

BURDEN ASSESSMENT SCHEDULE OF SCARF

The Burden Assessment Schedule developed at SCARF is based on an integrative framework encompassing subjective and objective components of burden. Qualitative and quantitative methods were adopted in the process of development. The initial steps in the ethnographic exploration were unstructured interviews of primary caregivers of chronic mentally ill patients. This helped in identifying broad domains of burden experienced by the caregivers.

Repeat interviews using a semi-structured framework based on information obtained from the initial interviews helped to clarify the domains. These were further validated by focus group discussions with caregivers. Itemisation of the instrument was undertaken and an initial 65 item questionnaire was developed.

This 65 item instrument was field tested on 250 respondents. A factor analyses using varimax rotation was done. This helped to delete items with low factor loadings, below 0.4. The resultant instrument comprised 40 items.

Inter-rate reliability exercises were carried out at the commencement of the quantitative phase. Kappa value of 0.8 was obtained. Reliability was also carried out for every 10th interview to ensure that the level of reliability was maintained.

Criterion validity was established by comparing with the Family Burden Schedule (Pai and Kapur, 1981). Both instruments were administered on 60 caregivers by two different researches. Comparable items of both instruments were found to be highly correlated.

The Burden Assessment Schedule has been developed at SCARF with the support of the WHO SEARO & the technical support from Dr. Helmut Sell, WHO SEARO.

CLIENT AND INFORMANT DETAILS

Name of client : _____

Age

Sex

Male 1

Female 2

Marital Status

Single 1

Married 2

Separated 3

Divorced 4

Widowed 5

Living with a partner 6

Other 9

Educational Level

Elementary School 1

Secondary School 2

Technical School 3

University 4

Post-Degree 5

Other 9

Working Status

Full-time paid job 1

Part-time paid job 2

Full-time unpaid job 3

Part-time unpaid job 4

Do not work 5

Other 9

1. **Is the current financial position adequate to look after the patient?**
 - Not at all 3
 - To some extent 2
 - Very much 1
2. **Are you concerned that you are largely responsible to meet the patient's financial need?**
 - Not at all 1
 - To some extent 2
 - Very much 3
3. **Does the patient's future financial situation worry you?**
 - Not at all 1
 - To some extent 2
 - Very much 3
4. **Has your family's financial situation worsened since the patient's illness?**
 - Not at all 1
 - To some extent 2
 - Very much 3
5. **Is the patient's illness preventing you from looking for a job?**
 - Not at all 1
 - To some extent 2
 - Very much 3
6. **Do you feel forced into going to work to support the patient?**
 - Not at all 1
 - To some extent 2
 - Very much 3
7. **Does the patient's illness affect your efficiency at work (at home/at work place)?**
 - Not at all 1
 - To some extent 2
 - Very much 3

8. **Are you satisfied with the way the patient looks after himself?**
- | | |
|----------------|---|
| Not at all | 3 |
| To some extent | 2 |
| Very much | 1 |
9. **Do you feel you have to take the responsibility of ensuring that the patient has everything he needs?**
- | | |
|----------------|---|
| Not at all | 1 |
| To some extent | 2 |
| Very much | 3 |
10. **Do you think you have to compensate the patient's shortcomings, in general?**
- | | |
|----------------|---|
| Not at all | 1 |
| To some extent | 2 |
| Very much | 3 |
11. **Does support from your family help in caring for the patient?**
- | | |
|----------------|---|
| Not at all | 3 |
| To some extent | 2 |
| Very much | 1 |
12. **Does the patient cause disturbances in the home ?**
- | | |
|----------------|---|
| Not at all | 1 |
| To some extent | 2 |
| Very much | 3 |
13. **Are you able to care for others in your family?**
- | | |
|----------------|---|
| Not at all | 3 |
| To some extent | 2 |
| Very much | 1 |
14. **Has your family stability been disrupted by your relative's illness (frequent quarrels, break-up) ?**
- | | |
|----------------|---|
| Not at all | 1 |
| To some extent | 2 |
| Very much | 3 |

15. Do you think that you family appreciates the way you handle the patient ?
- | | |
|----------------|---|
| Not at all | 3 |
| To some extent | 2 |
| Very much | 1 |

16. Does the patient's illness prevent you from having satisfying relationship with the rest of you family ?
- | | |
|----------------|---|
| Not at all | 1 |
| To some extent | 2 |
| Very much | 3 |

(If the spouse is the ill member in you family please answer the next 4 questions).

