Quality of Life and Care in the End-of-Life Phase of Patients with a Malignant Brain Tumour
Questionnaire for Relatives

Contents
This questionnaire covers the last phase of life of patients with a malignant brain tumour. In this study, the last three months of life are regarded as the last phase or end-of-life phase.

This questionnaire covers the following issues:
• Symptoms and signs
• Quality of life
• Health care system
• Residence of care
• Wishes
• End-of-life care

The questionnaire consists of two sections. We ask you to complete both parts.
Part 1 contains questions about your deceased partner or relative, from now on called ‘relative’. Please answer the questions as you think your relative probably would have answered the questions.
Part 2 is about your own experience. Please answer the questions for yourself.

Instructions
• For most questions one answer will suffice. If multiple answers possibly apply, this is indicated. There are no “right” or “wrong” answers.
• In some questions we ask for the situation in both the last 3 months before death as well as in the last week. With these questions, we try to outline the situation in the last 3 months and track changes in the last week.
• Most questions are multiple choice questions. We ask you to check the box that best applies to your opinion. If none of the possible answers apply, please write your answer next to the box ‘other’. If you cannot answer the question please check the box ‘unknown’.
• At the end of the questionnaire, there is room for clarification. We would like you to indicate your explanations or remarks here along with the number of the question.

Confidentiality
The information that you provide will be used exclusively for research and will remain strictly confidential.

We thank you in advance.
Part 1

1A. General questions about your relative

1. For whom are you filling out this questionnaire?
   - My partner
   - My parent
   - My child
   - My sibling
   - My friend
   - Other: ……………………………………………………………………………………………

   The person for whom you are completing this questionnaire is in the following questions indicated with the word ‘relative’

2. What was the marital status of your relative before death?
   - Single
   - Living with partner
   - Married
   - Divorced
   - Widow/widower
   - Other, specify:…………………………………………………………………………………………

3a. Was your relative religious or did he/she feel connected with a spiritual belief?
   - No → go to question 4
   - Yes, specify…………………………………………………………………………………………

3b. How important was religion or spirituality in your relatives’ life?
   - Very important
   - Important
   - Not important/ not unimportant
   - Not important
   - Not important at all

4. What is the highest level of education your relative completed?
   - None
   - Elementary
   - Secondary
   - University
   - Graduate school
   - Other, specify:…………………………………………………………………………………………

5. When did your relative die?

Date: ……………………………
1B. Signs and symptoms displayed by your relative

6: Please check the box for all the symptoms listed that most accurately apply to your relative in the last three months excluding the last week, and in the last week before death?

