maintain with the care recipient. An examination of this problem allows women to follow the clues in their immediate environment and their own feelings about what is appropriate, and what is not appropriate for them to do, as a caregiving practice, keeping in mind their own self-preservation. While Kaniya did not share food with her husband, Rajvati maintains physical and sexual distance from her husband.

Rajvati told me

> I give him a massage on his hands and legs… His hands and legs pain all the time, wash his clothes but I do not spend much time with him… I do not sleep next to him much. Maybe after 4 days, sometimes 8 days… I give him medicines, food, water… In the morning, I give him breakfast.

Rajvati does not share the bed with her husband as frequently as she did before, as a way of protecting herself from worsening her health. Rajvati's assertion that she does

not like to spend time with her husband with the same frequency as before is reflective of her feelings of fear for her own health as well as her feelings of anger and emotional distance.

Some other women received conflicting advice from family and community members about what contact they should maintain with their care recipients, making them feel confused and guilty about what they should be doing. Zeenat describes her experience

> He would just keep lying… All the time… It was a lot of work… Family members said… To keep his cups and plates separately and to not talk to him and not eat from his food... So, for some time I did that, but then I could not… And then I could not stay away from him... I did not think that if he is sick I will also get worse from him… I did everything for him.

Like Zeenat, several women received advice about caregiving practices they should be following. Despite receiving different advice from different family and community members, women ultimately deferred to their own sensibilities and did what felt appropriate to them. As a solution to the second problem, that HIV happens to 'bad people,' women define their role as caregiver and build the caregiver identity by <u>not</u> distancing themselves from their husbands as care recipients. This is because if women distanced themselves from their husband and care recipient, her distancing would reinforce the idea that he is a 'bad person.' This is women's way of not contributing to the ill treatment with which family and community members may treat her husband due to their HIV-positive status. In this way, women separate themselves from the crowd of

people who would ill-treat their husband based on being HIV-positive, and instead reinforce their positive role as a spouse and HIV caregiver.

At this stage of caregiving, women bring focus to a realm of knowledge (information about HIV and caregiving) to which they actually have had little or no access. Accurate information and the trust in the accuracy of information that one receives can generate feelings of certainty. Women were in a situation where they could not access this sense of certainty, but by way of utilizing their ability to create an impact on their life situation or practicing self-efficacious behaviors, they begin to generate practices that serve them. In this way, women generate certainty in their immediate environment where none exists and trust their own authority in their knowledge about caregiving practices that will serve them. I call this emotional and mental process 'environ-info' where women begin to notice and use the clues in their immediate environments and their feelings, to assert individual control and generate individually driven, time constrained, micro information, where the broader context does not support the subject on which they need to focus; in this case, environ-info guides women's practices as an HIV caregiver.

The process of 'environ-info' then must be understood as a mental and emotional process where information is generated and created on a moment-by-moment basis. The decisions generated by environ-info are highly contextualized because women created this information to assist with the issue at hand, it was flexible and could easily be changed should there be more definitive information on the subject. The idea of 'environ-info' is in line with Heidegger's (1996/27) assertion that 'entities are grasped in their being as presence' (p 47). This then implies that experience is in fact embedded in

the present moment, captured in one dimension of time and reality. Thus, in Heideggerian terms, existence can only be understood in one point in time, a moment that encompasses the individual's past, present, and future.

Zeenat is now widowed and she takes care of her HIV-positive child. She recalls feeling a push and pull between what her family members told her to do and what she thought was the right thing to do, which in her perspective was to not distance herself from her husband. Although 'environ-info' is flexible, in this moment, women find their 'authoritative knowledge' within themselves. The building of 'environ-info' seems to lend itself to the constitution of authoritative knowledge about informal care provision in the moment. Despite counseling at the ART center, once women returned to their homes from the clinic, their environment and the advice of the family and community members exerted influence over their caregiving practices. Despite the influence of such advice, women predominantly understood and carved out their own solutions to their problems as a caregiver and defined their boundaries individually.

Women's dilemmas that arose during caregiving, their search for accurate information and authoritative knowledge on the subject must be seen in the context of the myths surrounding issues of sexuality and HIV/AIDS in India, and especially Northern India. Some of the common myths include ideas of transmission through handshakes, mosquito bites and living together (Sawal, Hans, & Verma, 2015; Puwar, Patel, Vyas, Oza, & Kapoor, 2015). Over time, women who connected with a community health care worker or attended regular meetings at the positive people's network had their questions answered and felt more relaxed in their caregiving roles. Kaniya explained:

Everyone would say … 'do not eat from his food,' 'do not drink the water he touches,' 'do not use his plates.' Now slowly, because of Asha bahu (female community health worker), I got information, then there was no problem… Else before it was a lot of problem... He used to sit far off… He used to cover himself and move out… That he has AIDS and he has TB… In that situation… I was very troubled.

It appears that women who were able to connect repeatedly with community health workers felt more informed and exerted positive control in their role as a caregiver, over a period of time. In the following section, I will discuss the role of husbands as caregivers and women's experiences and texture of relationships with their husbands as care recipients.

Husbands as caregivers.

In the extended phase of caregiving that required every day care for both partners, respondents described their relationships with their partners and their thoughts and feelings about their partner's caregiving actions or lack of actions towards them as a caregiver. Women described the participation and assistance of their husbands in their daily caregiving tasks. Husbands' caregiving roles included being emergency caregivers, being every day, consistent, action-oriented caregivers, or being those who offered almost no assistance. The themes of 'exigency husbands', 'everyday husbands,' and 'unrequited care' comprise the larger theme of 'Husbands as caregivers'.

A mapping of the self-adopted caring roles of husbands and the quality of spousal relationships as revealed by the narratives of women, demonstrated an association between the two. Women in distanced and resigned or emotionally abusive spousal

relations received less assistance from husbands and experienced relatively higher levels of strain and burden as compared to women who were in healthier relationships with their partners.

Exigency husbands. 'Exigency husbands' represents partners whose presence as caregivers was experienced by women in their lives only when they were severely sick or they had an emergency in which they could not function without any external help. Rajvati initially portrayed a positive picture of her husband's helping role, however on probing further, she revealed that the only time she received any assistance was when she was in dire need.

> Hmmm… (Thinks for a while) … What do I say… He does not give me medicine or anything, but if I am very very sick he will get me injections and then I may get better.

Rajvati was one of my respondents who were bearing a large share of caregiving responsibilities for their HIV-positive husbands and children. Begum Zara also lives with a husband who helps only when she is extremely unwell. On being probed about what kind of assistance she had, she revealed that "Yes, when I fall very sick, then my man and my daughter, they do for me." Women who did not receive any assistance from their partners often developed feelings of resentment and anger for being left with no option but to do all the housework and the caregiving work. Begumsharara complained during the interview.

> Sometimes I am very angry, that you should at least do your things with your own hands, I do not feel like doing anything … So, I grumble… Yes… And sometimes

> when I am very unwell then he may do a few things on his own, wash his (own)
>
> clothes.

She hopes and expects that at least her husband should do a few things for himself, such as washing his own clothes when she is ill. In her tone, I felt a sense of helplessness and feelings of anger. She seems to want to rest and complains about it, but continues to receive help only when she is extremely unwell. Women expected appreciation and reciprocity from their husbands for consolidating and fulfilling to the best of their abilities, their role as a good woman and wife who is a good caregiver. When this expectation for acknowledgement goes unmet, it often led to fueling feelings of anger.

Everyday husbands. Some husbands provided help on a consistent, every day basis. Women who received every day care were usually in healthier relationships with their partners as compared to women who were not. Nazma is in a supportive relationship with her husband. She shared with me that no one in her husband's family has ever ill-treated her due to her HIV status and they can sit, talk, and eat together as a family. Even though she does a lot of caregiving work for her husband, she also feels that she receives sufficient help from him.

> For me, he will heat water, food, he will feed me with his own hands... We take
>
> care of each other, we live together, after the disease happened… Since then we
>
> are even more in love.

Nazma, talked about receiving care and support from him and falling more deeply in love with her husband. Although this phenomenon of falling more deeply in love after being diagnosed with HIV was not predominant among my respondents, a few women did feel as if they had found a new purpose in life, to support each other.

Unlike Nazma, Jhilmil has been unable to share her health status with anyone in the family except her husband. Jhilmil explained to me that although she takes her ART medicines regularly, by evening every day she gets a fever because of the work she does. She also cares for her HIV-positive young daughter. She perceived being free from doing things for her husband as an important help from him.

> My husband is such that he does his own things on his own… His clothes and all ... He takes care of himself, I don't have to do much for him, only for child and keeping track that meals are timely… That is what I do. If I feel very sick then my husband does that too.

Jhilmil's perception of receiving help for herself when her husband is doing things for himself, speaks to the predominant roles that govern women's lives. In a society where most women are expected to complete tasks for each family member, Jhilmil perceives her husband's actions of taking care of his personal tasks, as an important help to her.

Although women were the predominant caregivers, when their partners were comforting and solace-giving, it made a difference to how women experienced their everyday lives. Many of my respondents faced immediate blame for being HIV-positive, from their husbands, in-laws, or other family members. In this common context, not being blamed but instead comforted in their everyday lives made a critical difference.

Dolly said:

> They did not say anything, my husband… He did not … He said with love only that… It is just a virus and it may have come through the needle… He asked me not to take any tension.

Her husband's support made a difference to how Dolly processed her life situation and it affected her sense of well-being positively. She further narrates:

> I was taking too much tension before this, he told me not to take tension. That it is just a virus, it is not a big illness… That is why now I am more comfortable.

Although not all men who were solace providers were also 'doers,' women who could openly talk about the disease with their partners felt motivated and supported in their everyday caregiving tasks. Jhilmil talked about how she is supported by her husband:

> Now my husband is so nice that I do not have to worry about anything. He keeps explaining to me that I do not have to worry about anything… He says… "Do not think about the disease … Do not think how you got it, how we will live, how life will go by," …. He is there.

Women who were being supported, either through the verbal or action-oriented support of their partners or both, seemed to experience lower levels of strain and greater ease in performing their roles as caregivers, mothers, and wives.

Unrequited care. Some respondents expressed a deep sense of regret about not being appreciated or acknowledged for their efforts during phases of intense caregiving, leading to feelings of loss of emotional labor, for which ideally, reciprocity was expected from the care recipient. Asha believes that she played a major role in her husband's survival, nursing him back to health, and in fact believes that he is alive today because of her. Today she feels that now that he is healthier, he has forgotten her role in his survival.

> Even today my husband does not understand the ways in which I have supported him and the ways in which I have brought him from that condition to his good

condition today. He is so much better today because of me… I am not able to

forget those times. It does not seem anymore that he was that sick ever… When

the time is gone by, one can look back and understand and remember. But him...

He will not understand.

After Asha's husband recovered, she expected a reversal of roles. She expected

more of his participation and leadership in managing the household and a more active

role in the management of the disease but she finds herself in a position of responsibility

towards him, her children, and herself, that is a burden to her. She tells me further "today

he is better, but even today…. Everything is up to me, it is all up to me".

Rajvati described to me a deeply personal moment when her partner had asked

her for forgiveness, confiding in her about his visits to commercial sex workers. She

recalls that he had cried his heart and soul out, "He kept crying before me that he has

made a mistake… He kept crying." She describes this moment with a deep sadness but

then fast-forwards her narration and goes on to share how she feels today.

But now he is better… He does not cry anymore… I do not say… No… I keep

caring for him… He will complain that his body is aching so I will put oil on

him… Caring for him does not mean anything to him.

It is well established that reciprocity or mutuality in caring relationships, and the

caregiver's preparedness for caring, have the effects of reducing feelings of role strain for

the caregiver (Archbold, Stewart, Merwyn, & Harvath, 2007; Carruth, Tate, Miffed, &

Hill, 1997; Reid, Moss, & Hyman, 2005). Women who felt that their role as caregivers

did not mean anything to their partners had several unmet emotional needs in their

relationship that surfaced as regret and anger in their role as caregivers. They had

emotional needs to be seen, appreciated, and understood for their critical role as the caring and nursing wives.

Losing the Labor of Care

Caregiving labor intensified a few weeks or months before a husband's demise. In this stage, caregiving wives worked harder to save their husband's lives, often under distressful conditions including poverty, absence of any other family members for support, and lack of information about caring for a person on deathbed. Respondents who nursed their husbands on their death bed had no understanding of end of life care, concepts of pain management for the dying, the need for a peaceful environment, fresh air, and managing the feelings of the dying member; indeed, those expectations were perceived as burdens (Funk et al., 2010; McPherson, Wilson, & Murray, 2007). In a few cases, the diagnosis of HIV had been so delayed that the doctors gave up on patients and asked the family members to take them home and arrange for their last rites. In the interview, Noorjahan, a young widow, shared her story with a tremendous sense of regret and feelings of loss. During this phase, her husband's survival was her sole priority and after all her efforts to nurse him back to health, his demise was not only a personal loss but also felt as a loss of her efforts and her caregiving labor.

> My own care, I could not do much. If he had become better, then I would not have to run around so much. I used to do the errands, take him everywhere to the doctors and hospitals, go with him everywhere and get the doctor's prescriptions. Everything I did but he could not live.

As reflected in Noorjahan's words, women felt as if they were somehow responsible for the demise of their husbands and that more efforts on their part could

have saved the husband's life. The generation of 'environ-info' or temporary information

to bring focus to one's actions in the background of missing information on the subject,

seen in an earlier phase of 'caring every day,' required relative stability in the woman's

environment. In this stage, when women have to care for their dying husbands, they are

usually functioning in an environment of panic and distress. The use of 'environ-info'

becomes difficult to continue when women are faced with caring for their dying

husbands. In this stage, women once again experience similar feelings of helplessness

and panic as in the first phase before accurate diagnosis of HIV was made. Faced with

having to care for a dying partner, the women are alarmed, distressed, and confused.

There is little evidence that women are able to use the creative process of identifying

problems and generating solutions in this phase. Rather, they feel extremely

overwhelmed and confused as a caregiver in this phase.

 Several of my respondents felt at some point in their caregiving experience that if

they did not bear the burden of caring, no one else would. This reflects a deep sense of

individual responsibility for their care recipient's health. Many of them thought that they

had successfully revived their husbands from their deathbeds and those who lost their

husbands thought that they could have done something better. Noorjahan further shared

with me this feeling of being solely responsible, which was shared by many other

respondents.

> If I had not done[cared]…. There was no one else who would have done[cared]
>
> for him. If I had stepped back, he would not even have been able to walk the way
>
> he was able to walk. Whom should I tell my story? So I had to put in all my
>
> effort.

Another woman, Noor described painful moments of nursing her husband in his last days.

> I took care of him… And while I was still caregiving… He died… With my own hands, I had to wash him… He would pass out on the bed itself all the time… I would have to hold his body and wash him with my own hands… He was so sick and helpless… He could only eat if I fed him with my own hands… Only then he could eat a little.

Kaniya woke up night after night in the hope that her husband would revive. She also describes a range of feelings including boredom, exhaustion, irritation and anger. She details her exhaustion from the caregiving as she cared for her husband on his deathbed.

> I would get up at night. All night if one has to sit, all day one has to sit (next to the ailing person), then I will get bored and exhausted… Then in the morning I would wash his clothes, clean everything… It was cold then... He died in January… It was raining… Clothes were not drying… I also used to feel very angry… I used to feel irritated… That so much… (work) Whatever I wash… He makes it dirty again… I used to feel so angry.

The burden of caregiving was intense for women during the last stage of caregiving when they had to care for their dying husbands. Eleven respondents in this study were recent widows who had cared for their husbands on their deathbed without any understanding of how to provide such care, while they were HIV-positive themselves. Some had not even received the accurate diagnosis of HIV even at the time of their husband's demise.

Summary and Conclusion

Table 2 below provides a brief summary of themes and sub-themes delineated in the

chapter that comprise a trajectory of the caregiving women. The tabular summary offers

a summation of the experience of women at every stage of caregiving and the residual

experience of what it meant for women's lives or the effect it had on their personalities

and sense of being.

Stage	Sub-themes	Underlying experience	Aspects that consolidate caregiver identity	Residual experience
Stage 1. Walking in the dark	1. Mayhem 2. Pain of not knowing	1. Search for accurate information (AK). 2. Beginning of self-efficacious behaviors to impact the situation.	Eventually getting connected with accurate health provider and receiving accurate diagnosis.	Gaining Mastery of one aspect of caregiving.
Stage 2. Caring every day	1. Worrying and doing. 2. Caregiver's dilemmas and solutions 3. Husbands as caregivers. 4. Unrequited care	1. Management of everyday caregiving practices. 2. Finding solutions to problems. 3. Feeling and realizing the texture of relationship with care recipient.	1. Managing everyday caregiving practices. 2. Generating 'Environ-Info.'	Becoming one's own source of authoritative knowledge
Stage 3. Losing the labor of care		1. Helplessness, being overburdened 2. Feeling personally responsible for the demise.		

Table 2. Summary of women's caregiving stages.

The overarching themes that consistently emerge in various sections of this chapter include a 1) lack of information, 2) a deep sense of personal responsibility for not having that information, 3) the search for authoritative knowledge on the subject of caregiving, and 4) self-efficacious behaviors that consolidate women's role as a caregiver.

Women's lack of information about HIV, its modes of transmission, and associated health care services is seen in all stages of caregiving. Certainty that arises from having information that can contribute to a sense of control over one's life situation is a normal human need. In the absence of such certainty and information, women grappled with developing exactitude in their practices as a caregiver, a role that they had accepted as part of their gender obligations. Keeping in mind the Heideggerian 'fore-structure of interpretation,' (fore-having, fore-sight, and fore conception) explained in the earlier chapter on methodology, women had a vague and limited 'fore-having' or prior knowledge about HIV. They had no constructive information about how the disease can be managed but vaguely understood its negative social implications for their identity and social status. As part of consolidating their identity and role as a good wife and caregiver women constantly felt responsible for not having access to this information and searched for information on HIV and caregiving that was trustworthy and 'authoritative' for them (Jordan, 1997). Despite other sources of information such as counselors, family and community members, in the stage of 'caring every day,' women resort to their own sensibilities and display self-efficacy by defining their role as caregiver. The search for authoritative knowledge on the subject of HIV and caregiving is a continuous theme throughout the narratives of women. I will revisit this theme in a later chapter to demonstrate the trajectories of women who experienced greater ease in their role as caregivers when they were able to consistently utilize health services for people living with HIV and build connections with health workers. However, many respondents experienced caregiving as described in Stage 2, despite accessing HIV health services. This is

predominantly because many respondents were accessing free ART medications regularly but not visiting care and support centers for psychosocial services as regularly.

The trajectory of women as caregivers demonstrates that women often saw their own efforts either as insufficient due to lack of information or other barriers, or saw themselves as failing to save their partners' lives despite their full efforts. In spite of having the awareness of their own needs for rest and care, women consistently put their care recipient's needs before their own, rationalizing their actions in terms of barriers experienced (such as lack of information and health provider neglect) and relational terms (putting family members first or thinking that they had to take charge or else no one would). The following chapter explores in depth, women's worldviews, the meaning-making process of women's acts of caregiving and how it intersects with notions and acts around self-care.

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Chapter 4.
A Rope Becomes Thinner and Thinner: Making Sense of Caregiving

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Overview

The inquiry about why phenomenon exist and how people make sense of the

phenomenon and participate in its creation is a central philosophical question. The

subject of being an everyday caregiver, however, is a seemingly mundane, monotonous

and unquestioned issue, despite the fact that people and especially women have

participated in such caregiving for centuries. Given that from a phenomenological stand

point, all social issues are issues of meaning (Dodd, 2009), in this chapter I attempt to

uncover how women make meaning and sense of this mundane, routine caregiving when

they are ailing themselves. 'Meaning-making' processes employed by caregiving women

are central to the overarching inquiry about women's experience of providing informal

care, while they are living with HIV themselves. The ways in which women understood,

rationalized, stabilized, or destabilized their role as a caregiver, provide deep insights into

the workings of their inner mental and emotional world.

'Meaning-making' has multiple context driven definitions (Klinger, 1998).

Baumeister (1991) proposed to understand meaning as a "mental representation of

possible relationships among things, events, and relationships" (p.15), thus meaning-

making assists in making connections. Meaning-making processes are diverse and may

be contextual and/or individualized when making sense of stressful life events, moments

of transitions, or changes in life. Some examples of meaning-making include assigning

positive meanings to the event and one's role, in an attempt to finding purpose in the

midst of stressful life circumstances (Affleck et al., 1985), finding spiritual meaning in a

life circumstance (Johnson, 2003; Lips-Wiersma, 2002), and coping through acceptance

of a life situation (Davis & Morgan, 2008). In this chapter, I use Park's framework of 'Global' and 'Situated meanings' (Park, 2013) to explain women's worldviews and the meanings they make of their caregiving role. Global meanings refer to the broader world views that people acquire over a period of time due to their upbringing, socialization, internalized messages, and beliefs that inform their choices and decisions in a particular context. Situated meaning refers to the use of the broader world views to make sense of a specific life situation such as being a caregiver.

The first section titled 'Global Meanings: Discovering normative world views,' reveals women's personal value frameworks and worldviews and how they govern women's lives and provide a framework for their meaning-making process. Value frameworks explored here are particularly associated with the texture of the institution of marriage in India, women's views about marriage and relationships, and their views about their role as wives and mothers. The second section titled 'Making meaning' examines women's meaning-making process, including the ways they interpret the events and circumstances of their lives as a caregiver. In the first section, I explore women's 'value frameworks' and 'world views' (global meaning) and in the following section, I explore how women make meaning of their caregiving experience as a situated meaning (Park, 2013). Four sub-themes in the first section include 1) a necessary love, 2) being a courageous wife, 3) a compulsive doing, and 4) a permitted dependency.

Women's narratives are explicit testimonies to their meaning-making processes and I utilize women's own words to demonstrate their experience. Nevertheless, meaning-making has an extended definition in qualitative research that allows the researcher to become a part of the interpretive research process and the meaning-making

process. Thus, meaning is made first by the respondents, while acknowledging the space for the researcher's worldviews to enter the interpretive process (Becker, 1996). The final section, 'Serving from their reserves' with the sub-theme of 'Self-care: A strange resource,' captures intense forms of caregiving and explores consequences when such caregiving is combined with low or no perspective of the caring for the self.

Global Meanings: Discovering Normative World Views

The understanding that normative values and beliefs in cultures can exercise a powerful influence and provide a framework for choice of behaviors and actions, goes back to Durkheim (1951) and others (see Campbell, 1964). Social psychologists posit that people adopt group behaviors and attitudes depending on their need for community association, their needs for attachments, or to be able to compare themselves with other members of a group (Festinger, 1954). Conformity to group behaviors and social pressure (Asch, 1951, 1952) and the need to have a 'reference group' (Newcomb, 1943; Newcomb & Wilson, 1966) also play an important role in developing and reproducing social norms and normative behaviors. More recent research examining the relationship among normative values, cultural context, and people's behaviors and attitudes demonstrates a powerful impact of normative values on individual and collective behaviors. The impact of normative values on behaviors has been studied in diverse subjects and contexts. Examples include the study of people's normative influences on energy conservation (Nolan, Schultz, Cialdini, Goldstein, & Griskevicius, 2008), alcohol misuse among college students (Perkins, 2002), the development of social identities and self-categorization (Hogg & Reid, 2006), and role of social norms on the acceptance of the use of technology in certain cultures (Srite & Karahanna, 2006).

