

# SATISFACTION OF CAREGIVERS OF Serious Mental illness (SMI) PATIENTS AT REHABILITATION SERVICE CENTRE

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**ABSTRACT**--Psychiatric rehabilitation services have a goal of catering to the rehabilitative needs of patients such as their psychiatric symptoms, cognitive needs, emotional needs, social needs, vocational training needs and placement. The satisfaction of caregivers of patients with the rehabilitation services is an important marker of the success of any rehabilitation facility. To assess the satisfaction of caregivers of serious mental illness (SMI) patients at Disability Assessment & Rehabilitation Triage (DART), Chandigarh, with the services provided. The assessment of satisfaction was done using a semi structured interview based on a questionnaire adapted from the "Patient Satisfaction Questionnaire" by the Wirral Community, NHS Trust, UK. The sample consisted of 25 caregivers of patients seeking treatment from DART. Descriptive statistics was used to analyse the data. The results indicated that 84% of caregivers feel involved in and informed about treatment decisions regarding treatment of the patient. 74% of caregivers feel that they have been better able to understand the patient's illness after coming to DART. 96% caregivers believe in the competency of the professionals. 92% believe that patient information is kept confidential. 76% agree there is improvement in the mental health of patients post rehabilitative care. 68% report improvement in the functional living skills of patients and 80% report improvement in QOL of both patients and family members. The individual feedback & suggestions involved, adding more no. of activities, taking measures to avoid patient neglect, more attention to caregivers and improvement in placement services. The study reveals that majority of caregivers interviewed are satisfied with rehabilitative care of patients at DART, GMCH, Chandigarh. However, feedback included useful suggestions for improvement in the areas of patient care, caregiver support and placement.

**Keywords**-- DART, Caregiver, Satisfaction, Rehabilitation services, Serious mental illness.

## I. INTRODUCTION

Psychiatric rehabilitation is aimed at helping individuals with persistent and serious mental illness to develop the emotional, social and intellectual skills needed to live, learn and work in the community with the least amount of professional support. <sup>[1]</sup> Psychiatric rehabilitation and psychiatric treatment are considered as separate but complementary aspects. <sup>[2]</sup> It is known that caregivers play an important role in the rehabilitative process. Most caregivers take up the caring role in the absence of any significant knowledge about the illness. <sup>[3]</sup> In India,

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more than 90% of patients with chronic mental illness live with their families.<sup>[4]</sup> The family caregiver plays multiple roles in caring for persons with mental illness, including taking day-to-day care, supervising medications, hospital visits and financial support. The stress of caregiving has been labelled as caregiver burden in the literature.<sup>[5]</sup> Therefore, rehabilitative care must ensure care to patients as well as caregivers. There is need for employing family-based interventions, as well as, psychoeducation to the caregivers. The satisfaction of caregivers of patients with the rehabilitation services is an important marker of success of any rehabilitation facility. It has been a trend for most of the treatment in mental health care to be directed towards patients. However, caregivers play a crucial role in the overall recovery of patients suffering from mental illnesses. Caregiving is a stressful and demanding role, often associated with negative outcomes such as emotional strain, burden, grief, and stress. Therefore, it is worthwhile to explore the mental health of caregivers, while researching the aspects of rehabilitative care. Few studies examine the direct effect of rehabilitative care, on “the invisible patients”, i.e. the caregivers.<sup>[6]</sup> Efficacious rehabilitative care is often reflected in reduced caregiver burden of family members, which may be indicated by their expressed sense of satisfaction with the rehabilitation facility. Therefore, it is an important indicator of the success of a rehabilitation centre. Patient satisfaction is a separate concept but closely related to caregiver satisfaction, which also reflects the effectiveness of a rehabilitation centre. Patient satisfaction has various important predictors such as, personal aspects of care, including full communication, and it is associated with patient compliance and better outcomes.<sup>[7]</sup> Other factors such as age, education and social status show weak relationships with satisfaction levels.<sup>[8]</sup> Rehabilitative care demands development and improvement in Rehabilitative care, such as, participation in work on the open market and more work-like occupations in the day centre, accompanied by some remuneration<sup>[9]</sup>, as such facilities haven't been developed in all rehabilitation centres. Thus, feedback from caregivers and assessing their satisfactions and dissatisfactions will provide insights into the potential for growth and betterment in rehabilitative care. As length of stay in a rehabilitation centre increases, there has been a trend for increased participation in activities, however the length of stay is negatively correlated with life satisfaction in patients.<sup>[10]</sup> Therefore, it may be helpful to understand the perspective of both patients and their caregivers in improving rehabilitative care to account for such aspects of poor psychological well-being.

