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CAREGIVERS IN

COMMUNITY MENTAL HEALTH –
A RESEARCH STUDY

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Preface

The presence of a person with serious mental illness impacts family members in several ways, and has been reported extensively in the literature, as the burden of care. Research studies in India have documented that the vast majority of Persons with Major Mental illness live with their family members, who are required to provide care and support for extended periods of time. In fact, the National Mental Health Program, which seeks to deliver mental health care through community based approaches, is based on the premise that the locus of care, for persons with serious mental illness, will continue to be the natural kin network . Yet, there is limited holistic understanding, of both the difficult circumstances under which relatives look after persons with serious mental illness, as also the emotional and practical challenges they face through the different phases of the illness. Consequently, families receive limited support and guidance from professionals, suggesting that the mental health establishment often regards family members as a low cost, plentiful resource in the community, who are required to offset the limitations of a poorly funded mental health system.

However, if these primary care providers have to offer long term sustainable care, it is both ethical and imperative that their needs have to be understood and addressed in a systematic manner.

Rural India is characterized by a paucity of mental health services, and the very basic challenges of poverty and illiteracy. How do rural families provide care for persons with major mental illness? What difficulties do they face and how do they cope? What role does the natural kin network play, in a community mental health program? There are major lacunae in the literature pertaining to these issues, and this research volume is a pioneering attempt to address these important questions.

The strengths of this research initiative are many: Most importantly, it has been designed within an ongoing, multi –location, community mental health initiative of Basic Needs India in rural south India. In doing so, the research questions, design, methodology and execution have incorporated the experiences of front line field health workers who not only have a robust understanding of the community they are working in, but also high level of community acceptance. In addition, the study has very appropriately incorporated a fundamental, but often over looked fact mental illness is not static cross sectional entity.; Consequently, care giving too is a multi layered, multi dimensional process that changes over time, requiring role adaptations and skill acquisition by families.

Probably for the first time in India, the authors have identified the core components of physical, medical, psychological and social care that are provided by the primary care givers, describing them in practical terms, at different phases of the illness. The study has also drawn attention to the issues of multiple caregivers within and outside the family and offered valuable understanding to the gender perspective of providing long term care .The importance of cultural and socioeconomic realities that impact the ability of family members to provide on going support have also been documented. Overall, the research creates graphic and compelling images of the daily challenges of care giving, as well providing direction to issues that have to be addressed in programs of family intervention.

Community Mental Health program should be designed and delivered in active collaboration with the local community. This research study has used family members as key stakeholders, to identify important needs that should drive service delivery. The role of self-help groups and family members as a valuable resource whose experiences can be meaningfully harnessed to create community awareness and help fight stigma has also emerged as an important finding.

In India, community care often translates into care by the family. This research study has succinctly highlighted the fact that family caregivers need to be supported and nurtured through programs of information and guidance and practical assistance .It is hoped that the authors will take this important research initiative forward by identifying critical components of family intervention in rural areas, validating it through further research, and then developing a manual for working with families.

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ABSTRACT

The research report on 'Caregivers in Community Mental Health' by BasicNeeds India, working in the area of community mental health and development, describes people with mental illness (PWMI) and their caregivers within the family and examines the load of care giving with reference to the types of care during the symptomatic and stabilised phases of the illness and further examines the load in terms of sex and age group of the persons with mental illness. The report also brought out the support given by the 'Community Mental Health and Development Programme' provided by BNI to the caregivers, their learning from the programme inputs and also their contributions to the programme. This report examines the various ways in which caregivers adapt their lives to the needs of a people with mental illness. The research report draws its data from the 200 families with mental illness in Andrapradesh, and Karnataka. The report also relies substantially on data gathered from group meetings in which caregivers share their concerns with each other. The data presented in the study are from the interviews using interview schedule of open ended questions. The present research diffuse notion of "care" as "physical", "medical", "psychological" and "social" aspects. Amongst the many factors (such as gender) affecting caregiving, the report demonstrates powerfully how poverty compounds the problems of caregivers - most obviously in the loss of daily wages spent looking after the PWMI. Yet the study also underlines the indispensability of the family in the care of PWMI. Despite their own hardships, family members by and large take on the care of their PWMI as a matter of course. Caregivers are a largely under-studied, unsung population who shoulder many of the social and psychological costs of mental illness. Used to giving the credit for any improvement to the doctors and the medicines, the report records the incredulous gratitude of caregivers at being acknowledged for the work they do. In that regard, the study itself provides a boost to the morale of tired, unacknowledged caregivers. Besides this benefit, BNI in strengthening the community programme.

CARE GIVERS IN COMMUNITY MENTAL HEALTH

1. INTRODUCTION

1.1. Background

Severe mental disorder affects nearly one percent of the population world wide (world health report 2001, Janardhan and Naidu 2006). The illness is characterized by delusional and confused thinking, hallucinations and social isolation. In fact, nearly one third of people with severe mental disorders have problem in participating in the structured activity on a daily basis. Constant care should be provided for motivating people with mental illness to lead life with dignity.

Especially for poor persons with mental illness, it leads to extreme marginalization of the individual and the family, as both these hamper the ability to be productively engaged, and to access necessary resources for that. PWMI's initiative is affected by internal factors (within the individual) and external factors (due to lack of specific support facilities). The social stigma further blocks community support and access to resources (Janardhan and Naidu 2006). Poverty and Gender compound these dynamics. Being mentally ill and a female, the family's investment for care is likely to be less and so also other support needed for recovery. Consequences are unhappy lives of individuals sometimes leading to extreme crisis, poor coping abilities of the family, lost productivity and stress in the community.

Family has been an essential part of the mental health care programmes in Basic Needs, India Programme. The emphasis on the family as the single most important source of care is fairly unique for India and contrasts with the emphasis on professional and institutional mental health care in developed countries.

Because of the paucity of mental health care, families have been given more responsibilities to care their mentally ill family member, whether it was by choice or our cultural influence or due to the lack of facilities, it is difficult to conclude, though there is some evidence to support that family involvement in care was and continues to be a preference of families .(Khurana and Wig.1978. ICMR 1988). It is unfortunate that the experiences of the families have not been adequately studied and the strengths not been optimally utilized in the recovery of people with mental illness (Srinivas Murthy and Ghosh 2001)

The needs and support required are

1. Access to beneficial care- medical and psychological
2. Livelihood opportunities for the individual and family members.
3. A supportive community environment.

All these measures need to be strengthened through a gender rights perspective.

1.2. Basic Needs, India:

Having recognized the growing needs of PWMI and their families in rural areas and lack of opportunities / facilities, Basic Needs India's (BNI's) Community Mental Health and Development (CMHD) programme has a strong focus on poor PWMI in rural areas. BasicNeeds India was established with the following objectives:

- To restore mental health and human dignity through appropriate interventions thus resulting in acceptance, de-stigmatization and relief to care givers.
- To support PWMI to exercise their rights through new initiatives in mental health and development.
- To bring financial stability to these families through economically viable income generation activities designed for mentally ill people and family members.
- To develop and promote social horticulture / land related activities appropriate to the community.
- To promote and carry out action research (involving PWMI) and disseminate the information / results so as to contribute to the overall body of knowledge in the area of community mental health and development.
- To work with established government organizations / NGOs to enable them to have the capacity to adapt their programmes to take into account the needs of PWMI.
- To focus on 'advocacy', 'proper legislation' and 'gender and equality issues'

1.3 Care-giving

In the CMHD programme of BNI, most of the PWMI identified and treated are living with their families. In taking care of the people with mental illness. The care givers play an important and difficult role, especially when their wards have severe mental illness. community-based approach places more demands on family caregivers.

1.4 Family Care-giving

The provision of assistance and support by one family member to another is a regular and usual part of family interactions, and is in fact a normal and pervasive activity. Thus, caregiving due to chronic illness like mental illness and disability represents something that, in principle, is not very different from traditional tasks and activities rendered to family members. This is especially true for women. Across cultures, women have traditionally shouldered a disproportionate amount of family caregiving responsibility (McGoldrick 1989; Lefley 2001; Olson 1994).). The difference, however is that caregiving in chronic illness often represents an increase in care that surpasses the bounds of normal or usual care.

Caregiving in mental illness involves a significant expenditure of time and energy over extended periods of time, involves tasks that may be unpleasant and uncomfortable and is often a role that had not been anticipated by the caregiver. When these unanticipated roles are incongruent with stereotypical gender expectations (e.g., when a male caregiver must attend to physical hygiene of female mentally ill or when a female

caregiver is responsible for controlling a violent mentally ill relative's dangerous behavior), the stress can be exacerbated (Tessler and Gamache 2000).

However, there is now growing recognition among service providers and researchers that family caregiving will become more significant in the future because of demographic, economic, and social changes in the late twentieth century that are anticipated to continue into the next century.

- ❖ A responsible caregiver is one who:

- ➢ Lives close to PWMI
- ➢ Has good emotional relationship with the PWMI
- ➢ Has positive attitude towards the PWMI
- ➢ Has time for the PWMI
- ➢ Has patience.
- ➢ Is positive in approach to the condition of mental illness.
- ➢ Is motivated to care and also has capacity to motivate the PWMI.
- ➢ Has the ability to create favorable atmosphere for the PWMI to be rehabilitated at home.

The basic aspects or elements of care a person with mental illness requires is

a) Motivating and monitoring a PWMI for maintaining personal hygiene
b) Provision of adequate amount of nutritious food
c) Medication/supervision of the intake of medicine by PWMI
d) Motivating the PWMI for taking small responsibilities
e) Engaging the PWMI in income generation/productive activities
f) Create awareness among the community so that the PWMI is accepted and integrated in all community activities
g) Encouraging the PWMI for socialization

2.   REVIEW OF LITERATURE:

A review of available literature related to care giver and care giving of PWMI especially within the family underlined (i) importance of the family in mental health care ;(ii) problems of care givers and their needs; (iii) factors that influence care giving of PWMI within the family; (iv) positive influences of care giving on the care giver; (v) factors that increase family burden; and (vi) factors that decrease family burden.

