Psychosocial Wellbeing, Stress, And Support Systems Among Caregivers of Persons with Disabilities: A Cross-Sectional Study

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Abstract

Background: Currently, there is significant pressure on caregivers supporting PwD in India; the pressure is felt due to inadequate support infrastructure in the country. In this regard, the paper explores the levels of psychosocial well-being, stress levels, and support infrastructure among the PwD caregiving community across varying demographics.

Methods: A cross-sectional study consisting of 335 caregivers of PwD, including 168 female and 167 male caregivers, recruited via a convenient sampling strategy from healthcare and rehabilitation services. A structured questionnaire examined physical and emotional strain, financial burden, challenges faced in terms of social and cultural issues, supportive system, psychological well-being, WHO 5, and stress levels.

Results: Differences in female caregivers, as compared to their male counterparts, included a higher burden of physical and emotional challenges, as well as difficulties in terms of social challenges, with significance levels of $p = 0.001$ and $p = 0.011$, respectively. Differences in caregivers in terms of burden, stress, and wellbeing outcomes, as compared to the extended family, indicated higher burden and stress, but lower wellbeing outcomes. Differences in caregivers in terms of burden, stress, and wellbeing outcomes, as compared to rural caregivers, indicated higher difficulties due to social and cultural challenges, with a significance value of $p = 0.001$. Differences in caregivers in terms of burden, stress, and wellbeing outcomes, as compared to urban caregivers, indicated higher levels of stress in urban caregivers, but lower levels of wellbeing

Conclusion: Caregiver burden differs according to factors such as gender, family arrangement, geographic location, employment status, and economic status. Appropriate interventions to meet the particular demands of different at-risk caregiving groups are vital to strengthen supporting services.

Keywords: Caregiver burden, persons with disabilities, psychosocial wellbeing, stress, support systems, India, gender differences, socioeconomic factors

Introduction

Being a caregiver for people with disabilities (PwD) is not limited to providing physical assistance only, there is also the element of providing emotional support, attention to the finances of the PwD, etc. In India, there is a population of 2.68%, as confirmed in the Indian census in the year 2011, suffering from disability. Most PwD in India get care from family members due to the lack of proper caring facilities in India; the onus is on the family members to care for the members (Sharma & Deepak, 2001).

Studies have shown that caregivers of PwD experience fatigue, emotional distress, and exclusion from social activities (Mehta, 2012). Research in India indicates that caregivers of PwD experience challenges, such as financial matters, lack of awareness of available support, and attitudes of people in society towards PwD (Patel & Raval, 2019). Again, women caregivers experience more challenges than others, especially since they have more roles to handle at one time and do not receive support (Lakshmi & Akhtar, 2013). For instance, factors like disability, duration of caregiving, level of income, and family types affect caregivers of PwD and cause more or less distress (Chappidi & Kiran, 2016).
Even though people are becoming more aware about the needs of caregivers, research about the mental and social wellbeing of Indian caregivers is not ample. The majority of research involves only considering a single disability type and only urban, etc., so little is actually known about what influences caregiving, depending upon the type, where they live, etc. (Soundararajan et al., 2015). The research was done by considering 335 caregivers of PwD, considering the need to determine what kind of care they need, what kind of stress they are going through, and what kind of help they need. There are also differences depending upon individual factors, family types, where they live, etc., so this research focused on those differences.

Method

The used cross sectional descriptive cross sectional design To explore the differences that exist within the aspects of psychosocial well-being, caregiver burden, perceived stress, and support extended by caregivers towards persons living with disabilities based on their gender, family type, place of residence, nature of employment, marital status, duration, monthly family income, type of disability, among other factors. To find out the factors responsible for causing more caregiver burden or stress.

Sample

Sample composition consisted of 335 caregivers of PwD, where 168 were males and 167 were females. Caregiver status in this study determined as individuals who provided primary care for a minimum of six months. Convenience sampling methods were used to recruit study samples from health care/rehabilitation settings. Sample inclusion criteria were a desire to participate in data collection and ability to provide informed consent.