In this section, I will examine the normative and value-based statements in women's narratives as a means to explore their worldviews and what they are allowed and not allowed to think, feel, or do. Most respondents demonstrated multiple values and normative worldviews. However, it became apparent that any single one or combination of their values was more relevant to how they thought, felt, or acted and their meaning-making process, as a caregiver.

A necessary love.

'A necessary love' reflects normative values around what love between couples should look like. As explained in the literature review chapter, conjugal love in traditional arranged marriages lies in honoring the relationships and bonds established in marriage. Women demonstrate love by showing respect for their marriage irrespective of the texture of relationship. Swagati told me that 'we have to be there for each other' with a lot of emphasis. She values togetherness with her partner and it is almost normative for her to be with her husband, despite their life situation. Her emphasis on the normative, compulsory, and binding nature of marriage reflects the predominant and traditional view of the institution of marriage. However, in addition to this normative view, Swagati also expressed a more personal belief about how people relate with each other. She believes that it is only "One who is in pain can only understand the other... A common person cannot understand." She implies that she can understand her husband only because she is in the same life situation as him, as they are both living with HIV. She believes that it is only people experiencing the same life situation and circumstances who can impart understanding to each other. This normative understanding helps her foster a loving

relationship with her partner. Swagati explains this further to me by using a Hindi metaphor,

> We also have quarrels... That is only a good relation... Like they say…That where there are 4 utensils, only there, will there be noise.

This metaphor normalizes verbal conflict between couples by implying that there is exchange of heated words between couples only where there is love, just like there is noise only where there are (as if filling an empty space) lots of cups and saucers. Where there is no love, there is silence and distance, there are no quarrels. Swagati used this metaphor to articulate how her relationship is bound by these values. Other women articulated more clearly how feeling love for their spouse was their only option. Women were very aware that their primary role as women was to maintain the ties of marriage to show respect for their families. Women's normative world views about conjugal relationships were shaped within a very early marriage which did not allow my respondents any opportunity to explore alternative views.

Phool explained to me that it was love that was the driving force in her role as a caregiver. However, on interrogating this closely, it became clear that she believes in a social norm that places the honor of a family as a high priority, one that is exhibited by the maintenance of their daughter's marriage. She told me "We have to live together. Our family members have brought us together so I have to honor that." As I will observe later in the section on meaning making, Phool makes sense of her caregiving labor through love for her partner, but her normative value of honoring her family by compulsorily living with her partner serves as the framework within which she makes meaning of her life situation and circumstances. Especially notable was the fact that she

said that "I have to honor that" and not that "we (she and her partner together) have to honor that," therefore taking on a lot of personal responsibility for her marriage. Most women were married as teenagers and had little understanding of the terms of the contract they were entering through marriage. 'A necessary love' reflects women's acceptance of the social order, making peace with it, and finding love in the relationship they have.

Being a courageous wife.

For other women, personal strength was deeply embedded as a gender based social value. Courage and women's strength is a predominant theme in religious Hindu narratives where different mythological, religious, or real female characters are worshipped and valorized for demonstrating different forms of individual courage. The following are narratives commonly known in this area of India and my respondents surely were aware of the morals of these stories. For example, Goddess Kali in Hinduism is a warrior Goddess who triumphs over evil 'rakshasas,' similar to devils in western culture. There are several stories about wives who demonstrate courage in their wifely role. For example, in the Ramayana, one of the central Hindu texts, Sita, the wife of God Ram is the epitome of wifely courage for persevering in the face of dishonor when Ravana, the opponent of Lord Ram, makes her a captive. Sita remains graceful, compassionate, and loving towards Lord Ram under all circumstances. Although this is a broad and mainstream interpretation of Sita's character, there are several versions of the Ramayan in different parts of the country that portray Sita differently. In 'Dharm's Daughter,' Mitter (1991) explains how the Ramayana and the various stories woven within the metanarrative, inspire and guide people's lives in India.

Another famous example of a brave Indian wife is the character of Savitri in the '*Book of the Forest'* in another major Hindu text, the Mahabharata, or '*The Grand Story*.' Savitri is accorded courage and bravery as a wife for saving her husband's life from '*Yama,'* the lord of death himself. Even though Savitri's husband's demise is set in stone, when Yama comes to receive her husband's soul, Savitri impresses Yama, the lord of death, with her quick-witted answers and her dedication towards her family. When asked for a blessing, Savitri asks to be the mother of a hundred sons. Her request then requires Yama to let her husband stay alive in order for her to have a hundred sons in partnership with him. Savitri is therefore valorized as a courageous wife who saved her husband in the face of the God of death himself (Shepard, 1992).

Warrior queens in Indian history are found among both Hindu and Muslim women such as Razia Sultan, who was the Queen of Delhi in 13th century (Bhushan, 1990) or the Queen of Jhansi who fought the British in the mutiny of 1857 (Singh, 2002). They have also been deemed courageous for being warriors who led their armies to protect their kingdoms. Tales of Indian women's courage and bravery reflect a variety of values and norms about how women can demonstrate bravery. Almost always, there is an element of personal sacrifice in women's courageousness.

Among respondents in this study, women saw courage as a personal value. Although they did not refer to any of the stories or examples discussed above, women reflected bravery in similar terms of personal sacrifice, as in the mythological and historical examples of brave Indian women discussed above.

Suraiya articulated the importance of having courage in her situation. "I was very weak… But I showed courage, I had a lot of courage." Despite being in physical pain,

she valued demonstrating courage. Suraiya described different values at different points during the interview, but it was a sense of being courageous and possessing a strong sense of wifely duty that shaped her meaning-making process.

Another respondent, Jhilmil made sense of her caregiving role in terms of courage with personal responsibility. She said: "I think no one can do it better than me... You cannot trust anyone else to do it for you." Jhilmil believes that no one can care better for her partner than herself, thus exuding a strong sense that she does not permit herself to depend easily on people, because she distrusts them for an important task such as providing care for her husband. Personal strength and being a courageous wife was therefore an important theme that guided and propelled women in their role as a caregiver.

A compulsive doing.

Some women articulated the importance of having a husband, as an important personal value they held in their lives. The internalization of the idea of having a husband, being held in deep regard by women, speaks to the texture of patriarchy in north Indian society, where husbands are essentially seen in high regard by women, across religious and caste groups (Dube, 1988; Mandlebaum, 1993; Wadley, 1980). Because having a husband is of great importance by itself, caring for him and ensuring that his needs are met is only the next logical step. Several respondents highly revered being married. 'A compulsive doing' represents the compulsory and unquestioned nature of duty towards husbands internalized by women, as a natural consequence of placing a high value on the presence of a husband in their lives.

Zeenat has a stringent idea about her husband's place in her life. She expresses her strong belief, "He was my husband that is why I did it… For one's husband, one has to do." Zeenat emphasized her role as a "doing person" and as it becomes clear later in the section on meaning making, she has internalized a social value that "for one's husband one has to do", along with a fear of being criticized harshly if she is unable to adhere to this normative value. Phoolandevi expressed a similar view that "husbands have to be taken care of," again reinforcing an internalized patriarchal value that places women in a compulsory position of being action takers to care for their husbands.

Women, who held a normative value that husbands must be taken care of, often rationalized their caregiving role out of a sense of fear of being criticized by family and community members. This lens for their meaning-making process guided women who demonstrated an internalization of this caregiving value that "husbands must be taken care of." Suraiya shared at another point during the interview that,

> If I have a lot of pain... he (her husband) may put oil [on me] ... But you know, he is the husband so I do not like him to do anything. You know it feels like a crime, it is true, it is true. I do not want him to do anything.

Her saying that "it feels like a crime" defines a gendered value for Suraiya. Even though she needs her partner's help when she is in pain, she cannot allow herself to receive his care and attention fully because that feels like a crime to her.

Her assessment of receiving care from her husband, feeling as a crime, may be seen as rooted in her normative value where she shared with me the importance of the physical presence of her husband. "He is my husband, at least he is there...Biggest thing is it is a matter of social respect and pride." She emphasized that "At least he is there,"

meaning that even the presence of her husband is extremely valuable and therefore it is her primary duty to care for him. 'A compulsive doing' reflects aspects of women's internalized values which were stringently focused upon being do-ers and action takers for the purpose of caring for their husbands. Women's words reflect certain rigidity in their value base with little room for movement outside the internalized norms.

Permitted dependency.

I use the term 'permitted dependency' to refer to women's internalization of a gender-based norm that allows them to permit themselves to be financially dependent on their partners, but to not depend on him for other aspects of their life such as caregiving. This gender-based norm allows women to view themselves as the weaker person when it comes to the provision of material things for sustaining themselves and naturally puts the male partner in a position of strength. Although women had to demonstrate courage and strength as caregivers, they gave themselves the permission to be non-earning family members, financially dependent on their husbands. This economic arrangement reflects a key channel through which patriarchy operates- it locates importance and honor in women's roles when they serve others directly and serve themselves indirectly. Manju articulated this well when she shared with me that,

> He is a man… He can run around, work hard, and make arrangements for us. Women have to work at home for the most part, men can go out.

For most respondents, their families were dependent on the sole income of their husband, and that led women to rationalize their caregiving role in terms of the gendered division of labor. Phool has a similar idea about her role and her husband's role in the provision of material resources for her family.

If he is not well and he will not work, where will the money come from? Where will the goods and grocery come from? It is not sufficient to just have medicines; many other things are needed, so if there is less money, how will those things be arranged? If he will not be well, it is hard for me. I am at home, I eat at home, so I will eventually get fine, but if he is not well he cannot go out to work and then that will be a problem.

Women's limited occupational avenues and low economic status relative to men in the Indian economy, is reflective of the traditional gendered division of labor in households and perpetuates the idea that even when women earn, they are secondary income earners for their family (Bennett, 1992). Further, even when a few of my respondents had an occupation, it was in the informal sector as a domestic laborer, a worker at a dry-cleaning store, or a washerwoman. Respondents in this study had few avenues for achieving financial independence and many did not perceive the need for financial independence either. In addition, their poor health, role as a caregiver, and responsibilities for child care made it almost impossible for them to explore occupational opportunities.

A combination of a lack of occupational opportunities for women and their own ill health prevented women from actively taking part in the provision of material things for their families. Yet, the most important emerging aspect was women's acceptance of men as the primary providers of material things for their family and the traditional gendered division of labor. In the following section I will demonstrate how women's meaning-making process intersects with their normative worldviews, which were discussed in this section.

Situated Meanings: Making Sense of Caregiving

In this section, I demonstrate the connections between women's world views or 'global meanings' (Park, 2013), discussed in the section above and their meaning-making about their role as a caregiver. The first sub-theme, 'The proof of love is in doing' connects with the global meaning of 'a necessary love.' The second sub-theme, 'on my strong shoulders' connects with the global meaning of 'being a courageous wife' where courage takes the form of being responsible against all odds. The third sub-theme of 'what will they think?' maps over the global meaning of 'a compulsive doing' and the final sub-theme, 'an old social contract,' maps onto women's worldviews in the section on 'permitted dependency'.

The proof of love is in doing.

Women overwhelmingly had positive notions about their own health and framed their own situation in a position of strength as compared to their husbands for whom they were caring. They did not always have the language to express this explicitly, but in conversations with me, they portrayed themselves as the physically stronger partner. This framing was temporarily accurate because many women were in the earlier stages of HIV infection, while their husbands were in the more advanced and severe stages. Women found meaning in their caregiving labor by understanding it as an act of love from a wife to a husband, which was only natural and a given. Seeing themselves as the physically stronger partner assisted this meaning making.

Neelam asserted "I was Ok then. I was not sick... I could walk... So, I used to take care of him." She also assured me that she took care of him because he was her life

partner in good faith and the provider of her children. She also made it very clear that the fact that they had been HIV-positive did not change her feelings for him.

> I took care of him because I used to love him so much. He was mine only. I did not start hating him when I got to know that he is HIV-positive, I had love for him, I used to take care of children, and because of him my children live.

Women used love for their husband and the role of their husband as the provider for themselves and for their children as a basis for making meaning of their caregiving role.

Phool initially expressed feelings of concern and a desire for the well-being of her husband and daughter. She believes that it is this desire she holds for their well-being that motivates her for their caregiving. From conversations with Phool, I perceived that she derived her own sense of well-being from the well-being of her child and husband, therefore making it of paramount importance to her. On probing more deeply about her emotions, she confessed that "it was just love."

> I think that he should stay fine. That will make me feel better and if my daughter stays fine then that will make me feel better… Reason is ... It is an emotion, it is a feeling that comes to mind.

> Shri-What would you call this emotion?

> Phool-Love, what else?

Swagati also rationalizes her caregiving labor in the form of love. She believes that as human beings we have to work hard and it is not that she can have absolute physical comfort anywhere, whether it is her husband's or her parent's home. Her

thought process is reflective of gender norms that expect young girls and women to be predominantly nurturing and care taking entities, irrespective of their own health.

> The biggest reason is… that there is love. When there is no love, then I will think that I can go somewhere, where I can be very comfortable. That will not happen anywhere, there is no comfort anywhere, not even in my parents' family.

Women thought that in marriage, they must demonstrate their love by consistent action-oriented caregiving and management of the household. While women all over the world take up such responsibilities, for respondents in this study there was little leeway that they allowed themselves in the performance of household and caregiving tasks, despite their own ill health. Swagati shares with me further,

> He married [me], so why did he marry? So, I have forgotten my illness, I do not have any illness, I have forgotten it and I run my household like any other woman does.

When Swagati says 'why did he marry', she actually meant that her husband married her as a favor to her and that she must return that favor by taking care of him and their children. In saying that she has forgotten her illness, Swagati clearly prioritizes her roles as a wife and mother over and above her own wellbeing. Love in conjugal relationships in traditional societies like India is a deeply complex phenomenon, held together by the strength of the marriage as an institution, within which individuals make sense of how and what makes them feel love.

On my strong shoulders.

Women articulated their caregiving labor in terms of responsibility and duty. Overwhelming numbers of respondents thought that they were the emotionally stronger

partner, in addition to their assessment of being physically stronger as discussed above. Suraiya shared with me that she sees her caring labor as a responsibility.

> It is my responsibility... It is my duty... I was very weak...I could hardly walk but I showed courage, I had a lot of courage, I would give him food and water... everything.

Women who made sense of caregiving in terms of responsibility believed that they were being fearless and undaunted in the face of adversity and being responsible against all odds. Suraiya's words that "I could hardly walk but I showed courage," reflects women's understanding of responsibility in this situation. Their responsibility was to persevere, be brave, courageous, and responsible against all odds. In other parts of the interview as well, Suraiya emphasized the value of being bold and unflinching in the face of hardships in life. Jhilmil also saw her acts of caring as an intrinsic part of her wifely responsibilities. She added that she does not have to worry about the whole world, because everyone has someone caring for them. Her only job is to worry about her husband and child. She also saw herself as replaceable by another woman in her husband's life, if she failed to perform her duties. I found this interesting because other parts of the interview did not reveal any signs of emotional abuse or pressure from her partner to perform any particular tasks. Perhaps she took the burden individually upon herself as a manifestation of her gendered socialization, without external pressures from family or community.

> I only worry about my husband and daughter, for everyone else there is someone or the other to take care of them… If I will not be there, someone else will come to take care of him… But while I am here... I should conduct my duties.

Perhaps Jhilmil's perceptions about her roles represent one of the ways in which women internalize who they should be and what they should do, irrespective of the treatment from people around them. She reiterates that life would have been better without the disease, but she accepts her liabilities. "I wish I did not have this disease, it would be nice if I was not like this... But it is my duty to do this." Respondents were aware that their caregiving labor is more difficult for them to perform due to their own ill health. Despite this awareness, their sense of duty was stronger and they chose to be courageous by overcoming odds to fulfill their responsibility. Kashi stated,

> It is a responsibility only... I think I will do this or it will keep lying around and not get done … It is only me who will know that I am sick and I am not able to work and I am doing it slowly… When I will start in the morning then it may finish by evening… But if I do not start… It will just lie around.

Even when women were aware of the effects of their caregiving labor on their health, they saw their health as an obstacle to their role as a caregiver. Women believed that they had to overcome or ignore their ill health to fulfill their duty as a caregiver. Despite having an awareness of the effects of their caregiving labor on their health, women did not always see their caregiving role as an obstacle to improving their own health and well-being. Women's values as a caregiver were more important to them than their physical and emotional well-being.

What will they think?

Respondents felt an overwhelming sense of external pressure and fear of criticism from relatives and community members to put their husband's and children's health before their own. In their attempt to fulfill this role obligation and avoid tensions with

other family members who prioritized the care of men and children, women rationalized their caregiving labor as a way of avoiding conflict. Zeenat told me "If I will not do things for him, then neighbors and in-laws will criticize me. That I do not do it."

Although the fear of being criticized was not the only factor that propelled women to provide care, it appears that even in moments where women may have had the choice to opt out of caring temporarily, external pressure from family members moved them into caregiving actions. For example, Phoolandevi, now a widow, recalls her days of caring for her husband and shares with me that her husband never wanted her to nurse him in bed and he felt shame in accepting her care. Even so, she felt consistent pressure from family members and did not want to look like a bad person. She says, "It was important to care for him... If I did not, then people would say that you are married and you are not caring for him?"

Noor was advised in her familial circles, especially by her parents, to maintain physical distance from her care recipient to keep herself safe, but she felt compelled in her assigned role, out of fear of criticism from her in-laws for not being a good person. "I had to care for him…. People would say that she does not care for him, she hates him."

Another woman, Noorjahan recalls,

There was no other reason, it was just that what would the family members say? They would also say that 'call your bride, she should take you to the toilet,' and if the bed is wet, they would call me. So, I had to do everything. People would come and see… So, if the bed was dirty, they would wonder why it was like that. Everyone would ask, his sisters and all would say to me that she is not doing

anything, 'you are not keeping it clean enough for him' so I had to get up… Do things.

As Noorjahan's story demonstrates, their husband's parents or siblings often monitored women to ensure that the smallest needs of the care recipient were being fulfilled. Family members often took on the role of directing and managing the caregiving labor of women. The force of normative values is apparent here, when women's need to look like a good woman and wife in the family, and the fear of verbal criticism, moved them into caregiving actions even when there were moments in which they may have otherwise found rest. Another issue worth noting is the sheer absence of conversation about the woman's health in her family or community circles as she provided care to husbands and children living with HIV, thus promoting her invisibility as a woman living with HIV and as an HIV caregiver.

An old social contract.

The theme of 'An old social contract' refers to the traditional gender role of men as providers for their families and the role of women as childbearing and caregiving entities. This theme, as a situated meaning, connects with the worldview or global meaning (Park, 2013) theme on the value of 'permitted dependency.' Women made meaning of their caregiving role in terms of the importance of their husband's earning role. Most of the respondents were living in poverty. Women made sense of their caregiving labor through the context of their resource constrained environments where the husbands were primary earners and they depended heavily on their partners, even for the most basic needs in life such as food and shelter. Due to this dependence, women rationalized that they required their husbands to revert to better health, in order to return

to work so that the husbands could continue in their role as providers. Manju is currently married and caring for her husband. Throughout the interview she talked about how much she is in love with her husband, but when asked about how she made sense of her caring labor, her primary rationale was about the need for her husband to work, to be able to financially support their family.

> When he is not well, then I have to do things. When he will be well and rested... Be healthy, then he can go outside, and work, and feed us. Else how will he feed us? I tell him that first you rest and once you have rested, go out and earn.

Other women narrated similar reasons for their caregiving labor. Neelam worries:

> Somehow, he should get healthier... So, we can live decently ...If he does not live then what will we do? So, I used to take care of him.

Phool remarked:

> If he is not well and he will not work, where will the money come from? Where will the goods and grocery come from? It is not sufficient to just have medicines. Many other things are needed, so if there is less money how will those things be arranged? So, if he will not be well, it is hard …If he is not well he cannot go out to work and then that will be a problem.

Women who were wives and mothers were more concerned about their husband's health for financial reasons. Women's subjective experience of caregiving came with a deep concern about the provision of material things for their family. Women perceived that they had no options as far as their informal caregiving labor was concerned.

As the sections above demonstrate, women made sense of their caregiving labor in various ways, influenced by their worldviews and the normative values that they had

internalized over a period of time. Meaning-making is, however, a complex process and women predominantly did not associate their caregiving role with any single factor mentioned above but some combination of the factors discussed above. It is worth noting that women made sense of their caregiver role predominantly in positive terms or in terms of acceptance of social norms and their life situation. Positive meaning-making assisted women in altering their emotional state from negative to positive, and finding relief in a situation that was chronically stressful. Meanings made in terms of love or courage are particularly helpful to women in altering to a positive emotional state. Altering one's emotional state is understood as a resource people use towards self-efficacious behaviors, as a coping mechanism (Bandura, 1993). Connecting with the theme of evolving self-efficacy in chapter 3, it becomes clear here that women were able to move towards self-efficacious behaviors assisted by predominantly positive meaning-making of their life's situation and their role as a caregiver. The chart below (Fig. 1) summarizes the connections between women's world views as global meanings and women's situated meaning-making as a caregiver.

• A necessary love

- Values similarity of life experience as basis of connection.
- Qurrels, long periods of silences and verbal arguments are normal.
- Honor of families lies in the maintenance of marriage.
- Our family members have brought us together, so I have to honor that.

• Complusive doing

- For one's husband, one has to do.
- 'He was my husband that is why I did it...For one's husband, one has to do'

Meaning of caregiving is made in terms of proof of love.

Meaning is made in terms of determination to live a spousal value.

Meaning is made in terms of being a responsibile care giver as a reflection of personal strength.

Meaning is made in terms of gender division of labor.

• Being a courageous wife

- No one can do it better than me.
- It is important to be strong and independent.

• Permitted dependency

- It is OK for women to be at home and men to work outside.
- He is a man...He can run around, work hard, and make arrangements for us. Women have to work at home, for the most part, men can go out.

Figure1: Boxes outside the circle represent Global meanings (Park, 2013), a fore-having (Heidegger, 1996/1927) or pre-existing world views. These global meanings are internal to the respondents and a part of their inner emotional world. The inner circle represents corresponding and associated 'situational meanings' (Park, 2013) made as a caregiver.

