CHAPTER I

INTRODUCTION

Title of the Study

Determinants of quality of life among HIV positive widows under ART medication – A social work perspective.

General Introduction

Status of women depends on the attitudes of the society. For centuries, women are treated as secondary inhabitants in the family and the society (Muni, 2006). Women play a significant role in the family and the society (Jaya Kumar, 1994; Rao, 2005) and most of their activities are confined within the four walls of their houses (Nelasco, 2010). They shoulder all the responsibilities – fulfilling the needs of the male members care for the children, maintaining the household activities, managing the limited budget, and besides, they suffer from ill-health due to repeated pregnancies and malnutrition (Jaya Kumar, 1994).

In the modern times, a new challenging role and status have aroused for the Indian women owing to urbanization, westernization, industrialization and politicalization (Kumar & Chakrapani, 1994). Women are more aware of their social position and started utilising their potential (Nelasco, 2010) and some have made their social advancement with pride and dignity (Bhuyan, 2006). Though the
roles are increasing day by day in and outside the home (Rao, 2005; Muni, 2006) but still in the modern society the women’s status has not improved considerably (Kumar & Chakrapani, 1994; Rao, 2005) and they face inequalities (Rao, 2005; Muni, 2006).

In India, where female identity is almost determined by her being an appendage to a male, widowhood has a much larger dimension than losing one’s husband as commonly understood. Widowhood is universally considered as a disastrous thing to happen in any married women’s life (Reddy, 2004). The Sanskrit term Vidhava (meaning widow) is traced back to pre-Vedic languages to Indo-European origin (Dutt, 2001; Reddy, 2004; Nayar, 2006). The term widow or vidhava signifies that a woman whose husband is dead and who has not remarried (Dutt, 2001; Reddy, 2004; Nayar, 2006). According to Sample Registration System (cited in Chen & Dreze, 1995), widows constitute a little over 8 per cent of the female population in India. Widow, is indeed miserable in the Indian scenario, since she faces economic misery and cultural seclusion (Reddy, 2004).

Entering into widowhood is more hazardous, aching and humiliating to women than to a widower because of discrimination, ritual sanctions of the society against widows (Reddy, 2004). Durkheim (cited in Reddy, 2004) observed that the number of suicidal cases is higher among the widows. According to Christie Fernando, many widows face extreme poverty, discrimination and inhuman treatment (cited in Parthasarathy & Jayalakshmi, 2004). Caste norms often discourage women and widows in particular, from
working and, in many cases, they face complexities in retaining control of their husband’s land upon his death (Jensen, 2005).

If a widow is infected with HIV then her condition is in further dismal state (Burn & Sidhu, 2004; Haacker & Claeson, 2009). Most HIV positive widows discover their HIV positive status only after the death of their husbands (Mitra & Kumar, 2004; Hollen, 2013) and most of them were infected by unprotected sex with their infected husband (Susser, 2009; AVERT, 2013). On the sudden demise of the HIV infected husbands, the surviving wives not only carries the burden of the virus (Haacker & Claeson, 2009) but also the economic crisis (Haacker & Claeson, 2009; Das, Mukhopadhyay, & Ray, 2009). They often face greater stigma and discrimination than men within their families (Hollen, 2013). Till the survival of their husbands, they feel secure in terms of social and economic aspects, but on the death of their husbands, they feel more insecure. Widow face double burden of stigma of having HIV and suffer discrimination from the family and the society (Pradhan & Sundar, 2006). They don’t have freedom to participate in the social and religious functions. Besides, they have to strive to earn income for fostering their children as well as struggle to care their health. The HIV positive widows belonging to socially and economically backward communities are less likely to have access to socio-economic resources.

The current prophylactic and therapeutic strategies have given hope for the persons living with HIV/AIDS to improve their quality of life (cited in Mweemba, 2008).
The World Health Organization (2006) has defined quality of life (QOL) for individual as

“Perception of their position in life in the context of the culture and value systems in which they live in and in relation to their goals, expectations, standards and concerns.”

