The validity and reliability of the ‘Cancer Caregiving Tasks, Consequences and Needs Questionnaire’ (CaTCoN)

LINE LUND¹, LONE ROSS¹, MORTEN A. PETERSEN¹ & MOGENS GROENVOLD¹,²

¹The Research Unit, Department of Palliative Medicine, Bispebjerg Frederiksberg Hospital and University of Copenhagen, Copenhagen NV, Denmark and ²The Department of Health Services Research, Institute of Public Health, University of Copenhagen, Copenhagen K, Denmark

ABSTRACT

Background. Caregivers are often involved in and affected by the patient’s disease. The questionnaire ‘Cancer Caregiving Tasks, Consequences and Needs Questionnaire’ (CaTCoN) was developed to measure caregivers’ experiences. The aim of this study is to evaluate the construct validity and reliability of the multi-item scales in the CaTCoN using psychometric analyses as well as tests of convergent and discriminant validity with the existing instruments FAMCARE and Family Inventory of Needs (FIN).

Material and methods. Based on theoretical considerations, a subscale structure in the CaTCoN was hypothesized, and the subscales were tested by item-item correlations, followed by factor analysis, calculation of internal consistency by Cronbach’s alpha, and multitrait-scaling analysis. Further, theoretically based hypotheses about convergence and divergence between CaTCoN and FAMCARE/FIN (sub)scales were formulated and tested.

Results. Analyses were based on 590 caregivers’ responses. Initially, 11 CaTCoN subscales were hypothesized. The item-item correlations and factor analysis lead to some revisions, but the analyses confirmed the hypothesized subscales to a large extent, resulting in nine CaTCoN subscales (Cronbach’s alpha range 0.65–0.95). The hypothesized convergent CaTCoN and FAMCARE/FIN subscales correlated 0.59–0.74, and hypothesized divergent CaTCoN and FAMCARE/FIN subscales correlated −0.11–0.25, thus confirming the hypotheses concerning convergent and discriminant validity between CaTCoN and the existing questionnaires FAMCARE and FIN.

Conclusion. Taken together the psychometric analyses and tests of convergent and discriminant validity indicate that the validity and reliability of the CaTCoN are satisfactory.
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As no existing questionnaire or combination of questionnaires covered the aims of a survey of cancer caregivers’ perception of tasks, consequences and needs, a new questionnaire, the ‘Cancer Caregiving Tasks, Consequences and Needs Questionnaire’ (CaTCoN) was developed [19].

The aim of this study was to evaluate the construct validity and reliability of the multi-item scales in the CaTCoN using psychometric analyses as well as tests of convergent and discriminant validity with other instruments.

Material and methods

The ‘Cancer Caregiving Tasks, Consequences and Needs Questionnaire’ (CaTCoN)

The details of the initial development of the CaTCoN have been published elsewhere [19]. In brief, we identified themes relevant to cover in the questionnaire on the basis of a literature review and focus group interviews with cancer patients’ caregivers, cancer patients, clinicians and cancer counselors. For each theme, one or more items were developed. During the development process, all items were evaluated by cognitive interviews with cancer patients’ caregivers, in order to reduce problems with comprehension and response.

The CaTCoN contains 72 items [numbered 1–41 (with some items containing several items, e.g. 14a, b, c, etc.), including two open-ended items for qualitative comments] aiming to measure the extent of cancer caregiving tasks and consequences, and the caregivers’ needs, mainly concerning information from and communication and contact with the health care professionals. The majority of items contain four ordinal response categories and a ‘don’t know/not relevant’ category. The CaTCoN questionnaire can be found in Supplementary Appendix A (available online at http://informahealthcare.com/doi/abs/10.3109/0284186X.2014.888496).

Questionnaire scoring

CaTCoN. Subscale scores were estimated as the mean of ‘information carrying’ item scores (i.e. responses in all other categories than the ‘don’t know/not relevant’ category). That is, the subscale score was made by dividing the sum of ‘information carrying’ ratings with the number of ‘information carrying’ ratings done. The subscale score was calculated, if less than half of the items were missing or in the ‘don’t know/not relevant’ category. However, one CaTCoN subscale (‘lack of information from the health care professionals’) was calculated, if at least one item was ‘information carrying’ (non-missing), as it would be reasonable to assess satisfaction with information even if the caregiver had needed information regarding only one or few topics.

