Consequences for caregivers of patients with severe mental illness: the development of the involvement evaluation questionnaire

van Wijngaarden, B.

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Appendix II: final IEQ-EU version

(used in the studies described in Chapters 2, 3, 4, and 6)

Respondent identifier: ............

IEQ-EU
Involvement
Evaluation
Questionnaire

European Version

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INVolVEMENT EVALuATION QUESTIONNAIRE

Introduction

In the field of psychiatric care, attention has been concentrated almost exclusively on the patients themselves. In recent years, however, more concern has been shown towards the families, friends and others involved.

You too are involved in the care of someone with mental health problems and this questionnaire has been designed to assess the personal consequences of such a situation for carers like yourself.

Completing the questionnaire

The questionnaire is divided into 8 sections, each representing a different aspect of caring. Each part is headed by a brief explanatory paragraph to lead you into the theme of the section.

Only one answer is possible for each question, unless otherwise indicated - please tick accordingly. In some cases, we will ask you to fill in a few personal details, such as your age.

It is quite possible that in some cases, a question will not be relevant to your particular circumstances. The questionnaire will clearly indicate, therefore, which questions you can ignore and at which point you should start again.

The consequences of your caring for someone who has mental health problems might have existed for several years already, but it is important to bear in mind that this questionnaire is mostly concerned with an analysis of the current situation. Most of the questions, therefore, cover your experiences during the past four weeks, whilst a few questions are about your more long-term experience. The questions themselves will make this clear.

All information will be treated confidentially, and you do not have to give your name if you do not wish to. If there are questions which you would prefer not to answer, we will, of course, respect your wishes - in this case, however, please write ‘no answer’ next to the question.

Take your time to answer each question in turn and remember that what matters most of all is that your answers truly reflect your own personal experience.
Before we turn to the matter of your own experiences, we would first like to have some general information about you personally and about the relative/friend you are caring for.

1. What is your age?
I am ..... years of age.

2. Sex?
   - female
   - male

3. Your education/training?

4. What is your civil status?
   I am:
   - single
   - married/in a long-term partnership
   - divorced
   - widowed

5. Do you live alone or with others?
   - I live alone (PROCEED TO QUESTION 7)
   - I live with my spouse/partner and/or children
   - I live with my parents and/or sisters/brothers
   - I live with other relatives
   - I live with friends
   - other (please indicate) ........................................

6. How many people, including yourself, are there in your household?
   My household consists of ..... (no | people

7. What is your relative/friend's age?
   My relative/friend is ....... years of age.
8. My relative/friend's sex is.
   - female
   - male

9. When did your relative/friend's mental health problems start?
   That was in 19 ....

10. Is your relative/friend currently receiving help for his/her mental health problems?
    Please note that more than one answer is possible.
    - I do not know
    - no professional help
    - yes, from G.P./family doctor
    - yes, from a social worker
    - yes, from an occupational therapist
    - yes, at the Community Mental Health Centre/from the Community Mental Health Team
    - yes, from a psychologist or cognitive/behavioural therapist
    - yes, as an outpatient at a psychiatric hospital or the psychiatric department of a general hospital
    - yes, in a psychiatric day hospital
    - yes, as an inpatient in a psychiatric hospital or the psychiatric department of a general hospital
    - yes, living in supported housing
    - yes, other (please specify) .................................................................

11. What is your precise relationship with your relative/friend?

   I am her/his:
   - mother/father (step, foster and adoptive parents included)
   - daughter/son
   - sister/brother
   - other relative
   - wife/husband, partner or girl/boy friend
   - friend
   - neighbour
   - colleague/fellow student
   - other (please indicate) .................................................................

12. Is your relative/friend part of your household?

   - no
   - yes
13. How many days have you and your relative/friend lived together at the same address during the past four weeks?

☐ none
☐ some, namely ..................... no. 1 days
☐ the full four weeks

14. What is your family's approximate net income (wage/salary, welfare benefits, pension etc.) after deductions for tax, national insurance etc.?

☐ less than £300 per month
☐ £300 - £500 per month
☐ £500 - £900 per month
☐ £900 - £1500 per month
☐ £1500 - £2250 per month
☐ more than £2250 per month

15. What has been your average weekly telephone or personal contact with your relative/friend, over the past four weeks?

☐ less than 1 hour a week  (PROCEED TO QUESTION 37)
☐ 1-4 hours a week
☐ 5-8 hours a week
☐ 9-16 hours a week
☐ 17-32 hours a week
☐ more than 32 hours a week

The following questions are about the encouragement and care you have given to your relative/friend during the past four weeks.

16. How often during the past four weeks have you encouraged your relative/friend to take proper care of her/himself (e.g. washing, bathing, brushing teeth, dressing, combing hair etc.)?

