

Buffering effects of social security benefits for persons with psychiatric disability on caregivers' burden and quality of life

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ABSTRACT

Introduction: Out-of-pocket mental health care expenditure has a catastrophic impact on the families living with severe mental illness, with high levels of burden and poor quality of life. **Aim:** The present study aims to understand the buffering effects of social security benefits for persons with psychiatric disability on caregivers' burden and quality of life. **Methodology:** Two groups of caregivers of people with severe mental illnesses, those receiving disability benefits ($n = 100$) for the past 6 months and those who were not receiving any benefits ($n = 72$), were recruited from the out-patient follow-up services. Both the groups were assessed with the Burden Assessment Scale (BAS) and the World Health Organization Quality of Life (WHO QoL-Bref). **Result:** Those who were receiving the disability-related social benefits had reported better quality of life only in psychological and social domains. The maximum value of Pearson's correlation coefficient was observed between physical and psychological domains ($r = 0.12$; not significant), and the values did not change even after controlling for the social security status. **Discussion:** The current study did not find full support for buffering effects of social security benefits on caregivers' quality of life. Thus, there is a need for a comprehensive plan for social security benefits, especially for persons with psychiatric disability, as caregivers are already experiencing high levels of financial stress.

Keywords: Buffering, caregivers, mental disability, quality of life, social security

Introduction

There is growing concern about the increasing burden of mental health conditions which are evident in the form of excess health care costs and out-of-pocket expenditure which can have a negative impact on the families of persons with severe mental illness. These out-of-pocket expenses are for individuals who do not anticipate many medical expenses to push further downward in the social sphere in which one belongs. In a developed country, health care costs are borne by federal organizations, whereas in

developing countries such as India, health care costs are incurred by families seeking health care services. Reports suggest that a total of 3.6% of India's gross domestic product is allocated for health. The government expenditure on health is 0.9% of GDP, whereas 2.5% of GDP is an out-of-pocket expenditure, that is, expenses borne by individuals.^[1]

Any chronic mental health condition that requires a long-term follow-up treatment has significant financial implications for poorer households in India. Many families of persons with mental illness lose their income because of involving themselves in care for their family members with mental illness. A good chunk of the family budget is being spent on patient care; hence, they have to adjust or compromise with their daily home needs. Previous research findings suggest that the indirect health care

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cost is 3 times higher than the direct cost of health.^[2] Financial stress is one of the most powerful predictors for mental illness and relapses.^[3-5] Tangible social support often buffers stress, enhances mental health conditions, and improves the quality of life.^[6,7] Persons receiving adequate social support tend to have a reduced risk of health outcomes, including mental,^[8,9] physical,^[10] and mortality.^[11]

Various studies found that persons with mental illness use more health services than those with other health problems^[12] because of significant functional impairments, cognitive deficits, limited social support, poor drug compliance, and long-term follow-up treatment. Thus, the family has to bear excess health care costs.^[13-15] As health is a state subject, the majority of the Indian states have not covered social security benefits and insurance policies for persons with mental illness, therefore aggravating the caregiver burden. Because of disruptive and violent behavior, caregivers have to face an overwhelming care burden, higher levels of stress, and anxiety.^[16] Family members need to spend extra time caring for the mentally ill persons. Further, it can impact the quality of life.^[16] A few studies have provided an empirical comparison between the different supports that affect the quality of life of caregivers. The factors channelizing motivation to caregivers to help persons with mental illness are unknown.^[17] Numerous studies suggest that caregivers experience burden because of constant and continuous contact and caring persons with severe mental illness and often receive inadequate assistance from mental health professionals.^[18] Family members compromise quality time and personal well-being.^[16,19] Negative feelings, shame, embracement, guilt, and self-blame emerged because of social life restriction and the lack of tangible support.^[20-22] Therefore, policies, programs, and schemes should assist persons with mental illness and their caregivers. Direct monetary benefits or tangible support would promote family motivation toward patient care, improve family quality time, promote recreation, strengthen family relationships, promote healthy communication, promote emotional safety, and develop strong problem-solving skills.