- *17. Does your spouse help with family responsibility ?
- | | |
|----------------|---|
| Not at all | 3 |
| To some extent | 2 |
| Very much | 1 |

- *18. Is your spouse able to satisfy your sexual needs ?
- | | |
|----------------|---|
| Not at all | 3 |
| To some extent | 2 |
| Very much | 1 |

- *19. Is your spouse still affectionate towards you ?
- | | |
|----------------|---|
| Not at all | 1 |
| To some extent | 2 |
| Very much | 3 |

- *20. Has the quality of your marital relationship declined since your spouse's illness ?
- | | |
|----------------|---|
| Not at all | 1 |
| To some extent | 2 |
| Very much | 3 |

21. Does caring for the patient make you feel easily tired and exhausted ?
- | | |
|----------------|---|
| Not at all | 1 |
| To some extent | 2 |
| Very much | 3 |

- | | | |
|------------|---|---|
| | Not at all | 1 |
| | To some extent | 2 |
| | Very much | 3 |
| 23. | Do you think that your health has been affected because of the patient's illness ? | |
| | Not at all | 1 |
| | To some extent | 2 |
| | Very much | 3 |
| 24. | Do you find time to look after you health ? | |
| | Not at all | 3 |
| | To some extent | 2 |
| | Very much | 1 |
| 25. | Are you able to relax for sometime during the day ? | |
| | Not at all | 3 |
| | To some extent | 2 |
| | Very much | 1 |
| 26. | Do you sometimes feel depressed and anxious because of the patient ? | |
| | Not at all | 1 |
| | To some extent | 2 |
| | Very much | 3 |
| 27. | Do you sometimes feel that there is no solution to your problems ? | |
| | Not at all | 1 |
| | To some extent | 2 |
| | Very much | 3 |
| 28. | Do you feel sometimes the need for temporary separation from the patient ? | |
| | Not at all | 1 |
| | To some extent | 2 |
| | Very much | 3 |

29. Does reducing the time spent with the patient (work/other activities) help you ?
- | | |
|----------------|---|
| Not at all | 3 |
| To some extent | 2 |
| Very much | 1 |
30. Does the patient's unpredictable behaviour disturb you ?
- | | |
|----------------|---|
| Not at all | 1 |
| To some extent | 2 |
| Very much | 3 |
31. Has your sleep been affected since the patient took ill ?
- | | |
|-------------------|---|
| <i>Not at all</i> | 1 |
| To some extent | 2 |
| Very much | 3 |
32. Does your relative's illness prevent you from having satisfying relationships with you friends ?
- | | |
|----------------|---|
| Not at all | 1 |
| To some extent | 2 |
| Very much | 3 |
33. Have you started to feel lonely and isolated since the patient's illness ?
- | | |
|----------------|---|
| Not at all | 1 |
| To some extent | 2 |
| Very much | 3 |
34. Does support from friends help in caring for the patient ?
- | | |
|----------------|---|
| Not at all | 3 |
| To some extent | 2 |
| Very much | 1 |
35. Does sharing your problems with others make you feel better ?
- | | |
|----------------|---|
| Not at all | 3 |
| To some extent | 2 |
| Very much | 1 |

36. Do you feel that your friends appreciate the way you handle the patients ?
- | | |
|----------------|---|
| Not at all | 3 |
| To some extent | 2 |
| Very much | 1 |
37. Do you often feel frustrated that the improvement of the patient is slow ?
- | | |
|----------------|---|
| Not at all | 1 |
| To some extent | 2 |
| Very much | 3 |
38. Do you feel that you are doing more than the patient to improve his/her situation ?
- | | |
|----------------|---|
| Not at all | 1 |
| To some extent | 2 |
| Very much | 3 |
39. Do you have the feeling that your relative understands and appreciates your effort to help him/her ?
- | | |
|----------------|---|
| Not at all | 3 |
| To some extent | 2 |
| Very much | 1 |
40. Are you satisfied with the amount of help that you are getting from health professionals regarding you relatives illness ?
- | | |
|----------------|---|
| Not at all | 3 |
| To some extent | 2 |
| Very much | 1 |

BURDEN ASSESSMENT SCHEDULE — Scoring Sheet

Name of Client :

Age :

Sex :

Marital Status :

Educational Level :

Working Status :

Relationship with ^{informant:} ~~patient~~ :

Living Status :

Contact with patient :

Name of informant :

Age :

Sex :

Marital Status :

Educational Level :

Working Status :

Relationship with patient :

Living Status :

Contact with patient :

BURDEN ASSESSMENT

1. 3 2 1
2. 1 2 3
3. 1 2 3
4. 1 2 3
5. 1 2 3
6. 1 2 3
7. 1 2 3
8. 3 2 1
9. 1 2 3
10. 1 2 3
11. 3 2 1
12. 1 2 3
13. 3 2 1
14. 1 2 3
15. 3 2 1
16. 1 2 3
17. 3 2 1
18. 3 2 1
19. 1 2 3
20. 1 2 3

21. 1 2 3
22. 1 2 3
23. 1 2 3
24. 3 2 1
25. 3 2 1
26. 1 2 3
27. 1 2 3
28. 1 2 3
29. 3 2 1
30. 1 2 3
31. 1 2 3
32. 1 2 3
33. 1 2 3
34. 3 2 1
35. 3 2 1
36. 3 2 1
37. 1 2 3
38. 1 2 3
39. 3 2 1
40. 3 2 1