## II. METHODOLOGY

**Objective:** To assess the satisfaction of caregivers of serious mental illness (SMI) patients at Disability Assessment & Rehabilitation Triage (DART), Chandigarh, with the services provided.

**Sample:** The sample consisted of responses from 25 caregivers of serious mental illness (SMI) patients coming to the Disability Assessment & Rehabilitation Triage (DART), Chandigarh, India. The sampling method was convenience sampling.

**Inclusion criteria:** Consenting caregivers above 18 years of age, who are providing care to SMI patients at DART.

**Research Design:** Descriptive Research Design was used for the study.

**Tool Used:** A questionnaire adapted from the Patient Satisfaction Questionnaire (Wirral Community, NHS Trust), UK, was used to collect data.

**Procedure:** Ethical clearance and permission from the authorities of the rehabilitation service centre, i.e. Disability Assessment and Rehabilitation Triage (DART) was taken for conducting the study and collecting data from the caregivers of patients. Caregivers were invited to participate in the study and informed consent was taken from both patients and caregivers. The data was collected from a total of 25 caregivers of patients at DART. Data collection was completed in two phases based on convenience and preference of participants. First phase involved caregivers filling out a questionnaire adapted from the Patient Satisfaction Questionnaire (Wirral Community, NHS Trust) to get a feedback on their satisfaction levels with the rehabilitation centre services. Second phase involved caregivers participating in a face to face/telephonic interview based on the same questionnaire. Socio-demographic details of both patients and caregivers were documented in each phase. Descriptive statistics was employed to analyse the results.

### III. RESULTS

**Table 1:** Socio-demographic Details of Caregivers: Age and Gender.

Age	Adults (%) 19 -59 years	Senior Adults (%) 60 years & above.
	64	36
Gender of Caregiver	Male (%)	Female (%)
	52	48

Majority of the caregivers were adults, i.e. age range 19-59 years (64%), and the rest were senior adults (36%). This implies that while senior adults form a small proportion of the overall sample, it is still a large percentage. This strengthens the notion that caregiving is a lifelong process and caring for SMI patients may become a burden if rehabilitation services and other aids are not at the disposal of caregivers. The caregivers represented both genders roughly equally, i.e. 52% males and 48% females.

**Table 2:** Relationship of caregivers with patients.

Relationship with the patient	Parent (%)	Sibling (%)	Spouse(%)	Others(%)
	68	20	8	4

Majority of the caregivers were parents, i.e. 68%, followed by siblings, 20% and then spouse, 8%. Other relatives included an uncle, aunt or a cousin.

**Table 3:** Caregivers responses on different domains of satisfaction with Rehabilitative care.

Question	Agree (%)	Disagree (%)
Feeling involved and informed about treatment decisions	84	16

Better understanding about patient's illness	72	28
Trust in competency of professionals	96	4
Privacy and confidentiality	92	8
Treat with respect and maintain dignity	92	8
Functional living skills	68	32
Quality of life	80	20

The study reveals that majority of caregivers of patients feel involved and informed about treatment decisions (84%), understand the patient's illness better after coming to DART (72%), have trust in the competency of professionals (96%), believe that privacy and confidentiality is maintained (92%), believe they are treated with respect and their dignity is maintained (92%), believe that the functional living skills of the patients have improved after coming to DART (68%), and that their quality of life has improved after seeking rehabilitative services from DART (80%).

**Positive Feedback:**

Positive feedback given by caregivers was documented. This included feedback regarding the cooperativeness and polite demeanour of all mental health practitioners working at the centre –“Doctors are very cooperative, and they motivate the patients a lot. All the doctors are polite and approachable”. They also mentioned how the patients had been improving during rehabilitative care – “My son has improved and become more confident after coming to DART. I have seen a change in him”. Some caregivers indicated how the facility was keeping the patients engaged and improving their functionality as well as skills, “She was very ill, and I couldn't give her time. DART is good for keeping her engaged. She loves coming to DART and would complain if she ever misses going there”, “I'm very satisfied, as earlier the patient would keep lying on bed and complain about pain. But now he is better”, “DART helps maintain a routine in all patients, which is very good”, “He has learned a lot of skills such as making envelopes. He is improving”.

