International Journal of Psychosocial Rehabilitation, Vol. 24, Issue 08, 2020
ISSN: 1475-7192

Gender, Health and Healing: Perceptions and Experiences from Women Survivors Affected by Tuberculosis in Kashmir.

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ABSTRACT*--The concept of right to health as a human right has emerged as a result of growing consciousness about the dignity of human life all over the world. Healthcare is undoubtedly considered as a socio-medical concept, and not just a medical one, therefore, it doesn't mean that mere medical treatment during illness is an achievement or progress. Since women constitute nearly half of the world's population and they have also an additional responsibility of reproduction and motherhood, therefore, they must be given equal status in accessing health care services and should be adequately informed about a particular disease or illness. Gender for women has been a powerful indicator of inequality and discrimination, which influences not only their state of health and wellbeing but also their ability to seek care. Same is true for Tuberculosis which has been plaguing humankind since time immemorial. Women are often affected differently by Tuberculosis than men. Growing evidence suggests that Tuberculosis has implications for women's reproductive health, including links with infertility, risks of prematurity, obstetric morbidity, and low birth weight. The present paper is an attempt to sketch a picture of women's suffering from Tuberculosis in Kashmir. It also tries to document their perceptions and lived experiences of being Tuberculosis survivors.*

Keywords--*Gender, Health, Inequality, Reproduction, Motherhood.*

I. INTRODUCTION

The notion of health itself has been conceptualized in many ways. (Turner 2003) charts the manner in which the concepts of health and illness have changed historically, from primitive societies where they were linked to spiritual notions of purity and danger, to the dominant biomedical, scientific and professional definitions that focus on disease and pathology that affects the body and body parts (Saks & Allsop 2013). In the modern context, there are still many debates about interpretation. Typically, social scientists view health as a moral norm defining a socially constructed, prescriptive standard that tends towards an ideal of wellbeing or social functioning. Although, people in different social groups also define health very differently depending on variables like social class, gender, ethnic group and age (Scambler 2008). Within this perspective, illness is usually conceptualized as the obverse of health. Social scientists have conceptualized illness as subjectively defined, socially sanctioned and legitimated. It is also socially patterned through the interpretations of individuals themselves and significant others such as family, friends and health providers (Saks & Allsop 2013, p. 6). The debate on reproductive health has attracted more attention than any other of their general health problems. The maternal mortality rate has been used as one of the

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Received: 27 Mar 2020 | Revised: 20 Apr 2020 | Accepted: 05 May 2020

main and common indicators for assessing women's health status. But apart from maternal mortality rate, other health indicators are equally important to consider women's health. Taking a comprehensive health indicator like maternal mortality, child sex ratio, anemia level, prevalence of various communicable and non-communicable diseases, sexual violence faced by women into account, it becomes clear that women's health status in India as well as the state of J&K is not upto the level that it should have been. If a person will paint these dimensions and discriminations in black, India will shame to look like a dark continent. In this contemporary world and most probably in rest of the poor and developing countries, getting Tuberculosis is not less than any crises. India alone bares nearly one fifth of the total burden of Tuberculosis across the world. In the State of Jammu & Kashmir, the World Tuberculosis Day is celebrated with great pomp and show. The health officials in their time to time deliberations have constantly assumed that Tuberculosis in the state is declining but as per the latest figures it was estimated that the twin capitals of the state have witnessed the highest incidence of Tuberculosis cases in the year 2017, even as the overall prevalence of the disease has increased by about 5 per cent compared to the preceding year (Dharma, 2018). Tuberculosis is not only a physical ailment but a psychological, social and economic catastrophe resulting in not only a physical woe but also a psycho social sufferings especially for the vulnerable section of the society (Yasir 2014).

Women always neglect their own health and priorities because they are more concerned towards their family and children. In case of certain diseases like Tuberculosis, women face more adverse effects, intense social stigma and are more vulnerable to social isolation in comparison to men. For women who have no bread earning member in the family, she has to work for herself and her children. In most of the cases, they are abandoned and discarded by their own family and relatives and in such circumstances merely a simple medical approach does not help. It has been exceedingly understood that health outcomes can no longer be simply understood as the product of medical intervention or pharmaceutical treatment alone. How patients access services, the ways they participate in decisions about treatment and the social context in which they are treated, live and work are all important to health outcomes. There is no interest greater than that of the patients in any healthcare system. If a health system does not recognize and fulfil the patients' needs and safeguard their interests, it is failing in its duty and is unlikely to be a success (Mehra &Swaminathan 2018). Termed a ***Ticking Time Bomb*** (Mehra & Swaminathan 2018) Tuberculosis remains one of the India's most significant health challenges, killing over a thousand Indians every day. Tuberculosis despite being fully curable disease but utmost defamed one, and is believed a machine of poverty and debt. Since Tuberculosis can extinguish any gender quite intensely so it has very strong crippling implications on women as well and the same has been grasped through various discourses where usually own family members shun and abandon them before society. In such circumstances, women in particular are disproportionately compressed by the stigma of Tuberculosis (Mehra & Swaminathan 2018). Tuberculosis despite being fully treatable and curable carries with it a deep seated stigma and can be termed as curse so affected persons are more reluctant to share their disease status with family and friends. This situation worsens if the women is married as she faces enormous challenges and may be vulnerable to abandonment by in-laws or significant other.

