

Needs of Caregivers of Persons with Mental Illness: Rehabilitation Perspective

Rajesh Kumar¹, Anindya Das²

¹Assistant Prof. & INC Ph. D. Scholar, College of Nursing, ²Assistant Prof. Dept. of Psychiatry
AIIMS, Rishikesh, Uttarakhand, India

ABSTRACT

Introduction: Chronic nature of major mental illnesses can have a devastating impact on persons with mental illness (PWMI) and the caregivers. Rehabilitation is a long lasting phase of psychiatric treatment. The study focus on rehabilitation needs of the caregivers of PWMI attending psychiatric outpatient department at a tertiary care hospital. **Method and Materials:** A cross sectional study was carried out at All India Institute of Medical Sciences (AIIMS) Rishikesh, Uttarakhand. A purposive sample of 100 caregivers of persons with mental illness was interviewed to assess rehabilitation needs. Information on socio-demographic profile and rehabilitation needs was ascertained by using a self-administered pre-tested questionnaire. Appropriate descriptive statistics was applied to formulate the results. **Results:** Findings revealed that medical needs (10.04±2.61), self-care (10.11±2.48) and stress management needs (10.20±4.72) were more compared to others needs. Few caregivers reported the incidences of facing stigma at workplace and society (9.74±2.49) because of their ward's mental illness. Further, it also revealed that needs related to peer/community support, development of right attitude towards the care of the PWMI and management for worries and apprehension due to the condition of PWMI are quite frequently reported rehabilitation needs by the caregivers. **Conclusion:** A successful rehabilitation services always should be need based. Types and severity of disability of the PWMI will also play an important role in designing a structured rehabilitation programme. This study warrants further study based on large sample size to design successful rehabilitation services for persons with mental illness.

Keywords: Mental illness, rehabilitation, needs, caregiver

INTRODUCTION

Mental illness is listed as one among the ten leading causes of the disability worldwide.^[1] Recovery is heavily undermined by the disruptive symptoms, abnormal behaviour and inadequate skills. Psychiatric rehabilitation aims to provide pharmacological and psychosocial treatment to help the PWMI to go back to his/her previous independent stage of life.^[2] Mental illness not only affects the PWMI but also their

family members, friends and neighbours who directly and indirectly involved in their care^[3]. Family members become direct target and they face problems, scarcity and challenges in the care of mentally ill resulting in needs among caregivers commonly known as 'rehabilitation needs'.^[4]

Caregivers play an important role in providing day to day care to their ward and feel constrained due to unfulfilment of their own personal and professional needs.^[5] It is an occupation that

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Address for the Correspondence : Mr. Rajesh Kumar, Assistant Professor, College of Nursing, AIIMS Rishikesh, Uttarakhand - 249203 Email: rajeshrak61@gmail.com

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can encompass 24 hours in a day; 7 days in a week with no sick leave, no payback or no praise^[6]. These challenges put the caregiver to experience many physical and psychological problems termed 'burden'.^[7] Investigating the needs and problems of caregivers of people with mental illness could help in formulating the services for them and can help in reframing the existing policies related to the distribution of mental health services^[8].

However, a very limited research has focused on this area so far. It is need of present era to explore this neglected but crucial step of care of the PWMI. The result of the quantitative study can be utilized in the reviewing the importance and adequacy of existing mental health services, policy and may help in revision of existing policies as per the identified needs of the caregivers of PWMI.^[9] Indeed, the government can better allocate and prioritize resources for better utilization of mental health services in order to meet minimum essential mental health needs of the population.

In a 'need-led' approach, policy researchers argue that supplies of services should be based on an empirical assessment of needs of the population from multiple perspectives. The scarcity of services and rehabilitation needs should be well understood before allocation of resources to the community for adequate utilization of the resources.^[10] Assessment of rehabilitation needs will help to identify the gaps in existing services and resolving them.

Therefore, the investigators aimed to identify the rehabilitation needs of the caregivers to build empirical evidence and provide a better understanding of the varied needs of caregivers. This could help to bridge the gap between medical practice, psychiatric rehabilitation and policy formulation and development.

AIM

The study aimed to identify the perceived rehabilitation needs of caregivers of PWMI.

METHODS AND MATERIALS

A descriptive cross sectional study was conducted at the out-patient psychiatric department of All India Institute of Medical Sciences (AIIMS) Rishikesh, Uttarakhand. The study population comprised of purposively selected 100 caregivers of PWMI attending psychiatric out-patient department. Caregivers whose wards were diagnosed by a psychiatrist as per ICD-10^[11] were included in the study. Inclusion criteria also included healthy caregivers aged 18 years or more, staying with the PWMI and are blood relatives of the PWMI with neurotic illness i.e. obsessive-compulsive disorders, somatic disorders, anxiety, and mild depression without psychotic symptoms. The caregivers, who refused to participate in the study and having chronic psychiatric and medical conditions, were excluded from the study. The caregivers who were involved in the care of any person with physical illness were also excluded from the study. The tools were administered to caregivers in the out-patient department at AIIMS Rishikesh.

