INTERVIEW SCHEDULE FOR THE CARE GIVERS

A STUDY ON SOCIAL AND EMOTIONAL REACTIONS OF CARE GIVERS OF ELDERLY DEMENTED PERSONS.

Researcher: V.P. Shibu

Guided by Dr. Celine K. Scaria

Case No.

Date:

Details of the patient

1. Name of the Patient:

2. Age:
   (1) Below 65
   (2) 66-75 years
   (3) 76-85 years
   (4) 86 and above

3. Sex:
   (1) Male
   (2) Female

4. Education
   (1) illiterate
   (2) Primary education
   (3) Secondary and above.

5. Occupation:
   (1) Coolie
   (2) Business
   (3) Services

6. Type of Dementia
   (1) AD
   (2) MID
Personal information of primary Care givers

7. Name & Address

8. Location

9. Age

10. Sex

11. Relationship of informant with patient

12. Education

<table>
<thead>
<tr>
<th>Location</th>
<th>Age</th>
<th>Relationship with Patient</th>
<th>Education</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urban</td>
<td>20-30 years</td>
<td>Spouse</td>
<td>Illiterate</td>
</tr>
<tr>
<td>Semi urban</td>
<td>31-40 years</td>
<td>Sibling</td>
<td>Primary</td>
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<tr>
<td></td>
<td>41-50 years</td>
<td>Sister/brother in law</td>
<td>Secondary</td>
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<tr>
<td></td>
<td>51 above</td>
<td>Son/daughter</td>
<td>High School</td>
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<tr>
<td></td>
<td>61- above</td>
<td>Son/daughter in law</td>
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<td></td>
<td>Marital Status</td>
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<td>Religion</td>
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<td>13.</td>
<td>Married</td>
<td>5</td>
<td>Intermediary</td>
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<td>13.</td>
<td>Widowed/widower</td>
<td>3</td>
<td>Muslim</td>
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<tr>
<td>13.</td>
<td>Separated/divorced</td>
<td>4</td>
<td>Any other</td>
</tr>
<tr>
<td>14.</td>
<td>Marital Status</td>
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<td>Religion</td>
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<tr>
<td>14.</td>
<td>Unmarried</td>
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<td>Hindu</td>
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<tr>
<td>14.</td>
<td>Married</td>
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<td>Christian</td>
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<td>14.</td>
<td>Widowed/widower</td>
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<td>Muslim</td>
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<tr>
<td>14.</td>
<td>Separated/divorced</td>
<td></td>
<td>Any other</td>
</tr>
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</table>
19. Family size

(1) 4-below
(2) 5-8
(3) 9-above

20. Domicile

(1) Urban
(2) Semi urban
(3) Rural

II. Emotional Reactions of Caregivers

21. When you care the patient do you become angry

(1) Very often
(2) Sometimes
(3) Rarely
(4) Never

22. Do you become restless

(1) Very often
(2) Sometimes
(3) Rarely
(4) Never

23. Do you feel hostile towards the patient

(1) Very often
(2) Sometimes
(3) Rarely
(4) Never
<table>
<thead>
<tr>
<th></th>
<th>Question</th>
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</thead>
<tbody>
<tr>
<td>24</td>
<td>Do you become critical towards the patient</td>
<td>1</td>
<td>Very often</td>
<td></td>
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<td>Sometimes</td>
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<td>3</td>
<td>Rarely</td>
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<td>4</td>
<td>Never</td>
<td></td>
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<tr>
<td>25</td>
<td>How often do you feel grief towards patient</td>
<td>1</td>
<td>Very often</td>
<td></td>
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<td>Sometimes</td>
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<td>Rarely</td>
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<td>4</td>
<td>Never</td>
<td></td>
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<tr>
<td>26</td>
<td>Do you express rejection towards the patient</td>
<td>1</td>
<td>Very often</td>
<td></td>
<td></td>
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<td></td>
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<td>2</td>
<td>Sometimes</td>
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<td>3</td>
<td>Rarely</td>
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<td></td>
<td>4</td>
<td>Never</td>
<td></td>
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<tr>
<td>27</td>
<td>Do you feel guilty towards the patient</td>
<td>1</td>
<td>Very often</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td>2</td>
<td>Sometimes</td>
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<td>3</td>
<td>Rarely</td>
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<td></td>
<td>4</td>
<td>Never</td>
<td></td>
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<tr>
<td>28</td>
<td>How often you become anxious while caring for the patient</td>
<td>1</td>
<td>Very often</td>
<td></td>
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<td></td>
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<td>2</td>
<td>Sometimes</td>
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<td>3</td>
<td>Rarely</td>
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<td>4</td>
<td>Never</td>
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</tbody>
</table>
29. How often you become worried while caring the patient.