☐ never
☐ sometimes
☐ regularly
☐ often
☐ (almost) always
17. How often during the past four weeks have you helped your relative/friend take proper care of her/himself (e.g. washing, bathing, brushing teeth, dressing, combing hair etc.)?

☐ never
☐ sometimes
☐ regularly
☐ often
☐ (almost) always

18. How often during the past four weeks have you encouraged your relative/friend to eat enough?

☐ never
☐ sometimes
☐ regularly
☐ often
☐ (almost) always

19. How often during the past four weeks have you encouraged your relative/friend to undertake some kind of activity (e.g. go for a walk, have a chat, hobbies, household chores)?

☐ never
☐ sometimes
☐ regularly
☐ often
☐ (almost) always

20. How often during the past four weeks have you accompanied your relative/friend on some kind of outside activity, because he/she did not dare to go alone?

☐ never
☐ sometimes
☐ regularly
☐ often
☐ (almost) always

21. How often during the past four weeks have you ensured that your relative/friend has taken the required medicine?

☐ not relevant: relative/friend has no medicines
☐ never
☐ sometimes
☐ regularly
☐ often
☐ (almost) always
22. How often during the past four weeks have you guarded your relative/friend from committing dangerous acts (i.e. setting something alight, leaving the gas on, forgetting to stub cigarettes out etc.)?

☐ never
☐ sometimes
☐ regularly
☐ often
☐ (almost) always

23. How often during the past four weeks have you guarded your relative/friend from self-inflicted harm (i.e. cutting her/himself, excessive medicine intake, burning, suicide attempt etc.)?

☐ never
☐ sometimes
☐ regularly
☐ often
☐ (almost) always

24. How often during the past four weeks have you ensured that your relative/friend received sufficient sleep?

☐ never
☐ sometimes
☐ regularly
☐ often
☐ (almost) always

25. How often during the past four weeks have you guarded your relative/friend from drinking too much alcohol?

☐ never
☐ sometimes
☐ regularly
☐ often
☐ (almost) always

26. How often during the past four weeks have you guarded your relative/friend from taking illegal drugs?

☐ never
☐ sometimes
☐ regularly
☐ often
☐ (almost) always
27. How often during the past four weeks have you carried out tasks normally done by your relative/friend (household chores, financial matters, shopping, cooking etc.)?
   - never
   - sometimes
   - regularly
   - often
   - (almost) always

28. How often during the past four weeks have you encouraged your relative/friend to get up in the morning?
   - never
   - sometimes
   - regularly
   - often
   - (almost) always

29. How often during the past four weeks has your relative/friend disturbed your sleep?
   - never
   - sometimes
   - regularly
   - often
   - (almost) always

The following questions are about how you have got on with your relative/friend in the past four weeks.

30. How often during the past four weeks has the atmosphere been strained between you both, as a result of your relative/friend's behaviour?
   - never
   - sometimes
   - regularly
   - often
   - (almost) always

31. How often during the past four weeks has your relative/friend caused a quarrel?
   - never
   - sometimes
   - regularly
   - often
   - (almost) always
32. **How often during the past four weeks have you been annoyed by your relative/friend's behaviour?**

- never
- sometimes
- regularly
- often
- (almost) always

33. **How often during the past four weeks have you heard from others that they have been annoyed by your relative/friend's behaviour?**

- never
- sometimes
- regularly
- often
- (almost) always

34. **How often during the past four weeks have you felt threatened by your relative/friend?**

- never
- sometimes
- regularly
- often
- (almost) always

35. **How often during the past four weeks have you thought of moving out, as a result of your relative/friend's behaviour?**

- never
- sometimes
- regularly
- often
- (almost) always

36. **How often during the past four weeks have you been able to pursue your own activities and interests (e.g. work, school, hobbies, sports, visits to family and friends)?**

- never
- sometimes
- regularly
- often
- (almost) always
The following questions are about the worries which may arise from your involvement with a relative/friend who has mental health problems.

37. How often during the past four weeks have you worried about your relative/friend's safety?
   - never
   - sometimes
   - regularly
   - often
   - (almost) always

38. How often during the past four weeks have you worried about the kind of help/treatment your relative/friend is receiving?
   - never
   - sometimes
   - regularly
   - often
   - (almost) always

39. How often during the past four weeks have you worried about your relative/friend's general health?
   - never
   - sometimes
   - regularly
   - often
   - (almost) always

40. How often during the past four weeks have you worried about how your relative/friend would manage financially if you were no longer able to help?
   - never
   - sometimes
   - regularly
   - often
   - (almost) always

41. How often during the past four weeks have you worried about your relative/friend's future?
   - never
   - sometimes
   - regularly
   - often
   - (almost) always
42. **How often during the past four weeks have you worried about your own future?**

- never
- sometimes
- regularly
- often
- (almost) always

43. **To what extent have your relative/friend’s mental health problems been a burden to you during the past four weeks?**

- no burden at all
- a slight burden
- a fairly heavy burden
- a heavy burden
- a very heavy burden

44. **Have you got used to your relative/friend having mental health problems?**

- no
- a little
- fairly well
- very well
- completely

45. **How often have you felt able to cope with your relative/friend’s mental health problems?**

- never
- sometimes
- regularly
- often
- (almost) always

46. **Has your relationship with your relative/friend changed since the onset of the mental health problems?**

- no
- a little
- rather a lot
- a lot
- a great deal
The following questions are about the financial cost to you and your household, as a result of your relative/friend’s mental health problems.