Further, some caregivers discussed how their understanding about patient's illness has improved – “I learnt about the illness and changed my own attitude towards patient. She has improved drastically”, “The culture at DART is very open. The patients aren't restricted or confined, and family members can visit frequently. It was surprising to me to learn that. It is much better from other institutions I have seen”. Other caregivers mentioned about it being helpful in terms of resources, “It is convenient, as we even get the medicines over there”, “The clinic and infrastructure is very good”.

**Suggestions for Improvement:**

Caregiver also gave some constructive feedback and suggestions for improvement which were documented. These included caregivers having greater expectations from the institution – “If they could find out what is causing the illness and cure it completely, it would really help me”, “They should follow up with patients a little more if possible. Sometimes, patients don't listen to us, so they can help with that”, “Doctors often do not follow up and I have to take care whether medicine is to be reviewed or changed”, “Sometimes, there is a long wait before I can see the doctor”. A caregiver gave feedback regarding long-stay of some patients – “I would just say that the patient should get better sooner, and not stay too long over there”. Some caregivers believed that the family needed more support – “Sometimes there is a lack of social support to some families, for example, I am alone and very burdened, and it is hard for me to travel back and forth to DART and take medicines and take care of my son”, “Family members should be given more attention and care”. Few caregivers made suggestions regarding improvements in the activities held at the centre – “Some more sports or activities may be added. Excursions and incentives for good behaviour or participation in activities”, “I think the staff must engage the patients in Masala Grinding section more, and it will be nice if they can help in placement of my son at a job”, “There needs to be more activities”. While few others made suggestions regarding improvement in the services – “There was one instance when my son wanted hot milk and the staff refused to cooperate in helping me heat it. I had to arrange it from outside. They should cooperate for such occasional things”, “I think the food quality could improve. The preparation should be up to date and if possible, there should be variety” A caregiver expressed concern regarding increasing functionality of a patient further – “She should learn to take care of her children. If doctors can encourage her to focus on that, it will help”.

Finally, few expressed occasional concern regarding behaviour of staff – “Some professionals are not polite and maybe want us to simply adhere to their treatment because they might feel that they know better”. One caregiver also suggested the possibility of awareness programs that may be organised by the centre – “Awareness should be increased among people who do not know about such services through regular camps in slums and other cities”.

#### **IV. DISCUSSION**

The study reveals satisfaction of caregivers with domains of rehabilitative care such as the clinic, the infrastructure & environment, behaviour of mental health professionals, and the treatment outcome. Higher satisfaction is associated with patient compliance and better outcomes.<sup>[7]</sup> The dissatisfaction of the caregivers was with aspects such as follow-ups, no. of activities, placement and length of stay. Length of stay, is negatively correlated with life satisfaction.<sup>[10]</sup> Satisfaction of caregivers with improvement in patient's functional living skills was assessed, and it revealed majority with improved functional and independent living skills. Measures of patient satisfaction with rehabilitation should include items regarding progress and degree of return to independent living.<sup>[7]</sup>

#### **V. STRENGTHS**

1. The study focuses on the caregiver's perspective and satisfaction with the rehabilitation services.

2. The data collected indicated objective measures of satisfaction, as well as, a subjective component of feedback from caregivers.

3. The study provides valuable insights and caregiver feedback for improving the services of the rehabilitation service centre.

## VI. LIMITATIONS

1. The study did not compare the satisfaction of caregivers in terms of whether they were caring for a patient outpatient or inpatient departments of the rehabilitation centre.

2. The expectations of caregivers may not indicate objectively the areas that may need improvement in the rehabilitation centre, as their expectations may be unrealistic, and may need to be moderated.

3.

## VII. CONCLUSION

The study reveals that majority of caregivers who participated in the study are satisfied with rehabilitative care of patients, while feedback included some useful suggestions for improvement in the areas of patient care, caregiver support and placement.

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