Serving from Their Reserves

This section explores women's experiences of caregiving that were harsh and severe and required them to serve from their energy reserves. Women performed caregiving labor even when their bodies did not cooperate with the tasks they were expected to perform, or even when they felt emotionally and mentally drained. Here, the deterioration in women's health becomes evident and an important turning point in the caregiving process emerges, where women attribute the deterioration in their own health

to their caregiving labor. When I asked Asra about the tasks she did at home, she explained that she could not work as much anymore, as she did before her diagnosis.

> I am not able to do more because I am also unwell… Whole day I work ... I make
> sure that he takes his food on time. I am very careful that food is on time and so
> medicines are on time. I cook no matter what, no matter where I go, I always
> cook and make sure that he is good.

Despite realizing the deterioration in their own health, women continued to perform their regular work, ignoring their body. Women often chose strictly putting their family members first. Asra's words "no matter what" meant that no matter how she felt and irrespective of where she had to go, her highest priority was to ensure that she prepared food and ensured that medicines were available to her husband on time. Saloni was living in a large joint family at the time of her diagnosis. As a young bride, she felt the pressure to please everyone around her.

> I used to work all the time, even when I was sick I had to look after the house. It
> was important to get things done… Taking care of everyone, giving people things,
> despite my health being bad all the time, I could never say to anyone around me
> that I am not feeling well and will not be able to do something… I wanted to keep
> everyone happy… I would cook for everyone, serve them, feed them, and clean
> up after them.

Saloni is now living with her parents due to marital conflict and hopes that she can soon reunite with her partner on better terms. She feels better taken care of in her parental home, because she had no support from her family members in her husband's home. She

recalls "If I got a little bit of time, I would lie down and eat painkillers… I took lots of painkillers because my body was always aching."

Women shared incidences when their care recipients placed harsh demands of caregiving on them. Leela remembers times when she was made to get up in the middle of the night to cook.

At 2am in the night, he would get up and say that he is hungry… I would not even see whether it is hot or cold, or night or day. I would cook for him in the middle of the night. From my side… I did not leave any leaf unturned.

She further narrates;

I did everything, even while I was sick… I was sick, whether I have fever or anything else but he would not even fetch a glass of water... That was the situation.

Leela was one of my respondents who cried during the interview explaining her experiences caring for her husband, from whom she is now seeking a divorce. She felt so deeply neglected and drained in her relationship over time, that she came to a point that she described to me as a rope becoming thinner and thinner until it broke into two pieces.

Like Leela, Rakhi also had similar harsh demands placed on her when her care recipient expected her to wake up in the middle of the night to arrange for his food and other necessities.

Sometimes he would wake me up in the middle of the night at 2 am and ask for things, 3 am… And then it would really irritate me. At night at 2 am or 3 am he wanted me to get up and cook… But then I would think that Ok, he is a sick

person, I should care for him and I would do it... When I separated, I did not want to, but I had to.

Like Leela, Rakhi also separated from her partner before his demise. She was herself in deep physical and emotional pain and felt forced to give up on the relationship. She contemplates that she did not really want the separation, but eventually she came to a point where she had to choose between taking care of her physical and emotional self and living with and caring for her husband.

Women traced the deterioration in their own health during phases of intense caregiving. Some clearly recalled a drop in their own CD4 count (a measure of immunity in the body) at times of intense caregiving that eventually led them to the initiation of ART medications. In different life circumstances, it may have been possible for them to maintain better levels of immunity and to stay off antiretroviral treatment.

Noorjahan recalls how her household and caregiving work intensified and her own health deteriorated rapidly. She clearly distinguished her workload going up from her regular domestic chores before the couple was diagnosed with the illness. Noorjahan also believes that if it was not for that intense caregiving work, it was possible that she would have never been initiated into ART.

Bathe him in the morning, help him in the toilet, clean the sheets, and wash everything. So, after he was sick, it was harder work, I had to do more… I had also started feeling sick then, I had become very weak. My CD4 was low that time, it was around ... my medicine had to be started, else it would not have been started. …. So, in this whole thing I was miserable.

It was not only the physical strain of the caregiving labor, but also the anxiety that women lived with on an everyday basis that caused their mental health to deteriorate, in turn impacting their physical sense of well-being. In the following narration, Suraiya clearly articulated that over a period of time, she felt a greater sense of anxiety and began to lose weight, eventually leading to a worsening of her own health. She contracted HIV from her partner while they were still unaware of his health status.

> When I started taking care of him, I was OK... but when I took care of him for a long time, then I started having more tension and then I lost weight and I became sicker… Initially I did not know how he is sick... And I also got the disease from him.

Noor also experienced deterioration in her own health during an intense phase of caregiving for her husband. She said:

> Even those who looked at me felt pity for me that how I was taking care of him, looking after children, working at home, doing things for husband… So, I got worse and worse… I got thinner... People would say that 'she has anxiety and worry in her heart, that is why she is becoming thinner.'

Noor told me at another time during the interview that she felt as if she was being forced to breathe under water. Perhaps, nothing expresses the inner lives of the women better than the metaphors they used to describe their life situations and feelings. 'Breathing under water' illustrates the weight of her being, what she felt every day and the feeling of struggling every moment for a breath of fresh air, struggling to just stay alive.

I consider the narrative aspects of 'serving from their reserves' to be one of the most important aspects of this research. This is because it was in the process of the conversation with the researcher that women acknowledged the connections they felt between the work of their care provision and their health. This was a connection they had not had an opportunity to purposefully think or talk about previously with anyone. In the following section, I explore women's understanding of self-care.

Self-Care: A Strange Resource

Self-care in health care in western societies has been understood as a form of personal and individual care where a person takes preventive and curative measures to promote their physical health and overall well-being. Self-care may be informed by professional practitioners but is essentially characterized by routine personal efforts that are non-professional (Levin & Idler, 1983). Prior studies with women living with HIV in western parts of the world demonstrate that women who practice more self-care behaviors, such as daily consumption of vitamins, low or no usage of alcohol, adequate sleep and exercise, and management of stress experience improved physical and mental health (Gielen, McDonnell, Wu, Campo, & Faden, 2001; Plach, Stevens, & Keigher, 2005). However, self-care among women living with HIV has predominantly been examined among western populations. In this dissertation study, when I asked women questions about how they thought they took care of themselves, there were no meanings exchanged between us that implied use of any luxury activities (such as use of a spa or beauty) as it may typically be understood in western cultures where self-care is promoted and advertised as an individualistic goal. The questions were asked to understand

women's awareness of the need to take care of their own physical health and their perceptions of how they were or were not taking care of themselves.

Women's narratives in this study revealed a limited understanding of taking care of the self. When asked about what how they took care of themselves in their life circumstances, many women found my questions strange and had a difficult time connecting with the question about how they took care of themselves. The scarcity of detailed responses on how women took care of themselves in women's narratives reveals that they did not consciously think about self-care as a necessary aspect of their lives. In my conversation with Asra, I attempted to ask her about her care routine or practices in different ways.

Shri- What are the things you do to take care of yourself?

Asra- I eat and sleep in a timely manner… what else?

Shri- Is there something you may be doing every day to take care of yourself?

Asra- No, not really. Mainly nothing.

Shri-Do you feel like taking better care of yourself?

Asra- Yes, why not? Yes, I do… I think that if I work harder then it may happen (that she may have more money).

Asra like many other respondents does not connect with my questions about taking care of herself. She does associate eating and sleeping on time with doing something good for herself, but does not refer to any further practices such as limiting work, having a nap or caring for spiritual needs. Despite her health and life circumstances that would benefit from practices of taking care of herself, she does not

express a fuller awareness for self-care. After repeated inquiries, she associates my questions with her material conditions and the tremendous effort on her part for mere survival. She thinks that if she can work professionally, she will have more resources at hand to be able to do things she cannot do right now. Like Asra, Kashi's responses were also similarly directed.

> Shri- How do you take care of yourself these days?

> Kashi- I take care of food and all... Take my medicines on time and maintain cleanliness in the house... What else?

> Shri-Is there anything you do on a regular basis to care for yourself?

> Kashi- These are the things I do. That I told you about.

Women's lack of awareness and connection with the idea of self-care may be seen in the context of deeply internalized gender normative values that do not allow women to consider their own physical and emotional health. My questions did not resonate with women because taking care of the self may be seen as antithetical in their sociocultural context. Even while women may have some practices that may be categorized as taking care of themselves, they may have viewed it as a breach of norms. Jhilmil clearly stated that the health of her family members is more important to her than her own health and does not have the time to actually think about herself.

> Shri- How do you take care of yourself?

> Jhilmil- First for my husband and child, I fulfil their needs then I take care of myself if I have time... I want to see their happiness before my own happiness...

> Shri- How does that make you feel?

Jhilmil- It makes me happy too, if something happens to my husband or child I get very worried due to this disease. I think that no matter what happens to me, these two should be well... nothing should happen to them...

Shri- When you do care for yourself, what do you do?

[Long pause.]

Shri- When you do take care of yourself, what do you do?

Jhilmil- The care that I am able to give to them (child and husband) that much I am not able to think about myself. [Long pause]

Shri- Would you like to do more for yourself?

Jhilmil- Yes, I do think and I think what more can I do so that I get much better.

Shri- What kind of practices do you have in place right now to care for yourself?

Jhilmil- After they go to work, then I shower, have breakfast, if there are fruits etc., because I live alone at home I do not feel like eating…But then I think that if I do not eat, I will not get power in my body. So, thinking such thoughts then I have to eat…I eat so that my health gets better, because when it gets better then I will be able to take care of my husband and child even better… If I do not stay fit, then I will not be able to take care of them... then who will take care of them?

After much interrogation, when Jhilmil revealed that she tried to eat well, she added that she forces herself to eat well because she must be in decent health to be able to care for her husband and child. Practices of self-care can play an important role in women's experience of care provision. Yet, it appears that self-care is primarily a western concept, with limited resonance for the respondents in this study.

Over a period of time, despite the positive meanings women make of their caregiving labor, they begin to experience physical deterioration in their health. The section, 'Serving from their reserves' represents aspects of caregiving that take on an oppressive character and contribute to the deterioration of women's physical and emotional health. Women's narratives of positive meaning-making of their caregiving role shift when caregiving takes on an oppressive character. Forms of oppression faced in the role of caregivers include being woken up in the middle of the night to cook or clean, or being faced with harsh verbal criticism from relatives about being unable to maintain cleanliness for the care recipient. When women are oppressed in their role as caregivers, they lose

access to the ability they had initially found through emotional and individual action-oriented responses to define their role as a caregiver and dutiful wife. When husbands or other family members make severe physical and emotional demands of caregiving on women, women can no longer define their own practices or exercise any form of autonomy as a caregiver. An important factor that must be evaluated is the lack of women's ability to care for themselves and develop practices that assist with personal care and how that contributes to the deterioration of their health.

As the relative absence of data in the domain of caring for themselves demonstrates, women did not perceive that caring for themselves was a personal resource to which they had access; their limited awareness about the idea of self-care is in line with the gendered pathways they are utilizing to consolidate their role as a caregiver. This is the turning point that occurs at the conjunction of low self-care and externally pressured caregiving or 'oppressed caregiving,' where women break away from the

caregiving role they were initially willing to practice. In the few cases where women did break away from the care recipient, the oppression as a caregiver is accompanied by intense neglect or forms of physical, emotional or financial abuse that forces women to return to their parental families, separate from their spouses, live alone, or seek formal divorce. Figure 2. below demonstrates a relationship among externally controlled caregiving and low or no perception of taking care of one's self that lead to a woman being an oppressed caregiver, that when combined with other forms of abuses led to breaking away.

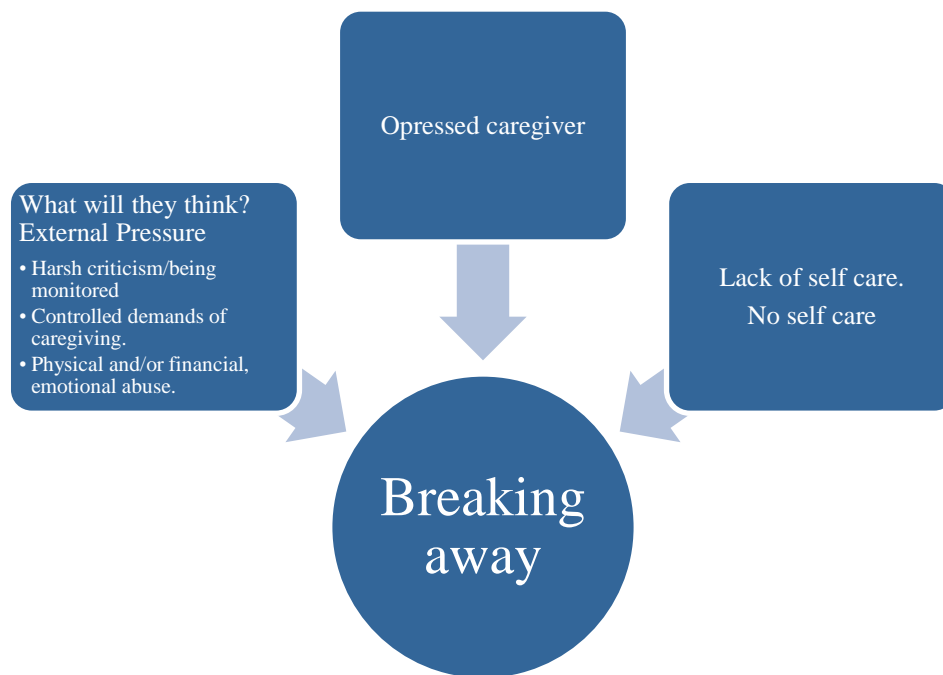*Figure 2.* This model demonstrates how 'breaking away' from the caregiving role and the care recipient occurs at the conjunction of low or no awareness of taking care of one's self and external pressures to be a caregiver as oppressive caregiving.

Summary

This chapter provides insights into the inner mental and emotional lives of women, women's worldviews and their meaning-making processes of their role as a

caregiver. In addition, this chapter also elucidated factors that influenced women's decision making in life and as caregivers, such as harsh external pressure from family members to be caregivers and women's understanding of self-care. Despite experiencing distress, women are focused upon consolidating and perfecting their role as a caregiving woman. The overwhelmingly positive meaning-making processes employed by women are supported by the larger cultural context, roles assigned to women and expectations from them in Indian society. Therefore, women are able to use positive meaning-making of their life situation, and of their role as a caregiver, as a resource of self-efficacy that assists them in feeling positive emotions. The positive framing of these efforts further assists women in perfecting their role as a caregiver.

Nevertheless, the narratives of positive meaning-making are occasionally shifted by interference from external harsh demands for caregiving. External harsh demands for caregiving disallow women any autonomy as caregivers and deprive them of any opportunities for defining their own caregiving practices as positive, as witnessed in the previous chapter. When combined with other forms of abuse such as physical and financial abuse, women break away from their care recipients. The title of this chapter 'A rope becomes thinner…' is excerpted from a woman's narrative and metaphorically captures the shift from the positive meanings women made of their caregiving role to times when such positive meanings were no longer possible in the face of being an oppressed caregiver. The eventual breaking of the rope represents the severing of ties with their care recipients for women who faced unbearable oppression as caregivers and wives.

Chapter 5.
The Missing Intersections of Women's Informal Care Provision with Formal
Systems of Care

Overview

In this chapter I explore women's experiences accessing care and services at two major sites of HIV health service provision: 1) the Antiretroviral therapy center (ARTC) and the Care and Support Center (CSC) and 2) the woman's home, during the health worker's home visit. At each site, I explore barriers and facilitators for access to services, women's persistence in overcoming barriers to access, and how the subject of women's informal care provision is made almost non-existent at both sites of service provision. In addition, I explore health worker's perceptions about the utility of the home visit and their practices during the home visit. I use a combination of the concept of resiliency and Gullifard and Morgan's (2013) conceptualization of access to health services.

The concept of resilience has been defined as the human capacity for positive adaptation despite severe exposure to adversity (Luthar, Cicchetti, & Becker, 2000; Masten, Best, & Garmezy, 1990). Two conditions are implicit within the construct of resilience. First, one has been exposed to adverse conditions that can create severe disadvantages for the individual. Second, the individual is able to positively adapt to the adverse conditions and situations and yet continue in the direction of their overall development and wellbeing (Luthar, Cicchetti, & Becker, 2000; Masten, Best & Garmezy, 1990). Women from my study were exposed to several forms of adversity, which included being HIV-positive, living in poverty, being primary caregivers to others living with HIV, and having poor family social support networks. In addition, women had accumulated

disadvantages through their lifetime such as little or no access to education and employment and poor general and health literacy. Self-efficacious beliefs and behaviors are positively associated with the overall hardiness or resilience in an individual (Milioni et al., 2015). Self-efficacious beliefs and resilience represent two different layers in an individual's coping style. Therefore, in continuation with the study of women's self-efficacious behaviors in prior chapters, I examine women's resilience as a critical personal resource.

Access to health care is a complex concept, which includes client-end facilitators to access and the provider's availability and suitability of health services. Gulliford and Morgan (2013) identify major components of access to healthcare. From the client end, access includes the affordability, geographic access, and sociocultural acceptability of the services being provided. From the provider's end, access implies the availability of services and also the relevance, quality, and effectiveness of the services so that it leads to desirable health outcomes. Apart from the key factors mentioned above, Gulliford and Morgan (2013) emphasize that barriers to the utilization of services by clients must be understood within the contextual features of the populations being served, health needs being met and sociocultural factors unique to different communities and places.

The first major theme presented in this chapter is "Breaking through the darkness: Women's experiences at the ARTC and CSC," which includes the sub-themes of "Retrieving physical strength," "Developing peer relationships, sense of community, and purpose," "Overcoming barriers to access," and "Thin-box messaging" about women's informal caregiving labor at the ART-CSC." These themes represent shifts in women's physical and psycho-emotional health as a result of high ART adherence and the new

supportive relationships they found in the community of women who are also living with HIV, at the site of the ART-CSC. Even so, the themes reveal barriers to access to health care services that women were willing and able to overcome. We also come to understand processes through which the subject of informal caregiving remains invisible. The second primary theme of this chapter is the "Home visit." This is comprised of five sub-themes. These include "Facilitators: Comforts of the home visit," "Barriers in the inner circle of care: Women's living arrangement and HIV stigma," "Women's management of threats of stigma and discrimination," "Assessment during the home visit," and "Health worker construction of the "harmful" home visit." In the second theme of the "Home Visit," I explore how the subject of women's informal caregiving burden is made invisible as a topic of assessment. Despite the real challenges women face in managing threats to stigma while accessing services at home, health worker's tendency to construct the home visit as a health delivery tool that does more harm to women than good, combines with their focus on ART adherence and hygiene in ways that erase women's caregiving role. I argue that the real and perceived challenges of managing the provision of services during the home visit, from both the client end and the provider's end, ultimately render the home visit as ineffectual, even though it offers opportunities for addressing challenging topics in the lives of married women living with HIV.

Breaking Through the Darkness: Women's Experiences at The ARTC and the CSC

Women experienced improvements in their physical, mental, and emotional wellbeing at the site of the ARTC-CSC despite the fact that women's roles as informal care providers seemed invisible. The first sub-theme, "Renewing physical strength"

pertains to the beneficial effects that consistent ART usage brought for women: combined

with self-efficacious behaviors, resilience of personality, and sense of competency, these

factors contributed to an improvement in women's overall sense of wellbeing. The

second sub-theme "Peer relationships and sense of community" demonstrates how

women benefitted by building community at the CSC through repeated visits and

building relationships with staff members. The third sub-theme, "Overcoming barriers to

care" is a description of women's resilience in consistently overcoming barriers to care in

accessing services at the ART-CSC. The final sub-theme, "'Thin box messaging' about

women's informal caregiving labor at the ART-CSC," describes communication patterns

between women and health workers on the subject of informal care provision.

Renewing physical strength.

One of the major facilitators of women's access to care was the physical

improvement in their health. Women's physical recovery was a result of a combination

of the positive medical effects of ART and women's resilience in their ability to follow

instructions and counseling received at the CSC. Ironically, because their husbands were

ill and they were helping them find appropriate healthcare, women were often diagnosed

and referred for care that improved their health. Once women were connected with the

ARTC in one of the two public hospitals in Lucknow, they received free ART and begun

ART treatment.   Despite initial side effects of ART, within a month or two, women

experienced improvements in their health, and these improvements motivated them to

keep coming back for their scheduled monthly visit to the ART center. Women

described a trajectory in which they found it difficult to practice behaviors advised by

counselors in the beginning, including adherence to the ART regimen, but over a period

of time, they were able to adapt positively to the prescribed health behaviors. Women

explained how they felt before starting ART and how they felt after several months or

years of being on ART medications.

> Since I started medicines, I feel much better… Before that, I could not even drink
>
> a glass of water without feeling pain. Now I can cook, clean, do roza and namaz
>
> (pray).

Improvement in physical health assisted women in living their everyday lives

with greater ease and in performing caregiving activities. In addition to experiencing

physical improvements, women used the new information they received at the ARTC and

the CSC. Given that women had been seeking information about HIV and informal

caregiving, once this information came from an authoritative source (the counselors and

health workers) it appears that women found it reassuring and easy to follow. Women's

narratives about their experiences of being counseled demonstrate faith in the counselor

and an uncritical surrender to the information they received. Women attributed the

improvement in their physical health to the medicines but also to the new behaviors they

learned at the CSC related to nutrition, cleanliness, or condom use.

> Now we always use condoms. I am comfortable after eating the medicines.
>
> Initially, my whole body would get this burning sensation. We did not use
>
> condoms before… Everyday I would feel unwell but since I have started taking
>
> the medicines, it really feels much better.

Another woman described how she follows all the information she receives from

health workers at the ARTC-CSC. Dolly (below) seems to easily absorb information

received from the counselors. Given that women were provided a lot of information on

various subjects, it is possible that they often left the counselor with information that was somewhat open to interpretation. As Dolly's quotation below indicates, it appears that women were often making sense of pieces of information on their own, when it was not clear why they had been asked to take certain actions.

> Yes, I do everything like it is told…That information was helpful… Before that I did not know at all how these things are done. Initially, I could not speak proper Hindi also… Now I have learnt a lot, I use my brains to think about things…What has been told and why it has been told and I follow the information.

Because Dolly lived in a village and spoke what is generally considered a dialect of Hindi (in contrast with more traditional and clear Hindi language spoken in Lucknow), she attributes her learning of proper Hindi to her repeated visits to the CSC and her interactions with health workers. She also describes the way in which she processes the information she is offered, by thinking about why she has been asked to behave in certain ways and what the advantages may be. When saying that "I use my brains to think about things," Dolly demonstrates a certain level of self-reliance. The perceived sense of autonomy and self-reliance an individual feels, and the autonomous language and behaviors one uses have been associated with resilience (Masten & Garmezy, 1985) that assists individuals in adaptation during adversity. Another woman uses similar language, which demonstrates high levels of self-reliance in overcoming the adverse situations in her life. Here, Leela emphasizes depending on herself for improvement in her health. Leela asserts:

Yes, I support myself, I am my own best friend because who else is there? I make

my own timetable, I eat, take my medicines, I take care of myself…Now this is

the 4th year of my medication… I have been going on, on my own.

