Supplementary material for Lund L, et al. The validity and reliability of the ‘Cancer Caregiving Tasks, Consequences and Needs Questionnaire’ (CaTCoN) Acta Oncol 2014;53:966–74.

Supplementary Appendix A.

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?	☐	☐	☐	☐	☐
b. Personal care to the patient?	☐	☐	☐	☐	☐
c. Psychological support to the patient?	☐	☐	☐	☐	☐

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?	☐	☐	☐	☐	☐
b. Had a negative effect on your own physical health?	☐	☐	☐	☐	☐

- c. Meant that you have not had enough time for (the rest of) your family? ☐ ☐ ☐ ☐ ☐
- d. Meant that you have not had enough time for (the rest of) your friends/acquaintances? ☐ ☐ ☐ ☐ ☐
- e. Increased your awareness of the important things in life? ☐ ☐ ☐ ☐ ☐
- f. Caused you to make positive changes? ☐ ☐ ☐ ☐ ☐
- g. Made you value your relationships with other people more? ☐ ☐ ☐ ☐ ☐

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 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?	☐	☐	☐	☐	☐
b. Lacked information about how long one has to wait at different times in the process?	☐	☐	☐	☐	☐
c. Lacked information about when to press for an answer?	☐	☐	☐	☐	☐
d. Lacked information about the paper flow in the health care system?	☐	☐	☐	☐	☐
e. Lacked information about 'normal' waiting times in the out-patient clinic?	☐	☐	☐	☐	☐
f. Lacked information about the illness and its course?	☐	☐	☐	☐	☐
g. Lacked information about what symptoms and side-effects to keep an eye on as a caregiver?	☐	☐	☐	☐	☐
h. Lacked information about the best ways to help and support a person with cancer?	☐	☐	☐	☐	☐
i. Lacked information about likely psychological reactions in a person with cancer?	☐	☐	☐	☐	☐
j. Lacked information about nutrition?	☐	☐	☐	☐	☐

(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
k. Lacked information about how to search for information on the internet?	☐	☐	☐	☐	☐
l. Lacked information about who to turn to as a caregiver after discharge, should any questions or problems arise?	☐	☐	☐	☐	☐
m. Lacked information about rights and possibilities of assistance on discharge and in general (for example home care, psychologist, leave of absence, insurances, etc.)?	☐	☐	☐	☐	☐
15. Have you telephoned health care professionals to ask questions?					
☐ No					
☐ Yes. Have you received adequate assistance when you telephoned?			☐ Always/almost always ☐ Mostly ☐ Only sometimes ☐ Rarely/never ☐ 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> ?					
☐ No					
☐ Yes. Has your need for help been met?		☐ To a high degree ☐ To some degree ☐ To a low degree ☐ Not at all ☐ 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> ?					
☐ No					
☐ Yes. Has your need for help been met?		☐ To a high degree ☐ To some degree ☐ To a low degree ☐ Not at all ☐ 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?					
☐ Not at all		☐ To a low degree	☐ To some degree	☐ To a high degree	
☐ 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. Overall, 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. In general, have the health care professionals 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 surroundings 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 had a need for physical surroundings at the hospitals that 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

Supplementary Appendix B.

Multitrait-scaling: Correlations between the final CaTCoN subscales, and the correlations between each of the CaTCoN subscales and all CaTCoN items (subscales corrected for item overlap).

CaTCoN subscales	Caregiving workload (items 1a, 1b, 1c, 3, 4)	Lack of attention from HCPs on the caregivers wellbeing (items 10, 11, 29, 30)	Lack of information from HCPs (items 14a-m, 33)	Lack of personal growth (items 6e, 6f, 6g)	Lack of privacy during conversations with HCPs (items 35, 36)	Lack of time for social relations (items 6c, 6d)	Need for contact to other caregivers (items 32, 37c)	Need for help from HCPs (items 16, 17)	Problems with the quality of information and communication from HCPs (items 21-25, 27, 28)
Caregiving workload (items 1a, 1b, 1c, 3, 4)	1.00								
Lack of attention from HCPs on the caregivers wellbeing (items 10, 11, 29, 30)	-0.05	1.00							
Lack of information from HCPs (items 14a-m, 33)	0.15	0.65	1.00						
Lack of personal growth (items 6e, 6f, 6g)	-0.28	0.10	-0.07	1.00					
Lack of privacy during conversations with HCPs (items 35, 36)	0.20	0.33	0.35	-0.08	1.00				
Lack of time for social relations (items 6c, 6d)	0.45	0.08	0.21	-0.28	0.24	1.00			
Need for contact to other caregivers (items 32, 37c)	0.26	0.08	0.19	-0.09	0.16	0.27	1.00		
Need for help from HCPs (items 16, 17)	0.30	0.21	0.42	-0.18	0.26	0.35	0.23	1.00	
Problems with the quality of information and communication from HCPs (items 21-25, 27, 28)	0.11	0.76	0.80	-0.03	0.42	0.20	0.15	0.43	1.00