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Last 3 months before death</th>
<th>Last week before death</th>
</tr>
</thead>
<tbody>
<tr>
<td>6a. Did your relative suffer from headaches?</td>
<td>□ Not at all</td>
<td>□ Not at all</td>
</tr>
<tr>
<td></td>
<td>□ A little</td>
<td>□ A little</td>
</tr>
<tr>
<td></td>
<td>□ Quite a bit</td>
<td>□ Quite a bit</td>
</tr>
<tr>
<td></td>
<td>□ Very much</td>
<td>□ Very much</td>
</tr>
<tr>
<td></td>
<td>□ Unknown</td>
<td>□ Unknown</td>
</tr>
<tr>
<td>6b. Did your relative often feel nauseated?</td>
<td>□ Not at all</td>
<td>□ Not at all</td>
</tr>
<tr>
<td></td>
<td>□ A little</td>
<td>□ A little</td>
</tr>
<tr>
<td></td>
<td>□ Quite a bit</td>
<td>□ Quite a bit</td>
</tr>
<tr>
<td></td>
<td>□ Very much</td>
<td>□ Very much</td>
</tr>
<tr>
<td></td>
<td>□ Unknown</td>
<td>□ Unknown</td>
</tr>
<tr>
<td>6c. Did your relative have diplopia and/or blurred vision?</td>
<td>□ Not at all</td>
<td>□ Not at all</td>
</tr>
<tr>
<td></td>
<td>□ A little</td>
<td>□ A little</td>
</tr>
<tr>
<td></td>
<td>□ Quite a bit</td>
<td>□ Quite a bit</td>
</tr>
<tr>
<td></td>
<td>□ Very much</td>
<td>□ Very much</td>
</tr>
<tr>
<td></td>
<td>□ Unknown</td>
<td>□ Unknown</td>
</tr>
<tr>
<td>6d. Did your relative have weakness on one side of the body?</td>
<td>□ Not at all</td>
<td>□ Not at all</td>
</tr>
<tr>
<td></td>
<td>□ A little</td>
<td>□ A little</td>
</tr>
<tr>
<td></td>
<td>□ Quite a bit</td>
<td>□ Quite a bit</td>
</tr>
<tr>
<td></td>
<td>□ Very much</td>
<td>□ Very much</td>
</tr>
<tr>
<td></td>
<td>□ Unknown</td>
<td>□ Unknown</td>
</tr>
<tr>
<td>6e. Was your relative tired?</td>
<td>□ Not at all</td>
<td>□ Not at all</td>
</tr>
<tr>
<td></td>
<td>□ A little</td>
<td>□ A little</td>
</tr>
<tr>
<td></td>
<td>□ Quite a bit</td>
<td>□ Quite a bit</td>
</tr>
<tr>
<td></td>
<td>□ Very much</td>
<td>□ Very much</td>
</tr>
<tr>
<td></td>
<td>□ Unknown</td>
<td>□ Unknown</td>
</tr>
<tr>
<td>6f. Was your relative drowsy?</td>
<td>□ Not at all</td>
<td>□ Not at all</td>
</tr>
<tr>
<td></td>
<td>□ A little</td>
<td>□ A little</td>
</tr>
<tr>
<td></td>
<td>□ Quite a bit</td>
<td>□ Quite a bit</td>
</tr>
<tr>
<td></td>
<td>□ Very much</td>
<td>□ Very much</td>
</tr>
<tr>
<td></td>
<td>□ Unknown</td>
<td>□ Unknown</td>
</tr>
<tr>
<td>6g. Did your relative suffer from lack of bladder control?</td>
<td>□ Not at all</td>
<td>□ Not at all</td>
</tr>
<tr>
<td></td>
<td>□ A little</td>
<td>□ A little</td>
</tr>
<tr>
<td></td>
<td>□ Quite a bit</td>
<td>□ Quite a bit</td>
</tr>
<tr>
<td></td>
<td>□ Very much</td>
<td>□ Very much</td>
</tr>
<tr>
<td></td>
<td>□ Unknown</td>
<td>□ Unknown</td>
</tr>
<tr>
<td>6h. Did your relative have difficulty speaking?</td>
<td>□ Not at all</td>
<td>□ Not at all</td>
</tr>
<tr>
<td></td>
<td>□ A little</td>
<td>□ A little</td>
</tr>
<tr>
<td></td>
<td>□ Quite a bit</td>
<td>□ Quite a bit</td>
</tr>
<tr>
<td></td>
<td>□ Very much</td>
<td>□ Very much</td>
</tr>
<tr>
<td></td>
<td>□ Unknown</td>
<td>□ Unknown</td>
</tr>
<tr>
<td>Question</td>
<td>Last 3 months before death</td>
<td>Last week before death</td>
</tr>
<tr>
<td>-----------------------------------------------</td>
<td>-----------------------------</td>
<td>------------------------</td>
</tr>
<tr>
<td>6i. Did your relative have trouble swallowing?</td>
<td>□ Not at all □ A little □ Quite a bit □ Very much □ Unknown</td>
<td>□ Not at all □ A little □ Quite a bit □ Very much □ Unknown</td>
</tr>
<tr>
<td>6j. Was your relative short of breath?</td>
<td>□ Not at all □ A little □ Quite a bit □ Very much □ Unknown</td>
<td>□ Not at all □ A little □ Quite a bit □ Very much □ Unknown</td>
</tr>
<tr>
<td>6k. Did your relative suffer from bodily pain?</td>
<td>□ Not at all □ A little □ Quite a bit □ Very much □ Unknown</td>
<td>□ Not at all □ A little □ Quite a bit □ Very much □ Unknown</td>
</tr>
<tr>
<td>6l. Did your relative have trouble understanding things?</td>
<td>□ Not at all □ A little □ Quite a bit □ Very much □ Unknown</td>
<td>□ Not at all □ A little □ Quite a bit □ Very much □ Unknown</td>
</tr>
<tr>
<td>6m. Was your relative forgetful?</td>
<td>□ Not at all □ A little □ Quite a bit □ Very much □ Unknown</td>
<td>□ Not at all □ A little □ Quite a bit □ Very much □ Unknown</td>
</tr>
<tr>
<td>6n. Did your relative have trouble concentrating?</td>
<td>□ Not at all □ A little □ Quite a bit □ Very much □ Unknown</td>
<td>□ Not at all □ A little □ Quite a bit □ Very much □ Unknown</td>
</tr>
<tr>
<td>6o. Did your relative become confused?</td>
<td>□ Not at all □ A little □ Quite a bit □ Very much □ Unknown</td>
<td>□ Not at all □ A little □ Quite a bit □ Very much □ Unknown</td>
</tr>
<tr>
<td>6p. Did your relatives behaviour change?</td>
<td>□ Not at all □ A little □ Quite a bit □ Very much □ Unknown</td>
<td>□ Not at all □ A little □ Quite a bit □ Very much □ Unknown</td>
</tr>
<tr>
<td>6q. Was your relative anxious?</td>
<td>□ Not at all □ A little □ Quite a bit □ Very much □ Unknown</td>
<td>□ Not at all □ A little □ Quite a bit □ Very much □ Unknown</td>
</tr>
</tbody>
</table>
6r. Was your relative sad/depressed?
- □ Not at all  □ Not at all
- □ A little  □ A little
- □ Quite a bit  □ Quite a bit
- □ Very much  □ Very much
- □ Unknown  □ Unknown