- (1) Very often
- (2) Sometimes
- (3) Rarely
- (4) Never

30. Do you experience chronic fatigue due to caring for the patient.

- (1) Very often
- (2) Sometimes
- (3) Rarely
- (4) Never

31. Do you think that you are really fed up with care giving.

- (1) Very often
- (2) Sometimes
- (3) Rarely
- (4) Never

32. Do you generally feel a loss of interest due to caring for the patient.

- (1) Very often
- (2) Sometimes
- (3) Rarely
- (4) Never

III. Social reactions of Care givers

33. How often do you get socially isolated.

- (1) Very Often
- (2) Sometimes
34. How often do you get social support in the care-giving process

<table>
<thead>
<tr>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rarely</td>
</tr>
<tr>
<td>Never</td>
</tr>
</tbody>
</table>

35. How often do you feel socially rejected.

<table>
<thead>
<tr>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very often</td>
</tr>
<tr>
<td>Sometimes</td>
</tr>
<tr>
<td>Rarely</td>
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<tr>
<td>Never</td>
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</tbody>
</table>

36. How often do you face difficulty in social interaction

<table>
<thead>
<tr>
<th>Frequency</th>
<th>(1) Very often</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sometimes</td>
<td>(2) Sometimes</td>
</tr>
<tr>
<td>Rarely</td>
<td>(3) Rarely</td>
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<tr>
<td>Never</td>
<td>(4) Never</td>
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</tbody>
</table>

37. How often do you face difficulties in interpersonal relationship

<table>
<thead>
<tr>
<th>Frequency</th>
<th>(1) Very often</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sometimes</td>
<td>(2) Sometimes</td>
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<tr>
<td>Rarely</td>
<td>(3) Rarely</td>
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<td>Never</td>
<td>(4) Never</td>
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</tbody>
</table>

IV. Nature / Extent of problems.

38. Do you feel difficulty in managing incontinence

<table>
<thead>
<tr>
<th>Frequency</th>
<th>(1) No difficulty</th>
</tr>
</thead>
<tbody>
<tr>
<td>Slight</td>
<td>(2) Slight difficulty</td>
</tr>
</tbody>
</table>
39. Do you feel difficulty in communicating with patient
   (1) No difficulty
   (2) Slight difficulty
   (3) Great difficulty

40. Do you feel difficulty in feeding the patient
   (1) No difficulty
   (2) Slight difficulty
   (3) Great difficulty

41. Do you feel difficulty in bathing the patient?
   (1) No difficulty
   (2) Slight difficulty
   (3) Great difficulty

42. Do you feel difficulty in handling the wandering behaviour of patient
   (1) No difficulty
   (2) Slight difficulty
   (3) Great difficulty

43. Do you feel difficulty in dressing the patient
   (1) No difficulty
   (2) Slight difficulty
   (3) Great difficulty

44. How often the patient becomes aggressive to you
   (1) Very often
   (2) Sometimes
   (3) Rarely
   (4) Never
45. Does the patient make injury to you
   (1) Very often
   (2) Sometimes
   (3) Rarely
   (4) Never

V. Extent of reduction of social participation of Care givers

46. Are you a member of any religious group/social group
   (1) No
   (2) Yes

47. If yes, do you get adequate time to participate in its activities
   (1) Very often
   (2) Sometimes
   (3) Rarely
   (4) Never

48. Do you get adequate time to visit your neighbours
   (1) Very often
   (2) Sometimes
   (3) Rarely
   (4) Never

49. Do you get adequate time to visit your relatives
   (1) Very often
   (2) Sometimes
   (3) Rarely
   (4) Never
50. Do you get adequate time to spare with your colleagues