Women who had been on ART for longer periods of time mentioned the ways in

which they disciplined themselves to ensure ART adherence. They also traced the

changes between initial difficulties faced in forming new habits and their eventual

success in persisting with the new behaviors. Phool said:

First, I had ART in the morning and evening but now only once at night. In the

beginning, I used to forget. So… I told myself that I have to eat food and

medicine together. Everyone remembers to eat food. So, when I start eating, I

keep the medicine next to the food. Now it has become a habit, I remember

now… When to eat ART. For many days, I have been eating now, so I do not

have to remember the time any more.

Women's experience of physical improvement must be seen as a combination of

the positive medical effects of ART and their resilience in adhering to the ART regimen

that requires high levels of adherence to be effective (Bangsberg, 2006). Women

practiced high levels of ART adherence despite facing negative side effects of ART and

other adverse circumstances such as poverty and their caregiving burden.

Interviews for this study were conducted at the Care and Support center and

therefore, respondents who participated in this study were those who consistently

returned to the ARTC center to receive ART and were able to overcome initial barriers to

accessing care such as costs associated with transportation and accommodation, long

distances to the ARTC/CSC, and problems associated with women's personal safety

when traveling long distances. Apart from the improvements women experienced in their physical health, another factor that motivated women to return to the ARTC for repeat service utilization were feelings of community with the health workers and counselors.

Developing peer relationships, sense of community, and purpose.

Developing positive relationships with peer counselors and other health workers was an important motivational factor for women to return to the ARTC and the CSC. The integration of peer relationships in health care provision for HIV/AIDS is an important aspect of health promotion, especially when counselors and outreach workers who are HIV-positive themselves stand as examples and role models for newly diagnosed patients (Mwai et al., 2013; Simoni, Nelson, Franks, Yard). For many women, relationships with staff members at the CSC were the most supportive relationships they had in their lives, especially because women could easily confide in female staff members about the status of their health and their family situations. Women described feelings of community, safety, and togetherness at the CSC. Women who regularly attended community meetings felt supported in their life by the outreach and health workers at the CSC. Leela asserts:

> Here I feel good. It feels as if everyone is a family… Even if someone is HIV-negative, it does not feel as if they are separate from us, everyone's feelings are similar, it feels good. Even when I go to the ART, no one will misbehave, everyone talks properly and respectfully.

Women experienced a safe environment where they could speak freely, talk about their emotions and worries, and develop relationships with other HIV-positive women

and outreach workers, some of whom are also HIV-positive. Shanhaz describes what she likes about visiting the Care and Support center regularly.

> I feel very good coming here (CSC), I feel togetherness. Talking to everyone, laughing with everyone here, it feels very good. It feels like a family and community. There is no discrimination here and everyone who comes here is HIV-positive so everyone can understand each other's feelings.

Women who repeatedly visited the CSC for group meetings and other community events such as the celebration of festivals or camps held for a specific purpose such as getting clients' identity cards made, developed deep bonds with staff members and found a new purposefulness in their lives. Staff members encouraged and assisted widowed women or those separated from their spouses to find new partnerships with other HIV-positive men, helping women find support and purposefulness in their everyday lives.

> I have received good help, they explain to me… They motivated me, they even told me that I could try for marriage again if I wanted… If a woman feels demotivated in life and loses strength, if she comes here she will feel motivated again, she will feel stronger. She will want to live.

At the time of their HIV diagnosis, many women had assumed that they were not going to be able to live long lives anymore. Many recalled having suicidal thoughts or thoughts of not wanting to live anymore. It appears that when improvement in physical health was accompanied with social support developed through relationships built at the agencies, it offered women a new sense of purposefulness in life.

> There is a difference between then and now… A big difference… That time I thought I will die… But there is a big difference now, I am there, there are many

other people who also have children, who are helpless and do not have much information. They are not able to attend meetings, and they are just having medicines somehow (just surviving) ... So yes, I feel stronger now with the information I have.

Social support from family or non-family networks plays a critical role as a protective factor against stress and poor mental health and assists individuals in building resilience (Guidance & Watch, 2007; Yadav, 2010). In the case of respondents for this study, non-family social support networks developed through health workers at the CSC played a critical role in improving clients' general feelings of wellbeing and developing a new sense of purpose in life.

Overcoming barriers to access.

Women faced barriers in accessing services at the ARTC and associated CSC. It appears that women's resilience in overcoming initial barriers to access facilitated their connection with HIV services. Once women experienced some relief from accessing health (medical and psychosocial) services, they were able to better overcome similar barriers to access continually. One common barrier was long distances to travel to the hospital offering free ART. Women living in poverty often had to scrimp and save money for their travel to the ARTC. Every month, Noor saves money for transportation to collect her medicines on time. On the day that she travels to collect her medicines, she is unable to work, causing a loss of wages in a life situation where she is already feeling immensely financially constrained. Noor says:

I have to travel so far to get the medicines, it causes loss of work or somehow or the other, gather money for transportation, my railway pass is made but other costs are still there, jeep costs… But my health is better, so I come.

Sakhi explains:

The day I come to collect medicines, I do not send my daughter to school. I tell her that she has to stay at home and be around the other children. She is a 12 year old girl, so she goes to school. Today I did not let her go to school so she can look after the baby boy. So, there is loss… Loss of work and study time.

Women lost time and wages, and their children lost school time as they acted as baby sitter for their younger siblings while the mother was away traveling to the hospital. In addition to these constraints, women felt unsafe in traveling long distances, using public or privately pooled transportation. Respondents often had to commute overnight over two or three days to arrive at the ART center. Rani is the oldest participant in my study and a recent widow. She describes the costs of transportation and long distances as barriers, but what felt most disturbing to her was the lack of physical safety she felt as a female traveler.

If it is night and I come from very far off, it takes 200 rupees one way for transportation costs, it helps to have a male accompany … During the day, it is fine (to travel) but when I come here at night I do not feel safe.

Women feared for their physical safety and felt scared of being mugged, molested or attacked. This was especially true for women who were traveling long distances alone and could not afford to stay overnight in hotels or more comfortable dwellings. Despite the difficulties they experienced in accessing care, participants in this study continued to

travel consistently to the ARTC, convinced of its value by the improvement in their overall wellbeing.

It appears that there are mutually reinforcing influences between the initial self-efficacious behaviors that women use and how they accumulate into a deep sense of self-reliance over a period of time. Overcoming barriers to access to health services, through actions such as raising money for traveling and arranging for transportation and childcare, perhaps led women to an enhanced sense of self-reliance. In a culture that encourages women to depend on men, these women's independence in areas such as financial, infrastructural, and logistic support seem to enhance women's sense of self-efficacy.

"Thin Box Messaging" about women's informal caregiving labor at the ART-CSC.

In this section I demonstrate the counseling and messaging women received from health workers at the site of the ART-CSC about home-based care and their role as caregivers. Health workers followed guidelines under the National AIDS Control Organization's rubric of "home-based care" (NACO, 2013a) for training women for informal care provision. Women's narratives demonstrate that health workers did not perceive women's role as caregivers as a burden women carried while living with HIV themselves, but as a given normative role. Information and education offered to women for their caregiving role was directed especially towards their husbands as care recipients. Their information was limited to measurable and concrete subjects such as nutrition and cleanliness, rather than the woman's psycho-emotional wellbeing as a caregiver living with HIV. When I asked women about what kind of help or information they had

received from health workers at the ARTC/CSC as it pertained to their caregiving role, they almost always focused on cleanliness and nutrition. Manju says:

> Yes. How to take care… To keep everything clean… How to change clothes… These kind of things… I was told how to take care of your husband and how to keep clean. So, I had some information. To give him nutritious food… Green vegetables… Do not give him stale food… Never give him old food… Do not touch oily food. I follow all of this.

Women were sometimes told to not nurture bad feelings towards their partners. Although such health workers' counseling appears to be well intentioned, it failed to address women's feelings of resentment, anger, and the many dilemmas women faced as caregivers. Given that women were making positive meanings of their caregiving labor, as seen in Chapter 4, and seeking authoritative knowledge on the subjects of HIV and informal caregiving, it made it easy for them to follow health worker's instructions and counseling without asking more questions or critically thinking about the messages they received about what they should do as caregivers. Another respondent, Dolly asserted:

> Yes, they told me that you provide timely food and medicine for the husband… It is not good to keep bad feelings towards him. Eat and drink on time, sleep on time… When I get up on time, then whole day I will be energetic.

The cursory information women received about caregiving may be attributed partly to the short amount of time allotted to counseling each woman individually and partly to health worker's perceptions of women's caregiving labor as a given way of living for women in society, rather than viewing their labor as a burden on already ailing women. Neelam says:

Yes, the counselor at the ARTC, she told me about food and nutrition. She

explained that it is not a disease of untouchability... It will not happen by food…

It is just that he has TB (tuberculosis) so I should not eat from his food.

Apart from the emphasis on nutrition and cleanliness, counseling about home-based care

included dispelling myths about condom use and modes of HIV transmission. Women

were almost never told to prioritize their own health, to develop healthy boundaries with

the care recipient, or to ask the care recipients to participate more actively in caring for

the woman herself (e.g. eliciting psychosocial care).

I call this process of offering cursory information on the subject of women's

informal caregiving burden "thin-box messaging." Thin-box messaging is a process in

which repetitive, yet "thin," messages are sent to clients about what they should and

should not do. Messages are thin because they do not communicate with clients at a

deeper level about the psycho-emotional aspects of the issue at hand and do not answer

the purpose or rationale of the solution or advice that is being offered. Further, when

clients who are already seeking authoritative knowledge easily accept thin-box messages,

such messages help create a narrow view on the subject of informal caregiving among

women and put women in a position where they develop caregiving practices based on

that narrow view.

Thin-box messaging allowed health workers to perform their duties according to

guidelines without ever addressing deeper issues women faced in their caregiving role

while ailing themselves. In addition, women's positive meaning-making about their

caregiving role assisted in their uncritical surrender to health worker's messages, creating

a limited or box-like view of their role and what they should and should not be doing.

Caregiving practices based on thin-box messages received at the ARTC-CSC reinforce women's action-orientation as a caregiver, discussed in previous chapters by repetitively focusing on nutrition and cleanliness rather than acknowledging and addressing the emotional journey of the ailing woman as a caregiver. The process of thin-box counseling messages about home-based care does not acknowledge women as ailing women, nor even as women juggling many responsibilities. Thin-box counseling reinforces societal messages about women that view them as the natural and given predominant caregivers of ailing men and children.

Women experienced shifts in their physical and psycho-emotional health through connections with health services at the ARTC-CSC. Given women's prior search for information, women were extremely receptive and diligently followed instructions from health workers. While in some cases, this was highly effective, such as assisting women in maintaining high levels of ART adherence, in other cases, women's uncritical surrender in being receptive to thin-box messages from health workers reinforced narrow views of their role as informal caregivers, roles they themselves did not question.

The Home Visit

The home visit serves as a critical point of intersection between formal and informal care provision. The purpose of the home visit is to provide personalized services, tailored specifically to the woman's life situation. In this section I describe facilitators and barriers women face in accessing services during the home visit. This section includes five sub-themes, including "Facilitators: Comforts of the home visit," "Barriers in the inner circle of care: Women's living arrangement and HIV stigma," "Women's management of threats of stigma and discrimination," "Assessment during the

home visit," and "Health worker construction of the "harmful" home visit." The home visit offers women relief from barriers faced while accessing services at the ARTC-CSC, such as travel, expenses, and safety. Yet, unlike the ARTC-CSC, where women do not feel so deeply threatened by the effects of any potential stigma and discrimination, accessing health services during the home visit requires women to manage threats of stigma and discrimination from family and community members in order to access health services during the home visit.

Facilitators: Comfort of the Home Visit.

Participants expressed both comfort and discomfort in being visited at home in almost equal proportions. In this section I describe responses from women who were comfortable having health workers as home visitors and identify the reasons for their comfort. Some women preferred being visited at home because they felt greater ease in being able to speak with outreach workers while avoiding the costs and time associated with traveling to the ART center. In addition, women felt comforted and assured being visited in person by a health worker. One of the women participants, Phool explains:

> I have no problem with anyone coming home. If they come more frequently, I will feel more helped. If I have a problem I will be able to talk to them, now we talk on the phone first, but that is different. If they come home and we talk face to face then that will be better.

India has a diverse and complex family system. For the purposes of this chapter, single or nuclear family arrangement refers to family units comprised of a couple and their children, while extended or joint family living arrangements, which are more

common in India, comprise of two or three generations of couples living together along with their children (D'Cruz & Bharat, 2001).

Women who were willing to be visited at home by outreach workers were often those who were living in nuclear family arrangements, had revealed their health status to family members, and faced no discrimination from family based on their health status. Other women who were willing to have outreach workers at home were those who were self-assured, irrespective of their living arrangement (nuclear or joint family arrangement) that they would face no discrimination from their family members (fewer respondents), or those willing to manage their confidentiality with family or community members who may raise questions about frequent visitors, especially when they were male. Asra says:

> It (home visit) is good and sometimes people visit me also... If they can visit once or twice a month that will be very good, from time to time that will be good. I do not have any problem (having visitors). It will be useful… It makes me feel cared for, it makes me feel supported and if my problem increases, I have someone to talk to about it.

> Shri: How do you think it affects your confidentiality?

> Asra: It does not matter… I am careful that people around, neighbors, do not ask me questions… Nothing really happens... If someone asks, I will tell him or her that she is my friend who is visiting.

Another respondent, Begumsharara, lives in a joint family arrangement with her sons and daughters. Everyone in her family is aware of her health status but she does not experience any stigma or discrimination, partially because she holds a position of

authority in her family as an elderly widowed woman. She describes how she appreciates receiving assistance from the health workers because she does not have many family members in her vicinity to assist her. She feels a sense of community with the outreach workers who visit her. Begumsharara expounds on this:

> The advantage is that if something happens to me, these people will show me (to the doctor), take me there, all this they will get done. That is the happiness (advantage). We do not have many people in my husband's family, they all live in far off places. So, these people (outreach workers) will help me get my work done. That is the happiness, they feel like our own people. It makes me feel happy to invite them, host them, feed them food and water, whatever I can do for them.

The home visit offered women ease in accessing health services when health workers connected women with other services and helped avoid barriers to access in traveling to the ART-CSC. Yet, the extent to which women were able to use health services offered through the home visit was dependent upon their living arrangement and their management of confidentiality and health status. Even so, some women expected HIV related discrimination and stigma from their inner family circles. Women's nuclear or joint family arrangement often played a critical role in whether they could use the option to have health workers as home visitors.

Barriers in the inner circle of care: Women's living arrangement and HIV stigma.

HIV-related stigma and discrimination are major barriers to access of services and ART adherence in India. HIV-positive people experience stigma from health workers

and in the family and community (Kumarasamy et al., 2005; Mahajan et al., 2008; Rahangdale et al., 2010; Rintamaki, 2006). In this section I demonstrate how some women expected stigma and discrimination from their immediate family members such as their siblings or parents-in-laws, neighbors, and community members. For many women, having a visitor at home depended upon their single or joint family living condition, the woman's perceived threat of stigma and discrimination from family and community members, and whether she had already disclosed her health status to family members.

Many respondents shifted between nuclear and joint family arrangements. Women lived in the city with their husband and children but had extended family members from their village of origin visit them for long periods of time. Jhilmil currently lives only with her husband who is also HIV-positive and the couple is aware of each other's health status. However, out of fear of being stigmatized and discriminated against, she has not revealed her health status to other family members who visit her. While Jhilmil sees the benefits of being visited by health workers, she considers the home visit a problem if other family members are present during the health worker's visit. Further, if the outreach worker wants to talk to her alone, as a cultural gender norm in her family, she would have to be accompanied by a male family member. In her situation, where only her husband is aware of her HIV-positive status, she does not want to be accompanied by anyone else, except her husband. Jhilmil says:

> Right now, no one is there at our home... Right now, it is not a problem… If there were other people in the family it would be a problem… They would ask why are they calling you (for medicines) … Someone would accompany me… Then I

would not want that anyone except my husband should accompany me… Right now, no one else (extended family members) is there, so someone (health worker) can come home.

Women who had non-abusive relationships with family members free from physical and emotional abuse, could safely confide about their health with them. Women who were living in nuclear family arrangements felt more comfortable having outreach workers visit them because their living and family conditions made it possible for them to not feel serious threats of stigma.

Other women did not prefer having health workers at home; this blocked an important and convenient channel of accessing personalized services, tailored to their life and family situation. Women worried about how community members, especially people who had influence on her life situation such as a landlord who could ask for an eviction, would perceive her character as a woman if she has frequent visitors (especially when they are male). Sakhi is worried that her landlord could find out about who her visitors are and the purpose of their visit. She worries they might discriminate against her family for being HIV-positive and ask them to vacate the dwelling. Sakhi says:

> Someone will do it then only (act of discrimination against her) … I live in a rented house so I cannot say who will think and say what… It is not only us who lives in the house, it is shared… Now if someone comes regularly to visit me… People will think, 'who this is?' If it was my own house, then it would not be a problem... If they will go to another person's house then people will think what is wrong with us and what if they ask us to empty the house? Then where will we

go? So that is why I do not call anyone (for a home visit). I go on my own (to the ART center).

The community environment where women lived and their type of family arrangement was connected with their perceived fear of stigma and discrimination. In some rural or township environments, where many of my respondents lived in close proximity with other families, it was not socially acceptable for women to be frequently seen having visitors, especially having male visitors when other male members of the family were away at work during the day. In addition, sharing space with other families or extended family members implied limited privacy for women where there was always a possibility for people to create a group discussion out of what was originally meant to be a one on one counseling session. Women had limited control over such circumstances that threatened unwanted disclosure of their HIV-status and therefore often did not want outreach workers to visit them. Roshni says:

> No, I do not like it (home visit) … In smaller places if someone visits, people around will look and want to know who has visited and they may even collect around and that may lead to a discussion...in that case… Status can be opened… I do not like someone coming home.

Women experienced one set of barriers when accessing services at the ART center and the Care and Support center such as costs associated with transportation, loss of hours and wages, and lack of sense of personal safety while traveling. However, despite having the option of receiving personalized health services at home, the threat of being stigmatized and the fear of unwanted disclosure to family or community members

was a critical barrier to women receiving the benefits of a home visit from the outreach worker.

Women's management of threats of stigma and discrimination.

This section describes women's every day practices and decisions managing threats of stigma and discrimination. Women's decisions and practices of managing threats of stigma included the choice of who to confide and who not to confide in, about their health status, when to invite or not invite outreach workers for a home visit, and which aspects to share about their whereabouts and their health with different people. As seen in earlier sections of this chapter, women continue to demonstrate self-efficacious and self-reliant behaviors that cumulatively may be seen as a form of resilience women develop over a period of time. Managing threats of stigma and discrimination required women to make deeply personal decisions on their own, in their everyday interactions. Roshni is a recent widow who has two daughters also living with HIV. She ensures that she manages disclosure around the disease very carefully. Although she currently lives with her parents-in-law, she has managed to keep her own and her daughter's HIV-status hidden from her father-in-law because he carelessly talked about her husband's HIV-positive status with people when her husband was alive. She is particularly concerned for her daughters because she realizes that girls and women experience stigma and discrimination in more severe ways than men. She says:

> Yes… I live with my in laws family, I have not told them, my father-in-law does
> not know… Because when he had it (her deceased-husband), he [her father-in-
> law] would go and tell everyone very casually that my husband is HIV-positive.
> For myself, I am not so scared, but I have daughters. The society is not so aware

that they will participate in their marriages and other social things later in life...

So that is why I keep it confidential, I did not tell him.

Family and community members who did not understand the health or social implications of being HIV-positive often surrounded women. In addition, in the absence of information or health literacy about HIV/AIDS, friends and family members of the woman often did not take seriously the women's health situation or the implications of talking about the woman's health publicly and casually among people. When women expected discrimination based on their health status, they commonly practiced telling family members that they are "ill" but withheld any information about themselves about being HIV-positive. Manju says:

> In-laws are there, I have not told them about it (HIV). They do not know. They know that I am taking medicines; everyone knows that I am taking medicines but I have not told them about it (HIV)… I have not told them because then they will start discriminating. That is the reason that I have not told them.

Women expected discrimination, based on their health status, from family members and particularly in-laws if they revealed their health status to them. This discrimination could take the form of blaming a woman for the couple's HIV status, asking her to leave the house, withholding social contact from her, isolating her, or other forms of ill treatment. Women coped with the threat of stigma and discrimination by making up false stories about the places they visited and the people they met, as it concerned their health. Dolly whispered:

> I think there will be discrimination… Already when I eat medicines, they ask so many questions, for what are you eating medicines?… In my mother's family

also, I have my brother's wives who will keep asking me-for what are you eating all this medicine? For what purpose are you constantly going out on these meetings? I tell them that I do the meetings for something but I do not tell them that I meet for this purpose (HIV).

Asra was in a physically and emotionally abusive relationship with her husband. Now she is seeking a divorce and lives with her brothers in her parent's house. She has been unable to share her health status with her brothers because of the fear of being stigmatized and discriminated against and being asked to leave the house. She narrates hiding her medicine boxes from her family members and being discreet about her explanations in case she is seen using the medicines.

I hide my medicine boxes from everyone because my brothers will say, "What is all this medicine you are eating?"' They observe me. They will say, "Show me your medicines." He (her brother) has a medical store so he understands medicines… He said- "I will get your medicines" so I said… "No, my medicines come straight from the hospital and it does not cost me anything." Then he did not put too much pressure on me to show the medicine to him. But if he puts pressure, sometimes I will tell him that I do not take the medicines anymore, they have been stopped... I feel that if I tell them the reality, they will discriminate, they may ask me to leave.

Apart from the management of the physical aspects of the disease, managing perceived threats of stigma and discrimination added another layer of work that required consistent vigilance from the women. Women tended to have more negative expectations of being stigmatized and discriminated against from their family and community

members, versus having positive expectations of receiving informal support. Women

spent considerable time and energy thinking and planning to protect themselves from

unwanted disclosure to people around them.

In the following section I describe health workers' perceptions of their role during

the home visit. Health workers' roles during the home visit are partially driven by

guidelines by the National AIDS Control Organization for the home visit (NACO, 2013a)

yet there was a broad scope for health workers to define their own agenda and order of

importance of issues to be addressed to clients during the home visit.

Assessment during the home visit.

In this section I demonstrate how the agenda for the home visit is pre-defined by

health workers and contributes to the marginalization of women's voices and the

invisibility of the subject of women's informal caregiving burden. Although the home

visit is an opportunity for health workers to assess women's burden of caregiving and

address women's health, a narrow and predefined plan for the home visit limits the utility

of the visit itself.

