

**Report**

*Of the Research Study*  
**“Rehabilitation of  
Female Mentally ill Patients”**

*Implemented by:*

**SEVAC**

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**National Commission for Women**  
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## Preface

The scientific researches have already brought revolutionary changes in the field of neuroscience. Psychiatry and psychosocial science have expanded in each of its sub-sphere and have given exciting results. Scientific progress has evolved the diagnostic and therapeutic capabilities of psychiatry all over the world and India has not been an exception. But the interest in rehabilitation waxed and waned in our country over the last several decades although there is a widespread agreement that it plays a very important role in comprehensive treatment of mentally ill patients. As a consequence the people suffering from mental illness are the worst suffering ailing folks in our country. Other than psychopharmacological intervention no significant rehabilitation programme has been undertaken either by the Central Government or State Governments. The attempts made in the private sector are also not enough to address the rehabilitative needs of these poor souls.

Since gender bias is omnipresent in Indian society, the women folks suffering from mental illness are often stigmatized in varied ways. But scientific research on the needs for rehabilitation of female mentally ill people in our population is negligible. So it is a dire social need for exploring avenues in order to facilitate the rehabilitation of the women suffering from mental illness. Hence with the generous support of the National Commission for Women (NCW) SEVAC conducted a research study on '*Rehabilitation of female mentally ill patients*'.

The objectives of this study were to assess the actual living condition of the female mental patients, their acceptance within the society and family as well as their treatment compliance in order to identify the basic needs of their rehabilitation.

In the present report, *Section I* deals with the Introduction along with the background of the topic covered under the research study. The aims and objectives, design and methodology including survey and sampling techniques are discussed in this section. The tools along with their proper description are also included here. In *Section II*, the empirical information are arranged into grouped data and then statistically analyzed. *Section III* deals with the summary of the statistical findings and observations as well as relevant Discussions and Recommendations by the team. The annexure/ appendices along with the information schedule and the case histories, original scales

are incorporated in **Section IV**. Here the essence of the experience that our team gathered during the implementation of this study has also been briefly highlighted. Lastly the bibliography and relevant references are added to this section.

Now we would like to take the opportunity to convey our heartfelt gratitude to the **National Commission for Women** for supporting the research project and **W.B. Commission for Women** for extending the moral support to SEVAC team. We also convey our thanks to the **Director of Health Service Authorities** of the **State Government Hospitals** for providing us the addresses of our target group i.e. the female patients discharged from these institutions. We thank all the **staff of the SEVAC team** who enthusiastically supported for proper running of the study. Our target group i.e. the **patients covered under the research study**, who willingly provided the necessary data without any hesitation, deserve special gratitude.

18 th May, 2006

Dr. Prativa Sengupta  
Coordinator of the Study Team

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## **Section I**

### **Introduction**

In a country like ours mentally ill patients are one of the most vulnerable ailing folks from the perspective of human rights because human dignity is absent in their living condition. Due to disease process their activities of daily life, self care, social and familial functioning are too much constricted. So most of them need continuous support in varied forms just to lead a meaningful life.

As per available information, 1% –2 % of the country's population suffers from Major Mental Disorders while 8%-10 % of the total population needs regular psychiatric care. But due to the inadequate infrastructure, only 10 % of these suffering souls have got any access to the existing mental health care delivery system and the rest of the patients simply go waste without having any treatment and care and live in a subhuman condition.

If we take stock of the accessibility of the acute mental patients to the institutional care in West Bengal we find that as per paper arrangements around 1100 beds have been earmarked in different government hospitals for the treatment of the mental patients. Again, around 300 beds are there in different Psychiatric Nursing Homes and NGO run Psychiatric Hospitals. It is needless to mention that due to the exorbitant expenses it is impossible for the patients coming from the economically disadvantaged sections to get admitted to the Psychiatric Nursing Homes. Similarly, the capacity of the NGO run psychiatric hospitals is too meager to cater to the needs of all the acute mental patients who seek immediate institutional care. So the mental patients in general depend on the government hospitals for receiving institutionalized treatment.

Record shows that the scope of admission of the mental patients in the Medical Colleges and District Hospitals in West Bengal is almost nonexistent due to multifarious reasons. As a consequence, only a few government psychiatric hospitals in West Bengal like Calcutta Pavlov Mental Hospital, Lumbini Park Mental Hospital, Beharampur District Mental Hospital can offer institutional treatment to the mental patients. Generally, no admission is possible to these hospitals directly from these hospitals' Outpatients' Department. 'Order' either of the Health Department or of the Learned Court is required for the admission of the patients to these

institutions. Hence, it is evident that some helpless caregivers of acute mental patients find no other alternative but to keep the acute mental patients under lock and key, restrain them with the rope or chain.

It is an open secret that the living condition in the indoor of the aforementioned government psychiatric hospitals is so deplorable that it violates the basic human rights of the patients almost in every step. Physical torture and lack of human care are the indispensable parts of the system. Even some female patients are kept stark naked, either due to the apprehension that they may commit suicide using their garments or on the plea that the patients themselves tear off their garments.

Since a majority of the mental patients, who are admitted to the government hospitals, come from the economically disadvantaged sections, their basic needs are neglected and basic rights are violated in every sphere of life, even after their discharge from the hospitals. Their willingness to integrate themselves within the family as also into the society goes futile because of stigmatization of mental illness as well as the disability arising from their illness. Sometimes financial constraints in respect of extending necessary care to these patients also lead them to utter neglect. Since there is no rehabilitative infrastructure in our country for assisting the helpless caregivers to facilitate the societal bonding of these patients, treatment outcome of these helpless souls obviously becomes very poor. As a result, gradually, they become completely disabled with a loss of productivity. Ultimately they become a burden not only upon their respective families but also upon the society in general. So it is a common social tendency to do away with these unfortunate souls from the mainstream of life rendering them to wander in the streets being branded as 'Wandering Lunatics'.

The misery goes beyond the extreme while assessing the condition of the female mentally ill patients who are the most neglected and stigmatized in the society. The gender role for female is entrusted with high expectations of duties towards family, especially husband and children. The women who fail to keep in such a demanding role are considered incompetent and inconsonant to the family and the society. Although they have been deinstitutionalized from the respective hospitals for living in community settings, yet they are far from being integrated into their families. This is because the environments in which they live play a crucial role on the process of

their integration in the society. A relationship is developed between the patient and the society or group where she is placed during the integration process. Hence social integration and perceived social support are the indicators for assessing their quality of life. The process of integration for female mentally ill patients goes futile as they cannot pass through the complex interaction needed for social integration due to the lack of support either from the family or community at large. As a result, the societal burden of the mental illness reaches a significant proportion. Here it needs mentioning that using *Disability Adjusted Life Years (DALY)* which measures the severity, chronicity and burden of a disease, researchers have pointed out that Schizophrenia and Bipolar Disorder are among the top five causes of disability for the 15-44 year old female population. (WHO Report 2001).

Apart from integration, rehabilitation in terms of medical, occupational, social, familial and other areas of life has never been given due importance in our country. In India, there is also no suitable, cost effective, easily replicable model of psychiatric rehabilitation for people who are mentally ill, mainly because of poverty, unemployment, negative social attitude towards mental illnesses and extreme geographic disparities in the distribution of manpower and facilities (Nagaswami 1990).

In this context it is noteworthy that compliance is a crucial determinant of the treatment outcome of any psychiatric condition. Poor treatment compliance may affect the therapeutic alliance; create skepticism in both therapist and patient; create resistance; worsen the disease or the prognosis; increase health care costs; grossly affect the mental health wellbeing of the said group. Hence, rehabilitation and integration succeed when such therapeutic compliance is guaranteed.

Hence, a holistic approach including **government** and **non-government organization** collaboration for forming a community support program may be considered the best solution in addressing their needs. As a matter of fact, organizing such tasks is a huge endeavor. An evaluation is necessary by mental health professionals and health care delivery workers to throw light on the quality of life, living status and needs assessment of the mentally ill patients.

Precisely, the aforementioned reality prompted the SEVAC team to undertake the current research study. This study aims at taking a look at the overall condition of the mentally ill female patients

released from mental hospitals in West Bengal and to analyze their needs into categorical constructs. Thus it intends to motivate the appropriate authorities in respect of building an infrastructure to rehabilitate this unfortunate section of the population in a meaningful manner. We are confident that the outcomes of this research study would provide a valuable resource to the mental health workers in India.

## **Aims and Objectives**

**The aim of the research study was to assess the specific needs in respect of facilitating rehabilitation of the mental patients who have been restored into their families following their discharge from the government mental hospitals situated in Kolkata.**

Keeping this objective in view, the Research Team emphasized on the following domains in order to track the basic rehabilitative needs of the mentally ill female patients, released from mental hospitals namely,

- i. Living Status**
- ii. Social Integration**
- iii. Treatment Compliance**

## **Materials and Methods**

The *SEVAC* team conducted the study in and around Kolkata for a time period of 3 months (December 2005 to March 2006) supported by the “*National Commission for Women*”. The *SEVAC* team gathered the data from patients released in the past three years from Government Mental Hospitals (viz. Calcutta Pavlov Mental Hospital and Lumbini Park Mental Hospital. A total number of 100 cases were approached).

### **Design of the Study**

- Forming a general idea about the targeted sample living in and around Kolkata.
- Developing an idea about the targeted sample, in terms of their case histories as well as to construct the variables, in line with the three domains chosen.
- Constructing the following variables:

- A. Sociodemographic variables
- B. Living status variables
- C. Social integration variables

A. Sociodemographic Variables included:

1. Age
2. Education Level
3. Occupation
4. Monthly Family Income

B. Living Status Variables included:

1. Marital Status
2. Residing Status
3. Type of Family Living with
4. Mental Status Examination (MSE) Report Summary
5. Brief Psychiatric Rating Scales (BPRS) Scores
6. Quality of Life Scores

C. Social Integration Variables included:

1. Multidimensional Scale of Perceived Social Support (MSPSS) Total Scores
  2. Multidimensional Scale of Perceived Social Support (MSPSS) Significant Other Subscale Scores
  3. Multidimensional Scale of Perceived Social Support (MSPSS) Family Subscale Scores
  4. Multidimensional Scale of Perceived Social Support (MSPSS) Friends Subscale Scores.
  5. Relationship with Caregiver
  6. Acceptance by family as perceived by the patient.
  7. Cohesion between family members as perceived by the patient.
  8. Cohesion between patient and family members as perceived by the SEVAC team.
- Administering the tools or tests to the sample.

- Developing a strategy for categorizing the sample according to the needs and the outcomes of the data collected.

### **Categorization of the Samples**

The samples investigated were hypothetically categorized into 4 groups:

#### **Group I**

This group consists of women who lack all the three domains of normal functioning and therefore the needs for Living Status, Social Integration and Treatment Compliance are reflected.

#### **Group II**

This group consists of women whose Living Status can be said to be adequate reflecting the needs for Social Integration and Treatment Compliance.

#### **Group III**

This group consists of women whose Living Status and Social Integration can be said to be adequate reflecting only the need for Treatment Compliance

#### **Group IV**

This group consists of women who are adequate on the three domains of Living Status, Social Integration and Treatment Compliance. This group would serve to exemplify the heights to which proper rehabilitation can serve to bring up the level of normal functioning of mentally ill patients.

### **Tools Used**

A number of tools were chosen, keeping in view our set aims and objectives which included:

- **Information Schedule (attached in Appendix) developed by SEVAC Team members.**
- **Mental Status Examination questionnaire (attached in Appendix)**
- **Brief Psychiatric Rating Scale developed by Overall & Gorham, 1962**
- **Multidimensional Scale of Perceived Social Support developed by Zimet et al., 1988 (adapted from Journal of Personality Assessment, 1988, 52, 30-41).**
- **Quality of Life questionnaire developed by Burckhardt and Anderson, 2003 (adapted from Health and Quality of Life Outcomes, 2003, 1: 60).**

## Description of the Tools

### Information Schedule:

Brief descriptions of the groups of variables in the information schedule are discussed below:

- Sociodemographic History
- Mental Health Status and Treatment:
  - Treatment History
  - Diagnosis
  - Compliance
  - Follow Up to
- Family type
- Family cohesion and adjustments:
- Certain variables like
  - 1) the acceptance of the mentally ill subjects by their family members,
  - 2) relationship of the patient with caregiver,
  - 3) cohesion among the family members as perceived by the patient,
  - 4) cohesion between patient and family members as perceived by the SEVAC team,
 were scaled on a 7 point scale ranging from extremely good to extremely bad.

The scale for **acceptance by family** was scaled as:

1. Extremely accepting 2=Moderately accepting 3=Slightly accepting 4= indifferent 5=Slightly rejecting 6=Moderately rejecting 7=Extremely rejecting

The **scale for relationship with caregiver** was scaled as:

1=Extremely good 2=Moderately good 3=Cordial 4=Indifferent 5=Not cordial 6=Moderately cordial 7=Extremely cordial

The scale for **cohesion among family members and between patient and family members** was scaled as follows:

1=Extremely cohesive 2=Moderately cohesive 3=Slightly cohesive 4=Indifferent 5=Slightly non-cohesive 6=Moderately non-cohesive 7=Extremely non-cohesive

Certain variables like the acceptance by family, relationship with caregiver, cohesion between family members as perceived by the patient, cohesion between patient and family members as perceived by the SEVAC team, were scaled on a 7 point scale ranging from extremely good to extremely bad.

The scale for **acceptance by family** was scaled as:

1=Extremely accepting 2=Moderately accepting 3=Slightly accepting 4=Indifferent

5=Slightly rejecting 6=Moderately rejecting 7=Extremely rejecting

The **scale for relationship with caregiver** was scaled as:

1=Extremely good 2=Moderately good 3=Cordial 4=Indifferent 5=Not cordial

6=Moderately cordial 7=Extremely cordial

The scale for **cohesion between family members and between patient and family members** was scaled as follows:

1=Extremely cohesive 2=Moderately cohesive 3=Slightly cohesive 4=Indifferent

5=Slightly non-cohesive 6=Moderately non-cohesive 7=Extremely non-cohesive

If the patients were not found to be present at the residence temporarily for some reasons like going to work, follow-up treatment, they were contacted again.

Please refer to the *Appendix* for further details of the Information Schedule.

### **Mental Status Examination**

The standard pattern of MSE questionnaire was followed according to “*Comprehensive Textbook of Psychiatry*” by Kaplan and Saddock, 8th Edition. Please refer to the Appendix for further details of the questionnaire.

- ***Procedure for Summarizing the MSE Report***

For the purpose of the present study, the MSE reports were summarized into 4 categories depending upon certain features in the patients as assessed by the SEVAC team. These four categories devised were:

1. **Improved:** Those patients who were functioning perfectly at the normal level, and were engaged in work, were employed and were contributing productively to their own family and society at large.
2. **Stable (But not improved):** Those patients who were found to be normally functioning but not able to function as responsible and productive individuals. They were capable of taking care of them, had intact reality perception and insight into their previous illness, and found to be in groomed condition, capable of sustaining their own personal hygiene.
3. **Unstable:** Those patients who were not capable of taking care of themselves, being ungroomed since they were not able to sustain their personal hygiene, were dependent on caregiver for their sustenance, had disturbed sense of self, reality contact, and insight into own illness and were en route to relapse of their disorder.
4. **Deteriorated (Relapsed):** Those patients found in totally disheveled condition, with total relapse of their disorder.

#### **Brief Psychiatric Rating Scale (developed by Overall & Gorham, 1962)**

The Brief Psychiatric Rating Scale (BPRS; Overall & Gorham, 1962) is one of the most frequently used instruments for evaluating psychopathology in patients with mental illness especially schizophrenia. Its psychometric properties in terms of reliability, validity and sensitivity have been extensively examined.

As with the BPRS, the following scores can be given:

1. **Normal, not at all ill;**
2. **Borderline mentally ill;**
3. **Mildly ill;**
4. **Moderately ill;**
5. **Markedly ill;**
6. **Severely ill;**
7. **Most extremely ill patients.**

BPRS is an 18-item scale, each rated on a 7 point scale of severity, ranging from “Not Present” to “Extremely Severe”. If a specific symptom is not rated, it is marked “0” = Not Assessed. The score for the description, which best describes the patient’s condition is entered.

0=Not Assessed, 1=Not Present, 2=Very Mild, 3=Mild, 4=Moderate, 5=Moderately Severe, 6=Severe, 7=Extremely Severe

### **Interpretation**

The clinical implications of the BPRS scores provide an insight into how severe is the psychiatric illness as well as the subset of the psychiatric symptoms that are predominant.

The Clinical Global Impression scale (CGI; Guy, 1976), another frequently used instrument, is to some extent more informative in regard to overall clinical state (Nierenberg & DeCecco, 2002). The CGI corresponding to BPRS have been widely accepted as to how severe is the mental illness as well as differentiating it into mild, moderate, severely ill categories. (*Kane et al The British Journal of Psychiatry (2005) 187: 366-371*):

### **According to the study**

- **‘Mildly ill’ according to the CGI approximately corresponded to a BPRS total score of 31;**
- **‘Moderately ill’ to a BPRS score of 41;**
- **‘Markedly ill’ to a BPRS score of 53;**
- **‘Severely ill’ (CGI–S score 6) corresponded to BPRS scores of 65;**
- **‘Extremely ill’ (CGI–S score 7) corresponded to BPRS scores of 88.**

According to these guidelines for scoring and interpretation of the scores, the scores obtained by the patients were scored and interpreted.

The other details are summarized in the Appendix

### **Multidimensional Scale of Perceived Social Support (MSPSS) (1988)**

Developed by Gregory D. Zimet, Department of Pediatrics, Case Western Reserve University School of Medicine & Nancy W. Dahlem, Sara G. Zimet and Gordon K. Farley, Department of Psychiatry, University of Colorado Health Sciences Center.

(Adapted from *Journal of Personality Assessment*, 1988, 52(1), 30—41).

#### **Introduction**

The Multidimensional Scale of Perceived Social Support (MSPSS) is designed to assess perceptions of social support adequacy from three specific sources: family, friends and significant other. It is a self-explanatory, simple to use, and time-conserving instrument which make it a favorable and ideal research instrument for use when subject time is limited and/or a number of measures are being administered at the same time. Research has demonstrated that MSPSS has a good internal and test-retest reliability as well as moderate construct validity.

#### **Description of the Scale**

The MSPSS consists of 12 items with the responses given as a 7 point scale from 1 meaning “Very Strongly Disagree” to 7 meaning “Very Strongly Agree”.

The 12 items assess the three sources of perceived social support: family, friends and significant other. Each subscale consists of 4 items each.

The significant other subscale consists of item #1,2,5 and 10.

The family subscale consists of item # 3,4, 8 and 11.

The friends subscale consists of item # 6,7,9 and 12.

#### **Development of Norms: reliability and validity**

The standardization sample included 136 females and 139 male university undergraduates, age ranging from 17—22 years.

The mean and standard deviations for the three MSPSS subscales and total scale were found to be:

<b>MSPSS Subscales</b>	<b>Mean</b>	<b>Standard Deviation</b>
<b>Significant Other</b>	<b>5.74</b>	<b>1.25</b>
<b>Family</b>	<b>5.80</b>	<b>1.12</b>
<b>Friends</b>	<b>5.85</b>	<b>.94</b>
<b>Total</b>	<b>5.80</b>	<b>.86</b>

Cronbach's coefficient of alpha, a measure of internal reliability, was obtained for the scale as a whole as well as for each subscale. For the Significant Other, family and Friends subscales, the values were 0.91, 0.87 and 0.85 respectively. The reliability of the total scale as a whole was 0.88. these values indicate good internal consistency for the scale as a whole and for the three subscales.

69 of the 275 subjects were retested 2 to 3 months after initially completing the questionnaire. The test-retest reliability for the Significant Other, Family and Friends subscales were 0.72, 0.85 and 0.75 respectively. For the whole scale, the value obtained was 0.85. in effect the MSPSS demonstrated good internal reliability and adequate stability over the time period indicated.

### **Administration and Scoring**

It is self-administered since it is simple to use. Scoring for each subscale is obtained by adding the scale chosen and thus the summation gives the total score.

### **Development of Working Norms for the current Project**

For the current project it was essential to develop the working norms based on the relevant Indian population, specifically the population of Kolkata. Thus the scale was administered to 57 normal adults between the age range 21—60 years engaged in various occupations (doctors, lawyers, engineers, managers, CEOs, teachers, housewives and students). The mean and standard deviations obtained from these scores (total scores) are:

<b>Subscales</b>	<b>Mean</b>	<b>Standard Deviation</b>
<b>Significant Other</b>	<b>22.23</b>	<b>6.208</b>
<b>Family</b>	<b>23.63</b>	<b>4.186</b>
<b>Friends</b>	<b>23.05</b>	<b>5.52</b>
<b>Total</b>	<b>68.91</b>	<b>12.787</b>

On the basis of the means and standard deviations obtained from the working normative sample, the scores were devised into categories:

**Categorization of the MSPSS Total Scores:**

<b>Category</b>	<b>Score</b>	<b>Standard deviation</b>
<b>Very Good</b>	<b>&gt;102.27</b>	<b>Beyond +3 s.d</b>
<b>Good</b>	<b>94.484—102.27</b>	<b>Between +2 s.d and +3 s.d</b>
<b>Above Average</b>	<b>81.697—94.484</b>	<b>Between +1 s.d and +2 s.d</b>
<b>Average</b>	<b>56.123—81.697</b>	<b>Between –1 s.d and +1 s.d</b>
<b>Below Average</b>	<b>43.336—56.123</b>	<b>Between – 1 s.d and – 2 s.d</b>
<b>Poor</b>	<b>30.549—43.336</b>	<b>Between –2 s.d and – 3 s.d</b>
<b>Very Poor</b>	<b>&lt;30.549</b>	<b>Below – 3 s.d</b>

**Categorization of the MSPSS Significant Other Subscale Scores:**

<b>Category</b>	<b>Score</b>	<b>Standard deviation</b>
<b>Very Good</b>	<b>&gt; 40.858</b>	<b>Beyond +3 s.d</b>
<b>Good</b>	<b>34.65—40.858</b>	<b>Between +2 s.d and +3 s.d</b>
<b>Above Average</b>	<b>28.438—34.65</b>	<b>Between +1 s.d and +2 s.d</b>
<b>Average</b>	<b>16.022—28.438</b>	<b>Between –1 s.d and +1 s.d</b>
<b>Below Average</b>	<b>9.814—16.022</b>	<b>Between – 1 s.d and – 2 s.d</b>
<b>Poor</b>	<b>3.606—9.814</b>	<b>Between –2 s.d and – 3 s.d</b>
<b>Very Poor</b>	<b>&lt;3.606</b>	<b>Below – 3 s.d</b>

**Categorization of the MSPSS Family Subscale Scores:**

<b>Category</b>	<b>Score</b>	<b>Standard deviation</b>
<b>Very Good</b>	<b>&gt; 36.188</b>	<b>Beyond +3 s.d</b>
<b>Good</b>	<b>32.002—36.188</b>	<b>Between +2 s.d and +3 s.d</b>
<b>Above Average</b>	<b>27.816—32.002</b>	<b>Between +1 s.d and +2 s.d</b>
<b>Average</b>	<b>19.444—27.816</b>	<b>Between –1 s.d and +1 s.d</b>
<b>Below Average</b>	<b>15.258—19.444</b>	<b>Between – 1 s.d and – 2 s.d</b>
<b>Poor</b>	<b>11.072—15.258</b>	<b>Between –2 s.d and – 3 s.d</b>
<b>Very Poor</b>	<b>&lt;11.072</b>	<b>Below – 3 s.d</b>

**Categorization of the MSPSS Friends Subscale Scores:**

<b>Category</b>	<b>Score</b>	<b>Standard deviation</b>
<b>Very Good</b>	<b>&gt; 39.61</b>	<b>Beyond +3 s.d</b>
<b>Good</b>	<b>34.09—39.61</b>	<b>Between +2 s.d and +3 s.d</b>
<b>Above Average</b>	<b>28.57—34.09</b>	<b>Between +1 s.d and +2 s.d</b>
<b>Average</b>	<b>17.53—28.57</b>	<b>Between –1 s.d and +1 s.d</b>
<b>Below Average</b>	<b>12.01—17.53</b>	<b>Between – 1 s.d and – 2 s.d</b>
<b>Poor</b>	<b>6.49—12.01</b>	<b>Between –2 s.d and – 3 s.d</b>
<b>Very Poor</b>	<b>&lt;6.49</b>	<b>Below – 3 s.d</b>

**Quality of Life**

Developed by **Carol S Burckhardt** , School of Nursing Oregon Health & Science University, Portland, Oregon, USA and **Kathryn L Anderson**, School of Nursing, Seattle University, Seattle, Washington, USA. (Adapted from **Health and Quality of Life Outcomes 2003**, 1:60 doi: 10.1186/1477-7525-1-60)

## **Introduction**

The Quality of Life Scale (QOLS), created originally by American psychologist John Flanagan in the 1970's, has been adapted for use in chronic illness groups. Reliability, content and construct validity testing has been performed on the QOLS and a number of translations have been made. The QOLS has low to moderate correlations with physical health status and disease measures. However, content validity analysis indicates that the instrument measures domains that diverse patient groups with chronic illness define as quality of life. The QOLS is a valid instrument for measuring quality of life across patient groups and cultures and is conceptually distinct from health status or other causal indicators of quality of life.