   (1) Very often
   (2) Sometimes
   (3) Rarely
   (4) Never

51. How often do your relatives visit you

   (1) Very often
   (2) Sometimes
   (3) Rarely
   (4) Never

52. How often your social participation has been reduced due to care-giving

   (1) Very often
   (2) Sometimes
   (3) Rarely
   (4) Never

53. Do you get adequate time for religious worship

   (1) Very often
   (2) Sometimes
   (3) Rarely
   (4) Never

54. Do you think that the care giver's support group is effective

   (1) Very often
   (2) Sometimes
   (3) Rarely
55. Do you get adequate support from social service organisation/Health organisation

(1) Very often
(2) Sometimes
(3) Rarely
(4) Never

VI. Burden in different areas of family functioning

56. How long have you been caring the patient

(1) Less than 1 year
(2) 1-3 year
(3) 3-6 year
(4) Above 6 year

57. Do you get enough time to perform your house hold chores

(1) Very often
(2) Sometimes
(3) Rarely
(4) Never

58. Do you get enough time to meeting the needs of your children

(1) Very often
(2) Sometimes
(3) Rarely
(4) Never

59. Do you get enough time for looking after other members in the family

(1) Very often
(2) Sometimes
(3) Rarely
60. Do you get enough time to meet your Physical needs

<table>
<thead>
<tr>
<th></th>
<th>Very often</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Never</th>
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61. Do you get enough time for leisure

<table>
<thead>
<tr>
<th></th>
<th>Very often</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Never</th>
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62. Does anybody in the family help you in caring the patient

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<tr>
<th></th>
<th>Very often</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Never</th>
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</table>

63. Are you really aware about the nature of the disease

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<thead>
<tr>
<th></th>
<th>Fully aware</th>
<th>Partly aware</th>
<th>Not aware.</th>
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<tbody>
<tr>
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64. Does this help you in improving the quality of care of patient

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<tr>
<th></th>
<th>Very often</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Never</th>
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</table>
65. Do you get enough help from family members in carrying out the household chores

(1) Very often
(2) Sometimes
(3) Rarely
(4) Never

66. Do you think that your family relationship has been affected due to caring for the patient

(1) Very often
(2) Sometimes
(3) Rarely
(4) Never

67. Does any members in the family criticise you in spending more time with the patient

(1) Very often
(2) Sometimes
(3) Rarely
(4) Never

68. Do you think that your work has been doubled since started caring the patient

(1) Very often
(2) Sometimes
(3) Rarely
(4) Never

69. Have you forsaken your job to look after the patient.

(1) Yes
(2) No.

70. Do you think that you are facing the situation alone

(1) Very often
(2) Sometimes
(3) Rarely
71. Have you ever been thought of death of patient

72. What are your suggestions for improving the care

73. Level of co-operation of care giver

Signature of the Researcher
FAMILY BURDEN ASSESSMENT INTERVIEW- SCHEDULE

Name of the Care giver: Date of Interview:

*Instruction to the relative:*

We are trying to assess various difficulties felt by the family of a psychiatric patient and will ask you a few questions about these. Please do not hesitate to express your true feelings.

*Instruction to the raters:*

Please interview the relative on the following guidelines. You may probe further in order to assess a particular item if you feel it necessary. During the interview not your rating for each general category, as well as for each individual item on a three-point scale.

viz,

<table>
<thead>
<tr>
<th>Severe burden</th>
<th>-</th>
<th>2</th>
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<tbody>
<tr>
<td>Moderate burden</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>No burden</td>
<td>-</td>
<td>0</td>
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</tbody>
</table>

After completing the interview, please assess the burden on the family as a whole and give the rating on similar three-point scale.

A. Financial Burden

1. Loss of patient’s income:

   Has he lost his job?

   Stopped doing work, which he was doing before

   To what extent does it affect the family burden (0 1 2)
2. Loss of income of any other member of the family due to patient’s illness:

Has anybody stopped working in order to stay at home?

Lost pay

Lost a job

To what extent are the family’s finances affected (0 1 2)

3. Expenditure incurred due to patient’s illness and treatment:

Has he spent a lot money irrationally due to his illness?

