Ill-health and Social Inequalities faced by Women Tuberculosis patients of Kashmir Valley: A Study on Inter-relation between Society, Gender and Treatment Seeking Behavior

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ABSTRACT

The gender inequality entrenched in our social structure manifested through patriarchal structure puts women in an unequal position in terms of health indicators. Regardless of age, gender, socio-economic or ethnic background, we consider health to be the most basic and essential asset. However, gender for women has been a major indicator of inequality and discrimination, which influences not only their state of health and well-being but also their ability to seek care. In relation to this, Tuberculosis is a major health issue for women and poses a huge threat to women than any other communicable disease. Although, the incidence and prevalence of tuberculosis has been found disproportionately higher in males than females however, gender perception of the disease places the female patients at a particular disadvantage due to the greater stigma and lower prioritization of women's health. The present study is an attempt to understand how in a patriarchal society, tuberculosis related stigma and discrimination interacts with existing social inequalities and discrimination associated with women.

***Keywords: Gender, Ill-health, Inequalities, Stigma, Tuberculosis, Women*.**

Study Limitations

As it is not possible to document all the cases and experiences of female tuberculosis patients. The researcher will provide a description of few cases of married female tuberculosis patients.

I.INTRODUCTION

Gender in sociological and feminist thought, denotes the cultural constitution comprising notions, perceptions and premises concerning feminity or masculinity and the ways in which these serve ideologically to maintain gendered identities. Gender is a matter of culture. The downgrading of gender to sex may be understood as a key move in the ideological justification of patriarchy. The primary identity of a person in a human society is that of gender, which according to psychologists, gets fixed in early infancy. Feminist expositions have assembled considerable evidence to drive home the point that gender is culturally constructed [1] . Over the past many

years we witnessed tremendous change in the world wide outlook of the people largely influenced by the social dynamics of the west and also the languishing steps of the east. Efforts by great social reformers directed to imparting women education have helped in bringing them out of the purdah system and have resulted in a progressive and happy society in terms of regard for the half world. Gender inequality springs from many sources and it is often difficult to determine which form of inequality is declining by the effects of globalization, and which change being undermined. Empowering women is an inseparable tool for advancing development and reducing poverty, yet discrimination against women, together with gender based violence, economic discrimination, reproductive health inequalities and traditional dogmas, remains so wide and persistent. The health and health services are not recent phenomena, they have their history [2]. Women have the right to the enjoyment of the highest attainable standard of physical and mental health. The enjoyment of this right is vital to their life and wellbeing. However, health and wellbeing elude a majority of women in the world. A major barrier for women to achieve the highest attainable standard of health is inequality. Women have different and unequal access to and use of basic health services, including primary health services for prevention and treatment of childhood diseases, malnutrition, anaemia, diarrhoeal diseases and tuberculosis among others. Health policies and programmes often perpetuate gender stereotypes and fail to consider socio economic disparities and other differences among women [3]. There is no dearth of literature on gender issues. However, the thrust is uniformly the same i.e., the unequal status of women in one form or the other, under different pretexts and their consequences. Given this status gender biases are exhibited both implicitly and explicitly with the exceptions of few protests by progressive men and women [4]. The status of women is a complex issue. It is not amendable to any simplistic explanation of social reality. Literature on the status of women is varied and addresses mainly the key issues affecting the women in various areas of development, such as education, employment, polity, society, law, health etc. The Constitution of India not only grants equality to women but also empowers the state to adopt measures of positive discrimination in favor of women. Within the framework of a democratic polity, our laws, development policies, plans and programmes have all aimed at women's emancipation. But, the inequalities inherent in traditional social structures have still a significant bearing on women in different spheres of life[5].Tuberculosis (TB) is distinctly a social phenomenon. Medical sciences looked upon consumption that it is curable, but what about the Social Stigma, which is so immense, that the disease itself is not doing that much of worse to the patients, than the attitude of the people towards the tuberculosis patient. The stigma that accompanies Tuberculosis has crippling social implications. Due to the ease with which disease is transferred, people do not want to be in close proximity to any other infected individual. Women especially feel the intense social stigma, as there have been deteriorating sexual lives and crumbling mother child relationship resulting from fear of infection. It has been revealed through various literatures that the families of male TB patients accepted the disease while on the other hand; women TB patients suffered adverse reactions like women being restricted from conceiving, breastfeeding their children or even outright rejection [6]. Moreover, when a women is affected with tuberculosis, household loses the activities which a women routinely perform. Tuberculosis disease mostly affects the daily routine activities of female patients like cooking, washing of clothes and serving food to the family members. Moreover, it has also been found that female tuberculosis patients are unable to feed their children, because there is a general notion that, tuberculosis might pass through lactation, which has not been medically proven yet, but is a myth in itself. [7]. TB has far-reaching economic and social consequences for those infected and for their households and communities. The social and economic impact of