Have you, during the past four weeks, had to incur extra expenses on behalf of your relative/friend?

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>47. Professional help for your relative/friend</td>
<td></td>
<td></td>
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<tr>
<td>48. Damage caused by your relative/friend</td>
<td></td>
<td></td>
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<tr>
<td>49. Large expenditures incurred by your relative/friend</td>
<td></td>
<td></td>
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<tr>
<td>50. Relative/friend’s travel expenses</td>
<td></td>
<td></td>
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<tr>
<td>51. Medicine for your relative/friend</td>
<td></td>
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<tr>
<td>52. Paying off debts incurred by your relative/friend</td>
<td></td>
<td></td>
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<tr>
<td>53. Other expenses (please indicate):</td>
<td></td>
<td></td>
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</tbody>
</table>

54. If you add up all the extra expenses which you have incurred on behalf of your relative/friend during the past four weeks, what is the estimated total figure?

- [ ] less than £25
- [ ] £25 - £50
- [ ] £50 - £125
- [ ] £125 - £250
- [ ] more than £250
Please read the questions below and each of the four possible answers. We want to know how your health has been in general over the last four weeks. Please answer all the questions by circling the response that best applies to you.

Have you recently:

<table>
<thead>
<tr>
<th>Question</th>
<th>Better than usual</th>
<th>Same as usual</th>
<th>Less than usual</th>
<th>Much less than usual</th>
</tr>
</thead>
<tbody>
<tr>
<td>55. been able to concentrate on what you're doing?</td>
<td></td>
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<tr>
<td>56. lost much sleep over worry</td>
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<tr>
<td>57. felt that you are playing a useful part in things?</td>
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<tr>
<td>58. felt capable of making decisions about things?</td>
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<tr>
<td>59. felt constantly under strain?</td>
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<tr>
<td>60. felt you couldn't overcome your difficulties?</td>
<td></td>
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<tr>
<td>61. been able to enjoy your normal day-to-day activities?</td>
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<tr>
<td>62. been able to face up to your problems?</td>
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<tr>
<td>63. been feeling unhappy or depressed?</td>
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<tr>
<td>64. been losing confidence in yourself?</td>
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<tr>
<td>65. been thinking of yourself as a worthless person?</td>
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<tr>
<td>66. been feeling reasonably happy, all things considered?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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67. Are you receiving help from your G.P./family doctor for any of these complaints?
   □ yes
   □ no

68. Are you receiving help from a social worker, a psychologist, a psychiatrist or an outpatient department for any of these complaints?
   □ yes
   □ no

69. Are you taking any kind of medicine for these complaints?
   □ yes
   □ no

If a father or mother has mental health problems, this may have consequences for their children, if any. The following questions are about these consequences.

70. Has your relative/friend with mental health problems any children (incl. step/foster/adopted children)?
   □ no (PROCEED TO QUESTION 81)
   □ yes, .......... (number of) children.

71. Has your relative/friend any children under the age of 16 years?
   □ no (PROCEED TO QUESTION 81)
   □ yes, .......... (number of) children under the age of 16 years.
How often has it happened during the past four weeks that the child or children has/have:

<table>
<thead>
<tr>
<th></th>
<th>never</th>
<th>sometimes</th>
<th>often</th>
<th>don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>72.</td>
<td>Shown loss of appetite</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>73.</td>
<td>Been sleepless at night</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>74.</td>
<td>Been less attentive at school</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>75.</td>
<td>Shown fear of father/mother</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>76.</td>
<td>Not attended school</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>77.</td>
<td>Displayed difficult behaviour</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>78.</td>
<td>Played less often with friends</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>79.</td>
<td>Felt ashamed of father/mother</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>80.</td>
<td>Had to stay with neighbours, relatives or friends</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

The items listed in this questionnaire cannot, of course, cover all your experiences. If you would like to make any further comments, therefore, please feel free to write them in the space below.

Comments:

It is important for the purposes of this study that all the questions that apply to you personally, are answered. We would appreciate it, therefore, if you would carefully check that no questions have been overlooked.

Please accept our sincere thanks for your help and co-operation.