



UNMET NEEDS OF INDIAN WOMEN'S LIVING WITH DISABILITY; A CROSS-SECTIONAL DATA

Hariharasudhan Ravichandran¹, Balamurugan Janakiraman²,
Mohammad Sidiq³, Parthasarathy Ranganathan⁴, Nalini Devarajan⁵,
Sureka Varalakshmi⁶, Kshama Susheel Shetty⁷

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Abstract

Background: The unmet needs are a significant predictor of quality of life among women living with disability, particularly in countries like India where discrimination and social norms against women is still a concern. UNICEF, India and recent researches have demonstrated considerable attention in unmet needs of women living with different health conditions.

Objectives: The aim of this study was to identify the factors associated with unmet needs of adult Indian women living with disability, predictors, and adverse consequences.

Methods: A Cross-sectional survey was conducted during November 2022 to January 2023. Convenient sampling method was used to recruit participants who consented, disabled care service providers and NGO's were approached to locate eligible women in Chennai. A total of 145 women with disability were included in the survey. Data were collected through face to face interview method using a structured closed ended questionnaire.

Results: Of 145 women surveyed, 45% are illiterates, 64% are unemployed, 24% are not affordable to utilise any rehabilitation services, 45% are dependent in activities of daily living (ADL), 88% were not affordable to buy assistive devices, 83% are physically inaccessible to public transportations, 64% of adults are unemployed and 81% are unaware of government benefits.

Conclusions: These results are important in that they give us an indication of where Velachery, Chennai, now stands in terms of meeting the needs of women with disabilities. Our survey findings will be instrumental in informing future policies and in improving service delivery to women living with disabilities.

Keywords: Disability, Gender, India, Unmet needs, Quality of Life

^{1,7}Faculty, Alva's College of Physiotherapy and Research Centre, Moodubidire, Dakshina Kannada, Karnataka, India

^{2*,5,6}Department of Research, Meenakshi Academy of Higher Education and Research (MAHER), Tamil Nadu, India

⁴Faculty of Physiotherapy, Meenakshi Academy of Higher Education and Research (MAHER), Tamil Nadu, India

³Department of Physiotherapy, School of Medical and Allied Health Sciences, Galgotias University, Greater Noida, Uttar Pradesh, India

***Corresponding investigator:** Balamurugan Janakiraman,

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2. Background

Disabled women in general been silenced within society, denied their rights, equal economic and social opportunities. They face a pattern of discrimination that repeats itself globally, in differing forms, in rich countries as well as poor. Most families have a disabled member, and many non – disabled people take responsibility for supporting and caring for their relatives and friends with disabilities [1]. Disabled women live at the corner of disability and womanhood – with two minority identities, a double dose of discrimination and stereotyping multiple barriers to achieving their life goals [2]. Women with disabilities are most marginalised in Indian society. They are deprived of political, social, economic and health opportunities. Apart from such issues, disabled women face complex situation such as social stigma and poverty [3].

According to the National sample survey office (NSSO) 58th round survey in 2002 there are 18.49 million people in India who are disabled. This number has increased from 13.67 million in 1981 to 16.36 million in 1991. Out of the 18.49 million disabled people, 10.89 million males and 7.56 million are females, which constitutes of around 58 per cent males and 42 per cent females respectively. These people are suffering from some form of disability. Disability is a complex social phenomenon and as such people with disabilities must be given due consideration across all sectors of humanitarian intervention. [5]

There is a common concern that disabled persons are the most excluded ones in the development process of the country. For an effective and efficient policy intervention to improve the lots of the disabled persons, it is of utmost importance to get a clear idea of unmet dimensions of disabled in India [6]. Disabled are also not a homogenous group. Different types of disabilities need different requirements. Each one's problems, needs and help required are different from the other. In general terms unmet needs refers to the needs that a person didn't manage to satisfy yet. Just like there are physical needs such as the need to eat or the need to sleep, there are needs that people must satisfy in order to feel good [7, 8].

The pattern of isolating and ignoring disabled women is repeated throughout national and international policies, researches and rehabilitation programs. One of the major problems, which affect any intervention on the issue of disabled women, is the lack of proper data on the number, the extent and the magnitude of their problem. Since disability among women can be more challenging particularly in countries with discrimination, cultural-based gender constraints, and social norms like India. Reducing the unmet needs of disabled

women will significantly improve the quality of life among those women, and in large the country.