The Webster dictionary defined ‘quality of life’ as one’s personal satisfaction with the cultural or intellectual conditions under which she or he lives. Felce & Perry (1995) perceived quality of life as multidimensional and it covers an individual’s physical wellbeing, material wellbeing, social wellbeing, emotional wellbeing, and development and activity. Remien and Mellins (2007) stated that some of the threats to quality of life are of psychological origin and other created by the medical treatment. According to Brown, Renwick and Negler (cited in Quraishi, 2011), the interest in quality of life stems from trends towards greater appreciation of the personal needs and wishes and in individuals within the health and social services.

Women, other than marginalised and vulnerable, have better physical, social and emotional wellbeing. The HIV uninfected women in better socio-economic status have a better standard of living. They live in less environment pollutant areas, and have economic independence, mobility, confidence to face challenges of violence at home and society to a better extent. But they do have certain physical and emotional discomforts, but which are based on the experiences in certain contexts and time. (D'Souza, Karkada, & Somayaji, 2013)
The permanent absence of the male spouse in the family lead the young and adult women to have predicaments in the form of caring the children and old aged of the family, and concurrently also face the challenges of the persecutors, who are often the members of the in-laws family, neighbours, co-workers, employers and persons of the dominant class (Ariyabandu, 2000). Phillips (2002) viewed cultural ostracism as a key determinant in forcing the social marginalisation of female-headed households.

The situation is worse for HIV positive widows than the widows without HIV infection, who have the chances of getting remarried. The HIV positive widows are facing multiple discrimination due to both HIV infection and widow status. Health related quality of life among widows is poor (Vigneshwaran, Padmanabhareddy, Devanna, & Alvarez-Uria, 2013). The impacts of HIV/AIDS on HIV positive women complicates family caregiving responsibilities, causes anger and frustration and augments to the risk of losing the children (O’Connor & Earnest, 2011). They often experience a decline in quality of life due to factors other than disease stage and physical condition (Tuck, McCain, & Elswick, 2001), such as poverty, addiction, depression, and violence (Arando-Naranjo, 2004). Their quality of life are affected in the domains of physical health, work and earnings, daily activities and appetite and food intake (Kohli, et.al., 2005). The HIV positive widows experience higher economic deprivation, cultural ostracism and health predicaments compared to the widows without HIV infection.

To improve quality of life, antiretroviral therapy is administered to HIV patients (Kumarasamy, Patel, & Pujari, 2011). HIV infected persons who adhere
for at least one year are less likely to experience AIDS related mortality (Mweemba, et al., 2010). It has greater likelihood of CD4 normalisation and lesser risk of development of toxicities (Kumarasamy, et al., 2011). Efficacy of antiretroviral treatment in HIV/AIDS is showing inhibition of viral replication and reduction of viral load to a point where viral particles are undetectable in the blood of infected individuals (Mweemba, et al., 2010).

Anti-retroviral therapy (ART) effectively suppresses replication, if taken at the right time. Successful viral suppression restores the immune system and halts onset and progression of disease as well as reducing the chances of getting opportunistic infections – this is how ART is aimed to work.

There are 342 ART centres across India and 43 ART Centres in Tamil Nadu (as per NACO, January, 2012), these centres provide free health services to people living with HIV/AIDS, with specific focus on seropositive women and infected children. In order to make treatment more accessible ART centres are located in medical colleges, district hospitals and non-profit charitable institutions providing care, support and treatment services to PLHA. Community Care Centres and Positive Networks facilitates the HIV infected persons to have access to care and treatment services in the ART Centres. Significantly, the ART centres provide counseling, ART medication and follow up on treatment, adherence and support services.

The present study assesses the quality of life among HIV positive widows under ART medication in Madurai district of Tamil Nadu in a descriptive way. The universe of the study is 1502. Stratified proportionate simple random
sampling was used in picking up 376 samples. The study focused the HIV positive widows living in Madurai district. The primary data were collected from the rural HIV positive widow from May 2013 to July 2013.

The World Health Organization has developed a WHOQOL-HIV instrument for observing the quality of life for HIV positive people. This standardised WHO tool was used to analyse the quality of life of HIV positive widows covers. The physical health, psychological state, level of independence, social relationships, environment and spirituality/religion/personal beliefs of the HIV positive women under ART medication. Quality of life is very much essential to any individual. It reveals the living pattern of any positive individual and their level of contentment to lead a positive life.