Outreach workers received a brief three-day training to perform home visits and

conduct outreach work in communities. Outreach workers had a broad framework and an

undocumented list of subjects they would attempt to address during the home visit such

as ART adherence and HIV related stigma. Outreach workers were trained to intervene

and counsel HIV-positive people in their homes on subjects like cleanliness, nutrition and

monitoring ART adherence. In addition to these subjects, health workers intervened in

situations of stigma and blame towards the women from family members, especially in

situations where women had recently disclosed their health status to their family, on

being diagnosed HIV-positive, unaware of the potential consequences of disclosure. Gulab is a counselor at the ART center. She provides a description of how she thinks outreach workers should approach their work and the subjects they should cover with the clients in their homes. Gulab asserts:

> Sanitation should be checked. On next visit if the wife is not tested, get that done. Third time go talk about home-based care… Notice what is coming out in their plates (what kind of food) …What is their nutrition? How much stigma they are facing? How their in-laws are behaving with them? How their husband is behaving with them? These are just things you have to quietly observe, there is no need for conversation. Anyone's house you go and just sit quietly, you can get to know the history of the household…What is the situation? The home visit should be planned for multiple purposes, not just for missed or lost to follow up cases.

Raees is a male outreach worker. On visiting women's homes, he gives attention to the environment in which women are living and its effect on their physical health. He also uses the home visit to connect HIV-positive people with other health or welfare services.

> Where the cooking is being done, it is not clean; they are drinking running water from the tap so we tell them to boil the water. To cover their food, cut their nails and wash their hands. If they can be connected to another institution then we do it... For example, if there are positive children… They can be sent to the Aanganwadi [government school and nutrition program for children]. From there, they can get nutritious food.

Home visits may be scheduled previously or may be surprise visits when the client does not have a phone connection or another channel of communication prior to the visit. In some cases, home visits are conducted in emergency situations. Angad is a trainer for outreach workers currently and he has previously served as an outreach worker himself. Angad recalls an incident when a wife received a HIV-positive result first and on informing her husband about her health status, her husband blamed her for having extramarital relationships and asked her to leave the house. She contacted Angad and he went to intervene in the situation the following day to counsel the couple and ask the husband to get tested.

> Angad: He was angry and he asked her to leave the house. We received calls at night… Next day I visited the village myself and took along with me team members from the village and the doctor who had referred her… We went to the lady's house and her husband was not willing to listen at all. He was saying that she is cheating. I told him that "Look, the situation is this, that it so happens that your wife's checkup has happened before… So that is why you are thinking that… She is wrong and has bad relationships and behaviors. Same condition if you were tested first and you were HIV-positive, would your wife treat you the same way and say that your behaviors are off and you do wrong things... One time please get yourself tested, let us see what happens."

While issues associated with nutrition, stigma, and general health are important in their own right, the informal caregiving burden of the woman to HIV-positive family members was not a point of assessment or consideration during the home visit. Despite being ill themselves and reporting a deterioration in their own health during most intense

phases of caregiving, as demonstrated in the chapters before, women seem to have rarely brought up their informal caregiving burden as a topic of discussion during the home visit due to their deeply internalized gendered role as a caregiver. In addition, as noticed at the site of the ARTC-CSC in an earlier section of this chapter, women demonstrated an uncritical surrender to the information they received from health workers during the home visit as well. Women had been seeking an authoritative source of knowledge and once they find it in the health workers, they are comforted and unlike the earlier phases of caregiving where they follow their own sensibilities about what they should and should not do as caregivers, at this stage when women are well connected with health services, they uncritically follow advice, instructions, and counseling offered by health workers during the home visit.

Health workers did not seem to consider women's informal caregiving burden of any particular importance. Although stigma and discrimination were important topics in the context of women's psychosocial well-being, most of the topics of assessment during the home visit (such as cleanliness and ART adherence) were meant to be means for targeting the improved physical health of the client and her family rather than her overall psychosocial well-being.

Health worker construction of the "harmful" home visit.

Outreach health workers, some of who were living with HIV themselves, were well aware of the threats of stigma and discrimination that women faced. Health workers thought that frequent home visits were not a good idea due to the potential negative effects it could have on a woman's confidentiality. SherSingh believes that it is better

that outreach workers conduct few home visits and spend more time with the clients on each visit, rather than visiting them frequently.

> SherSingh -The thing is that if for any woman, if we are visiting her home regularly then any one can question her, from the neighborhood or anyone, and this way we may put disclosing her identity at risk… Whatever her need is, visit her accordingly, minimum visits should be made, once a month, once in 2 months but when one visits then spend a few hours, understand her needs, document everything properly, sort things out for her.

Health workers understood that the home visit could risk disclosure of women's health status. As a response to the risks a home visit posed to a female client, health workers viewed the home visit as a necessary evil since it is part of the guidelines of routine work for outreach workers at the CSC. Bhanupratap asserts:

> I do not understand the idea of going to everyone's house… Because suppose a woman is sitting with her entire family, she has guests over, now I go there… On the way, my mobile battery goes off (runs out of charge). Now I was not able to call her. I visit the house and now the woman gets so nervous seeing me, she thinks, "I hope he does not say anything by mistake. I hope it does not happen that he says something that people in my family get to know that I have HIV" These kinds of problems we have… But according to guideline we have to do. It is part of our job.

In addition to the family environment and living conditions of the woman, the gender of the outreach worker impacted the quality of the home visit. Although ideally a male and a female outreach worker are expected to visit an HIV-positive couple's home

together, given the shortage of staff members, this was not always possible. Gulab raises the issue of rapport building with a female client and women's general discomfort in being counseled by male outreach workers. Although health workers realized the cultural appropriateness of having female outreach workers on every home visit, this was not always possible.

> We try to be careful, if a female does not go then there is no rapport building. If a man talks about STI (sexually transmitted infections) to a woman then she will not be able to talk. Even though we are very educated, we also will not feel comfortable. So, this is an important criterion. For females, females should go (for outreach work). This they have to plan at the CSC level.

Health workers explained the necessity of maintaining gender balance among staff members so that female counselors and outreach workers could assist female clients.

> We are trying that the gender balance should not be disturbed and if we have two outreach workers, then we should have one male, one female, if we have two counselors, one male, one female, … And according to need we can send a man or a woman for the visit but it is not always like that.

Health workers face two concerns in providing health services during the home visit. First, they believe that the home visit could cause more harm to the woman than being of assistance to her due to the fear of unwanted disclosure of women's HIV status. Women's narratives corroborate that threat to unwanted HIV disclosure is very real, because women's living environments do not afford the privacy required for having confidential conversations with outreach workers. The second problem that outreach workers face is the practical challenge of not always having female outreach workers on

site who would be better counselors for married women in their homes, due to women's preference for speaking with a person of the same gender. These factors undermine the sociocultural acceptability of the home visit as a feasible outreach process for female clients living with HIV.

However, to address the issue of dealing with the home visit as a threat to the woman's unwanted HIV disclosure, health workers develop consensus that frequent home visits cause more harm than benefit. Although the threats of unwanted HIV disclosure due to frequent home visits is very real, in developing consensus about the "harmful home visit," outreach workers mirror women's fears surrounding stigma and discrimination. In mirroring women's fears, they lose the opportunity to manage threats to stigma on a case-by-case basis or develop more sustainable solutions. By developing consensus that home visits can do more harm to women than benefit them, health workers respond to the situation as a protective measure towards women and simultaneously reduce their work load from the need for more frequent home visits.

Because this is not a study on stigma and discrimination, it is hard to offer solutions as an alternative to not conducting frequent home visits. However, it seems that health workers develop a blanket solution that deprives women of opportunities to build rapport with outreach workers and gradually address each of their concerns. By perceiving issues associated with stigma and discrimination and lack of sufficient numbers of female outreach workers as problems that cannot be solved, and by viewing themselves as somewhat ineffectual in addressing these problems, health workers mirror women's fears, maintain the problem, and abstain from finding any real solutions. Further, in believing and developing consensus that home visits can do more harm to

women than benefit them, health workers establish their benevolence and protectiveness for women clients as a way of keeping women safe from the negative consequences of unwanted disclosure, while reducing their own work load in lowering the number of home visits.

Health workers put more emphasis on the quality of the visit rather than the frequency of the visits as their solution to managing threats of stigma. On face value, this seems to be a reasonable solution. However, at this point, it is important to observe that health workers predetermine the agendas for the home visit in two ways that may undermine the quality of the home visit. First, the agenda for the home visit is set up to address emergency situations with women, such as cases of severe ill treatment from family or community members, for example, being asked to leave the house based on allegations due to HIV health status. Second, the agenda for the home visit is predetermined to address more tangible and measurable issues such as to teach a woman to maintain sanitation and cleanliness or address ART adherence.

Further, it appears that there may be an association between the lowering of the number of home visits to women and addressing only measurable issues. When health workers do not visit women frequently, they lose the opportunity for difficult topics such as gender division of labor or informal care to evolve organically in conversation. In addition to reducing the number of home visits, another factor that prevents informal care provision as a topic for assessment is women's inhibitions in delineating their concerns during the home visit. When the health worker's agendas are predetermined, they do not permit space for the evolution of a conversation that allows women to reflect on their experiences as an HIV-positive, caregiving married woman and to identify their own

concerns and priorities. These factors contribute to the invisibility of women's informal caregiving burden as a subject worthy of being addressed during the home visit.

Conclusion

At both sites of health services delivery, the ARTC-CSC and the home visit, women in this sample demonstrate their resilience by consistently overcoming barriers to accessing care. Women overcome logistic and financial barriers to access to services, and overcame personal barriers such as fear, forgetfulness or loss of motivation to maintain high ART adherence. In addition, women demonstrate an uncritical surrender to health worker messages as part of seeing health workers as figures with authoritative knowledge. Women's uncritical surrender to health worker messages assists in some spheres, such as women's maintenance of high ART adherence, but limits women when it comes to their overall psychosocial wellbeing and women's internalization of "thin-box messages" from health workers. Thin-box messages create narrow and limited understanding in women about their role as informal caregivers, contributing to the invisibility of women's caregiving burden, especially as ailing women themselves.

At the site of the home visit, women demonstrate resilience by consistently managing threats to stigma and discrimination to support a home environment that would allow them to access services in their homes. Women's preference for having health workers as home visitors depended upon their living arrangement, their perceived or real threats from stigma and discrimination, and their comfort with having a male outreach worker as a visitor. The socio-cultural acceptability of the home visit is therefore low among women. From the provider's end, health workers view women's threat of HIV related stigma and discrimination at home as a problem that renders the home visit

problematic itself and they aim to reduce the frequency of the home visits, while

attempting to increase its perceived quality by trying to increase the number of female

staff members. In the Table 3. below I summarize women's and health workers'

behaviors that enhance or impede access to care at both sites of service delivery.

Site of health care delivery	Client end Access (Gullifard & Morgan, 2013)	Women's behaviors that assist in overcoming barriers to care or maintain status quo	Health worker behaviors that assist in overcoming barriers to care or maintain status quo.
ARTC-CSC	1. Affordability-low 2. Geographic access -low 3. Sociocultural acceptability-high 4. Effectiveness-high	**Behaviors associated with resilience.** 1. Arranging costs of transportation. 2. Arranging childcare. 3. Practicing high ART adherence. 4. Uncritical surrender to health worker advises.	**Overcome barriers** 1. Supporting and encouraging women for high ART adherence. 2. Psychosocial support through various community activities at the CSC. **Maintain status quo** 1. Thin-box communication about care provision. 2. Lack of exploration of women's' psycho-emotional responses to providing care for others.
Home Visit	1. Affordability-High 2. Geographic access –High 3. Sociocultural acceptability-low Barriers a) Stigma/discrimination. b) Gender of the outreach worker, c) Woman's living arrangement 4. Effectiveness-low	**Behaviors associated with resilience** 1. Making decisions about whether/ with whom to share their health status. 2. Managing threats of stigma from family and community. **Maintains status quo** 1. Uncritical surrender to health worker advises.	**Overcome barriers** 1. Attempts to improve gender balance among staff to improve sociocultural acceptability of the home visit. **Maintain status quo** 1. Predefined agenda during the home visit. 2. Construction of the harmful home visit. 3. Preference for infrequent home visits.

Table 3. Represents levels of access to care at the two sites of health care delivery and the behaviors of the two set of respondents in overcoming barriers or maintaining the barriers to care.

Health services at the ARTC and CSC offered relief to women by alleviating their physical condition and providing a sense of community and support that facilitated women's building of resilience. Peer support and physical enhancement in health facilitated women's stay in the formal network of services. The health worker's home visit emerged as a key opportunity for the assessment of women's health, their informal caregiving burden, and the potential impact of women's informal labor on their psychosocial well-being yet it was under-utilized. Also lost is health workers' opportunity to see the home environment and the challenges it creates for women. However, these opportunities are lost because of the low sociocultural acceptability of the home visit among women and health workers' construction of the home visit as harmful itself.

Women and health workers' internalization and normalization of women's role as informal caregivers, health worker's thin-box messaging on the subject of informal care provision, women's uncritical surrender to these messages, and the low socio-cultural acceptability of the home visit, all together contribute to the invisibility of women's informal caregiving burden.

Chapter 6.
The Implicit Contract: Health Workers as Street-Level Bureaucrats and a
Discourse on Women's Health

Introduction

In this chapter, I use descriptive data from health workers to explore the working

context and experiences of frontline health care workers in their professional role, and

their provider-client relationships with female clients, particularly married women. An

exploration of health workers' working conditions is important because their work

conditions interact with their construction of married women's client characteristics,

which, in turn plays a role in defining the treatment of women and the solutions sought to

solve problems associated with delivering services to married women. Although this

dissertation is primarily a phenomenological examination of women's experiences of

being HIV-positive caregiving wives and mothers, I also wanted to examine the

circumstances of the care they are provided, in order to adequately triangulate any policy

recommendations I make as a result of my findings.

I use salient concepts from Lipsky's theory (1980/2010) of "street level

bureaucrats" (SLBs) as a lens to understand health workers' descriptions of their role and

challenges which in turn effect their interactions with women. This lens became a way of

reanalyzing the descriptive health worker data after initially examining the themes that

emerged across the health worker interviews. Lipsky's seminal work (1980/2010) makes

several important propositions about the functioning of frontline workers across public

services and their role in what government policies actually become as they are

implemented on the ground with clients. Here I describe salient concepts that are

applicable to the population of HIV health workers interviewed for this study. Health

workers interviewed for this study met several assumptions underlying Lipsky's theory

about SLBs. These assumptions include the following

1) SLBs are well intentioned and at least initially have a deep commitment to

public service and a strong desire to serve people. Over time though, the hardships and

constraints of their work environments often make committed and complete service

delivery almost impossible.

2) SLBs operate under severely resource constrained environments where they

face paucity of personal and organizational, or community resources, to meet the service

needs of their clients. In addition, in bureaucratic settings, when the supply of services

increases, the demand for those services also increases because these are mostly cost-

effective or free services. Increase in services results in further increases in caseload and

work pressure for SLBs, while resources provided often remain the same.

3) SLBs in their client-facing role end up defining and interpreting policies and

therefore shape what service delivery and public policy actually become on the ground.

Frontline workers who have client facing, helping roles are pivotal actors in shaping

services and public policies because they possess discretion in implementation. Given

that all bureaucracies must manage bureaucratic rationality as a function of knowledge

control (Townley, 2008), and SLBs attempt to justly apply meager resources with

policies that may be conflicting, discretion is inevitable. SLBs individual actions also

shape and amount to agency behaviors.

4) As part of their "patterns of service" (Lipsky, 1980/2010), SLBs develop

coping mechanisms to deal with the pressures and the resource constraints of their jobs.

Following are some examples of such coping mechanisms. SLBs may sort and classify

clients using the process of "creaming" where clients who are most likely to not only benefit but demonstrate the effectiveness of the government service or program are prioritized for services. Creaming takes place because organizations reward SLBs for goals met or client successes, but not for the risks associated with the success, which inevitably implies that clients who are most likely to succeed are chosen first for services. Further, Lipsky provides the example of "triage," a process used by military medical personnel during the world wars to differentiate between dying soldiers, soldiers in need of little medical attention, and those who could be saved with some care and attention, to determine who would be served to maximize the use of resources. The concept of "triage" offers an important analogy to understand the treatment of clients in bureaucratic settings, such that SLBs can make optimal use of limited resources. SLBs may use cursory information to make judgment calls or may decide that some clients are worthier of receiving services than others; or SLBs may also transfer work responsibilities to others such as easily approving others' decisions, or referring clients to other organizations.

Using Lipsky's broad framework, I will first describe health workers' structural constraints and conditions of work in their agencies. Following this I provide examples of how health workers use personal discretion in the redistribution or rationing of services, followed by processes of client differentiation and client construction of married women, as an aid to the pressures of their service provision. I discuss how meanings are made about women's health in dialogic interactions between health workers and women and the appearance of psychological benefits for women in such interactions, which I argue, actually come with unintended underlying harm.

Structural Constraints and the Working Conditions of Health Workers as SLBs

One of the critical responsibilities of health workers is to connect married women living with HIV with welfare services in the state of Uttar Pradesh, in addition to connecting them with HIV related health and medical services at anti-retroviral therapy (ART) and Care and Support (CSC) centers. Health workers in this study faced structural limitations within the non-profit agencies, in delivering services to clients and in interface with the welfare and health systems. Health workers are placed at the Care and Support Centers that follow government policies but are operated through non-government agencies. As in many other parts of the world, India's localized development activities operate through a public-civil-society partnership. In this section, I describe common structural barriers that are an intrinsic part of the agency environment and the broader context of welfare and health service provision in many parts of India, including the site of this study.

Context: A Rutted Road to Welfare.

The provision of welfare services in India operates through a broad and complex government delivery system with a patchwork of government programs provided through different government offices. Welfare programs have varying benefits and eligibility criteria, which on the ground implies that each client served by the health workers may have different eligibility for welfare and requirements for documentation work. Further, individual characteristics such as the health and literacy of the client, along with personal resources, determine how fast and adequately a client is able to receive welfare benefits for which they are eligible. Although health workers had accurate information and knowledge of the required documentation and responsible people in charge in

government offices, they experienced 'red tapism' (Gupta, 2012) or the practice of bureaucratic delays, corruption, inconsistent flow of funds to the beneficiaries, and lack of awareness among people living with HIV about the existence of welfare programs. Some of these circumstances may apply directly to the non-profit agencies that operate the Care and Support Centers but the problems discussed here are an intrinsic and chronic aspect of government service provision, in both welfare and health services in government hospitals.

Akhil is a project-coordinator and one of his responsibilities is connecting clients with welfare programs. He opines,

> One of the major things is red tapism, if a form is needed to be submitted… Our clients are not influential people. A "Below Poverty Line" card needs to be made, the Pradhan (village head) needs to be contacted, these steps take so much time and so much energy is wasted along with expenses, for example, to get certificates made; income certificates or caste certificate, these things take time and money to get done, along with transportation costs or if there are any fees.

Given that SLBs are well intentioned and desirous of serving people and helping clients reach their health and life goals, bureaucratic barriers to accessing services for clients are deeply frustrating and gradually erode SLBs' ability to offer fully committed performance in their roles.

SherSingh sounds frustrated at the state of the functioning of the welfare system and his opinions resonate with a normalization and expectation of corruption in the welfare and government system.

This is India. In India, there is corruption in every government office. One who

earns Rupees 5000 also, he will do corruption for 10 rupees; one who earns

50,000, will do corruption worth 2500, it goes up in proportion. From the lowest

to the highest level, it is everywhere so who all can be addressed… Where to

begin?

Health worker experiences of corruption in the welfare system are supported by

literature that demonstrates high rates of monetary bungling (Dutta, Kar, & Roy, 2013;

Gupta, 1995; Neihaus & Sukhantar, 2013) and bureaucratic red tapism (Gupta, 2012), a

tendency for delays, and a normalization of corrupt practices at multiple levels of

accessing government services (Gupta, 2012). Another common factor why eligible

beneficiaries are unable to access welfare services is lack of information about the

programs and the eligibility criteria. Anand is a project co-ordinator and talks about a

general reluctance in people to access the welfare programs, he says "They are primarily

unaware that programs exist … And the other thing is that, do they want to be

connected?" Anand is frustrated that even when health workers work hard to inform

people living with HIV about available welfare programs, clients are often unwilling to

access the programs because they do not see the benefits of the programs. Although the

structural barriers that accompany welfare provision are indeed troubling, Anand's

narrative about clients' reluctance to access welfare services is actually reflective of one

of the many ways in which health workers construct their perspectives about clients.

Given that most clients are living in poverty and in poor health, it is more likely that they

are unwilling to jump the hurdles in accessing welfare, rather than rejecting welfare

benefits altogether. Health workers' narratives about clients' unwillingness to access

services may be being used as a device to lower case load for welfare provision- health workers cannot provide what clients are not seeking.

Inadequate and inconsistent flow of cash benefits from welfare programs added another layer to the challenges and frustrations faced by health workers when they genuinely wanted to help clients. Although it will be demonstrated in later sections of this chapter that SLBs do have discretion in the implementation of services, there are several areas where they would likely want to effect change but have no power of influence. For example, Bhanupratap has been doing outreach work for several years now and he scoffs at the meager cash benefits that the government's widow pension plan delivers to widowed women. He is further annoyed at the ways in which it makes a widowed woman, living in a poor community, look privileged for receiving money in her bank account. Bhanupratap says this dripping with sarcasm:

> Pension program so that their family and children (can be taken care of)! Widow pension they get ... (Laughing)...It is so much (being sarcastic, lifts his hands to gesture "big") that nothing can happen... She cannot even get vegetables for that much.... If you see you cannot even buy a week's vegetables for that much… And they say that she gets widow pension (as if it is a privilege). She is seen from that perspective that "Oh… She gets widow pension" but if you look closer, what does she get? It is nothing...150–200 per month…In one year Ruppes1800 (27 USD) … In 6 months... So, in that much what can be done? If it is 300 per month.

Bhanupratap's words resonate with a sense of helplessness that many health workers expressed in their inability to have any control over the amount or timing of the

delivery of cash or in-kind benefits from welfare programs. While it is true that the

amount of money that flows through the widow pension programs is inconsistently

delivered to the beneficiaries and is small in amount at Rs300 per month ($4.52), a study

on cash benefits for widowed women in Gujarat, a northwestern state in India, shows that

for many beneficiaries, it was an important and sole source of income on which they

depended for their most basic needs like food and housing (Dullemen & Bruijn, 2015).

Obstacles faced accessing welfare benefits for people living with HIV frustrated and

generated feelings of helplessness among health workers. The following section offers a

picture of the workload and agency environment for health workers.

Working Conditions: One Person, 457 Families.