	Caregiving workload (items 1a, 1b, 1c, 3, 4)	Lack of attention from HCPs on the caregivers wellbeing (items 10, 11, 29, 30)	Lack of information from HCPs (items 14a-m, 33)	Lack of personal growth (items 6e, 6f, 6g)	Lack of privacy during conversations with HCPs (items 35, 36)	Lack of time for social relations (items 6c, 6d)	Need for contact to other caregivers (items 32, 37c)	Need for help from HCPs (items 16, 17)	Problems with the quality of information and communication from HCPs (items 21-25, 27, 28)
CaTCoN items									
Item 1a	0.64	-0.10	0.07	-0.21	0.15	0.37	0.23	0.21	0.02
Item 1b	0.56	-0.11	0.09	-0.27	0.13	0.32	0.23	0.27	0.08
Item 1c	0.48	0.04	0.17	-0.26	0.16	0.33	0.10	0.23	0.17
Item 2	0.37	0.06	0.20	-0.15	0.25	0.25	0.08	0.23	0.20
Item 3	0.51	0.03	0.21	-0.22	0.21	0.33	0.23	0.28	0.17
Item 4	0.45	-0.03	0.07	-0.10	0.08	0.31	0.14	0.18	0.00
Item 5	0.17	0.54	0.49	0.02	0.37	0.24	0.16	0.26	0.54
Item 6a	0.28	0.10	0.22	-0.27	0.19	0.45	0.16	0.28	0.20
Item 6b	0.31	0.05	0.17	-0.25	0.19	0.42	0.21	0.18	0.15
Item 6c	0.46	0.07	0.21	-0.27	0.22	0.76	0.25	0.36	0.20
Item 6d	0.41	0.08	0.19	-0.26	0.24	0.76	0.26	0.31	0.18
Item 6e	0.26	-0.04	0.06	-0.61	0.08	0.30	0.13	0.15	0.02
Item 6f	0.25	-0.11	0.06	-0.60	0.07	0.20	0.06	0.15	0.07
Item 6g	0.20	-0.08	0.08	-0.63	0.07	0.24	0.07	0.15	0.02
Item 7	0.07	0.19	0.21	0.03	0.23	0.19	0.14	0.11	0.20
Item 8	0.31	0.12	0.20	-0.11	0.20	0.40	0.15	0.27	0.20
Item 9	0.36	0.07	0.18	-0.11	0.19	0.42	0.27	0.25	0.15
Item 10	0.07	0.66	0.56	0.04	0.32	0.12	0.09	0.21	0.69
Item 11	-0.08	0.82	0.51	0.12	0.27	-0.01	0.00	0.12	0.60
Item 12	0.06	0.73	0.61	0.03	0.34	0.10	0.12	0.27	0.71
Item 14a	0.12	0.52	0.76	-0.05	0.29	0.15	0.17	0.28	0.63
Item 14b	0.18	0.49	0.75	-0.09	0.34	0.22	0.19	0.30	0.62
Item 14c	0.26	0.44	0.76	-0.09	0.35	0.23	0.20	0.34	0.60
Item 14d	0.20	0.48	0.74	-0.10	0.29	0.22	0.14	0.31	0.59
Item 14e	0.19	0.45	0.69	-0.04	0.30	0.20	0.19	0.25	0.52
Item 14f	0.06	0.54	0.74	-0.08	0.32	0.15	0.11	0.29	0.67
Item 14g	0.09	0.59	0.79	-0.04	0.30	0.15	0.12	0.36	0.69
Item 14h	0.07	0.60	0.82	-0.07	0.29	0.15	0.10	0.37	0.70
Item 14i	0.13	0.56	0.76	-0.10	0.22	0.17	0.13	0.40	0.67
Item 14j	0.13	0.50	0.71	-0.06	0.28	0.14	0.10	0.27	0.61
Item 14k	0.07	0.41	0.61	-0.01	0.15	0.07	0.09	0.25	0.49
Item 14l	0.10	0.50	0.74	0.02	0.31	0.14	0.15	0.29	0.67
Item 14m	0.18	0.51	0.76	-0.02	0.25	0.22	0.20	0.38	0.63
Item 15	0.35	-0.09	0.06	-0.17	0.09	0.30	0.20	0.31	0.06
Item 16	0.34	0.08	0.29	-0.14	0.26	0.35	0.21	0.48	0.28