2.1. Importance of the family in mental health care

The first formal recognition of the importance of the family as part of mental health care can be traced to the work of Prof.Vidyasagar in the early periods of post-independence India. He observed that patients were brought for admission only when their mental illness was already long standing and when their relatives had been drained of by care giving. Vidyasagar encouraged the relatives of people to stay with the patient during the treatment period in the mental hospital., To accommodate the relatives in the hospital, tents were built in the hospital campus. He encouraged family members to involve themselves in daily nursing care and by doing so they learned about managing medication, including watching for the side- effects of medicines. They also learnt about psychological aspects of care giving for those with mental illness. Vidyasagar encouraged caregivers to form self help groups. The mental hospital became a renowned center for active treatment and for public mental health education (Carastairs 1974).

2.2. Problems of care givers and their needs

A study in India carried out to understand the needs of families of those with mentally ill members and the impact of family level interventions at the community level on those families, revealed that the psychosocial problems of families were related to their high level of expectations (of the person with mental illness) and of their emotional (over) involvement (Suman et al, 1980). Problems also arose with regard to the long term treatment plans of people with mental illness especially due to lack of understanding of patients' residual symptoms on the part of the caregivers . Other problems, from the perspective of both caregivers and patients, lay in the question of patients' marriages and general rehabilitation into society. Most families were not able to understand the residual symptoms of those with severe mental illness. The study concluded that "family members have multiple needs when living with a person with chronic schizophrenia. The needs should be understood and met to enhance the functioning of the family to provide care and thereby reduce emotional problems of the family members". (Suman et al 1980).

Caring for people with severe mental illness, particularly in the community, carries a heavier burden. Such burden manifests in reduced caregiver well-being (Jungbauer and Angermeyer 2002), which admittedly depends in part on caregiver factors such as care giving style (Stengard 2002). In turn, as caregivers are less able to provide support to their ill relatives, their relatives' well-being, and ability to remain in the community suffer (Song et al 1997; Leff and Vaughn 1985).

2.3. Factors that influence care giving of PWMI within the family

Despite the apparently direct cause-and-effect relationship between the level of patient disability and the psychological distress felt by the caregiver, there exists considerable variability in caregiver outcomes. Differences between the nature of the relationship between caregiver and the mentally ill person, pre-existing emotional resources of the caregiver, coping ability of the caregiver, availability of economic and social support and factors such as gender, personality, caregiving beliefs and values have been found to be significant. (Adler 2001; Songwathana 2001; Yates, Tennstedt, and Chang 1999). The structure of the family as well as where they are in their life stage as a family - e.g. elderly parents caring for an adult with severe mental illness, or a former family breadwinner incapacitated by mental illness - can present different challenges to caregivers (Pot et al 2001). Female caregivers show higher levels of caregiver burden than males (Miller and Cafasso 1992).

2.4. Positive Influences of care giving on the caregiver

While care giving remains a difficult, even onerous responsibility, it can also have positive effects on the caregiver (Beach et al. 2000; Bulger et al 1993). Findings from a Swedish study suggest that satisfaction from caregiving derived from varied sources and that most caregivers do experience some kind of benefit, help them to continue (Lundh 1999). In some families of adults with severe mental illness, the care recipient is able to reciprocate emotionally (Tessler and Gamache 2000). Elderly caregivers demonstrated improved mental and physical health as caregiving activity increased. Adult sons and daughters who are caregivers to elderly parents report that they find caregiving gratifying because they can "pay back" the care that their parents provided to them when they were young. In addition, caregivers report that being a caregiver helps them gain inner strength, for their personal growth and increased their understanding of family problems and learn new skills (Michael Bulger etal 1993)

2.5. Factors that increase family burden

Certain patient factors may increase family burden. These factors include the severity of patient's symptoms, length of time in the hospital, number of hospitalizations, the length of time the patient has been ill and the level of social functioning (Magliano et al 1998; Dyck et al 2000).Care givers of persons with mental illness report that disruptive or bizarre behaviors are especially troubling. In addition, caregivers' perceptions that ill relatives are increasingly dependent and that other family members are not contributing assistance and support may increase the burden (Rolland 1994; Magliano et al 1998; Cuiipers 1999). There is evidence to suggest that positive symptom behaviors such as hallucinations and delusions along with the high degree of social dysfunction and frequent relapses are associated with greater family burden than negative symptoms of apathy and social withdrawal (Magliano et al 1998; Webb et al 1998). Verghese (1982) studied the problems faced by the families of people with schizophrenia, mania and major depression. The study concluded that families with manic patients had more severe and disruptive psychopathology and caused maximum burden on the families.

2.6. Factors that reduce family burden

Research studies suggest that level of burden is reduced when family members have a more positive attitude toward the patient, when there is an increase in social support and fewer hospitalizations as well as improved social functioning for the person with mental illness.(Magliano et al 1998; Cuiipers 1999; Magliano et al 2000; McDonnel et al 2003; Magliano et al 2002; Saunders 2003). In this regard, several interventions with the families and caregivers have been developed that combine family intervention along with neuroleptic medication as a means of preventing relapses and faster recovery of person's with mental illness (Goldstein et al 1978; Leff et al 1982; Fallon et al 1984; Tarrier 1991). The results have shown that family psycho education, particularly the caregiver's involvement in the treatment process increases the level of social competences, decreases the subjective burden on relatives, and brings about change in communication patterns and in the overall interaction within the family.

3. THE RESEARCH STUDY

3.1 Rationale for the study

As part of the Alliance building programme in South India BasicNeeds India planned for the annual review of Community Mental Health and Development programme in south India. A team was constituted to visit each partner to review the community mental health and development programme. The team came out with a finding that often caregivers/family members do not recognize their role in the recovery , the credit is attached to the medicines and the doctor – which plays only 25 % of its role in recovery[1]. Caregivers perceive that caring is their responsibility and do not feel that they have contributed to the recovery of the mentally ill family member. It was felt important that the caregivers must recognize their role in the well-being of their wards.

It was also observed that during the meetings, more number of female caregivers were seen to be participating. This raised gender as an issue in carrying the burden of caring for the mentally ill person.

3.2   Aim of the study:

To understand the profile of the care givers and the roles they play in the recovery of their mentally ill family members and also their role as resource of the CMHD programme for strengthening the caregivers in care giving and as resource to the Community Mental Health.

3.3   Objectives of the study

- To understand the profile of the care givers;
- To specifically pinpoint the roles played by care givers while caring people with severe mental illnesses;
- To identify the facilities they have and difficulties they face and the ways in which they cope up or do not cope up ;
- To recognize the kind(s) of support available, and needed by, care givers in order to cope up with difficulties and to map out the indigenous modes of support available and used and to suggest possible support system model in this regard.
- To identify the strengths of the care givers especially in terms of their serving as resources of the CMHD Programme through specifying the ways in which they have served the various aspects of the programme (such as identifying other MIs in the area, in creation of awareness, in providing guidance in caring) - enlisting possibilities of systematic approach

3.4   Research Design

Descriptive research design is used for collecting information for the present study

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[1] Psychiatrist share during consultations and training field staff, focusing on importance of caring in the process of recovery.

3.5 Population of the study

Population of the study was all the care givers of people with severe mental illness in all the programmes of NGO partners of Basic Needs India. BNI worked with three primary partners in Andhra Pradesh, and Karnataka and three secondary partners, who in turn worked with several NGO partners in the respective areas of operation in Tamil Nadu and Kerala.

3.6 Sampling and Sample Size

- All the caregivers of people with severe mental illness who are stabilized, who have been in the Community Mental Health and Development programme for two years or more formed the sample.

- Selective or Purposive sampling of partner NGOs : All primary partners of Basic Needs India which are medium sized CBOs working in the area of community mental health and development formed the sample. The primary partners of BNI are, SACRED (Ananthapur) in Andhra Pradesh; GASS (Doddaballapura) and Narendra Foundation (Pavagada) in Karnataka.

- Consultations and discussions were held with the heads and the mental health coordinators and also the field staff of these partner organizations about the research study

- 201 persons with severe mental illnesses in the programme area of the Primary partners of BNI and their primary caregivers were identified. They formed the sample of the present study.

3.7 Development of the tool:

An Interview schedule was developed for collecting information about caregivers efforts and their role in the wellbeing of PWMI.

The process of developing the interview schedule is described below

a) Reviewing of the existing life stories written by BNI staff and listing out the kinds of care givers support in the recovery of the PWMI
b) Developing an interview schedule – based on the aspects of care as revealed by the life stories.
c) Circulating list of care giving roles among BNI staff and advisers for further addition.
d) Grouping care giving roles (described more in detail in the analysis chapter).
e) Discussing and developing the draft of the interview schedule. The first draft of the questionnaire sought responses based on three categories, i.e. the caring that was provided when the PWMI was highly symptomatic, moderately symptomatic and stabilized.

  The pilot administration of the questionnaire by the research   team revealed the difficulties in seeking responses based on this scale. At the same, time discussions among the research team enunciated the importance of knowing the

change in care giving that was provided for a PWMI from when s/he was highly symptomatic to when s/he was stabilized.

Thus the questionnaire was modified to address this issue and it was designed such that the questions were asked under only two categories i.e. the care that was given when the PWMI was highly symptomatic and when s/he was stabilized. Caregivers recalled the care given to their patient during the symptomatic phase, as their wards were stabilized at the time of the study.

    f) Field testing of the interview schedule in urban programme by BNI team

    g) Discussing with the research team and making further modifications.

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    h) Translating the finalized interview schedule into Kannada and Telugu languages.

3.8 Description of the tool:

The **interview** schedule was designed to collect information on:

- ➢ Socio demographic details of persons with mental illness: their age, sex, educational qualification, occupation, family type, marital history and family income. This also elicited information about the illness, duration of illness and treatment and since how long they were stabilized.

- ➢ Socio demographic details of the caregiver: caregivers age, sex, educational qualification, occupation, years of caring, changes in caring, and amount of time spent on caring. This section also obtained details of profile of the multiple caregivers,

- ➢ Care giving schedule: this section lists out the different types of care giving activities which are classified as physical care, psychological care, medical care and social care. (described in detail about the types of care giving in the analysis chapter)

- ➢ Caregivers as resources: this section asked for information about the care givers problems, their coping skills, support they received from the organization, their expectations from the self help groups, their participation in, and their learning from, the self help groups.