Research Tools

The tools used for the study were socio-demographic information sheet, and self-structured perceived rehabilitation needs questionnaire.

Socio-demographic Information data sheet: This was developed for collecting the personal information of caregiver and PWMI i.e. age, gender, occupation, education, marital status, monthly family income, leisure time activity(s), habitat, availability of social support, and duration of care in a day (hours/day) from caregivers. From the PWMI information on age, gender, diagnosis and duration of illness were collected.

Perceived rehabilitation needs questionnaire: It is a self-developed comprehensive questionnaire has items related to needs perceived by the caregivers while living/managing the PWMI. Response is designed as a 5 point Likert scale with (1) not important to (5) very important. It has total 36 items on 11 domains; 3 items in all domains except the last domain with 6 items covering the needs related to:

- 1) workplace and employment
- 2) community support and welfare system
- 3) medical needs
- 4) financial needs
- 5) social life and activities
- 6) family life
- 7) awareness of the illness & discrimination
- 8) self-care
- 9) care of the PWMI
- 10) entertainment and leisure time activities
- 11) stress management.

Minimum score can be 36 and maximum 180. One open ended question was also kept in the questionnaire to express any other unmet needs not covered in the questionnaire. Tools were translated into the Hindi language with the help of an expert. The questionnaire was developed by following the methods used in previous studies^[12,13]

The validity of the scale was sought for the present study by submitting the scale to experts in the field of Community Medicine, Psychiatric Social Work, psychologist and psychiatrist. The reliability was calculated by Chronbach's alpha and it came 0.81 for the scale.

Ethical Consideration

A written permission was obtained from the Ethical Committee of All India Institute of Medical Sciences (AIIMS) Rishikesh to collect the data from the caregivers. After explaining the study objectives, a verbal consent was also sought from an individual caregiver. Anonymity and confidentiality of the subjects were maintained during the study and participants were given full autonomy to withdraw from the study at any time. While questioning, it was assured

that subjects were free from all types of distractions to furnish the necessary details. It took around 20-25 minutes to furnish the asked details. The data was then entered into SPSS 20.0 evaluation version and was analyzed using descriptive and inferential statistics.\

RESULTS

Socio-Demographic Profile

It is evidenced from table 1 that caregiver's mean age was 40.99±12.42 years, (range 17-70 years). Majority (79%) caregivers were male and educated up to senior secondary level (62%) and were employed (60%). More than half (53%) caregivers belong to the rural community with a monthly family income 5001-10,000 (44%) and using television and radio (62%) to pass their leisure time at home. Most of the (98%) caregivers reported availability for social support for the care of the PWMI. In terms of PWMI profile, 61% were male with a mean age of 34 ± SD 14.72 years with a range 11-76 years and 50% PWMI's disease duration was more than 2 years. The mean duration of care was 7.29±5.38 hours/day.

Rehabilitation Needs

Table 2 shows the rehabilitation needs of the caregivers of PWMI. Needs related to medical facilities (10.04±2.61), entertainment and leisure time activities (9.45±2.52), family life (9.71±2.71) and self-care (10.11±2.48) were more emphasized by the caregivers as compared to other rehabilitation needs.

Table 3 and 4 revealed top 5 most and least frequently reported rehabilitation needs in the caregivers. Needs related to worries

Table 2
Caregivers Needs (n=100)

Rehabilitation need	Mean ± SD
Workplace and Employment	8.90±2.90
Community support and welfare system	9.76±2.95
Medical needs	10.04±2.61
Financial needs	9.58±2.56
Social life and activities	9.77±2.60
Family life	9.71±2.71
Awareness of the illness and discrimination	9.94±2.49
Self care	10.11±2.48
Care of the PWMI	9.33±2.76
Entertainment and leisure time activities	9.45±2.52
Stress management	19.50±4.72

Table 1
Socio-demographic Characteristics of Caregivers and PWMI (n=100)

Variables	Caregiver/PWMI (%)
Age of caregiver (years)	Mean 40.99±12.42
Range 17 -70	
<25	11(11)
26 -35	24(24)
>35	65(65)
Gender	
Male	79 (79)
Female	21(21)
Education Status	
Informal	12(12)
Up to 12 th school	62(62)
Graduate and above	26(26)
Occupation	
Employed	40(40)
Unemployed	60(60)
Family income (Rs)	
<5000	30(30)
5001 -10,000	44(44)
>10,001	26(26)
Habitat	
Urban	47(47)
Rural	53(53)
Leisure time activities	
Watching TV/radio	62(62)
Playing Games/Sport	10(10)
Prayer and religious activities	28(28)
Social support availability	
Yes	98(98)
Gender of PWMI	
Male	61(61)
Female	39(39)
Age of PWMI (years)	Mean 34±14.72
Range 11 -76	
<25	32(32)
26 -35	31(31)
>35	37(37)
Hours of care/day (hours)	Mean 7.29 ±5.38 hrs
<5	38(38)
5- 10	10(10)
>10	
Duration of disease	
<1 month	12(12)
1-6 months	38(38)
>2 years	50(50)

and frustration for future and fluctuation in PWMI's condition was frequently and most important needs perceived by caregivers. Again, need to boost up the motivation for participating in leisure time activities was another frequently reported rehabilitation needs. Further, it was also revealed that needs related to the development of right attitude in the care of the PWMI and obtain peer or community support in the care of the PWMI were reported equally important by the caregivers.