As Lipsky observed of SLBs working conditions, health workers in this study

found themselves extremely burdened by the sheer number of clients and families they

were expected to serve at the Care and Support Centers. Outreach workers were assigned

to make home visits with families with one or more HIV-positive members in one

geographic area. Outreach work is often made difficult by missing addresses, hard to

find locations and severe weather conditions, in addition to the fact that several health

workers were living with HIV themselves and often suffered poor health. Bhanupratap is

an outreach worker who thinks that he is unable to do justice to the families he serves

because, despite wanting to, he is unable to spend an adequate amount of time in

counseling them. He explains;

> If government made a proposal and sent it, or NGO made a proposal and sent it,
>
> then they had made proposal for 200-250 families… (He thinks that was the
>
> original intention of the policy). But now I have 457 families, so I have to do the

work... But accordingly, the distance increases. If I had 200-250 families…It may be doable, but now it cannot be given so much time… If there are ten people, then one can give much more time… 20… Then there will be shortcomings; the person cannot be taken care of fully… Person leaves the ART, from far off we tell to go here or there and get this or that checkup done… Or when 3–4 people are collected then I can take them there… (To the CSC from the ART center).

Bhanupratap's narrative of his workload demonstrates the tensions health workers experience between what they think the policies initially intended and how health workers are expected to implement them. This then differs from how health workers actually end up implementing service provision under conditions of severe time, energy, and resource constraints. This also reinforces the good intentions of health workers as SLBs in their preference to spend more time with clients and offer quality services and referrals.

Another health worker spoke about the absence of adequate salaries and how the burden of work then affects health workers' motivation to carry out their duties. Dharmendra reminds his staff members of their purpose in serving the community to encourage them. He considers motivating his staff an important part of his work as a project coordinator, even though he is similarly overburdened with excessive case load and managerial responsibilities.

Work is too much; staff is low, contacting 2,000 people! …Our staff gets unnerved, they start to give up and they do not want to do it… That is why when we see the amount of work, our salary is very low… For 6–7 thousand rupees they will stay in the field all day, then they will work in the office, keep contact

and records of 600 clients, so they get unnerved…We have to motivate them and
then they think that they are doing it for the community… If they are providing a
fresh breath to someone, then they can keep doing it. God has provided them with
this opportunity.

As in most government services, wages for workers are low. Here it is worth
noting that public-civil society partnerships function in similar environments and working
conditions as Lipsky had originally theorized for public services alone. Lipsky himself
noted in his public lecture at Rutgers (November 19, 2016) that he had not anticipated the
vast increase in public-private partnerships and the large-scale corporatization of services
at the time of the initial release of his work.

Health workers receive low wages for work that is both physically and
emotionally challenging, adding other dimensions of personal depletion and difficulty to
the social context of the resource constraints they face in their work environments. It
becomes clear that resource-poor women had to actually depend on assistance from
health workers who are also resource poor, both personally and in terms of what is
offered by their work conditions. Team leaders such as Dharmendra appealed to the
emotional motivation and original good intentions of their staff members to keep them
going at work.

 In addition to organizational and personal resource constraints, health workers
often lacked sufficient and consistent training to perform their tasks. The paucity of
trained health workers in the Indian health system is a persistent issue highlighted in prior
studies. Trained health workers tend to be concentrated in urban areas and even then,
they often lack monetary or non-monetary incentives to provide services (Rao, Rao,

Kumar, Chatterjee, & Sundararaman, 2011). They face rigid hierarchies in the health system, and lack institutional support to perform their role (Scott & Shankar, 2010). The ongoing training and support they receive is minimal.

This section offered insights about the structural constraints and working conditions of health workers that make it impossible for them to execute their good intentions for optimal service delivery. In the following section, I demonstrate how health workers use personal discretion despite and within such resource constrained and limiting work environments.

Health Worker Discretion: Redistribution and Rationing

Resource-constrained service provision environments offer broad scope for frontline workers to exercise discretion in the redistribution and rationing of services and goods (Lipsky, 2010). Given the vast numbers of clients to be served, health workers decide whom to prioritize for services and which requests to accommodate or deny. Two examples of health worker discretion emerge from the data with regards to free service delivery to women. Typically, women are expected to collect a monthly dosage of ART from the ART center at the hospital. However, health workers often made decisions to 1) offer more than a monthly dose of medicine to some women or ration medicines and offer less when medicines were under stocked, or 2) bring medicines to women in their homes during home visits.

Caregiving married women who were also financially constrained often wanted to receive their quota of medications for longer than one month in order to avoid the time and costs associated with multiple visits to the ART centers. ART distribution guidelines state that a client is to be offered a monthly dosage of ART, but there are no regulations

clearly prohibiting over distribution (National AIDS Control Organization, 2013b).

Given that predominantly female clients face greater financial, transportation-related, and

HIV-stigma related barriers in visiting the ART center, female clients tend to pose

requests for higher quantities of ART. It appears that health workers feel compelled to

adjust for such requests as a way to support female clients, especially those who are

living with and caring for other family members living with HIV. However, health

workers are often faced with shortages in the supply of medications and must ration and

distribute medicines using their own discretion.

SherSingh describes how sometimes he is able to coordinate with doctors and

other staff members to allow some women to take higher quantities of medicines home,

while in other instances he feels helpless because health workers have little control

(except in times of organized advocacy for bigger stocks of medicines by the UP Welfare

for PLHIV society) over the supply of medications. It appears that when health workers

are unable to assist women in specific ways, they often felt that it was a reflection of their

inability to provide appropriate assistance to women.

> With women… When they come here they ask for 2 months of medicine. If we
>
> are able to coordinate with the doctors and the ART, we try to get it done. But
>
> now recently, only 15 days of medicines are being given out, for the past 15 days-
>
> 20 days… Only some medicines are available, for example the TLE is available
>
> only for 15 days.

It appears, in this instance, that women whose requests are fulfilled are those who

ask, and it is also possible that health workers are making random "worthiness" oriented

decisions, or assisting women who are more likely to be interviewed by senior managers

as part of a government program evaluation process. In this way, health workers may be engaging in a process of "creaming" (Lipsky, 1980/2010) where some women experience greater comfort in accessing larger amounts of ART and are therefore able to reduce the number of visits to the ART center. Although such a decision makes some women feel helped and makes health workers feel that they are helping women, one unintended consequence of such a decision is that women who visit the ART center less frequently, are also cut off from the possibility of receiving psychosocial services which are offered at the linked Care and Support Centers. Care and Support Centers are located a few miles from the hospital where the ART center is located and when women do not visit the ART center for medications, they miss out on the opportunity to receive psychosocial services as well.

When rationing and redistributing medicines, it appears that health workers make more egalitarian decisions as they halved the supply to all clients. Such decisions are often being made in the context of shortages of medical supplies. For example, although several medicines for opportunistic infections are mandated to be freely available to people living with HIV, given that they are often under stocked, clients are then expected to buy them in the free market. In a different interview, Ramkumar talked about the frequent unavailability of medicines for opportunistic infections, despite the fact that they are supposed to be freely available in public hospitals with ART centers.

Shri: I thought that they do get free treatments for opportunistic infections?

Ramkumar: Policy says it should be free but how much we are able to actually provide for free is a separate issue that you can see at the grassroot level. Doctors will prescribe ten medicines and then may be one of those 10 may be available for

free at the hospital and for that medicine also… We may have to ration it and provide only half the dose.

Here it is clear that the rationing of medicines is done out of fear of running out of medicines and of medications not being re-stocked on time. In this situation, again health workers decided to offer all clients half of the mandated free dose. Another health worker corroborated the paucity of medicines and recognized the financial burden of multiple trips on clients due to transportation costs and loss of work and wages. Manoj says:

Sometimes we have to send people back home with medicines for just 5, 10, or 15 days. So, with medicines for ten days, we are asking an HIV-positive person to visit us thrice in the month. Suppose that she is visiting from Barabanki to Lucknow to collect medicines, 3 days or 5 days later she comes again and in a month if she has to visit four times because we do not have the needed stock of medicines then, she has lost four work days.

The discretionary decisions that health workers were called to make required a nuanced balance of assisting female clients in their specific life situations when needed, while simultaneously ensuring that one type of assistance (receiving more ART) did not close doors to receiving other forms of assistance (psychosocial services) because they were always linked with each other. However, it appears that health workers were overwhelmed and did not always think about the unintended consequences of their decisions with clients.

Another realm where health workers exercised their discretion involved bringing medicines to women in their homes. It appears that this discretion rests upon the

relationship of an outreach worker with a female client. Bringing medicines to a woman
at home meant that an outreach worker had to build a special case for a woman and place
a request at the ART center. While left to the discretion of the outreach worker, it was
still a decision that had to be made known to other staff members. An outreach worker
told me, "Sometimes I will take medicines to a woman's home if she is very sick or if she
has a problem and she just cannot come… I have done this few times."

It appears that sometimes out of empathy for particular clients and depending on
the client's particular situation, outreach workers decided to take medicines to a woman's
home. However, this was commonly discouraged because client visits to the ART center
assist in the maintenance of records for treatment regularity. This section offered
examples where health workers exercise discretion. In the following section I
demonstrate how the working conditions of SLBs naturally put them in a situation that
makes it difficult to assist certain clients such as the married women participants of this
study.

Client Construction

In this section I describe health workers' construction of married women as
clients, driven partly by their experiences delivering services to women, partly their own
gendered views, and partly as a result of their work environment that requires the
categorization of clients to simplify service delivery.

Women and paper work do not go together!

The context of the health worker's structure of work discussed in prior sections,
made it more difficult to serve some clients, such as married women living in poverty.
This contrasts with service provision to men or perhaps people living with HIV in higher

income groups. As Lipsky had theorized, the poorer a client is, the more likely it is for SLBs to have influence over them. Even though clients may be typically seen as independent service-seeking individuals, in reality they are often deeply dependent on the public services being provided. This is true for the population of married women living with HIV because they were predominantly living in poverty and had few resources of financial or other support systems. The ways in which health workers constructed their perspective of married female clients may be seen as a combination of factors including gendered perspectives embraced by health workers as members of society, women's actual vulnerabilities and disadvantages in accessing services, and health workers' overburdened and resource-constrained work setting that required that they develop general consensus about the problems associated with client groups in order to rationalize their discretion.

In their attempt to connect women with welfare services, health workers believed that women were immediately perceived by government officials, village heads, and intermediaries in government offices as more vulnerable and easy targets for getting bribes, making it more difficult for health workers to connect women with services, in contrast to men. Most of the women who are receiving services from with the health workers have poor or no literacy skills. They lack basic information about social services and even have little personal information about themselves, such as their own age. The complex and voluminous documentation required of welfare recipients is a barrier to providing welfare benefits in India, generally. Gupta (2012) provides accounts of poor and illiterate people living in villages attempting to access welfare services from government offices. They are unsuccessful because they are unable to provide their true

age because their births were generally undocumented. This obviously creates insurmountable barriers to accessing services and benefits for the clients and makes these types of clients more demanding for the health workers.

Perhaps the gendered treatment of women in public offices is also reflective of the fact that men's literacy rates in the state of Uttar Pradesh are comparatively much higher at 77% as compared to women at 57% (Census of India, 2011). As a project coordinator, Dharmendra preferentially uses outreach workers to escort women living with HIV to welfare offices, even when they are short staffed, to ensure that women are assisted with paper work. Perhaps, the health workers are unconsciously using the principles of "triage" here, to set priorities about which clients are to be served first. In this instance, resources (outreach workers' time and services) are being directed towards those who are perceived to be the weakest, yet likely to benefit, especially as they are caring for husbands and children who will also benefit. This kind of assistance reflects health workers' empathetic view of female clients, yet it is paired with the ideas that women are consistently dependent on their assistance, take more resources to be helped, and are somewhat burdensome. Another health worker noted how welfare officers' perception of women as soft targets make women more difficult to assist and make them a greater responsibility on the system providing HIV/AIDS services.

> If it is a man, we tell them to fill it up (forms) themselves and all these forms and papers when we ask from a woman … It is problematic, women and paperwork do not go together. We ask our staff, but we have only 6–7 staff. We cannot send someone with everyone. We have 800 clients in Lucknow itself and 1200 from outside. If we send one staff for each person…It is not possible and then you

know… If we want anything out of a government office, going once is never enough. Two to three times is average.

Dharmendra describes how many women clients were repeatedly, heavily overcharged (approximately ten times the original cost), for using a computer at a public welfare office. Computer use was required to access their recently made identity card. Further, they needed assistance to log in. Each step was an additional burden and barrier for the HIV-positive women and the health workers who were trying to help them access services and benefits.

If we are unable to go… She will go once and she is asked to come another day. When they see a woman, they will think that it is an opportunity to get money from her… Now the government has decided that it will cost Rs 20. All forms will be logged in from the public welfare office…150-200 rupees were asked out of them. Then they spoke to us, and then we spoke to the government officers and asked them "Why you are charging them so much"? So, then they returned the money to the women.

Clients living with HIV, lacking in literacy, find the excessive and detailed requirements of documentation challenging. When combined with women's poor health and lack of personal finances to do repeated trips to the welfare offices, it meant that women accumulated disadvantages over time that made it difficult for them to access welfare benefits, even when they needed it the most. Another health worker, Ramkumar analyzes the situation when people with HIV and especially married women, attempt to access welfare benefits on their own:

Women accept surrender and think that they do not have the capacity to get the

welfare benefits or insist on it. There are no special welfare programs for people

living with HIV. Whatever is there, is there for everyone… For example, the

widow pension scheme is for all widows, but documentation work, which a

healthy woman can do, for a woman living with HIV, she will not be able to do it.

It is far too much running around offices, different procedures for income

certificates, death certificates, separate steps for Below Poverty Line card. I mean

on every step, she will be reminded of her grief. In all her grief, she sometimes

gives up and denies taking the services all together. She decides she does not

want it.

Explaining that "on every step she will be reminded of her grief," Ramkumar

provides us with an important insight about the experiences of women accessing welfare

services. Grief here refers to different types of disadvantages women are confronted

with, in their experience of navigating welfare offices. First, a woman faces

discrimination based on her being poor and illiterate. Second, she may have already

disclosed her HIV-positive health status to family or community members or may need to

specify it while accessing the welfare benefit which in turn makes her vulnerable to

experiencing HIV related stigma from the village head, community or welfare officer

with whom she is interacting. Third, she is reminded of her status as a widowed woman

in society who now has limited support because her husband may have navigated these

visits with her while he was alive.

It appears that health workers have a patronizing sympathetic view towards

female clients and often attempt to divert resources towards them in ways that are

unspecified by guidelines for operating the Care and Support Centers or the treatment of

clients (NACO, 2013a). However, it is also clear that health workers have a difficult

relationship with female clients because of the additional burdens they pose and the

difficulties faced in assisting them. This section demonstrated how, despite their good

intentions, health workers end up constructing their views about female clients based on

real and expected difficulties in assisting them. This then mirrors traditional gender

dichotomies that may serve women temporarily but do not offer opportunities for opening

a dialogue for sustainable changes in gender relations.

Married women's construction as women who make personal sacrifices

In conversations with health workers, I discovered that they had developed a

common understanding about married female clients as women who made consistent

personal sacrifices for their families. Given that personal sacrifices for the sake of the

family are the hallmark of 'good' women and women <u>did</u> make personal sacrifices for

their families, health workers saw married women sympathetically and with a natural

acceptance of their perceived need to make those sacrifices. Women's personal sacrifices

were self-directed but they were driven by the heavily gender normative socialization of

women. Given that according to Lipsky (2010, p. 59) "client characteristics do not exist

outside of the process that gives rise to them," the ways in which health workers

characterize clients defines the way they treat them. Health workers' understandings of

client characteristics reinforce their practice with clients. As members of society, health

workers replicated women clients in an image, which was not dissimilar from women's

treatment in everyday life in a patriarchal social context as highlighted earlier through a

review of literature on women's lives in India. Anand explains traditional expectations of

a good woman, which he thinks are the same for a woman who is healthy or living with

HIV. Anand also thinks that women are not serious about their own health,

subconsciously placing individual blame on women for not being able to care for

themselves.

> Even when a woman is healthy, even then it is tradition that the woman will be
>
> the last one to eat. If no vegetables are left, she will eat chapatis (bread) without
>
> the vegetables. She is not very aware regarding her health and that is part of
>
> reason that she will do whatever it takes (for her family). Even though her role
>
> should be that she takes care of herself, only then will she be able give service for
>
> her family and children, but she does not think that way… They are not aware or
>
> serious about their health.

It is a strange dichotomy that on the one hand, health workers agreed that tradition

forces women to eat last in their families, and yet on the other hand they thought that

women are not serious about their health and do not care for themselves sufficiently.

Health workers unconsciously located women in a position where they are expected to

take good care of themselves irrespective of circumstances or the structural normative

forces in which women live. Anand also thinks that women should care for themselves

first so that then they can "give services" for their family and children, further building

married women's characterization as "service providers" to families. Women are

therefore in a double bind where if they do take care of themselves, they are no longer

practicing 'good woman behavior.' Asmita is a technical counselor and like Anand, she

also observes that women have adopted a sacrificing role and consistently attend to

themselves last, especially in resource-constrained families where resources, including food, are scant.

> For women especially, I have seen that husband is positive, child is positive, themselves also they are positive, but they will not care for themselves much. They will feed their husbands, if there is one glass of milk at home they will assure that half glass should go to the son and half to the husband, for themselves they will not think much, although they need it the most because they do double work. Women have weaker bones, they need calcium a lot, but they will not care for themselves… I have seen this with my own eyes…This aspect of women's lives.

Another health worker, Bhanupratap has formed a similar perspective during his outreach work with families. He added that men were generally not so kind as to keep up with women's nutritional routines or be concerned about women's health.

> Women may not eat themselves for once… Yes… I am telling what I have seen. Some women have come out that they have lots of financial problems. If they have a cow who gives one litre of milk, she will give to husband then to children, herself she may have chapatti (bread) with salt and (go to bed) sleep… But husbands will not turn around and look into what wife has eaten.

Health workers had developed a sympathetic yet accepting view of women's lives and sacrificing role within their families. In their narratives, health workers simultaneously held women responsible for not caring for themselves, being careless or not serious about their health, while simultaneously expecting them to prioritize their husbands and children. They valorized women for caring for their families and located

women's traditional role in society as sacrificing individuals. Although health workers were well intentioned and wanted to serve every client to the best of their abilities, the language they used in describing problems associated with serving women turned women clients into clients who were careless about their own health yet deserving of sympathy; this came with expectation that they serve others (valorizing). These contradictory expectations then placed a huge responsibility and load on the system (burden) as health workers attempted to help the women.

Good Counseling: Women as Instruments of Caregiving.

Health workers, in their role as SLBs, coped with the tensions they experienced in helping married women as clients by developing a collective discourse about women clients and including it in their counseling practice with women. As SLBs, one of the ways in which health workers exercised control over clients is by "structuring the context of interactions with clients and teaching clients how to behave as clients" (Lipsky, p. 60).

In counseling women clients, health workers told women that they must care for themselves in order to be fit enough to care for their families. Health workers' collective counseling discourse with women had elements of valorizing women as informal caregivers and helpers while simultaneously utilizing them by informally including women as a part of their own (the workers') workforce to provide care to men and children living with HIV. Deepa is a counselor at the CSC and also works at the Prevention of Parent to Child Transmission (PPTCT) centers. She thinks that it is a positive aspect of her counseling practice that she tells women to care for themselves well so that they can care for their families.

> Because she has to manage the family, she has to pay attention to her own health. During counseling, we explain to her "If you will not take care of yourself, how will you manage your family?" … So, it is very important that she takes care of herself and then will she be able to care for her husband and children.

Chandramukhi, another counselor emphasizes this as a "good counseling" practice.

> If we tell women that only when they take care of themselves and they stay fit, they will be able to care for them (family members) … If good counseling is done, then they are able to care for themselves.

Married women respondents in this study corroborated this counseling practice with a tone of pride about the "good counseling" they had received. Women's tone clarified to me that women were feeling, thet psychologically benefitted from the counseling discourse that encouraged them to care for themselves as a conduit to caring for their families, because it offered a sense of relief, while also maintaining the status quo with regards to gender roles and the gendered division of labor within their families. Lipsky stated that psychological benefits are often the hidden rewards for clients, for interacting with SLBs. The counseling strategy discussed above appealed to women partly because women were truly invested in their families as a priority but also because this counseling interaction reinforced women's predominant view of themselves as their family's channel of well-being. This mirrored their existing beliefs. Further, in prior chapters, it became clear that women are seeking "authoritative knowledge" that comes with a sense of certainty and clarity that they are often unable to access in their life situation, thus making it easier for women to accept what they are being told by health workers.

Roshni, one of the married women respondents says:

To be honest my counseling was done in such a manner… When it came out
(HIV-positive status), the counselor said that if I will not eat properly I will not
have a long life. And if I die, then there will be no one to look after my children.
So inside me there is a mother's love (Mamta). Anyhow, I have to take care of
myself. Only then I will be able to care for my children. This (idea) came inside
me. To take care of myself, I eat on time. Take medicines on time and food is
very important... And in this disease, taking medicines on time is important, it is
important to not take gaps in medication.

As evident in Roshni's narration, women were motivated to care for themselves
better and practice better ART adherence when they were told their "utility" in being
alive, which was their role as a caregiver to their family members. Another woman
expressed feeling motivated to care for herself through the counseling she received.
Jhilmil says:

I do not feel like eating, but then I think that if I do not eat, I will not get power in
my body. Then thinking such thoughts, then I have to eat…. Because [they]
explained in counseling that when it [her health] gets better, then I will be able to
take care of my husband and child even better… If I do not stay fit, then I will not
be able to take care of them… Then who will take care of them?

Although women demonstrated a positive response to the exhortations to "caring
for themselves to be able to care for their family," by being more disciplined and
adherent to medications, this framing was actually appealing to their prior internalization
of their gendered roles as informal caregivers and in turn worked to consolidate their

identities as informal, unpaid, invisible instruments of caregiving. A mutual meaning was made about women's health through dialogic interactions that play a critical role in meaning-making and social construction of phenomena, events, or groups of people (Berger & Luckmann, 1966; McNamee & Gergen, 1999). Meaning was made about women's health as a valuable channel of men's and children's well-being through repetitive, psychologically familiar gendered messages.

Lipsky (1980/2010) theorized that street level bureaucrats develop coping mechanisms to deal with the stresses of their working environments. In the context of this study, health workers as SLBs adopted this conversational and counseling strategy that helped them resolve the tensions and position of women's health in society. Instead of questioning women's burden as informal caregivers that often led to deterioration in women's health, health workers found simple solutions in their dialogue with their women clients who live with HIV and care for their HIV-positive husbands and children. In a society where women's gender roles expect them to be informal caregivers, health workers made women's health valuable through the channel of their traditionally precious roles as caregivers. Health workers simultaneously shifted some of their own responsibilities to women, as a part of their own workforce to care for HIV-positive men and children. Utilizing women's roles as informal caregivers as a channel to their own wellbeing implies that women are reduced to instruments of caregiving for their families and that their intrinsic health and well-being has little meaning or value. This re-inscription of women's roles as only of worth to the extent that they provide care for others is insidious as it reinforces an idea that if they have no one to care for them, they have no worth at all.