3.9 Field testing of the tool.

The interview schedule was field tested by members of the research group before the actual field work started. The objective of this was to enable the investigator to know if certain questions in the interview schedule could be administered properly and also to understand if it yielded the appropriate response ranges. Based on the experiences of the field testers, the tool was continuously modified and field tested again.

Once the final schedule was ready, the mental health coordinators of the primary partner organizations of BNI were trained to administer the interview schedule. They administered it and gave a feedback of their experiences of administering it. They discussed with the research group their observations and the issues they faced. Further

modifications were made in the tool and it was finalized. (A copy of the tool in English is in Annexure 1)

The core field staff under the mental health coordinator of each partner was again trained on the interview schedule. They administered the same, in the field, to the sample.

Capacity-Building

Several steps were taken in building capacities of the partner staff on administering the interview schedule. Initially, the partners were consulted about the research study and discussions were held on the importance of recognizing the care giving roles of the care giver and use them as resource of Community Mental Health programme.

Further, sessions were held with the field staff on listing all the possible care giving roles and categorizing them. Then the finalized questionnaire was reintroduced to them and the field staff were trained on the various items in the questionnaire. Later sample pilot interviews were conducted to help them to be familiar with the questionnaire.

At the field level, when the interview schedules were administered, the care givers expressed that they felt happy that someone is recognizing their efforts in taking care of the PWMI. At some point the care givers thought that it was the medicine that was doing all the magic, but administering the questionnaire made themselves recognize their efforts.

3.10 Validity and reliability

Validity and Reliability of the developed tool was checked through regression analysis of the collected information which indicated high level of internal consistency among different types of care (Refer annexure 2).

3.11 Data collection.

The finalized questionnaire was administered in the field and data were collected by the field staff during January – April 2007.

The responses to the interview schedule were collected back by BNI, the data were coded during July – August 2007. The responses were checked for completeness and wherever they were incomplete, efforts were made to get back to respondents to complete the data.

3.12 Definitions:

Some terms defined:

Severe Mental Disorders (SMD): It is a severe type of mental disorder in -which patients talk and behave abnormally. The functions of the body and mind are severely disturbed resulting in gross impairment of individual and social activities. The types of SMD are Schizophrenia, Bi-polar Affective Disorder, Psychosis not otherwise specified (Psychosis NOS).

Schizophrenia: is a severe mental illness which results in delusional thought patterns hallucinations, inappropriate affect, apathy, de-motivation, and lack of interest. These people will often suffer from social and occupational difficulties, in addition to personal disability

Affective Disorder: a class of mental disorder characterized by a disturbance in mood disorders in which the essential feature is severe disturbance in mood (depression, anxiety, elation, and excitement) accompanied by psychotic symptoms such as delusions, hallucinations, gross impairment in reality testing etc.

Psychosis NOS: a mental disorder characterized by gross impairment in reality testing as evidenced by delusions, hallucinations, markedly incoherent speech or disorganized and agitated behaviour without apparent awareness on the part of the patient, of the incomprehensibility of his behaviour and having difficulty in meeting the ordinary demands of life. When the person does not qualify the diagnostic category specified in Schizophrenia and Affective disorder, he/she will be diagnosed as Psychosis NOS.

Symptomatic : A person during **symptomatic phase** exhibits gross dysfunction in physical, psychological and social functioning:

Physical symptoms: dramatic changes in eating and sleeping habits, bowel and bladder disturbances, sexual disturbances and many unexplained physical problems

Psychological symptoms: Irritability/anger; excessive fear, worry, anxiety and sadness; extreme highs and lows in mood; thought disturbances, confused thinking, delusions, illusions, perceptual abnormalities, memory disturbances, difficulty in concentration and gaining attention, and in judging the situations.

Social symptoms: social withdrawal, difficulty in maintaing personal hygiene, increasing inability to cope with daily problems and activities

Stabilized: The indicators for **stabilization** could be seen at two levels i.e. personal level and family level.

Individual level:
1. Reduction of symptoms to a large extent and this stage is consistent for not less than three months, with or without treatment.
2. Attending to self care, personal hygiene and daily activities
3. Greater understanding of the situation and voluntarily taking the prescribed dose of medication.
4. Regaining the insights, judgment, etc.
5. Showing interest to participate/ to involve in the activities of family and community

6. Beginning to take responsibilities voluntarily and exploring gainful occupations.

Family level:
1. Carer gets relieved of the burden and finds time to engage in her/his own work
2. Increased understanding of the illness and its management results in appropriate support to the affected person.

3.13 Analysis of Data:

The coded data were entered into the computer for analysis though statistical package-SPSS.

SPSS is among the most widely used programs for statistical analysis in social science. It is used by market researchers, health researchers, survey companies, government, education researchers, marketing organizations and others. In addition to statistical analysis, data management (case selection, file reshaping, creating derived data) and data documentation (ametadata dictionary is stored with the data) are features of the base software.

Statistics included in the base software:

- Descriptive statistics: Frequencies and Cross tabulations
- Bi-variate statistics: Means, t-test, ANOVA, Correlation (bi-variate, partial, distances), Nonparametric tests
- Prediction for numerical outcomes: Linear regression
- Prediction for identifying groups: Factor analysis, cluster analysis (two-step, K-means, hierarchical), Discriminant

Analysis of data was done using both qualitative and quantitative techniques. The frequencies were computed for the socio demographic variables of persons with mental illness (PWMI) and their caregivers. The cross tabulation on gender was carried out for the socio demographic variable. The total score of different dimensions of caring was computed and the mean scores were compared between male and female, between symptomatic and stabilized phases, and among different age groups using t test and ANOVA. The correlation matrix was computed for the types of caring. The qualitative data were coded and analyzed and presented along with the quantitative data wherever relevant in the chapter on 'Findings and Discussion.'

4. FINDINGS AND DISCUSSIONS

This section presents the results of quantitative and qualitative analyses of data collected in the present study. The results are presented under five sections:

4.1: Profile of the persons with mental illness

4.2 Family profile

4.3 Profile of the caregiver

4.4.Care giving

4.5 Support to caregivers

4.1 Profile of the Persons with Mental Illness (PWMI)

Table 1: Distribution of PWMI according to sex

Sex	Frequency	Percentage
Male	101	50.2
Female	100	49.8
Total	**201**	**100**

The sample had almost equal number of males and females, which reflect the general pattern in the population. With decline in sex-ratio in India in favor of men, this indicates that the female PWMIs are proportionately higher. This may also be due to severity of illness of the PWMIs in the sample. Women, in general, seem to come for treatment when their illness is severe.

The results also confirm that almost equal number of male and female have mental illness as per the epidemiological studies.

Table 2 : Distribution of PWMI according to age

Age group of PWMI	Male	Female	Total
18 – 20 years	3	7	10
21- 35 years	54	39	93
36 – 50 years	32	35	67
51 years and above	12	19	31
Total	**101**	**100**	**201**

Nearly half of the sample was in the age group of 21 to 35 years and a third of the sample was in the age group of 36 to 50 years. About 15 per cent were over 51 years.

Only five percent were between 18 and 20 years of age. The findings confirm the earlier research finding that mental illness affects the prime earning age, thus diminishing the occupational functioning leading to disability.

Among both male and female PWMIs in the sample, the mental illness seems to be occurring between 21-50 years. Male PWMIs were more in number between 21 and 35 years whereas female PWMIs were more than males in the age groups of 36 - 50 years and 51 years and above showing that the women PWMIs were older. This probably may be due to the prevailing practice that women generally do not come for treatment early or they are not taken for treatment early.

Is this disparity a social issue, in the sense, a gender issue? It can be.

Table 3: Educational qualification: *Distribution of the PWMI according to sex*

Educational qualification	Male	Female	Total
Illiterate	17	41	58
1- 7th standard	41	24	65
8- 10 standard	28	13	41
11- 12th standard	5	6	11
Above 12th standard	4	0	4
Information not available	6	16	22
Total	**101**	**100**	**201**

The above table indicates the prevalence of more number of illiterates among women. Inequality seems to persist even in basic education level. 40% of women are illiterate which is somewhat similar to the figures of the Census of India 2001.

Among PWMIs, about one half have had some school education, about a third were illiterates and a small percentage had studied beyond high school. There is disparity in educational levels of men and women. Majority of women were either illiterates or had schooling up to the elementary level or less. Whereas, majority of the men have had some schooling up to elementary level or beyond. It is interesting to note that at the junior college or higher secondary level the number of men and women were almost equal.

Table 4: Occupation: Distribution of PWMI according to sex

Occupation	Sex		Total
	Male	Female	
Not working	11	2	13
Agriculture	33	27	60
Coolie and labour	24	23	47
Domestic work	1	25	26
Salaried work	3	0	3
Business	5	4	9
Weaving	9	0	9
Student	0	1	1
Others	7	1	8
Not available	8	17	25
Total	101	100	201

The occupations of PWMIs varied. They seem to be mainly engaged in agriculture (farming), labour work and domestic work. A small number were engaged in small businesses and weaving. There seems to be some variations between male and female occupations. Domestic work is dominated by women. Agriculture and weaving seems to be engaged in by men more than women. Both men and women are almost equally engaged in coolie or labour work and small businesses. It is quite striking that among those not working, men are more in number, compared to women. This picture brings out a kind of hierarchy in the occupations and in that of gender disparity.

Table 5: Marital Status: Distribution of the PWMI according to sex

	Sex		
Marital status	Male	Female	Total
Single	34	15	49
Married	54	61	115
Divorced	2	4	6
Deserted	7	9	16
Widowed	1	9	10
Not available	3	2	5
Total	101	100	201

The above table brings out some interesting results:

- Majority of persons with mental illness were married;
- Among those who were single, men were almost double the number of women;

- Among those widowed, women were more in number. This could be because of the tradition of men remarrying;

- Divorce and desertion were seen among both men and women, though women seem to be affected more than men. Cases of husbands deserting their wives could be the triggering factor for the onset of illness for the wife.