FAMCARE. The 20-item FAMCARE instrument measures family members’ satisfaction with the health care. Response options range from 1 (very satisfied) to 5 (very dissatisfied) [17]. The middle category (3) is ‘undecided’. Originally four subscales were proposed: information giving (5 items), availability of care (4 items), psychosocial care (4 items) and physical patient care (7 items) [17], while others have found evidence of FAMCARE as a unidimensional scale [20–22]. In this study we included FAMCARE both as a unidimensional scale and as the four originally suggested subscales. Scale and subscale scores were estimated as the mean of ‘information carrying’ item scores (not including ‘undecided’) and were calculated, if less than half of the items were missing or in the ‘undecided’ category.

Family Inventory of Needs (FIN). FIN is a 20-item tool assessing family needs relating to the present situation. The instrument (in the revised version developed in Iceland) consists of two parts: one part measuring the importance of 20 care needs [response options range from 1 (not important) to 5 (very important)], and another part measuring whether the care needs rated as important (rated 4 or 5) have been met, partly met, or not met by the health care professionals. Both parts have been found to be unidimensional subscales [18,23]. In this study we only included the results from the subscale concerning fulfilment of care needs. This score was estimated as the mean of item scores and was calculated, if less than half of the items were missing.

Study population

From January to July 2010, cancer patients were identified by medical records in five hospital departments on three hospitals in the Copenhagen area, and in a written invitation, containing the caregiver questionnaires, the patients were asked to pass the questionnaires on to 1–3 caregivers involved in their disease course. Each patient received three caregiver questionnaires to pass on, each consisting of three instruments; CaTCoN, FAMCARE [17], and FIN [18,23], supplemented by questions on age, gender, relation to the patient, and socioeconomic characteristics.

Psychometric analysis of the CaTCoN

The methods used to develop the questionnaire ensured high face and content validity. The analyses
in this study examined the construct validity and reliability of the multi-item scales in the CaTCoN.

Items were first examined for frequency of non-response; items with a non-response rate > 10% were tagged for potential elimination (these items might be difficult to understand and therefore not valid). Also, the Spearman’s correlation coefficients between individual items were calculated; if two items had a correlation coefficient greater than 0.8, the items were considered very similar, and theoretical considerations should determine, if one of the items was redundant and should be eliminated from the CaTCoN.

Second, it was explored whether the remaining items could form valid and reliable subscales. Based on the original development process, we specified an a priori hypothesized subscale structure for the CaTCoN, which was tested in the analyses. In the first step, all item-item correlations in the CaTCoN were calculated using Spearman’s correlation coefficients. Correlations between the items within the hypothetical subscales were examined as well as correlations between the subscale items and all items not included in the subscale. If a subscale contained internal correlations below 0.30, which is often considered an acceptable lower limit during the initial scale development [24], the subscale was revised if theoretical considerations allowed this, and otherwise the subscale was abandoned. Likewise, if the highest correlation between subscale items was significantly lower than correlations between a subscale item and one or more items not included in the subscale, the subscale was revised if theoretical considerations allowed this, and otherwise the subscale was abandoned.

Finally, it was examined whether potential subscales had been missed in the process of hypothesizing the subscale structure. This was done by examining whether any items outside the established subscales correlated strongly (correlation at least 0.6) with each other, and whether the correlation(s) between the items was not significantly lower than correlations between one of the items and any other items. If this was the case, and if it was theoretically meaningful, new subscales were formed.

The subscales established on basis of the correlations were evaluated using factor analysis methods. We used factor analysis methods for ordinal data based on weighted least square mean and variance adjusted (WLSMV) estimation [25]. Our approach was confirmatory, but to strengthen the analysis, we also used relevant techniques with roots in a more exploratory approach. Thus, for each subscale eigenvalues and explained variance were calculated in order to evaluate the factor structure, and for each subscale the fit of a one-factor solution was evaluated using the comparative fit index (CFI) [26], the Tucker-Lewis Index (TLI) [27], and the Root Mean Square Error of Approximation (RMSEA) [28]. Often, an acceptable fit of a one-factor solution is defined as CFI and TLI greater than 0.90, and RMSEA less than 0.10 [29].