Conclusion: Understanding the Implicit Contract

I suggest that there is an implicit contract in the relationship between health workers and female clients. In this implicit contract, health workers offset the extra burdens of time and energy required to assist women by eventually controlling them as clients in ways that they are included as part of their workforce by caring for men and children living with HIV. Social control through counseling practices offers the following temporary benefits: 1) maintaining the status quo with reference to the standing of women's health in society, 2) psychological benefits offered to women enable the conversation to be maintained, and 3) women end up sharing the burden of work with the health workers by serving men and children and therefore provide 'pay back' for the burden caused to health workers.

Rather than being agents of change who could help connect women with the intrinsic value of their own health and their own lives, in the background of the hardships and constraints of their work as experienced in connecting women with welfare and health services, health workers sought simple solutions in dealing with women clients (Shukla & McCoyd, 2018). Health workers unintentionally consolidated women's identities and their sense of self as "instrumental caregivers" whose lives and health were important, only as an asset to be able to serve their families, rather than recognized as having intrinsic existential value.

Chapter 7. Conclusions

The predominant meanings that emerge from women's accounts emphasize their wifely duty as a caregiver and often as a mother, irrespective of their personal health. Women view their health status as a barrier to their caregiver role rather than viewing their caregiving burden as a barrier to their fulfillment of physical, mental and emotional well-being. Women's personal values are aligned with the social expectations of them. Women make positive meanings of their caregiving role, their life situation, and demonstrate willingness to improve their life situation from where it is, rather than dwelling on the events that led to their life situation and circumstances. Even though this study demonstrates that the women in my respondent group eventually build resilience (through self-efficacy, building social supports and finding AK), women simultaneously utilize 'gendered pathways' (sense of wifely duty, worrying as a caregiver, putting their husbands' and child's health before their own) reinforced by health workers and built into interactions with their broader familial, community, and health systems. Women utilize gendered pathways towards the mastery of the caregiving role because these cultural pathways (discussed in Chapter 4) are what is known and available to them through processes of socialization and the building of feminine values.

The following aspects of my inquiry are distinctive as I a) examine the complex sociocultural and individual factors that affect the development of a caregiving identity among women living with HIV; b) examine the role of health workers as a stakeholder group influencing women's informal care provision and affecting their identity as female caregivers; c) demonstrate pathways to enhanced self-efficacy and resilience among women; and d) demonstrate the actors and processes involved in the co-option of

women's caregiving role into the service workforce for people living with HIV, for the purpose of caring for men and children living with HIV.

The ability to assimilate in society, fulfill expected social roles, and be recognized for the fulfillment of those roles is a basic human need and contributes to the development of human identity as individuals and as social beings. Humans desire both, a need for connection and socialization, while simultaneously being recognized for their distinctiveness and individuality (Brewer, 1991; Hornsey & Jetten, 2004; Vignoles, Chryssochoou, & Breakwell, 2000). Socialization in specific cultures, however, may tip the balance between individuals being desirous of individuality and distinctiveness or being an inseparable part of the social fabric and emphasizing the need for socially desirable attributes. As the literature review in Chapter 1 demonstrates, Indian society places importance on individuals' cultivating attributes and ways of living and being that put the collective needs of families and communities over and above the self. Given that north Indian social and cultural values place importance on the personal sacrifices of women for their families, it follows then that to be a 'good woman,' a wife must demonstrate being a good caregiver to be assimilated in society and be seen as a valuable member of her family and community. However, the caregiving work appears to come with a perceived expectation from women themselves that such work may not necessarily need support from external sources. Since the beginning of their story (when they had symptoms of illness), women narrate a sense of being alone or being solely responsible for bringing about improvements in their life. It is possible that living in poverty may also imply stretching the utilization of personal resources and individual labor when one is aware that buying services or goods is not an option. This creates a tremendous

burden on women who possess limited social support but also do not have major expectations of being supported, primarily due to limited exposure to a world beyond their family and community and limited information about government support systems.

Women's goal is to ensure the well-being of their families and they rarely consider the personal costs of caregiving in terms of their physical, mental, and emotional health or in terms of personal resources utilized such as their time and money. Women had not articulated the decline in their health previously, seemingly because they did not perceive their caregiver role as a barrier to their own health. Women face various challenges in the process of mastering their role as a caregiver and fulfilling what they often consider their duty. A major challenge women face is the lack of access to information about HIV and strategies for provision of informal caregiving for HIV-positive people. Women actively search for definitive information (authoritative knowledge) about HIV/AIDS and informal caregiving. Women's narratives demonstrate that they had incorrect information (myths) about modes of HIV transmission and what they should and should not do as a caregiver, sometimes even after they were well connected with health services. This demonstrates that there are some disconnections between how, when, and where public information programs for HIV/AIDS awareness are delivered and how the general population receives messages about HIV/AIDS. The majority of the successful HIV-reduction programs in India (for example, Avahan, 2003; Kavach, 2005 and Link-worker scheme, 2007) are targeted at high-risk populations and this may partially explain the myths and lack of basic HIV-information among the general population, including the women in this study. My findings indicate that there are persistent gaps in information-communication and that information about HIV is still

not accessible to women in the ways that it enables women to take basic preventive precautions such as condom use. Additionally, mythic associations of HIV with 'immoral behaviors' mean that women who are living moral lives believe they are safe, which may actually put them at higher risk.

Women's lack of information about HIV/AIDS is consistent with reports from the recent Indian National Family Health Survey data (NFHS, 2015-16). In the NFHS (2015-16), only 19% of women had comprehensive knowledge about HIV/AIDS and information levels were even lower in rural areas where only 14% women in the age group of 15-49 were able to answer questions about HIV/AIDS. The information gap and information absorption about HIV has been a consistent problem in India spanning decades. In a famous TED-talk by Stanford researcher and founder of 'TeachAIDS,' Piya Sorcar (2011) illustrated how HIV-information, communication materials in India in the 2000s were at least somewhat unacceptable to the people and therefore culturally inappropriate for delivering information. Findings from this dissertation study therefore demonstrate that government programs still need to increase their reach of HIV information to general population groups. Mass information, communication, and education campaigns need to identify which communication channels are effective in which cultural contexts so that HIV-information messages are linguistically and culturally appropriate, and creative. They need to be framed in ways that they get the message across for people to remember and practice in their daily lives. In the absence of initial information on the subject, and as an act of assertion to influence their circumstances, women resort to their own sensibilities of how to be a caregiver and what boundaries to draw (or not) with the care recipient. This leads to the utilization of a

personal sense of knowing or 'environ-info' (Shukla & McCoyd, 2018) as part of

discovering and building authoritative knowledge. Women's building of authoritative

knowledge is an iterative process where they are receiving information in the form of

advice from family, or community members, or health workers but must make personal,

immediate decisions about what to do or not do in their particular environment and

situation, in moment to moment caregiving.

In the face of repeated attempts at building their caregiver role and the multitude

of actions and behaviors it requires from women (such as visiting multiple health care

providers, building their own boundaries with the care recipient, providing grueling care

routines), some women harness a latent self-efficacy in the face of hardship and distress.

Women from my sample consistently attempt to consolidate their identity as a caregiver

through engagement in emotional processes (such as self-efficacious thoughts) and

action- oriented behaviors (self-efficacious behaviors) towards their care recipient.

Women's need and purposefulness in becoming a good caregiver, despite their own ill

health, arises from within a patriarchal framework where men are the primary care

recipients and women are valued for being a good woman, wife, and caregiver.

Women's growing self-efficacious thoughts, behaviors and resiliencies, as demonstrated

in their stories, point practitioners and policymakers towards harnessing women's self-

efficacy by offering them support that is not merely general to their life situation (such as

the emphasis on 'positive living'), but is specifically targeted towards their roles as

caregivers while they are ailing themselves. Such support could take the following

forms: 1) provision of accurate and early information about HIV/AIDS such that it

satisfies women's search for authoritative knowledge and timely connection with HIV

testing and ART; 2) support and training for self-care among women so that they do not experience deterioration in their own health due to hectic caregiving demands; and 3) conversations about

informal caregiving with women, via community health and outreach workers, doctors, ASHA (Accredited health workers) workers to bring visibility to women's work and create awareness about the potential detrimental effects of informal care provision while women are ailing themselves. Finally, given that this study and cultural norms indicate minimal involvement of men in everyday caregiving, efforts should be made to enhance the involvement of men in every day caregiving so that women can also be care recipients.

Over time, women build social support through the resources offered at the Care and Support centers. This is hypothesized to help build more resilient individuals as it also assists them in building stronger connections with health care agencies and seeking the assistance they need. Most women in the respondent group for this study had lived a trajectory of hardships through early marriage as a teenager or child, combined with limited education or occupational opportunities. Yet, there is no evidence in the narratives that those hardships had led to search for information or other self-efficacious behaviors or opportunities for building resilience prior to their husband's illness. Yet, due to their own and their family's illness, women interact with systems outside those they had previously encountered- health systems (doctors, nurses, workers) and welfare offices.

Perhaps, the most important of these are the Care and Support Centers where women build relationships of trust and care with each other and are able to confide in female

health workers. Women actively searched for information, and upon connecting with that information and the resources they needed, they actively built their own self-efficacy and resilience.

An important contribution of this study is confirmation of the fact that women had an awareness that they experienced deterioration in their own health during phases of intense caregiving. Although hypothesized, no study to date had subjectively explored this with women caregivers. Some women became oppressed caregivers, where harsh and unreasonable caregiving demands were made of them despite their own health. This theme reflects gender-related power dynamics within marriage and spousal-family relationships, reflected in the caregiving role expectations of women. Women who are oppressed as caregivers may also face other forms of emotional, financial, or physical abuse and occasionally decide to break away from the care recipient. This clearly demonstrates that while women are willing to be caregivers and even want to consolidate their identity as good wives and caregivers, they are only willing to do so as long as they can act at least somewhat autonomously on their own terms and define their role, and have that role be valued.

In Chapter 5, I use a conceptualization of "access to care" (Gulliford & Morgan, 2013) to explore the behaviors that are enacted by both women and health workers which promote or hinder women's access to health services. Women are responsive to new health behaviors once they are connected with appropriate health care and services and work to overcome barriers to care such as arranging transportation or child care. Women show improvement in physical and psychosocial health once connected with health care services and psychosocial support. They develop resiliency over time through repeated

self-efficacious thoughts and behaviors. Despite barriers to access, women in this study were eager to learn and bring about change in their lives. Policymakers and practitioners in the fields of women's issues or HIV/AIDS must take into account women's life circumstances and experiential knowledge. Women's individual resources of self-efficacy and resilience offer opportunities for practitioners and policymakers to build on these strengths, signaling hope and the potential for result oriented improvements in women's health and well-being when women are provided with adequate support and resources. Women's experiences caused them to become experts on their own lives and therefore women themselves must be able to participate in the development of programs and policies for them.

Despite utilizing gendered pathways towards mastery of the caregiver role, through the hardships women face in the process of becoming a caregiver, women gain access to their individual resources such as harnessing self-efficacy and, over time, developing personal resilience (Fig. 3).
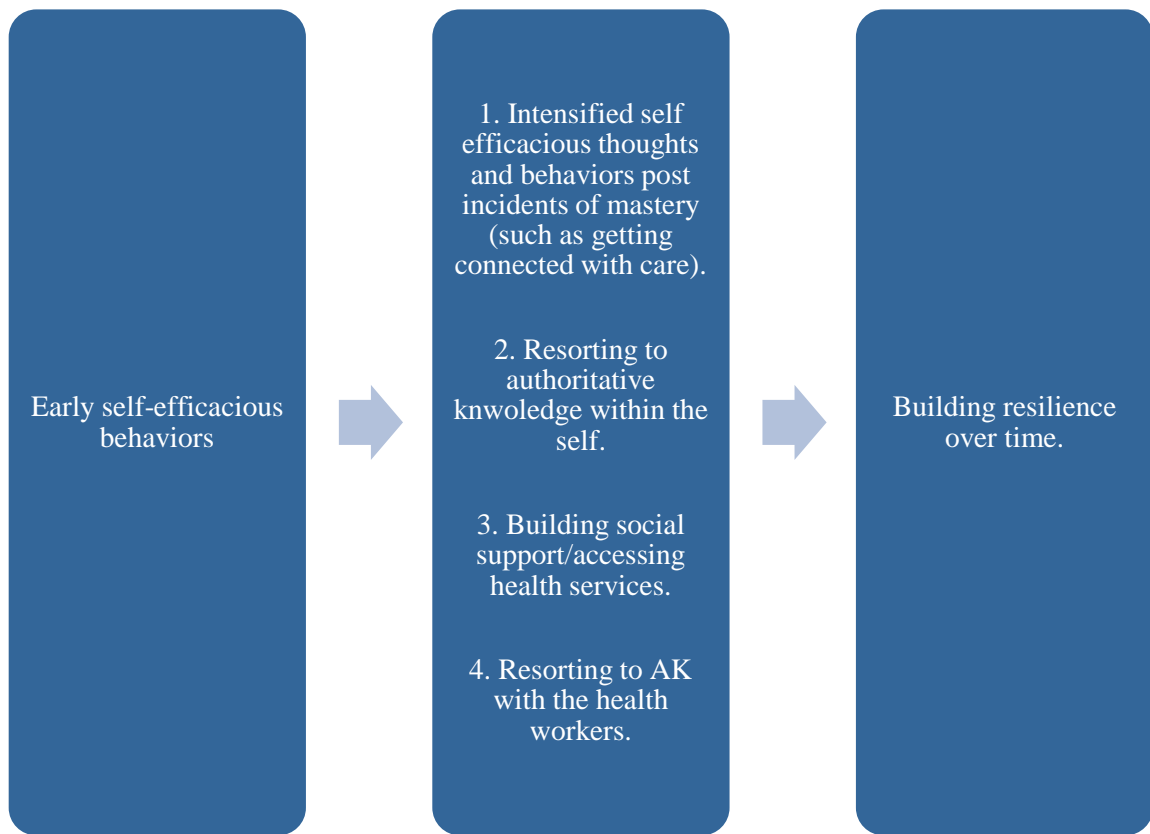
| Early self-efficacious behaviors | 1. Intensified self efficacious thoughts and behaviors post incidents of mastery (such as getting connected with care).

2. Resorting to authoritative knwoledge within the self.

3. Building social support/accessing health services.

4. Resorting to AK with the health workers. | Building resilience over time. |

Figure 3.   Associations between self-efficacy and resilience among women.

Interviews with health workers made it possible to view women's experiences in the context of formal health services for HIV/AIDS. The main finding in this area is that although health service provision is well intended, the sites and actors involved in service provision have limited understanding of the special needs of women living with HIV in poverty and they pay little attention to the specific needs of women. At best, although health workers are well intended, they end up offering no more than bandage solutions for women's needs. Health workers also exhibit their gendered socialization in north India in their interactions with women and end up reinforcing women's goals towards being a good caregiver, even at the cost of women's personal health. Lipsky's theory of street level bureaucracy is apt for explaining women's interactions with health workers

because it provides a framework for how frontline workers often set up their interactions

and relationships with clients in the context of resource shortages. In this study too,

health workers are themselves overburdened as a workforce and therefore seek

convenient channels of conversation and counseling that bring women temporary relief,

yet maintain the status quo in women's lives as it pertains to their health and their burden

as informal caregivers. Health worker narratives demonstrate the meanings they attribute

to perceived problems and the solutions they create to address the problems. Findings

from this study indicate that health workers face two major types of resource crisis in

their work environments. First, they face material and human resource shortages such as

low supplies of medications, low wages for long working hours, lack of sufficient

numbers of female staff members to work with women clients, lack of ongoing training,

and excessive workload and responsibilities on each staff member. The structural

constraints of their work environments, as in many resource-constrained settings, impose

mental and emotional burden and distress on health workers and often make them feel

ineffectual in spite of all their efforts.

　　　Second, health workers made shortsighted or deficient judgements about the

meanings of the problems that were presented to them and their solutions, particularly

with regards to female clients. Although they were well intentioned, health workers

maintained a normative social view of female clients and expected them to care for ailing

men and children. In their practice with female clients, they often viewed them as the

weaker sex who had limited options when it came to serving their families. Although

accurate that the women had limited options, the health workers tended to remain within

those social strictures rather than challenge the status quo. The meanings health workers

make, their counseling strategies, and their coping mechanisms all point towards the need for strategic and focused training for health workers that would enable culturally appropriate communication with women that is more empowering. Health workers also need to be trained to understand the design of programs they run, how and why programs require them to deliver certain services, and the results expected for clients.

One of the troubling themes that emerged in this study is about the meanings health workers attach to the home visit. Their hesitations seem to render it ineffectual, and they conclude that it is a not a very useful program intervention. There are challenges and difficulties faced in the provision of services during the home visit, the most critical of which was the management of HIV-related stigma and discrimination and the avoidance of unwanted disclosure of women's health status. Despite such difficulties, practitioners tend to act on subjects, as they think about them. This means that having a home visit that confronts workers with the problems directly may improve the interventions they use. Although health workers saw the home visit as an ineffectual intervention, it is one of the most potentially effective tools for them to address women's concerns in a manner that is personalized to their familial environment and needs, and to deliver information and resources. In fact, home visits can also be used as a preventive measure where families who appear at risk (household members may include long distance truck drivers or intravenous drug users) can be targeted for delivering HIV information along with other community health information through community health workers.

Health workers can be trained to clearly see the benefits of the home visit and offered a clear road map for avoiding unwanted disclosure of women's health status.

Health workers should be offered more support and training for conducting home visits and for making the home-visit personalized to the client's needs, which should be allowed to evolve rather than having a set of predefined agendas. The home-visit is an important intersection between formal and informal care provision and can be systematically utilized to address women's burden of informal care provision.

This study offers insights about challenges health workers face in their work: they point practitioners and policymakers in two distinct yet inter-related directions. First, an expansion of material and human resources may lead to greater satisfaction among health workers in their professional role and improve their overall sense of well-being. Health workers should be provided training, resources, and support to manage the stress and constraints of their work environments. Second, health workers need to be provided with gender sensitive training for delivering services to women. Health workers attempted to be benevolent to women by allocating extra time and resources to them, yet they simultaneously perpetuated a discourse about women's health that was not sustainable or conducive to women's health over the long run (e.g. that they must preserve their health in order to care for their husbands and children). Health workers need training that helps them focus on strategies for helping women with problems such as access to formal welfare and care resources rather than reinforcing cultural norms that maintain women's worth primarily as caregivers. Appropriate training can simultaneously restore morale among health workers, improve interactions between clients and workers, and improve self-esteem among women by harnessing their self-efficacious thoughts and behaviors.

Economic Implications of Women's Work

This study is a contribution to understanding processes that make women's work invisible while simultaneously co-opting women's informal care work to assist health systems that should ideally be responsible for providing such care. Lack of proper health messaging, human resources, absence of up-to-date medical technologies, and shortcomings in coordination and access to health systems shift burdens of time, money and individual resourcefulness to vulnerable and marginalized people such as the respondents in this study. Although in this study I do not assess the economic value of the work that women are doing, they have clearly been co-opted by health workers as a resource to provide care for men and children while normalizing women's work through 'gendered pathways' where women themselves, as well as the health workers, assign meanings of sacrifice and courage to women for such work. Hence, women's value is deemed to be connected to their sacrifices of care.

Women who are caregivers to other family members living with HIV should explicitly receive information and support for their role as a caregiver rather than health workers assuming that informal care provision is a given normative role in women's lives. Further, the health workers must attend to the ways care provision has detrimental effects on women's health. Interventions that are aimed at bringing structural change to gender norms and promote egalitarian caring relationships between men and women should be pursued, especially given the rigid gendered cultural orientations in Uttar Pradesh, compared to other parts of India. Such change can take a long time in socially conservative settings such as the site of this research and therefore should be simultaneously pursued with individual-level interventions (discussed in a section below on practice implications) that can bring about immediate respite to women. Given the

social context and women's gendered socialization, it appears that to a certain extent, there is an inevitability of women's role as caregivers. Health systems can be tailored to meet women's needs by working towards a home health system that functions with visiting nurses to provide in-home care. In the meantime, community health workers who reside with the community can assist women in providing such care. Initial interventions and programs should be targeted at providing women with support and resources that offer comfort in their role as a caregiver such as training women for developing healthy boundaries, knowing when to make time for rest, or being provided with information that assists caregiving.

The Invisible Themes

Themes that were expected to emerge, but did not, are worth discussing here. They bring light to women's experience by virtue of their absence.

Self-care.

The concept of self-care is broadly understood as non-professional preventive and curative measures that an individual can take without intervention from an external source or service (Wilkinson & Whitehead, 2009). Self-care has its traditions in health promotion, nursing, and mental health. However, self-care also has cultural meanings and practices attached to it. In the Indian context, the predominant cultural demands for women are the service of others and sacrifice; women are to view themselves as secondary to the needs of the family and community. The language of the pursuit of well-being does not only include 'self' but rather is framed as the pursuit of general well-being that includes the self, family, community, and the nation or world. There are a multitude of religious traditions (flowing from Hinduism, Buddhism and other religious

traditions) that define the pursuit of well-being in terms of a certain emotional detachment from material things, pursuit of contentment, practicing wisdom, love, patience while treating the body as a temple by practicing balance in food and exercise (Shukla, 2015; Singh & Raina, 2015). However, this well-being is understood as well-being that assists in the flourishing of all and not only the individual practicing the principles mentioned above. This is, perhaps, why the respondent women were unable to answer questions about self-care as these questions forced a focus on self, and implied that women may care for themselves separate from care of their families.

Betrayal or Infidelity.

Another theme that did not clearly emerge in the language of the respondents was that of 'betrayal' or 'infidelity.' In women's narratives, they rarely brought up the issue of betrayal or infidelity in their marital relationship, neither did they express anger towards their partners for the specific reason of him visiting commercial sex workers or engaging in extramarital sex. Although many women appeared to be aware of these possibilities when they mentioned that 'he was doing something wrong' or 'bad,' most women seemed to absolve their partners by mentioning to me that there may have been another factor such as a bad blood transfusion in a hospital that was responsible for his illness. Some women may not have brought it up with me due to a sense of shame attached to their partner's extramarital sexual activities. However, the absence of this theme in the narratives points to the broader socio-cultural contract of marriage where women often do not question men's behaviors. In order to maintain their marriage, they often

purposefully ignore or detach from men's behaviors, while focusing on the rearing of and caring for children and maintaining family ties with other family members. This also points at women's inability or lack of information for negotiating or advocating for safe sex practices with their partners. Research indicates that men who engaged in extramarital sexual relationships or visited commercial sex workers in Mumbai, in South India, were in the younger age group where the wife was often much younger than the male partner; such men had low levels of educational attainment or were migrants and often used alcohol (Schensul et al., 2006). Although women in this dissertation study did not express a sense of betrayal, many expressed anger and other emotions that communicated high dissatisfaction within their marriage, along with a sense of resignation.