Tools

Structured questionnaires were employed to investigate the level of burden faced by the caregivers of the PwD.

Section A: Socio-Demographic

In this section, the background of the caregivers in terms of certain categorical responses is gathered. Some of the responses cover age, gender, marital status, type of family, place of residence, relationship to the person with disability, duration of the caregiving role, nature of the disability of the person under the care, educational attainment of the caregivers, employment status, and household income per month, among others.

B: Physical and Emotional Burden

This section assessed the physical and emotional impact of caregiving. Seven items addressed physical exhaustion, pain or fatigue, sleep disturbances, health issues related to caregiving, neglect of self-care, emotional stress, and decline in quality of life. Responses were recorded on a 5-point Likert scale, with higher scores indicating greater burden.

Section C: Financial Strain

Measurement of financial outcomes of caregiving: Measurement of financial outcomes of caregiving consisted of seven questions, which assessed caregiving-related expenses, impact on work, use of savings or borrowing money, decrease in household or personal spending, preparedness for long-term caregiving, and financial support received from family, government, or non-government organizations. Higher numbers on these questions indicated a worse perception of financial caregiving outcomes, with all questions being reverse-scored to assess preparedness and received support.

D. Social and Cultural Challenges

This section has five items, focusing on social and cultural challenges. These include perceived stigma, cultural beliefs about caregiving, gender, social isolation, and avoiding social activities because of caregiving duties. The scale has higher scores in social and cultural challenges.

Section E: Support Systems and Services

Support availability and access were measured using six items: awareness of government schemes, access to caregiver services, satisfaction with emotional and psychological support, workplace policies, assistance from community or non-governmental organizations, and access to medical care for caregivers. Higher scores indicated better support.

Section F: Psychological Measures

TWHO-5 Well Being Index was used for the assessment of subjective psychological well-being over the last two weeks. Five questions were used: cheerfulness, calmness, vitality, restfulness, and having an interest in life. Higher scores represent better psychological well-being.

The Perceived Stress Scale, short form, was used to measure the perceived stress that the caregivers experienced. It contained five items that measured the stress that caregivers faced, the lack of control, problems in dealing with problems, and the caregivers' ability to cope. Two of the items that were positively framed had been reversed in the scale.

Scoring

All items in sections B-F employed the same scale, namely the 5-point Likert scale (1 = strongly disagree, 5 = strongly agree), where items in section C-F would be reverse-scored before analysis. The standard scale allowed the data entry system to work optimally in SPSS, Excel, or R, where the data would be comparable across the domains.

Statistical analysis

Data analyses employed the SPSS, for sociodemographic descriptions of the participants, as well as the psychosocial outcomes under study. As the data did not meet the criteria of normality, non-parametric analyses conducted. For comparing the two or more than two groups of participants, the Mann-Whitney U-test and the Kruskal-Wallis tests used. For analysis p value <0.05 considered significant.

Table 1. Demographic Profile of the Participants

Variable	Category	Frequency (n)	Percentage (%)
Gender	Female	168	50.15
	Male	167	49.85

Marital Status	Divorced	59	17.61
	Married	80	23.88
	Single	129	38.51
	Widowed	67	20
Family Type	Extended	96	28.66
	Joint	116	34.63
	Nuclear	123	36.72
Domicile	Rural	116	34.63
	Semi-Urban	90	26.87
	Urban	129	38.51
Relationship with Person with Disability	Caretaker	50	14.93
	Other	39	11.64
	Parent	53	15.82
	Relative	64	19.1
	Sibling	51	15.22
	Spouse	78	23.28
Duration of Caregiving	< 1 year	44	13.13
	1–3 years	94	28.06
	4–6 years	117	34.93
	≥ 7 years	80	23.88
Type of Disability	Intellectual	74	22.09
	Multiple	116	34.63
	Physical	73	21.79
	Sensory	72	21.49
Education	Illiterate	34	10.15
	Primary	68	20.3
	Secondary	98	29.25
	Undergraduate	71	21.19
	Postgraduate	64	19.1
Employment Status	Full-time	103	30.75
	Part-time	84	25.07
	Unemployed	148	44.18
Monthly Income	< ₹10,000	106	31.64
	₹10,000–30,000	86	25.67
	₹30,000–60,000	83	24.78
	≥ ₹60,000	60	17.91