To measure the internal consistency (reliability) of each subscale, Cronbach’s alpha was calculated. A Cronbach’s alpha > 0.70 was considered acceptable [30].

As a test of whether the subscales were in fact distinct subscales, and of whether all items were correctly included in or excluded from the subscales, all correlations between subscales were calculated, and all correlations between each subscale and all items in the CaTCoN were examined (multitrait-scaling analysis) [24] using Spearman’s correlation coefficients.

The CaTCoN was developed because no existing instruments completely covered the content of a planned survey, and it therefore provides a broader measurement of cancer caregivers’ experiences than existing questionnaires. The instruments FAMCARE and FIN cover some of the aspects that we wished to measure by the CaTCoN, but as we wished to explore these aspects in a somewhat different way than in FAMCARE and FIN, new items regarding these aspects had been developed for the CaTCoN. It was therefore expected that some CaTCoN subscales would correlate strongly with FIN and FAMCARE, as they were intended to measure similar concepts, and that other CaTCoN subscales would correlate poorly with FIN and FAMCARE, as they were theoretically unrelated. These expectations were used for additional investigation of the construct validity of the CaTCoN: Theoretically based hypotheses about convergent (strongly correlated) and divergent (unrelated) subscales between the CaTCoN subscales and FAMCARE (both as a unidimensionel scale and as the four subscales originally proposed by Kristjanson [17]), and FIN (the subscale concerning fulfillment of care needs), respectively, were formulated. For some correlations, we had no clear expectations. The correlations between each CaTCoN subscale and the FAMCARE and FIN (sub)scales were calculated using Spearman’s correlation coefficients.

All analyses were done using SAS version 9.1.

Results

Study population

In total 856 patients were identified and were mailed questionnaires to pass on to their caregivers. Subsequently, 104 of these patients were excluded from
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A total of 609 caregivers responded to the questionnaire. Subsequently, 19 questionnaires were excluded, because the patient was terminal/deceased (N = 10), the caregiver was < 18 years old (N = 5), the questionnaire was filled in by the patient (N = 3), or the caregiver had not been involved in the disease course (N = 1), resulting in a final sample of 590 participating caregivers included in the analyses. The caregivers were related to 415 (55%) of the 752 eligible patients, as some patients had provided more than one caregiver. Characteristics of the 590 caregivers are shown in Table I.

Instrument properties and subscale structure

No items had a non-response rate > 10% (range 0.5–10.0%). Four pairs of items had a correlation coefficient greater than 0.8 [14b & 14c (0.82), 14c & 14d (0.83), 14g & 14h (0.81) and 29 & 30 (0.82)], but we chose not to eliminate any of these eight items, as the two similar items in each pair were considered slightly theoretically different and important to keep in the questionnaire.

Eleven CaTCoN subscales were hypothesized (see Table II, left column) on the basis of theoretical considerations.

Table II shows the correlations within the hypothesized subscales (Table II, second column from the left) and the content of the subscales after revisions (Table II, third column from the left) with new intercorrelations (Table II, right column).

After the estimation of correlations within the initial, hypothesized subscales, six subscales were retained, two subscales were revised, and three subscales were abandoned. The retained subscales were ‘caregiving workload’ (5 items), ‘lack of attention from health care professionals on the caregivers’ wellbeing’ (4 items), ‘lack of personal growth’ (3 items), ‘lack of privacy during conversations with health care professionals’ (2 items), ‘need for help from health care professionals’ (2 items), and ‘problems with the quality of information and communication from health care professionals’ (7 items). The lowest internal correlations in these subscales were acceptable (range 0.30–0.69). The lowest internal correlations in the subscales ‘lack of personal growth’ and ‘lack of privacy during conversations with health care professionals’ were significantly higher than the highest correlations between a subscale item and all items not included in the subscales. Some items not included in the subscales

Table I. Caregiver characteristics.

