

Supplementary material for Lund L, Ross L, Groenvold M. The initial development of the ‘Cancer Caregiving Tasks, Consequences and Needs Questionnaire’ (CaTCoN). Acta Oncologica. 2012;51:1009–1019.

Appendix: The Cancer Caregiving Tasks, Consequences and Needs Questionnaire (CaTCoN)

Questions 1–5 concern the help and support you have given the patient

1. To what extent have you had to provide:

(Please tick one answer in each line)

	None	A little	Some	A lot	Don't know/ not relevant
a. Practical help to the patient?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Personal care to the patient?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Psychological support to the patient?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. It is the responsibility of the hospitals to make referrals and appointments for examination and treatment. Have you felt that you have been partially responsible for keeping track of whether the patient has been referred and called for examinations and treatments quickly and correctly?

- Not at all To a low degree To some degree To a high degree
 Don't know/not relevant

3. Have you felt that you have had too much responsibility in relation to home care (personal care, medications, etc.)?

- Not at all To a low degree To some degree To a high degree
 Don't know/not relevant

4. Have you spent time transporting the patient?

- No, not at all Yes, a little Yes, some Yes, a lot
 Don't know/not relevant

5. As a caregiver one cannot necessarily set aside a long time for each appointment at the hospital (in connection with for example consultations, examinations and treatment). Have you felt that this has been taken into consideration at the hospitals?

- Always/almost always Mostly Only sometimes Rarely/never
 Don't know/not relevant

Questions 6–9 concern the consequences you may have experienced in connection with being a caregiver

6. Has the patient's cancer disease:
(Please tick one answer in each line)

	No, not at all	Yes, a little	Yes, some	Yes, a lot	Don't know/ not relevant
a. Caused you stress?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Had a negative effect on your own physical health?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Meant that you have <u>not</u> had enough time for (the rest of) your family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Meant that you have <u>not</u> had enough time for (the rest of) your friends/acquaintances?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Increased your awareness of the important things in life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Caused you to make positive changes?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Made you value your relationships with other people more?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. Have you been able to take time off, get a leave of absence from work, or make similar arrangements to the extent it has been necessary?

(If you have not been working during the course of the illness, you may tick 'not relevant')

- Always/almost always Mostly Only sometimes Rarely/never
 Don't know/not relevant

8. Has the patient's illness meant that you have had to be absent from work so much so that it has posed problems at your workplace?

(If you have not been working during the course of the illness, you may tick 'not relevant')

- Not at all To a low degree To some degree To a high degree
 Don't know/not relevant

9. Have you experienced negative financial consequences of being a caregiver?

- Not at all To a low degree To some degree To a high degree
 Don't know/not relevant

Questions 10–13 concern your contact with the health care professionals in the hospitals

10. Have the health care professionals paid attention to you?

- Always/almost always Mostly Only sometimes Rarely/never
 Don't know/not relevant

11. Have the health care professionals shown interest in how you have been feeling?

- Always/almost always Mostly Only sometimes Rarely/never
 Don't know/not relevant

12. Have the health care professionals involved you in the patient's illness/treatment/care in the way in which you have wished to be involved?

- Always/almost always Mostly Only sometimes Rarely/never
 Don't know/not relevant

13. Have you any thoughts about how to improve the involvement of caregivers? If so, please write them here:

Questions 14–24 concern knowledge and information from the health care professionals in the hospitals

14. We would like to know whether you have lacked (more) information about different areas. Have you as a caregiver:

(Please tick one answer in each line)

	Not at all	To a low degree	To some degree	To a high degree	Don't know/ not relevant
a. Lacked information about how the health care system works in relation to treating cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Lacked information about how long one has to wait at different times in the process?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Lacked information about when to press for an answer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Lacked information about the paper flow in the health care system?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Lacked information about 'normal' waiting times in the out-patient clinic?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Lacked information about the illness and its course?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Lacked information about what symptoms and side-effects to keep an eye on as a caregiver?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Lacked information about the best ways to help and support a person with cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Lacked information about likely psychological reactions in a person with cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(Continued from previous page)

Have you as a caregiver:

- | | Not at all | To a
low degree | To some
degree | To a
high degree | Don't know/
not relevant |
|--|---|---|---|--------------------------|-----------------------------|
| j. Lacked information about nutrition? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| k. Lacked information about how to search for information on the internet? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| l. Lacked information about who to turn to as a caregiver after discharge, should any questions or problems arise? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| m. Lacked information about rights and possibilities of assistance on discharge and generally (for example home care, psychologist, leave of absence, insurances, etc.)? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 15. Have you telephoned health care professionals to ask questions? | | | | | |
| <input type="checkbox"/> No | | | | | |
| <input type="checkbox"/> Yes. Have you received adequate assistance when you telephoned? | <input type="checkbox"/> Always/almost always
<input type="checkbox"/> Mostly
<input type="checkbox"/> Only sometimes
<input type="checkbox"/> Rarely/never
<input type="checkbox"/> Don't know/not relevant | | | | |
| 16. Have you needed help from health care professionals to find out the best way for you and the patient to handle the illness <u>in practical terms</u> ? | | | | | |
| <input type="checkbox"/> No | | | | | |
| <input type="checkbox"/> Yes. Has your need for help been met? | <input type="checkbox"/> To a high degree
<input type="checkbox"/> To some degree
<input type="checkbox"/> To a low degree
<input type="checkbox"/> Not at all
<input type="checkbox"/> Don't know/not relevant | | | | |
| 17. Have you needed help from health care professionals to find out the best way for you and the patient to handle the illness <u>emotionally</u> ? | | | | | |
| <input type="checkbox"/> No | | | | | |
| <input type="checkbox"/> Yes. Has your need for help been met? | <input type="checkbox"/> To a high degree
<input type="checkbox"/> To some degree
<input type="checkbox"/> To a low degree
<input type="checkbox"/> Not at all
<input type="checkbox"/> Don't know/not relevant | | | | |
| 18. Have you felt that the health care professionals have given you an unrealistically positive idea of the patient's situation? | | | | | |
| <input type="checkbox"/> Not at all | <input type="checkbox"/> To a low degree | <input type="checkbox"/> To some degree | <input type="checkbox"/> To a high degree | | |
| <input type="checkbox"/> Don't know/not relevant | | | | | |