The sample included a near-equivalent distribution of females, 50.15%, and males, 49.85%. The majority of the respondents were single, 38.51%; married, 23.88%; widowed, 20%; and divorced, 17.61%. Slightly more than one-third came from a nuclear family composition, 36.72%, while the rest were from joint, 34.63%, and extended families, 28.66%. Similarly, 38.51% were from urban backgrounds, 34.63% from rural backgrounds, and 26.87% from semi-urban backgrounds. Spouses constituted the highest percentage of participants regarding their relationship with the person with a disability: 23.28%, relatives 19.10%, parents 15.82%, siblings 15.22%, and caretakers 14.93%. Most participants had provided care between 4–6 years, 34.93%, whereas about a quarter of the participants had caregiving experience of seven years or more, 23.88%. The most common types of disabilities reported were multiple, 34.63%. The majority had secondary-level educations, at 29.25%, while almost half of the sample were unemployed, 44.18%. The low-income background was very high, with nearly one-third of the participants earning less than ₹10,000 per month (31.64%), which indicates high socio-economic vulnerability in the sample.

Table 2: Comparison of Psychosocial Outcomes by Two-Group Variable

Domain	Female (n=168)	Male (n=167)	Cohen's d	p value
Psychological Wellbeing	29.02 ± 4.37	30.10 ± 4.43	0.25	0.018*
Physical & Emotional Burden	21.93 ± 2.94	20.26 ± 2.73	−0.59	0.001**
Financial Strain	20.61 ± 3.17	20.95 ± 4.01	0.09	0.41
Social & Cultural Challenges	16.49 ± 3.41	15.51 ± 2.83	−0.31	0.011*
Perceived Stress	14.39 ± 3.33	15.58 ± 3.49	0.35	0.001**
Support Systems & Services	17.82 ± 3.00	17.88 ± 3.56	0.02	0.63

Male participants had slightly higher levels of psychological well-being than female participants ($p = 0.018$), while the female participants had greater levels of physical and emotional burdens ($p = 0.001$). There were no significant differences found regarding financial burdens between the participants ($p = 0.41$). Females faced more social and cultural challenges than the participants of the study ($p = 0.011$), whilst males faced higher levels of perceived stress than the participants of the study ($p = 0.001$). Also, the levels of perceived support systems and services were similar between the participants of the study (female participants and male participants) ($p = 0.63$

Table 3: Comparison of Psychosocial Outcomes by Family Type

Domain	Extended (n=96)	Joint (n=116)	Nuclear (n=123)	p value
Psychological Wellbeing	30.42 ± 5.33	28.19 ± 3.52	30.18 ± 4.12	0.001**
Physical & Emotional Burden	22.60 ± 2.85	20.28 ± 3.24	20.70 ± 2.24	0.001**
Financial Strain	21.36 ± 2.40	21.47 ± 3.55	19.67 ± 4.17	0.001**
Social & Cultural Challenges	15.23 ± 2.95	16.27 ± 3.50	16.36 ± 2.93	0.011*
Perceived Stress	16.69 ± 4.14	14.18 ± 1.62	14.41 ± 3.69	0.001**
Support Systems & Services	17.84 ± 2.94	18.01 ± 3.76	17.70 ± 3.08	0.833

Participants of extended and nuclear families had higher psychological well-being as compared to the participants of the joint family ($p = 0.001$). Physical and emotional burden is higher among the people of the extended family as compared to the participants of the nuclear or joint family, ($p = 0.001$). Financial burden is lower among the participants of the nuclear family as compared to the participants of the extended or the joint family ($p = 0.001$). Social and cultural challenges among the participants of the joint and the nuclear family are higher as compared to the participants of the extended family (p = 0.011). It is indicated in the results table that the participants of the extended family had higher levels of stress as compared to

