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D) Psychological Tests:

Attitude and Awareness Scale.

Dimensions of psychological, Emotional and Behavioral Scale

Best Battery of stress scale (BBSS)-Frustration, conflict, anxiety and stress scale

Family Climate Scale. Three point scale of rating and dimensions.

All above and more test used in social and psychological tests are available: Anant agency, Anant publication, shanipar, pune. Email: tulpule@vsnl.com. Anant@pn3.vsnl.net.in

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Chaitanya rony@hotmail.com Chitanya and Mental health care centre. Pune

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Email: saa2003@vsnl.net

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Email: Info@who.in

Email: Deepgrih@vsnl.com

Website: www.Deepgriha.org
Deepgriha society, community development programmes, Tilak Road, Pune.

World Health Organization, marketing and dissemination, Switzerland.

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Website: www.who.int

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APPENDIX I

INTERVIEW SCHEDULE

Interview details of the respondents of the mentally ill, to investigate the awareness about mental illness and family burden:

Note: The investigator will put the tick mark (V) wherever necessary, and answer to the question required.

Section I

General Information:

Personal profile of the respondent

1. Sample No.

2. Age group: 18 to 30 yrs/ 31 to 45 yrs/ more than 45 yrs.

3. Sex: M/F


5. Education: Graduate & undergraduate/Secondary & Primary educated/Illiterate.

6. Marital status: Married/Unmarried/Widow-Widower/Divorced

7. Type of family: Joint/nuclear/extended

8. Religion: Hindu/Muslim/Christian

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9. Income per month: <5,000/5,000 to 10,000/>10,000

10. No. of family members: 2-3/5-6/>6

Information of respondent in relation to the mentally ill

Relationship with mentally ill

- Grand Parent
  - Mother
  - Father

- Parent
  - Mother
  - Father

- Spouse
  - Husband
  - Wife

- Son

- Daughter

Other significant relatives- please specify relation.
Duration of the mentally ill client:

< 2 years / 2 to 5 years / 6 to 10 years / > 10 years

Built: Thin / average / abase

Physical posture: Erect / lean / stumped

Personal aspects of respondents of the mentally ill

Dressing and grooming:
Neat and tidy / untidy / shabby / unkempt

Personal Hygiene:
Maintained / not maintained

Habits:
Consumption of alcohol / tobacco / drugs / sleeping pills / other

Physical health problems if any:
Diabetic / heart problem / blood pressure / overweight / tuberculosis / surgery – if any performed / any other.

Information about mentally ill:

Age group: 18 to 30 / 31 to 45 / > 45 yrs.

Sex: Male / Female

Mental illness: Acute / chronic

Occupation before illness - Unemployed / labour / business / service / retired

Position in the family: husband / wife / son / daughter / grandfather / grandmother / other.

Treatment taken: Regular / Irregular

Outcome of treatment: Recovered / improved / not improved
Type of medication: Free / paying / both

Habits: Consumption of tobacco / alcohol / drugs / other

Current mode of treatment: Religious / traditional / medical / all three

Section II

Awareness of the respondents about mental illness

Physical factors may lead to the mental illnesses.
Please tick mark (V) against the factor, if you feel that it leads to mental illness.
What are the factors that lead to mental illness?
1. Health problems such as frequent illness (Physiological/ Chemical)
2. Long term illness such as brain problems/epilepsy/AIDS/blood pressure/heart problems/diabetic.
3. Sleeplessness (Insomnia – very often)
4. Loss of appetite (very often anorexia)
5. Nutritional deficiency such as deficiency of iodize/vitamins/minerals.
6. Occupational health hazards lead to illness such as chemicals/mechanical/environmental
7. Genetic such as hereditary such as from parent to child/marriage with close relatives.
8. Persistent stress and strain, worries, anxiety, tension may lead to mental illness.

Psychological and personality traits may lead to the mental illness.