**The QOLS was originally a 15-item instrument that measured five conceptual domains of quality of life:**

- **material and physical well-being**
- **relationships with other people**
- **social, community and civic activities**
- **personal development and fulfillment**
- **recreation.**

After descriptive research that queried persons with chronic illness on their perceptions of quality of life, the instrument was expanded to include one more item:

- **Independence, the ability to do for yourself.**

Thus, the QOLS in its present format contains 16 items.

The QOLS is a reliable and valid instrument for measuring quality of life from the perspective of the patient.

## **Reliability and Validity**

The 15-item QOLS satisfaction scale was internally consistent ( $\alpha = .82$  to  $.92$ ) and had high test-retest reliability over 3-weeks in stable chronic illness groups ( $r = 0.78$  to  $r = 0.84$ ) [13].

Convergent and discriminant construct validity of the QOLS in chronic illness groups was evidenced first by the high correlation's between the QOLS total score and the Life Satisfaction

Index-Z (LSI-Z) [18] ( $r = 0.67$  to  $0.75$ ) and its low to moderate correlation's with the Duke-UNC Health Profile (DUHP) physical health status subscale ( $r = 0.25$  to  $0.48$ ) and a disease impact measure, the Arthritis Impact Measurement Scales (AIMS) ( $r = 0.28$  to  $0.44$ ).

### **Administration of the Scale**

The QOLS is usually self-administered either by completing the questionnaire in a clinic setting or by mail. It can also be completed by interview format. If the interview format is chosen, the patients are given a copy of the 7-point response scale to refer to when making their decision as to the most appropriate point on the scale. The QOLS can be completed in about 5 minutes.

### **Scoring**

The QOLS is scored by adding up the score on each item to yield a total score for the instrument. Scores can range from 16 to 112. There is no automated administration or scoring software for the QOLS.

### **Interpretation of the Scores**

The QOLS scores are summed so that a higher score indicates higher quality of life.

### **Development of Working Norms for the Current Project**

Since for the current project, the QOLS was chosen to measure the quality of life of the patients, it became necessary to develop the working norms of the 16- item QOL scale in the relevant Indian population, specifically the population in the city of Kolkata. Hence, for the purpose, **57 adults**, both males and females, between the age range of 21—60 years from different occupations (doctors, lawyers, housewives, managers, CEOs, engineers, teachers and students) were administered with the 16 item form of the QOLS.

On the basis of the responses provided by these 57 normal adults, the scoring procedure was followed as mentioned in the original article.

**The mean score obtained from the scores of these 57 adults was 82.949 and the standard deviation calculated was 9.619.**

On the basis of the mean and standard deviation calculated, 7 categories were classified in the following manner:

<b>Name of Category</b>	<b>Score</b>	<b>S.D</b>
<b>Extremely Good</b>	<b>&gt;111.806</b>	<b>Beyond +3 s.d</b>
<b>Good</b>	<b>102.187—111.806</b>	<b>Between +2s.d and +3 s.d</b>
<b>Above Average</b>	<b>92.568—102.187</b>	<b>Between +1s.d and +2 s.d</b>
<b>Average</b>	<b>73.33—92.568</b>	<b>Between – 1 s.d and + 1 s.d</b>
<b>Below Average</b>	<b>63.711—73.33</b>	<b>Between – 1 s.d and – 2 s.d</b>
<b>Poor</b>	<b>54.092—63.711</b>	<b>Between – 2 s.d and – 3 s.d</b>
<b>Extremely Poor</b>	<b>&lt; 54.092</b>	<b>Below – 3 s.d</b>

The scores of the sample were thus scored according to the working norms developed for the current purpose.

## Procedure

The procedure followed by the SEVAC team is outlined below:

- **Stage I:** At the very beginning, the working team consisting of Psychiatrists, Psychologists, Field investigators and Statistician was formed for conducting the Research Study.
- **Stage II:** Necessary permission from the Department of Health, Govt. of West Bengal was procured for collecting relevant data required for this study from the respective project fields i.e. Calcutta Pavlov Mental Hospital, Lumbini Park Mental Hospital and all Medical Colleges situated in Kolkata. However, the data were collected only from Pavlov and Lumbini Park mental hospitals, as other tertiary care hospitals do not provide inpatient care (though it is present in pen and paper).
- **Stage III:** Superintendents/ Heads of the Department of all project fields were contacted and access to necessary information about the target group i.e. female mental patients released from their respective institutions in last three years, was sought.
- **Stage IV:** Names and Addresses of the target groups were collected from the office records of the hospitals (i.e. project fields).
- **Stage V:** Since it was initially decided that this particular Research Study would cover the female mental patients coming from Kolkata, Howrah, Hooghly, South 24 Parganas and North 24 Parganas Districts, a district wise Home Visit Schedule was prepared for contacting all of the target groups in order to collect necessary information directly from them as well as to assess their overall condition.
- **Stage VI** In the meanwhile, project designing was done, appropriate tools were selected and information schedule was developed in order to achieve the project objectives in a desired manner.

- **Stage VII** According to the Home Visit Schedule, the psychiatrist, psychologists and field investigators of the SEVAC team searched all the collected addresses in order to reach the doorsteps of all the patients, aiming at interviewing them and/or family members and neighbors by applying the tools/ schedule.
  
- **Stage VIII:** During the interview, the Sociodemographic profile of the patients was revealed first. Then the Clinical Examination as well as Mental Status Examination (MSE) of the patients were done. The family cohesion and adjustment as described previously were administered simultaneously. Thereafter, ‘Brief Psychiatric Rating Scale’ (BPRS), the ‘Multidimensional Scale of Perceived Social Support’ (MSPSS) and the ‘Quality of Life’ (QOL) questionnaire were also administered. Here it needs mentioning that **the patients who were found to be in an unstable condition according to the findings of the MSE and BPRS, were not administered the QOL Scale and the MSPSS Scale because both the scales essentially require reality contact to be present in the subject for appropriate appraisal of quality of life and perceived social support.**
  
- **Stage IX:** The working norms were developed for the two instruments—the Quality of Life Scale and the Multidimensional Scale of Perceived Social Support, for use on the Indian Population in Kolkata. Data for this purpose were collected from normal adults, both males and females, from different sectors of employment, including doctors, lawyers, students etc.
  
- **Stage X:** The data gathered were then tabulated and statistical analysis was done.

## Section II

### STATISTICAL ANALYSIS

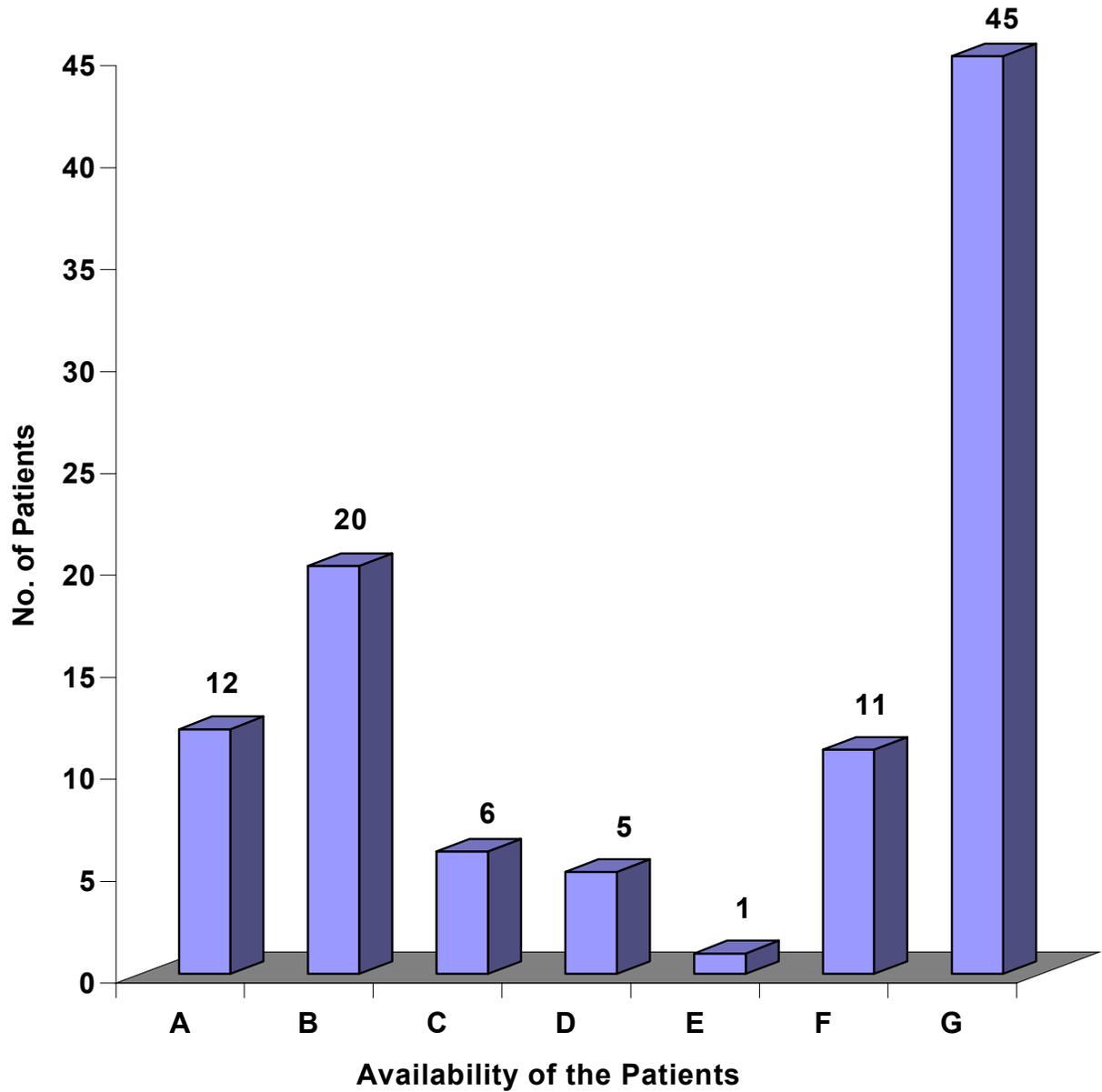
Details of a total of **100** female mentally ill patients released in the last 3 years were collected from the two Government mental hospitals in Kolkata, viz., Calcutta Pavlov Mental Hospital and Lumbini Park Mental Hospital.

However, all these 100 patients could not be approached and interviewed for a variety of reasons. The reasons are listed in the following table

**Table 1: Distribution of the patients according to their contact details collected from the two Govt. Mental Hospitals**

<b>Inadequate Address (could not be located)</b>	<b>Wrong Address (was not found to exist)</b>	<b>Dead</b>	<b>Changed Address (left address)</b>	<b>Missing</b>	<b>Shifted to other place (readmitted to other hospital or Home, or in police custody)</b>	<b>Patients Interviewed</b>	<b>Total</b>
<b>12</b>	<b>20</b>	<b>6</b>	<b>5</b>	<b>1</b>	<b>11</b>	<b>45</b>	<b>100</b>
<b>12%</b>	<b>20%</b>	<b>6%</b>	<b>5%</b>	<b>1%</b>	<b>11%</b>	<b>45%</b>	<b>100%</b>

**Figure 1: Distribution of the patients according to availability.**



**A: Inadequate Address**

**B: Wrong Address**

**C: Dead**

**D: Left Address**

**E: Missing**

**F: Readmitted to other hospital/Home or in police custody**

**G: Patients Interviewed**

Table 1 and Figure 1 indicate that at the time of admission **a number of relatives of the patients did not follow the rules properly in citing their address.** As seen from the above table, the figures in percentage indicate that **20% of the patients provided wrong address.** This is alarming statistical information since this leads to the conclusion that these wrong addresses could have been provided by the family members of these patients to avoid stigmatization in the society or they were not careful in citing their proper address. There is certainly some **gross negligence on the part of the hospital authorities** in noting the addresses of these patients at the time of admission.

In short, **only 45% of the patients could be reached and interviewed** by the SEVAC team. However, the silver lining is that **only 1 patient was found to be missing in the sample of cases.** However, since a good number of patients could not be reached, whether they were traceable or were missing cannot be concluded. **11% of the sample was found to have been readmitted to other hospital or Home or N.G.O or even in police custody. This points out to the fact that these patients possibly have nowhere to return since their families do not accept them back as normally functioning human beings.** They are the stigmatized section who are deserted, lonely and perhaps under these circumstances, suffer a relapse of their disorder. **This 11% of the sample represent the Group III hypothesized previously and have the inadequate Living Status.** They reflect the need for a proper infrastructure in the form of half-way homes which would provide shelter to the ‘stigmatized’ and ‘rejected’ mental patients and make arrangements for their meaningful rehabilitation. This 11% of patients have been readmitted due to relapse of their psychiatric illness which points towards treatment compliance.

## Analysis of the Sample of Cases Interviewed

**45% of the sample of patients who were traced and interviewed can now be analyzed in terms of the 3 domains chosen by the SEVAC team, viz., Living Status, Social Integration and Treatment Compliance and also in terms of the socio-demographic variables studied.**

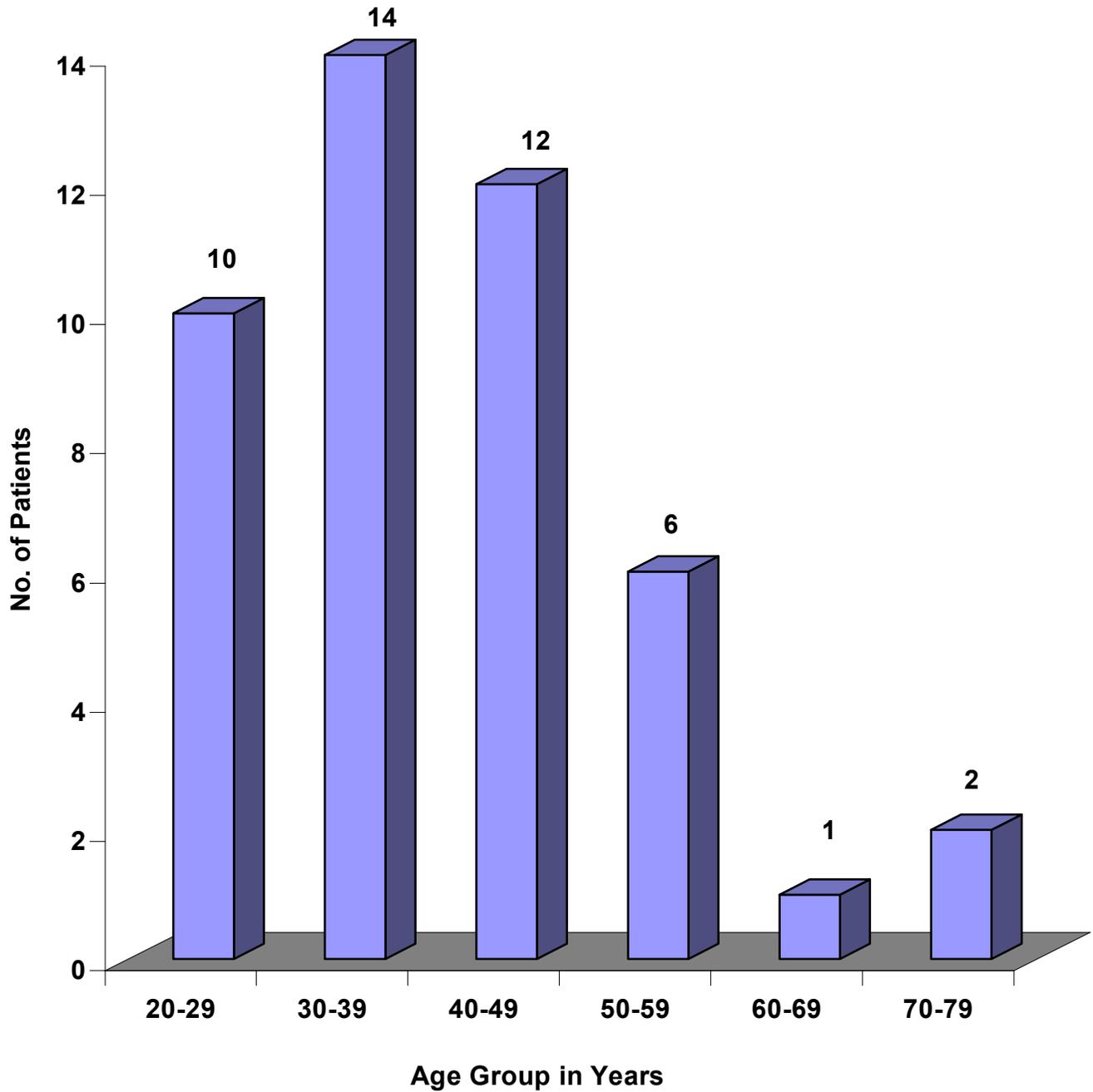
### Analysis with Sociodemographic Variables

The 45 cases covered from the actual sample of 100 will first be analyzed with respect to the **socio-demographic variables**, viz., age, education, occupation and monthly income of the family.

**Table 2: Distribution of the patients according to their age**

<b>Age Group (in years)</b>	<b>No. of Patients</b>	<b>Percentage of Patients</b>
<b>20-29</b>	<b>10</b>	<b>22.2%</b>
<b>30-39</b>	<b>14</b>	<b>31.1%</b>
<b>40-49</b>	<b>12</b>	<b>26.8%</b>
<b>50-59</b>	<b>6</b>	<b>13.3%</b>
<b>60-69</b>	<b>1</b>	<b>2.2%</b>
<b>70-79</b>	<b>2</b>	<b>4.4%</b>
<b>Total</b>	<b>45</b>	<b>100%</b>

**Figure 2: Distribution of the patient according to their age**

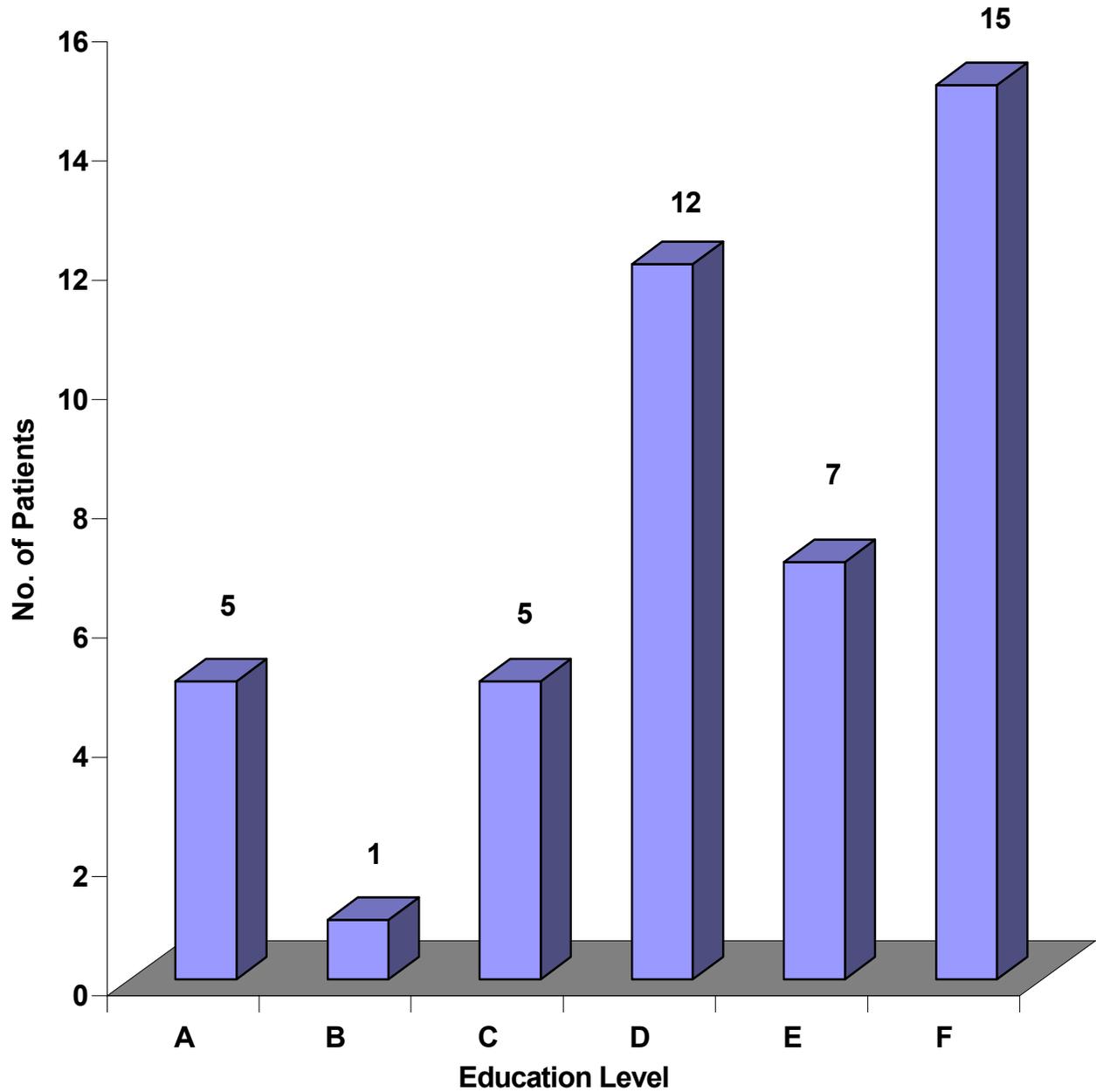


From Table 2 and Figure 2, it is evident that **the peak age of the sample is around 30-39 years. The age of maximum number of patients clustered around 20- 50 years.** It must be noted here that this is the **significant period of the female life cycle**, and disruption in the life cycle at this stage causes enormous suffering for women. The range of age was found to be years with the lowest age being 20 years and the highest being 79 years. In the later part of this section, associations between age and the three domains have been tested using Chi-square test.

**Table 3: Distribution of the patients according to their educational level**

<b>Education Level</b>	<b>No. of Patients</b>	<b>Percentage of Patients</b>
<b>Graduate</b>	<b>5</b>	<b>11.1%</b>
<b>Inter/Post High School Diploma</b>	<b>1</b>	<b>2.2%</b>
<b>SSLC/its equivalent</b>	<b>5</b>	<b>11.1%</b>
<b>Completion of Elementary/Middle School</b>	<b>12</b>	<b>26.7%</b>
<b>Literate/Going to Elementary School for few years.</b>	<b>7</b>	<b>15.6%</b>
<b>No formal education</b>	<b>15</b>	<b>33.3%</b>
<b>Total</b>	<b>45</b>	<b>100%</b>

**Figure 3: Distribution of the patients according to their educational level**



**A: Graduate**

**B: Inter/Post High school diploma**

**C: SSLC/its equivalent**

**D: Completion of Elementary or Middle School**

**E : Literate/Going to elementary school for few years**

**F : No formal education**

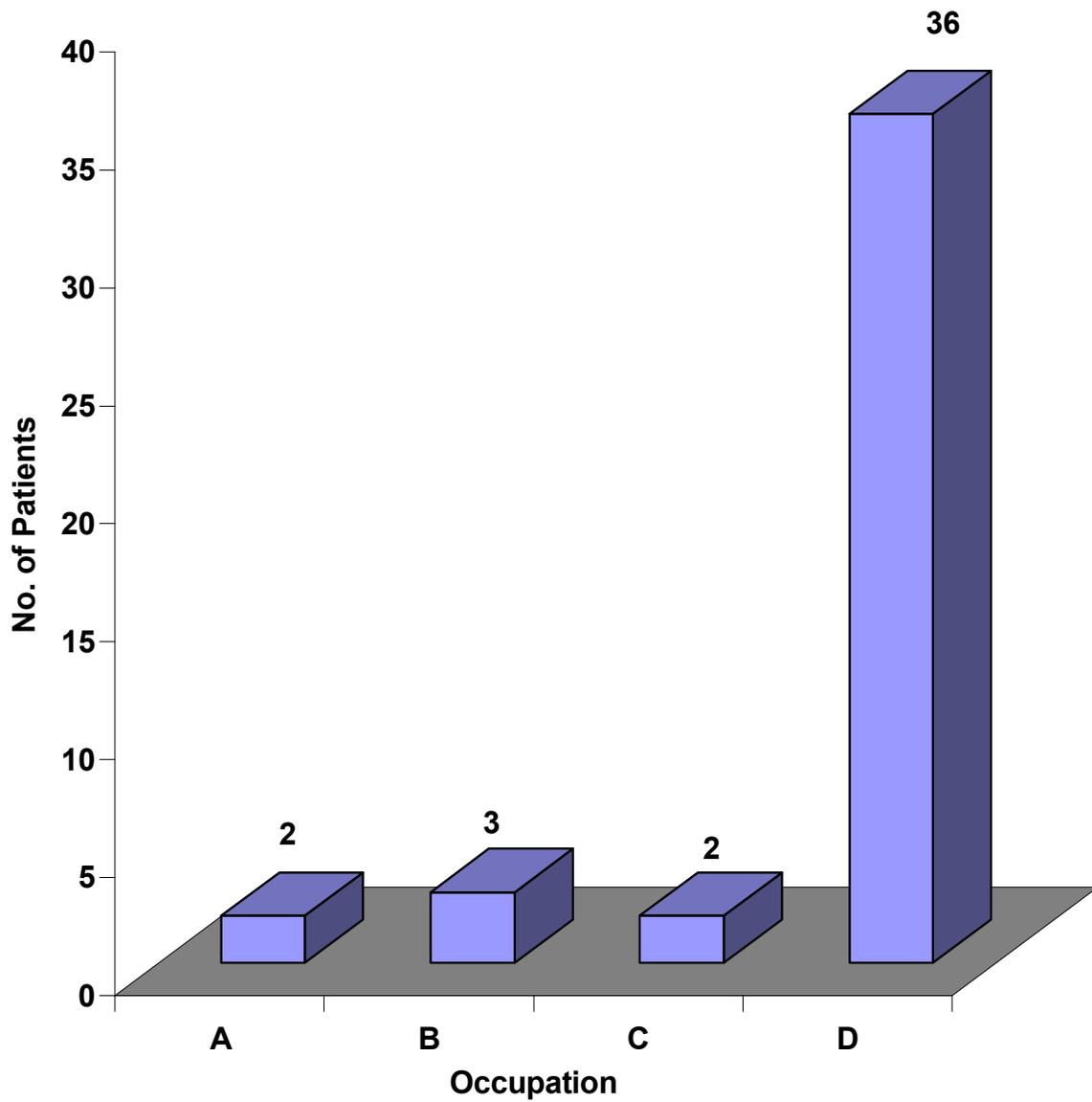
As evident from Table 3 and Figure 3, **the majority (33.3%) had no formal education**, followed by 26.7% of women who have studied up to primary or middle school level. However, a considerable percentage **(11.1%) of women was found to be graduate**. Hence, it cannot be said that only women of a low education level suffer from mental illnesses. There could be a difference in treatment compliance and social integration between the groups of no formal education and the educated group. Hence, in later part of this section, Chi-square test has been used to find statistically significant association between education level and other relevant variables, if any.