6s. Was your relative irritable?
- □ Not at all  □ Not at all
- □ A little  □ A little
- □ Quite a bit  □ Quite a bit
- □ Very much  □ Very much
- □ Unknown  □ Unknown

6t. Was your relative less interested in others?
- □ Not at all  □ Not at all
- □ A little  □ A little
- □ Quite a bit  □ Quite a bit
- □ Very much  □ Very much
- □ Unknown  □ Unknown

6u. Did your relative have trouble accepting things?
- □ Not at all  □ Not at all
- □ A little  □ A little
- □ Quite a bit  □ Quite a bit
- □ Very much  □ Very much
- □ Unknown  □ Unknown

7: Please check the box with the sentence that best applies to the health status of your relative in the last three months excluding the last week, and in the last week before death.

<table>
<thead>
<tr>
<th></th>
<th>Last 3 months before death</th>
<th>Last week before death</th>
</tr>
</thead>
<tbody>
<tr>
<td>7a. Mobility, my relative:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Had no trouble walking</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>• Used an aid while walking etc.</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>• Used a wheelchair</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>• Was confined to bed</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

7b. Care for oneself. My relative:
- □ Had no trouble washing/dressing himself/herself
- □ Needed help with washing/dressing himself/herself
- □ Was not able to wash/dress himself/herself

7c. Epilepsy (seizures). My relative:
- □ Had seizures (almost) every day
- □ Had weekly seizures
- □ Had monthly seizures
- □ Had less than one seizure per month
- □ Had no seizures
8. Did your relative display other signs or symptoms?
   □ No
   □ Yes, specify ........................................................................................................
   ............................................................................................................................
   ............................................................................................................................
   ............................................................................................................................
   ............................................................................................................................

1C Social functioning and quality of life

9. Did the physical condition of your relative interfere with family life?
   □ Not at all
   □ A little
   □ Quite a bit
   □ Very much

10. Did the physical condition of your relative interfere with his/her social activities?
    □ Not at all
    □ A little
    □ Quite a bit
    □ Very much

11. Has the physical condition of your relative caused financial difficulties?
    □ Not at all
    □ A little
    □ Quite a bit
    □ Very much

12. Did your relative receive sufficient support from his/her social environment (other than yourself)?
    □ Yes
    □ Yes, but not from everyone
    □ No, not at all
    □ Unknown

13. How do you think your relative would have rated his/ her quality of life in the last three months before death?

    1  2  3  4  5  6  7
    Very poor Neutral Excellent
1D Health care

14. Which health care workers did your relative encounter during his/her disease as far as you know?

- General practitioner
- Nursing home doctor/ hospice doctor
- Specialist in the hospital
- Psychiatrist
- Psychologist
- Specialized nurse in the hospital
- Specialized nurse in primary care
- Nurse
- Clergyman
- Practitioner of alternative medicine
- Other, specify: ................................................................................................................................

15. What was your relative’s opinion of the amount of information provided about the disease by the health care professionals?