What are the factors related to psychology and personally which may lead to mental illness?
1. A person with short temper.
2. A person quarrelling very often without any reason.
3. A person with many traumatic events such as death of beloved one / withdrawal from children / accident / natural calamity (flood, earth quake)
4. A person with always negative thoughts and attitude such as gloomy/ unhappy /aloof.
5. A person with sensitive nature, stress after failure in examination/gambling/love/lottery/share.
6. A person with unrealistic demons of life.
7. High expectations from job/family/society.
8. A person with broken family such as divorced / quarrels of parents / orphans / aged ones / crime court and police matters.
9. A person with economic insecurity such as below poverty / excess income / low income.

Social Factors may lead to mental illness

Which social factors may lead to the mental illness?
1. Family environment such as broken home/ single parent / multiple problems in the family / large family / lack of unity/ conflict in the family.
2. Social factor related to marriage such as: inter-caste marriage/dowry/divorce/remarriage/late marriage/polygamy/unmarried.
4. Urbanization: unable to meet basic needs (poverty/of food, shelter and clothing.)
5. illiteracy/ignorance regarding factors affecting mental illness.
6. Job related factors such as: unemployment / no job security or safety/no promotion/ frequent transfers/ lack of co-operation with employer or co-workers.
Knowledge of respondents in relation to mentally ill patients’ care and management taken by caretaker at home.

Which daily activities of care are you assisting or carrying out for mentally ill at home (please put tick mark (✓) against the activities) meeting personal hygiene, nutritional needs, elimination need, social need,

1. Bathing
2. Hair combing/hair washing
3. Toileting
4. Feeding
5. Care during menstrual period for female patient
6. Giving medicine
7. Nail care
8. Oral care – brushing
9. Mobility such as
   Moving or turning from bed.
   Walking
   Travelling
10. Taking care of his/her belongings
11. Leisure and recreational activities
12. Follow up for treatment
13. Taking him to self help group / rehabilitation activities
14. Providing safety and security to mentally ill.
15. Sharing memories with him, making him laugh, smile.
16. Emergency handling such as: rowdy excitement/self injury/injury to others.
17. Observing effect and side effects of drugs
18. Involving him in social activities and social functions.
Data pertaining to perceived needs

Family Needs
1. Need for information
2. Need for support and help
3. No need (independent family)
4. No response

Family environment scale
1. Supportive family
2. Conflict oriented family
3. Discourage

Section III

Expressed emotions of the respondent of mentally ill

Which emotional expressions towards mental illness in relation to caring of your mentally ill you are experimenting? (Please put tick mark (✓) against the expressions, if you feel that it led to burden or stressed you?)

Depression
Denial
Shamefulness, feeling of guilt
Social rejection
Stigma
Discrimination
Angry
Hopelessness
Indifference
Acceptance

Feeling isolated or rejected from the society, neighbour
Low self esteem/ humiliation
Hesitation to visit psychiatrist
Negative attitude towards the mentally ill
Inadequate support from society, government
Unpredictable behavior from mentally ill
Privacy decreased or lost at home
Increased workload
Increased financial problems
Mentally ill becomes more dependent
Decrease family unity

Exclusion: Keeping the mentally ill isolated from activities such as marriage / social functions / entertainment / education / family functions.

Section IV

Awareness about misconceptions, myths and beliefs of the respondent about mental illness

Which myths, misconceptions and beliefs about mental illness may lead to worsen the mental illness and was practiced by you and or are practicing? (please put tick mark (V) against the item)

Myths, beliefs and misconceptions

1. Mental illness is a curse: It is a wish of god / black magic / practice to settle family rivalry / breaking the taboo and becoming mentally ill / supernatural power curse.
2. Mental illness must be treated by Tantric and faith healers: Traditional healer have a major role to get rid of it.
3. Use of Taweez, black thread, pumpkin, lime and offering of goat, chicken to evil power minimizes mental illness.

4. Religious activities reduce mental problems such as: worship, poojas, navas (offerings) festivals, visiting churches, temples, dargas etc.

5. Marrying mentally ill will help cure mental illness.

6. Hospitalization leads to worsening symptoms as only mad people are admitted there.

7. Mental illness is hereditary and incurable.

8. Schizophrenic mentally ill are useless, dangerous to self and others unproductive and a burden on the family and society.

Section V

Identification of various types of family burdens on respondents of mentally ill.