	Caregiving workload (items 1a, 1b, 1c, 3, 4)	Lack of attention from HCPs on the caregivers wellbeing (items 10, 11, 29, 30)	Lack of information from HCPs (items 14a-m, 33)	Lack of personal growth (items 6e, 6f, 6g)	Lack of privacy during conversations with HCPs (items 35, 36)	Lack of time for social relations (items 6c, 6d)	Need for contact to other caregivers (items 32, 37c)	Need for help from HCPs (items 16, 17)	Problems with the quality of information and communication from HCPs (items 21-25, 27, 28)
Item 17	0.18	0.25	0.42	-0.17	0.21	0.25	0.18	0.48	0.45
Item 18	0.09	0.22	0.33	-0.01	0.20	0.06	0.02	0.20	0.30
Item 19	0.11	0.15	0.26	-0.11	0.15	0.10	0.09	0.16	0.21
Item 20	0.13	0.03	0.13	-0.10	0.08	0.20	0.15	0.24	0.14
Item 21	-0.01	0.69	0.69	0.04	0.34	0.08	0.12	0.31	0.76
Item 22	0.23	0.51	0.65	-0.08	0.29	0.28	0.20	0.41	0.68
Item 23	0.17	0.57	0.69	-0.05	0.32	0.20	0.15	0.43	0.75
Item 24	0.01	0.71	0.75	0.01	0.35	0.13	0.09	0.35	0.84
Item 25	0.02	0.69	0.66	-0.02	0.33	0.12	0.10	0.36	0.79
Item 27	0.13	0.57	0.59	-0.05	0.37	0.18	0.11	0.28	0.69
Item 28	0.04	0.53	0.53	-0.00	0.39	0.14	0.09	0.27	0.62
Item 29	-0.13	0.74	0.60	0.13	0.28	0.03	0.08	0.17	0.66
Item 30	-0.05	0.79	0.63	0.16	0.34	0.01	0.07	0.15	0.66
Item 31	-0.01	0.35	0.29	0.09	0.17	0.08	0.11	0.12	0.24
Item 32	0.25	0.09	0.16	-0.08	0.14	0.22	0.62	0.18	0.14
Item 33	0.10	0.53	0.69	-0.07	0.26	0.23	0.21	0.43	0.66
Item 34	0.20	0.14	0.27	-0.19	0.15	0.28	0.32	0.34	0.26
Item 35	0.18	0.31	0.34	-0.09	0.69	0.22	0.13	0.24	0.40
Item 36	0.19	0.29	0.27	-0.06	0.69	0.21	0.13	0.21	0.34
Item 37a	0.22	-0.01	0.16	-0.14	0.19	0.30	0.26	0.25	0.15
Item 37b	0.19	-0.04	0.03	-0.16	0.07	0.24	0.26	0.26	0.05
Item 37c	0.20	0.04	0.16	-0.04	0.13	0.22	0.62	0.22	0.13
Item 38	-0.23	-0.14	-0.31	0.09	-0.29	-0.34	-0.24	-0.36	-0.35
Item 39	0.19	0.06	0.11	0.03	0.12	0.19	-0.02	0.14	0.09
Item 40	0.11	-0.05	-0.08	-0.03	-0.02	0.11	0.00	-0.03	-0.06
Item 41	0.37	0.11	0.27	-0.18	0.24	0.52	0.23	0.33	0.25

HCPs, health care professionals.

Correlations marked with bold: The items are included in the subscale.

Supplementary Appendix C.

Correlations between the final CaTCoN subscales and FAMCARE and FIN.

	FAMCARE subscale Availability of care (items 6, 11, 12, 20)	FAMCARE subscale Information giving (items 2, 3, 4, 16, 17)	FAMCARE subscale Physical patient care (items 1, 5, 8, 10, 14, 18, 19)	FAMCARE subscale Psychosocial care (items 7, 9, 13, 15)	FAMCARE As one scale (items 1-20)	FIN The subscale concerning fulfillment of care needs (items 1-20)
CaTCoN subscales						
Caregiving workload (items 1a, 1b, 1c, 3, 4)	-0.11 (-)	-0.03 (-)	-0.02 (-)	-0.06 (-)	-0.05 (-)	-0.00 (-)
Lack of attention from HCPs on the caregivers' wellbeing (items 10, 11, 29, 30)	0.59 (?)	0.60 (?)	0.48 (?)	0.61 (?)	0.62 (?)	0.65 (+)
Lack of information from HCPs (items 14a-m, 33)	0.58 (?)	0.64 (+)	0.51 (?)	0.59 (+)	0.64 (+)	0.71 (+)
Lack of personal growth (items 6e, 6f, 6g)	0.07 (-)	0.03 (-)	0.03 (-)	0.07 (-)	0.05 (-)	0.03 (-)
Lack of privacy during conversations with HCPs (items 35, 36)	0.33 (?)	0.41 (?)	0.34 (?)	0.35 (?)	0.39 (?)	0.42 (?)
Lack of time for social relations (items 6c, 6d)	0.04 (-)	0.08 (-)	0.10 (-)	0.08 (-)	0.09 (-)	0.15 (-)
Need for contact to other caregivers (items 32, 37c)	0.05 (-)	0.09 (-)	0.04 (-)	0.04 (-)	0.06 (-)	0.14 (-)
Need for help from HCPs (items 16, 17)	0.20 (-)	0.25 (-)	0.20 (-)	0.25 (-)	0.25 (-)	0.33 (?)
Problems with the quality of information and communication from HCPs (items 21-25, 27, 28)	0.64 (+)	0.70 (+)	0.52 (?)	0.65 (+)	0.69 (+)	0.74 (+)

HCPs, health care professionals.

In parentheses: + Hypothesized strongly correlated subscales; - Hypothesized unrelated subscales; ? No clear expectations.