**Table 4: Distribution of the patients according to their occupation**

<b>Occupation</b>	<b>No. of Patients</b>	<b>Percentage of Patients</b>
<b>Semi-profession</b>	<b>2</b>	<b>4.7%</b>
<b>Semi-skilled Worker</b>	<b>3</b>	<b>6.9%</b>
<b>Unskilled Worker/ Casual Labour</b>	<b>2</b>	<b>4.7%</b>
<b>Unemployed</b>	<b>36</b>	<b>83.7%</b>
<b>Total</b>	<b>43</b>	<b>100%</b>

Note : Of the 45 women, one was deaf & dumb and the other was non-communicative.

**Figure 4: Distribution of the patients according to their occupation**



- A** - **Semi-profession**
- B** - **Semi-skilled Worker**
- C** - **Unskilled Worker/ Casual Labour**
- D** - **Unemployed**

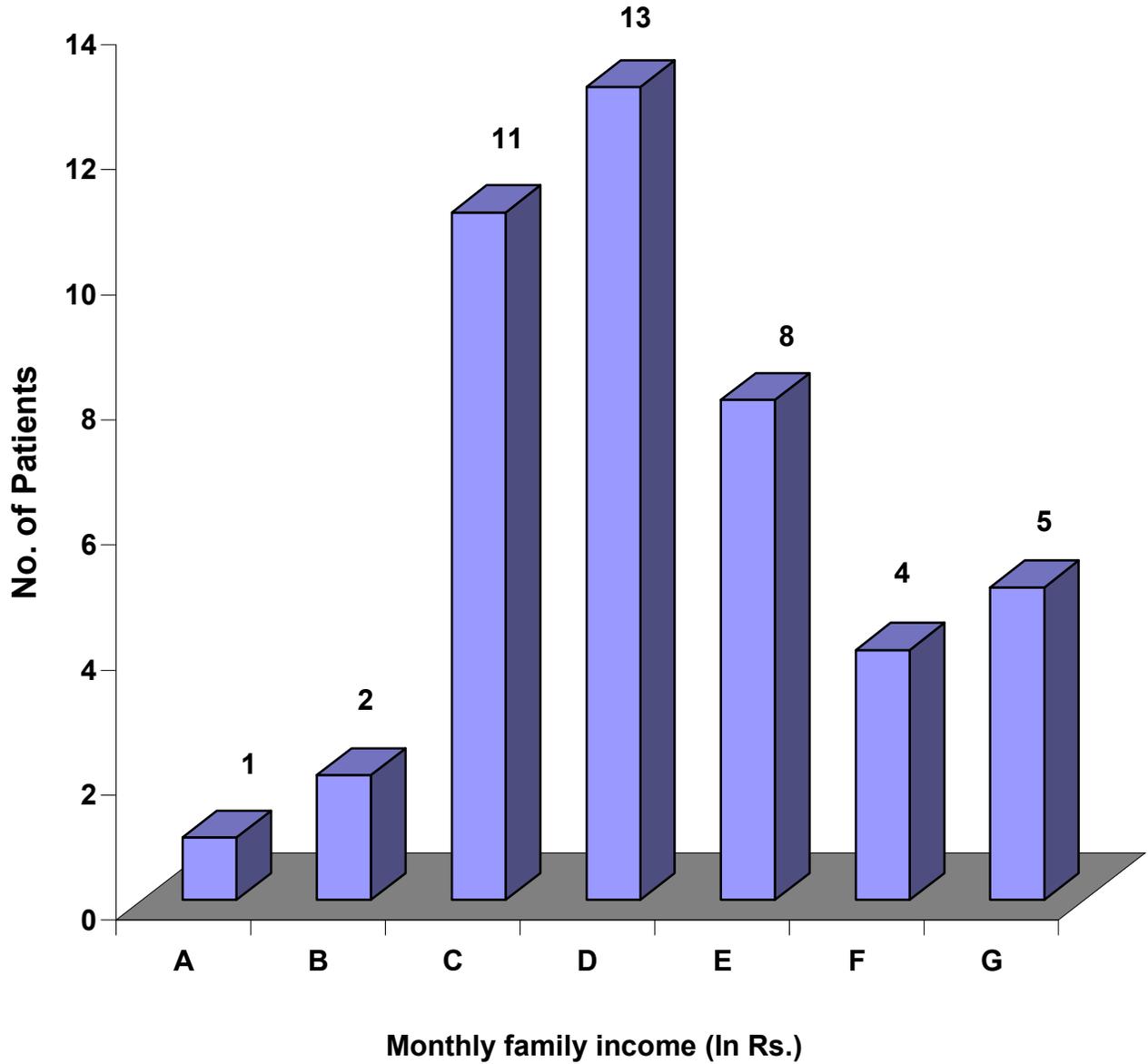
As evident from Table 4 and Figure 4, a majority of the patients' sample that is **83.7% are unemployed**. Hence, it may be inferred that a good number of these women are not able to become independent and contribute to their family income.

**Table 5: Distribution of the patients according to the monthly income of the families**

<b>Monthly Income of the Family (In Rs.)</b>	<b>No. of Patients</b>	<b>Percentage of Patients</b>
<b>Above 10,000</b>	<b>5</b>	<b>11.4%</b>
<b>5,000-10,000</b>	<b>4</b>	<b>9.1%</b>
<b>2,000-5,000</b>	<b>8</b>	<b>18.2%</b>
<b>1,000-2,000</b>	<b>13</b>	<b>29.5%</b>
<b>500-1,000</b>	<b>11</b>	<b>25%</b>
<b>Below 500</b>	<b>2</b>	<b>4.5%</b>
<b>No income</b>	<b>1</b>	<b>2.3%</b>
<b>Total</b>	<b>44</b>	<b>100%</b>

**Note: The monthly family income of 1 patient could not be revealed.**

**Figure 5: Distribution of the patients according to their monthly family income**



A - Above 10,000  
B - 5,000-10,000  
C - 2,000-5,000  
D - 1,000-2,000

E - 500-1,000  
F - Below 500  
G - No income

From Table 5 and Figure 5, it is evident that the highest monthly family income of the sample is between **Rs. 1000-2000, comprising of 29.5% of the sample**, closely followed by **25% of the sample whose monthly family income is between Rs. 500- 1000**. Although there is a considerable number of patients of the sample having higher monthly income, **most of the patients live below the poverty line**.

### **Analysis with Variables Used for Interpreting Living Status**

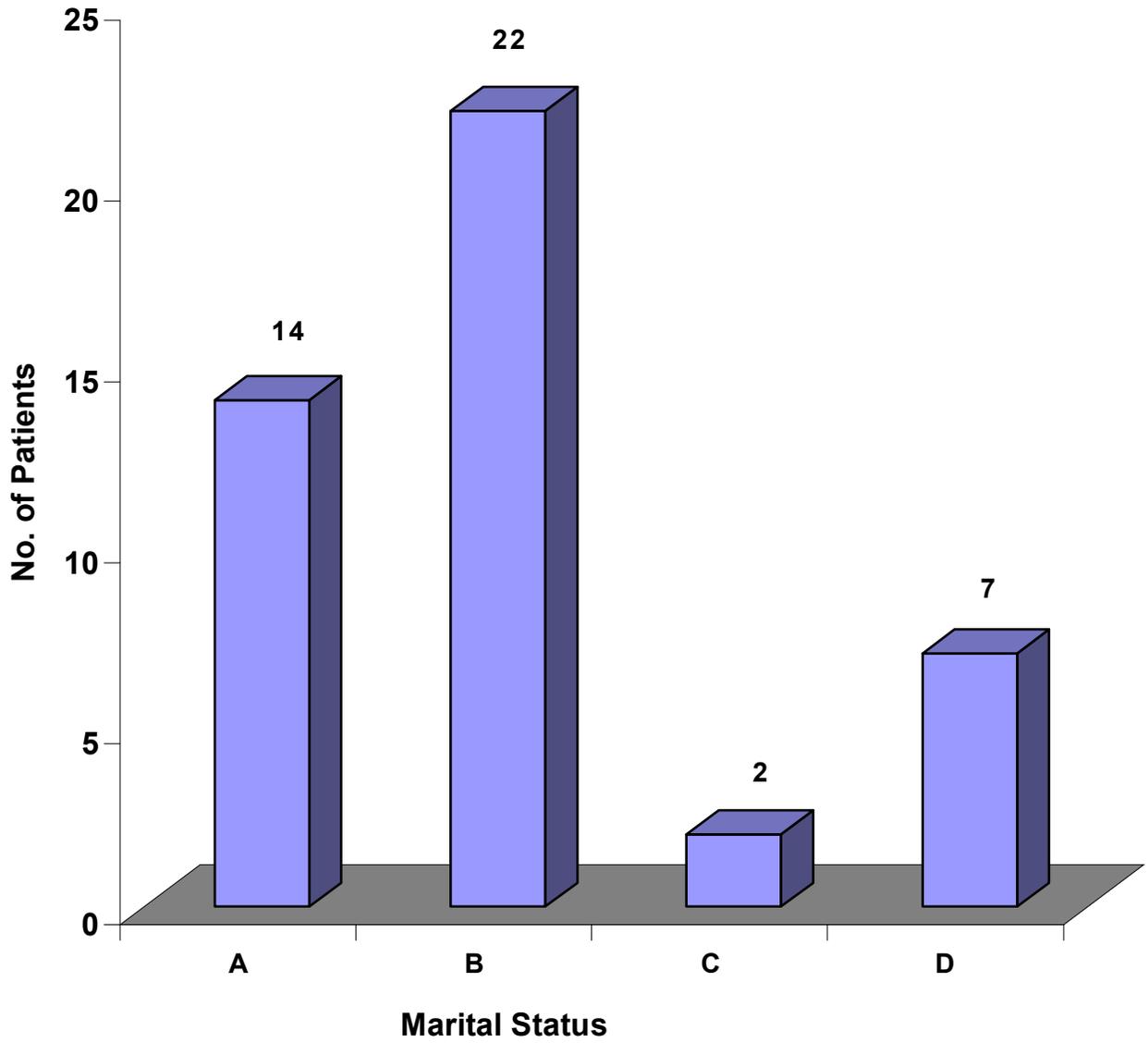
The 45% of the cases covered having been described in terms of the socio-demographic variables, now will be studied in terms of the variables under Living Status, viz.,

- Marital Status
- Residing status
- Type of family
- Mental State Examination (MSE) Report Summary
- Brief Psychiatric Rating Scale (BPRS) Scores
- Quality of Life (QoL) Scores

**Table 6: Distribution of the patients according to their marital status**

<b>Marital Status</b>	<b>No. of Patients</b>	<b>Percentage of Patients</b>
<b>Married</b>	<b>14</b>	<b>31.1%</b>
<b>Single</b>	<b>22</b>	<b>48.9%</b>
<b>Widow</b>	<b>2</b>	<b>4.4%</b>
<b>Separated</b>	<b>7</b>	<b>15.6%</b>
<b>Total</b>	<b>45</b>	<b>100%</b>

**Figure 6: Distribution of the patients according to their marital status**



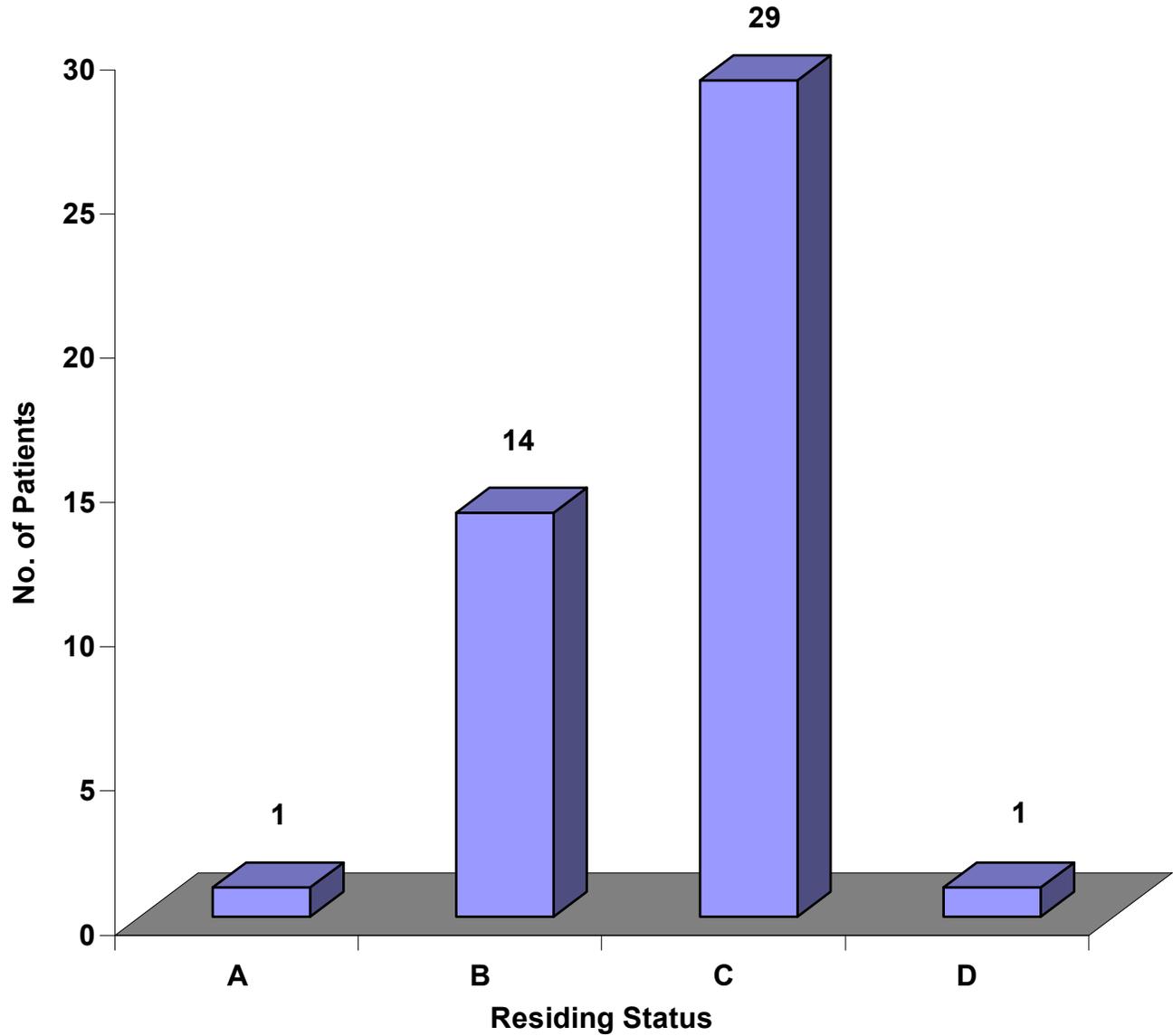
- A** - **Married**
- B** - **Single**
- C** - **Widow**
- D** - **Separated / Deserted**

As evident from Table 6 and Figure 6, **48.9% of the patients are single, followed by 31.1% of the patients who are married.** From table 2 it is revealed that 48.9% of the sample are single inspite of attaining marriageable age. One such explanation is that the stigma associated with mental illness is so high that the society considers 31.1% of them not fit for marry & have a family. Moreover, the fact that **there are no divorced women among this sample and yet 15.6% are separated, it can be pointed out that the spouses of these women shunned them in the face of extreme difficulties.** They did not even bothered to divorce these women. In fact, they deliberately tried to shrug off the responsibilities that arising from divorce.

**Table 7: Distribution of the patients according to their residing status.**

<b>Residing Status</b>	<b>No. of Patients</b>	<b>Percentage of Patients</b>
<b>Living without family (with neighbors or other caregivers)</b>	<b>1</b>	<b>2.2%</b>
<b>Living with in-laws/husband/children</b>	<b>14</b>	<b>31.2%</b>
<b>Living with parents/brothers/sisters</b>	<b>29</b>	<b>64.4%</b>
<b>Living on the roads/found wandering</b>	<b>1</b>	<b>2.2%</b>
<b>Total</b>	<b>45</b>	<b>100%</b>

**Figure 7: Distribution of the patients according to their residing status**



- A** - Living without Family (with neighbors or other caregivers)
- B** - Living with in-laws/husband/children
- C** - Living with parents/brothers/sisters
- D** - Living on the roads/found wandering

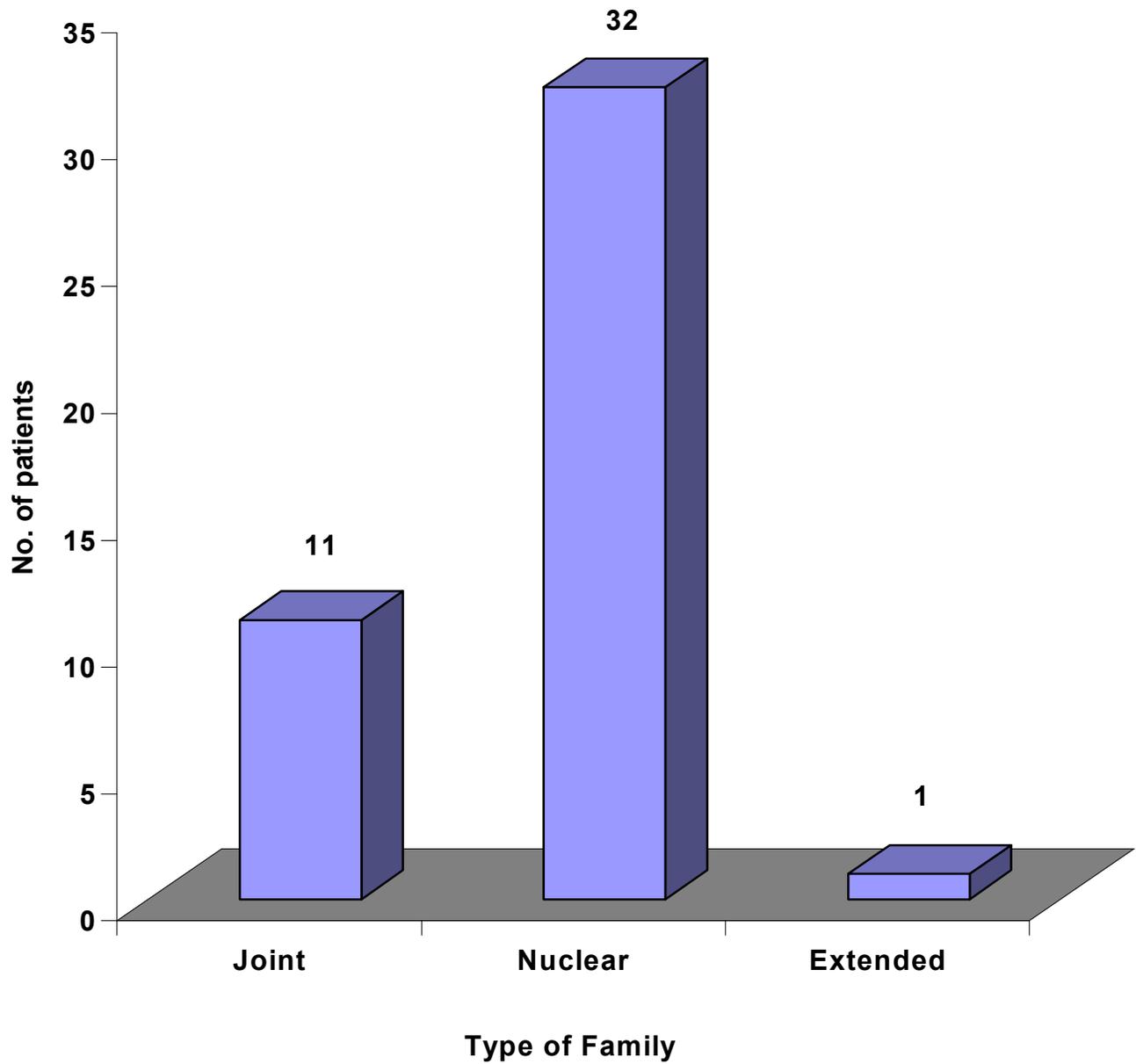
As evident from Table 7 and Figure 7, majority of the sample, **comprising of 64.4% lives with their parents, which is not surprising, keeping in view their marital status** shown in table 6. This is closely followed by **31.2% of the women who live with their in-laws/husbands/children**. Hence, although these women live either with their parents or in-laws/husbands, the social acceptance and social environment by the family need to be focused. This would truly point out their current living status, whether in spite of having a shelter they have a “home” with caregivers in that shelter.

**Table 8: Distribution of the patients according to their type of family**

<b>Type of Family</b>	<b>No. of Patients</b>	<b>Percentage of Patients</b>
<b>Joint</b>	<b>11</b>	<b>25%</b>
<b>Nuclear</b>	<b>32</b>	<b>72.7%</b>
<b>Extended</b>	<b>1</b>	<b>2.3%</b>
<b>Total</b>	<b>44</b>	<b>100%</b>

Note: Since 1 patient was found to be living on the road, the total is 44.