In this direction, the role of physicians and general practitioners in prevention and promotion of mental health is very significant as many psychiatric patients delay their treatment because of stigma, mis-information, and poor economic conditions.^[23] Physicians and general practitioners are the first contact persons who can guide or refer to the appropriate hospital. Timely referral of patients would avoid frequent re-admission, prevent drug resistance, lower the treatment cost, and help in better prognosis.^[24,25] Hence, the general practitioners and physicians in rural India should hold manifold skills, knowledge, and support resources available within and outside the community to carry out effective and efficient health programs. The prerequisite of such instinct is that many rural poor people are unfamiliar with various health schemes and social welfare benefits which can be mitigated through physicians and general practitioners.

As per the Rights of Persons with Disabilities Act, 2016, the minimum qualifying condition for availing disability schemes for

disablement and dependent benefits is above the >40% score on the IDEAS scale (Indian Disability Evaluation and Assessment Score). However, there is a literature gap from Indian settings concerning the impact of social security benefits on caregivers' burden to explain social security benefits' advantage and challenge to avail the benefit. Therefore, the present study examines the burden and quality of life in the caregivers of persons with psychiatric disability in relation to the social security benefits.

Materials and Methods

Study design and sampling method: This study adopted a cross-sectional descriptive design and used the purposive sampling method to recruit the participants.

Setting: The study was conducted at the National Institute of Mental Health and Neurosciences (NIMHANS), a tertiary care hospital in Bengaluru, India, from July 2017 to August 2021.

Sample size: A total of 170 caregivers of people with severe mental illness attending the out-patient department were recruited. Out of this, 100 (group 1) people were receiving disability benefits and came for a follow-up and the remaining 70 (group 2) had potential beneficiary scores above 40% on IDEAS. All the participants were selected based on inclusion and exclusion criteria.

Inclusion Criteria were as follows: (i) Caregivers of persons with an ICD-10 diagnosis of severe mental illnesses, (ii) those receiving disability benefits for the past 6 months, (iii) caregivers who can communicate (in Kannada, Telugu, Hindi, or English), (iv) age range between 18 and 60 years, (v) both genders, and (vi) informed consent to participate in the study.

Exclusion criteria: (i) Caregivers of persons with a physical disability receiving welfare schemes and (ii) those who are not willing to take part in the study.

Measures:

1. Socio-demographic and clinical data sheet: The socio-demographic and clinical data sheet consisting of age, gender, education, occupation, religion, caste, inhabitant, mode of transport, and so on and clinical information on duration of illness, past illness, and type of diagnosis were collected from the participants.
2. Burden Assessment Scale (BAS):^[26] BAS is a scale with a total of 40 items. It is an instrument to measure caregiver burden; this scale has been standardized in the Indian population. This instrument covers nine sub-domains: spouse-related, physical and mental health, external support, caregiver's routines, support of patient, taking responsibility, other relations, patient's behaviors, and caregiver's strategy. The items are rated on a 3-point scale. A higher score indicates higher burden. The scale has good reliability (Kappa, 0.80), and it has very good face validity in terms of the relevance of the items in measuring caregiver burden.

3. The World Health Organization Quality of Life - Brief (WHOQoL-Bref)^[27]: The WHOQoL-Bref was used to assess the patients' quality of life. The WHOQoL-Bref includes 26 items measuring the following domains: physical health, psychological health, social relationships, and environment. Two further items evaluate the individual's overall perception of quality of life and the individual's overall perception of his/her health. Domain scores are scaled in a positive direction (i.e., higher scores correspond to better quality of life). The average score of items within each domain is used to calculate the domain score. Mean scores are then multiplied by 4 in order to make domain scores comparable with the scores used in the WHOQOL-100. Where more than 20% of data is missing from an assessment, the assessment should be discarded. Where an item is missing, the average of other items in the domain is substituted. Where more than two items are missing from the domain, the domain score should not be calculated (with the exception of domain 3, where the domain should only be calculated if <1 item is missing).

Procedure: Ethical clearance was obtained from the NIMHANS ethics committee (Ref. No. NIMHANS/IEC (BEH.SC.DIV.) 7th MEETING/2017, Date: 19.8.2017) to carry out the study. Prospective participants were approached in the out-patient services of NIMHANS. Data collection was initiated only after

obtaining the informed consent. Demographic details and clinical data were collected from the respondents. The burden assessment scale and the WHOQoL-Bref were administered to know the burden and quality of life among the participants. Informed consent was taken from the patients and caregivers.