Needs related to the concern of safety security, handling PWMI's strange behaviour, time for leisure time activities and

Table 3
Top Five Rated Needs by the Caregivers (n=100)

S.N	Rehabilitation needs	Mean±SD
1.	Obtain peer support and encouragement	3.43±1.07
2.	Increase the motivation for participating in leisure time activities	3.43±1.10
3.	Reduce apprehension of the change of condition of the PWMI	3.42±1.03
4.	Need to develop right attitude of PWMI care	3.40±1.09
5.	Reduce worries over the PWMI 's future	3.40±1.04

Table 4
Least Five Reported Needs among Caregivers (n=100)

SN	Rehabilitation needs	Mean± SD
1	Reduce the worries over the PWMI's safety and security	2.97±1.20
2	Accept some of the strange behaviour of the PWMI	2.77±1.36
3	Spare the time for leisure time activities	2.76±1.07
4	Reduce the influence on one's own work performance because of attention to the care of the PWMI	2.44±1.34

influence on work performance were the least reported needs among caregivers. These least reported needs are highly reported among caregivers of psychotic PWMI. Caregivers of neurotic PWMI were studied in the present study and this could be a possible reason for least reporting of these needs.

The association was computed between rehabilitation needs and socio-demographic variables of caregivers. It did not show any significant association, indicating needs are independent of socio-demographic variables of the caregivers.

DISCUSSION

Rehabilitation is a process which includes pharmacological and psychosocial treatment to help the PWMI in the community and society for independent survival. The present study was conducted to quantify the rehabilitation needs of caregivers of the PWMI attending outpatient department at a tertiary care hospital.

The present study shows that caregivers had needs in one or another area of rehabilitation and the desire to meet these needs to have a good quality of life in line similar study from a tertiary care setting in India.^[14] Study suggests psychosocial interventions based on the bio-psycho-social model to meet the needs of the caregivers. It also indicates that despite the advancement of medical technology and treatment strategies, needs of the caregivers are largely unmet. Needs related to medical assistance, meeting social needs, needs of entertainment and self-care were common and frequent reported needs. These findings are consistent with previous study findings conducted by Chien^[15] and his colleagues and Chan^[16], which reported that needs related to mental health, social life, financial worries and physical conditions are frequently reported by family members as compared to other rehabilitation needs.

Needs considered more important in the present study included stress management, social life and activities, complete information about mental illness and discrimination, community mental health services and financial support for the family of a person with mental illness. However, among all these rehabilitation needs, 'need related to community support services', 'social life and activities' and 'information about mental illness' are more frequently reported needs by the caregivers. These findings are in line with the previous study findings conducted by Pearce et al.^[17] and Chien et al.^[18] which reported that caregivers are in need of information about mental illness, prevention and treatment. Similarly, a study conducted by Ma & Yip^[19] in Hong Kong also reported poor knowledge related to mental illness among caregivers.

Caregivers fears for the future of PWMI and often gets frustrated by the fluctuating condition of the latter. This justifies the stress management need. Similarly, it was reported in a study conducted by Cleary et al.^[3] that caregivers are seen worried about PWMI's health, financial arrangement, and their own future. Needs related to community support and welfare were equally rated high by the caregivers. Tesslerr et al.^[20] too pointed out that accessibility and availability of financial resources, community mental health services and mental health professionals were also equally important needs for caregivers and PWMI.

CHALLENGES AND IMPLICATIONS

Planning and implementation of rehabilitation services for caregivers and person with mental illness is challenging for community mental health professionals. Viability of rehabilitation programme depends on coordinated efforts of different mental health professionals. The present study findings can be used by community mental health professionals and students during their community postings to make the community people aware about mental illness, their causes, stigma and discrimination, and rights of a family member and their loved one.

LIMITATIONS

The study has many limitations that have to be taken care while interpreting results. There are many factors that can hinder the generalization of the findings. For instance, small sample size and cross sectional one-time survey approach may impede the broad generalization of the findings. The selection of the participant was through purposive sampling in the study may hinder external validity of the results. Caregivers recruited were of those clients who had neurotic problems. This study should be considered preliminary in this area and recommend to design a longitudinal qualitative study for in-depth exploration of rehabilitation needs of the caregivers.

CONCLUSION

The study was able to recognize the major rehabilitation needs of caregivers of persons with mental illness and it is the responsibility of health professionals working in psychiatric set-up to probe and address these needs. Tailor made interventions are essential and the same may help them to meet the needs.

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