Table 4: Comparison of Psychosocial Outcomes by Place of Residence

Variable	Rural (n = 116) Mean ± SD	Semi-Urban (n = 90) Mean ± SD	Urban (n = 129) Mean ± SD	p value
Psychological Wellbeing	28.92 ± 4.03	29.69 ± 5.19	30.04 ± 4.13	0.175
Physical & Emotional Burden	20.79 ± 3.08	21.21 ± 2.70	21.29 ± 3.00	0.222
Financial Strain	20.91 ± 2.38	20.36 ± 3.53	20.95 ± 4.48	0.285
Social & Cultural Challenges	17.56 ± 2.99	14.17 ± 3.38	15.88 ± 2.38	0.001**
Perceived Stress	14.15 ± 3.17	15.11 ± 3.99	15.64 ± 3.16	0.001**
Support Systems & Services	18.45 ± 3.35	18.40 ± 2.62	16.92 ± 3.45	0.001**

Psychological well-being, total wellbeing in terms of physical and emotional burden, and financial hardship did not show significance in relation to the location of the respondent (p = 0.175, p = 0.222, and p = 0.285, respectively). However, the perceived social and cultural challenges faced by the rural dwellers were found to be greater than in the urban population (p = 0.001). Perceived stress levels in the lives of the urban population appeared to be more than in the rural population (p = 0.001). Perceived support systems and services appeared to be less in the urban population compared to the rural and semi-urban population (p =

Table 5: Comparison of Psychosocial Outcomes by Employment Status

Variable	Full-time (n = 103) Mean ± SD	Part-time (n = 84) Mean ± SD	Unemployed (n = 148) Mean ± SD	p value
Psychological Wellbeing	30.48 ± 4.16	26.57 ± 3.67	30.61 ± 4.24	0.001**
Physical & Emotional Burden	22.29 ± 3.36	20.70 ± 2.05	20.49 ± 2.84	0.001**
Financial Strain	21.35 ± 3.89	21.73 ± 3.07	19.84 ± 3.50	0.001**
Social & Cultural Challenges	17.10 ± 1.89	16.67 ± 2.98	14.86 ± 3.60	0.001**
Perceived Stress	15.60 ± 3.52	12.92 ± 3.16	15.72 ± 3.11	0.001**
Support Systems & Services	17.81 ± 3.27	17.21 ± 2.40	18.24 ± 3.67	0.069

Employment status significantly differed in psychological wellbeing, with the lowest wellbeing being for part-time workers compared to full-time and unemployed participants (p = 0.001). Full-time workers reported a higher physical and emotional burden (p = 0.001). Financial difficulties were lower for unemployed participants (p = 0.001). The highest level of social and cultural problems was found for full-time workers and the lowest for unemployed participants (p = 0.001). Full-time and unemployed participants reported higher perceived stress than part-time workers (p = 0.001), whereas perceived support systems and services did not differ depending on the employment status (p = 0.069).

Table 6: Comparison of Psychosocial Outcomes by Monthly Family Income

Variable	**< ₹10,000 (n = 106) Mean ± SD**	**₹10,000–30,000 (n = 86) Mean ± SD**	**₹30,000–60,000 (n = 83) Mean ± SD**	**≥ ₹60,000 (n = 60) Mean ± SD**	**p value**
Psychological Wellbeing	28.92 ± 3.52	29.49 ± 5.18	28.53 ± 4.01	32.22 ± 4.28	0.001**
Physical & Emotional Burden	21.00 ± 2.36	20.08 ± 2.32	20.94 ± 2.19	22.95 ± 4.45	0.001**
Financial Strain	21.03 ± 4.10	20.05 ± 3.42	20.92 ± 3.68	21.20 ± 2.65	0.013*
Social & Cultural Challenges	15.34 ± 3.45	16.88 ± 3.29	16.92 ± 2.14	14.65 ± 2.97	0.001**
Perceived Stress	15.08 ± 2.68	14.49 ± 4.38	14.14 ± 2.71	16.68 ± 3.56	0.001**
Support Systems & Services	16.65 ± 3.64	18.65 ± 3.05	18.02 ± 2.58	18.57 ± 3.30	0.001**