TB comes from the size of the problem and from the fact that in developing countries the majority of those affected are in the economically active segment of the population [8].

Although Government of India has initiated a number of policies and programs including the National Tuberculosis Control Programme (NTCP) in 1993 and the Revised National Tuberculosis Control Programme (RNTCP) in 1997 including mass propaganda about the disease through electronic and print media for the eradication of TB, but still the stigma associated with it has not been eliminated yet. The present work is an attempt to enquire into the problems faced by women with Tuberculosis in Kashmir, perceptions on the disease and the behavior towards women with Tuberculosis. The aim of the researcher in conducting such study is to explore this unexplored area. Thus, it becomes imperative on part of the researcher to have a deep understanding of such research study that, despite this disease is treatable and curable, but why is it still a major global threat.

II.STUDY SETTING

The present study was carried out in Central Kashmir, which includes Srinagar, Ganderbal and Budgam Districts of Kashmir Valley, as no study of its kind has been carried out in these districts earlier. There are about seven Tuberculosis Units (TU's) of these three districts which includes a total of 61 cases of married females out of which 59 cases are falling between the age group of 15-45. The study population comprised of all the married women between the age group of 15-45 with confirmed tuberculosis. The researcher met concerned District Tuberculosis Officers of all districts in order to discuss with them the purpose of research study. With proper permission and consent, the researcher carried out her study inside the hospital premises. The respondents who participated in the present study were drawn from the list of patients maintained by the healthcare providers and who were still on Directly Observed Treatment Short course (DOTS). Moreover, the real names of patients were replaced by Pseudo names, so as to maintain the principle of confidentiality. In order, to carry out this study, both qualitative and quantitative techniques were employed. This approach of the researcher allowed her to document the unique experiences of female tuberculosis patients in a highly detailed and rigorous manner.

III.REVIEW OF LITERATURE

There is a substantive literature on social inequalities on health. The available literature is very wide and diverse, covering issues concerning both women and men.

Women and men share many similar health challenges; however the health of women deserves particular attention. Women generally live longer than men because of both biological and behavioral advantages. But in some settings, notably in parts of Asia, these advantages are overridden by gender-based discrimination so that female life expectancy at birth is lower than or equal to that of males. Moreover, women's longer lives are not necessarily healthy lives. There are conditions that only women experience, and that potentially has negative impact on them and that is the thing where only they suffer. Some of these are pregnancy and childbirth. These are not diseases, but biological and social processes, that carry health risks and require substantial health care. Some health challenges affect both women and men, but have a greater or different impact on women and so

require responses that are tailored specifically to women's needs. Other conditions affect women and men more or less equally, but women face greater difficulties in getting the health care they need. Furthermore, gender-based inequalities for example in education, income and employment limit the ability of women to protect their health [9].

According to a study which was carried out by Global Fund [10] it was recommended that there should be provision of such programs aimed at removing gender related barriers to Tuberculosis Prevention, diagnosis and treatment services and facilities to help all stakeholders to ensure promotion and protection of human rights and gender equality.

Another study carried out by European Center for Disease Prevention and Control [11] revealed that health inequalities play a strong but often underappreciated role in infectious disease transmission. It has been further revealed that, differences in income, education and social status lead to differing living and working conditions, which in turn result in certain exposures that can impair health.