Statistical Analysis: Statistical Package for Social Sciences for Windows (SPSS 22.0, Armonk, NY: IBM Corp Released 2013) was utilized for the data analysis. Descriptive statistics was presented with mean \pm SD, frequency, and percentage; the independent sample t-test/Mann-Whitney U test was used to compare differences between two independent groups. Pearson correlation test was performed to see the association between social security benefits and quality of life. The level of significance was set at $P < 0.5$ to describe the statistics.

Results

Socio-demographic variables of the participants and clinical characteristics are given in Table 1. The (mean and SD) age distribution of the subjects with social security benefits and without benefits was 36.63 ± 10.43 , and 35.52 ± 9.59 , respectively; the majority were males (53.00% and 61.1%) and married (71.00, 77.8%). There were no significant group differences in other key socio-demographic variables except for occupation and transportation expenses, with a higher percentage

Table 1: Socio-demographic profile of the respondents

Caregiver's Profile	Variables	With disability benefits n=100 (%)	Without Benefits n=72 (%)	χ^2 Test/U-test	P
Age [#]		(36.63 \pm 10.43)	(35.51 \pm 9.59)	0.716	NS
Sex	Male	53 (53.0)	44 (61.1)	=1.12	NS
	female	47 (47)	28 (38.9)		
Education	With benefits	Mean/SD	Median score	0.98*	NS
	Without benefits	36.630 \pm 10.431	7.0 (4.0, 9.0)		
Marital status	Married	71 (71)	56 (77.8)	=0.995	NS0
	Unmarried	29 (29)	16 (22.2)		
Religion	Hindu	48 (48)	43 (59.7)	=2.523	NS
	Muslim	35 (35)	21 (29.2)		
	Christian	17 (17)	8 (11.1)		
Occupation	Student	9 (9)	0 (0)	=7.973	<0.05
	Farmer	21 (21)	20 (27.8)		
	Unemployed	48 (48)	32 (44.4)		
	Daily Laborer	22 (22)	20 (27.8)		
Socio-Economical Status	Lower	62 (62)	45 (62.5)	=0.004	NS
	Middle	38 (38)	27 (37.5)		
Habitant	Urban	63 (63)	51 (70.8)	=1.149	NS
	Rural	37 (37)	21 (29.2)		
Family Type	Nuclear	70 (70)	49 (68.1)	=0.074	NS
	Joint	30 (30)	23 (31.9)		
Transportation Fare	Less than 1000	44 (44)	18 (25.0)	=8.690	<0.01
	1000 to 1500	32 (32)	38 (52.8)		
	More than 1500	24 (24)	16 (22.2)		
Distance	Less than 50 km	15 (15)	7 (9.7)	=1.179	NS
	50 to 100 km	22 (22)	20 (27.8)		
	100 to 150 km	29 (29)	22 (30.6)		
	More than 150 km	32 (32)	23 (31.9)		

[#]mean \pm standard deviation= χ^2 square, *U=Mann-Whitney U test, NS=Not significant. Significant <0.05 and <0.0

of unemployed and higher costs of transportation among those receiving the social security benefits.

Table 2 indicates that there were no significant group differences in reference to the clinical diagnosis, severity of disability, duration of illness, and history of past illnesses.

Table 3 shows the quality of life among caregivers availing social security benefits and without benefits. Significant differences were noted in psychological and social domains, with those receiving the social security benefits reporting better quality of life.

Figure 1 depicts the distribution of categories of the burden assessment scale, among participants with and without social security benefits, with social security benefits having low buffering effects on burden.

Table 4 shows there is no correlation between physical, psychological, environmental, and social domains of quality of life among the study participants. The maximum value of Pearson’s correlation coefficient was observed between physical and psychological domains with $r = 0.12$, and the values did not change even after controlling for the social security status.

Table 2: Clinical characteristics of the respondents

Variables	With disability benefits n=100 (%)	Without Benefits n=72 (%)	Test	P
Schizophrenia	35 (35)	25 (34.7%)	1.781	NS
BPAD	35 (35)	31 (43.1%)		
Depression	19 (19)	11 (15.3%)		
OCD	11 (11)	5 (6.9%)		
Disability Score				
<40% mild	27 (27.0)	13 (18.1)	2.324	NS
41-70 moderate	45 (45.0)	33 (45.8)		
>71%severe	28 (28)	26 (36.1)		
Duration of Illness				
0-2 years	21 (21)	26 (36.1)	4.988	NS
2-5 years	34 (34%)	18 (25.0%)		
5-10 years	45 (45%)	28 (38.9%)		
Past History of illness				
Present	53 (53%)	36 (50.0%)	0.151	NS
Absent	47 (47%)	36 (50.0%)		

χ^2 =Chi square, NS=Not significant.