- Too much
- Sufficient
- Too little
- Unknown

16. Were the health care workers able to treat the symptoms and signs sufficiently according to your relative?

- Yes
- Not completely
- No

17. Was the mental support provided by the health care providers sufficient according to your relative?

- Yes
- Not always
- No

18a. How would your relative have judged the quality of care received in the last three months before death?

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very poor</td>
<td>Excellent</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

18b. How would your relative have judged the quality of care received in the last week before death?

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very poor</td>
<td>Excellent</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
1E. Residence

19. Where was your relative living exactly 3 months before death?
* In this question is asked for the specific moment 3 months before death

- [ ] At home
- [ ] In a nursing home
- [ ] In a hospital
- [ ] In a hospice
- [ ] Other, specify …………………………………………………………………………

20. Had your relative moved or been admitted to an institution during the last three months before death?

- [ ] Yes → go to question 21
- [ ] No, explain
  - [ ] It was decided not to move my relative
  - [ ] Moving was not an option
  - [ ] My relative was on a waiting list but there was no room available → go to question 25

21. Where has your relative been moved? (multiple answers possible)

- [ ] Home for the elderly
- [ ] Nursing home
- [ ] Hospital
- [ ] Hospice
- [ ] Back home
- [ ] Other, specify: …………………………………………………………………………

22. When did the last relocation take place?

- [ ] In the last week
- [ ] In the last month
- [ ] In the last three months

23. How often has your relative been relocated in the last three months?
(example: home → hospital → home = 2 relocations)

…… times

24. What was the reason for the last relocation or admission? (multiple answers possible)

- [ ] My relative needed more or different care
- [ ] My relative needed specific medical treatment
- [ ] It was my relative’s wish
- [ ] It was my wish and / or the wish of other important relatives
- [ ] Other reason, explain …………………………………………………………………………
25. Where did your relative die?
   □ At his/her home
   □ In a home for the elderly
   □ In a nursing home
   □ In a hospital
   □ In a hospice
   □ Other, specify……………………………………………………………………………………………

26a. Where would your relative have wanted to die?
   □ At his/her home
   □ In a home for the elderly
   □ In a nursing home
   □ In a hospital
   □ In a hospice
   □ No specific preference
   □ Other, specify……………………………………………………………………………………………

26b. If your relative did not die at the place he/she wanted, please explain:
   …………………………………………………………………………………………………………………
   …………………………………………………………………………………………………………………
   …………………………………………………………………………………………………………………

1F Wishes

27a. Did your relative express specific wishes for receiving or withdrawing treatments (regardless whether this was possible) three months before death?
   □ No, no treatment desires expressed
   □ My relative wanted all possible (tumour) treatment
   □ My relative expressed desire in part of the tumour treatment, but not in all of it → Please explain under comments referring to question 27a
   □ My relative only wanted supportive treatment (for example dexamethasone)
   □ My relative wanted no treatment at all

27b. Did these wishes change in the period short before death?
   □ No, these wishes did not change
   □ Yes → Please explain under comments referring to question 27b
   □ Not applicable

28a. Did your relative have a advanced written directive?
   □ Yes
   □ No → go to question 29
28b. What instruction had been given?
- Euthanasia
- Refusal of treatment
- Appointment of a health care representative
- Care instructions
- Other, specify …………………………………………………………………………………………………

29a. Did your relative, as far as you know, ever request a doctor to end his/her life (euthanasia or physician assisted suicide)?
- Yes, my relative requested euthanasia
- No, my relative did not want euthanasia → go to question 32
- My relative never expressed an opinion about euthanasia → go to question 32
- Unknown → go to question 32

29b Was euthanasia or physician assisted suicide carried out?
- Yes
- No

29c If euthanasia was not carried out, what was the reason for this?
…………………………………………………………………………………………………………
…………………………………………………………………………………………………………
…………………………………………………………………………………………………………

29d Do you find this a valid reason?
- Yes
- No

Comments
Please refer to question number?
…………………………………………………………………………………………………………
…………………………………………………………………………………………………………
…………………………………………………………………………………………………………
…………………………………………………………………………………………………………
…………………………………………………………………………………………………………
…………………………………………………………………………………………………………
…………………………………………………………………………………………………………
…………………………………………………………………………………………………………
1G. Care at the end of life