Several attempts [6-10] were made to address the unmet needs of special populations in women such as pregnant mother, older women, mother's with disabled children, and mental health, but there is scarce of studies investigating the problem of unmet needs among disabled Indian women's. Therefore, with lack of regional data and considering the vital societal role of the women in India this study aims to determine the burden of unmet needs of adult Indian women living with disability, predictors associated, and adverse consequences.

3. Methods

This study used a cross-sectional survey design to investigate the burden of unmet needs among disable women. The study was conducted during November 2022 to January 2023 and reported according to the recommendations of STROBE (STrengthening the Reporting of OBservational studies in Epidemiology) checklist for cross-sectional design. The proposal of the study was presented to the Institutional Human Ethics Committee, MMCHRI (Meenakshi Medical College Hospital and Research Institute, DHR, India reg no EC/New/INST/2021/2220). The study adhered to the declaration of Helsinki and written informed consent was obtained from all the participants.

Participants and sampling

The community dwelling women those who were medical diagnosed to suffer permanent visual, hearing, and physical disability were approached using convenient sampling method. The disability care service and non-governmental organizations operating at South-Chennai were identified through webpage search and contacted. Permission to conduct face-to-face interview with the disabled women registered was obtained. Participants who consented were included. During the study period 281 disable women participated in the study.

Women participants aged 18 and above, medical diagnosed disability, and living the study area for the past 10 years were included. Disabled women with cognitive impairments, and completely dependent for all the basic ADL were excluded. A structured self-administered questionnaire was used for data collection. Ten subscales captured disabled women's needs such as education, employment, Economic status, dependency in ADL and self-care, Family relationships, utilisation of rehabilitation services, expectations, confidence level and awareness.

Operational definitions:

Disabled women are those who live with permanent or with long standing (5 years) impairment that are physical, visual or hearing secondary to any diagnosed medical conditions.

Dependent variable

This study defined unmet needs of disabled women based on the following criteria, constructed from extant literature [6-10]. Unmet needs definition is conceptualized based on the factors like difficulty and/or unable to perform activity, needing human assistance, and/or assistive devices, needing help to don/doff orthotic devices, restriction in community participation and healthcare needs.

A disabled woman who reported that she was not able to or needs assistance to perform at least one of the ADL for instance; don/doffing of assistive device, bathing, dressing, transfers, ambulation/mobility, stairs, grooming, food preparing, feeding, household activities, washing cloth was considered to have unmet needs.

Independent

variables

The variables from categories; socio-demographic, activity limitations, and perceived restrictions in social and health utility participations included age, level of education, employment status, marital status, household income, level of independence, disability type, self-reported abuse encountered, affordability and social participation status. Based on the International Monetary Fund (IMF, 2022) recommendation for extreme poverty (\$ 1.9 USD per person per day equivalent to rupees 152.00 per day or 4560 rupees per month per person in the family) household income was categorized into a dichotomous group (above & below poverty line). Restrictions perceived and/or encountered during social participations related to institutional and non-institutional access/facilities at hospitals, health centres, spiritual centres, and recreational places were categorized as restricted versus not restricted.

Data analysis

Data was analysed using the SPSS (SPSS Inc., Chicago, IL, USA) version 19 for Windows. Data was expressed as frequency distribution for unmet needs and without unmet needs, percentage, means, and standard deviations. Categorical variables were tested for association using Chi-square test between unmet needs of the disabled women and independent variables. Variables associated were entered into the logistic model and results were considered statistically significant when 95% confidence intervals.

4. Results

A total of three hundred and fifty disabled women were approached and 281 participants consented and participated in this study. The mean age of the participants was 26.2 years \pm 5.84 and majority (55.5%) of the participants were younger, in the age group of 18 to 45 years. Majority of women with unmet needs were in the age group ranging from 18 and up to 45.

Among the respondents with unmet needs majority of them (61.5%) lacked formal school education and the graduates reported to have 11.2% of their needs unmet. Accordingly, employment status also significantly affected the needs of disabled women. Unemployed women with disability demonstrated higher rate (64.2%) of unmet needs, while comparing with employed women. Employed women reported 9.5% of their needs unmet. There was a significant difference between employed and unemployed women in meeting their needs and the significance was proven by chi square test value of 5.71 (table 1).

Impact of Marital status of women with disability has its effect on their unmet needs. It is observed that 64.8% of unmarried women or single women with disability, solely depending on parents or guardians tend to live with most of their unmet needs. While the married respondents, with the support of spouse demonstrated 35.2% difficulty in reaching their necessities.