II. THE STUDY

The present study was carried out in three District Tuberculosis Centers one from Central Kashmir, one from South Kashmir and one from North Kashmir in the Valley of Kashmir. In each of three districts, a total of three Focused Group Discussions (FGD) were conducted, two including only women participants who were in the age group of 15-49 with confirmed Tuberculosis and one including both women with confirmed Tuberculosis and their attendants. The reason for including attendants group was only to get the individual and community perceptions regarding Tuberculosis. The participants who participated in the discussion process were purposively selected by the health care officials working in the concerned districts. The study participants were selected on the basis of the treatment received from the last 12 months. The FGD's were arranged by the concerned District Tuberculosis Officers and Health Care Officials of the concerned districts. All the discussions were arranged in a separate hall properly maintained by the concerned officials. A majority of participants gave their consent after being informed about the nature and purpose of the study and those study participants were not included who despite being intimated by the concerned health care officials couldn't come due to one or the other reason. The FGD's were held in hospital settings and each FGD continued about 1-2hr. The discussion flowed from the general health issues to more specific topics e.g. Tuberculosis and its impact on women, changes in the relationship between tuberculosis patients and their spouses, the relationship with their children, in-laws, relatives and neighbours and the researcher used recorder in order to record all the proceedings of the discussion.

III. REFLECTION AND CASE ILLUSTRATIONS

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, anemia, diarrheal diseases and Tuberculosis among others. A major barrier for women to achieve the highest attainable standard of health is inequality. Health policies and programmes often perpetuate gender stereotypes and fail to consider socio economic disparities and other differences among women (Chatterjee 1990). 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 (Misra 2014). The status of women is a complex issue. It is not amendable to any simplistic explanation of social reality. Women are biologically different because they reproduce, even though men do not have that capacity. The reproductive system in function, dysfunction and disease plays a central role in women's health, so she needs extreme care and support in this phase. But unfortunately the figures have revealed a fettering fallout and the major losses were recorded in this phase, be it due to biological imbalances or due the contraction of life threatening diseases.

Saika* had only middle level of schooling when she started helping her mother in household activities. She had a marriage of her choice at the age of 21. Her husband is a mechanic by profession and was working at a shop in a nearby village.. Saika stayed in a joint family of small 4 room house with a full time servant. Her husband was the only earning member in a family who feeds about 6 members including Saika. She was affected and diagnosed with tuberculosis after 1 year of marriage when she had an abortion. After getting contracted with this illness, her husband rejected her and left her with her poor family. From that day, it was a hell like situation for Saika to live with the deadly disease. Earning her medicine expenses by working on a pashmina shawl, she never disclosed

about her illness among her relatives or neighbours. She felt ashamed when she used to look at her poor father. Her father's hopes got shattered narrated a terribly weak and ill Saika.

There are conditions which only women experience and that have negative health impact that only women suffer. They are given partial importance in society and are seen only as bearers of the heir to carry the family forward. Although, motherhood is looked at as a very positive experience by most of the women mainly because of its social importance but at the same time it is a full time occupation which alienates a woman from herself. In the course of upbringing, the children and taking up responsibilities of the family, the mother quietly forgets her own health sufferings, tension, anxiety and pain which gets shelved to the dark oblivion of the interior of the house(Krishnaraj 2009).

Shareefa* has a 2 year old daughter and was still in her father's home after delivery. Sharefa's* first pregnancy was also after many years of married life and after a lot of effort. She was afflicted with tuberculosis after her delivery and frequently visited tuberculosis center along with her mother for her checkup. Her relationship with her husband had altered after he got to know about her illness and ordered her to keep their daughter as he is hardly concerned about their wellbeing.

The social construction of motherhood was influenced by customs and practices in which motherhood was assigned a sacrosanct space as a crucial determinant of the ultimate identity and worth of women (Sinha 2010, p. 320). The identity of motherhood completely overshadowed all other identities of a women and as a result women is raised in a culture that trained her to be an ideal mother from early childhood. But together with the feelings of joy and happiness, the sentimental emotions doubles the intensity and stress for mother and more notably to that mother who has been detected with life threatening illness.

Rabia* had a strong desire when she got married to become a mother, but didn't know that she would be harassed so badly by her in-laws for not producing babies after 3 years of marriage. "I and my husband were informed that I have tuberculosis in my uterus and we shouldn't think of having a child until full treatment. My husband no doubt supports me but how long will he be able to stand by my side". Rabia's married life was threatened by her in-laws who exerted pressure on her husband to have atleast one child. Her husband sometimes argued with them saying that they had not grown old and it all depends on Almighty's will.