**Figure 8: Distribution of the patients according to their type of family**



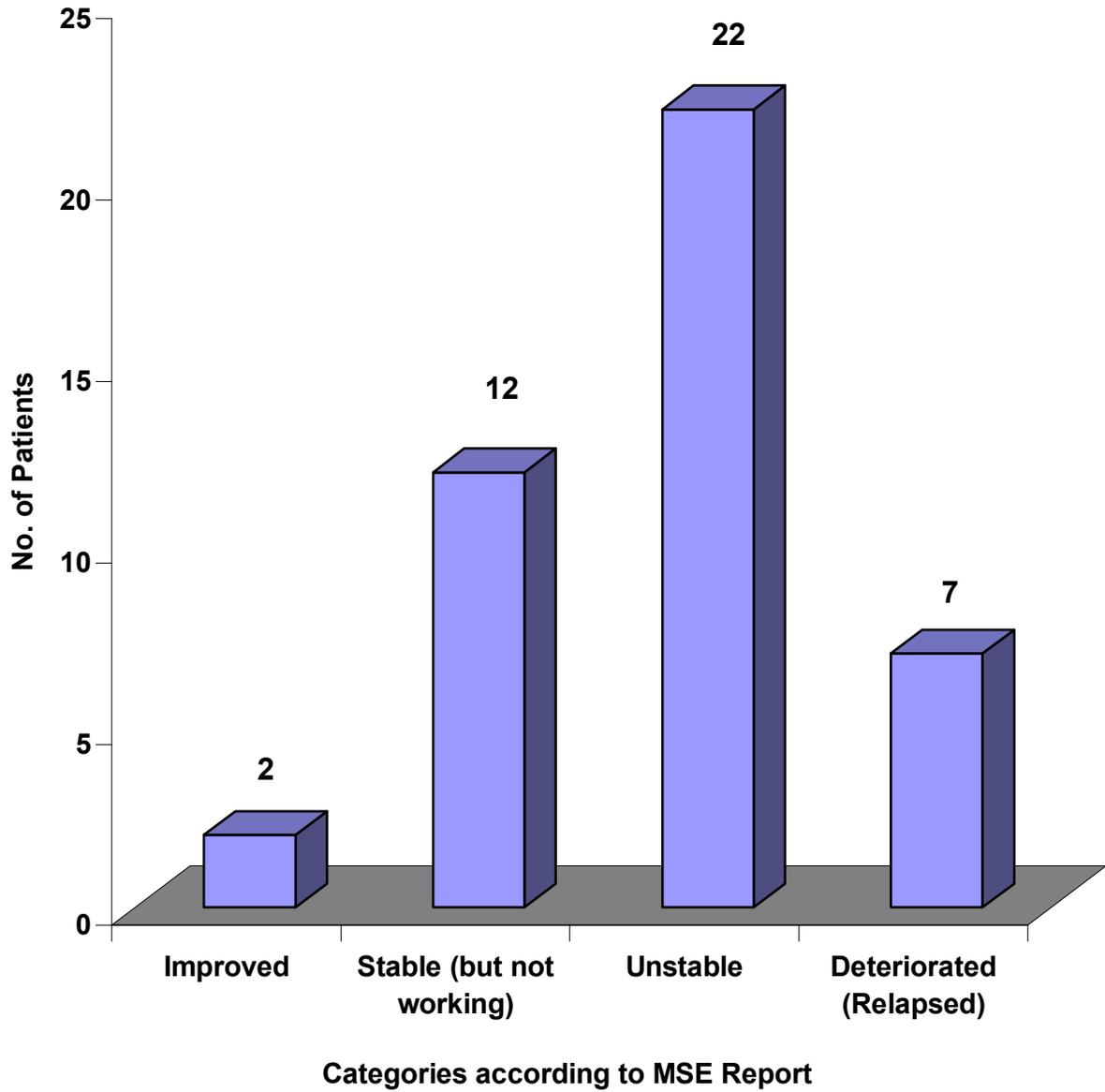
The Table 8 and Figure 8 show that **72.7% of the patients belong to nuclear families**. It is needless to mention that nuclear families **with lesser no. of caregivers face more difficulties than joint or extended families which have more no. of caregivers**.

**Table 9: Distribution of the patients according to the categories of Mental State Examination (MSE) report.**

<b>MSE Summary</b>	<b>No. of Patients</b>	<b>Percentage of Patients</b>
<b>Improved</b>	<b>2</b>	<b>4.7%</b>
<b>Stable but not working</b>	<b>12</b>	<b>27.9%</b>
<b>Unstable</b>	<b>22</b>	<b>51.1%</b>
<b>Deteriorated (Relapsed)</b>	<b>7</b>	<b>16.3%</b>
<b>Total</b>	<b>43</b>	<b>100%</b>

Note: 2 of the patients could not be administered with MSE.

**Figure 9: Distribution according to the categories of MSE report**



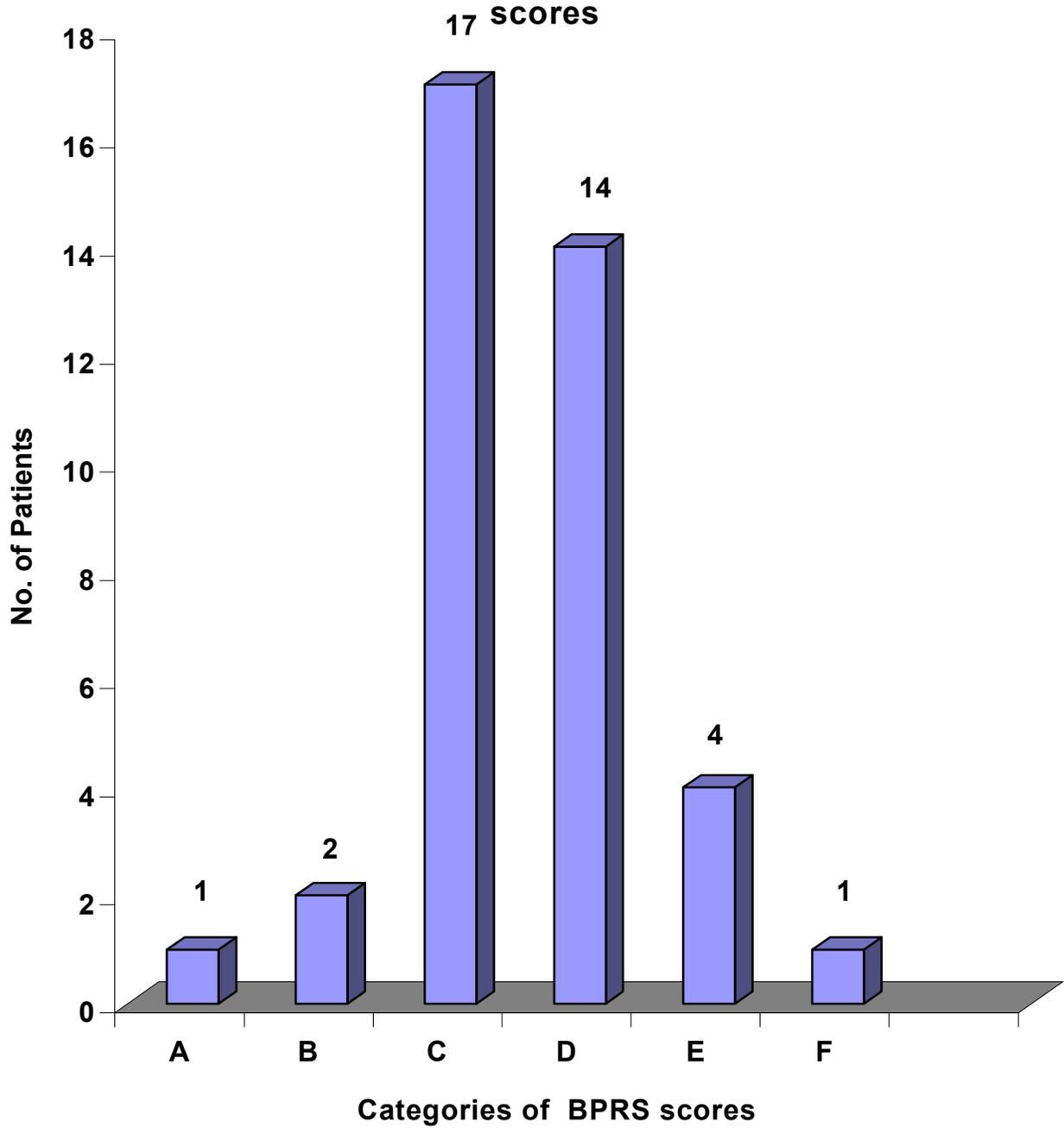
The Table 9 and Figure 9 show that **51.1% of the sample are unstable**, followed by **27.9% of the sample who are stable and can take care of themselves but are not fit for working**. The ray of hope is provided by **4.7% of the sample who are in improved condition** and are working besides being able to take care of themselves and their families. These exemplifying cases are discussed in details in later part of this section.

**Table 10 Distribution of the patients according to the Brief Psychiatric Rating Scale (BPRS) scores.**

<b>Category according to BPRS Scores</b>	<b>No. of Patients</b>	<b>Percentage of Patients</b>
<b>Normal (Not at all ill)</b>	<b>1</b>	<b>2.6%</b>
<b>Borderline Mentally Ill</b>	<b>2</b>	<b>5.1%</b>
<b>Mildly Ill</b>	<b>17</b>	<b>43.6%</b>
<b>Moderately Ill</b>	<b>14</b>	<b>35.9%</b>
<b>Markedly Ill</b>	<b>4</b>	<b>10.2%</b>
<b>Extremely Ill Patients</b>	<b>1</b>	<b>2.6%</b>
<b>Total</b>	<b>39</b>	<b>100%</b>

Note: 6 patients could not be administered with BPRS.

**Figure 10: Distribution according to the BPRS**



**A - Normal (Not at all ill)**  
**B - Borderline Mentally Ill**  
**C - Mildly Ill**

**D - Moderately Ill**  
**E - Markedly Ill**  
**F - Extremely Ill Patients**

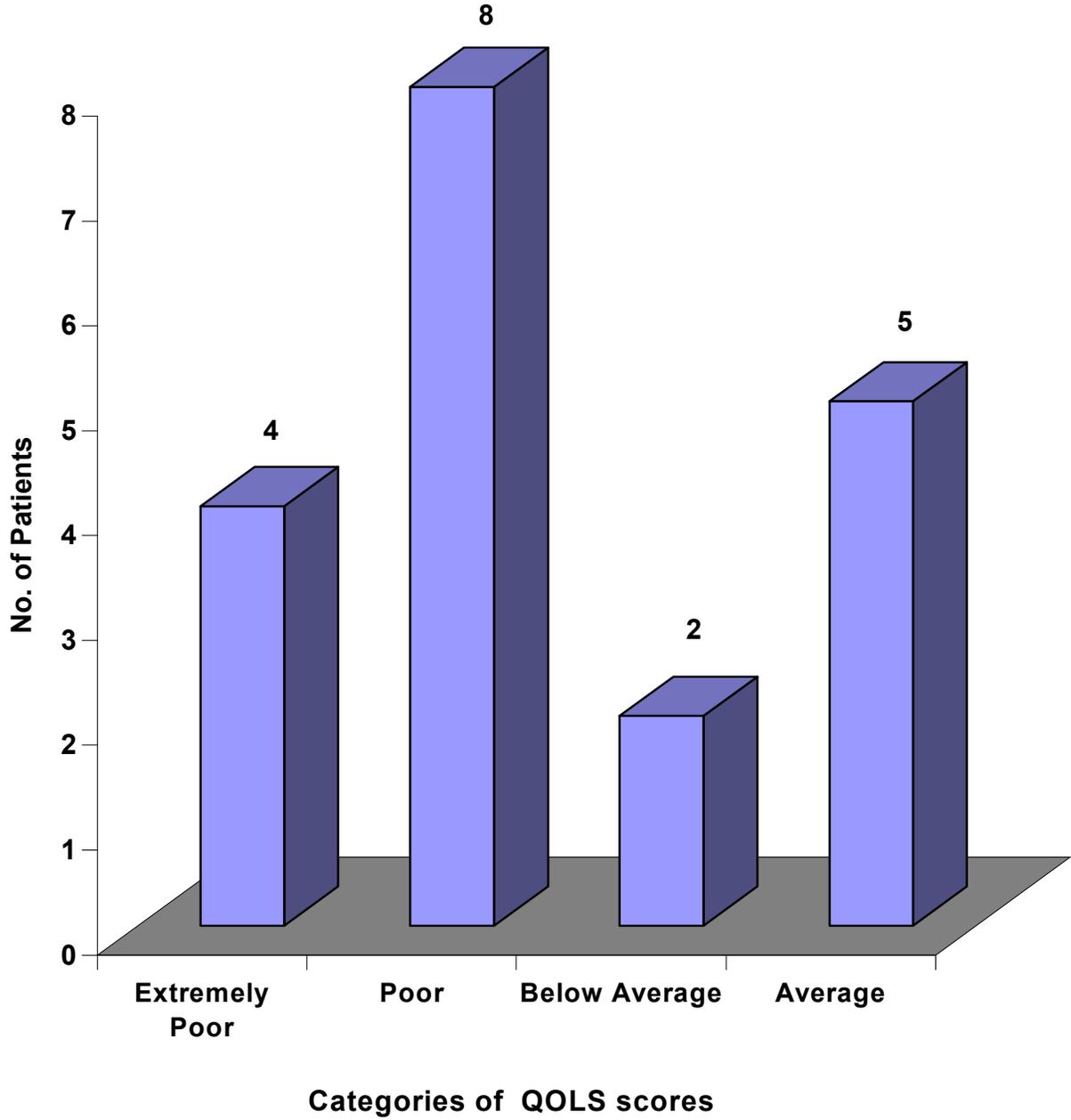
From the Table 10 and Figure 10, it is evident that **43.6% of the patients are mildly ill** according to BPRS scores, closely followed by **35.9% of the sample, who are moderately ill**. Hence, majority of the sample may be said to be not in a clinically stable condition in spite of the fact that most are living with their families. Therefore, there is a need to probe into the kind of support received by the patients from their families.

**Table 11: Distribution of the patients according to the QOLS scores**

<b>Category According to QoL Scores</b>	<b>No. of Patients</b>	<b>Percentage of Patients</b>
<b>Extremely Poor</b>	<b>4</b>	<b>21.1%</b>
<b>Poor</b>	<b>8</b>	<b>42.1%</b>
<b>Below Average</b>	<b>2</b>	<b>10.5%</b>
<b>Average</b>	<b>5</b>	<b>26.3%</b>
<b>Total</b>	<b>19</b>	<b>100%</b>

Note: 26 of the patients showed poor reality contact, and hence could not be administered with QOL, since they would not have been reliable indicators.

**Figure 11 : Distribution according to the QOLS scores**



From Table 11 and Figure 11, it can be said that **42.1% of the sample reported poor quality of life**, followed by **26.3% who reported average quality of life**. None of the patients reported above average quality of life. Hence, the analysis with QOL scores leads us to the conclusion that the **quality of life of most of these patients is below average**.

### **Analysis with Variables Used for interpreting Social Integration**

Now, the 45% sample interviewed may be assessed from the other domain of **social integration**.

The variables studied under social integration are:

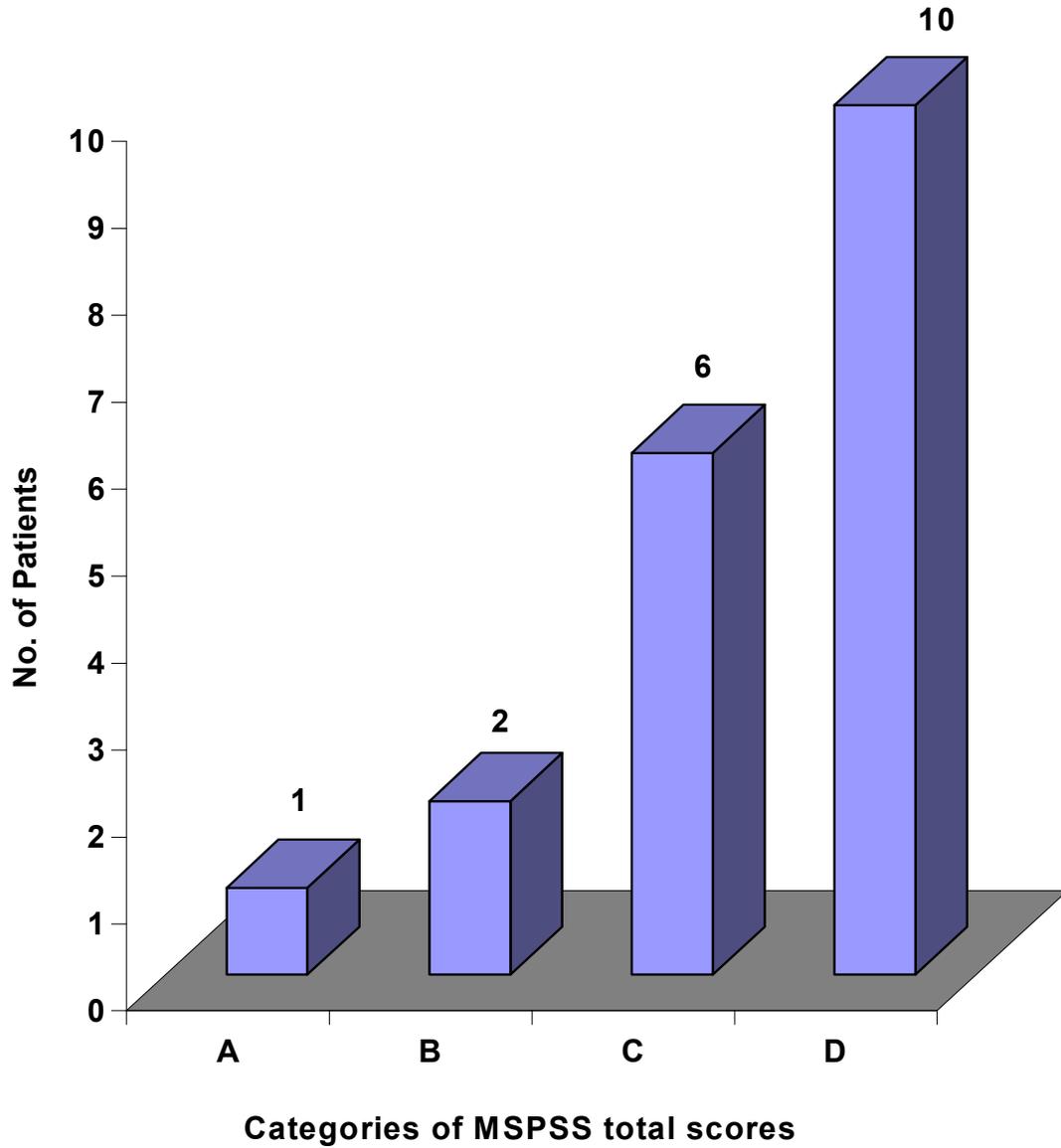
- Multidimensional Scale of Perceived Social Support (MSPSS) Total Score
- Multidimensional Scale of Perceived Social Support (MSPSS) Significant Other Sub scale Score
- Multidimensional Scale of Perceived Social Support (MSPSS) Family Subscale Score
- Multidimensional Scale of Perceived Social Support (MSPSS) Friends Subscale Score
- Relationship with caregiver
- Acceptance of the mentally ill subject by the family members as perceived by SEVAC team
- Cohesion between family members as perceived by the patients
- Cohesion between patient and family members as perceived by the team

**Table 12: Distribution of the patients according to the MSPSS total scores.**

<b>Category</b>	<b>No. of Patients</b>	<b>Percentage of Patients</b>
<b>Very Poor Perceived Social Support</b>	<b>1</b>	<b>5.26%</b>
<b>Poor Perceived Social Support</b>	<b>2</b>	<b>10.53%</b>
<b>Below Average Perceived Social Support</b>	<b>6</b>	<b>31.58%</b>
<b>Average Perceived Social Support</b>	<b>10</b>	<b>52.63%</b>
<b>Total</b>	<b>19</b>	<b>100%</b>

Note: 26 patients were not fit to be administered with MSPSS. The figures in percentages are values corrected upto one decimal place.

**Distribution according to the MSPSS total scores**



- A - Very Poor Perceived Social Support**
- B - Poor Perceived Social Support**
- C - Below Average Perceived Social Support**
- D - Average Perceived Social Support**

From the Table 12 and Figure 12, it is evident that **majority of the sample (52.63%) possesses average perceived social support**, followed by below average perceived social support.

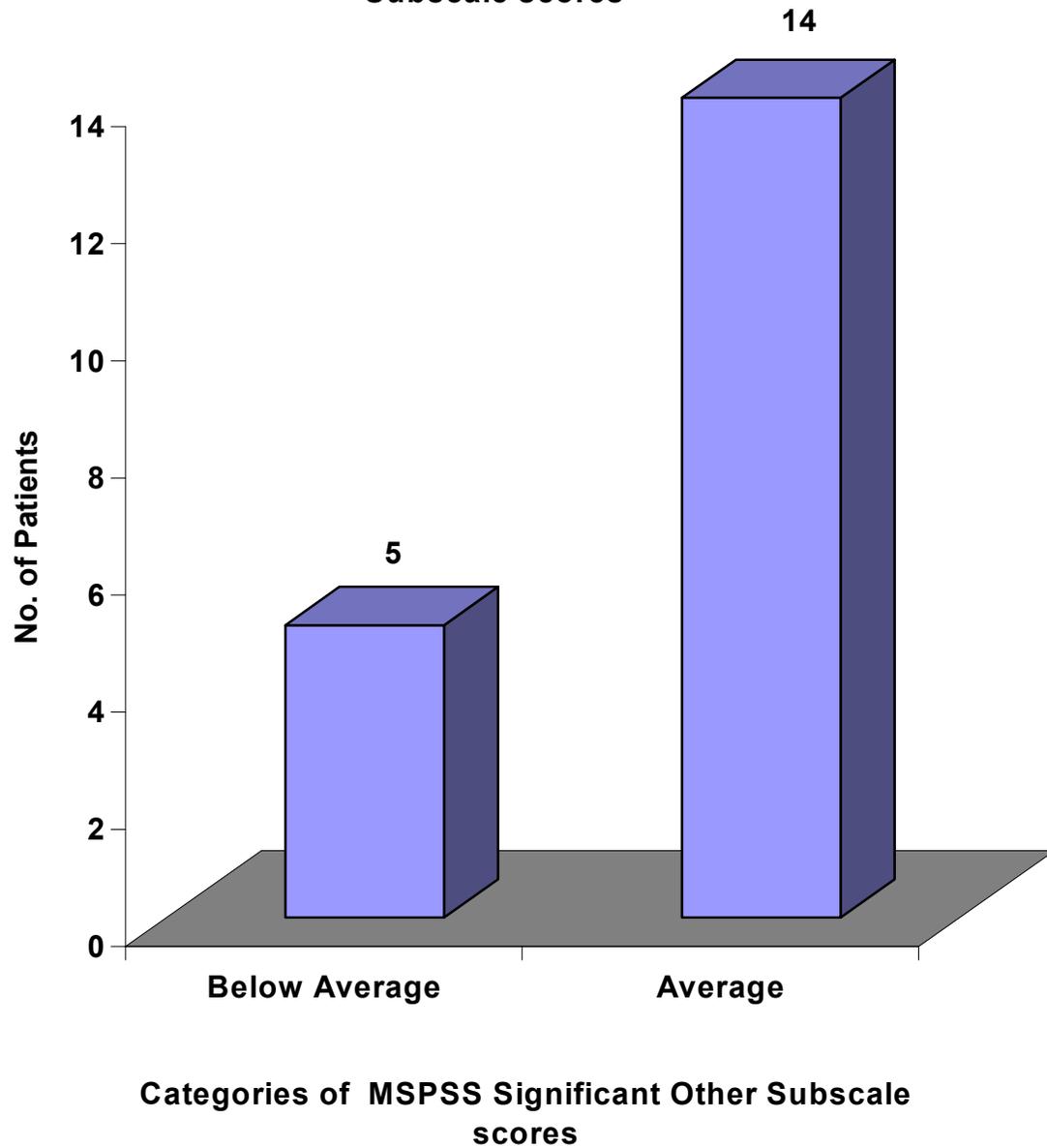
**Analysis with MSPSS Subscale scores:**

Since MSPSS provides the scope of looking at social support from the three different agents- viz., significant other, family and friends, we shall now look into these sub scores.

**Table 13: Distribution of the patients according to the MSPSS Significant Other Sub Scale scores**

<b>Category</b>	<b>No. of Patients</b>	<b>Percentage of Patients</b>
<b>Below Average</b>	<b>5</b>	<b>26.3%</b>
<b>Average</b>	<b>14</b>	<b>73.7%</b>
<b>Total</b>	<b>19</b>	<b>100%</b>

**Figure 13 : Distribution according to the MSPSS Significant Other Subscale scores**



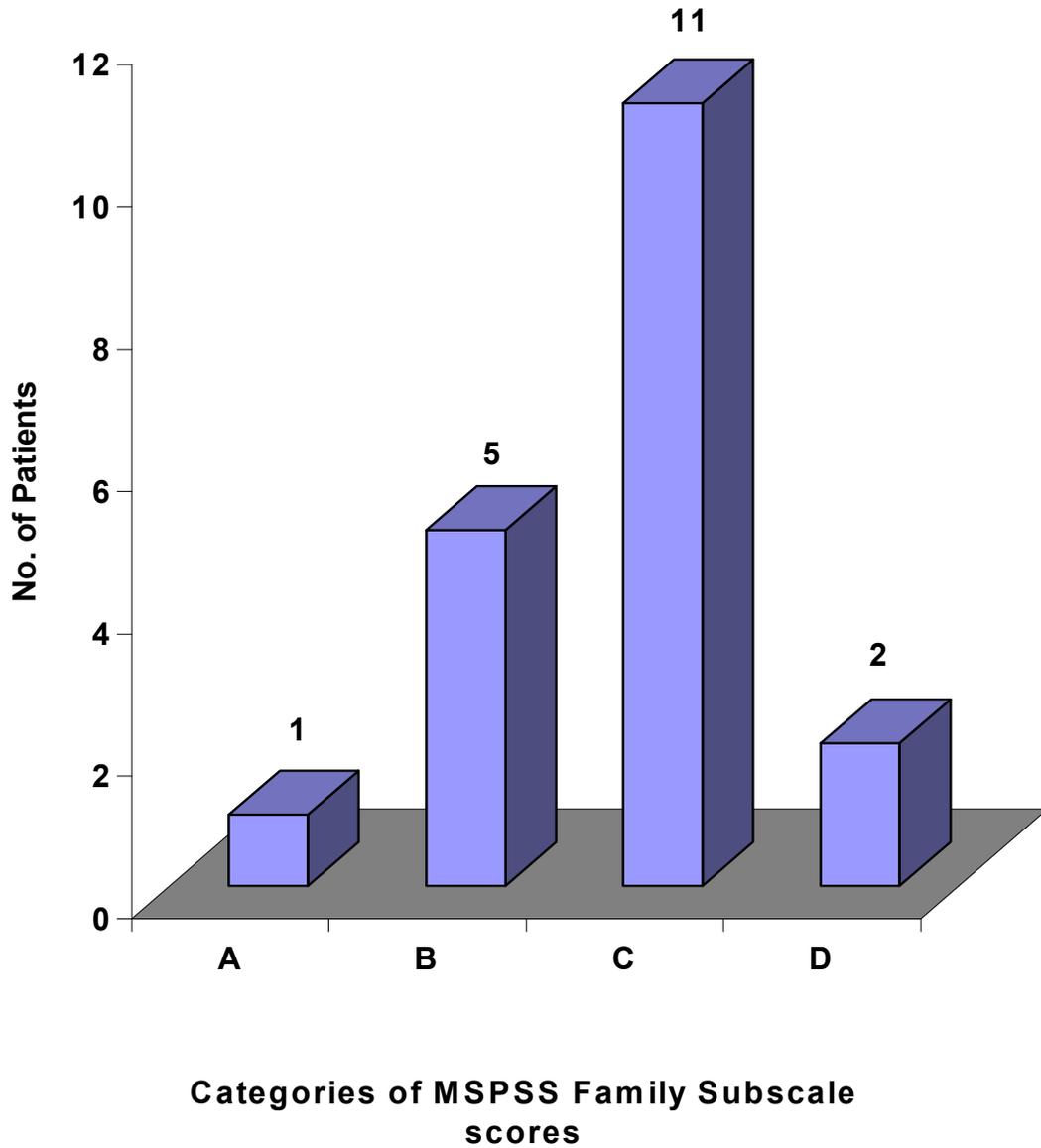
From the Table 13 and Figure 13, it is evident that **73.7% of the sample reflects average perceived social support from a significant other person.** This is followed by **26.3% of the sample that reflects below average** perceived social support from a significant other person. There were found to be **no case reflecting above average perceived social support** from a significant other person.