| Caregiver age (years)  | N = 590 | % |
|-----------------------|---------|---|
| 18–29                 | 38      | 6 |
| 30–39                 | 79      | 13|
| 40–49                 | 120     | 20|
| 50–59                 | 128     | 22|
| 60–69                 | 143     | 24|
| 70–79                 | 67      | 11|
| 80+                   | 12      | 2 |
| Missing               | 3       | 1 |

| Caregiver gender      | N = 590 | % |
|-----------------------|---------|---|
| Female                | 358     | 61|
| Male                  | 228     | 39|
| Missing               | 4       | 1 |

| Relation to the patient | N = 590 | % |
|-------------------------|---------|---|
| Spouse/partner          | 271     | 46|
| Child                   | 182     | 31|
| Parent                  | 47      | 8 |
| Sibling                 | 39      | 7 |
| Friend                  | 24      | 4 |
| Colleague               | 2       | 0 |
| Other                   | 22      | 4 |
| Missing                 | 3       | 1 |

| Caregiver level of education | N = 590 | % |
|-----------------------------|---------|---|
| No education                | 43      | 7 |
| Student                     | 18      | 3 |
| Special worker education    | 23      | 4 |
| Short education (<1 year)   | 19      | 3 |
| Trainee education           | 62      | 11|
| Shorter theoretical education (1–3 years) | 109     | 18|
| Longer theoretical education (≥3 years) | 188     | 32|
| Academic education          | 106     | 18|
| Missing                     | 22      | 4 |

| Caregiver habitation       | N = 590 | % |
|-----------------------------|---------|---|
| Country/village             | 94      | 16|
| Smaller provincial town     | 97      | 16|
| Bigger provincial town      | 90      | 15|
| City or suburbs             | 301     | 51|
| Missing                     | 8       | 1 |

| The patient’s diagnosis    | N = 590 | % |
|-----------------------------|---------|---|
| Head and neck               | 44      | 7 |
| Gastrointestinal            | 119     | 20|
| Lung                        | 24      | 4 |
| Gynecological               | 140     | 24|
| Prostate                    | 16      | 3 |
| Urinary                     | 2       | 0 |
| Breast                      | 37      | 6 |
| Leukemia                    | 121     | 21|
| Other locations             | 85      | 14|
| Missing                     | 2       | 0 |

| Patient’s cancer stage (TNM) | N = 590 | % |
|------------------------------|---------|---|
| Stage 1                      | 110     | 19|
| Stage 2                      | 69      | 12|
| Stage 3                      | 83      | 14|
| Stage 4                      | 83      | 14|
| Unknown                      | 245     | 42|

The patient’s diagnosis, ‘lack of attention from health care professionals on the caregivers’ wellbeing’, ‘caregiving workload’, ‘need for help from health care professionals’ and ‘problems with the quality of information and communication from health care professionals’
correlated strongly with the subscale items, but due to theoretical considerations they were not added to the subscales.

The two subscales ‘lack of information from health care professionals’ (13 items) and ‘negative consequences of being a caregiver’ (6 items) were revised. The revisions consisted of including additional items (if they fitted the subscale regarding both correlations and theoretical considerations) or excluding items from the subscale (if the internal correlations in the subscale were poor).

The three subscales ‘lack of balanced information’ (2 items), ‘lack of possibility for taking time off from the role as caregiver’ (2 items), and ‘need for taking time off from the role as caregiver’ (2 items), were abandoned, as they did not correlate internally at an acceptable level, and/or the internal correlation was significantly lower than correlations between a subscale item and one or more items not included in the subscale (there was no theoretical basis for revising the subscales).

The test of correlations to examine whether any subscales had been missed in the process of hypothesizing the subscale structure resulted in the establishment of one additional subscale: ‘need for contact to other caregivers’ (32 & 37c, internal correlation 0.62). The subscale items did not correlate significantly higher with any items outside the subscale, and the content of the subscale was theoretically meaningful.

The internal correlations of the nine subscales suggested on basis of the correlations are seen in Table II, right column.

Four subscales (‘lack of personal growth’, ‘lack of privacy during conversations with health care professionals’, ‘lack of attention from HCPs on the caregivers’ wellbeing’, and ‘problems with the quality of information and communication from HCPs’) were abandoned due to low internal correlations or correlations significantly higher with an item not included in the subscale.

Table II. Hypothesized CaTCoN subscales (left) with internal correlations (second column from the left), and the revised CaTCoN subscales after tests of correlations (third column from the left) with intercorrelations (right column).
The validity and reliability of the CaTCoN subscales, and as it made most theoretical sense, the one-factor structure was accepted.