Another factor that may explain the absence of the theme of betrayal in women's narratives is the fact that living in poverty with severe resource constraints may impede women's ability to prioritize their emotional needs over and above their material needs (Mani, Mullainathan, Shafir, & Zhao, 2013). Women did not have the time to pause and process their emotions of anger or other negative emotions. They focused on ensuring that their own and their children's needs of food, medicine, shelter, and other basic needs were being met. They did not have the resources to access couples counseling or mental health services.

Limitations

This research has limitations that arise from the time bound nature of a doctoral degree and the need for me to work individually on all aspects and research processes as compared to working with a team of researchers. Limitations include the following.

First, this study included a small sample size of respondents. This was because of the time it required to ensure that respondents met sample criteria. The sample size is appropriate for a phenomenological study but limits the generalizability of results. An important consideration about the respondents in this study is that they may be considered a select sample group because they were already visiting the ART-CSC centers and had found their way to needed resources and services at the time of the interviews. Respondents' stories therefore may be considered to be more representative of aspects of individual and social processes that worked in their favor versus those that did not. The select respondent group in this study, by its nature excluded women who could not mobilize themselves to move beyond their communities because they were more debilitated physically or because they were intimidated and unable to travel for the resources at the ART/CSC. Health worker accounts observed that large numbers of women living with HIV perhaps rarely visited the care and support centers for psychosocial services due to constraints of time, money, and lack of provision of accommodation or shelter at the care and support centers (Shukla, Muchomba, & McCoyd, 2018) and many more are perhaps not connected with basic services. This makes the respondents in this study a relatively select group.

Second, this study was conducted at one site in Uttar Pradesh, which again limits the generalizability of results. A multi-site research design would have produced more rigorous results and perhaps offered insights about intersections in women's experiences by class positions in society. Third, this study includes limited groups of stakeholders that influence women's experience of informal care provision while ailing themselves. Health workers in formal health care settings (e.g. hospital workers) form an important

group of stakeholders to offer insights about intersections of women's experiences with formal care provision. However, women's husbands as care recipients form an equally important set of stakeholders to fully understand women's experiences. Investigations about how the construction of masculinities in India and other parts of the world intersect with notions of care provision for chronic illnesses can provide us with a more holistic understanding. Such investigations may identify what options women have to bring more balance to their caregiving role and to what extent they can expect assistance from their partners for a more egalitarian division of household labor and improved psychosocial health.

Implications for Social Work Practice

Married women in India have not yet been recipients of targeted interventions for HIV prevention or to receive packages of care tailored to their needs. This study demonstrates that married women's risk of contracting HIV, and further deterioration in their health while living with HIV, can arise from power imbalances within marriage and due to women's socialization towards being a caregiver. Social work practice with married women who are living with and caring for other family members living with HIV should follow a multi-level approach that requires not only individual counseling with women, but also addresses women's problems with their partners and within their families. In individual practice with women, social workers should focus on assessing women's caregiver strain and working towards lowering caregiver strain. Some recommendations include:

1) Experiential training in self-care. Respondents were unaware of the concept of self-care, perhaps because it is predominantly a concept culturally and socially common in

more individualistic societies and uncommon in collective societies where duty towards others is held in higher esteem. Social workers can assist in expanding women's concept of self-care through culturally appropriate practices that allow women to care for their health along with their family members.

2) Data in this study demonstrate that women associate being good caregivers as a hallmark of being a good woman and wife. Social workers can attempt to expand the range of roles and activities that women engage in and assist them in finding other channels of self-discovery and the building of a sense of agency. This may shift women's ideas of 'being good women' from being good caregivers to other facets of life where they may find more opportunities for expressing themselves, feeling in control, and finding an avenue for creativity and productivity.

3) A strengths-based social work practice approach (Graybeal, 2001; Saleebey, 1996) is suitable for work with women and with their families too. Strengths-based approaches are aligned with humanistic assumptions that people have innate abilities to change attitudes and behaviors and positively influence their circumstances. Further, a strengths-based approach assumes that individuals and families have 'strengths' that they may not be aware of, or may not be practicing yet. People are more than the problems in their lives and have the ability for change, provided the right resources. This approach emphasizes assessing people's knowledge, skills, adaption, survival strategies, and resources to see where they can assist themselves and this assessment then assists in helping the individual to build resilience (a needed resource in the face of adversity). Women in this study have definite strengths as individuals that they did not perceive as strengths.

There are several examples of women's strengths in this study. For example, in chapter 3, we see women's consistent and repeated attempts at connecting with the correct health provider in the absence of information or health literacy, and their persistence in arranging finances by selling personal assets or jewelry to conduct multiple trips. This is a form of tenacity women practice, yet they do not perceive it as a strength. Another example of women's strength emerges in chapter 5. They actively work to manage confidentiality about their own and their husband's or children's health status to reduce potential harm from unwanted disclosure. A strengths-based practice approach will allow women to find their voice, discover their authentic strengths, abilities, and talents as individuals, and improve their ability to participate in their own well-being (Graybeal, 2001; Early & GlenMaye, 2000). Data from this study demonstrate that over time, women's self-efficacious behaviors and strong connections with health and psychosocial services helped women develop resiliency. Therefore, a strengths-based approach can assist in harnessing any latent self-efficacy and assist early on in the development of resilience within this population. However, social work practice with women should be culturally appropriate and be mindful of the negative effects of women's empowerment within their family, ensuring that it does not create ripple effects increasing abusive behaviors of violence towards women.

Another approach that may be suitable for working with women at the individual (micro) level is motivational interviewing (MI) (Miller & Rollnick, 2012; Rollnick & Miller,1995). Motivational interviewing is a client-centric approach that puts the social worker or counselor in an empathetic position. In MI, the counselor leads with the understanding that the client is capable and will be making their own decisions while they

can offer informational resources and attempt to gently persuade the client in a specific direction. MI has been assessed to be of greater impact than conventional counseling (Rubak, Sandbæk, Lauritzen, & Christensen, 2005). This framework is anticipated to work well with women because women were motivated to be primary caregivers by social and cultural ideals and they may resist other family members, especially men, providing care in the family. Motivational interviewing then is a productive technique that can slowly bring awareness to women about their caregiving burden, its impact on their health, and assist them in practices of self-care.

At the community and health systems level (mezzo level), women's burden can be addressed by including education and awareness in community institutions such as schools and hospitals simply by discussing the subject of informal care provision, in general, for all households whether living with any illness or not. This involves shifting peoples' expectations for informal caregiving, no longer viewing it solely as women's work. Women's needs can be met in health systems by implementing "differentiated care" for HIV/AIDS (Myer et al., 2017). Differentiated care refers to a patient centered approach where a health system adapts to the specific needs of a population group and services are delivered keeping the needs of a population group in mind, as well as attending to the context of their lives. Differentiated care models are tailored with the recognition that different population groups have different needs and a one-size-fits-all approach may not yield results. Differentiated care is a suitable approach for the women's respondent group in this study because it allows for the recognition of the different needs of married women, including their burdens of time and safety while traveling to clinics, childcare burden, and informal care provision burden. A

differentiated care plan for women can be developed by the health workers at the agency level involving women and managerial staff; such plans have been successfully implemented in other settings (Myer et al., 2017).

One important theme that emerges in this study is about women's provision of palliative care for their dying husbands. Palliative care refers to a comprehensive set of health care services for pain relief, symptom management, psychosocial, and emotional support along with addressing spiritual dimensions of death and grieving (Harding et al., 2005; Schitenger, 2005). This is the most physically, mentally, and emotionally exhausting phase of caregiving for women in this study. This is also a phase of caregiving that induces maximum feelings of helplessness and personal responsibility in women for being unable to save their husbands from dying. The World Health Organization (2004) recommends palliative care as a necessary part of the care and support package for people living with HIV, where community health workers and/or family caregivers can be trained to provide pain relief, comfort, and psycho-emotional support to the dying person. In this study, women cared for their husbands on their deathbed without any information or resources about their own needs as caregivers in that situation, or the needs of their dying husbands. There are no particular programs in Uttar Pradesh that address the care of people dying from advanced AIDS. Findings from this study suggest the need for stronger efforts towards training community health workers for generic palliative care in communities and not only for people living with HIV. Community based shelter homes should be developed that accommodate all dying people, including people living with HIV, for specialized palliative care so that caregiving at the deathbed is not solely left to family support. The provision of palliative

care among the general population is important because, in some cases, families may not

be aware (even at the time of advanced AIDS) that the dying person is living with HIV.

Therefore, stronger efforts should be made towards assisting family caregivers and

especially women, in caring for their dying husbands. A dignified and painless death is a

human right, which should be supported by community members and health workers for

all people living with HIV or other conditions.

At the international level, there is emerging advocacy for more equal sharing of

responsibilities among couples living with HIV/AIDS (UNAIDS, 2008), yet scanty

research on the topic has limited any movement forward towards the development of

interventions with concordant couples, particularly on the issue of informal care

provision. Informal care provision, although invisible everywhere, has even fewer

institutional supports in societies where rigid gender norms dictate what should and

should not be women's work. There is need for stronger advocacy for recognizing the

value of women's informal care work within women's groups and the departments of

women's welfare at the national level so a conversation can be started to support women,

especially those in acute life situations such as the women in this group.

Implications for Policy

The Convention on the Elimination of All Forms of Discrimination against

Women (CEDAW) and the Convention on the Rights of the Child (CRC), each adopted

by the United Nations as human rights treaties, recognize the obligations that nations

have to promote egalitarian sharing of responsibilities within the household, between

women and men. CEDAW (1981), in particular, emphasizes that appropriate measures

should be taken to "modify the social and cultural patterns of conduct…, with a view to

eliminating prejudices and practices which are based on the inferiority or superiority of either of the sexes or on stereotyped roles for men and women (p. 3)". Informal caregiving, in the context of this study, is a stereotyped role for women and perhaps there are other stereotyped roles for men that prevent them from assisting women, while creating rigid and 'hegemonic masculinities' (Connell, 1987) within the north Indian culture. Aligned with the aims of CEDAW, findings from this study demonstrate the continued need for the development of supporting policies for home-based HIV caregivers who are predominantly women and undertake the largest share of informal caregiving.

Macro level policy recommendations include the development of a social security net for female caregivers where government policies support women's informal care work and promote men's work at home simultaneously. One of the ways this can be achieved is by promoting vocational training among women without formal education, and semi- flexible hours of work for women. Flexible hours of work for women has been promoted to assist women in building their professional careers. However, for the women in this study there may be too many factors at home (including caregiving burden and excessive expectations of house work) and in their family lives that make it impossible for them to work while being at home. Policies that assist with semi-formal spaces for women such as women's support groups that promote community building (e.g. groups with goals such as saving money for the family, learning a new skill, or planning for a child's education) may be more effective in supporting caregiving women living with HIV than flexible work hours.

The Indian government needs to invest in building more frequent and safe transportation systems for women, particularly those in rural areas. A repeated emergent theme in this study was about women's feelings of lack of safety while using public transportation systems and public shelters. When women feel unsafe, it creates greater barriers to their access to health care, which in turn makes it less likely for them to make attempts to access dispersed health services. Women's feelings of lack of safety were not merely thoughts and feelings, but backed by their own personal experiences of physical threats to safety.

Another issue that needs serious consideration is the provision of home nurses and home-based support services for families living with HIV. Home nurses should be available in communities to assist families and women with caregiving labor on a daily basis. The nurses should be trained and specialize in HIV care and palliative care because many women in this study faced serious challenges in the provision of care for their dying husbands. Palliative care is a highly specialized area of training in the Indian health care scenario and needs to be made more prevalent and easier to access in both urban and rural communities (Khosla, Patel, & Sharma, 2012).

The Indian government needs to conduct a more thorough analysis of which factors work for which populations and contexts in the delivery of HIV health services in India. India is a diverse nation where communities have varying and specific needs, dependent on context. The mass provision of free ART is insufficient and does not ensure the uptake and utilization of medications, adherence, or psychosocial support services. The government needs to ensure that HIV health services are tailored to population needs. In this dissertation study, in the context of U.P, women got connected

with HIV health services because their husbands had symptoms before them and needed health services. On a broader scale, women in U.P have lower utilization of health services compared to men. This then implies that women who receive health services often receive them via others (their husbands or other family members) whose health is of higher priority than women. This raises ethical concerns about how gendered access to health care is produced, maintained and how gendered access to health care promotes men's health over women's. National policies therefore need to be framed to promote women's access to primary health services, including testing for HIV.

Community based participatory approaches can be helpful in understanding what the population needs are, what barriers they face to access to health care and how their needs can be met. Implementation of programs should include the perspectives and opinions of communities and end-users of health services.

Mezzo level policy recommendations include state level policies developed to emphasize the role of men in the rearing of children and in the participation of household labor. The government can use brief messages on national and state television that house work and informal caregiving work is not women's work alone. These messages can be popularized with focus on north and central Indian states where women have worse development indicators of health, education and employment than men and women in the South Indian states. Men can also be provided incentives to participate in household work and in sharing caregiving responsibilities to a greater extent through measurable activities and time spent during providing caregiving work. For example, offices and work spaces can offer men pockets of time off from work

specifically for helping women and family with caregiving work and ask for a brief description/ record of the activities performed.

India has existing policies that recognize and support the needs of caregivers in other life situations. For example, the Rehabilitation Council of India recognizes the need of caregivers for persons with disabilities and offers tax benefits and subsidized or free legal aid to caregivers of people living with mental health related disabilities (Angothu & Chaturvedi, 2016). However, the implementation of these policies and their utilization by beneficiaries has been low due to barriers to access such as low literacy, poor information about existing welfare schemes and bureaucratic hurdles (Parry, 2007). HIV affected families where multiple members of the family are living with HIV tend to be resource and income poor due to effects of the disease. As this study suggests, women face a life situation where they make personal sacrifices at the cost of their own health to care for other family members. Policies should be developed to support women such as the provision of information and training for caregiving, cash incentives or financial support for transportation to improve access to health services. Further, gender sensitive training for health workers and the greater community should be developed and support groups that empower women to care for themselves along with caring for their families should be implemented.

Micro-level recommendations include a complete assessment of women's mental and psychosocial health at the initiation of treatment and regularly thereafter at the settings where HIV services are provided (ART centers and care and support centers). National and state policies broadly aim towards enhanced mental health and "positive-living" for people living with HIV. However, at the site of this study, it was clear that

medical services (the provision of medications and ART adherence) were top priorities. While medication provision and adherence should continue to be priorities, this should be balanced with an equal emphasis on women's mental health needs. Each woman, and other clients living with HIV should be provided with a counselor who manages their case on a personalized level so that counselors can tailor services to clients' needs and connect women to their nearest community supports.

At the micro level, efforts should be made to identify women who can lead the development of localized support services and disperse mental health services to others in their area who are living with HIV. Such delivery of mental health services does not need to be specialized (as for mental health conditions that need specialized care such as bi-polar disorder or schizophrenia), but they should offer regular and consistent emotional support while also identifying when clients need more specialized services and connect them with the needed services.

Future Research

The HIV/AIDS epidemic is a complex issue that needs to be tackled one community at a time, cognizant of the social and cultural ethos of the place and the availability of resources. This study highlights the importance of 'context' in addressing the complexities that arise for different population groups in living with HIV. Uttar Pradesh is an example of a socially conservative setting where power-dynamics in favor of men within gender relationships are normative and socially embedded. This study is a contribution to understanding the lives of married women living with HIV and their interface with formal systems of HIV care provision. The strength of this study lies in

providing deep insights and rich narratives from a hard to reach population group. In the future, research questions can be focused in the following areas:

For future research on the subject of HIV-positive women's informal care provision, I suggest mixed methods approaches and the engagement of multiple stakeholders as respondents who are in a position to influence women's care provision. One of the key findings of this study is that caregiving provided by ailing women under extremely stressful circumstances led to a worsening of women's health. Women's narratives are explicit testimonies about decline in women's health during intense phases of caregiving. In the future researchers can focus on what aspects of caregiving (caregiver's action orientation, worrying and doing, and/or, micromanagement of care recipient's health, among others) are associated with deterioration in health. Second, findings in this study indicate that women who are in non-abusive relationships with their spouse and other family members experience greater ease as an informal caregiver because they receive more family support. Therefore, future research can focus on examining the connections among spousal relationships, women's informal care provision and women's health. Third, intervention research can offer insights about how women's informal care burden can be addressed in their daily lives, such that women can care for themselves and their own health in an HIV/AIDS affected household, and their caregiving burden does not affect their own health negatively.

In summary, this study is a call to social justice for women caregivers, especially those living with HIV in developing parts of the world with limited or no support and resources. Caregiving expectations must not fall on marginalized women alone, and

instead work should be done at a community and systems level to ensure that ailing

women are not suffering and facing deterioration in their own health due to the burdens

of caregiving.

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Appendix1.Interview guide for married women living with HIV

Part 1. *Objective-To explore the caregiving experiences of HIV-positive married women.*

Can you please describe an ordinary day in your life?

How do you see your life as a married woman living with HIV? How was the situation when you found out about your health status?

Prompt- Are your immediate family members (husband, in-laws, children, parents) aware of your health status?

How did your husband respond on being aware of your health status? How did your parents respond? How did your in-laws respond?

All relationships have highs and lows, what has been the story of your relationship with your husband?

Prompts-How do you talk about your health with your partner? How do you talk about your health with other family members? What meanings do you attach to such conversations?

What is your experience of being a caregiver in your family to other infected family members?

Prompts-How does the care you provide differ from the normal care you would provide if your family member/s were not infected?

What kind of challenges do you face in taking care of them? What kind of help do you receive from your partner or others with the caregiving tasks?

Do you ever refuse to take on caregiving tasks and responsibilities? Please describe an instance when you did so.

If no, can you please explain why?

Part 2. *Objective-To explore factors that influence women to be caregivers to other infected family members.*

What factors do you believe influence you to be a caregiver to your family members**?**

What reasons do you have for doing this caregiving? How do you think you would manage your life without your family? How do you think your family members would manage their lives without you?

How do you feel while providing care for your family members while you are ill yourself?

Part 3. *Objective-To explore HIV-positive married women's experiences of self-care and receiving care from formal and informal sources of care*

How do you take care of yourself and your health?

Prompts- What practices, if any do you follow to take care of yourself?

How do you think through decisions about times you need to put your health needs before other sick family members?

What sources of care and support do you receive, such as family, friends and neighbors?

Prompts- What does that support look like? Does it feel sufficient?

What are the positives and negatives do you see to support coming from friends and family as opposed to hospitals and clinics?

Part 4. *Objective-To explore how caregiving HIV-positive married women experience HIV/ AIDS service provision in India.*

What is your experience of the formal sources of care you are connected with?

Prompts- Do you feel you get enough support from the formal sources of care you mention?

Do you receive any training to provide home based care at any of the health centers you attend?

Is the training helpful? If yes, how? If no, why is not helpful?

What kind of services would make your life as a caregiver easier?

Prompt- What extra support from formal sources of care such as hospitals or community care centers would you wish to receive?

What barriers do you experience in accessing help with caregiving?

What alternatives do you see to providing care for your loved ones?

What parts of your caregiving experience have I not asked you about that you think are important for me to understand how the experience of caregiving plays out for you in your day to day life?

Demographic information sheet

Which region are you coming from?

- Lucknow, the capital city of Uttar Pradesh
- Another city in Uttar Pradesh
- A township or rural area in Uttar Pradesh
- Immigrant from another state in India

2. Which age group do you belong to?

- 18 - 24 years
- 25 - 34 years
- 35 - 45 years
- 46 – 55 years
- 56 – 65 years

3. **What is your highest level of education?**

- No education at all
- Standard 8th and below.
- High School degree
- Undergraduate degree
- Master's degree
- Vocational training

4. How many years have you been married?

- < 1 year
- 1 – 2 years
- 3 -4 years
- 5 – 10 years > 10 years
- Previously married.

5. How old were you at the time of marriage?

- <18
- 18-21
- 22-25
- 25-29
- >29

6. How old was your husband at the time of marriage?

- <18

- 18-21
- 22-25
- 25-29
- >29

7. How many living children do you have?

- 1 child
- 2 children
- 3 or more children
- None
- Any children who have died and at what ages?

8. What kind of household do you live in?

- Joint family- living with in-laws or extended family in the marital home
- Nuclear household- living with partner and children
- Nuclear household- living only with the partner, no children
- Living in the parental family home
- Any other type, please describe.

9. If you work outside the house, which of these income brackets per month would your income fall in?

- Income > Rs 15000
- Rs 10,000 – Rs 15,000
- Rs 5000 – Rs 10,000
- Income < Rs 5000 No personal income

10. As a family which of the following categories would you associate with?

- Struggle to put food on the table
- Getting by with basic needs of life
- Have some money for extras
- Financially comfortable

11. How many years has it been since you discovered your HIV-positive status?

- <1 years
- 1 -2 years
- 3 – 4 years
- 5 – 10 years
- >10 years

12. How long have you been a caregiver to other sick family members?

- >10 years
- 5-10 years
- 2-4 years
- <2 years

13. Of the organizations and services listed below which ones are you using?

- State AIDS Society
- Antiretroviral therapy center
- Voluntary counseling and test center
- Prevention of transmission from mother to child center Family planning canter
- Community care center
- Public district or state hospital/ government doctor
- Home visits by a community health care worker Other (please describe)

Appendix 2. Interview guide for health professionals.

Objective

1) To explore health professional's perspectives and opinions of the lives and support needed by HIV-infected caregiving married women.

2) To triangulate data for completeness of understanding of the phenomenon.

What is your helping role?

Have you had a previous job in this type of care?

What has been your experience working with HIV-positive married women?

What feels like a success when working with HIV-positive women?

What feels like a failure when working with this population?

What do you think their informal caregiving responsibilities look like?

What do you think these women's home environments are like?

Why do you think HIV-positive married women often provide everyday informal care in their households despite being sick themselves?

What kind of support do you think this population needs from formal and informal sources of care for people living with HIV/AIDS?

How do you think formal sources of care can support this population of women in their caregiving roles?

Please give a few examples of how they may be best supported?

Demographic information sheet for health professionals.

1. What is the role in which you have you worked with HIV-positive married women?

Community health care worker

Social Worker Any other- please specify?

2. How many years have you spent working with HIV-positive women?

- 1 – 2 years
- 3 - 4 years
- 5 – 10 years
- >10 years

3. In which region/state of India did you spend most of your time working with HIV-positive married women?

- Lucknow, the capital city of Uttar Pradesh
- Another city in Uttar Pradesh
- A township or rural area in Uttar Pradesh
- Another state in India

What is your highest level of education?

- Standard 8th and below
- High School degree
- Undergraduate degree
- Master's degree or higher
- Vocational training

5. Which of the organizations listed below have you worked for?

- State AIDS Society Antiretroviral therapy center
- Voluntary counseling and test center Prevention of transmission from mother to child center
- Family planning canter
- Community care center
- Public district or state hospital/ government doctor
- Nonprofit organization
- Other (please describe)