**Table 14: Distribution of the patients according to the MSPSS Family Subscale scores**

<b>Category</b>	<b>No. of Patients</b>	<b>Percentage of Patients</b>
<b>Very Poor Perceived Social Support from Family</b>	<b>1</b>	<b>5.3%</b>
<b>Below Average Perceived Social Support from Family</b>	<b>5</b>	<b>26.3%</b>
<b>Average Perceived Social Support from Family</b>	<b>11</b>	<b>57.9%</b>
<b>Above Average Perceived Social Support from Family</b>	<b>2</b>	<b>10.5%</b>
<b>Total</b>	<b>19</b>	<b>100%</b>

Note: The figures in percentage indicate values approximated upto one decimal place.

**Figure 14 : Distribution according to the MSPSS Family Subscale scores**



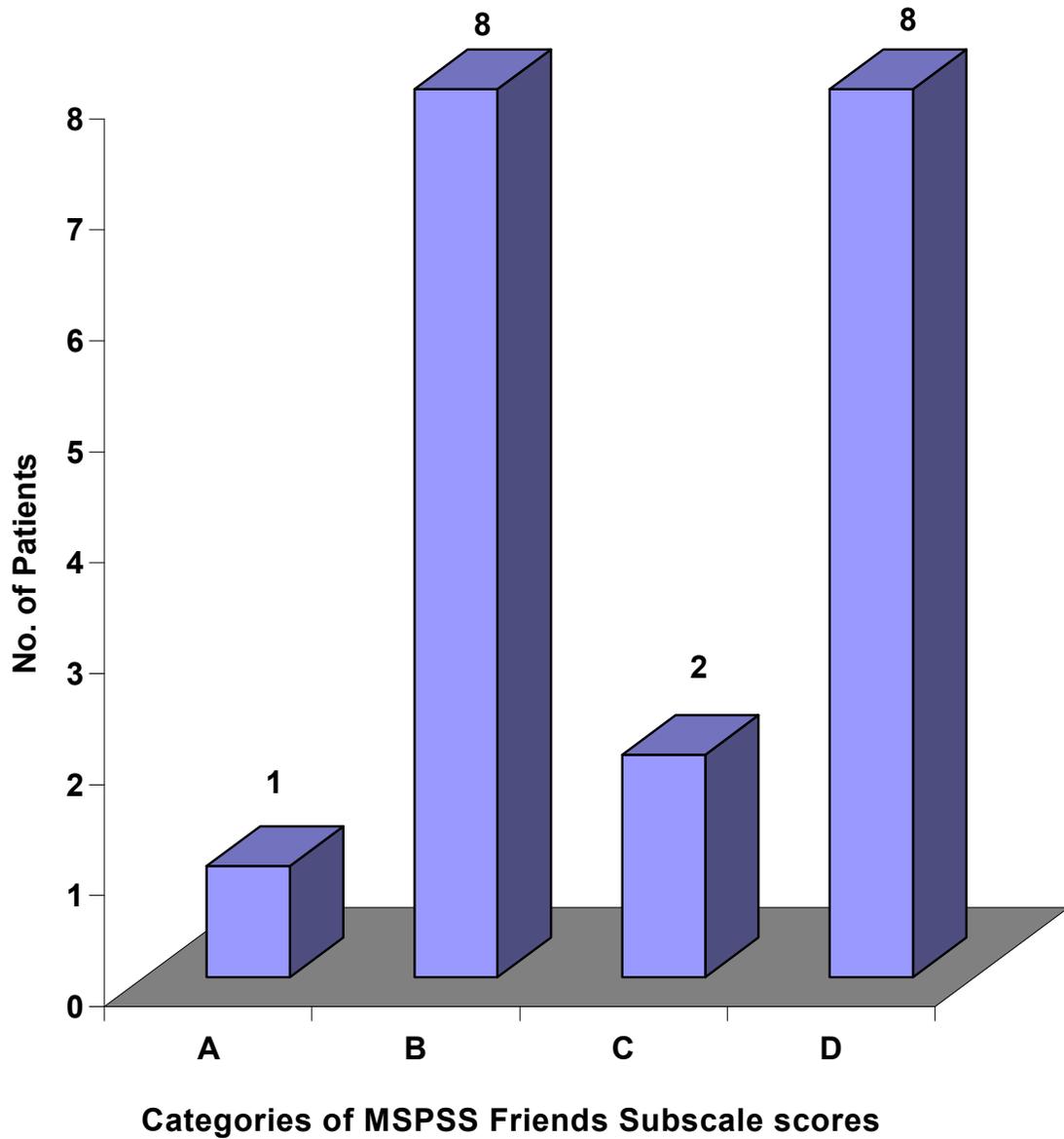
- A- Very Poor Perceived Social Support from Family**
- B- Below Average Perceived Social Support from Family**
- C- Average Perceived Social Support from Family**
- D- Above Average Perceived Social Support from Family**

From the Table 14 and Figure 14, it is evident that **57.9% of the sample report average perceived social support from family**, and 26.3% of the sample report below average perceived social support from family. Thus the perceived social support from family offers a much better picture than that perceived from significant other persons.

**Table 15: Distribution of the patients according to the MSPSS Friends Subscale scores**

<b>Category</b>	<b>No. of Patients</b>	<b>Percentage of Patients</b>
<b>Very Poor Perceived Social Support from Friends</b>	<b>1</b>	<b>5.3%</b>
<b>Poor Perceived Social Support from Friends</b>	<b>8</b>	<b>42.1%</b>
<b>Below Average Perceived Social Support from Friends</b>	<b>2</b>	<b>10.5%</b>
<b>Average Perceived Social Support from Friends</b>	<b>8</b>	<b>42.1%</b>
<b>Total</b>	<b>19</b>	<b>100%</b>

**Figure 15 : Distribution according to the MSPSS Friends Subscale scores**



- A** - **Very Poor Perceived Social Support from Friends**
- B** - **Poor Perceived Social Support from Friends**
- C** - **Below Average Perceived Social Support from Friends**
- D** - **Average Perceived Social Support from Friends**

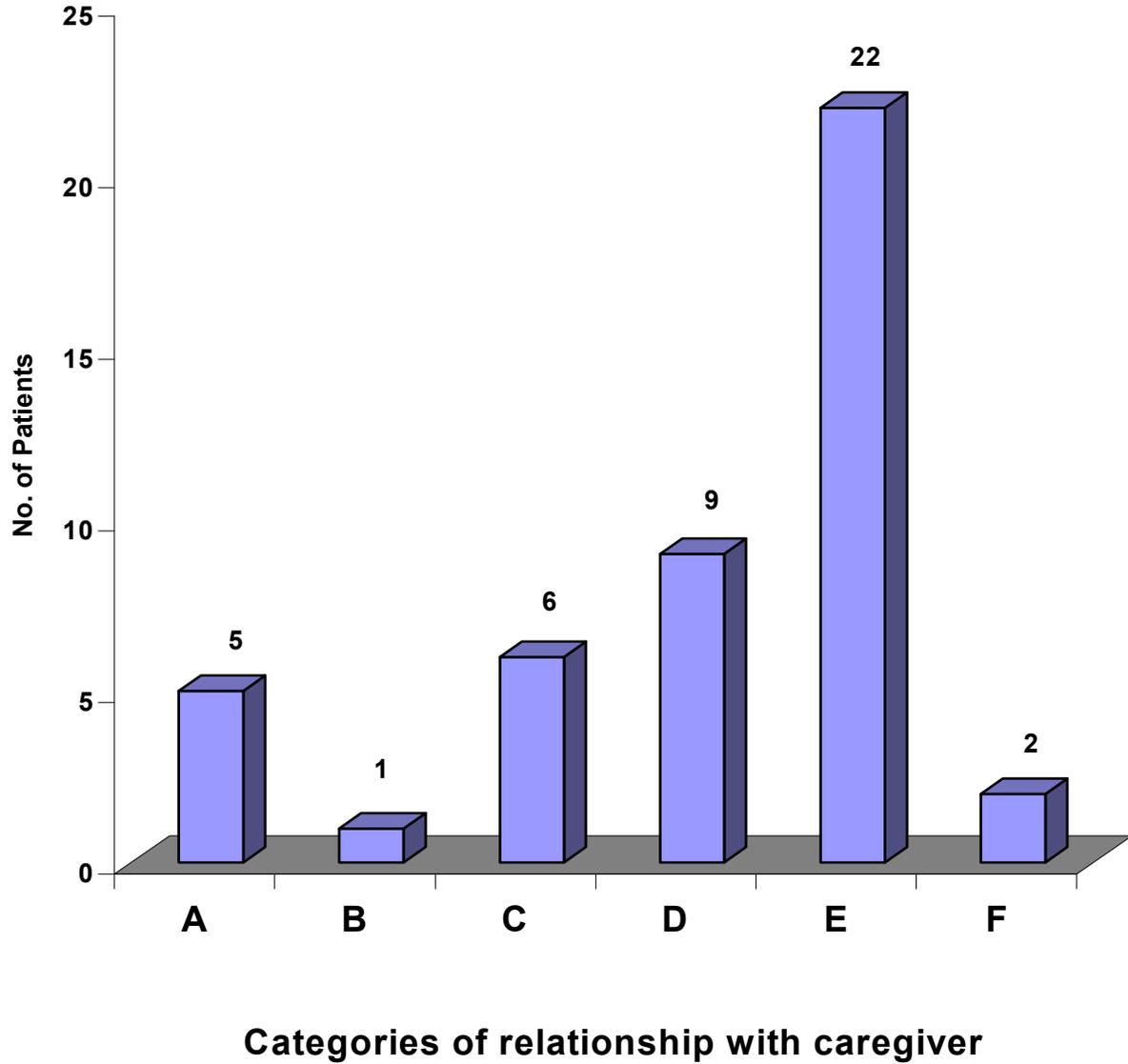
From the Table 15 and Figure 15, it is evident that **42.1% of the sample reflects poor perceived social support from friends and 42.1% sample also responded in favor of average perceived social support from friends.** This is followed by 10.5% who report below average perceived social support from friends.

Thus, compared to significant other and family sub scale scores, the friends sub scale scores indicate that these patients perceive very little social support from friends or the social circle outside their home. The statistical analysis also shows that the significant other sub scale score and family sub scale score are better than the friends sub scale score. This finding also indicates that perceived social support is yet to come from the society at large.

**Table 16: Distribution according to the relationship with caregiver**

<b>Category</b>	<b>No. of Patients</b>	<b>Percentage of Patients</b>
<b>Extremely Bad</b>	<b>5</b>	<b>11.1%</b>
<b>Moderately Bad</b>	<b>1</b>	<b>2.2%</b>
<b>Indifferent</b>	<b>6</b>	<b>13.4%</b>
<b>Cordial</b>	<b>9</b>	<b>20%</b>
<b>Moderately Good</b>	<b>22</b>	<b>48.9%</b>
<b>Extremely Good</b>	<b>2</b>	<b>4.4%</b>
<b>Total</b>	<b>45</b>	<b>100%</b>

**Figure 16: Distribution according to the relationship with caregivers**



**A** - **Extremely Bad**  
**B** - **Moderately Bad**  
**C** - **Indifferent**

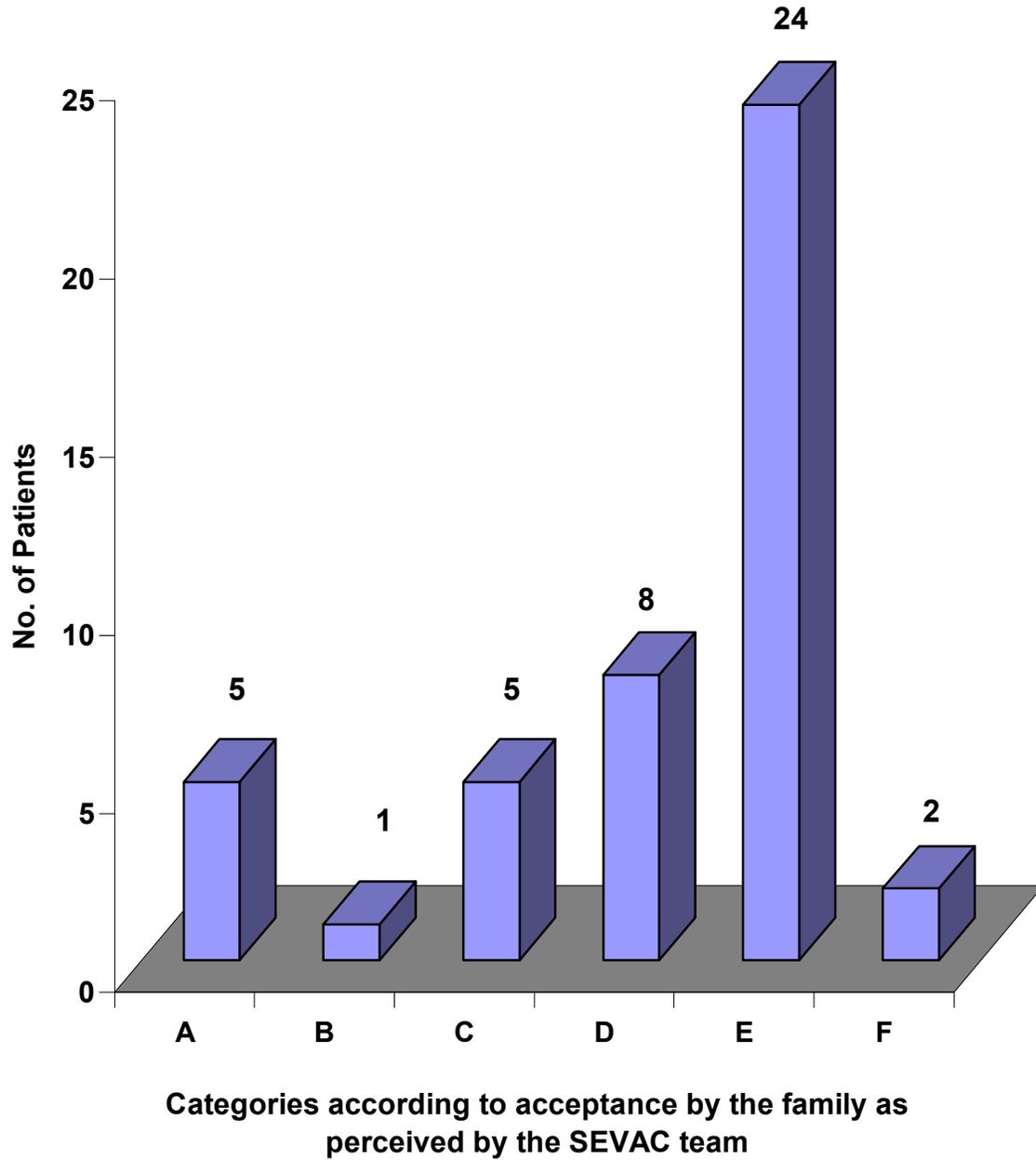
**D** - **Cordial**  
**E** - **Moderately Good**  
**F** - **Extremely Good**

From the Table 16 and Figure 16, it is evident that **48.9% of the sample report moderately good relationship with the caregiver**, followed by **20% of the population who report cordial relationship with the caregiver**. This also validates the MSPSS Family Sub scale Score analysis, which reflected (57.9%) patients responded in favor of average perceived social support from family members. However, **13.4 % report indifferent attitude of caregivers** and **11.1% report extremely bad relationship with caregiver**.

**Table 17: Distribution according to the acceptance of patients by the family as perceived by the SEVAC Team**

Category	No. of Patients	Percentage of Patients
<b>Extremely Rejecting</b>	<b>5</b>	<b>11.1%</b>
<b>Slightly Rejecting</b>	<b>1</b>	<b>2.2%</b>
<b>Indifferent</b>	<b>5</b>	<b>11.1%</b>
<b>Slightly Accepting</b>	<b>8</b>	<b>17.8%</b>
<b>Moderately Accepting</b>	<b>24</b>	<b>53.4%</b>
<b>Extremely Accepting</b>	<b>2</b>	<b>4.4%</b>
<b>Total</b>	<b>45</b>	<b>100%</b>

**Figure 17: Distribution according to the acceptance by the family as perceived by the SEVAC Team**



**A** - **Extremely Rejecting**  
**B** - **Slightly Rejecting**  
**C** - **Indifferent**

**D** - **Slightly Accepting**  
**E** - **Moderately Accepting**  
**F** - **Extremely Accepting**

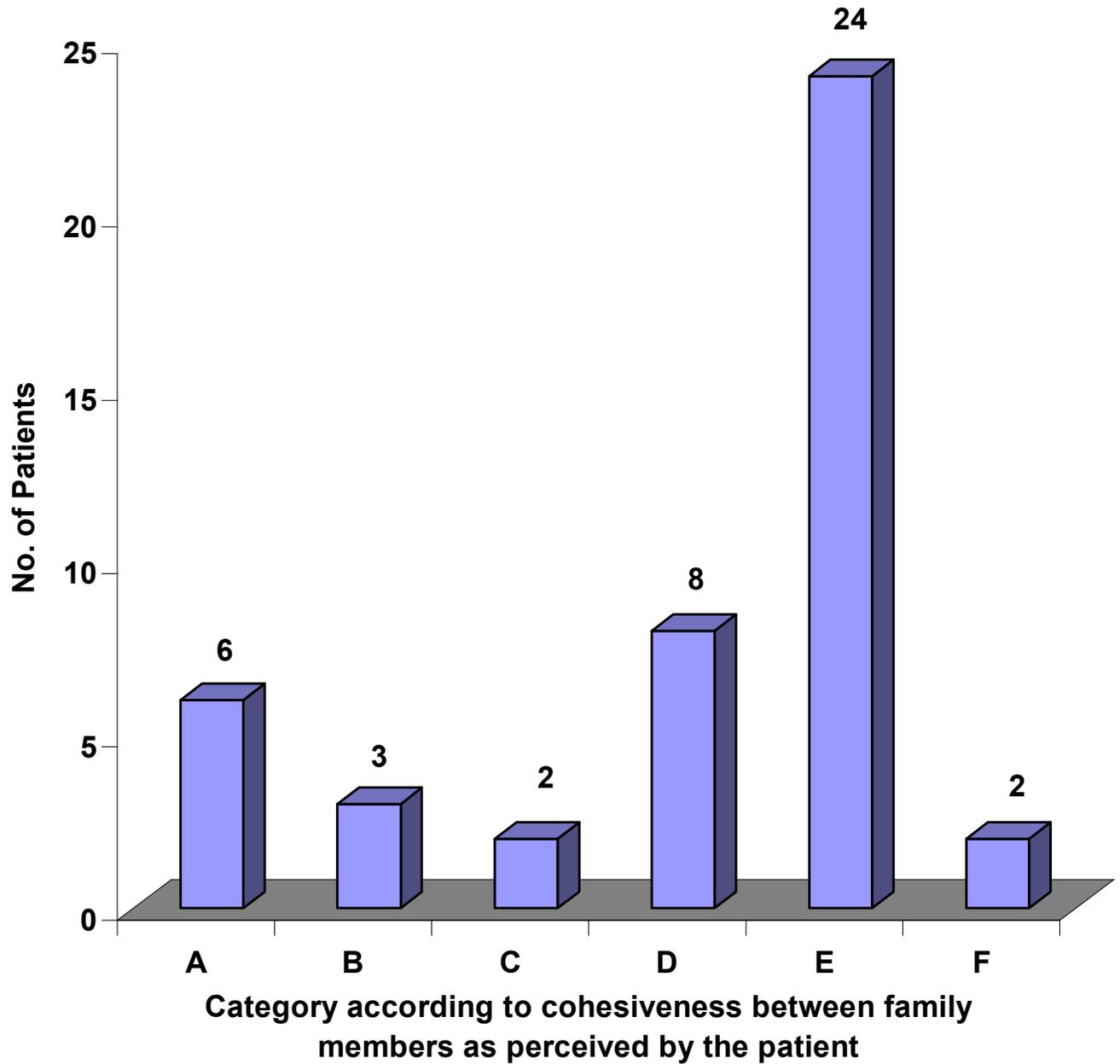
As evident from Table 17 and Figure 17, **53.4% of the sample reported moderate acceptance by the family**, while **only 11.1% reported extreme rejection**.

**Table 18: Distribution according to the cohesion between family members as perceived by the patients**

<b>Category</b>	<b>No. of Patients</b>	<b>Percentage of Patients</b>
<b>Extremely Non-Cohesive</b>	<b>6</b>	<b>13.3%</b>
<b>Moderately Non-Cohesive</b>	<b>3</b>	<b>6.7%</b>
<b>Indifferent</b>	<b>2</b>	<b>4.4%</b>
<b>Slightly Cohesive</b>	<b>8</b>	<b>17.9%</b>
<b>Moderately Cohesive</b>	<b>24</b>	<b>53.3%</b>
<b>Extremely Cohesive</b>	<b>2</b>	<b>4.4%</b>
<b>Total</b>	<b>45</b>	<b>100%</b>

Note: the figures in percentage are corrected upto one decimal place.