As the eigenvalues for the subscale ‘negative consequences of being a caregiver’ indicated that a second factor explained 18% of the variance, and as the RMSEA = 0.271, a one-factor solution did not seem reasonable. On this basis the subscale was dropped. Instead, the two-item subscale ‘lack of time for social relations’ consisting of items 6c and 6d was constructed. Internal correlation was 0.76, which was significantly higher than correlations between one of the two subscale items and items not included in the subscale. The subscale was therefore accepted as a one-factor subscale.

Regarding the ‘lack of attention from health care professionals’ subscale, we found that two factors had an eigenvalue above 1, and the value for RMSEA ( = 0.198) was above threshold. Yet, as the subscale was predefined as different from the other subscales, and as it made most theoretical sense, the one-factor structure was accepted.

For the subscale ‘problems with the quality of information and communication from health care professionals’ had RMSEA = 0.197, but as the remaining results supported a one-factor structure, the subscale was accepted.

Test of correlations and factor analyses thus resulted in nine subscales. Cronbach’s alpha showed that all but one had acceptable to excellent internal consistency ranging from 0.77 to 0.95 (Table III). For the subscale ‘need for help from health care professionals’, ‘need for contact to other caregivers’ and ‘need for help from health care professionals’) contained only two or three items each and were accepted as one-factor subscales on basis of the correlations. The five remaining subscales underwent factor analysis (Table III).

Regarding the subscale ‘caring workload’, the explained variance of the second factor (14%) could suggest a two-factor solution, but inspecting the remaining results of the factor analysis, we concluded that they confirmed a one-factor structure.

For the subscale ‘lack of attention from health care professionals on the caregivers’ wellbeing’, the eigenvalues/explained variance, CFI and TLI supported a one-factor structure. Only the value of RMSEA ( = 0.285) was above the predefined threshold. We therefore accepted ‘attention from health care professionals, as a one-factor subscale.

Regarding the ‘lack of information from health care professionals’ subscale, we found that two factors had an eigenvalue above 1, and the value for RMSEA ( = 0.198) was above threshold. Yet, as the subscale was predefined as different from the other

Table III. Results from factor analysis of each of the CaTCoN subscales established on basis of test of correlations, and Cronbach’s alpha for each of the final CaTCoN subscales (right).

| CaTCoN subscales | 1st factor eigenvalue (explained variance) | 2nd factor eigenvalue (explained variance) | CFI | TLI | RMSEA | Cronbach’s alpha |
|------------------|------------------------------------------|------------------------------------------|-----|-----|-------|-----------------|
| Caregiving workload | 3.034 (60%) | 0.689 (14%) | 0.988 | 0.986 | 0.070 | 0.77 |
| (items 1a, 1b, 1c, 3, 4) | | | | | | |
| Lack of attention from HCPs on the caregivers’ wellbeing | 3.502 (88%) | 0.334 (8%) | 0.996 | 0.987 | 0.285 | 0.92 |
| (items 10, 11, 29, 30) | | | | | | |
| Lack of information from HCPs | 10.080 (72%) | 1.103 (8%) | 0.944 | 0.977 | 0.198 | 0.95 |
| (items 14-m, 33) | | | | | | |
| Lack of personal growthc | – | – | – | – | – | 0.78 |
| (items 6c, 6f, 6g) | | | | | | |
| Lack of privacy during conversations with HCPsec | – | – | – | – | – | 0.85 |
| (items 35, 36) | | | | | | |
| Lack of time for social relationsc,d | – | – | – | – | – | 0.87 |
| (items 6c, 6d) | | | | | | |
| Need for contact to other caregiversc | – | – | – | – | – | 0.77 |
| (items 32, 37c) | | | | | | |
| Need for help from HCPsec | – | – | – | – | – | 0.65 |
| (items 16, 17) | | | | | | |
| Negative consequences of being a caregiver | 2.730 (68%) | 0.714 (18%) | 0.982 | 0.945 | 0.271 | b |
| (items 6a, 6b, 6c, 6d) | | | | | | |
| Problems with the quality of information and communication from HCPs | 5.385 (77%) | 0.587 (8%) | 0.972 | 0.984 | 0.197 | 0.92 |
| (items 21-25, 27, 28) | | | | | | |

HCPs, health care professionals.

aNo subscales had eigenvalues above 1 for more than two factors; bThe subscale ‘negative consequences of being a caregiver’ was abandoned on basis of the factor analysis; cThe two- and three-items subscales did not undergo factor analysis; dThe subscale was formed after the abandonment of the scale ‘negative consequences of being a caregiver’.
professionals’, Cronbach’s alphas was 0.65, but as the subscale consisted of only two items, and each item had only two response options, this was considered acceptable. Cronbach’s alpha did not improve by removing any items from a subscale.