19. Have you felt that the health care professionals have deprived you of hope?
 Not at all To a low degree To some degree To a high degree
 Don't know/not relevant
20. Have you needed financial counselling?
 No
 Yes. Have you had the offer of financial counselling? Yes No
21. Do you think enough time has been spent informing caregivers?
 To a high degree To some degree To a low degree Not at all
 Don't know/not relevant
22. Have you had to ask the health care professionals questions in order to get the information you have needed?
 Rarely/never Only sometimes Mostly Always/almost always
 Don't know/not relevant
23. Have you lacked being given information from the health care professionals, without having to ask for it yourself?
 Rarely/never Only sometimes Mostly Always/almost always
 Don't know/not relevant
24. All in all how well do you think the hospitals have informed you as a caregiver?
 Very well Pretty well Pretty poorly Very poorly
 Don't know/not relevant

Questions 25–28 concern communication with the health care professionals in the hospitals

25. How well do you think the health care professionals have communicated with you?
 Very good Pretty good Pretty bad Very bad
 Don't know/not relevant
26. If you have experienced communication problems, please describe them here:

27. Do you think that information has been given to you in a good and sensitive way?
 Always/almost always Mostly Only sometimes Rarely/never
 Don't know/not relevant
28. Have the health care professionals generally signalled that it is OK for you as a caregiver to ask questions?
 Always/almost always Mostly Only sometimes Rarely/never
 Don't know/not relevant

Questions 29–31 concern support from the health care system (i.e. from hospitals and general practitioner)

29. Have the health care professionals in the hospitals shown interest in whether you as a caregiver have been able to handle the situation?

- Always/almost always Mostly Only sometimes Rarely/never
 Don't know/not relevant

30. Have the health care professionals in the hospitals noticed and reacted to signals from you, if you have not been doing well?

- Always/almost always Mostly Only sometimes Rarely/never
 Don't know/not relevant

31. Have you as a caregiver received adequate support from your own and/or the patient's general practitioner?

(If you have not needed support from the general practitioner, you may tick 'not relevant')

- Always/almost always Mostly Only sometimes Rarely/never
 Don't know/not relevant

Question 32 concerns contact with other caregivers

32. Have you wanted contact with other caregivers in the hospital?

- No
 Yes. Has your need for contact with other caregivers been met?
 To a high degree
 To some degree
 To a low degree
 Not at all
 Don't know/not relevant

Questions 33–34 concern help for yourself

33. Have you *lacked* information about where to get help as a caregiver?

- Not at all To a low degree To some degree To a high degree
 Don't know/not relevant

34. Have you needed to see a psychologist as a consequence of the patient's illness?

- No
 Yes. Have the health care professionals offered you the opportunity to see a psychologist? Yes No

Questions 35–37 concern the physical framework for caregivers in the hospitals

35. Have the health care professionals' conversations with you (with or without the patient) taken place without being disturbed?

- Always/almost always Mostly Only sometimes Rarely/never
 Don't know/not relevant

36. Have the health care professionals' conversations with you (with or without the patient) taken place out of the earshot of other patients and caregivers?
- Always/almost always Mostly Only sometimes Rarely/never
 Don't know/not relevant
37. Have you needed a physical framework at the hospitals that has made it possible for you to:
- a. Withdraw? No
 Yes. Has your need been met?
 To a high degree
 To some degree
 To a low degree
 Not at all
 Don't know/not relevant
- b. Stay overnight? No
 Yes. Has your need been met?
 To a high degree
 To some degree
 To a low degree
 Not at all
 Don't know/not relevant
- c. Talk to other caregivers? No
 Yes. Has your need been met?
 To a high degree
 To some degree
 To a low degree
 Not at all
 Don't know/not relevant

Questions 38–41 concern the role as a caregiver

38. Have you had the need to be able to take a break from the practical tasks (in the role of caregiver) in connection to the illness?
- To a high degree To some degree To a low degree Not at all
 Don't know/not relevant
39. Have you felt that you have had the possibility to take a break from the practical tasks?
- To a high degree To some degree To a low degree Not at all
 Don't know/not relevant
40. Have you had the need to lead a 'normal' life at the same time as you have been a caregiver?
- To a high degree To some degree To a low degree Not at all
 Don't know/not relevant
41. Have you felt that you have had the possibility to lead a 'normal' life at the same time as being a caregiver?
- To a high degree To some degree To a low degree Not at all
 Don't know/not relevant