Consequences for caregivers of patients with severe mental illness: the development of the involvement evaluation questionnaire
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Citation for published version (APA):
van Wijngaarden, B. (2003). Consequences for caregivers of patients with severe mental illness: the development of the involvement evaluation questionnaire

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Appendices
Appendix I: the first version of the IEQ
(used in the studies described in Chapters 2, 5, and 6)

Involvement
Evaluation
Questionnaire

(IEQ)

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The Netherlands
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 patients' families, friends and others involved in their immediate environment.

You too are involved with someone who has mental health problems and this questionnaire has been designed to evaluate the consequences such a situation may have for you personally.

You will notice that we use the term person, by which we mean the person suffering from the mental problems.

Completing the questionnaire

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

It is quite possible that in some cases, a question is not 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 involvement with 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 only concerned with an analysis of the current situation. Most of the questions, therefore, cover your experiences during the last four weeks, whilst a few questions are about your more long-term experience. The questions themselves will make this clear.

All information will be anonymous and confidential. If, however, there are questions which you would prefer not to answer, we will, of course, respect this but would ask you to be kind enough to indicate it accordingly.

Please answer each question in turn. Take your time and remember that your answers to the questions are neither right nor wrong. What is important is that your answers truly reflect your own personal experience.
Before we turn to the matter of your own involvement, we would first like to know something about you personally and your relationship with the person.

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

2. **Sex?**
   
   □ female  □ male

3. **Education/training?**
   
   (please indicate)  
   
   .................................................................
   .................................................................
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   **Completed?**  
   
   yes  no
   
   □  □
   □  □
   □  □
   □  □
   □  □

4. **What is the person's age?**
   
   The person is ....... years of age.

5. **The person's sex?**
   
   □ female  □ male

6. **When did the person's mental health problems start?**
   
   That was in 19
7. **Is the person currently receiving help for the mental health problems?**

- [ ] I do not know
- [ ] no additional help
- [ ] yes, from G.P./family doctor or social worker
- [ ] yes, as an outpatient
- [ ] yes, in a psychiatric day clinic
- [ ] yes, in a psychiatric hospital or psychiatric department of a general hospital
- [ ] yes, living in sheltered accommodation
- [ ] yes, other (please indicate)

8. **What is your relationship to the person?**

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

9. **What is your civil status?**

- [ ] unmarried
- [ ] married/long-term partnership
- [ ] divorced
- [ ] widowed

10. **Do you live alone or with others?**

- [ ] I live alone **(PROCEED TO QUESTION 14)**
- [ ] 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)

11. **How many people, including yourself, are there in your household?**

My household consists of ..........ino.) people.
12. *Is the person with mental health problems part of that household?*

☐ no
☐ yes

13. *How many days have you and the person lived together at the same address during the last four weeks?*

☐ none
☐ some, namely ____________ (no. of days)
☐ the full four weeks

14. *What is your family’s approximate net income (wage/salary, assistance benefits, pension etc.)*

☐ less than fl. 1000 per month
☐ fl. 1000 - fl. 2000 net per month
☐ fl. 2000 - fl. 3000 net per month
☐ fl. 3000 - fl. 4000 net per month
☐ fl. 4000 - fl. 5000 net per month
☐ more than fl. 5000 net per month

15. *What per week was the average duration of your personal or telephone contact with the person during the last 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 concern the attention and care you have given to the patient during the last four weeks.

16. *How often during the last four weeks have you urged the person to take proper care of her/himself (e.g. washing, bathing, brushing teeth, dressing, combing hair etc.)*

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

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17. How often during the last four weeks have you helped the person take proper care of herself/himself (e.g., washing, bathing, brushing teeth, dressing, combing hair etc.)?
   - [ ] never
   - [ ] sometimes
   - [ ] regularly
   - [ ] often
   - [ ] (almost) always

18. How often during the last four weeks have you urged the person to eat enough?
   - [ ] never
   - [ ] sometimes
   - [ ] regularly
   - [ ] often
   - [ ] (almost) always

19. How often during the last four weeks have you urged the person 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 last four weeks have you accompanied the person 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 last four weeks have you ensured that the person has taken the required medicine?
   - [ ] not relevant: person has no medicines
   - [ ] never
   - [ ] sometimes
   - [ ] regularly
   - [ ] often
   - [ ] (almost) always
22. How often during the last four weeks have you guarded the person 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 last four weeks have you guarded the person from self-inflicted harm (i.e. cutting her/himself, excess medicine intake, burning, suicide attempt etc.)?

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

24. How often during the last four weeks have you ensured that the person received sufficient sleep?

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

25. How often during the last four weeks have you guarded the person from drinking to much alcohol?

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

26. How often during the last four weeks have you guarded the person from taking illegal drugs?

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

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

28. How often during the last four weeks have you urged the person to get up in the morning?

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

29. How often during the last four weeks has the person disturbed your sleep?

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

The following questions concern the atmosphere between you and the person during the last four weeks.

