

## Maternal Health of Disabled Women-Issues and Remedies

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### **Abstract:**

*Disability is not a universal concept and its meaning varies according to cultural and attitudinal differences present in different societies. It may be defined as a kind of impairment, physical or mental, that makes it difficult for a person to do what other people are able to do because it hampers an individual's capability to perform a particular task significantly as per the standards. Disability is a human right issue, where these people are subject to multiple violations of their rights, abused, disrespected and discrimination. Disabled women also face systemic alienation, environmental and attitudinal barriers that lead to their increased risk of discrimination and abuse. Keeping in view, the present paper is an attempt to highlight the various issues of maternal health and care of disabled women. It is a review-based study which is aimed to identify the various issues regarding maternal health and maternity care of disabled women. There are also some barriers like access to education, health care facilities particularly reproductive healthcare information, communication and justice which affects their standards of living. The attitude of healthcare professionals also shadows their right to live a dignified life. An urgent need is required to provide effective measures, to meet their special needs initiating from the grassroot level to an administrative level so that they also have a right to live without any stereotypes by promoting their equality and empowerment.*

**Key words:** Disabled women, Maternal health, Maternal care, Healthcare professionals

### **Introduction**

Human beings are not perfect in all respects, the extent of imperfection varies widely. Any person who has a defect that causes physical deformity and as a consequence, interfere with normal life and leads to physical disability. In addition to this, physical disability is not a universal concept and its meaning varies according to cultural and attitudinal differences present in different societies. It may be defined as a kind of impairment, physical or mental, that makes it difficult for a person to do what other people are able to do because it hampers an individual's capability to perform a particular task significantly as per the standards. A disabled person could also be a person who in his/her society is regarded as disabled, because of a difference in appearance and behaviour. Disability is a consequence of impairment leading to functional limitation or activity restriction.

Traditionally, almost no attention was paid to the existence and experiences of people who are physically or mentally challenged. The general perception of disability was usually associated with defectiveness, insufficiency and imperfection. It has also been viewed that disability often meant a limiting case of disadvantages. For example, babies born disabled or deformed, degrades the value of human life or the disabled adults are considered non-contributing members of a society, particularly the disabled women. In everyday life, women with disabilities face various challenges, discrimination and in particular the issue of pregnancy and motherhood which is usually considered a taboo and it is assumed that their parenting abilities are doubtful. Maternal health and care of disabled women is a crucial issue, and knowledge about the experiences of women with disabilities during pregnancy and childbirth is also limited.

Maternal health is an important indicator of women's health and status. The World Health Organization (2009) defines maternal health as the health of women

during pregnancy, childbirth and the postpartum period. Motherhood seems to be a positive and fulfilling experience, but for too many women who are disabled, is linked with suffering, ill-health and even death. Health index of Jammu & Kashmir is below the national average and far below than Kerala. The sex ratio in Jammu & Kashmir has the second worst sex ratio i.e., only 883 females per 1000 males in 2011. The typical and adverse sex ratio of Jammu & Kashmir, lack of information about Maternal Mortality Ratio (MMR), poor educational attainments, the patriarchal cultural patterns and the impact of political violence on the social order makes it very important to understand the state of maternal health of women in general and the maternal health of disabled women in particular. Maternal health care includes antenatal care, delivery care and post-natal care, postpartum complications and maternal care indicators. The characteristics of individual women like age, residence, income, number of previous pregnancies, disability, the health system and education level play a significant role in determining inavailability of appropriate services. Age, number of children already bore and previous birth-giving experience can all influence pregnancy and delivery care of a disabled woman. The education level and specific knowledge about the importance of pregnancy and delivery care irrespective of any disability and awareness of accessing them also plays a role in uptake of services. Caste, wealth, and urban or rural residence all are found to have association with quality of antenatal services.

According to the World Health organization Report (2011) and World Bank Report (2011), about one billion people of world's population have disabilities. The main categories of disabilities are intellectual, cognitive, neurological, psychiatric, physical and sensory. It is also pertinent to mention that physical disability is most common form of disability. In addition to this, about 10% of women with disabilities are of child bearing age and there is an assumption in the society that these women should not be sexually active and not likely to have children. Studies have revealed that women with disabilities experience problems during pregnancy and childbirth due to physical barriers, lack of specialised services, problems with healthcare system and barriers to information, problems with communication and negative attitude of health care professionals, (Scheer et al. 2008).