The multitrait-scaling correlations testing the retained subscales are seen in Supplementary Appendix B (available online at http://informahealthcare.com/doi/abs/10.3109/0284186X.2014.888496). The analysis lead to questions about whether item 10 should be included in the subscale ‘problems with the quality of information and communication from health care professionals’ instead of the subscale ‘lack of attention from health care professionals on the caregivers’ wellbeing’, and whether item 12 should be included in one of these two subscales. However, theoretical considerations rejected these potential revisions, and the multitrait-scaling analysis did therefore not lead to revisions.

To evaluate the construct validity of the CaTCoN further, theoretical hypotheses about convergent and divergent CaTCoN and FAMCARE/FIN (sub)scales were developed.

We expected that the CaTCoN subscale ‘lack of attention from health care professionals on the caregivers’ wellbeing’ would correlate strongly with FIN; that the CaTCoN subscale ‘lack of information from health care professionals’ would correlate strongly with FIN, FAMCARE (as one scale), and the FAMCARE subscales ‘information giving’ and ‘psychosocial care’; and that the CaTCoN subscale ‘problems with the quality of information and communication from health care professionals’ would correlate strongly with FIN, FAMCARE (as one scale), and the FAMCARE subscales ‘availability of care’, ‘information giving’ and ‘psychosocial care’ [marked (+) in Appendix C, available online at http://informahealthcare.com/doi/abs/10.3109/0284186X.2014.888496]. We expected the CaTCoN subscales ‘caring workload’, ‘lack of personal growth’, ‘lack of time for social relations’, and ‘need for contact to other caregivers’ to be unrelated to FIN as well as FAMCARE (as one scale or subscales), and that the CaTCoN subscale ‘need for help from health care professionals’ was unrelated to FAMCARE (as one scale or subscales) [Supplementary Appendix C (available online at http://informahealthcare.com/doi/abs/10.3109/0284186X.2014.888496), marked (-)]. For the rest of the correlations, we had no clear expectations [Supplementary Appendix C (available online at http://informahealthcare.com/doi/abs/10.3109/0284186X.2014.888496), marked (?)].

The calculation of the correlations confirmed all hypotheses concerning both convergent (correlation range 0.59–0.74) and divergent subscales (correlation range -0.11–0.25). The correlations with unclear expectations correlated at an acceptable level falling between the two other groups (correlation range 0.33–0.62).

Discussion

In this study we have established the subscale structure of the newly developed CaTCoN by hypothesizing subscale structures and testing the subscales by item-item correlations, followed by factor analysis, calculation of Cronbach’s alphas, and finally multitrait-scaling analysis. With some revisions the hypothesized subscales were confirmed to large extent. All hypotheses regarding convergent and discriminant validity between the CaTCoN and the existing questionnaires FAMCARE and FIN were confirmed. Taken together these findings indicate that the validity as well as the reliability of the CaTCoN is satisfactory.

The CaTCoN provides a broader measurement of cancer caregivers’ experiences than existing instruments, which often focus primarily on a single or few aspects of being a caregiver, e.g. reactions, difficulties/burdens, patient treatment, or information needs [14–18]. We believe that the information obtained with this new and more multifaceted instrument will markedly increase the insight into caregivers’ situation.