Physical burden

Emotional burden

Social burden

Financial burden

The investigator has determined the level of family burden based on the Zerit burden of rating scale assessment. Alternative responses were ‘Never’=0 (indicate no burden), ‘Rarely’=1 (indicate minimum level of burden), ‘Sometime’=2 (indicates moderate level of burden), Quite frequently=3 (indicates maximum level of burden), nearly always=4.

The instructions for respondents; the question reflects on how persons feel when they are taking care of the mentally ill. After each statement, please circle the word that best describes how often you feel that way. There is no right or wrong answers.

Scoring instructions: Add to scores for the 40 questions for the total score range from 0 to 16. A high score correlates with high level of burden.
The levels of burdens are classified as:

- 1 to 39  – Minimum Burden
- 40 to 79  – Moderate Burden
- 80 to 119  – Maximum Burden
- 120 to 160 – Very High Burden
SECTION - VI

ZARIT BURDEN INTERVIEW (ZBI)

I. Physical Burden:

<table>
<thead>
<tr>
<th>Sr. No.</th>
<th>Item</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
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<tbody>
<tr>
<td></td>
<td>Do you feel that because of the time spent with your relative, that you don't have enough time for yourself?</td>
<td>Never</td>
<td>Rarely</td>
<td>Sometimes</td>
<td>Quite Frequently</td>
<td>Nearly Always</td>
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<tr>
<td>1</td>
<td>Do you feel that your relative is dependent on you?</td>
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<td>2</td>
<td>How burdened do you feel in caring for your relative?</td>
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<td>3</td>
<td>Do you feel that you get easily fatigued, tired and exhausted because of your mentally ill care?</td>
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<td>4</td>
<td>Do you feel that you have lost control on your life due to your relative's illness?</td>
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<td>5</td>
<td>Do you get enough time for sleep and rest?</td>
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<td>6</td>
<td>Do you eat well? Has your appetite decreased?</td>
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<td>7</td>
<td>Do you sleep well? Has your sleep been affected since your relative became is mentally ill?</td>
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<td>8</td>
<td>Do you feel lack of interest in usual activities?</td>
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<td>9</td>
<td>Has your job performance is destined? Since your relative's mental illness?</td>
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<td>10</td>
<td>Are your family responsibilities disturbed since your relative's illness and your role as caretakers?</td>
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<td>11</td>
<td>Is your health disturbed? (Suffering from minor health problems such as headache, body ache and pains)</td>
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</table>
I. Social Burden

<table>
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<tr>
<th>Sr.No.</th>
<th>Item</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite Frequently</th>
<th>Nearly Always</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Do you feel uncomfortable about having friends visiting your home when you are caring for your relative?</td>
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<td>2</td>
<td>Do you feel that, your social life has been disturbed because of the mentally ill staying in your home?</td>
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<td>3</td>
<td>Do you have a friend with whom you can confide in &amp; feel better?</td>
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<td>4</td>
<td>Have you been rejected from your friends, neighbours, society?</td>
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<td>5</td>
<td>Has the other family member's social life has been disturbed due to your mentally ill relative? (Such as problem of getting married)</td>
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<td>6</td>
<td>Do you feel that you could do a better job in caring for your relative?</td>
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<td>7</td>
<td>Do you sometimes feel that there is no solution to your problems?</td>
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<td>8</td>
<td>Do you feel that you have lost your personal and social activities since his/her illness?</td>
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### Emotional Burden

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<th>Sr. No.</th>
<th>Item</th>
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<td>Sometimes</td>
<td>Quite Frequently</td>
<td>Nearly Always</td>
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<tr>
<td>1</td>
<td>Are you doing the caretakers role voluntarily?</td>
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<td>2</td>
<td>Do you feel sorry and also feel angry about your relatives mental illness?</td>
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<td>3</td>
<td>Do you feel lonely and isolated?</td>
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<td>4</td>
<td>Do you feel stressed while caring for your mentally ill relative?</td>
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<td>5</td>
<td>Do you feel embarrassed over your relative's behaviour?</td>
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<td>6</td>
<td>Do you feel that your caring affects your relationship with other family members, friends or neighbours?</td>
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<td>7</td>
<td>Do you feel worried about your relative's future? (After me what next?)</td>
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<td>8</td>
<td>Do you often feel frustrated and complain that the improvement from illness of your relative is poor?</td>
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<td>9</td>
<td>Do you feel that you are neglecting yourself?</td>
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<tr>
<td>10</td>
<td>Do you feel emotionally drained? And feel life is not worth living?</td>
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<tr>
<td>11</td>
<td>Do you become short tempered and are angry very often?</td>
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<tr>
<td>12</td>
<td>Do you feel that someone else in the family could take over as caretaker's role?</td>
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<tr>
<td>13</td>
<td>Do you feel angry when you are around your relative?</td>
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IV. Financial Burden:

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<td><strong>Never</strong></td>
<td><strong>Rarely</strong></td>
<td><strong>Sometimes</strong></td>
<td><strong>Quite Frequently</strong></td>
<td><strong>Nearly Always</strong></td>
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<tr>
<td>1</td>
<td>Does your relative’s illness is prevent you from looking for your job?</td>
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<td>2</td>
<td>Do you feel, you have money is draining from your income due to relative’s illness?</td>
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<td>3</td>
<td>Did you sell or mortgage your property or valuables for treatment of your relative’s illness?</td>
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<td>4</td>
<td>Has your financial situation worsened since your relative’s illness?</td>
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<td>5</td>
<td>Do you feel that you don’t have enough money to take care of your relative by private professional caretaker such as an attendant or nurse?</td>
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<td>6</td>
<td>Have you taken loan from friends, neighbours, relatives or bank for treating your relative?</td>
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<td>7</td>
<td>Do you feel that you will be unable to take care of your relative for long?</td>
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</tbody>
</table>
Coping Strategy to Reduce Stress / Burden of the respondents.

SECTION VI

CHECKLIST

Which of the following social recreational, spiritual, personal hobbies/activities help you for releasing stress or burden?

<table>
<thead>
<tr>
<th>Social Activities</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Contact friends, family members, neighbours</td>
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<tr>
<td>2. Attend mela, gatherings, marriages and social ceremonies</td>
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<td>3. Talk to family members and discuss about solutions</td>
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<td>4. Seek reassurance and emotional support from beloved one</td>
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<td>5. Go for shopping or window shopping</td>
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<td>6. Try a game of chance such a lottery, race, play cards</td>
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<td>7. Blame your fate sometimes, you just had bad luck</td>
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<td>8. Avoid being with people and seek complete isolation</td>
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<td>9. Try to forget the whole thing</td>
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<tr>
<td>10. Become a member of group/club, organization for group activities</td>
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<td>11. Keep a positive attitude towards situation</td>
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<tr>
<td>12. You go over the problem in your mind to try to understand it</td>
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<td>13. Accept it since nothing can be done</td>
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<tr>
<td>14. Compare yourself with others and feel that you are better off</td>
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<td>15. Wish that you can change what has happened</td>
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<tr>
<td>16. Anticipate probable outcomes and mentally rehearse them</td>
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<tr>
<td>17. Retreat to a quiet favorable spot to think things over</td>
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<tr>
<td>18. Try to think over bright side of things</td>
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<td>19. Sleep more than usual to avoid the problem</td>
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<td>20. Try to feel better by eating</td>
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<tr>
<td>21. Seek professional help and do as they recommend</td>
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<td>22. Feel that other people are responsible for what has happened</td>
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<tr>
<td>23. Spend time in the company of the children</td>
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<tr>
<td>24. Learn to relax yourself and help other in trouble and distress</td>
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<td>25. Seek sexual comfort</td>
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<tr>
<td>Physical Activities</td>
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<tr>
<td>26. Go for long walks</td>
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<td>27. Engage in vigorous physical exercise</td>
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<td>28. Go for swimming or cycling</td>
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<td>29. Exercise and eat good nutritious food</td>
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<tr>
<td>30. Start yoga, meditation</td>
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<tr>
<td>Spiritual Activities</td>
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<td>31. Perform pujas and pray to god</td>
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<td>32. Consult a faith healer</td>
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<td>33. Attend religious philosophical discourse and talks</td>
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<td>34. Hope a miracle will happen</td>
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<tr>
<td>35. Consult a astrologer</td>
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<tr>
<td>36. Read a book on religious or philosophical topic</td>
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<tr>
<td>37. Make special offering to god (Visit church, mosque, dargah, temple)</td>
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<tr>
<td>38. Visit places of pilgrims for worship</td>
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<td>39. Attending Bhajan group</td>
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<td>40. Try to make yourself better by having drink</td>
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<tr>
<td>41. Listen to music</td>
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<tr>
<td>42. Start hobbies like painting, dancing, gardening</td>
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<td>43. Read novels and magazines</td>
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<tr>
<td>44. Make yourself better by smoking/tobacco</td>
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<tr>
<td>45. Make yourself better by using drugs (Narcotics)</td>
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<td>46. Make yourself better by using sleeping pills</td>
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<tr>
<td>47. Make yourself better by mood elevator drugs</td>
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<td>48. Swallow analgesics without medical advice</td>
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<td>49. Write a letter significant to other</td>
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<tr>
<td>50. Turn to work/studies to take your mind off the things</td>
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<td>51. Write short stories, poetry</td>
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<tr>
<td>52. Read a popular guide book for answer to your problems</td>
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<td>53. Attend self help groups</td>
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<td>54. Take a big chance or do something very risky</td>
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<td>55. Keep your feelings to yourself</td>
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<tr>
<th>Recreational</th>
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<tr>
<td>56. See more movies than usual</td>
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<tr>
<td>57. Write to ‘question-answer’ or puzzle columns in various paper/magazines</td>
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<tr>
<td>58. Go for long drive</td>
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<td>59. Go for tour as change in environment</td>
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<td>60. Feel that time will remedy things, the only thing to do is wait</td>
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<tr>
<td>61. Keep your family busy in picnics</td>
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<td>62. Watching television, movies, dramas</td>
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<td>63. Learn to relax with nature</td>
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<tr>
<td>64. Go to outing along a friend</td>
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<tr>
<td>65. Attend parties</td>
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<tr>
<td>66. Keeping yourself busy with friends</td>
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<tr>
<td>67. Prepare various food items and serve others</td>
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<td>68. Visit various social activities such as camps, fairs</td>
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<td>69. Join cultural activities</td>
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<td>70. Collecting of stamps, coins, labels, antique pieces</td>
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</table>
Coping Stress Relieving responses given by the respondents shows that most of the respondents were using spiritual activities as follows.