World Health Organization [12] claims that around the globe, the health of women is critically affected by social and economic factors such as access to education, household wealth and place of residence. Women's health matters not only to women themselves. It is also crucial to the health of the family and the health of children they will bear.

In order to determine, gender perspective in health, [13] found out that socio-economic and cultural factors play important roles in determining overall gender differences in rates of infection and progression to disease, and also access to case detection and successful treatment of Tuberculosis. The study also highlighted that Tuberculosis control and research programs need to be gender sensitive and should take the necessary measures in all their efforts.

In a study conducted by [14] the author has put forth that, although there have been a number of written documents on how tuberculosis emerged as a disease, but very little has been written on differential impact of tuberculosis on women and men. The author also revealed that, tuberculosis control programs in order to make successful, needs high level of case finding and case holding, and if there remains any population group that have limited access to effective treatment, then tuberculosis control on the whole will remain in effective.

There is no doubt about the fact that, socio economic status is a major determinant of health for both women and men. But under this umbrella, it's the women who are highly affected by socially as well as biologically. Statistically, the number of case detection of tuberculosis is high on males but at the same time, the disease has more repercussions on females than males.

IV. KEY FINDINGS

4.1 Economic Glitches

The economic burden was often one of the first problems which patients and their families had to cope with [15]. Generally, the sole income of the family, survival and development of family and children depends on the shoulders of men. So when a female is infected with such type of prolonged illness, she has to wholly and solely

depend on her male counterpart. Men tend to experience the financial burden of tuberculosis both indirectly and directly because illness limited their ability as breadwinners and seeking tuberculosis treatment could drain their financial resources to a huge extent. In contrast, women lacked financial independence, which limited their access to care. Women's lack of financial autonomy and lower status within households deprioritizes their health, leaving them dependent on spouses, families, or social services. There is no doubt that the economic burden of tuberculosis whether himself infected or not was greater on the shoulders of men, but what about those men who with scanty income manage to survive. In this study, majority of tuberculosis patients experienced number of socio economic problems than any other illnesses. Although a majority of study participants revealed that tuberculosis drugs are free but still treatment cost is a major concern which included travel charges, charges on other medical examinations and daily food.

According to one narrative during in-depth interviews

"*I never thought I would be here in Tuberculosis Centre one day. I was a jolly kind of a girl who never thought that her beautiful days would turn into a nightmare. After getting detected with Tuberculosis, I experienced a different kind of a behavior from my spouse. A labourer by profession, my husband was managing his entire household activities single handedly. He is a single earning member who feeds seven members in a family. This disease puts an extra burden on his shoulders. No doubt, medicines are free of cost for Tuberculosis patients, but an extra burden of clinical examinations prompted me to sell my gold assets. Shahida

4.2 Social Segregation

When a woman contracts Tuberculosis her life changes forever. There begins a strange isolation where she is forced into silence because of her condition. In this study, majority of study participants had to hide their disease from their in-laws. The reason being social rejection and discrimination. A few among them who have told their in-laws about Tuberculosis received harsh treatment. They have been thrown out of their homes and those who are allowed to stay have been kept aloof from their children. Social stigma is recognized as an important barrier in successful care of people infected with Tuberculosis. It has been found that in india the families of male TB patients accepted the disease while on the other hand; women TB patients suffered some adverse reactions like women being restricted from conceiving, breastfeeding their children or even outright rejection [16].

As per the narrative of Saika (Name changed), a resident of downtown Srinagar

"I was married one and a half year ago and I am living in a joint family comprising of 10 members. I became obese soon after the marriage, but i didn't pay much attention to this and was living normally with her family. After one year of marriage, we began to think of having children. Because of the intricacy of obesity, I was not able to conceive and consulted a Gynecologist. After consultation I came to know that I have a major Cyst on my Uterus and was immediately operated. But after surgery, I was having lower abdomen pain and I consulted the same Gynecologist, thereafter I was diagnosed with Tuberculosis in my Uterus. I cannot tell my in-laws that I have TB; I am forced to take all the medicines at night when everyone in the family is sleeping. "

Stigma occurs because of community and institutional ignorance and mistaken norms about undesirable diseases. The most common cause of Tuberculosis stigma is the perceived risk of transmission [17].Stigma associated with Tuberculosis is often regarded as a strong barrier to health seeking behavior and is a cause of

significant suffering. An affected person can find oneself unable to seek help, fearing a loss in social status, marital problems or hurtful response from the community.