It was expressed by the participants of the study that one of the problems they faced was that the persons with mental illness were deserted by their spouses. One of the reasons could be because of the stigma attached. The families did not disclose the fact that their family member was mentally ill to the families of the prospective bride or groom at the time of marriage. The stigma being that mental illness is a family illness and by having a person with mental illness in the family is concomitant with problems; one of them being difficulty in getting other eligible members married.

However, once the family members became aware that it was just an illness that can be treated and when the symptoms of the illness reduced, they sought advice from the psychiatrist about getting their PWMI married and informed the prospective families about the same.

Table 6: Diagnostic categories: Distribution of PWMI according to sex

Diagnostic categories	Male	Female	Total
Schizophrenia	52	41	93
Psychosis NOS	32	21	53
Affective disorder	17	38	55
Total	**101**	**100**	**201**

The diagnostic categories of mental illness identified were schizophrenia, affective disorders, and psychosis. Nearly one half of PWMIs were reported to have schizophrenia, one quarter had affective disorder, and other quarter had psychosis NOS. There appears to be a visible disparity between men and women with more women coming under affective disorder than men. Majority of the people diagnosed with psychosis have schizophrenia symptoms, but do not qualify for the diagnostic criteria. The affective disorder includes, uni-polar depression, dysthymia which could explain why women are high in number.

Table 7: Duration of illness: Distribution of PWMI according to sex

Duration of illness	Male	Female	Total
2 years	6	7	13
More than 2 years and less than 5 years	20	23	43
More than 5 years and less than 10 years	45	48	93
More than 10 years	29	22	51
Data not available	1	0	1
Total	**101**	**100**	**201**

The sample in the present study included only those PWMIs who were in the CMHD programme for two years or more. The data presented shows that a large number of PWMIs have had the illness for more than five years, up to 10 years or even more (about 70%). This indicates that most people who were included in the study were chronic cases of mental illness. Slightly more than one fourth have had the illness for two years, more than two years upto five years. There is hardly any difference between men and women in this regard.

Table 8: Duration of treatment: Distribution of PWMI according to sex

Treatment Duration	Male	Female	Total
2 years	10	13	23
2- 3 years	21	19	40
3- 4 years	22	14	36
More than 4 years	48	54	102
Total	**101**	**100**	**201**

Most of these people had long years of treatment and there is not much gender disparity.

4.2. Family Profile:

Table 9: Type of family: Distribution of PWMI according to sex

Type of family	Sex		Total
	Male	**Female**	
Nuclear	51	59	110
Joint	43	34	77
not available	7	7	14
Total	**101**	**100**	**201**

Majority of the families of PWMIs (more than half) were nuclear. About two fifths of their families were joint families. This is quite substantial in number. Generally, in the villages, even for nuclear families, the other family members maybe available for help, in the same village or in the villages around.

If we look up the census data of India from 1951 onwards, majority of Indians live not in a joint family setting as it was a few decades ago.

It appears from the data that in joint families, occurrence of mental illness seems to be lower because of sharing of responsibilities and hence the possibility of having more number of care givers.

Table 10: Distribution of families of PWMI according to their income

Income	Frequency	Percentage
Less than Rs.1000	76	37.8
1000- 2000 rupees	32	15.9
2001- 3500 rupees	19	9.5
3501 and above	74	36.8
Total	201	100

Almost all the families of the PWMIs in the present study were economically poor. Over one third of the families had less than Rs.1000/- per month. More than one half .of the families had an income less than Rs2000/- per month. Nearly one third of families have monthly income of 3500 rupees and more, as they have multiple earning member in the family, and living in joint families.

Table 11: Distribution of families of PWMI according to the number of earning members in the family

	Frequency	Percentage
Less than two members	149	74.1
More than two members	52	25.9
Total	201	100

This table can be seen in the light of the previous table, which suggests that of the 77 joint families 74 could be earning about Rs.3501 and above per month. The range of number of family members is 4- 16 people in joint families, and they had multiple earning members contributing to family income. This is reflected in Table 10 as well.

Invariably, all families in the sample expressed that poverty was one of the major problems they faced. Families expressed they did not have money for the treatment of the person with mental illness thus they had to either sell their family assets or take loans to meet this expenditure.

Due to illness the changes in the life schedule that were experienced were when care givers had to quit their jobs as someone had to be with the person with mental illness all the time, resulting in losing their daily wages (in case of daily wage earners). They were not able to go to work on time. They were burdened by the decreased income and increased expenditure. One care giver expressed "I don't know how I managed those days, when my son was ill. I was constantly drawing money from one place and used it elsewhere"

However, the caregivers expressed that when the PWMI became less symptomatic, they were less constrained to stay at home to look after the PWMI. They were able to go to work and earn their wages. When the PWMI were in a position to go back to their previous work, or had been provided a loan for animal husbandry or small businesses, they were less burdened economically and socially.

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4.3. Profile of the care givers

Table 12: Distribution of caregivers according to sex

Sex	Frequency	Percentage
Male	95	47.3
Female	106	52.7
Total	**201**	**100.0**

Women care givers were more in number compared to men. Traditionally, within the family women are considered to be more "caring" than men. It is note-worthy there were a large number of male caregivers as well. Maybe, within the family, when men need caring, women are there ad when women need caring, men are there. This implies the strength of the relationships within the family.

Table 13: Distribution of care givers according to age group

Careers age group	Frequency	Percentage
17 – 20 years	2	1.0
21- 35 years	48	23.9
36- 50 years	69	34.3
51 years and above	82	40.8
Total	**201**	**100.0**

Majority of the caregivers (40.8%) were above the age of 51years. This indicates the prevalence of aged caregivers.

The responsibility of care giving seems to be more with the older members in the family than with the younger members. This may be due to the fact that the elders are at home and are given the responsibility of looking after the PWMI. Nearly three fourths of the caregivers were above 36 years upwards, and much beyond 51 years. Only about one fourth were below 35 years, with almost all of them above 21 years. With age and experience, they may be more patient with PWMIs and in a better position to understand them and give the necessary care. At the same time they may need support as they may have less stamina to carry the burden.

Table 14: Distribution of PWMI according to the relationship of primary care giver with the PWMI

Relationship with PWMI	Frequency	Percentage
Father	34	16.9
Mother	47	23.4
Husband	38	18.9
Wife	35	17.4
Offspring	19	9.5
Brothers and Sisters	16	8.0
Others (daughter in law and son in law, grand mother, sister in law, niece)	12	5.9
Total	**201**	**100.0**

The table above indicates that more number of mothers care for their ward who is mentally ill. Almost equal number of fathers, husbands and wives were found to be caring for the PWMI in their family. The table also suggests that about 35% of the men and about 40.7% of the women cared for the PWMI

The data presented bring out that almost all relatives within the family served as care givers – fathers, mothers, husbands, wives, children, siblings, daughters, sons-in-law, grandmother, sisters-in-law and nieces. It appears that whoever was near the PWMI took care of them. This implies the strength of the relationships within the family. Family support comes out clearly which is the very basis of Community Mental Health.

Table 15: Distribution of PWMI according to the duration of care giving

Duration of caring	Frequency	Percentage
2 years	13	6.0
More than 2 years and less than 5 years	53	26.9
More than 5 years and less than 10 years	83	41.3
More than 10 years	51	25.4
Data not available	1	.5
Total	**201**	**100**

Majority of the PWMIs, about 67%, were taken care of by the care givers for more than five years up to ten years or more. Out of these, a large population were given care over ten years which is quite a long duration. Data presented in this table, matches well with the data presented in table 7. (duration of illness of the PWMIs)

Secondary caregivers:

The analysis revealed the presence of one or more secondary care giver for the PWMI. It was interesting to note that the secondary care givers were members of the immediate family or extended family, people from the neighborhood (SHG members, neighborhood shop owner, field staff of the same village, informal leaders and anganwadi workers). This finding brings to the fore the participation of the community in the care of the persons with mental illness. This could be because of the community awareness programme of the CMHD.

4.4.   Care giving

In the interview schedule care giving has been classified into physical, medical, psychological and social.

Physical care:

One of the major symptoms of SMD is deterioration in appearance, hygiene or personal care of the PWMI. This affects their social aspects, as many people would rather alienate themselves from someone who has poor personal hygiene than to tell them how they could improve. Thus the care givers play a major role in assisting them and caring for their personal hygiene so as to minimize the social stigma.

The types of physical care that were included in the questionnaire were, brushing, bathing, combing, helping with nature's call, haircutting, ensuring s/he wears clean clothes and feeding the PWMI.

In addition to these items, the caregivers included feeding nutritious food and also encouraging PWMIs to eat at the right time which focus on the Physical care further.

Medical care:

Psychotropic medications (psychiatric drugs) often are very useful in helping the person with mental illness think more clearly, gain control of his/her own thoughts and actions, and bring his/her emotional state back into a normal range. Psychotropic medications produce both beneficial effects and undesirable effects (side effects). People are highly variable in regard to how much benefit they will get from a drug and the type and severity of the side effects that they will experience.

PWMIs are usually not compliant with medications because of its treatment duration and side effects. This results in them discontinuing their medication which in turn results in relapse of the illness. The care givers have to constantly monitor if the medicines are taken or not, their effects etc.

To recognize the types of medical care that was provided, the schedule included questions on the types of treatment that the care givers provided, bringing them to the camps regularly, if required hospitalization, getting them admitted and staying with them, reminding the PWMI to take medicines, sometimes, giving the medicines themselves,

using tricks to ensure the medicines are taken, noticing side effects, reporting the same to the field staff etc.

Psychological care:

Changes in thinking, perception, mood and behavior are characteristic of SMD. It becomes very important to manage the PWMI when s/he is psychologically, and emotionally disturbed. The items included in the interview schedule regarding psychological care are:

- Treating the person with love and affection
- Being patient, not getting angry
- Not confining them to areas where no one goes, not chaining them
- Engaging them in small tasks,
- Not comparing them with the so called sane person etc.
- Listening to whatever the PWMI has to say.
- Looking after and talking to the PWMI like one would do to a baby

The caregivers in the study added few more items. They are:

- Paying attention to what the person with mental illness has to say;
- Insisting that the person with mental illness keeps him/herself occupied with something;
- Buying the person with mental illness clothes of his/her choice

Social care:

The stigma and discrimination associated with mental illness is huge. This manifests in the forms of denial of illness, harmful treatment, social boycott of the PWMI and the family members, denial of property rights, marriage and legal separations, family members not getting marriage alliance etc.