How much has this affected the family finances?

How much has been spent on treatment, medicine, transport, accommodation, away from home and so on?

How much has been spent on other treatment such as temples and healers?

How has this affected the family finances? (0 1 2)

4. Expenditure incurred due to extra arrangements:

For instance any other relative coming to stay with the patient, appointing a nurse or servant, bounding out children.

How have these affected the family finances? (0 1 2)

5. Loan taken or saving spent:

How large a loan?

How do they plan to pay it back?

How much does it affect the family?

Did they spent from the saving?
Were these used up?

How much is the family affected? (0 1 2)

6. Any other planned activity put off because of the financial pressure of the patient’s illness:

For instance postponing a marriage, a journey

a religious rite. How far is the family affected? (0 1 2)

B. Disruption of Routine Family Activities

1. Patient not going to work, school, college etc.

How much inconvenient is this for the family? (0 1 2)

2. Patient not helping in the house hold work:

How much does this affect the family? (0 1 2)

3. Disruption of the activities of other members of the family:

Has some one to spent time losing after the patient, then abandoning another routine activity?

How inconvenient is this? (0 1 2)

4. Patient’s behaviour disrupting activities:

Patient insisting on someone being with him?

Becoming violent?

Breaking things?

How much does this affect the family? (0 1 2)

5. Neglect of rest the family due to patient’s illness:

Is any other member missing school meals etc?
How serious is this? (0 1 2)

C. Disruption of family leisure

1. Stopping normal recreational activities:

   How do the family numbers react? (0 1 2)

2. Patient's illness loosing up another's holiday and leisure time:

   How is the person affected by it? (0 1 2)

3. Patient's lack of attention to other members of the family, such as children and its effect on them? (0 1 2)

4. Has any other leisure activity had to be abandoned owing to the patient's illness or incapacity?

   eg: a pleasure trip or family gathering.

   How do the family feel about it? (0 1 2)

D. Disruption of Family Interaction

1. Any ill effect on the general atmosphere in the home:

   Has it become dull or quiet?

   Is there a lot of misunderstanding etc?

   How do the family members view this? (0 1 2)

2. Do other members get in to arguments over this?

   For instance over how the patient should be treated

   Who should do the work?

   Whom to blame etc

   How are they affected? (0 1 2)
3. Have the relatives or neighbour stopped visiting the family or reduced the frequency of visits because of the patient's behaviour of stigma attached to his illness:

How does the family feel about this? (0 1 2)

4. Has the family been secluded?

Does it avoid mixing with the others because of shame or fear being misunderstood?

How do the members feel about this? (0 1 2)

5. Has the patient's illness had any other effect on relationships within the family between the family and neighbours or relatives, e.g., separation of spouses, quarrels between two families, property problems, police intervention, embarrassment for family members etc.

How does the family feel about it? (0 1 2)

E. Effect on Physical Health of Others

1. Have other members of the family suffered physical ill health: injuries etc. due to the patient's behaviour?

How has this affected them? (0 1 2)

2. Has there been any other adverse effect on health:

Eg: someone losing weight of existing illness being exacerbated.

How severe is it? (0 1 2)
F. Effect on Mental Health of Others

1. Has any other family member sought help for psychological illness brought on by the patient’s behaviour?

   For instance by the patients suicide bid or his disobedience or worry about his future?

   How severe is this? (0 1 2)

2. Has any other members of the family lost sleep become depressed or weepy expressed suicidal wishes, become excessively irritable etc.? How severe is this?

   Finally, is there any other burden about which we have not asked you? If so what is it?

   How badly does it affect you? (0 1 2)

Subjective Burden on the Family

This is to be assessed by asking the following standard question and scoring the relatives answer.