30a. Was your relative able to decide for him/herself in the last week before death with respect to end-of-life care?
   □ Yes → go to question 30
   □ Partly
   □ No

30b. Why was your relative not (fully) able to decide for himself/herself with respect to end-of-life care?
   □ My relative was unconscious
   □ My relative was drowsy
   □ My relative was confused/ had trouble understanding
   □ Other: ………………………………………………………………………………………

31. Were any decisions made in the last phase in contradiction with your relative’s wishes?
   □ Yes → Please explain under comments referring to question 31
   □ No

32a. Which doctor was mainly responsible for the care in the last week?
   □ General practitioner
   □ Specialist
   □ Nursing home doctor
   □ Hospice doctor
   □ Other, specify: ……………………………………………………………………………

32b. Did this doctor explain the options of care to your relative or to you in the last phase of the disease?
   □ Yes, to both of us
   □ Yes, only to my relative
   □ Yes, only to me
   □ No
   □ Unknown/ not applicable

32c. How satisfied was your relative with his/her relationship with this doctor?:
   □ Very satisfied
   □ Satisfied
   □ Not unsatisfied/ not satisfied
   □ Dissatisfied
   □ Very dissatisfied
   □ Unknown
33. Was your relative aware of his/her imminent death?
   □ Yes
   □ More or less
   □ No
   □ Unknown

34. Did your relative make (in)formal arrangements regarding a will as death approached?
   □ Not applicable
   □ Yes
   □ More or less
   □ No
   □ Unknown

35. Was your relative able to carry out these arrangements?
   □ Not applicable
   □ Yes
   □ More or less
   □ No
   □ Unknown

36. In the last days of his/her life, was your relative content and ready to die?
   □ Yes
   □ No
   □ My relative was unaware
   □ Unknown

37. End-of-life care is often associated with the phrase “dying with dignity”. How would you describe the death of your relative?
   □ Very dignified
   □ Dignified
   □ Neutral
   □ Undignified
   □ With no dignity at all

38. Can you indicate which conditions negatively affected the dignity of your relative’s dying? (multiple answers possible)
   □ Being unable to think clearly
   □ Being unable to communicate properly
   □ Unable to accept the truth
   □ Not being able to take care of oneself
   □ The feeling of losing control
   □ The feeling that life has lost its meaning
   □ The feeling to have become a burden to others
   □ Not being treated with respect
   □ Not applicable
   □ Other, explain: ...........................................................................................................
Part two

2A. General questions about you

39. What is your date of birth?
   Date: ........................................

40. You are
   □ Male
   □ Female

41. How intensive was the relationship between you and your relative during the last three
   months before death?
   □ We lived together
   □ We were in touch daily
   □ We were in touch weekly
   □ We were in touch monthly
   □ Other, explain .................................................................

42a. Are you religious or do you have spiritual beliefs?
   □ No → go to question 43
   □ Yes, specify: .................................................................

42b. How important is religion or spirituality in your life?
   □ Very important
   □ Important
   □ Neutral
   □ Not important
   □ Totally not important

43. What is the highest level of education you completed?
   □ None
   □ Elementary
   □ Secondary
   □ University
   □ Graduate school
   □ Other, specify: .................................................................
2B. Your symptoms
44. Please check the box that best applies to your own situation during the last 3 months before the death of your relative?

44a Were you anxious? □ Not at all □ A little □ Quite a bit □ Very much

44b Did you feel sad/depressed? □ Not at all □ A little □ Quite a bit □ Very much

44c Were you irritable? □ Not at all □ A little □ Quite a bit □ Very much

44d Were you less interested in others? □ Not at all □ A little □ Quite a bit □ Very much

2C. Social functioning and quality of life
45. Were you limited in doing your job during the last three months of your relative’s life?
   □ Yes, very limited □ Yes, moderately limited □ No, not limited □ Not applicable

46. Were you limited in your social activities in the last three months of life?
   □ Yes, very limited □ Yes, moderately limited □ No, not limited

47. Did the relationship with your relative change as a result of his/her illness?
   □ Yes, the relationship was disrupted □ Yes, the relationship became more intense □ No change

48. Has the medical condition of your relative altered your family life in the last three months?
   □ Yes, the family life was seriously disrupted □ Yes, the family life was moderately disrupted □ No, the family life was not disrupted
49. Have you received sufficient support in the last three months of your relative’s life?
   □ Yes, as much as I needed
   □ Not as much as I needed
   □ No, none at all