Studies have further emphasized on the fact that although the disabled women have the right to enjoy healthy motherhood and quality healthcare, but the health care providers are proving to be insensitive and not active. It has also been realised that technological advancements are only for normal women. The disabled women have been stereotyped to be asexual and do not deserve to bear children. Updated information has been also particularly disseminated for only normal women while neglecting the women with special needs. There is poor accessibility of transportation, facilities and equipment. There is a perception among general population and their lack of assertion for the motherhood of disabled. Further, quality of perinatal care remains unsatisfactory and the problems occurring are not resolved effectively because those remain largely unrecognised. Inaccessible care, negative attitude of people around and misunderstandings and misinformation regarding disability and its related needs are often leading to their miseries.

But over the last few decades, people from various disciplines have come forward to question the broader significance of pre-eminence assigned to normalcy and devaluation of the physically and cognitively disabilities. Recently, feminist thinkers moved to the forefront, to emphasise the disabled for their interest which is prompted by commitment to inclusiveness or their own personal contact with disability. Disability perspectives have become familiar in feminist approaches to philosophical topics like ethics, justice theory and the metaphysics of embodiment. The feminist disability studies are marked with the assumption that disability is always linked with gender, race, social class, sexuality, etc. The objective of the review-based paper is to analyse the issues related to maternal health of disabled women and to explore the wide-ranging, disciplinary and interdisciplinary remedies to overcome their difficulties.

#### **Research Studies:**

Ganle, Otupiri, Obeng, Edusie, Ankomah & Adanu (2016) in a qualitative research found that although a number of studies have examined the factors affecting accessibility and utilisation of healthcare services by persons with disability in general but there is little evidence about disabled women's access to maternal health services in low-income countries and few studies consult disabled women themselves to understand their experience of care and the challenges they face in accessing skilled maternal health services. The objective was to explore the challenges women with disabilities encounter in accessing and using institutional maternal healthcare services in Ghana. Findings

revealed that although women with disability intend to receive institutional maternal healthcare but their disability often makes it difficult for them to travel to access skilled care and to have access to friendly physical health infrastructure. The other related access challenges included healthcare providers' insensitivity and lack of knowledge about the maternity care needs of women with disability, negative attitudes of service providers, the perception from normal people that women with disability should be asexual and health information that lacks specificity in terms of addressing the special maternity care needs of women with disability.

A study conducted in rural Nepal showed that married disabled women considered pregnancy and childbirth to be normal and preferred normal delivery at home but the problem of lack of service and lack of family support were as pertinent for disabled women as compared to the non-disabled women. Moreover, cost for facilities was high and healthcare workers delivery set-up unprepared and ill-equipped to meet the special maternal healthcare needs of disabled women. (Morrison, Basnet, Budhathoki, Adhikari, Tumbahangphe, Manandhar, Costello, & Groce 2014). Further, in general healthcare providers' attitude towards disability was found to be negative with poor knowledge and skills about providing the special services and to some extent, it adversely had impact on utilization of maternal healthcare service by women with disabilities. Hence, more organized, effective training for healthcare providers is required through on-going mainstream efforts to develop favourable attitudes towards disability, (Devkota, Murray, Kett & Groce, 2017).

Blair, Cao, Wilson & Homer (2022) analysed various articles from eight high-income countries having moderate or high methodological rigour in the quality appraisal, reported numerous barriers faced by women with disability in accessing maternity care and expressed mixed and negative experiences of care. These findings were classified under three major themes, i.e., women with physical disabilities want normal pregnancy experience, strengthened knowledge and skills of maternity healthcare professionals and promotion of friendly and empathetic environment that enable improved access and experiences of maternity care.

In another qualitative study, Schildberger, Zenzmaier, & König-Bachmann (2017) investigated disabled women of Austria on the basis of personal meetings regarding experiences related to their pregnancy, childbirth and the puerperium through in-depth individual, semi-structured interviews of ten mothers with various mobility or sensory impairments. The qualitative content analysis of the data identified the three main themes or categories as the social network, self-efficacy and self-awareness and communication, transparency and information. Participants reported limited acceptance of their life decisions and experienced an environment of discriminatory attitudes. They experienced a lack of support and lack of confidence in their parenting abilities, which negatively influenced their self-efficacy and self-awareness. Violations of personal borders and a feeling of being watched and controlled were reported. Communication with health care professionals was often characterized by mutual aspects of fear, uncertainty and awkwardness, as perceived by women with disabilities. Adequate information about pregnancy, childbirth and the puerperium, particularly about measures taken and interventions are not satisfactory.