1. Social Activities : 168 = 56%
2. Exercise yoga, and meditation : 46 = 15.33%
3. Spiritual Activities : 286 = 95.33%
4. Hobbies and habits : 28 = 9.33%

Recreational Activities : 67 = 22.33%

Note: Most of the samples show involving or performing more than one stress relaxing activity.

APPENDIX II

Libraries and Mental Health Institutes visited for reading references.

- Tata Institute of social sciences Mumbai.
- Indian Institute of population studies Deonar Mumbai
- National Information center Govandi, Mumbai.
- Institute of Nursing Education, J. J. Hospital, Mumbai.
- Indian Institute of Education Pune.
- British library, Pune
- Tilak Maharashtra University, Pune.
- Pune university library, Pune.
- Maharashtra Institute of mental Health, Pune.
- Manodeep Institute of Neuro-psychiatric and behavioral science- De-addiction centre and rehabilitation for mentally ill, Barshi, Solapur.
- Shanti Nursing home for mental health, Aurangabad.
- Regional mental hospital, Pune.
- Regional mental hospital, Thane.
- International Institute of population science, Mumbai.
- World Health Organization, New Delhi.
• Schizophrenia awareness association, Pune.
• KEM Hospital, Pune.
• Yeshwantrao Chavan Memorial Hospital, Pune.
• Bharati Hospital and Research centre, Pune.
• Bapu Trust for research on mind and discourse Kondhwa, Pune.
• Tarang (masoom), Pune.
• Swadhara, Pune.
• ASHA Action for self reliance, hope and awareness, Pune.
• Muktanganamitra Yerwada, Pune.
• Manasvardhan foundation Balewadi, Pune.
• Janaseva Foudation, Pune.
• Chaitanya mental health care centre, Pune.
• Ruby hall clinic, Pune.

For detail information of schizophrenia and other related mental health organizations information is available with the investigator.