**Statement of the Problem**

This study attempted to analyse the quality of life among HIV positive widows under ART medication. Researches on quality of life using WHOQOL tools were largely done on general population among persons living with HIV/AIDS. Number of studies were conducted in various countries using this tool proves the applicability and reality. In India, specific study on HIV positive widows under ART medication requires greater attention. The identified research gap is that the studies about the quality of life among HIV positive widows under ART medication is minimal.

In the family and in the society, women are treated as secondary inhabitants. On the death of their husbands, they are branded with widowhood
status, which further isolate them from the mainstream society. Still worse is the condition of the widows with HIV infection, who have augmented HIV stigma and health risks. Every now and then, the quality of life of HIV positive widows is hammered. They face problems in physical health, psychological health, level of independence, social relationships and environment. This affect their quality of life. HIV positive widows are living in more vulnerable state than widows without infection. The multi-dimensional aspects of standard of living are neither accessed nor enjoyed by the HIV positive widows.

As per NACO guidelines, Madurai district has been classified as one of the sero high prevalence districts in Tamilnadu. HIV/AIDS (Acquired Immune Deficiency Syndrome) is a health problem and it affects the individual, family and the community at large. More over poverty, illiteracy, poor health and stigma are the crucial social problems associated with the disease. Persons affected with HIV often susceptible to health risks, when the antibodies lost their potential, the infected persons will get many opportunistic infections. It is a proven fact that HIV infected people are not dying due to HIV itself, but to the other ailments contracted due to HIV infection.

Preventive care and early treatment are always a challenge at the community level, when it comes to HIV +ve persons it again poses challenges of prejudice and stigma. The PLHAs are more prone to get sickness and reduced life span due to their personal problems.
Increasing the health utility services and bringing out attitudinal changes among the people living with HIV/AIDS to frequently access the existing health services and to practice the required health aspects, are very much essential. Stigma and discrimination is an aggravating factor in pulling the people living with HIV/AIDS to suppress themselves and to damage their lifestyles.

HIV positive widows after the death of their husbands face various challenges. They are not accepted by their in-laws and even some of them were ditched by the parents too. Furthermore, those widows with young children, have to shoulder responsibilities to foster them. Added to that in the work place, they have various abuses.

This study analysed the socio-economic contour of the HIV infected widows under ART medication and their quality of life in the domains of physical health, psychological state, level of independence, social relationships, environment and spirituality/religion/personal belief.

Scope of the Study

This study on ‘Determinants of quality of life among HIV positive widows under ART medication – A social work perspective’ significantly focuses on the

a) physical health,

b) psychological health,

c) level of independency,
d) social relationships,

e) environment and

f) spirituality/religion/personal beliefs.

This research will provide a projection on the overall quality of life of the HIV positive widows.

The study might help the Government, Non-governmental organisations, professional social workers and researchers to understand the influencing determinants of quality of life of the persons living with HIV/AIDS (PLHA), with specific focus to vulnerable and marginalised groups among the PLHA.

Based on the outcomes of the studies the institutions working with the PLHA might devise effective programmes that ensure sustainable health of the people living with HIV/AIDS as well as to carry out effective programmes for enriching the quality of life of HIV positive women, specifically HIV positive widows. Health Care Institutions can develop workable strategies for mitigating the consequences of HIV/AIDS on the HIV positive persons.
**Chapters of the Study**

**Chapter I:** This chapter presents the introduction that describes about the discontentment on the subject and about the purpose of the study, problem statement, scope of the study and inclusion of chapterisation.

**Chapter II:** This chapter reviews on the literatures on HIV/AIDS aspects and quality of life of HIV infected persons and discloses the gaps in the research areas.

**Chapter III:** This chapter presents the research methodology that describes about the field of study, sampling, tools, data collection and limitations of the study.

**Chapter IV:** This chapter analyses the data, which is presented in tables and with statistical tests.

**Chapter V:** This chapter gives the major findings of the study, suggestions and conclusion.