#### **Remedial Measures to be taken:**

Mainstreaming of disabled women is a must and it is unaffordable to devalue these women just because they have some disability. There are instances where disabled women have excelled in various fields and have managed to be best mothers to their children like Deepa Malik braving chest-below paralysis is the first Indian paralympic to win a medal (silver) while adequately caring for her children. The concept of mainstreaming of disabled women can be eminently a desirable step in the larger social perspective, the family members, community members and health care professionals need to acquire special abilities to identify the out of ordinary maternal needs and care of a disabled women, develop among themselves appropriate management skills, use of special equipment and above all display a humane approach in handling them.

The first step is to identify the needs of women with disabilities. Their residual capacities are to be assessed and their interacting behaviours to be mapped, accordingly health care facilities should be modified and enhanced. Focus should be upon overall development of women with disabilities according to their specific needs in relation to their adjustment.

Self-care, safety measures, mobility training, development of coping strategies for their problems, community resources, development of positive self-image and overall personal development is necessary for them to not have feeling of neglect and self-derogation. These women should not be let

to develop any sense of negative self and should be integrated with other women without any discrimination.

The support services which are necessary for their integration should be made available. It is better for them to identify the things that are familiar with their daily life and it becomes easier for them to enjoy the bliss of motherhood. The functional orientation of training should be to facilitate the functioning of disabled women as an independent mother.

To develop a disabled women as an independent and functioning mother, specific objectives in terms of skills are required to be identified, listed and linked to various social settings in which the disabled woman has to live. These settings are family, community and the society. The skills to be developed include empathy, emotional intelligence, creativity, problem solving, positive thinking and energy, humour, fun and assertiveness.

With active involvement of community, medical advances and recognition of reproductive rights of women with disabilities have increased their opportunities for childbirth. Maternal healthcare services should be designed to address the needs of disabled women that provide flexibility and responsiveness to meet their special maternity care needs.

More disability-related cultural competence and patient-centric training for healthcare professionals and the provision of disability-friendly transport and healthcare facilities and services is must. There is an urgent need to provide training and ensure practice for healthcare workers to be aware of special needs to improve the maternity care facilities.

It is also suggested that improving maternity providers' disability knowledge and awareness, increasing the availability of support services for women, increasing individualised care through organisational policies and advanced trainings, may help in resolving the inequities women with disabilities face in accessing high-quality maternity care. Health care facilities need to be structured to ensure ease of access for women with disabilities.

Education should be offered to health care professionals to improve knowledge about care for women with disabilities and to strengthen communication skills. All necessary information needs to be prepared and provided in an adequate manner. The establishment of a health-promoting environment for mothers, their children and their families require a sensitive, respectful and non-judgmental attitude of society toward women with disabilities during pregnancy, childbirth and the puerperium. Policy makers should provide a framework for overall healthcare facilities that would enable to provide effective remedies to meet women's special needs. In nutshell, disabled should be able to enjoy motherhood and best facilities should be provided to them by the family and society as well.

#### **Constitutional Provision with reference to Jammu and Kashmir:**

The Jammu and Kashmir Rights of Persons with Disability Bill, 2018 ensures that persons with disabilities, have the access to appropriate information regarding reproductive and family planning, they should be not be subjected to any medical procedure which leads to infertility without his or her free and informed consent. Government and local authorities should take necessary measures for the women with disabilities to have free access to healthcare facilities.

#### **Conclusions:**

Maternal health of disabled women must be recognized as a key development issue by all countries and there should be collaboration for increasing the quality and accessibility of reproductive health care. This can be done by addressing social and cultural factors that discourage some of the most vulnerable women from seeking care. In addition to this, the disabled woman must be educated about her health and about the importance of proper care to be taken during pregnancy and childbirth. The experience of motherhood must be made rewarding for them. The family and the government as well as the society at large have an important role to play in supporting the development of disabled women by providing appropriate resources and encouraging them to live a dignified life.

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