During the initial development of the questionnaire, we realized that not all caregivers would have experiences concerning all CaTCoN items, and we therefore chose to include a ‘don’t know/not relevant’ category in the majority of items. In our opinion, the inclusion of a ‘don’t know/not relevant’ category made the questionnaire as meaningful and interpretable as possible. However, the inclusion of the ‘don’t know/not relevant’ category led to challenges concerning the methods for assessing construct validity of the questionnaire. In our attempt to use the traditional method, the exploratory factor analysis, an obvious first step was to test the model containing the 11 hypothesized subscales. As the answers ‘don’t know/not relevant’ were not included in the analyses, only 41 caregivers would be included in such an analysis. This sample was obviously too small and would furthermore not be representative. Therefore we tested the hypothesized subscale structure in the CaTCoN by item-item correlations, followed by factor analysis (including elements from both exploratory and confirmatory factor analysis), and finally by multitrait-scaling analysis.

The multitrait-scaling analysis revealed that the three CaTCoN subscales ‘lack of attention from health care professionals on the caregivers’ wellbeing’, ‘lack of information from health care professionals’ and ‘problems with the quality of information
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and communication from health care professionals’ were strongly correlated (range 0.65–0.80) (Supplementary Appendix B available online at http://informahealthcare.com/doi/abs/10.3109/0284186X.2014.888496), which makes good theoretical sense, as these subscales tap on related aspects. In our opinion, applying the three distinct subscales makes it possible to emphasize and measure important differences between these related aspects.

As hypothesized, the CaTCoN subscales measuring lack of attention from health care professionals, lack of information, and problems with the quality of information and communication correlated at an acceptable/high level with FAMCARE (unidimensional scale), all four FAMCARE subscales, and FIN (the subscale concerning fulfillment of care needs). This could indicate that the three CaTCoN subscales measure different aspects that are clearly related to the possibly more overall/mixed concepts measured by the FAMCARE and FIN. The CaTCoN subscales measuring caregiving workload, lack of personal growth, lack of time for social relations, and need for contact to other caregivers did not correlate strongly with FAMCARE and FIN, and the CaTCoN subscale measuring need for help did not correlate strongly with FAMCARE. This confirms that, as intended, the CaTCoN measures several aspects that are not measured by FAMCARE or FIN.

The fact that all correlations between CaTCoN subscales and FAMCARE/FIN with ‘no clear expectations’ turned out to correlate at an acceptable level (correlation range 0.33–0.62) indicates that the aspects measured by these CaTCoN subscales are also incorporated in FAMCARE and FIN, though less transparent due to the content and structure of the two questionnaires.

As the caregivers were invited by the patients, we cannot know, how many caregivers each patient chose to invite, but the fact that caregivers related to 55% of the eligible patients responded appears reasonable, when taking into account that some patients probably did not have any caregivers sufficiently involved to be considered relevant for the study by patients. The fact that the patients were ‘gatekeepers’ for the caregivers may have influenced the kind of caregivers who were invited; i.e. is it possible that patients would like to spare the most burdened caregivers from more disease-related issues and therefore have been more likely to invite caregivers with a lower burden. These limitations are also described in a recent study of caregivers of Girgis et al. [31].

The fact that the CaTCoN was tested on caregivers to patients with multiple cancer diagnoses is a limitation, since every type of cancer has its own special challenges for caregivers. Yet, as it was our intention to create a questionnaire containing items relevant for all cancer caregivers across diagnoses, we found this approach appropriate. However, additional validation in more homogeneous patient groups will also be relevant. We also acknowledge that in studies focusing on a specific cancer diagnosis, it may be relevant to supplement the study with additional items or questionnaires targeting specific aspects.

The CaTCoN contains 72 items, which makes it a lengthy questionnaire. However, this number of items will be feasible in most cases and allow a comprehensive description. As the instrument was developed and validated in Denmark, studies evaluating feasibility and cross-cultural validity are warranted before using CaTCoN in other cultures.

For further evaluation of the CaTCoN, known groups’ comparisons and longitudinal studies should be conducted to further evaluate validity and to examine and establish responsiveness to change and minimal clinically important differences.

Conclusion

This study investigated the newly developed CaTCoN questionnaire in psychometric analyses and by testing associations with the well-known questionnaires FAMCARE and FIN. To a large extent the theoretical models were confirmed and with some revisions the validity and reliability of the CaTCoN was found to be satisfactory.

The CaTCoN differs from existing caregiver measurements by providing a broader measurement of adult cancer caregivers’ experiences and will increase the insight into caregivers’ situation markedly.

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Declaration of interest: The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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Supplementary material available online

Supplementary Appendix A–C.