Table 3: Differences on WHO Quality of life scale in reference to the social security

Domain	With disability benefits n=100 (%) Mean/SD	Without Benefits n=72 (%) Mean/SD	95% CI	P
Physical	(51.4±14.01)	(51.68±8.96)	(-3.74, 3.18)	0.873
Psychological	(57.33±14.78)	(51.84±6.99)	(2.14, 8.83)	0.001
Environmental	(53.07±11.94)	(51.22±7.6)	(-1.10, 4.80)	0.218
Social	(56.94±15.25)	(52.63±8.46)	(0.72, 7.90)	0.019

Discussion

This study aimed to understand the buffering effect and compare with and without social security benefits for persons with psychiatric disability on their caregivers’ burden and quality of life. In that connection, two groups (with and without availing benefits) of samples were compared in the domains of socio-demographic variables.

Demographic variables

The groups did not have a significant difference in age, sex, education, occupation, religion, socio-economic status, type of family, transport fare, and distance. It means that they were well matched on these key socio-demographic variables. In the present study, the majority of the participants were from a lower socio-economic status, and their living standards, culture, and moral values are similar. Most importantly, a sizable number of participants are drawn from below-the-poverty-line (BPL) families. This further confirms the drift hypothesis, which says that the individual gradually deteriorates in social status because he/she fails in earning in his/her later life.^[28-31] Also, previous studies suggest that at a large scale, at least half of the beds in the hospital are occupied by severe mental illness and are frequently re-admitted in the hospital because of a low socio-economic phenomenon.^[32-34] Caregivers of persons with mental illness usually approach the hospital according to their socio-economic status; hence, they should not feel that standards and quality of care have been lower or deprived as they are from a disadvantaged family. Policymakers and stakeholders should set appropriate measures in disbursement of equitable treatment care for persons living in the poverty line.^[35-37]

Clinical variables

The clinical profile of the respondents suggests that there was no significant difference; however, the majority of the respondents were drawn from schizophrenia and bipolar affective disorder. Previous studies indicate that re-admission and repeated consultation have substantially increased across the country among psychotic disorders.^[38,39] This finding may vary according to their socio-cultural backgrounds. In our study, the findings suggest moderate to severe disability scores on the IDEAS scale. Psychiatry disability has significant prognostic indicators and implications, including social, economic, and health. Disability

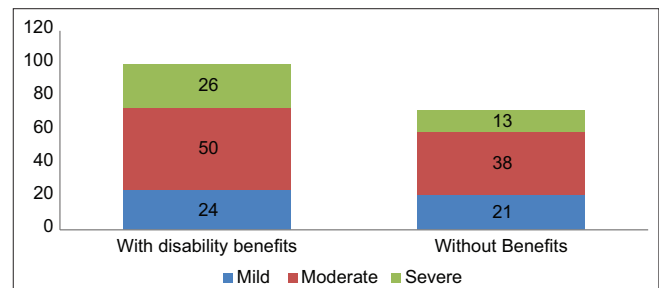


Figure 1: Buffering effects on burden with and without social security benefits

Table 4: Correlation between quality-of-life domains and perceived caregiver's burden in those with and without social security

QoL Domains	Correlation co-efficient				Point-biserial correlation			
	Physical	Psychological	Environmental	Social	Physical	Psychological	Environment	Social
Physical	1	0.12	0.02	0.01	1.00	0.12	-0.01	0.01
Psychological		1.00	0.09	-0.02		1.00	0.07	-0.05
Environmental			1.00	-0.04			1.00	-0.05
Social				1.00				1.00

r_{pb} = Point-biserial correlation coefficient

assessment is an essential element to determine the functional abilities, which is invisible. It would help the clinician determine an intervention plan for rehabilitation and facilitate in getting social security benefits.^[40] Because of invisible disabilities, many patients are being bullied, screamed, and insulted by the general public. It has become the prejudice in the minds of citizens and deceives that these people are pretending as sick to earn attention. Even awareness about the social security benefits was lacking among caregivers and authorities concerned. There is a need to conduct an awareness program as many people are vulnerable without receiving help or care because of the lack of information about welfare schemes.