Poverty line status of disabled women was used to obtain data related to their financial level, which indicated that there was no major impact of poverty affecting the financial level. It was demonstrated that 54.7% of disabled women below poverty line and 45.3% of women above poverty line survived with their needs unmet.

Activities of daily living tend to pose major threat in meeting the basic needs of disabled women. It is identified from the collected data that dependent women had 21.2% of unmet needs compared to the independent women with 44.1%. This result states that level of activities of daily living is insignificant in affecting the needs of disabled women.

It is also evident that the form of disability directly impacted the needs of disabled women. Women with physical form of disability 61.5% of them reported to suffer from unmet needs. Other forms of disability such as visual, (29.6%) and hearing (8.9%) challenged women towards meeting their necessities.

Abuses are commonly reported in disabled women. Among disabled women with physical abuse 27.9% of them reported difficulty in achieving their necessities, which was lesser compared to unmet needs of women without any abuses 34.6% and women with history of verbal abuse 37.4%, appropriately.

Community participation with peers and family members poses major challenge for disabled women. With 74.3% of disabled women with

history of restriction in social participation experienced their needs unmet. Their counterparts without history of restriction in social participation had lesser 25.7% of their needs unmet. Chi square test value 7.66, has proven that there exists significance in social participation towards unmet needs of disabled women.

Legislations and policies were planned and implemented for the benefit of disabled women. It is reported in this study that, awareness about the existing legislations could also impact the needs of disabled women. Among all the respondents 47.69% of them were not aware of legislations related to disabled women. This alarms the necessity to consider appropriate measures to improve awareness among the citizens regarding the rights and benefits of disabled women. The needs unmet was 51.4% among women aware of legislations and 48.6% in women with no awareness about the legislations.

Assistive devices and rehabilitation services were commonly utilised by disabled women. Affordable to those facility is a major threat. Among the respondents with unmet needs, there exists 64.2% of respondents with difficulty to afford assistive devices and 72.6% difficulty in affording rehabilitation services.

Accessibility constraints did not significantly affect the unmet needs of disabled women. Public transport, public places and health care centers were most commonly remained as constraints for disabled individuals. Level of accessibility has no impact towards unmet needs of disabled women.

The results of this study demonstrated that level of education, employment status and social participation has significant impact on unmet needs among disabled women. Additionally, it is also identified that economic status, marital status, forms of disability, type of abuses faced, awareness of legislations and rights, accessibility could also impact meeting the needs of disabled women.