Caregivers, especially among poor, suffer quite a lot. Care givers are faced with twin challenges - their own livelihood and caring and managing a person with mental illness in the family. Social care is a long drawn process. This starts from acceptance of the PWMI by her/his family first and then by the outside world. This is a process of inclusion.

To know the kinds of social care giving that is provided to the PWMI, the questionnaire sought responses for questions like educating the community about the illness, preventing the community from abusing the PWMI, physically, mentally and sexually, helping in social integration of the PWMI etc, taking the PWMI along with them to functions and celebrations, respecting their property rights, paying due attention to the wish of the PWMI to get married and informing the prospective bride and the family about the illness of the PWMI, encouraging the PWMI to mingle with peers and friends.

The items the caregivers in the study added with reference to social care were:

- Involving the person with mental illness while eating together with the whole family;

- Informing the PWMI about the family issues and help them develop awareness regarding the same

- Helping the PWMI to understand the expenditures involved ;

- Helping in exercising their right to vote.

Table 16: Mean Scores of types of care: Differences in types and dimensions of care during symptomatic and stabilized phases of PWMI

Types of caring	Mean score	Standard deviation	t value	p value
Physical care (symptomatic)	3.9	2.5	8.985	.000***
Physical care (stabilized)	1.54	2.4		
Medical care (symptomatic)	12.91	3.3	10.256	.000***
Medical care (stabilized)	8.65	4.7		
Psychological care (symptomatic)	8.92	4.5	1.654	.100
Psychological care (stabilized)	8.19	4.3		
Social care (symptomatic)	2.26	1.7	-10.862	.000***
Social care (stabilized)	5.0	2.8		

Care of PWMIs were seen in the present study as four different aspects of care giving which are all converging - physical care, medical care, psychological care, social care. Each of these four aspects of care giving were studied in terms of two phases of the lives of PWMIs, namely, the symptomatic and stabilized phase. It could be expected that the load/weight/burden of care giving would get lighter as and when PWMIs show signs of stabilization, which essentially means "inclusion" in mainstream development.

Physical care:

When the PWMI was highly symptomatic, s/he required significant amount of physical and medical care.

When the person was highly symptomatic, s/he is less aware of their physical appearance and personal hygiene. This required the care giver to be alert all the time and watchful of the PWMI. But upon treatment, the PWMI tends to get out of their

symptoms and become aware of their physical self. Thus the physical care that is required when the PWMI is highly symptomatic is much more than when s/he is stabilized.

From the data presented in Table 16, it is evident that the load of care giving gets significantly lighter with reference to physical care of PWMIs as shown by the significant differences of the mean scores during the symptomatic and stabilized phases.

Medical Care:

The same reasoning holds good for the medical care. When the PWMI is symptomatic, s/he requires assistance in taking medicines, or reminders to take them, observing and reporting side effects etc. But, once s/he is stabilized, the amount of care giving reduces, when the PWMI realizes the importance of treatment and takes the responsibility of taking medicines and attending the camps on their own. However, in certain chronic cases, the care giving is seen to continue even when the PWMI is free of symptoms.

Again with reference to medical care, the data presented show that the load of care giving gets significantly lighter as revealed by the significant differences of the mean scores during the symptomatic and stabilized phases.

The qualitative data analysis revealed that the problems faced by the care givers when caring for the PWMI medically were

- Unmanageable symptoms of the person with mental illness.
- Difficulty in bringing them to camps
- Difficulty in giving medicines
- PWMI thinks he is cured
- No money to come to the camps
- Non-availability of medicines on a regular basis
- Not equipped in terms of knowledge/awareness to look after the PWMI

Psychological Care:

With reference to the aspect of psychological care, the difference in mean scores is not significant in the two phases of life of PWMIs studied, indicating that psychological care giving continues even after stabilization. This implies that the emotional support and care need to be continued for PWMIs so that they gain confidence and strength within themselves for some more time after they get well physically.

The qualitative analysis revealed that there were many psychological implications for others within the family. The care givers expressed that there was no understanding of the PWMIs within the family. There were   problems in the PWMI or other eligible family members getting married. There was no one to cook at home if the woman of the family becomes mentally ill. They were unable to cope up with their work at home and in the field.

Social Care:

The aspect of social care of PWMIs is quite complex as it goes beyond the individual mental strength – namely, 'social acceptance' which is "social inclusion"

They are enabled to be accepted by the wider community and to participate in the community activities. The data in the table presented shows that "social inclusion" is a complex and hence a long time process, as it requires a change in the perspectives of the community as a whole. The difference in means of the scores of "social care" during the symptomatic and stabilized phases of PWMIs is negatively significant. This clearly indicates the weight of the social care would increase with the stabilization and continues for a duration not easy discernable. In other words, the activities for enabling social inclusion becomes a reality only when they are stabilized.

Mechanisms of coping up with the burden of care by caregivers

The caregivers expressed that they could overcome their problems giving care to PWMIs by being patient, taking the advice of the field staff, giving medicines regularly and supporting the persons with mental illness in completing their half done jobs. In one case, the mother severed her relationship with her son because she wanted to care for her daughter who was mentally ill. They showed examples of stabilized people with mental illness to create awareness about the fact that this illness is treatable. They discussed issues with friends and neighbours about the illness.

Table 17: Differences in care giving within/ between groups according to diagnostic categories

		Sum of Squares	df	Mean Square	F	Sig.
Physical care symptomatic	Between Groups	6.354	2	3.177	.485	.617
	Within Groups	1297.567	198	6.553		
	Total	1303.920	200			
Physical care in stabilized	Between Groups	10.792	2	5.396	.885	.414
	Within Groups	1207.178	198	6.097		
	Total	1217.970	200			
Medical care – symptomatic	Between Groups	75.005	2	37.502	3.041	.050
	Within Groups	2441.393	198	12.330		
	Total	2516.398	200			
Medical care stabilized	Between Groups	130.208	2	65.104	2.944	.055
	Within Groups	4201.533	190	22.113		
	Total	4331.741	192			

Psychological care Symptomatic	Between Groups	68.302	2	34.151	1.636	.197
	Within Groups	4134.425	198	20.881		
	Total	4202.726	200			
Psychological care – stabilized	Between Groups	1.297	2	.649	.034	.967
	Within Groups	3798.136	198	19.183		
	Total	3799.433	200			
Social care symptomatic	Between Groups	27.749	2	13.874	4.945	.008
	Within Groups	552.731	197	2.806		
	Total	580.480	199			
Social care Stabilized	Between Groups	11.964	2	5.982	.712	.492
	Within Groups	1654.016	197	8.396		
	Total	1665.980	199			

Table 18: Mean scores on various types of care giving: Differences in types and dimensions of care giving in different phases of mental illness according to diagnostic categories.

Types of care	Schizophrenia	Affective disorder	Psychosis
Physical care-symptomatic	3.9 ±2.6	3.7 ± 2.5	4.2 ± 2.4
Physical care – stabilized	1.6 ± 2.4	1.1 ± 2.3	1.7 ± 2.6
Medical care-symptomatic	12.9 ±4.2	13.5 ± 3.2	13.4 ± 2.0
Medical care-stabilized	9.5 ± 4.7	7.6 ± 4.3	8.2 ± 5.0
Psychological care-symptomatic	8.4 ± 4.7	8.8 ± 4.2	9.8 ± 4.5
Psychological care-stabilized	8.1 ±4.4	8.2 ± 4.4	8.2 ± 4.2
Social care-symptomatic	1.8 ± 1.7	2.6 ± 1.6	2.5 ± 1.6
Social care-stabilized	5.2 ± 2.8	4.8 ± 2.9	4.6 ± 2.9

In the three diagnostic categories of mental illness, namely, schizophrenia, affective disorder and psychosis, the differences in the mean scores of various aspects and dimensions of care giving show that with reference to "physical care" during symptomatic phase, the load of care giving is more or less the same for all three illnesses and during the stabilized phase, the weight of care giving got reduced for all the illnesses more or less the same way.

The mean distribution and the f value indicates the statistically significant difference with regard to medical care during symptomatic and stabilized phase among people with

schizophrenia, Affective Disorder and psychosis. This means, when symptomatic, people diagnosed with affective disorder require more medical care than people diagnosed with schizophrenia or psychosis.

Whereas, when stabilized, people diagnosed with schizophrenia require more medical care, as compared to people diagnosed with affective disorder and psychosis.

With reference to "medical care" again, the weight remains more or less the same for the three illnesses during the symptomatic phase and there was reduction of load showing a similar pattern in stabilized phase

With reference to "psychological care" for all the three illnesses the load remained more or less the same during symptomatic and stabilized phases – indicating the need for continued emotional care and support.

With reference to "social care" for all the three illnesses, the load was lower during the symptomatic phase and became higher in the stabilized phase.

It also indicates, people with affective disorder need more social care, during symptomatic phase

Table 19: Differences in types and dimensions of care giving between male and female

	Gender	Mean score/ SD	t test	p value
Physical care-symptomatic	Male Female	4.3 ±2.5 3.6 ± 2.5	2.0	.046**
Physical care – stabilized	Male Female	1.3 ±2.3 1.7 ±2.5	-1.1	.272
Medical care-symptomatic	Male Female	13.3 ±2.7 12.0 ±4.1	2.5	.012**
Medical care-stabilized	Male Female	8.47 ±4.9 8.8 ±4.5	-.544	.587
Psychological care-symptomatic	Male Female	9.0 ±4.6 8.8 ±4.5	3.3	.735
Psychological care-stabilized	Male Female	8.0 ±4.1 8.3 ±4.5	-.50	.615
Social care-symptomatic	Male Female	2.2 ±1.6 2.2 ±1.7	-.187	.852
Social care-stabilized	Male Female	5.3 ±3.3 4.6 ±2.7	1.62	.107

The above table indicates that there is statistically significant difference in care of men and woman during their symptomatic phase both with reference to physical and medical care.