Effects of social security benefits on quality of life

Our study assessed quality of life with buffering effects of social security benefits. These findings suggest that the impact of social security benefits was lower in the presence of higher financial stress. Therefore, a significant difference was not reflected in the quality of life. However, the analyses showed weaker effects in the reference group and no effects in the comparative group. The high degree of tangible social support would have influenced the most substantial buffering impact on individual well-being and quality of life.^[9,41] The majority of the respondents received the benefits that include bus or train travel concession, a monthly disability pension ranging from Rs. 500 to 1500, and free drugs, although they are inadequate for the patient care and treatment. However, previous findings suggest that transportation facilities to hospitals may reduce the risk of worsening health conditions.^[42,43] Therefore, national welfare schemes and policies for the psychiatric patients should connect directly to the beneficiary without any difficulty in accessing. Also, it should expand to cover all costs involved in treatment, including the private hospital.

Effects of social security benefits on burden

Our finding contrasted the buffering hypothesis as the severity of burden was not significantly associated with the benefit receiver group. A possible reason could be that the benefit reception group may not have perceived good benefits and care for the value of the support resources.^[6] Thus, the financial distress could not alleviate or moderate the support resources, thereby reducing the burden.^[9] In this direction, further investigation is required to find whether receiving low financial assistance can reduce burden, ease the distress, and influence both health care costs and quality of life among caregivers.

Quality of life domains (physical, psychological, environmental, and social)

There is no correlation between the study participants' physical, psychological, environmental, and social quality of life domains. The maximum Pearson's correlation coefficient value was observed between the physical and psychological domains with $r = 0.12$. These findings suggest that the effect of social security benefits was low in the presence of higher financial stress. Hence, quality of life is noticeably poorer with financial stress. However, a modest positive influence on the psychological and harmful physiological processes was observed. It suggests that covering a wide range of welfare benefits would affect health care costs and good quality of life.^[6,9] Some other confounding socio-demographic factors that were not controlled in our study may have influenced the findings, that is, occupational class, income, marital status, unemployment, and traditional value in the society. It needs further investigation, especially from the Indian perspective.

There are several limitations in the present study: Most of the subjects drawn are from BPL families as a low income and financial distress are already present, and the study was conducted with a small sample size; therefore, the present study should not be generalized. It is a cross-sectional method; experimental methods could have drawn a conclusion of cause-and-effect relation. A large-sample study may be considered in the future research, especially from the Indian population.

Conclusion

As a welfare state, the constitution of India ensures equal rights to all its citizens, including equitable access to health care facilities. Caregivers of persons with mental illness usually approach the hospital according to their socio-economic status; hence, they should not feel that standards and quality of care have been lower or deprived as they are from a disadvantaged family. To mitigate the psychiatric patients' needs, the Government of India has initiated welfare schemes across the country but still has to achieve the threshold where its people no longer struggle to access health care facilities. Many families of persons with psychiatric disorders are overwhelmingly burdened as they have to spend out of pocket to treat their family members. Welfare schemes are beneficial and empowering and instil rays of hope and play a crucial role in their lives to alleviate distress and motivate them to care. However, a comprehensive plan of care is required to address the problem encountered by

caregivers. Existing welfare schemes for psychiatric disability are implemented in various states. A pertinent question arises here: Have these schemes helped the persons with psychiatric illness and do even the parents/caregivers have a better quality of life after these schemes. Therefore, we recommend to conduct further research with a large sample in various centers in different parts of India.

Take home message

- Social security benefits are more important to people with mental illness, poor, rural people and for those with a low current period income.
- Many persons with psychiatric disability have poor quality of life as they are likely to have socio-economic disadvantages.
- Government functionaries involved in execution of the welfare programs should update their knowledge about the government schemes as many are uninformed.
- In regular intervals, awareness programs should be organized to enhance knowledge among stakeholders such as patients, caregivers, mental health professionals, and service providers at the community level.
- An adequate amount of tangible support is required to enhance self-esteem and quality of life as many of the caregivers are run through a long-standing quadriceps strained.

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Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patient(s) has/have given his/her/their consent for clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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Conflicts of interest

There are no conflicts of interest.

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