**Figure 18: Distribution according to the cohesion between family members as perceived by the patient**



<b>A</b>	-	<b>Extremely Non-Cohesive</b>	<b>D</b>	-	<b>Slightly Cohesive</b>
<b>B</b>	-	<b>Moderately Non-Cohesive</b>	<b>E</b>	-	<b>Moderately Cohesive</b>
<b>C</b>	-	<b>Indifferent</b>	<b>F</b>	-	<b>Extremely Cohesive</b>

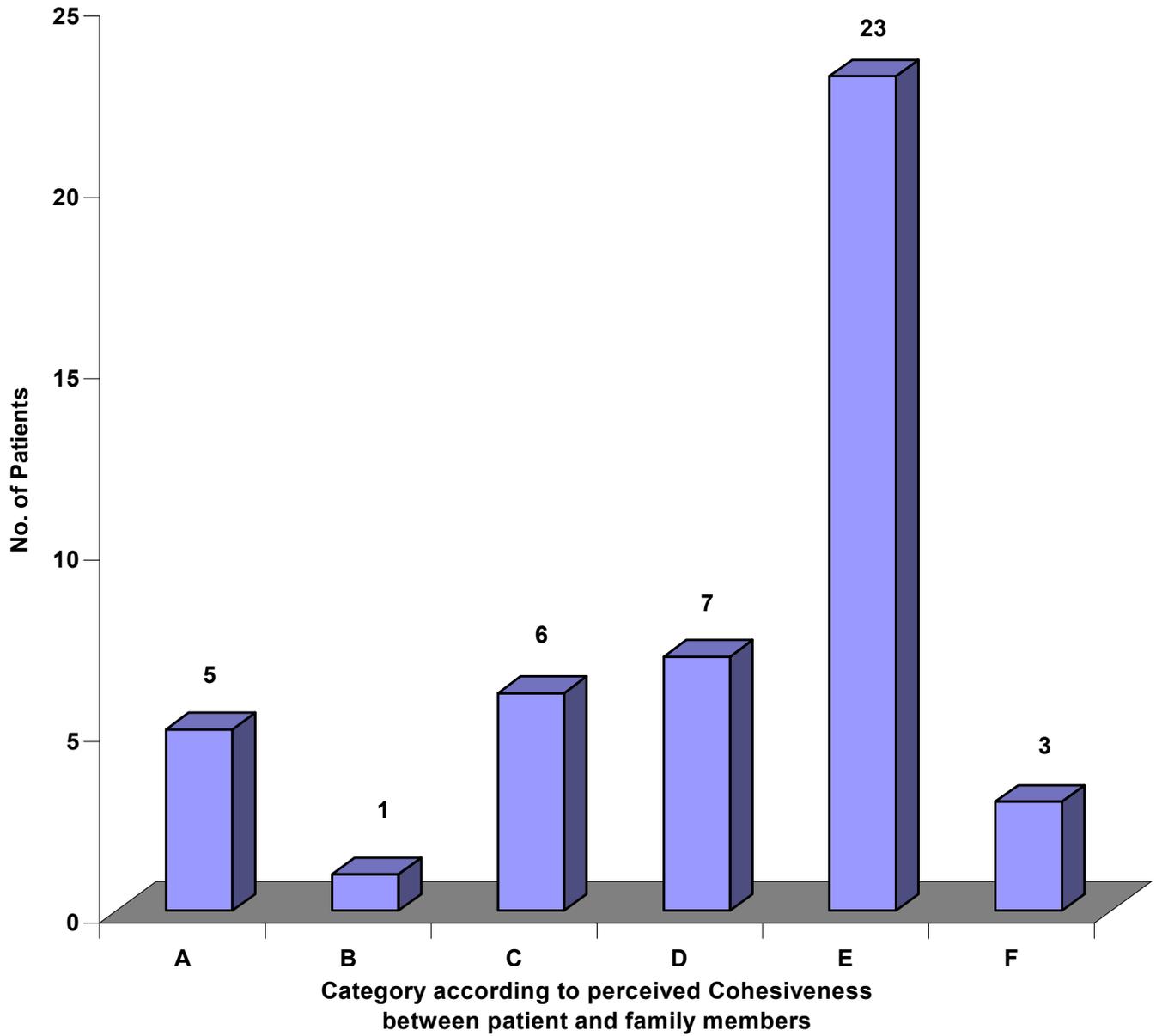
From Table 18 and Figure 18, it is evident that **53.3% of the family members of the sample reported moderately cohesive relationship between them**, followed by **17.9% who reported slightly cohesive relationship between them**. While 13.3% perceive extremely non-cohesive relationship. Now it is to be seen whether this cohesiveness is the same between the patient and family members.

**Table 19: Distribution according to the perceived cohesiveness of the patient between patient and family members.**

<b>Category</b>	<b>No. of Patients</b>	<b>Percentage of Patients</b>
<b>Extremely Non-Cohesive</b>	<b>5</b>	<b>11.1%</b>
<b>Slightly Non-Cohesive</b>	<b>1</b>	<b>2.2%</b>
<b>Indifferent</b>	<b>6</b>	<b>13.3%</b>
<b>Slightly Cohesive</b>	<b>7</b>	<b>15.6%</b>
<b>Moderately Cohesive</b>	<b>23</b>	<b>51.1%</b>
<b>Extremely Cohesive</b>	<b>3</b>	<b>6.7%</b>
<b>Total</b>	<b>45</b>	<b>100%</b>

Note: The figures in percentage are corrected values upto one decimal place.

**Figure 19: Distribution according to the perceived cohesiveness of the patient between patient and family members**



**A** - **Extremely Non-Cohesive**  
**B** - **Slightly Non-Cohesive**  
**C** - **Indifferent**

**D** - **Slightly Cohesive**  
**E** - **Moderately Cohesive**  
**F** - **Extremely Cohesive**

From Table 19 and Figure 19, it is evident that most of the patients felt cohesive with their family members. The **highest was 51.1 % who perceived themselves to be moderately cohesive with other members. 11.1% perceive extremely non-cohesive relationship with family members.** Thus this reflects that a good number of patients feel integrated within the family. So, it attributes well with the intra-familial cohesiveness

### **Analysis with the Variables Used for Interpreting Treatment Compliance**

In the next part the last domain of our objective (i.e. treatment compliance) shall be analyzed. The variables studied for analyzing treatment compliance are:

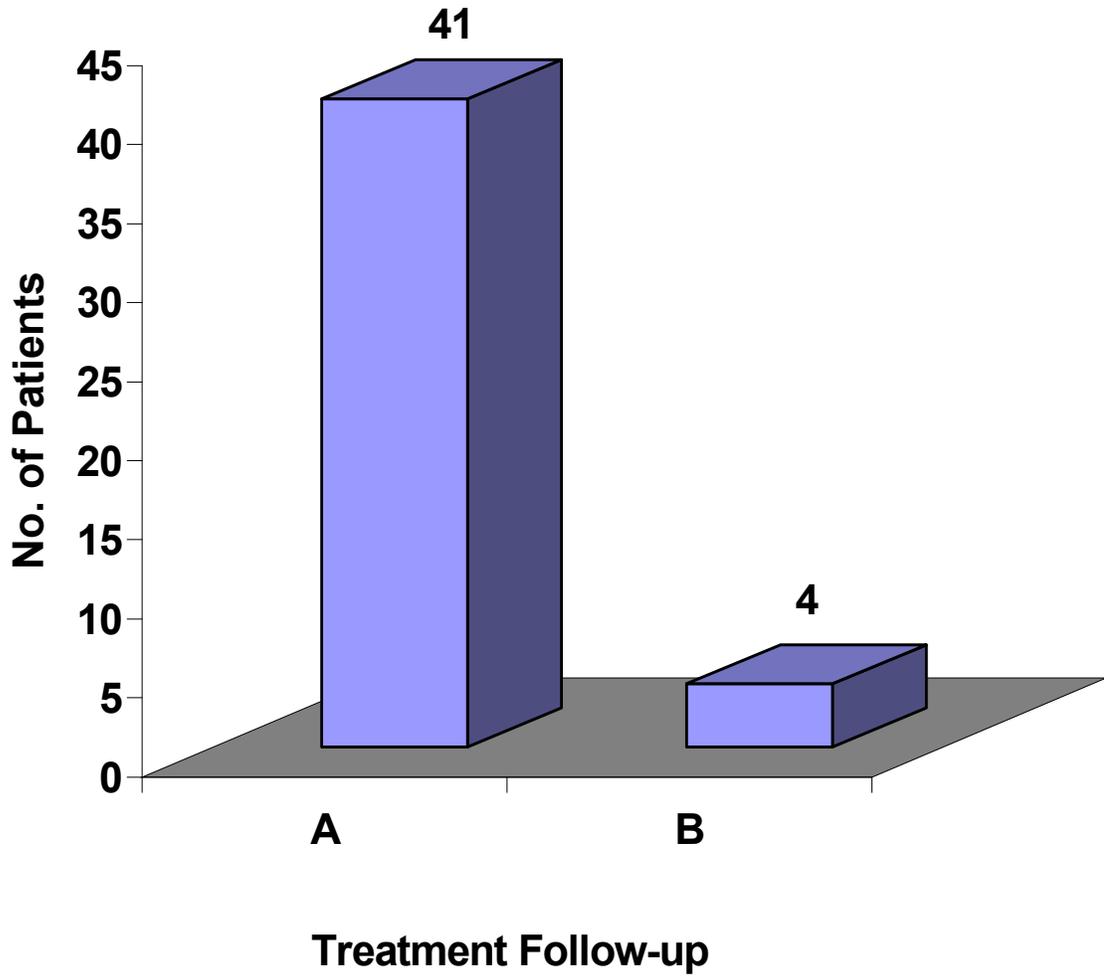
- Treatment follow-up
- Frequency of Visits for Follow-up Treatment
- Consultant Visited for follow-up Treatment
- Reasons for discontinuation/irregular treatment

**Table 20: Distribution of the patients according to the treatment follow-up**

<b>Treatment Follow-up</b>	<b>No. of Patients</b>	<b>Percentage of Patients</b>
<b>Continued</b>	<b>41</b>	<b>91.1%</b>
<b>Discontinued</b>	<b>4</b>	<b>8.9%</b>
<b>Total</b>	<b>45</b>	<b>100%</b>

Note: The figures in percentage indicate corrected values upto one decimal place.

**Figure 20: Distribution of treatment follow-up**



A - Treatment Continued  
B - Treatment Discontinued

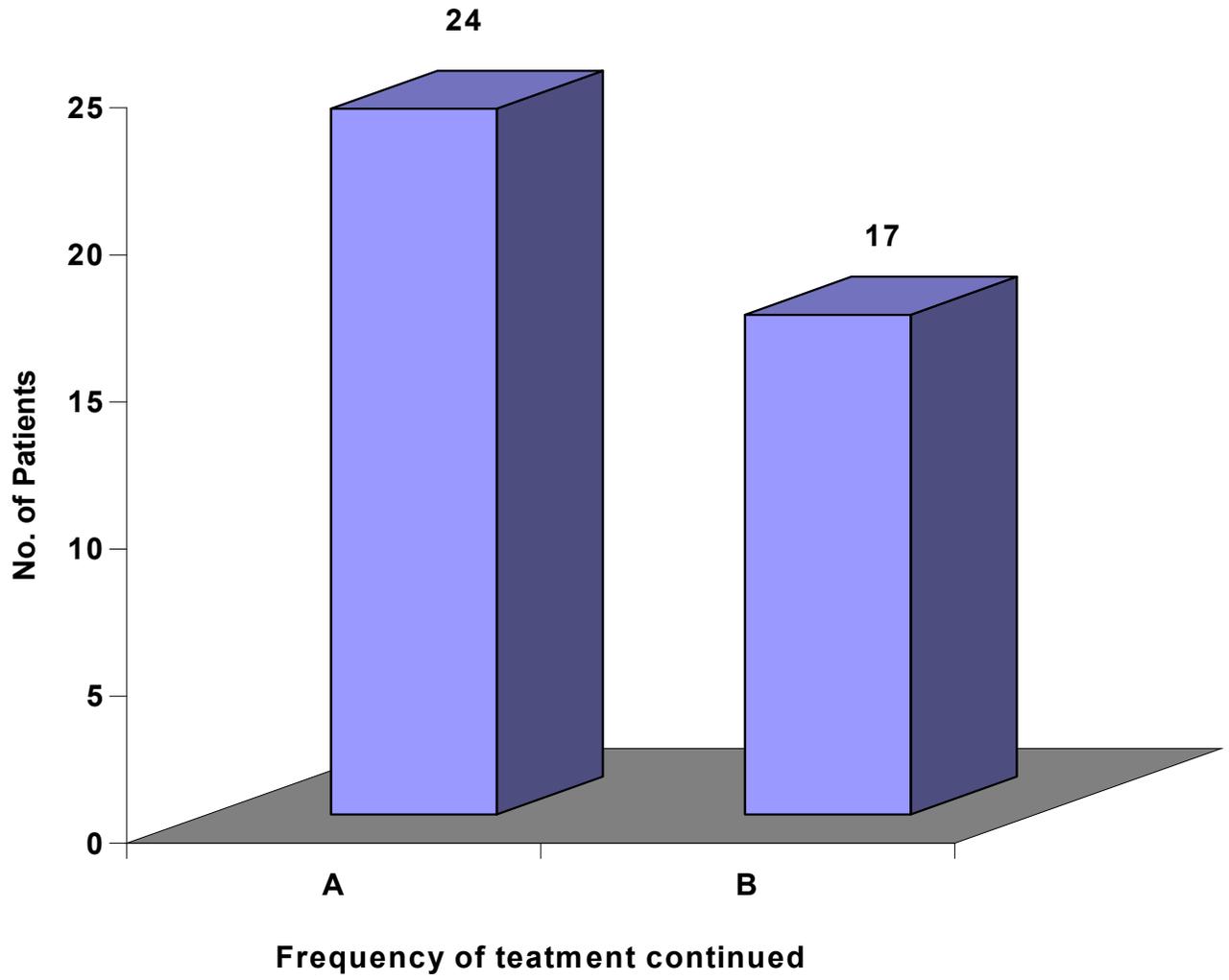
From Table 20 and Figure 20, it can be seen that **91.1% of the sample continued with follow-up treatment**. Keeping in view the economic condition (refer to Table 5) of these patients, this is a very encouraging information. Now it is to be seen whether treatment continued was regular or not and what are the reasons for discontinuation of treatment—if it is solely due to economic reasons or there are other reasons as well.

**Table 21: Distribution of the patients according to the frequency of visits for follow-up treatment:**

<b>Frequency of Treatment Continued</b>	<b>No. of Patients</b>	<b>Percentage of Patients</b>
<b>Regular</b>	<b>24</b>	<b>58.5%</b>
<b>Irregular</b>	<b>17</b>	<b>41.5%</b>
<b>Total</b>	<b>41</b>	<b>100%</b>

Note: 4 patients discontinued treatment. The figures in percentage indicate values corrected upto one decimal place.

**Figure 21: Distribution of frequency of treatment continued**



**A** - **Regular**  
**B** - **Irregular**

The Table 20 and Figure 20 show that although **58.5% of the sample continued regularly with the follow-up treatment, 41.5% could not do so**. It is extremely encouraging that almost 60% continued regularly with the treatment keeping in view the deplorable economic condition of the patients (refer to Table 5).

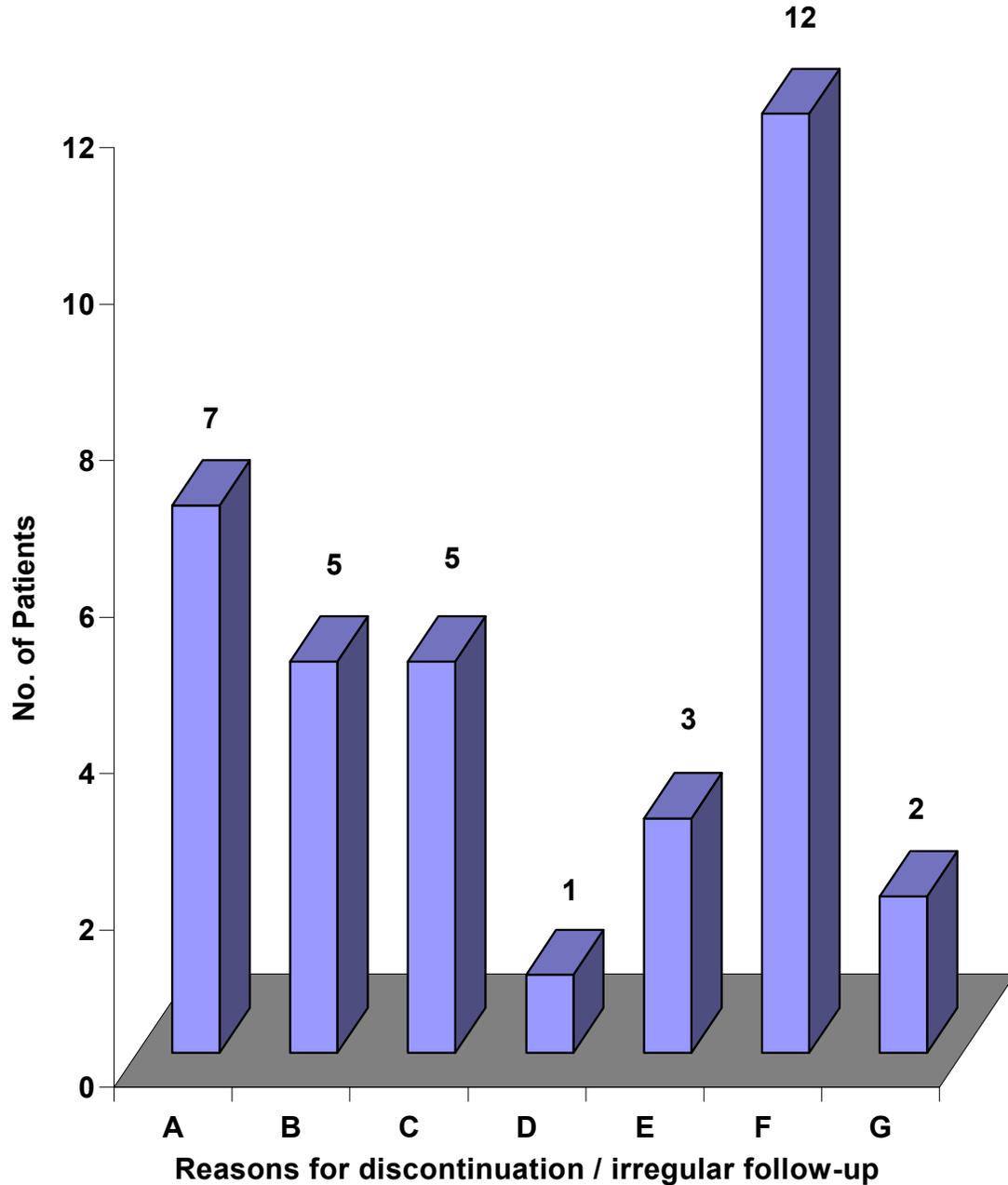
Hence, now arises the need to know the reasons for discontinuation or irregular treatment.

**Table 22: Distribution of patients according to reasons for discontinuation / irregular treatment.**

<b>Reasons</b>	<b>No. of Patients</b>	<b>Percentage of Patients</b>
<b>Financial Constraint</b>	<b>7</b>	<b>20%</b>
<b>Due to Disease Process</b>	<b>5</b>	<b>14.3%</b>
<b>Reluctance on the Part of the Caregivers</b>	<b>5</b>	<b>14.3%</b>
<b>Side Effects of the Drugs</b>	<b>1</b>	<b>2.8%</b>
<b>Distance to the Specified Hospital</b>	<b>3</b>	<b>8.6%</b>
<b>Reluctance on the Part of the patient</b>	<b>12</b>	<b>34.3%</b>
<b>Treatment Terminated</b>	<b>2</b>	<b>5.7%</b>
<b>Total</b>	<b>35</b>	<b>100%</b>

Note: Total no. of patients discontinued or irregular treatment is 21 (Irregular-17 and discontinued-4) Some patients have multiple reasons. Hence the total no of patients exceeds who discontinued treatment or continued treatment irregularly. The figures in percentage are values corrected upto one decimal place.

**Figure 22: Distribution according to the reasons for discontinuation / irregular follow-up treatment**



**A - Financial constraint**  
**B - Due to disease process**  
**C - Reluctance on the part of the caregivers**  
**D - Side effects of the drugs**

**E - Distance to the specified hospital**  
**F - Reluctance on the part of the patient**  
**G - Treatment terminated**

From Table 22 and Figure 22, it is seen that **34.3% of the patients have discontinued treatment because of reluctance on their part**, followed by **20% of the sample that discontinued due to financial constraints**. 14.3% have discontinued because of reluctance on part of the caregiver and also due to disease process. It is noteworthy that **a small section i.e. 2.9% discontinued treatment because of side effects of the drugs**. It is encouraging to know that in spite of financial obstacles, the sample manages to continue treatment. But the major reason for discontinuation or irregular visits may lead to two implications:

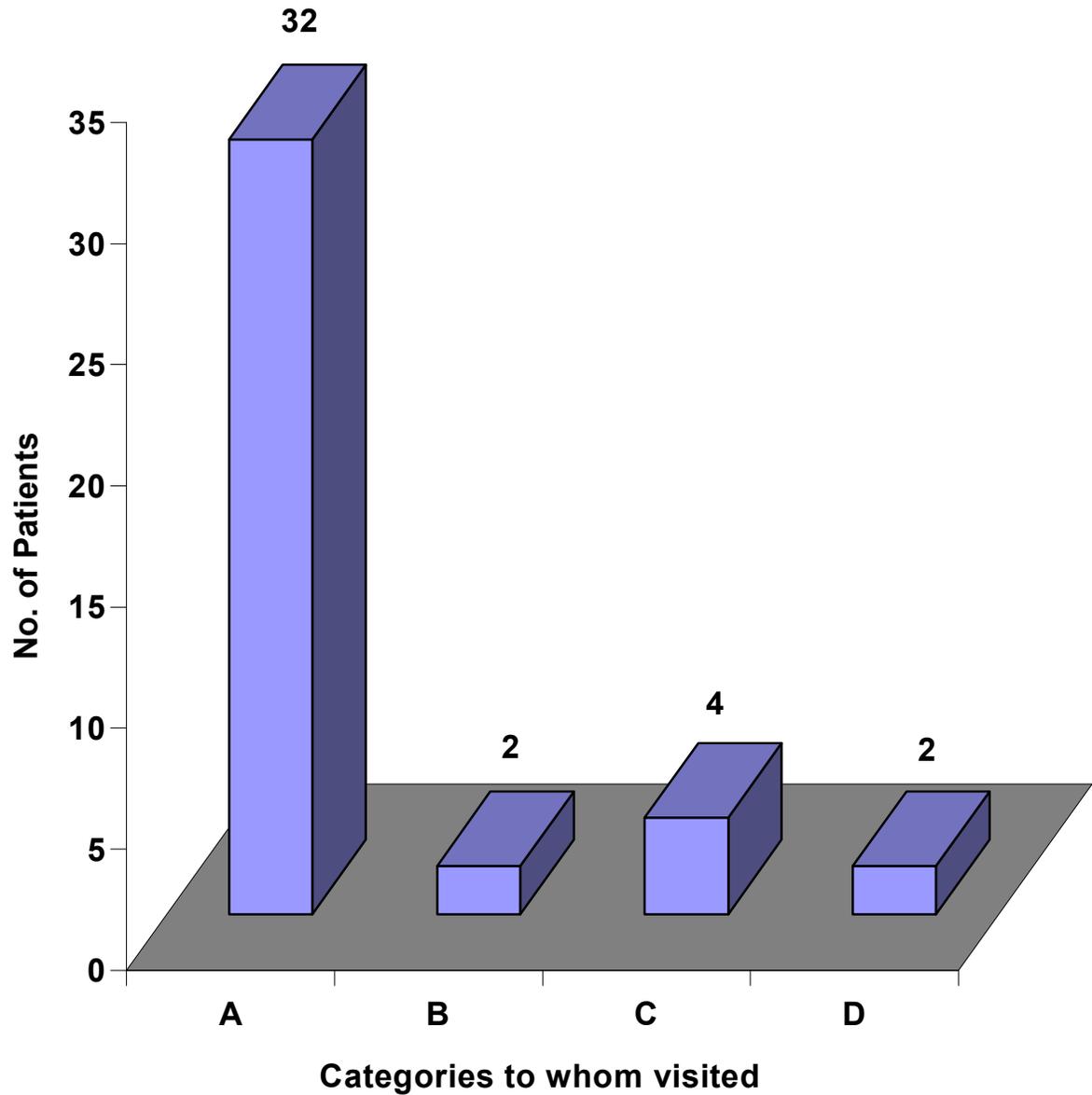
- As a part of disease process, the patients are unwilling to go for treatment;
- It could also be that due to the deplorable condition of the Govt. Hospitals, the patients are reluctant to visit the aforesaid hospitals;
- An initial side effect of the medication, the patients have acquired a negative attitude towards the hospital care.

**Table 23: Distribution of the patients according to whom visited for treatment**

<b>Whom Visited</b>	<b>No. of Patients</b>	<b>Percentage of Patients</b>
<b>Specified Hospital</b>	<b>32</b>	<b>80%</b>
<b>Local Hospital/NGO</b>	<b>2</b>	<b>5%</b>
<b>Private Practitioner</b>	<b>4</b>	<b>10%</b>
<b>Quack</b>	<b>2</b>	<b>5%</b>
<b>Total</b>	<b>40</b>	<b>100%</b>

Note: Information for 5 patients could not be obtained.

**Figure 23: Distribution according to whom visited for follow-up treatment**



- A** - Specified hospital
- B** - Local hospital/NGO
- C** - Private practitioner
- D** - Quack

As evident from Table 22 and Figure 22, **80% of the sample visited specified hospitals**. Since it is expensive to visit private practitioners most of the women belonging to BPL families (refer to Table 5), could not afford to visit anywhere else. But what is encouraging is that **only 5% of the sample have visited quacks**. This is highly encouraging considering the educational level and economical conditions of most of these women (refer to Table 2 and table 5).

Hence, in conclusion of this section, the following points may be pointed out:

- Majority of the sample (58.5%) was found to have continued regularly with follow-up treatment, in spite of the deplorable economic condition of most of the families.
- Majority of the sample(80%) was found to have continued with treatment to the specified hospitals.
- The most important reasons for discontinuation/irregular follow-up seems to be reluctance on the part of the patient(34.3%) and financial constraint.(20% )
- Very few of the cases (5%) in the sample followed up to a quack. It is highly encouraging since this point to the fact that in spite of low educational level and deplorable economic condition, they still insist on being followed up to the specified hospitals. .

**Analysis of associations between relevant variables with Chi-square tests.**

Chi-square tests were conducted between some relevant variables to test for associations in an attempt to arrive at certain conclusion for the findings.