4.3 Reproductive Apprehensions.

The focus of this research study was on female tuberculosis patients who are in their reproductive years. The majority of study participants got infected with tuberculosis with no earlier history of Tuberculosis from family. For many women the period of puberty and menopause offer multiple opportunities for personal fulfillment and development. But at the same time, women who do not know how to protect themselves from such phase face increased risk of deaths and illness. Moreover, when it takes two to make a baby, then why women alone face the health problems that are associated with pregnancy and childbirth.

As narrated by Aalia (name changed)

"I was living happily with my husband, untill I was infected with this deadly disease. The feeling of being pregnant is something which cannot be defined and the emotions associated with it cannot be described. Being pregnant is a great feeling for women and a positive experience of passing into the motherhood. My happiness knew no bounds when my pregnancy tests came positive, but in no time it turned into a nightmare. From the day, I was diagnosed with Tuberculosis, my husband forced me to leave my home"

Throughout human history, pregnancy and child bearing have been major contributors to death among women. Maternal Mortality (i.e, the death of women during pregnancy, delivery or the post-partum period is a key indicator to women's health and status. Health workers are often asked to advice mothers with tuberculosis about whether it is safe to breastfeed. In the past infants were separated from their mothers, untill their mothers became non-infectious. Separations made by breastfeeding and care by the natural mother impossible, and put infants at high risk of infections and mal nutrition caused by artificial feeding [18].

As narrated by Nighat* a mother of just 47 days old baby boy went to Chest Disease Hospital Srinagar in a very terrible state. During my pregnancy days, I was having a mild pain, which is normal in that period. I have never thought even in my wildest dreams that I will get Tuberculosis. It took me almost a week to adjust my baby to artificial feeding. I will never feed my baby untill I get cured".

V.ANALYSIS AND DISCUSSION

In social sciences, triangulation is often used to indicate that two or more methods are used in a study in order to check the results of one and the same subject. In this study, the researcher used triangulation method in order to get specific information on experiences of women infected with tuberculosis in Kashmir with statistical analysis. The study highlights the different beliefs and perceptions of women infected with tuberculosis, their socio economic status, knowledge regarding tuberculosis disease and attitude and behavior of society towards tuberculosis patients. The findings which emerged from the study clearly reflect the real picture of Tuberculosis and its impact on women in Kashmir. Despite working tremendously on tuberculosis control, the Govt. of India along with World Health Organization , still faces a huge challenge to curb this epidemic. Tuberculosis is still harsh on females, and its repercussions are more on them during their reproductive years. The study highlights that women diagnosed with tuberculosis completely hide their disease from their in-laws, due to threat of

ostracism and outright rejection. Moreover, the decision making powers of women are completely restricted to household chores. From the results of this study, the following phrases of reactions to the diagnoses of tuberculosis were revealed. Firstly, female patients were extremely shocked when they have been told about the detection of tuberculosis. Secondly, on accepting the disease, they have to be financially dependent on their men. Lastly, social stigma and isolation were common fears that have affected their social life. The concerns of men and women were different, because both have different roles in a family to play. It has been revealed that, when a man is diagnosed with such type of illness, he wants extreme care and support from his spouse but at the same time, when a woman contracts the same illness, that very care and support is lagging. Being financially dependent on husband and in-laws, women were more concerned for their marriage, rejection by husband, separation from children, harassment by in- laws and discrimination by society as a whole. Although Tuberculosis is preventable and treatable, but what about the social stigma which is still deep rooted in the society and community. It has been revealed by this study that it is stigma which has crippling consequences and which is doing more harm than the disease itself.

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