Analyzing the data in terms of differences in mean score of types and dimensions of care giving with reference to sex showed that,

- During the symptomatic phase, both in physical and medical care, there was a significant difference in the care given to male and female PWMIs in favour of men than women. Where as, in stabilized phase, in both these aspects of care, the difference is negligible and not significant. This implies the gender bias in care giving.
- In case of psychological care, the differences in mean scores for men and women are not significant in both phases of illness. Both men and women were cared for equally.
- In case of social care, in symptomatic phase, there is no difference in the mean scores in the care for both men and women. Whereas, in the stabilized phase, there is some difference in the mean scores for men and women though it is not significant. Hence, again, it is in the favour of men.

In short, there is a gender bias in the physical and medical care during symptomatic phase. Psychological care is deeply tied to the physical and medical care. Hence the gender bias should be reflected in the psychological care as well. Non-reflection of the bias in the psychological care may be due to the limitation of the items in the tool used.

Table 20: Differences in care giving within/ between groups according to diagnostic categories.

		Sum of Squares	df	Mean Square	F	Sig.
Physical care symptomatic	Between Groups	11.154	3	3.718	.567	.638
	Within Groups	1292.766	197	6.562		
	Total	1303.920	200			
Physical care in stabilized	Between Groups	50.391	3	16.797	2.834	.039
	Within Groups	1167.579	197	5.927		
	Total	1217.970	200			
Medical care – symptomatic	Between Groups	19.587	3	6.529	.515	.672
	Within Groups	2496.811	197	12.674		
	Total	2516.398	200			
Medical care stabilized	Between Groups	33.641	3	11.214	.493	.687
	Within Groups	4298.100	189	22.741		
	Total	4331.741	192			
Psychological care Symptomatic	Between Groups	36.094	3	12.031	.569	.636
	Within Groups	4166.632	197	21.150		
	Total	4202.726	200			
Psychological care – stabilized	Between Groups	6.882	3	2.294	.119	.949
	Within Groups	3792.551	197	19.252		

	Total	3799.433	200			
Social care symptomatic	Between Groups	3.033	3	1.011	.343	.794
	Within Groups	577.447	196	2.946		
	Total	580.480	199			
Social care Stabilized	Between Groups	33.832	3	11.277	1.354	.258
	Within Groups	1632.148	196	8.327		
	Total	1665.980	199			

Table 21: Differences in types and dimensions of care giving according to age groups.

	18-20 years	21- 35 years	36- 50 years	50 years & above
Physical care-symptomatic	3.2 ± 2.8	4.1± 2.5	4.0 ± 2.5	3.6 ± 2.6
Physical care – stabilized	.8 ± 1.9	1.1 ± 2.1	1.9 ± 2.6	2.2 ±2.8
Medical care-symptomatic	11.9 ± 2.1	12.9 ±3.6	12.4 ± 3.8	12.9 ± 2.9
Medical care-stabilized	9.6 ±4.8	8.2 ± 5.0	8.8 ±4.5	9.2 ± 4.2
Psychological care-symptomatic	10.5 ± 3.1	8.6 ± 4.6	8.9 ± 4.9	9.2 ±3.8
Psychological care- stabilized	8.3 ± 4.7	8.0 ± 4.3	8.2 ± 4.5	8.5 ± 3.9
Social care-symptomatic	2.3 ± 1.2	2.19 ± 1.7	2.42 ±1.7	2.1 ± 1.6
Social care-stabilized	4.0 ± 2.6	5.1 ± 3.1	4.5 ± 2.7	5.5 ± 2.1

The data in the above table indicates that the PWMI in the age group of 18-20 require less physical care as compared to the PWMI in the other age groups. This could also be because of the age and not solely because of the illness

The mean distribution scores of PWMI in the age group of 50 and above are higher than all other age groups for all types of care. This shows that they require more care.

Analysing the data on mean scores of types and dimensions of care giving, according to age groups of PWMIs showed that

- o With reference to physical and medical care, during both symptomatic and stabilization phases, the mean scores of care giving of the four age groups of the PWMIs did not show any significant differences, though there were slight variations

- In case of psychological care, the mean scores of care giving, according to the age groups of PWMIs did not show any significant differences in both symptomatic and stabilized phases of illness.

- In case of social care, again, the mean scores did not differ significantly among different age groups. The scores show a considerable increase in stabilization phase.

In short, the care given to the PWMI was more or less the same irrespective of their age-groups though the care required by the persons with mental illness may vary.

4.5. Support to caregivers

(i) Support given by the partner organization: The families acknowledged the immense support they received from the partner organization. The kind of support they received as expressed by them are:

- Trainings and building the capacities of the caregivers
- Awareness about the illness, its nature, medicines and providing free medicines
- Building confidence in caregivers
- Follow up by field staff
- Getting the person with mental illness involved in previous jobs or some new activity by providing IGP loans.
- Encouraging to join SHG

(ii) Response to support given by partner organization:

Table 22: Attendance of the caregivers in various meetings held by the partner organization:

Number of meetings participated	Frequency	Percentage
0	10	5.0
1	16	8.0
2	35	17.4
3	20	10.0
4	14	6.9
5	20	10.0
6	8	3.9
7	4	2.0
8	24	11.9
9	2	1.0
10	16	8.0
11	1	0.5
12	11	5.5
13	2	1.0
14	4	2.0

15	2	1.0
16	2	1.0
17	1	0.5
18	9	4.4
Total	201	100.0

The above table shows that the number of meetings attended by the caregivers varied. There is a wide range in the number of meetings attended, from not attending any meetings to attending 18 meetings .

(iii) Their expectations from the meetings:

Expectations varied from seeking good health of their mentally ill family member to getting an Income Generation Programme Loan to improve their economic status.

They expressed that they wanted to develop awareness about how to handle the symptomatic person with mental illness and how to ensure regular administration of medicines. They also wanted to seek help in accessing government facilitates like disability certificate and pension.

Though some of them were sceptical about how the meetings would help them, they were curious about what would happen in the meeting and they attended without any specific expectations.

(iii) Learning from the meetings

In their free responses to a question on their own learning caregivers expressed to have learnt a lot from these meetings, which   reflected in their participation and contribution in the programme.

Their expressed learning are classified, summarized and further analyzed in terms of knowledge, attitudes and skills and presented in the following table:

	Knowledge	Attitude	Skill
a) About mental health:			
• How to take care of the health of PWMI	Y		Y
• How to give medicines	Y		Y
• Knowing the reasons for mental illness	Y		
• Side effects and dealing with them	Y		Y
• Identifying other PWMI and sending them to the camps			Y
• How to control mental illness			Y
b) Economic matters			
• Availing government facilities,	Y		Y
• Saving money	Y		Y
• Repaying loans	Y		Y

• The person with mental illness can work and earn like anyone else		Y	
c) Psychological			
• It is necessary to pay attention to the needs and aspirations of the person with mental illness		Y	
• How to advice the person with mental illness	Y		Y
• "There are other people who have problems like I do"		Y	
• Time, discipline, confidence, communication skills and unity (to help the person to maintain daily living skills, help him/her for socialization as they have problems in interpersonal relationships, integrating them in to self help groups, motivating the person to take up productive work	Y	Y	Y
d) Social			
• Non-discrimination of PWMI		Y	
• Building relationships		Y	
• Giving awareness to neighbours and other community members on mental illness			Y
• Giving guidance to other caregivers			Y

The learning were mainly in terms of knowledge and skills related to mental illness and medical care of PWMIs; the knowledge, attitudes and skills regarding the psycho-social care of PWMIs and finally the knowledge and skills needed to improve their economic status.

Their contributions to the Community Mental Health and Development programme are well brought out in terms of Identifying other PWMIs and sending them to the camps, giving guidance to other caregivers, developing awareness regarding the mental illnesses in the community as a whole .These are very important contributions for the mental health of the community.

5. MAJOR FINDINGS

5.1. Profile of PWMIs

- The number of men and women in the study was almost equal.
- <u>Women PWMIs</u> (with mental illnesses of schizophrenia, psychosis and affective disorder ;higher proportion of them with affective disorder, majority suffering for over five years or even 10 years) seemed to be older in age , married, with a higher number widowed , divorced and deserted, educationally backward and engaged in occupations fetching low incomes , as compared to men.
- <u>Men PWMIs</u> (with mental illnesses of schizophrenia, psychosis and affective disorders; a higher proportion of them with schizophrenia and psychosis; majority suffering over five years or even over 10 years) seemed to be younger in age, mostly married and also a considerable number single; educationally better with majority having some school education; and engaged in occupations fetching low incomes and also in skilled occupations such as weaving and a number of them not engaged in any work , as compared to women.

5.2. Family Profile

The families of PWMIs /caregivers ,in general, were nuclear though joint families also formed a substantial proportion. These nuclear families were economically poor with very few earning members and very low incomes.

5.3. Profile of the caregivers

- Women formed slightly higher proportion of caregivers, though the number of PWMIs were almost equal.
- A higher proportion of caregivers, in general, were women, were older in age, were mothers of PWMIs
- It was found that almost all relatives within the family served as caregivers. There were also secondary caregivers who were members of the immediate family of the PWMIs or their extended familiy, people from neighbourhood, shop owners, field staff of the same village, informal leaders and anganwadi workers

5.4. Care-giving

- With reference to **physical care**, the load of care-giving remains more or less the same for all the three major illnesses during the symptomatic phase. The men were cared more than women during this phase whereas the physical care given to PWMIs did not vary with age. Load of care-giving gets significantly lighter with reference to physical care of PWMIs during the stabilized phase irrespective of the sex and age of PWMIs

- With reference to **medical care,** persons with affective disorders required more medical care during symptomatic phase whereas persons with schizophrenia required more medical care during both symptomatic and stabilized phases of illness. The men were cared more than women during symptomatic phase whereas the care-giving did not vary with age during this phase. The load of care-giving gets significantly lighter with reference to medical care during stabilized phase irrespective of the sex or age of the PWMIs

- With reference to **psychological care,** the load of care remained the same for all the three illnesses during both the symptomatic and stabilized phases. The care did not vary with sex or age – indicating the need for continued emotional care and support to PWMIs even after stabilization.