30. How often during the last four weeks has the atmosphere been strained between you both, as a result of the person's behaviour?

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

31. How often during the last four weeks has the person caused a quarrel?

☐ never
☐ sometimes
☐ regularly
☐ often
☐ (almost) always
32. How often during the last four weeks have you been annoyed by the person's behaviour?

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

33. How often during the last four weeks have you heard from others that they have been annoyed by the person's behaviour?

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

34. How often during the last four weeks have you felt threatened by the person?

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

35. How often during the last four weeks have you thought of moving out, as a result of the person's behaviour?

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

36. How often during the last 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 concern the worries which may arise from involvement with a person who has mental health problems.

37. How often during the last four weeks have you worried about the person’s safety?
   - never
   - sometimes
   - regularly
   - often
   - (almost) always

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

39. How often during the last four weeks have you worried about the person’s general health?
   - never
   - sometimes
   - regularly
   - often
   - (almost) always

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

41. How often during the last four weeks have you worried about the person’s future?
   - never
   - sometimes
   - regularly
   - often
   - (almost) always
42. How often during the last four weeks have you worried about your own future?

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

43. To what extent have the person's mental health problems been a burden to you during the last four weeks?

☐ none
☐ slight
☐ fairly heavy
☐ heavy
☐ very heavy

44. Have you got used to the person having mental health problems?

☐ no
☐ a little
☐ fairly
☐ very
☐ completely

45. How often have you felt able to cope with the patient's mental health problems?

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

46. Has your relationship with the person changed since the onset of the mental health problems?

☐ no
☐ a little
☐ rather
☐ a lot
☐ a great deal
The following questions concern possible financial consequences for you and your household, as a result of the person's mental health problems.

*Have you, during the last four weeks, had to incur extra expenses on behalf of the person?*

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>47. Professional help for the person</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>48. Damage caused by the person</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>49. Large expenditures incurred by the person</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>50. Person's travel expenses</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>51. Medicine for the person</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>52. Paying off debts incurred by the person</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>53. Other expenses (please indicate):</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If you add up all the expenses incurred on behalf of the person during the last four weeks, what is the total figure?

- [ ] less than fl. 100
- [ ] fl. 100 - fl. 200
- [ ] fl. 200 - fl. 500
- [ ] fl. 500 - fl. 1000
- [ ] more than fl. 1000
Being involved with a person who has mental health problems may sometimes be such a strain that one develops physical and/or mental health problems oneself.

Have you experienced any of the following problems during the last four weeks?

<table>
<thead>
<tr>
<th></th>
<th>never</th>
<th>sometimes</th>
<th>often</th>
</tr>
</thead>
<tbody>
<tr>
<td>55.</td>
<td>Headache</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>56.</td>
<td>Muscle pain</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>57.</td>
<td>Lack of appetite</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>58.</td>
<td>Sleeplessness</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>59.</td>
<td>Nervous tension</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>60.</td>
<td>Depression</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>61.</td>
<td>Quick tempered</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>62.</td>
<td>Extreme tiredness</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

If you have not ticked any of the questions from 55–62 (incl.), PROCEED TO QUESTION 66.
If you have ticked one or more of the questions from 55–62 (incl.), PROCEED TO QUESTION 63.

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

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

65. Are you taking any kind of medicine for these complaints?
   □ yes
   □ no
Involvement Evaluation Questionnaire (first version)

If a father or mother has mental health problems, this may have consequences for the children.

66. Has the person with mental health problems any children (incl. step/foster children)?
   - [ ] no (PROCEED TO QUESTION 77)
   - [ ] yes, ........... (no.) children.

67. Has the person any children under the age of 16 years?
   - [ ] no (PROCEED TO QUESTION 77)
   - [ ] yes, ........... (no.) children under the age of 16 years

How often has it happened during the last four weeks that the child or children has/have:

<table>
<thead>
<tr>
<th>Question</th>
<th>never</th>
<th>sometimes</th>
<th>often</th>
</tr>
</thead>
<tbody>
<tr>
<td>68. Shown loss of appetite</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>69. Been sleepless at night</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>70. Been less attentive at school</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>71. Shown fear of father/mother</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>72. Not attended school</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>73. Displayed difficult behaviour</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>74. Played less often with friends</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>75. Felt ashamed of father/mother</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>76. Had to stay with neighbours, relatives or friends</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
77. *Multiple choice questions cannot possibly cover all that you have experienced with the person. Please feel free to add any comments you may wish to make in the space below.*

Comments:

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*It is important for the purposes of this study that all relevant questions are answered. Please be kind enough to check carefully that no questions have been overlooked.*

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