Among these, the prevalence of psychological wellbeing was statistically different between income groups with the highest being reported among participants who earned ≥ ₹ 60,000 per month (p = 0.001). Similarly, physical and emotional encumbrance was highest in the highest category of income reporting subjects while financial constraints were only modestly significant at p = 0.013. Social and cultural concerns were more reported by middle categories of income classes while the lowest was stated by the highest income category subjects (p = 0.001). Stress was highest among subjects earning ≥ ₹ 60,000/ (p = 0.001). The presence of perceived support system and services was significantly lower in the low-income category subjects and higher in rest (p = 0.001).

Discussion

This study examined the psychosocial wellbeing, stress, and support systems among 335 caregivers of persons with disabilities in India. The findings show that several factors affect caregiver burden and wellbeing, including gender, family type, place of residence, employment status, and income level.

Gender Differences in Caregiving

The results revealed that the male caregivers had better psychological well-being than the female caregivers. However, female caregivers experienced more problems in terms of the burden. Similarly, previous studies found similar findings (Lakshmi & Akhtar, 2013) and reported that women caregivers faced more difficulties in their lives than men caregivers. Generally, the daughters or wives of the family are considered the main caregivers within the family, and most women have more responsibilities, such as managing the household, apart from caregiving (Patel & Raval, 2019). There are international studies that supported the current findings, such as the fact that the female caregivers experience more depression than the male caregivers, a study found that the female caregivers suffer more from depression than the male caregivers (Pinquart & Sörensen, 2006). These gender role expectations in Asian culture make it a burden on the woman (Kim et al., 2012). Interestingly, male caregivers reported a greater perceived stress than female caregivers, though their well-being is better than female caregivers. This could be because males feel a greater burden regarding financial issues and anxiety about providing for their family (Sharma & Deepak, 2001). Previous studies in Western cultures have demonstrated similar findings where male caregivers have different types of stress related to their role as providers (Greenwood et al., 2015). Levels of support from services were reported to be similar by male and female caregivers, indicating a lack of meeting different needs for both genders.

Impact of Family Structure

Family type made a clear difference in caregiver experiences. The psychological wellbeing of caregivers in extended and nuclear families was better compared to those in joint families. However, the physical and emotional burden along with higher levels of stress were felt more by caregivers within extended families. Again, it is a complex finding since in the extended family there might be a greater number of persons to share caregiving responsibilities. Yet there may also be conflicts on how the person with disability is to be cared for (Soundararajan et al., 2015). Studies from other Asian countries reveal that living in joint or extended families may facilitate or create stress for the caregivers because of family dynamics and diverse opinions about care (Lai, 2012). Joint and nuclear families appeared to have experienced even more issues in terms of the social and cultural challenges that the families faced, and this can be attributed to the fact that the family members have few people to share the social burden and that the families face direct stigmatization from the outside community. Stigma associated with disability continues to be a big issue in Indian society, and it affects the entire family (Ghai 2002). Nuclear families did not face financial problems, and this can be attributed to the fact that nuclear families have control of their own expenses and do not have the burden of competing to feed a large family as in the joint families.

Urban-Rural Differences

The place of living was responsible for affecting social issues, stress, and access to help. Rural caregivers dealt with more issues of social and cultural nature. This resonates with previous studies conducted concerning caregivers of persons with disabilities among the Indians. for instance, Mehta et al. found out that rural India has stronger beliefs and stigmas about disability (Mehta et al., 2012). Maulik and Darmstadt found out that parents of children with disability within the rural India context hide their children due to shame and lack of awareness about disability (Maulik and Darmstadt., 2007). The urban caregivers had increased stress levels; perhaps because of the fast pace of life and pressure of working and providing at the same time (Patel and Raval., 2019). Studies from other countries also support that urban caregivers encounter work-life balance and financial stressors. Urban caregivers surprisingly reported having less support from services compared to rural and semi-urban caregivers. This is unexpected since urban areas typically have more rehabilitation centers and hospitals. Perhaps the explanation is that there are greater expectations or even difficulties in utilizing services within cities regarding waitlists and costs of services (Lakshmi & Akhtar, 2013). According to this may be due to the cost of services, the lack of information provided about services, or the quality of the services themselves (Raina et al., 2005).