- With reference to **social care,** the load of care was lower during symptomatic phase for persons with schizophrenia and psychosis and the load increased during stabilized phase. The persons with affective disorder needed more social care even during symptomatic phase. The weight of the social care increased with the stabilization. It appears that the activities for enabling social inclusion increased only when they were stabilized and were, in fact, a direct result of the PWMI's stabilisation and ability to re-enter society.

5.5. Difficulties of caregivers

The difficulties faced by the caregivers were :

(a) Poverty, not having money for treatment of PWMIs , resulting in either selling their assets/taking loans to meet the expenditure;

(b) The changes in their life schedules – inability to go to work on time or even to quit their jobs resulting in decreased income and increased expenditure;

(c) Stigma regarding mental illness prevalent in   the community – considering mental illness as a "family Illness" causing difficulties in getting PWMIs or other eligible family members married and married PWMIs being deserted or divorced by their spouses; sometimes relationships within families get affected causing severing of relationships with other offsprings

(d) While giving medical care several difficulties listed showed that

- Difficulties with PWMIs themselves: unmanageable symptoms, administering medicines, bringing them to camps, their illusory thinking that they are cured;
- Difficulties with the families: no money to come to camps, not equipped to look after the PWMIs
- Difficulties with the system of medical care: non-availability of medicines

5.6. Facilities available for caregivers

- The indigenous modes of support available as shown by the study seem to be the multiple caregivers within and outside of the family, and patient care given by the caregivers themselves.

5.7. Support received from the CMHD programme of NGO partners

The kinds of support received were:
- Awareness about the nature of illness and medicines for the same and provision of free medicines;
- Building their capacities in care-giving and thereby their confidence;
- Help provided for improving their economic condition through encouraging the PWMIs to get back to their earlier jobs, taking loans for income generation activities, in becoming members of SHGs (Self Help Groups)

5.8. Major contributions of the caregivers to the project

- Identifying other PWMIs and sending them to camps;
- Gaining support from each other as caregivers;
- Giving guidance to other caregivers;
- Discussing issues with friends and neighbours.

6. IMPLICATIONS OF THE STUDY

6.1. For caregivers of PWMIs /their families /communities

The study brings to the fore, the occurrence of multiple caregivers from within the immediate family, extended family and community members. This indicates the strength of the relationships within families and within communities. Becoming conscious of this strength, perceiving them as strength, is important.

The study showed that

- The caregivers were mostly older and in that they were women and also mothers, who take responsibility for family care in general and hence already have a heavy load and the need to share the burden is imminent maintaining their physical and mental health;
- There are multiple caregivers – primary and secondary or supporting caregivers both within and outside the family (within the community) This implies that the load of care-giving by the caregiver could be shared with others around, taking into account the different dimensions of care, varying abilities of caregivers and the quantum of time they could give.

These two findings can be seen as complementary. Instead of taking it for granted the multiple caregiver phenomenon could be utilized fully if conscious efforts are made to focus on '**sharing the burden of care-giving of PWMIs'** by the primary caregivers.

Some of the issues of importance that are raised by the study deserve all attention of the caregivers, their families and the communities . They are:

- Care-giving of PWMIs is multi-dimensional and not uni-dimensional as it is generally perceived to be. It is not merely medical care.
- Different dimensions of care-giving gain priority in different phases of mental illnesses but care-giving continues.
- Gender as an issue is reflected in the profile of PWMIs/caregivers and also in the physical and medical care given during the symptomatic phases of major mental illnesses.

Multi-dimensional nature of care-giving and the need to give continued care for PWMIs can be quite taxing to the caregivers. Recognition of the complexity of care-giving and seeing them in the light of the strengths described above could be of value in sharing the burden of care-giving of mentally ill persons.

The caregivers, once they become conscious of their contributions to the stabilization of PWMIs , not only in terms of medical care but also in terms of physical, psychological and social care could gain confidence as they feel their own strength within themselves to carry through the burden, which is much more than merely administering medicines. Caregivers' multiple roles are to be recognised by them and also by all the others around them who are concerned with PWMIs and who lend their support to them.

Becoming aware of gender as an issue and its consequences on the development of individuals especially women, but also families and the whole community becomes crucial. Awareness and action on gender issue will surely be operative on the issue of burden resulting in its becoming less burdensome as both the issues are intertwined.

The study indicates that important contributions were made by caregivers to the CMHD programme in identifying PWMI, in giving guidance to caregivers and in developing awareness about mental illness in the community. Thus, they served as resources to the CMHD programme. This is a tremendous step forward. This implies their potential to participate in advocacy programmes beyond the village level. Their services on advocacy would be most valuable as they have with them the experience and the evidence of stabilized PWMI.

6.2. For the Field-staff (of NGO Partners)

The strength of the relationships within the family and in the community is borne out by the present study as caregivers were both men and women as well as several different relatives of PWMIs. This is significant especially for **Community Based Mental Health Programme.** Sustaining this positive aspect is vital for CMHD programme. In any programme organized by the field staff attention to and nurturance of this aspect is key to Community Based Mental Health Programme (CMHD) to take root to become a programme of the people.

- Developing an understanding of the phenomenon of multiple caregivers on the part of the field staff and ensuring the participation of all the primary and supporting caregivers in capacity building programmes are critical for mental health to be taken up as a community programme.

- Contents of caregiver training as brought out by the study (from the learning expressed by the caregivers) appear to focus more on creation of awareness about nature of mental illness, need for taking medicines, provision of free medicines and attention on the psycho-social care of the PWMIs.

- It is not clear whether psycho-social care was given as much attention as it deserved. This blurring of the medical and the psycho-social could be due to the fact that medical care is probably visible and hence measurable whereas the psycho-social dimensions are not easily measured. Observations of crucial inputs by the caregivers and the responses by the PWMIs are critical for understanding this dimension of care.

- Now the study points to the need to develop sensitivity to the nature of care-giving as multi-dimensional, the changing care-giving tasks with different phases of major mental illness. The field staff should develop this sensitivity within themselves and in turn help caregivers gain insights regarding the same and also develop skills in in-depth observations of behaviour of PWMIs.

- Gender issue is brought by the study in profile of PWMIs/caregivers, the stigma attached to mental illness and its influences on the arrangement of marriages of the family members, of desertion and divorces as a consequence of illness by in-laws and spouses. It is of utmost importance for the field staff to

gain insights on gender as an issue in the community in general and its influences on the programme activities and the resulting burden of care-giving as an issue.

- The families of PWMIs are economically very poor and it continues to remain a major issue in the treatment and support of PWMIs, which in turn, affects the caregivers. The approach to Community Mental Health in practice is developmental and hence focus on this is crucial. Livelihood component of CMHD programme striving to improve the economic conditions of the families of PWMIs requires further strengthening. Field staff are already familiar with these. Opportunities for them to look critically at their own experiences may take them further.

6.3. For NGO Partners /BNI

- Major findings of the study should be critically looked at by the NGO partners and BNI to identify areas of vital importance for further strengthening CMHD programme by focusing on these areas. (These areas have been presented in the implications of the study for field staff of NGO partners).
- It is meaningful to review the capacity building programme, especially of the caregivers, with attention to inclusion of all supporting caregivers.
- It is important to help the field staff to develop the critical skill of observation of caregivers' inputs in the psychological and social dimensions of care giving and the responses of the PWMIs for the same.
- It is also necessary to take a re-look at the CMHD programme, keeping the perspective of care-giving in the place of the perspective of the PWMIs.

7. RECOMMENDATIONS

It is recommended that

7.1. The study findings and implications be presented to the caregivers, field staff and NGO partners of BNI who participated in the study;

7.2. The study findings and their implications to be presented to caregivers, field staff and NGO partners of BNI who did not participate in the study with a view to elicit their responses to the study findings and their implications in the light of their own experiences in care-giving.

7.3. These presentations be made in forms that are appealing, stimulating and educative to the caregivers and the field staff. Attention to the forms is a necessary pre-requisite.

7.4. The capacity building module for caregivers be reviewed bringing to focus the strengths of the families and the caregivers and the issues related to multi-dimensional nature of care-giving with gender and poverty as issues of importance , all in the light of the responses of caregivers and field staff to the study presentations.

7.5. The process of capacity building to ensure developing awareness in the caregivers of their own strengths and also the issues that affect the quality of care-giving.

7.6. The services of the caregivers be effectively utilized in advocacy programmes of CMHD.

7.7 Along with the primary caregivers all the supporting caregivers be included in the capacity building programmes, probably through various avenues of reaching them – meetings, home visits, awareness programmes, visuals, audios etc.,

7.8. The research component of CMHD be of service to caregivers and field staff through its focus on life stories of caregivers, which very well could be the base material for developing awareness of their own roles, their strengths as well as the issues they faced.

7.9. The findings and insights of the study be disseminated to all those who are concerned with the quality of care given to PWMIs.

8. FUTURE RESEARCH

Life stories of caregivers could be of value in understanding care-giving In depth.

Factors that contribute to the strength of the relationships within the family and within the community – what keeps the relatives binding to take up the responsibility of care-giving to PWMIs – Is it cultural, religious, social or anything else ?

Factors influencing several different relatives taking up the role of the Caregivers

Phenomenon of multiple-caregivers – specific contributions of primary and supporting (secondary) caregivers of PWMIs; in depth studies on time and tasks of primary and supporting caregivers; of women and men caregivers

Gender differentials in treatment and care of PWMIs

Influences of social care on psychological care of PWMIs

Purposes served by the meetings as a means of training the caregivers

Load of care-giving in relation to livelihood programmes

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ANNEXURES

Annexure 1

Interview Schedule: Carers and their roles

PWMI: Personal details

Name	
Age	
Sex	M / F
Qualification (Educational) Special skills (if any)	
Occupation	
Income	
No. of earning members in the family	
Marital status	Single/married/Divorced/ Deserted/ Widowed
Type of family	Nuclear/joint
No. of people in the family	
No. of years of illness	
No. of children if any	
Type of illness diagnosed	
Duration of treatment	
How long was it highly symptomatic	
How long was it moderately symptomatic	
Since how many years/months has s/he stabilized?	