50. How would you rate your quality of life in the last three months before the death of your relative?

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very poor</td>
<td>Neutral</td>
<td>Excellent</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2D. Health care system

51. What is your opinion of the quantity of information provided by health care workers about the illness?
   □ Too much
   □ Sufficient
   □ Too little

52. Were you sufficiently involved in the decisions made about the medical care of your relative?
   □ Yes
   □ Partially
   □ No

53a. Was it clear what type of health care facilities were available for your relative?
   □ Yes
   □ Partially
   □ No

53b. How did you gather information about the type of care available for your relative?
   (multiple answers possible)
   □ Through the GP
   □ Through the specialist
   □ Through a specialist nurse
   □ Through flyers
   □ Through the internet
   □ Through others suffering from this illness
   □ Through family/ friends
   □ Other, specify: ………………………

54. Were the health care providers accessible if your relative or you needed them?
   □ Yes
   □ Sometimes
   □ No
55. Was the mental support provided by the health care professionals sufficient according to you?
   □ Yes
   □ Sometimes
   □ No

56. Who was closely involved in the care of your relative (other than health care professionals)? (Multiple answers possible)
   □ Partner
   □ Parent(s)
   □ Children
   □ Siblings
   □ Other relatives
   □ Friends
   □ Acquaintances
   □ Others, specify ………………………

57a. To what extent was the care for your relative the responsibility of yourself and the persons named in question 56? (Multiple answers possible)
   □ Totally
   □ Primarily
   □ About half □ A small part
   □ None at all

57b. Should the health care providers have taken on a larger role in the care for your relative?
   □ Yes
   □ No

58a. How would you rate the quality of health care during the three months before death?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very poor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neutral</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Excellent</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

58b. How would you rate the quality of care during the last week before death?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very poor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neutral</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Excellent</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
2E Care during end-of life phase

59a. How did you influence the treatment decisions in the last week before death?
   □ I made the final decision (with other relatives)
   □ I had extensive influence
   □ I had little influence
   □ I had no influence at all
   □ Not applicable

59b. Have decisions been made with which you did not agree?
   □ Yes
   □ No

60. How satisfied were you with the contact between you and the doctor responsible for the health care in the last week? *(We refer to the doctor named in question 32)*
   □ Very satisfied
   □ Reasonably satisfied
   □ Neutral
   □ Dissatisfied
   □ Very dissatisfied
   □ Unknown

61. In retrospect, how satisfied are you with your role as relative during the last phase of life?
   □ Very satisfied
   □ Satisfied
   □ Not unsatisfied/ not satisfied
   □ Dissatisfied
   □ Very dissatisfied
   □ Unknown

2F. Following the death of your relative

62a. Were you anxious?
   □ Not at all
   □ A little
   □ Quite a bit
   □ Very much

62b. Did you feel sad/depressed?
   □ Not at all
   □ A little
   □ Quite a bit
   □ Very much

62c. Were you irritable?
   □ Not at all
   □ A little
   □ Quite a bit
   □ Very much

62d. Were you less interested in others?
   □ Not at all
   □ A little
   □ Quite a bit
   □ Very much
63. Have you received sufficient support from friends and family after the death of your relative?
   □ Yes, as much as I needed
   □ Not as much as I needed
   □ No, none at all

64a. Were you in touch with the professional health care providers responsible for the care of your relative after his/her death?
   □ Yes
   □ No

64b. Was there an opportunity for an evaluation of care after the death of your relative?
   (Multiple answers possible)
   □ Yes, in the hospital
   □ Yes, with the GP
   □ Yes, with somewhere else, specify: ...........................................................
   □ No

65a. Did you need help from professional health care providers after your relative’s death?
   □ Yes
   □ No → (End of the questionnaire)

65b. Did you receive help?
   □ Yes, about as much as I needed
   □ Yes, but not as much as I needed
   □ No

Thank you for completing this questionnaire. On the next page, you can further clarify your answers

Please check that all questions have been answered.
Comments

Please refer to question number with each comment

---------------------------------------------------------------------------------

---------------------------------------------------------------------------------

---------------------------------------------------------------------------------

---------------------------------------------------------------------------------

---------------------------------------------------------------------------------

---------------------------------------------------------------------------------

---------------------------------------------------------------------------------

---------------------------------------------------------------------------------