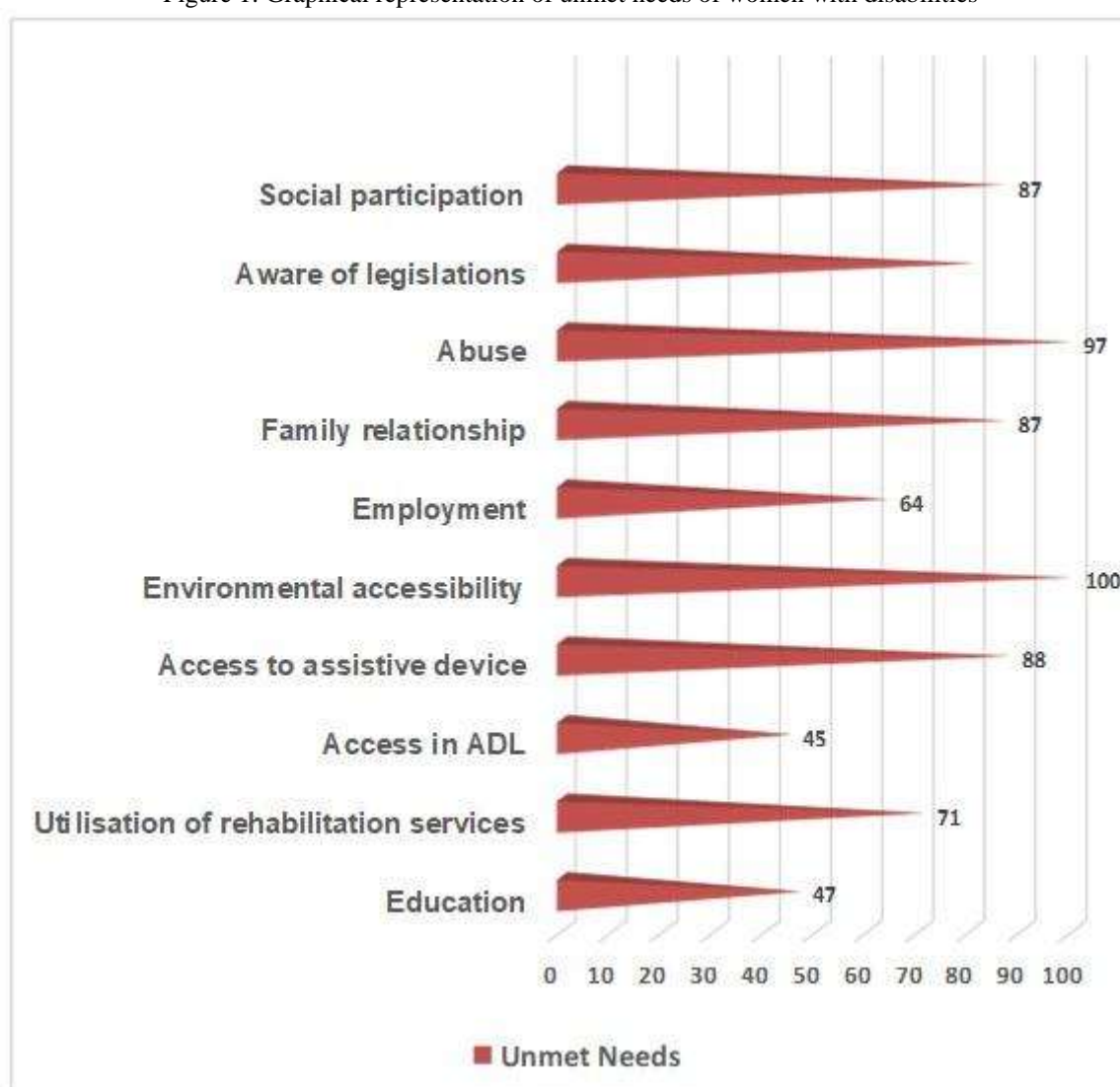
Table 01 The risk of unmet needs among disabled women living in Chennai, India by selected socio-demographic characteristics (n = 281)

| Variable | Sample total N (%) | | Without unmet | | Unmet needs | | X ² |
|---------------------------|-----------------------|-------|---------------|------|-------------|------|----------------|
| | | | n | % | n | % | |
| Age in years | | | | | | | |
| 18 – 45 | 156 | 55.52 | 53 | 52 | 103 | 57.5 | 3.21 |
| 45 – 60 | 82 | 29.18 | 36 | 35.3 | 46 | 25.7 | |
| >60 | 43 | 15.30 | 13 | 12.7 | 30 | 16.8 | |
| Level of education | | | | | | | |
| No formal schooling | 171 | 60.85 | 61 | 59.8 | 110 | 61.5 | 6.55* |
| Primary/secondary | 77 | 27.40 | 28 | 27.5 | 49 | 27.4 | |
| Graduate | 33 | 11.74 | 13 | 12.7 | 20 | 11.2 | |
| Employment status | | | | | | | |
| Unemployed | 149 | 53.02 | 34 | 33.3 | 115 | 64.2 | 5.71* |
| Self-employed | 76 | 27.05 | 42 | 41.2 | 34 | 19.0 | |
| Private | 27 | 9.61 | 14 | 13.7 | 13 | 7.3 | |
| Governmental | 29 | 10.32 | 12 | 11.8 | 17 | 9.5 | |
| Marital status | | | | | | | |
| Unmarried | 187 | 66.55 | 71 | 69.6 | 116 | 64.8 | 1.26 |
| Married | 94 | 33.45 | 31 | 30.4 | 63 | 35.2 | |
| Household income | | | | | | | |
| Below poverty line | 155 | 55.16 | 57 | 55.9 | 98 | 54.7 | |
| Above poverty line | 126 | 44.84 | 45 | 44.1 | 81 | 45.3 | |
| Level of ADL independence | | | | | | | |
| Independent | 134 | 47.69 | 55 | 53.9 | 79 | 44.1 | 3.17 |
| Partially dependent | 83 | 29.54 | 21 | 20.6 | 62 | 34.6 | |
| Totally dependent | 64 | 22.78 | 26 | 25.5 | 38 | 21.2 | |
| Disability category | | | | | | | |
| Physical | 187 | 66.55 | 77 | 75.5 | 110 | 61.5 | 2.42 |
| Visual | 73 | 25.98 | 20 | 19.6 | 53 | 29.6 | |
| Hearing | 21 | 7.47 | 5 | 4.9 | 16 | 8.9 | |
| Encounter of abuse | | | | | | | |
| None | 118 | 41.99 | 56 | 54.9 | 62 | 34.6 | 0.59 |
| Physical abuse | 64 | 22.78 | 14 | 13.7 | 50 | 27.9 | |
| Verbal | 99 | 35.23 | 32 | 31.4 | 67 | 37.4 | |