**Table 24: Chi-Square values for the test between family income and follow-up treatment.**

<b>Chi-Square Value</b>	<b>df</b>	<b>Significance</b>
<b>1.822</b>	<b>6</b>	<b>N.S</b>

The Table 24 clearly indicates that family income and treatment compliance is not significantly associated. Although one of the causes of discontinuation was found to be financial constraint., the present chi-square test reveals that there was no significant association between the two variables. Hence, it indicates that many families with low income have also continued follow-up treatment in face of all the difficulties.

**Table 25: The Chi-Square values for the test between family income and whom visited**

<b>Chi-Square Value</b>	<b>df</b>	<b>Significance</b>
<b>10.95</b>	<b>15</b>	<b>N.S</b>

Table 25 clearly indicates that family income and whom visited for follow-up treatment were not significantly associated. Hence, in spite of the fact that the families of the patients have very low income to support their treatment, they have continued treatment to specified hospitals, as revealed in Table 22, and not to any quacks.

**Table 26: The Chi-Square values for the test between MSPSS significant other sub scale scores and age**

<b>Chi-Square Value</b>	<b>df</b>	<b>Significance</b>
<b>18.39</b>	<b>15</b>	<b>N.S</b>

Table 26 indicates that perceived social support from a significant other person was not significantly associated with age.

**Table 27: The Chi-Square values for the test between MSPSS family sub scale scores and age**

<b>Chi-Square Value</b>	<b>df</b>	<b>Significance</b>
<b>17.61</b>	<b>25</b>	<b>N.S</b>

Table 27 shows that perceived support from family and age were not significantly associated. This clearly shows that all age groups have perceived adequate support from their families.

**Table 28: The Chi-square values for the test between QOL scores and level of education:**

<b>Chi-square Value</b>	<b>df</b>	<b>Significance</b>
<b>24.94</b>	<b>16</b>	<b>0.10</b>

Table 28 indicates a significant association between level of education and the quality of life scores of the patients. Hence, it may be said that education does serve to benefit these poor women in the face of such difficulties. Perhaps education stocks up on the coping skills which are so very important in dealing with mental health problems.

**Table 29: The chi-square values for the test between QOL scores and age:**

<b>Chi-square Value</b>	<b>df</b>	<b>Significance</b>
<b>12.106</b>	<b>20</b>	<b>N.S</b>

Table 29 indicates that there is no significant association between QOL scores and age. Hence, with age there is no difference in one's quality of life among these patients. Hence it may be inferred that the low educational level and poor economic condition are responsible for their poor quality of life.

**Table 30: The Chi-Square values for the test between family income and QOL scores**

<b>Chi-Square Value</b>	<b>df</b>	<b>Significance</b>
<b>16.65</b>	<b>20</b>	<b>N.S</b>

Table 30 indicates that there is no significant association between family income and QOL scores. Hence, it may be said that the quality of life does not depend on the family income. Two implications can come out of this finding, firstly, these women have become so habituated in living amidst their deplorable economic condition, that they have accepted their pathetic standards, and hence have partially learnt to live with it. Secondly, since the kind of social support perceived at home is quite good, it makes up for the other obstacles.

### **Section III**

#### **Summary of Statistical Findings from the Current Study and Conclusions**

- 11% of the total sample (100 women) have been shifted to other places like other hospitals, Homes or police custody. Hence the need for living status is reflected by 11% of the sample. Some infrastructure like Half-Way Home needs to be built for this group of the patients under study.
- 32% of the cases were found to have inadequate, untrue or misleading addresses. Specifically, the addresses were not sufficient or were not true for this section of the sample. This clearly shows the negligence on the part of the hospital authorities in noting down their proper detail. There may be some unwillingness on the part of caregiver in giving their details due to the stigma associated with mental illness.
- The age-wise analysis suggests that the peak age of the sample for mental illness is around 20-50 years. Since this is the productive period of the female life cycle, it is essential to provide these women with proper rehabilitation, so that these precious years of their lives are not lost and they can lead meaningful lives as productive individuals, fulfilling their roles of a wife, mother etc.
- Education level-wise analysis and occupation-level wise analysis suggest that majority of these women (33.3%) have no formal education and are unemployed (83.7%). Keeping in mind the significant association between education and quality of life (refer to Table 29) as per the analysis, it may be suggested that some form of rehabilitative therapy may be provided to these women during their stay at the hospital. In these essential rehabilitation sessions, a basic level of education may be provided to these women, so that education serves to add meaning to their lives and helps them raise the quality of life. Education may thus, also, prepare them for some occupation. Hence, educational and occupational rehabilitation are primary needs for these women. It is also revealed that financial constraints is one of the important causes for discontinuation of treatment (refer to Table 21). If these women are provided with some occupational rehabilitative therapy, they can become productive individuals by contributing to the family income on their own. This will not only help them to afford the costs of the follow-up treatment but also essentially

integrate them with their family members. This, in turn, will lead to better acceptance and support from their family members and thus their quality of life could be improved.

- 15.6% of the sample interviewed (45 women) have been found to have been separated, or simply dumped by their spouses. These women are now living in deplorable conditions, either in their parental homes or in a mostly non-caring environment. Some of them were even found roaming on the roads. Some form of legal protection needs to be provided to these unfortunate women, so that it doesn't become so easy for their spouses to just dump them amidst illness. This could also help them in getting some financial support from their spouses to help them continue with their treatment.
- The Mental Status Examination (MSE) reports of most women indicate that 51.1% of them are in unstable condition. The Brief Psychiatric Rating Scales (BPRS) scores also indicate that majority of the sample were mildly ill (43.6%) or moderately ill (35.9%). From Table 20 & 21 it is evident that 8.9% have discontinued treatment and 41.5% have continued with irregularity. This irregular treatment was mostly due to two factors—reluctance on the part of the patient to go for treatment, and financial constraint of the family. This could be attributed to two implications—
  - i) reluctance due to disease process
  - ii) reluctance to visit the specified hospital

The second implication is alarming because a good number (34.3%) have expressed their unwillingness to go for treatment and this reflects that the condition of health care in the government hospitals is quite a sore picture. Steps ought to be taken to ensure proper infrastructure to get a quality care service.

- Even in the face of financial difficulties and low educational level, 91.1% have continued with treatment, 58.5% have continued with follow-up treatment regularly and 80% of the sample have been found to have followed-up to the specified hospital, though the infrastructure and quality of care is lacking.
- Another major implication is to be pointed out with regards to the reasons for discontinuation or irregular treatment compliance. 2.8% of the sample discontinued follow-up treatment or continued with follow-up treatment irregularly due to side effects

of the drugs. It may be mentioned here that the drugs prescribed to these patients, as found out by the SEVAC team, were mostly backdated and having untoward side effects.

- The level of social integration is much better in the family than outside in the social circle. From Table 14 it is clear that 57.9% had average perceived social support from family while 42.1% reported poor perceived social support from friends (Table 15). It is interesting to note from Table 13 that 73.7% had average perceived social support from significant other persons and 26.3% reported below average perceived social support from significant other persons (refer to Table 13). These significant other persons are mainly attributed to their family members. About 48.9% of women have reported moderately good relationship with caregiver (refer to Table 16) and 51.1% have reported to have moderately cohesive relationship (refer to Table 18) within family; 53.4% have reported moderately accepting attitude from family members (refer to Table 17). Hence it may be pointed out that the social integration within the family is indeed very positive for the women who have a decent and sufficient living status. It balances the absence of treatment compliance due to financial constraint. Thus the perceived social support from a significant other person, therefore, may be said to be within the family rather than as a significant friend from outside the family circle. It may be added that most of the patients reported to be mildly or moderately ill according to BPRS norms, are withdrawn, and therefore do not have the capacity to socialize. Yet the social support they perceive from the family supports the notion that the family circle indeed provides good support. On the other side of the coin, a finer analysis with the statistics suggest that patients may have provided socially desirable answers when asked directly about the acceptance of family members. When tested with objective indicators such as the MSPSS, some significant findings are found which contradict the responses to the direct questions. Majority of the patients report moderately good relationship with caregiver (refer to Figure 16) and moderately accepting attitude of family members (refer to Figure 17), whereas, the MSPSS Family Subscale Scores indicate that majority of the sample reported average perceived social support from family (refer to Figure 14), as also the MSPSS Significant Other Subscale which show majority reported average or below average perceived social support from significant other person (refer to Figure 13). This interesting finding may be attributed to some unique psychodynamics in the relationship of the patients and their

caregivers. The social support from the caregivers or family may indeed be good. It may also be that the patients expect better attitude; in spite of being withdrawn they expect some family member to break the ice and create a trustworthy and friendly bond with them; in short, although seeming withdrawn, they crave for close interpersonal bonds; probably due to their higher expectations and low appraisal of reality, they project this expectation onto the caregivers' behaviors. Consequently they overrate the attitude or the social support received at home when asked directly. Hence, the attitude of caregivers at home, although good beyond the standards of that offered by friends, may be overrated as perceived by the patients.

- Another interesting finding is that from the Chi-square test between QOL and Family Income, which reports not significant association between these two variables (refer to Table 35). This suggests that although hailing from extremely low economic homes, the quality of life is not dependent on the comforts or luxuries that money can buy. It may also be suggested that due to their low economic profiles, these patients are habituated to live amongst poverty. Hence they are equipped with sufficient coping skills to survive amidst this deplorable condition. Hence, their quality of life is not dependent on their economic profiles. Perhaps contributing to this is the good quality of perceived support from family. Thus these patients provide an example that money cannot buy everything, not even a better quality of life. This is supported by the finding from the Chi-square test between education and QOL scores, which reports significant association (refer to Table 33). Hence, it points out the fact that education serves to improve quality of life, due to the sheer effect of education in refining one's perceptions, and other survival skills. Hence the need to extend educational training to these women, so that they become armed to handle the deficiencies and challenges in their lives and get to lead a healthy and meaningful life.
- Some exemplary cases who have been reported to have been working and are absorbed into the mainstream of society shall be highlighted. These women provide the track which other patients can follow. There are also case studies of a few women that the SEVAC team has come across, who can be described to be living in utter agony and deplorable conditions. Indeed, these case studies will help throw more light upon the needs of these unfortunate women.

## Discussion

In course of conducting the current research study we revealed some remarkable features that have never been highlighted previously in the context of rehabilitation of the mentally ill people in our country. In fact, the research study focusing on the living status, quality of life and treatment compliance for the female mental patients was most probably the first of its kind in India.

The first experience that our team gathered while implementing the project is that improper / incomplete address was given in the hospital register, accounting for about 32% of the sample. It was really frustrating to search such vague addresses in the remotest areas (if necessary, such addresses were visited multiple times) around our project fields i.e. Kolkata, 24 Parganas (North), 24 Parganas (South), Howrah and Hooghly. Our team opines that two factors may be responsible in this regard. One factor may be the reluctance and negligence on the part of the officials in respect of probing the accurate addresses of the patients at the time of admission. The other factor may be the caregivers' hesitation to reveal the accurate address and identity of the patients due to stigma associated with mental illnesses.

When our team reached the dwellings of the patients who furnished genuine addresses, we gathered mixed experiences about their living condition, which was indeed surprising. We came across some of our target groups who were kept in chains, one of them in particular was kept totally secluded in an iron cage constructed specially, some were wandering aimlessly, while some were isolated in garbage packed rooms. The statistical analysis revealed that 15.6 % of our sample size were isolated in such a way. But in some cases reality far exceeded the statistical intricacy. As for example, we found that some patients were not only dumped in such a stark condition, but also experienced sexual abuse and domestic violence frequently.

Precisely, such abuse and violence definitely correlates the increased risk factor for relapses and the resurgence of new mental health symptoms (Ramsay et al 2001). It also clearly points out that our modern society is still not prepared to prevent the exploitation of women folks, even if they are mentally unstable.

When we took stock of the socio demographic data, we found that most of the female patients were between 20-50 years of age and some of them had no formal education and were unemployed. There were obviously some exceptions where the patients were earning on their own. But it does not mean that they have sustained satisfactory social adjustment, improved interpersonal and social living skills to achieve significant quality of life.

It is noteworthy that approximately half of our target groups were married. On the contrary, a chunk of them was single. A certain percentage of the married population was deserted by their husbands and in-laws, which points out the inhuman and indiscriminate gender deprivation as well as stigmatization of the women with mental illness. In this context it is noteworthy that in most of the cases the spouse of the married mentally ill women do not bother to take any step for divorcing their counterparts legally. They simply purge them from their respective families and send them back to their parental house. Even if they were living in their own parental homes, they were overburdened with critical comments and high expressed emotions.

Numerous studies have pointed out that family psychoeducational interventions are effective in preventing relapses for severe mental illnesses (Dixon et al 2001). But it is unfortunate that such an important issue has never been given its due importance in our country and that no infrastructure for family intervention and supportive family counseling on the part of the Government Hospitals from where they were therapeutically benefited has yet been developed.

The team of mental health professionals of SEVAC also conducted the Mental State Examination of every patient covered under this project and found that more than half of them were unstable clinically. The BPRS score also validated our findings of the Mental State Examination of these patients. This instability was largely due to the poor treatment compliance by the patients.

In this context it is noteworthy that treatment compliance plays a pivotal role in respect of preventing the relapse and ensuring some quality of life. But treatment compliance is affected by many factors like the therapist's characteristics, the service, and the nature of treatment, financial constraints and the patient's idiosyncrasies (Montoya et al 2006). According to the observations of our team, in some cases "therapist's characteristics" as well as the "government mental health care delivery infrastructure" are inadequate for ensuring the treatment compliance on the part of

the patients. As for example, the use of backdated medication and their untoward side effects (worth mentioning about the presence of Extrapyramidal Side Effects among majority of them) are hindrances towards good treatment outcome. Still these poor souls do not have any option but to depend on the available infrastructure and therapists. Another observation made by our team in connection with the poor treatment compliance is the distance from the patients' homes to the follow up hospital as well as the non-existence of mental health care delivery in primary / community health care settings. Again, the reluctance on the part of the government hospitals in respect of following the recommended guidelines often hinder the therapy outcome.

The *Quality of Life Score*, as evident, reveals that majority of the patients (approx. 60% of the patients covered under the study) had poor life indices as rated by them. On the contrary, there is also a significant number of patients who maintained good quality and functioning by overcoming the difficulties from the disease process even after not having adequate social support. These women stand out as examples from whom other individuals may learn the different coping mechanisms under unfavorable life circumstances. When evaluating the statistical significance, the SEVAC team found that education has a significant association with the quality of life. But the validation of the Quality of life may be questioned particularly for patients with psychotic and affective disorder since scores may be influenced by affective bias, poor insight and adverse life events. (Am J Psychiatry 1997)

Approximately 53.6% of the patients covered under this study perceived their family as caring. According to them, the *social integration* and *perceived social support* were significantly better in the family than outside the social circle. They also opined that intra familial cohesiveness and accepting attitude of the family were satisfactory. Thus in one half of the coin, it seems that the family had been very supportive, maintaining an average cohesiveness.

We were astounded when we compared the Quality of life scores with the MSPSS scores which highlight the perceived social support. Precisely, we found that the Quality of life was below average though the perceived social support from the family was significantly satisfactory. Hence the question arises as to why the patients who have good social and familial support have such poor quality of life. One explanation that we ourselves tried to find in this regard is that, most probably, poor treatment compliance and meager rehabilitative measures have prevented these

unfortunate fellows from attaining proper quality of life. So, the necessity for further research study in this direction for determining the causes of such discrepancies cannot be simply ignored.

Under the circumstances, we made another attempt to see if any sort of rehabilitative facilities were extended to our target groups by the hospitals from where they were released. Unfortunately, again we found that the concept of Psychiatric Rehabilitation was non-existent in Government run mental hospitals. Practically these hospitals were only meant for psychopharmacological intervention and that too with old-fashioned drugs.

The majority of the patients under our project's purview suffered from Schizophrenia, Bipolar and related conditions. The negative symptoms of Schizophrenia, which are refractory to treatment, are effectively dealt with rehabilitative process (Anthony & Liberman 1986). Hence, without being provided proper rehabilitative measures, they would never show significant improvement in social stability and quality of life. Again, the newer atypical antipsychotics, which are very effective in reducing negative symptoms (Noordsy et al 2001), are not supplied to these unfortunate patients. Even the pharmacoeconomics of such medication was never given its due importance.

Since the last decade, WHO has been constantly emphasizing on the promotion of 'Biopsychosocial Model' of mental disorders and a community-oriented approach in mental health care. As a consequence, as per 'pen and paper arrangement', community and district based mental health programmes have been launched in our country. But our team did not find any strategy initiated by the government for the implementation of the said program for the benefit of the patients whom we came across. In our opinion, the lack of qualified personnel, psychiatric social and ancillary workers, poor funding and infrastructural lacunae may be the reasons for the failure of such strategies. According to our team's experience, the non-existence of 'Multidisciplinary Teamwork' is also responsible for the failure of the National Mental Health Programmes.

Now we would like to highlight a very interesting and significant findings of the present study. It is widely believed that the stigma associated with mental illness in primary care settings prompt people to choose traditional healers rather than medical professionals. (Chadda et al 2001). But to

our surprise we saw that less than 5 % of the patients among our target groups visited the traditional healers and that majority of them followed up from their respective hospitals.

All the members of the SEVAC team are convinced that the findings of this study would certainly go a long way in respect of highlighting the basic needs for facilitating the meaningful rehabilitation of the mental patients, with particular reference to the women with mental illness. The team members are convinced too that baseline study and research of this kind will facilitate the emergence of some effective policies in respect of incorporating the Rehabilitation Concept as an indispensable component of the mental health care delivery system in our country. Hence we are very much keen to be involved in conducting such type of work as a continuation of this study.

### **Limitation of the study**

Though our project revealed a lot of interesting findings on the living status, social integration and treatment compliance of the female mental patients yet, like any other research study, it also carried its own limitations.

- ❖ The first limitation was the poor sample size (only 45 cases were found from the total number of 100 patients). Hence further research studies with a larger sample size is required in order to substantiate the findings of this study.
- ❖ The study conducted was cross-sectional in nature: a longitudinal follow up study is essential in drawing up a more perfect conclusion.
- ❖ The samples collected were mostly suffering from Schizophrenia and related disorders with no variation. It would have been better if we could obtain other mental disorders and see their rehabilitative part.
- ❖ The age wise distribution of the sample did not reveal any variation. Hence the correlation between age and our objective was not significant.

- ❖ Most of the scales that we used were subjective in nature. Since the patients mostly belonged to psychotic group, a more objective scale would have been effective.

## **Recommendations**

In view of the statistical analysis and discussion as evident from the research study the SEVAC team recommend the following:

### **For Central Government**

- ❖ It is evident that due to the dearth of mental health professionals like Psychiatrists, Psychologists, Psychiatric Social Workers and Psychiatric Nurses a large number of mental patients cannot have proper access to the mental health care delivery system as well as to any rehabilitative facilities. So the team strongly recommends meaningful National Schemes, which would enhance the number of qualified mental health professionals.
- ❖ The central government should allocate adequate funding for the implementation of an acceptable as well as effective ‘Rehabilitative Programme’ for the mentally ill patients with particular reference to the women with mental illness
- ❖ The central government should evolve an effective strategy so that the benefit of the Rehabilitation Programme reaches the mental patients upto the grassroots level in order to enable them to attain the sustainable quality of life.
- ❖ An effective strategy for developing the GO-NGO collaboration for ensuring rehabilitative measures for the mentally ill patients with particular reference to the women with mental illness is to be evolved without any further delay.
- ❖ Further research studies are to be encouraged with adequate funding for pin pointing the needs for ensuring the rehabilitation of the mentally ill patients (with particular reference to the women with mental illness) keeping in view the sociocultural and socioeconomic factors relevant to our country.

- ❖ The research study shows that the patients among our target group who had some education had improved quality of life. Hence the government should put more emphasis on spreading education among the women folks so that they become armed to handle the deficiencies and challenges in their lives and get to lead a healthy and meaningful life.
- ❖ Regarding monitoring for the proper implementation of the Central Government Schemes meant for the rehabilitation of the mentally ill patients our team strongly recommends the ‘Vikramaditya Model’ (Here ‘Vikramaditya Model’ indicates the ‘Sudden Inspection by the concerned authorities with Fact Finding Attitude’ in order to ensure the proper monitoring of the implemented programme ).

### **For State Government**

- ❖ Lack of alertness on the part of the administration in varied forms is omnipresent in every hospital set up. As for example the concerned officials did not pay necessary attention while noting down the details of the inmates as well as their respective addresses at the time of admission. As a consequence our team could not reach the doorstep of a significant number of target groups. Hence it is strongly recommended that necessary steps should be taken in respect of noting down the detailed addresses and other relevant information of the patients at the time of admissions to the government hospitals. Such kind of alertness not only serves the purpose of surveys of this kind, but also helps in tracking down the family of the patient when they are about to be released.
- ❖ Lack of motivation and ‘Human Approach’ on the part of Hospitals in respect of extending care to the inpatients is an open secret. So it is strongly recommended that the hospital authorities should take adequate measures on war footings so that “*Human Care*” is ensured to every patient as well as the basic Human rights are not violated. Again it is strongly recommended that necessary measures should be taken for not keeping any female patient in a stark naked condition.
- ❖ It is an open secret that most of the Medical Colleges do not have inpatient care settings though they provide postgraduate training in Psychiatry. Similarly most of the District Hospitals do not have any inpatient care facilities. Even most of the district hospitals are

devoid of trained Psychiatrists and other mental health professionals. Hence it is strongly recommended that the government should adopt necessary policies for bridging such gaps on war footings.

- ❖ The government run mental hospitals must introduce a Multidisciplinary Teamwork (MDT) for ensuring a holistic care to all the patients. The therapist who is treating the patient must follow the proper guideline so that a good therapeutic alliance is created.
- ❖ We have learnt from our work experience that without developing the access of the female mental patients, who utterly need shelter and institutional support in order to live a dignified life Half-way Homes/ Shelter Homes need to be built across the state. So it is highly recommended that government should adopt meaningful schemes and ensure adequate financial assistance in order to encourage the capable and credible NGOs to establish and run Halfway Homes/Shelter Homes for facilitating the rehabilitation of the women with mental illness.
- ❖ It is strongly recommended that Continuing Medical Education in Psychiatry is to be made compulsory for all the doctors, nurses and other allied paramedical staffs in primary health care setting in order to strengthen the district mental health programmes.
- ❖ It is evident that no concept of outreach programme is existing in the mental health set up in our country that definitely enhances the treatment outcome. From our study it is evident that a good number of patients cannot continue the follow up treatment due to multifarious reasons hence they get an early relapse of their symptoms. So it is recommended that a policy is to be implemented based on our social context for providing outreach programme, early psychosis intervention team programme and home treatment delivery team programme by linking existing mental health hospitals with experienced and credible NGOs (*i.e. NGOs having the expertise in Assertive Outreach Programme*)
- ❖ The hospitals must ensure that ***newer psychotropic medications*** are available seeing the cost-benefit ratio so that the patients do not suffer from long standing side effects, which hinder the quality of life.

- ❖ The concept of ‘Psychoeducation’ must be imparted by effective training modules for mental health workers highlighting the role of family to minimize the overactive critical comments and expressed emotions.
- ❖ Education plays a key role to improve quality of life. Hence there is need for proper implementation of the existing plan and ongoing programme for education of women so that they become armed to handle the deficiencies and challenges in their lives and get to lead a healthy and meaningful life.
- ❖ There should be some government / non-government bodies to look after the legal aspect that crops up from sociofamilial perspective of the unfortunate women with mental illness.

### **Other agencies (NGOs)/ Local Self Government**

- ❖ Each and every Corporation and Municipality has it’s own health care delivery system. But this system is almost devoid of any psychiatric facilities. Hence it is strongly recommended that all corporation/municipalities should train up some of their doctors / health care workers in respect of tackling mental health issues and thus develop a primary infrastructure in tackling mental illnesses at the local level.
- ❖ It is evident that in our country there are some credible NGOs, which are significantly contributing in the area of health care delivery at primary level. It is strongly recommended that such NGOs should train up some of their staff in mental health so that they can play a key role in facilitating treatment and rehabilitation of the mentally ill patients at the grass root level.
- ❖ Without generating effective awareness regarding mental illness and its consequences at the community level, mental health of the community never can be improved. Hence the credible NGOs working in the field of health should incorporate mental health issues (with particular reference to the women mental health) as the indispensable components of their ‘Health Awareness Programmes’.

- ❖ It is strongly recommended that the credible NGOs working for the cause of WOMEN should take necessary measures for the capacity building of their staff team in respect of promoting the mental health of their respective target groups. They should also prioritize the rehabilitation issues of the mentally ill women.
  
- ❖ Without generating effective awareness regarding mental illness and its consequences at the community level, mental health of the community never can be improved. Hence the credible NGOs should incorporate mental health issues (with particular reference to the women mental health) as the indispensable components of their 'Health Awareness Programmes'.

## **Section IV**

### **APPENDIX I**

#### **CASE HISTORIES**

##### **CASE HISTORY I**

**MP** is one of the female mental patients, who was released from the Pavlov Mental Hospital on 26.03.2003. Earlier, she was admitted into the said mental hospital on 11.01.2002. As per the information provided by the concerned hospital authority on the basis of hospital records, MP's residence is situated at Garden Reach in the western part of Kolkata.