Employment and Economic Factors

Employment status was another factor that highly impacted caregivers' wellbeing. Caregivers who worked on a part-time basis had the lowest level of psychological wellbeing. Caregivers on a part-time basis may find it difficult to juggle their responsibilities, not having the secure finances that full-time employees do or the flexible time that the unemployed have (Sharma & Deepak, 2001). Caregivers, regardless of their reduced working hours, have both emotional and financial problems (Lilly et al., 2007), full-time employees, on the other hand, may experience both the emotional burden and the responsibilities that accompany caregiving, alongside their workload.According to research done in developed countries, employed caregivers are usually characterized by conflict and feelings of guilt due to inadequate time spent with the subject of care, as noted by Bainbridge et al. (2009). Unemployed caregivers, on the other hand, experienced less financial pressure. It may seem somehow strange, but it makes sense, especially due to the change they have adapted their lives to, not having the expense of working, such as transport, as noted by Chappidi & Kiran (2016).

Level of income had very interesting patterns as well. Caregivers whose monthly income was above ₹60,000 had the best level of psychological wellbeing, as well as the most burden and stress on a physical and emotional level. People whose access to medical care and other relevant facilities is better have higher levels of wellbeing (Soundararajan et al., 2015). People whose jobs require a better level of caregiving might also have a greater burden and higher levels of stress.

However, according to a study done by Schulz and Sherwood, it was noted that although monetary stability can alleviate some types of stress factors, it cannot remove emotional stress (Schulz and Sherwood, 2008). Notably, caregivers from middle-income groups experienced the greatest types of social and cultural challenges because they can offer better health care services to PWD. However, such caregivers are subject to some levels of stigma. Caregivers from low-income groups had access to few support services. This noted inequality to support services by low-income caregivers follows from noting how poverty acts as a barrier to accessing such services (Patel & Raval, 2019). Studies done on caregiving from a global perspective have acknowledged and noted that low-income groups experience some forms of barriers in accessing disability services.

Cultural Context and Support Systems

From the findings, it is evident that cultural values play an essential role in caregiving. India values family responsibilities and providing support to disabled family members at home (Dalal, 2002). While on one side it can extend support to disabled patients, it adds more burden to caregivers and makes it difficult for them to look for support from external sources. This situation is aggravated due to no support or awareness of schemes provided by the government (Kishore, 2011). Research has revealed that caregivers in India do not have knowledge of support provided by the government or community that may support them in providing health care.

Implications, Limitations and Conclusion

These findings indicate that support programs for caregivers also differ for each of these respective groups of caregivers. Support arrangements for female caregivers would help with their physical needs and emotional well-being with counseling and counseling facilities. In contrast, male caregivers would benefit with financial counseling and stress management programs (Lakshmi & Akhtar, 2013). Also, the service delivery arrangements would need improvement, especially for caregivers living in cities with cheaper and quicker service, and for caregivers living in rural areas with programs that help remove disability stigma and need increased awareness of disability and service issues (Maulik & Darmstadt, 2007). Working caregivers would need facilities for preferred working hours or leave with arrangements similar to programs followed internationally (Bainbridge et al., 2009). The government schemes would need increased publicity and easy access with arrangements for low-income families (Kishore, 2011).

However, some limitations of the current research have been noted. Firstly, the current research utilized the cross-sectional approach, which only allows the identification of the relationships that might exist across the variables without the capability of establishing causality. Additionally, the convenience sampling approach used in the current research might have been inadequate in representing the larger population of caregivers in India. It was also noted that the current research did not assess the levels of disablement, which might have a direct effect on the burden of the caregivers (Pinquart & Sörensen, 2003), and more research in the same field utilizing larger representative samples and utilizing longitudinal designs, where the changes in the needs of the caregivers can be ascertained, could be conducted in the future (Raina et al., 2005).

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