Carer(s): Personal Details

Name	
Age	
Sex	M/F
Marital status	Single/ Married / Divorced / Deserted / Widowed
Educational Qualification	
Occupation	
Relationship with the person with mental illness	
No. of years they have been caring	
Changes in life schedule if any	
Time spent on caring/day *	

Others (Who are all the other people who helped the carer in taking care of PWMI)

Sl no	Name	Age	Sex M/F	Occupation	Who they are	Description	Approximate time spent *

* Time spent could be specified in terms of total number of days/weeks/months during the course of the entire period of illness

Physical care

Type of care	Highly symptomatic		Stabilized		Not applicable
	Y	N	Y	N	
Brushing					
Bathing					
Combing the hair					
Helping with nature's call and cleaning afterwards					
Cutting the person with mental illness 's hair.					
Ensuring s/he wears clean clothes					
Feeding the person with mental illness					
Any other (specify)					
Remarks					

Psychological care:

Type of care	Highly symptomatic		Stabilized		Not applicable
	Y	N	Y	N	
Treating the person with love and affection 1. Caressing the person whenever the person is restless					
2. Listening to the person when s/he speaks					
3. Speaking to the person as and when physical care is given (as one would speak to the child)					
4. Comforting the person when upset					
5. With whatever the person does, being patient, not getting irritated or angry					
6. When others mocks at the person, chasing them away					
7. Confining the person where no one goes (isolating the person)					
8. Chaining/ tying the person with a rope					
9. Allowing the relatives or others who are nice to the person to come, be with the person and speak to the person					

10. Sleeping by their side, waking up to attend to the needs of the person					
11. To engage in activities from small tasks to big tasks					
12. Comparing the person with the other "so called sane people"					
13. Listening to the person with mental illness what work he wants to do and if feasible, encouraging him/her to do it.					
14. Engaging the person with mental illness in household work, decision-making and communication					
15. How much time they spent on other things once they are less symptomatic					
Any other (specify)					
Remarks					

Medical care:

Type of care	Highly symptomatic		Stabilized		Not applicable
	Y	N	Y	N	
Taking the person to faith healers, temples, churches, black magicians, etc.					
Following the instructions given by the above people religiously					
Motivating the person with mental illness to undergo treatment and spending money on the same.					
Bringing the person to the camps regularly					
If hospitalization is required, then being with the person with mental illness in the hospital and meeting his needs.					
Reminding the person to take medication					
Carers administering the medicines themselves to the person with mental illness					
Coming up with tricks, like mixing it with ragi balls, to ensure medicine intake					
Motivating the person with mental illness to take medicines					
Checking whether the medicines are taken or not					
Observing the changes					
Observing and understanding the side effects of medicines on the person					

Once the medicines are over, making sure that they bring it to the notice of the field staff and procure more medicines.					
Being supportive by letting the person oversleep and take rest.					
Helping the person with mental illness to overcome side effects by providing adequate food intake, liquid consumption etc.					
Observing keenly all this and making it a point to bring it to the notice of the field staff.					
Raise doubts and learn more regarding the illness, side effects etc					
Any other (specify)					
Remarks					

Social care (Family and community):

Type of care	Highly symptomatic		Stabilized		Not applicable
	Y	N	Y	N	
Making the community understand that his/ her behavior is only due to illness and nothing else					
Preventing the community from abusing the person with mental illness, physically, mentally and sexually.					
Telling the prospective spouse and their family about the illness of the person					
Taking the PWMI to the temples for praying					
Taking the person to religious and social functions of only close relatives					
Taking the person to all religious and social functions the family attends.					
Encouraging the person with mental illness to mingle and interact with friends.					
Safeguarding the property rights of person with mental illness.					
Honoring/ helping fulfill the wish of the person with mental illness to get married and lead a normal life, not compromising mutual interests					
Participating in SHG activities					

Any other (specify)	
Remarks	

Problems faced by the carers

How have they overcome those problems

Support given by organization staff for better caring.

Carers as Resources:
For the duration of your care of PWMI

Total number of meetings held:	
Total number of meetings attended:	

Participation in the meetings:

Spoke when asked for	Highly symptomatic		Stabilized		Not applicable
	Y	N	Y	N	
Reported on the condition of the person with mental illness (Progress/ relapse)					
Shared difficulties faced and how it was handled/ not handled					
Shared one's own experiences and ideas, useful to others					
Helped in identifying PWMI in the area and referring them for treatment					
Remarks					

Expectation from the meetings

Learning from the meetings

Annexure – 2 : Internal Validity and reliability between dimensions and types of care **Correlations**

		Total score on physical care in symptomatic	Total score on physical care in stabilized	Total score on psychological care - symptomatic	Total score on psychological care - stabilized	Total score- medical care- symptomatic	Total score medical care -stabilized	Total score -social care stab	Total score Social care - symptomatic
Total score on physical care in symptomatic	Pearson Correlation Sig. (2-tailed) N								
Total score on physical care in stabilized	Pearson Correlation Sig. (2-tailed) N	-.178(*) .011 201							
Total score on psychological care - symptomatic	Pearson Correlation Sig. (2-tailed) N	.241(**) .001 201	-.019 .787 201						
Total score on psychological care – stabilized	Pearson Correlation Sig. (2-tailed) N	.004 .956 201	.249(**) .000 201	.032 .657 201					
Total score- medical care symptomatic	Pearson Correlation Sig. (2-tailed) N	.293(**) .000 201	-.174(*) .013 201	.389(**) .000 201	.177(*) .012 201				
Total score medical care- stabilized	Pearson Correlation Sig. (2-tailed) N	.002 .983 201	.135 .062 201	-.198(**) .006 201	.432(**) .000 201	.026 .715 201			
Total score -social care stabilized	Pearson Correlation Sig. (2-tailed) N	.171(*) .016 201	-.051 .477 201	-.222(**) .002 201	.389(**) .000 201	.192(**) .007 201	.478(**) .000 201		
total score Social care symptomatic	Pearson Correlation Sig. (2-tailed) N	.105 .137 201	-.004 .955 201	.409(**) .000 201	.003 .966 201	.257(**) .000 200	-.098 .175 201	-.139 .051 201	

* Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).

Annexure 3

BasicNeeds India

BasicNeeds India Trust grew out of the belief that the rights of people who experience mental illnesses, especially those who are poor, must be addressed not only at an individual level, but also in the context of a wider world. BasicNeeds engages people with mental illnesses and their carers in processes that are mutually enhancing. All people involved in care and rehabilitation work learn, grow and are strengthened together. BasicNeeds addresses both people's mental health concerns and situations of poverty to ensure sustainable recovery.

The underlying conviction is that mental health issues must be seen not only in medical terms but just as importantly, as human rights issues.

BasicNeeds' main role is that of creating a caring, accommodating and understanding environment to ensure fair treatment of people with mental illnesses. Such an effort involves liaising with and including a host of people: people affected by mental illnesses, family members and other carers, community members, medical professionals, policy makers and government officials.

Vision

BasicNeeds seeks to satisfy the essential needs of all people with mental illnesses in India and to ensure that their basic rights are respected and fulfilled.

Process

The basis of all work is listening to affected people and involving them right from the very beginning in planning how situations may be handled. People's voices play a crucial role in a dialogue that shapes development processes.

The first step involves identifying community-based organisations (CBOs) and non-governmental organisations (NGOs) who are willing to include the needs of people with mental illnesses in their ongoing developmental work. Basic Needs works with such partner groups, dialoguing with their staff and facilitating appropriate orientation and capacity building processes.

Coverage

BasicNeeds India works with partner organisations in parts of 38 districts rural Tamil Nadu, Karnataka, Andhra Pradesh, Orrisa, Jharkhand and Bihar.

MENTAL HEALTH AND DEVELOPMENT MODEL

Community Mental Health

The purpose of this module is to assist individuals with mental illnesses in experiencing and acting upon their full potential as human beings in their own communities. With the assistance of professionals and BasicNeeds India staff, partner organisations receive training to design and implement care programmes in the community. People with mental illnesses attend camps to receive treatment. Community-based follow up processes are set up. These include individual home visits and group meetings. Local doctors are trained in basic psychiatry so that nearby services are available. Self Help Groups comprising people with mental illnesses and carers are formed.

Capacity Building

BasicNeeds India builds capabilities among a range of people: people with mental illnesses, family members, carers, BasicNeeds India staff members, staff members of CBOs and NGOs and psychiatric professionals, to adequately address mental health issues in various spheres. BasicNeeds India works continuously with CBOs and NGOs as a partner. Staff members of organisations are trained in animation techniques, process reporting, participatory evaluation, and basic research which involves information gathering. The training equips them with skills to bring affected people together and to address issues both within and outside communities. The focus is on community development by working with people with mental illnesses and their carers, recognising that such people are discriminated against and marginalised.

Sustainable Livelihoods

BasicNeeds believes that poverty is both an outcome and root of mental illnesses. Thus, involving people with mental illnesses and family members in economically viable activities is a crucial step. The programme addresses the central issues of sustainable livelihoods and poverty alleviation. BasicNeeds has developed an approach that builds the confidence of people with mental illnesses and addresses their treatment needs so as to permit them to engage fully in economic activities. Ensuring gainful occupation is an essential part of a process that enhances confidence and facilitates integration into the family, community and society. Economic development programmes suitable for the individual and family members are designed. CBOs and NGOs are trained in identifying local resources and economic opportunities. People with mental illnesses form their own savings and credit groups or join other such existing groups in the community. Necessary links are made with micro finance organisations and with locally based employment schemes run by the Government.

Research and Advocacy

Life stories and other relevant empirical data are documented. These provide the basis for significant insights that influence the programme and are shared with other organisations. Partner organisations track changes in individuals. Factors influencing changes are recorded and made use of for people's benefit. Advocacy work involves ensuring the implementation of existing government policies, influencing formation of new policies and enabling people to directly access government facilities.

Administration and Management

A Board of Trustees comprising individuals who offer their services voluntarily as custodians of the ethos of the organisation governs BasicNeeds India. Partner organisations are assisted in the areas of project management that includes finance, monitoring, evaluation and reporting.