Our team consisting of Psychiatrist and Psychologists reached the specified area on a particular day to locate her residence. When we inquired about MP in her neighbourhood local people informed that she did not reside at home. They said that she lived in the streets in the same locality but didn't have any particular place of stay. Nonetheless, we were able to locate her in-laws' house at the address that was given to them by the hospital authorities. On being knocked, MP's sister-in-law came forward and informed that MP left home long back. She was very reluctant to give a detailed past history of MP and provide any information about her parental home. We, however, succeeded in convincing MP's sister-in-law about providing us with a few necessary informations about her. Then she disclosed that it was after MP's marriage that the first symptoms of mental illness got noticed in her. According to her, the first symptoms that developed in her at that time were disorganized behavior, self-muttering, self-laughing, wandering, auditory hallucinations and sleep disturbance. Reportedly, her family members took all necessary measures to place her under psychiatric treatment. A few years after her symptoms were controlled following regular psychiatric care, she gave birth to a son and a daughter. However, as the family didn't make the desirable endeavor for ensuring regular follow-up treatment, she was never symptom-free.

Subsequently, with time, MP's mental health condition became more reduced and finally she became unmanageable. At this stage, her family admitted her to Pavlov Mental Hospital, Kolkata. This happened some four years ago. Unfortunately, although she was placed under psychiatric treatment, she fled from the said hospital, thereby disrupting the treatment procedure. After

fleeing from the hospital, MP came back home to her husband and others in the family. Yet, at this critical juncture, her family members refused to stand by her and make efforts to regularize her psychiatric treatment once again. On the other hand, they made it clear that she was no longer their responsibility as they had finished their duty towards her by admitting her to the hospital.

It was when we leaving MP's house that, with the help of the local residents, we spotted MP wandering aimlessly in one of the lanes in her neighborhood. When we walked up to MP, she appeared to be older than her stated age of 50 years. She had a disheveled look and lacked personal hygiene; quite obviously, her clothes were unwashed, dirty and emitting a foul stench and she didn't take a bath for long. We observed that MP spoke rather incoherently and had the tendency of muttering to herself. Besides, self-laughter, irrelevant talking, psychomotor agitation and manneristic posture were also noticeable in her. Also, her face remained expressionless throughout the team's session with her.

The local people who had collected there informed the team that MP's family members didn't take any care of her when her symptoms relapsed after her return from hospital. A few of the local people stated that owing to negligence and ill treatment by her own family, MP was forced to leave her house. As, after leaving her house, MP had nowhere to go, she started loitering in the streets and spent her days and nights in and around roadside eateries, the employees of which would give her some food at times. Sometimes she had to support herself by begging. The local people also informed that some local criminals exposed her sexual abuses almost every night.

## CASE HISTORY II

**SM** is another name that figures in the list of names collected by our team for conducting this study. According to hospital records at the Pavlov Mental Hospital, she was admitted therein on 26.05.2004. She was discharged from the hospital on 14.06.2004. We reached the address of SM in a slum at Kalighat, Kolkata. However, the family members informed that SM was missing from her home since last year.

We therefore spoke to SM's mother in order to learn about SM and her ailment. Her mother traced the history of her daughter since her childhood. She told that her daughter was brought up along with her other brothers and sisters in a poor family. Her father was a butcher and poor earner. She could not continue her studies due to their poverty. But she was very jovial, hard working, and an easy-going type. Her mother also reported that her daughter had no noticeable abnormalities during childhood. On attaining marriageable age, she was married off to a boy from the immediate neighborhood. Unfortunately for the girl, her husband turned out to be an alcoholic and used to abuse her physically and mentally.

According to SM's mother, the symptoms of mental illness were first noticed in her daughter after the birth of her first child. The symptoms, that were prominent in her at that time were restlessness, self-muttering, self-laughing, wandering, inappropriate behaviour and hostility. On the basis of her symptoms, SM was taken to the Nil Ratan Sarkar Hospital, Kolkata for being placed under treatment purview. There she was admitted and brought under the purview of psychiatric intervention. Thereafter, following the remission of her symptoms, she was discharged from the hospital

Thenceforth she led a fairly normal life and gave birth to two more children, a son and a daughter. Despite some regular tiffs with her husband, life for SM was continuing as it did for most women in that particular socio-economic group. In the meantime her husband, who was suffering from some sort of chronic illness, committed suicide. This incident came as a bolt from the blue to SM and she used to stay very depressed. Thereafter her mother and brother took on the responsibility of looking after her. Believing that some kind of engagement would keep SM tied up with work, her mother insisted that she took up some work. SM got herself a job of an 'AYAH' (Attendant)

and was doing her job quite satisfactorily. However, around this time, her symptoms relapsed once again and, one day, she escaped from home. She was found by her neighbors at some place near Baguihati. Then they admitted her to Pavlov Mental Hospital, Kolkata. With treatment at the hospital, there was remarkable remission of her symptoms. But her treatment process was disrupted again as she came back home within a fortnight leaving the hospital.

SM's mother recalled that each time her symptoms subsided due to psychiatric intervention, she either stopped taking the medicines or visiting the psychiatrist for getting her mental health condition monitored regularly. As a consequence, her symptoms would show up again after some days. During this time, her daughter was her primary caregiver. It is very unfortunate that despite having supportive and caring family members, she fled from her home once again when she was asked to get admitted to hospital for the third time. With tear-filled eyes the mother informed us that she has not returned home ever since she fled and that there is no information regarding her present whereabouts.

### Case History III

MM (28 years) is a resident of Uttarpara in the Hooghly district of West Bengal. She was admitted to Pavlov Mental Hospital, Kolkata on 28.02.2003 for psychiatric intervention. According to available records, MM fled from the hospital on 06.03.2003.

When we reached MM's door step we found that she lived with her invalid father and another mentally ill sister they in a dilapidated and deplorable room. This room was grossly uninhabitable. Precisely this room served the purpose of bedroom, kitchen, toilet and a lavatory as well. As a result, an overpowering foul odour nauseated us as soon as one we entered into the room. And the room, where hardly any sunlight peeped in, was strewn with piles of foul-stenched old and tattered clothes here and there, alongside a few utensils. Due to the lack of maintenance the house was covered with thick cobwebs and surrounded by tufts of tall wild shrubs, weeds and trees.

When we reached MM's house, her father came out limping and wanted to know our identity and base. Then we noticed that he barely had any proper clothing on him except a piece of dirty old cloth round his waist. Owing to the poverty, he had an old and haggard look on his face that was thickly covered with his wildly growing beard. After we gave him the relevant information and stated the purpose of our visit, he informed that MM was the eldest of three daughters. He also disclosed that his wife, who was dead, and all three of his daughters were mentally ill. It emerged that one of his daughters died in an accident, which she met with, in the acute phase of her mental illness. He admitted that MM was admitted to the specified hospital at the acute phase of her illness. But she ran away from the hospital within a few days. He also informed that due to the severe fracture in his leg, he could not stand nor could walk. But due to poverty, he could not make any arrangements for his treatment.

It was evident that the family was extremely poor, and as per the information passed down by MM's father, apart from the meagre amount that he receives as dues every month from the cinema hall where he worked earlier, there was no other source of income. Her father further disclosed that their economic condition being so bad, on most days they couldn't have a proper meal, and every morning they wondered what they would have for meal that day. In fact, on most days they either didn't have the fuel to light the *chullah* for cooking gruel or a handful of rice and

pulse to boil and eat. Consequently it was impossible for him to make any arrangements for the psychiatric treatment of MM.

From the moment the SEVAC team came across MM, she seemed quite loud and boisterous. She had a disheveled look and evidently lacked personal hygiene. The coat of dirt on her body parts, the unkempt and entangled hair and her crumpled and dirty clothes clearly reflected that she had been going without a bath for long. On seeing our team the first time, MM and her younger sister who was lying on a bed in the room, started using abusive words and threw their temper. Later, however, when their father asked them to cool down, the two sisters became calmer.

Our Psychiatrist in the visiting team diagnosed MM as suffering from Psychosis.

Precisely the deplorable living condition of MM and her mentally ill sister prompted us to make a move for bringing them under the purview of institutional care and psychiatric treatment. So we brought this matter to the knowledge of Prof. Malini Bhattacharya, Hon'ble Member, N.H.R.C. Prof. Bhattacharya kindly took immediate action and requested the Health Secretary, Govt. of West Bengal to make necessary arrangements for the admission of these two mental patients to any govt. hospital.

Thereafter, we were informed by the Dept. of Health, Govt. of West Bengal that necessary arrangements were made for the admission of MM and her sister to the Pavlov Hospital. We were also verbally requested for bringing them to hospital for admission.

Meanwhile we interacted with a youth club located at MM's neighbourhood and requested the club members to extended their help for taking MM and her sister to the Gobra Hospital. They gladly complied with our request. Thus following the continuous persuasion of SEVAC and intervention of the NCW MM and her sister were admitted to Pavlov Hospital, Kolkata on .....

## APPENDIX II

SEVAC

***Project of National Commission for Women  
INFORMATION SCHEDULE***

**A. SOCIO – DEMOGRAPHIC HISTORY*****Name*** –***Age*** –***Address*** –***Marital status*** : (Married / Single / Widow / Divorced / Separated)***Education*** : (Primary/ Secondary/ Graduation/ Post- Graduation/ Technical/ Illiterate)

***Occupation (before illness)*** : (Service in organized sector/ service in unorganized sector/ odd jobs/craftsman/ business/ unemployed/ house wife/ student/community work)

***Present Occupation*** : (Service in organized sector/service in unorganized sector/ odd jobs / craftsman / business / unemployed / house wife / student / community work)

***Personal Income*** :***Socio-Economic Status*** : (As per scale)***Name of the releasing hospital*** :***Date of admission*** :***No of admissions*** :***Date of last admission*** :***Date of discharge*** :***Diagnosis*** :***Duration of illness*** :

***Living with the family*** : (parents/in-laws)/living alone/missing

If missing then period / history of missing / past history of missing

***Family history of mental illness (If any) :***

## **B. HEALTH STATUS AND TREATMENT**

***General health condition*** : (Good/Average/Poor/III)

***Present status of mental illness*** : (Still under treatment/treatment discontinued)

***Past medical history/surgical history :*** yes / no (If yes, in detail)

## **I – TREATMENT HISTORY**

D. Past psychiatric history (before  
E. admission in the releasing hospital) : ***yes / no***

***Present psychiatric treatment*** : yes / no

- Pharmacological – yes / no

If yes in detail –

- Non – pharmacological - yes/no (If yes, in detail)

## **II DIAGNOSIS**

Current psychiatric diagnosis by treating doctor

***Duration of treatment*** : Any Gaps – yes/no (If so, why?)

## **III COMPLIANCE**

a) ***Treatment continued*** : Regular / irregular

***If irregular, please specify*** :

b) ***Treatment discontinued*** :

- Financial Constraint
- Due to disease process
- Unavailability of the drug
- Reluctance on the part of the caregivers
- Due to other medical problems



## APPENDIX III

### MENTAL STATUS EXAMINATION

#### 1. ATTITUDE AND BEHAVIOUR

- *General Appearance* :
- *Grooming, personal hygiene* : well kempt / kempt / disheveled
- *Facial Expression* : depressed/anxious/scary
- *Eye contact* : Present/partial/absent
- *Psychomotor retardation/agitation* : present/absent
- *Posture* : manneristic./perSMtory/stereotyped
- *Abnormal Movement* : present/absent/appropriate/inappropriate
- *Rapport Establishment* : fully/partially/not established

#### 2. SPEECH

- *Volume* : increased/decreased
- *Tempo* : increased/decreased
- *Tone* : increased/ decreased
- *Reaction time* : normal/delayed
- *Incoherence* : present/absent

#### 3. MOOD

- *Subjective*
  - a) Quality (Sad / Elated / Anxious / Mixed / Dysphoric)
  - b) Duration ( months)
  - c) Depth (Quantity 1 – 10)
- *Objective*
  - a) Appropriate / inappropriate
  - b) Congruent / incongruent
  - d) Range-normal / broad / restricted / blunted / flat

#### 4. THOUGHT

- **Stream** : (Increased or Decreased, Circumstantiality)
- **Form** : (Formal thought disorder – Derailment, Incoherence, Tangentiability, neologism)
- **Content** : (Delusions, Suicidal Ideation, Homicidal Ideation, Guilt, Hopelessness, Depressive Rumination, Obsession, Compulsion, Hypochondriasis)
- **Possession** : Thought Alienation

#### 5. PERCEPTIONS

- **Hallucinations** : (auditory, visual, somatic, gustatory, olfactory)

#### 6. COGNITION

##### a) *Orientation to* :

- Time
- Place
- Person

##### b) *Memory* :

- Immediate-Digit repetition
- Recent- 3 unrelated object
- Remote-personal information/historical facts

##### c) *Attention and Concentration* : (Digit Span)

##### d) *General Intelligence*

#### 7. JUDGEMENT

- Social
- Personal
- Test Judgement

#### 8. INSIGHT – say in verbatim –

- Do you think you had any illness?
- If yes, what is / was the nature of your illness?
- Do you think you need any treatment

#### DIAGNOSTIC FORMULATION –

## APPENDIX IV (SCALES)

### THE BRIEF PSYCHIATRIC RATING SCALE (BPRS)

This form consists of 18 – symptom constructs, each to be rated on a 7 point scale of severity, ranging from “not present” to “extremely severe”. If a specific symptom is not rated, mark “0” = Not Assessed. Enter the score for the description which best describes the patient’s condition.

0	=	not assessed
1	=	not present
2	=	very mild
3	=	mild
4	=	moderate
5	=	moderately severe
6	=	severe
7	=	extremely severe

1. - **Somatic Concern** : Degree of concern over present bodily health. Rate the degree to which physical health is perceived as a problem by the patient, whether complaints have a realistic basis or not.
  
2. - **Anxiety** : Worry, fear, or over concern for present or future. Rate solely on the basis of verbal report of patient’s own subjective experiences. Do not infer anxiety from physical signs or from neurotic defense mechanisms.
  
3. - **Emotional Withdrawal** : Deficiency in relating to the interviewer and to the interviewer situation. Rate only the degree to which the patient gives the impression of failing to be in emotional contact with other people in the interview situation.
  
4. - **Conceptual Disorganization** : Degree to which the thought processes are confused, disconnected, or disorganized. Rate on the basis of integration of the verbal products of the patient; do not rate on the basis of patient’s subjective impression of his own level or functioning.

5. - **Guilt Feelings** : Over concern or remorse for past behavior. Rate on the basis of the patient's subjective experiences of guilt as evidenced by verbal report with appropriate affect; do not infer guilt feelings from depression, anxiety, or neurotic defenses.
6. - **Tension** : Physical and motor manifestations of tension, nervousness, and heightened activation level. Tension should be rated solely on the basis of physical signs and motor behavior and not on the basis of subjective experiences of tension reported by the patient.
7. - **Mannerisms and Posturing** : Unusual and unnatural motor behavior, the type of motor behavior which causes certain mental patients to stand out in a crowd of normal people. Rate only abnormality of movements; do not rate simple heightened motor activity here.
8. - **Grandiosity** : Exaggerated self-opinion, conviction of unusual ability or powers. Rate only on the basis of patient's statements about himself or self in relation to others, not on the basis of his demeanor in the interview situation.
9. - **Depressive Mood** : Despondency in mood, sadness. Rate only degree of despondency; do not rate on the basis of inferences concerning depression based upon general retardation and somatic complaints.
10. - **Hostility** : Animosity, contempt, belligerence, disdain for other people outside the interview situation. Rate solely on the basis of the verbal report of feelings and actions of the patient toward others; do not infer hostility from neurotic defenses, anxiety, nor somatic complaints. Rate attitude toward interviewer under "uncooperativeness".
11. - **Suspiciousness** : Belief, delusional or otherwise, that others have now or have had in the past, malicious or discriminatory intent toward the patient. On the basis of verbal report, rate only those suspicions which are currently held whether they concern past or present circumstances.
12. - **Hallucinatory Behavior** : Perceptions without normal external stimulus correspondence. Rate only those experiences which are reported to have occurred within the last week and

which are described as distinctly different from the thought and imagery processes of normal people.

13. - **Motor Retardation** : Reduction in energy level evidenced by slowed movements. Rate on the basis of observed behavior of the patient only; do not rate on the basis of patient's subjective impression of own energy level.
14. - **Uncooperativeness** : Evidence of resistance, unfriendliness, resentment, and lack of readiness to cooperate with interviewer. Rate only on the basis of the patient's attitude and responses to the interviewer, and interview situation; do not rate on the basis of reported resentment or uncooperativeness outside the interview situation.
15. - **Unusual Thought Content** : Unusual, odd, strange, or bizarre thought content. Rate here the degree of unusualness, not the degree of disorganization of thought processes.
16. - **Blunted Affect** : Reduced emotional tone, apparent lack of normal feeling or involvement.
17. - **Excitement** : Heightened emotional tone, agitation, increased reactivity.
18. - **Disorientation** : Confusion or lack of proper association for person, place, or time.

### THE BRIEF PSYCHIATRIC RATING SCALE (BPRS)

0	=	not assessed
1	=	not present
2	=	very mild
3	=	mild
4	=	moderate
5	=	moderately severe
6	=	severe
7	=	extremely severe

1.	<b>Somatic Concern</b>	0	1	2	3	4	5	6	7
2.	<b>Anxiety</b>	0	1	2	3	4	5	6	7
3.	<b>Emotional Withdrawal</b>	0	1	2	3	4	5	6	7
4.	<b>Conceptual Disorganization</b>	0	1	2	3	4	5	6	7
5.	<b>Guilt Feelings</b>	0	1	2	3	4	5	6	7
6.	<b>Tension</b>	0	1	2	3	4	5	6	7
7.	<b>Mannerisms and Posturing</b>	0	1	2	3	4	5	6	7
8.	<b>Grandiosity</b>	0	1	2	3	4	5	6	7
9.	<b>Depressive Mood</b>	0	1	2	3	4	5	6	7
10.	<b>Hostility</b>	0	1	2	3	4	5	6	7
11.	<b>Suspiciousness</b>	0	1	2	3	4	5	6	7
12.	<b>Hallucinatory Behavior</b>	0	1	2	3	4	5	6	7
13.	<b>Motor Retardation</b>	0	1	2	3	4	5	6	7
14.	<b>Uncooperativeness</b>	0	1	2	3	4	5	6	7
15.	<b>Unusual Thought Content</b>	0	1	2	3	4	5	6	7
16.	<b>Blunted Affect</b>	0	1	2	3	4	5	6	7
17.	<b>Excitement</b>	0	1	2	3	4	5	6	7
18.	<b>Disorientation</b>	0	1	2	3	4	5	6	7

### QUALITY OF LIFE SCALE (QOL)

Please read each item and circle the number that best describes how satisfied you are at this time. Please answer each item even if you do not currently participate in an activity or have a relationship. You can be satisfied or dissatisfied with not doing the activity or having the relationship.

	Delighted	Pleased	Mostly satisfied	Mixed	Mostly dissatisfied	Unhappy	Terrible
1. Marital comforts home, food, conveniences, Financial security.....	7	6	5	4	3	2	1
2. Health – being physically fit and vigorous	7	6	5	4	3	2	1
3. Relationships with parents, siblings & other Relatives-communicating, visiting, helping..	7	6	5	4	3	2	1
4. Having and rearing children.....	7	6	5	4	3	2	1
5. Close relationships with spouse or Significant other.....	7	6	5	4	3	2	1
6. Close friends .....	7	6	5	4	3	2	1
7. Helping and encouraging others, Volunteering, giving advice.....	7	6	5	4	3	2	1
8. Participating in organizations and Public affairs.....	7	6	5	4	3	2	1
9. Learning-attending school, improving Understanding, getting additional knowledge	7	6	5	4	3	2	1
10. Understanding yourself-knowing your assets and limitations-knowing what life is about...	7	6	5	4	3	2	1
11. Work – job or in home .....	7	6	5	4	3	2	1
12. Expressing yourself creatively .....	7	6	5	4	3	2	1
13. Socializing – meeting other people, Doing things, parties, etc. ....	7	6	5	4	3	2	1
14. Reading, listening to music, or observing Entertainment .....	7	6	5	4	3	2	1
15. Participating in active recreation .....	7	6	5	4	3	2	1
16. Independence, doing for yourself .....	7	6	5	4	3	2	1

## MULTIDIMENSIONAL SCALE OF PERCEIVED SOCIAL SUPPORT

INSTRUCTIONS : We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Circle the "1" if you **Very Strongly Disagree**

Circle the "2" if you **Strongly Disagree**

Circle the "3" if you **Very Strongly Disagree**

Circle the "4" if you **Mildly Disagree**

Circle the "5" if you are **Neutral**

Circle the "6" if you **Mildly Agree**

Circle the "7" if you **Very Strongly Agree**

- |     |   |   |   |   |   |   |   |   |
|-----|---|---|---|---|---|---|---|---|
| 1.  | There is a special person who is around when I am in need         | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 2.  | There is a special person with whom I can share joys and sorrows  | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 3.  | My family really tries to help me.                                | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 4.  | I get the emotional help and support I need from my family.       | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 5.  | I have a special person who is a real source of comfort to me.    | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 6.  | My friends really try to help me                                  | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 7.  | I can count on my friends when things go wrong                    | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 8.  | I can talk about my problems with my family                       | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 9.  | I have friends with whom I can share my joys and sorrows.         | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 10. | There is a special person in my life who cares about my feelings. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 11. | My family is willing to help me make decisions.                   | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 12. | I can talk about my problems with my friends.                     | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

## APPENDIX V

### **A few words beyond the study guideline**

While our team consisting of a conglomeration of Psychiatrist, Psychologists and Field workers was focussing on this project, the unstable clinical condition of a significant number of patients prompted us to go beyond our project boundaries. Hence we decided to add outreach and emergency services to some of the severely ill patients. We still had the plan of including a good number of them under the purview of our treatment but financial constraints restrained us from such outreach programmes. Some of our achievements in this direction are as follows.

The first example to cite is the case of MM, a 24-year-old girl hailing from Uttarpara, Hooghly as described previously in the Case histories. It was indeed one of the worst possible cases that we encountered. The dilapidated and deplorable condition in which she was living with her father and another mentally ill sister was indeed beyond any description. We took the case in our toes and rendered an emergency psychiatric intervention and some financial assistance to the family. Thereafter we brought this matter to the knowledge of National Commission for Women and with their direction we got in touch with the Department of Health, Govt. of West Bengal. As a result both of them were admitted to the inpatient care setting of Pavlov Mental Hospital. The tasks of arranging for the necessary order for admission, motivating the local people and clubs to come forward for help etc., were difficult indeed. In this context it is noteworthy that we further plan to make necessary arrangement for the treatment of her father who has restricted mobility due to his broken leg.

The second one is JDR, a 46-year-old woman diagnosed as a case of Schizophrenia with bizarre somatic delusions. When we reached her house we saw that she was having an acute exacerbation of her illness. Immediately we prescribed some medication to calm her down and advised her family to visit SEVAC for possible inpatient care. The family complied and she was admitted to the SEVAC Crisis Intervention Unit after proper evaluation in the OPD. In the ward her condition gradually improved and she was made to participate in the Day Care Activities (refer to pics on page...) and was discharged subsequently. She is now regularly visiting our OPD for follow up treatment. We are very satisfied by whatever little we have done for her.

The third example to cite is that of SJ, a 30 year old woman who was deserted by her in-laws. During our visit we saw that she was lying under a cot in a cramped room in her parents' house (refer to pics on page....) with acute Extrapyramidal side effects like drooling of saliva, tremors and rigidity due to her psychotropic medication. It was after we prescribed medications as part of our team's immediate management strategy that the distressing side effects were waived away. We also tried to motivate her family with psychoeducational measures about the disease and the importance of follow up treatment. Now she is leading almost a stable life and is maintaining regular follow up treatment from the specified hospital.

Likewise, we also offered psychiatric services to a good number of patients who were brought under the purview of this project as because they required immediate psychiatric intervention when we met them. This may be an ideal example of Home Treatment Delivery Services, which we have strongly recommended in the subsequent section of this report. In this context it maybe noted that we are very much eager to introduce such kind of service in the ongoing project of SEVAC. But due to the dearth of adequate resources we are unable to make any move in this regard.

Words go beyond our imagination when we recount our experience while working on with the project. We felt how the lack of some outreach care and rehabilitative measures have reduced their living condition to a subhuman state. It would have been a pleasure for our team if we could respond to such sort of needs of these unfortunate souls. But we failed to do so because of the limited time, finances and other problems. Now the work experience, which we gathered, keeps haunting our mind- 'What next?'

Since we vow to cater to the needs of the mentally ill patients putting emphasis on the Human Rights Promotion, we are not ready to give up. Hence all the members of the SEVAC team are convinced that the findings of this study would certainly go a long way to facilitate the emergence of some effective policies in respect of incorporating the Rehabilitation Concept as an indispensable component of the mental health care delivery system in our country. We look forward in the days to come to see these patients leading a healthy and meaningful life.

## APPENDIX VI

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