IV. SOCIAL STIGMA AND DISCRIMINATION DUALITY: A CASE BEYOND MICROBIOLOGY

Stigma and discrimination is a very common concern among Tuberculosis patients. Along the adverse effects on treatment, stigma and discrimination poses numerous consequences for their psychosocial well-being for those suffering from the disease. Although, the presence of consequences can be found across the world but the manner and magnitude they manifest themselves varies across regions, countries, communities and individuals. Much of the emphasis is on microbiological cure of disease. Less attention is paid on the patient's experience and how it affects their social, mental and physical well-being, through stigma and discrimination (Yasir 2014).

There was as strong opinion that women infected with tuberculosis should not conceive as the child will also get affected (Ishfaq*). Most of the attendants were of the opinion that the tablets taken for curing tuberculosis will affect the child and hence they should not get pregnant. A few of the participants said that affected women can

conceive but only after consulting the specialist. Most of the study participants were of the opinion that, infected women should not breast feed as the illness will pass on the children through lactation.

Despite the spike in reported incidence of many epidemic diseases including the most stigmatized disease of Tuberculosis, there is not a very impressive response from health authorities for prevention and control of this epidemic. As per a recent study conducted by Directorate of Health Services Kashmir (DHSK), (April, 24, 2018), the incidence of Tuberculosis in Kashmir division is about 147 per lakh population as compared to an estimated national average of 217 per lakh. Despite reductions in the incidence of Tuberculosis over the years, a lot needs to be done in order to alleviate the sufferings caused by this deadly endemic. Like most parts in India, Tuberculosis in Kashmir has an intense social stigma attached to it which makes the situation worse particularly in rural areas (Kashmir News 2012). The notions attached to this deadly disease need to be dispelled first so that more and more people could come forward for the treatment. In Kashmir, it has been mostly found that the people living in crowded homes with poor ventilation usually fall prey to this disease, and the close proximity of people with the infected persons increases it's spreading. The treatment of Tuberculosis remains a constraint for patients and a heavy burden for healthcare system (Varaine & Rich 2014).

In such a system, there is no redress for social stigma, misinformation and the abuse that patients have to often cope with. The stigma associated with Tuberculosis doesn't allow patients to openly talk about their struggles.

In the year 2017, I felt terribly ill. My husband was a driver by profession and we had a joint family. I was all the time accompanied by my husband. When my health started deteriorating at the extreme level, my husband took me to a private hospital where after having a whole body scan, I was told that I have a big mass in my abdomen which need to be removed. It turned out to be pus, and after getting examined I was told that I have tuberculosis (Dilshada*).

My first reaction was utter shock. And the first thing that appeared in my mind was not the concern about my own health but the intense fear from relatives and neighbours. I have seen a few people with acute illness that their relatives and neighbors don't treat them the same way as they used to treat them before disclosure of the illness. This thing developed fear in me not to disclose the illness among my relatives and neighbors.

Patients affected with Tuberculosis face extreme stigma especially from the ones close to them. Given the social construction of Tuberculosis and the age old stigma associated with it, patients face harassment from every end. The results from the Focused Group Discussions were quite astonishing as the attendants revealed that the patients face extreme stigma from every end. Moreover, the level of stigma decreased with the increase in the education level of the attendants; more the illiterate attendants more the stigma and more the educated attendants less the stigma. Furthermore, the results also revealed that the stigma associated with Tuberculosis forces the patients to hide about the illness from people associated with them as there have been evidences that patients affected with Tuberculosis face extreme stigma from their loved ones, making them feel completely devastated. Therefore, as per the attendants, the need of the hour is to come up with intensive plans in order to work for the eradication of stigma at all levels.

V. CONCLUSION

Tuberculosis has been declared a global public health emergency by World Health Organization, way back in 1993. The disease has a great propensity to cause significant morbidity and mortality that World Health Organization sprang a number of tactics, in order to have a full control on this endemic. The disease has also been responsible for huge economic devastation and if there will be any population group that has limited access to effective treatment, then Tuberculosis control on the whole will remain ineffective. Despite World Health Organization's tremendous efforts and declaration to curb this emergency and despite the implementation of strong Tuberculosis control initiatives, this global threat continues to affect all vulnerable populations including women. Tuberculosis is a historical disease, had past, has present and undoubtedly is going to have a future because it is the social context and the social prejudice which is not helping and is in a way hampering to eradicate Tuberculosis as a disease and stigma as a barrier in society.

VI. ACKNOWLEDGEMENT

I would like to acknowledge everyone who played a role in this study. My gratitude goes to all the study participants who were the backbone of this study and played an active part in conducting this study. Moreover, I would like to acknowledge the support of the attendants who understood the purpose of the study and shared their experiences. Furthermore, no words can acknowledge the support received from all the District Tuberculosis Officers and other Health Care Workers who were actively involved and paved a way for successful culmination of the study. Lastly, I would like to pay gratitude to my Parents who have supported me with love and understanding and without their support, I could never have reached this level.

VII. SPONSORSHIP

This Research Study has been sponsored by ***Indian Council of Social Science Research ICSSR, New Delhi***. My sincere gratitude goes to them as well because without their support, this study would not have been possible. Thank you all for your unwavering support.

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