| | | | | | | | |
|----------------------------------|-----|-------|----|------|-----|------|---------------|
| Social participation | | | | | | | |
| Not restricted | 113 | 40.21 | 67 | 65.7 | 46 | 25.7 | 7.66** |
| Restricted | 168 | 59.79 | 35 | 34.3 | 133 | 74.3 | |
| Aware of disability legislations | | | | | | | |
| Yes | 147 | 52.31 | 55 | 53.9 | 92 | 51.4 | 1.85 |
| No | 134 | 47.69 | 47 | 46.1 | 87 | 48.6 | |
| Unable to afford | | | | | | | |
| Assistive devices | 55 | 53.9 | 55 | 53.9 | 115 | 64.2 | 0.68 |
| Rehabilitation services | 61 | 59.8 | 61 | 59.8 | 130 | 72.6 | |
| Accessibility constrains | | | | | | | |
| Public transport | 53 | 52.0 | 53 | 52.0 | 119 | 66.5 | 3.04 |
| Public places | 73 | 71.6 | 73 | 71.6 | 128 | 71.5 | |
| Health care centres | 47 | 46.1 | 47 | 46.1 | 99 | 55.3 | |

Multiple responses applicable, ADL- Activities of Daily Living

Figure 1: Graphical representation of unmet needs of women with disabilities



5. Discussion

The objective of this study is to identify the factors associated with the unmet of Indian women with disability. In this study, 281 disabled women were

surveyed and data related to the factors associated with their met and unmet needs were obtained. This study result concludes that needs of disabled women were significantly influenced by education, employment status and social participation.

The result of this study demonstrated positive association of education and the ability to meet their needs. Education empowers women. Though education empowers women, there exists contradictory evidence in the literature towards education and well-being of women. Previous studies by Clark et al (1996) [11], Nikolaev et al (2016) [12] and Nikolaev (2018) [13] reported negative association between education and well-being of women in their studies. Contradictorily our study results concluded that education had a significant role in improving the need of disabled women. Learning environment facilitated through schools could have attributed to their ability to overcome the challenges in meeting their needs.

Employed women respondents in this study had minimal barrier in meeting their needs. Similar to this findings, Kim (2020) [14] concluded that improvement in employment rate of disabled women improved self-efficacy and self-esteem. Also, education forms the basis for getting employed, especially disabled women could able to meet their needs through adequate educational qualification and employment opportunities. [15] The positive association of employment with the needs of disabled women could be attributed to the abilities to generate their own income without depending on the family members or spouse in meeting their necessities.

Social participation strengthens the social relationship of women with disability. In the present study it is identified that social participation significantly influenced disabled women in fulfilling their needs. Similar to our findings Matsuyama et al (2022) [16] in their 11 year follow up cohort data among 11,982 disabled individuals reported that social participation is strongly associated with disability free life expectancy among Japanese individuals living with disability. Several studies [17 – 20] also reported that social participation helped disabled individuals from associated mortality and disability. Social participation and interaction facilitates cognitive functions and also it involves physical tasks or activities that the disabled individual perform to accomplish social participation. This could be the possible mechanism that women with disability benefit in meeting their needs by community participation activities.

The study had fewer limitations such as small sample size and the data collected from a smaller geographical location. A larger data from wide topographical area could added more information on the unmet needs of women with disability. Also factors such as recreational activities, hobbies and extracurricular skills or activities. This study did not included the extraneous variables that could affect the needs of women with disability such as level of physical activity, body mass index (BMI),

quality of life, smoking or drug abuse, nature of caregivers or family members.

6. Conclusion

It is clear that large number of needs of the disabled women is still unidentified and unmet; there is a need for a new policy initiative to address and bridge the gaps existing in educational, employment and social participation factors to promote the ability of disabled women to meet their needs.

Abbreviations

ADL- Activities of Daily Living, BMI - body mass index, IMF – International Monetary Fund, UNICEF-The United Nations Children's Fund, NSSO - National sample survey office

Declarations

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