How much would you say you have suffered owing to this patient’s illness (Severely, a little or not at all?) (0 1 2)

Signature of Researcher

* No burden / not at all (score of Zero)

* Moderate burden / partially (score of one)

* Severe burden / completely (score of two)
GENERAL HEALTH QUESTIONNAIRE (GHQ)

A. Have you recently;

1. Been feeling perfectly well and in good health?
   (0) Better than usual (0) Same as usual
   (1) Worse than usual (1) Much worse than usual

2. Been feeling in need of a good tonic?
   (0) Not at all (0) No more than usual
   (1) Rather more than (1) Much more than usual

3. Been feeling run down and out of sorts?
   (0) Not at all (0) No more than usual
   (1) Rather more than (1) Much more than usual

4. Felt that you are ill?
   (0) Not at all (0) No more than usual
   (1) Rather more than (1) Much more than usual

5. Been getting any pains in your head?
   (0) Not at all (0) No more than usual
   (1) Rather more than (1) Much more than usual

6. Been getting a feeling of tightness or pressure in your head?
   (0) Not at all (0) No more than usual
<table>
<thead>
<tr>
<th></th>
<th>Rather more than</th>
<th>Much more than usual</th>
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<tbody>
<tr>
<td>7. Been having hot or cold spells?</td>
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<td>(        )</td>
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<tr>
<td></td>
<td>Not at all</td>
<td>No more than usual</td>
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<td></td>
<td>Rather more than</td>
<td>Much more than usual</td>
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<tr>
<td>B. Lost much sleep over worry?</td>
<td>(    )</td>
<td>(        )</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>No more than usual</td>
</tr>
<tr>
<td></td>
<td>Rather more than</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>2. Had difficulty in staying asleep once you are off?</td>
<td>(    )</td>
<td>(        )</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>No more than usual</td>
</tr>
<tr>
<td></td>
<td>Rather more than</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>3. Felt constantly under strain?</td>
<td>(    )</td>
<td>(        )</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>No more than usual</td>
</tr>
<tr>
<td></td>
<td>Rather more than</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>4. Been getting edge and bad tempered?</td>
<td>(    )</td>
<td>(        )</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>No more than usual</td>
</tr>
<tr>
<td></td>
<td>Rather more than</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>5. Been getting scared of panicky for no good reason?</td>
<td>(    )</td>
<td>(        )</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>No more than usual</td>
</tr>
<tr>
<td></td>
<td>Rather more than</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>6. Found everything getting on top of you?</td>
<td>(    )</td>
<td>(        )</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>No more than usual</td>
</tr>
</tbody>
</table>
(1) Rather more than (1) Much more than usual

7. Been feeling nervous and strung up all the time?

(0) Not at all (0) No more than usual
(1) Rather more than (1) Much more than usual

C.

1. Been managing to keep you busy and occupied

(0) More than usual (C) Same as usual
(1) Rather less than usual (1) Much less than usual

2. Been taking longer over the things you do?

(0) Quicker than usual (0) Same as usual
(1) Longer than usual (1) Much longer than usual

3. Felt on the whole you were doing things well?

(0) Better than usual (0) About the same
(1) Less well than usual (1) Much less well

4. Been satisfied with the way you've carried out?

(0) More satisfied (0) About same as usual
(1) Less useful than usual (1) Much less satisfied

5. Felt that you are playing a useful part in things?

(0) More so than usual (0) Same as usual
(1) Less useful than usual (1) Much less useful

6. Felt capable of making decisions about things

(0) More so than usual (0) Same as usual
7. Been able to enjoy your normal day-to-day activities

(0) More so than usual (0) Same as usual

(1) Less useful than usual (1) Much less useful

D.

1. Been thinking of you as a worthless person?

(0) Not at all (0) No more than usual

(1) Rather more than (1) Much more than usual

2. Felt that life isn't worthless person?

(0) Not at all (0) No more than usual

(1) Rather more than (1) Much more than usual

3. Felt that life isn't worth living?

(0) Not at all (0) No more than usual

(1) Rather more than (1) Much more than usual

4. Thought of the possibility that you might make away with yourself

(0) Definitely not (3) I don't think so

(1) Has crossed my mind (1) Definitely have

5. Found at times you couldn't do anything because your

moves were too bad

(0) Not at all (0) No more than usual

(1) Rather more than (1) Much more than usual
6. Found yourself wishing you were dead and away from it all?

(0) Not at all (0) No more than usual
(1) Rather more than usual (1) Much more than usual

7. Found that the idea of taking own life kept coming into your mind

(0) Definitely not (0) I don’t think so
(1) Has crossed my mind (1) Definitely have

Date : Signature of Research Scholar