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Title

A person-centred approach in nursing: validity and reliability of the Carer Support Needs Assessment Tool

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INTRODUCTION

Family caregivers play a fundamental role and carry a great responsibility in the care of patients with incurable illnesses who are cared for at home at the end of life (Hudson and Payne, 2011). They usually need to reframe their own life as they provide extensive assistance with personal care, medication and symptom relief, as well as emotional and existential support. In addition, they must cope with an uncertain future and the impending death of a family member (Grande and Ewing, 2008, McDonald et al., 2018). Family caregivers often have unmet needs and report strong interest in receiving more support (Collins et al., 2017, Dionne-Odom et al., 2017, McIlpatrick et al., 2017). In clinical care, the use of a person-centered approach and a short and direct but still comprehensive tool can facilitate the work of assessing family caregiver needs and ensuring adequate support (Ewing et al., 2013a, Ewing et al., 2013b).

BACKGROUND

One essential factor that makes it possible for patients to be cared for at home at the end of life is having the support of family caregivers (Gomes and Higginson, 2006, Grande and Ewing, 2008). A family caregiver can be any relative, friend, or partner who provides physical, social, and/or psychological support to the patient (Hudson and Payne, 2009).

Although the caring experience may be rewarding, accompanied by feelings of satisfaction and meaning (Andershed, 2006, Henriksson et al., 2013b), being a family caregiver involves considerable challenges (Candy et al., 2011). Many are insufficiently prepared to cope with

the situation where they often need to take a great responsibility for the physical and emotional care of the patient (Funk et al., 2010). As a result, they may experience emotional, physical and social distress (Abreu et al., 2017, McDonald et al., 2018, McIlfatrick et al., 2017). Family caregivers' distress often increases when patients are in more advanced stages of illness with more complex care needs (Williams and McCorkle, 2011). Furthermore, as the illness progresses, and as the patient deteriorates, more demands are often placed on family caregivers (Candy et al., 2011).

Well-targeted support for family caregivers may improve preparedness for caregiving and may decrease the number of negative consequences from caregiving (Henriksson et al., 2013a, Holm et al., 2016, Hudson et al., 2009). Adequate support can also help prevent a breakdown of the care situation at home (Sarmiento et al., 2017) and can contribute to patients experiencing safer and better care (Norinder et al., 2017). When caregivers feel confident in their skills, their care can be adapted to family life, enhancing the sense of normality and the management of uncertainty (Sarmiento et al., 2017).

An effective way to tailor targeted support is by employing evidence-based tools. The Carer Support Needs Assessment Tool (CSNAT) was developed in the United Kingdom especially for use among family caregivers in palliative care to provide a direct and comprehensive assessment of their support needs (Ewing et al., 2013b) and has been deemed appropriate for use in clinical care from the perspective of both family caregivers and nurses (Ewing et al., 2013a, Ewing et al., 2013b).

The CSNAT comprises 14 items, which represent broad domains encompassing areas in which family caregivers usually require support. These domains reflect the dual role of family

caregivers as both providers of care and support, and as people in need of support themselves. Family caregivers can respond to the items on the CSNAT by indicating how much more support they need, ranging from 'no more support' to 'very much more support'. The CSNAT is constructed as a communication tool where each item represents a domain. Hence, the CSNAT is not developed to be summed into a total score.

For use in practice, the CSNAT is integrated into a person-centered process of assessment and support; The CSNAT Approach (Ewing et al., 2016, Ewing et al., 2015). This process of assessment starts when the CSNAT is first introduced to the family caregiver who then is given time to consider which of the domains they need more support with. Next follows an assessment conversation with a nurse about the domains highlighted that enables the family caregiver to identify their specific support needs, prioritize those most important to them at this time and also to indicate the kind of support he or she thinks would be helpful in meeting these needs. From this assessment conversation, a shared action plan can be developed which is subsequently reviewed. This process derives from and is underpinned by the principles of person-centered care in which the person is treated with dignity, compassion, and respect and the care is personalized, coordinated and enabling (Collins, 2014). In this approach, nurses step back from being the expert in care and the process is led by family caregivers who not only identify their own needs of support but also appropriate solutions (Ewing et al., 2015).

There are many tools for family caregivers in palliative care available, but they are often measures of burden or distress and hence act as indicators of need, but do not identify what the support needs are (Hudson et al., 2010, Stajduhar et al., 2010). Therefore, the use of the CSNAT, which enables family caregivers themselves to identify their support needs, has been used widely and translated into several languages (Norwegian, Swedish, Icelandic, French-

Canadian, Dutch, Italian, Danish, and German). The original version has shown good face, content, and criterion validity (Ewing et al., 2013a). However, linguistic and cultural differences make it necessary to examine the validity of a translated measure to ensure measurement equivalence (Waltz et al., 2016).

The present study validates a Swedish version of the CSNAT and, in addition, it contributes with a test-retest reliability test of the CSNAT, which, to our best knowledge, has not been tested and published before. This is important as the CSNAT assessment is meant to be repeated at different time points. It is important to note that in practice the CSNAT is a communication tool designed to identify support needs, and then further discussion is required to establish what supportive input family caregivers need (Ewing et al., 2015). However, it is arguably still important to establish whether the tool is consistent in eliciting family caregivers' needs for support.

AIM

The aim was to translate and evaluate the validity and reliability of the CSNAT in a sample of Swedish family caregivers and nurses in a palliative home care context.

METHODOLOGY

The present study was conducted in three stages to reach conceptual, semantic, operational and measurement equivalence between the original UK version and the Swedish version (Streiner et al., 2015). In the first stage, CSNAT was translated into Swedish. In the second stage, content validity was evaluated. Finally, the measurement properties were examined in the third stage.

Ethical considerations

Family caregivers of patients in palliative home care may be considered as a vulnerable group due to their stressful situation. However, earlier research has demonstrated that this group might actually appreciate the opportunity to participate in research and benefit from their involvement (Aoun et al., 2017). During the process of the validation, a leading ethical principle has been acknowledged not to cause harm to the study participants. Written and oral study information emphasized the voluntary nature of participation and the right to withdraw from the study. When analyzing and presenting the results; data was treated according to the principle of confidentiality and the identity of participants was protected. The study was approved by a regional ethical review board in Sweden (No. 2015/1517-31/5).

Stage I- Translation process

The CSNAT was translated from English to Swedish following a translation procedure from the European Organization for Research and Treatment of Cancer, including forward- and backward-translation (Koller et al., 2007). Initially, two forward-translators; native Swedish speakers and fluent in English, provided translations independently. The translation was checked and discussed among the research group members to agree upon a first version of the translation. This version was then back-translated into English by two independent additional backward-translators, who were fluent in both Swedish and English, to ensure that the provisional forward-translation was an adequate representation of the English original. The two back-translations were reviewed and discussed among the authors of this study, which also included the original authors, of whom one also understands the Swedish language. All the authors have experience from working in palliative care and from research with special

focus on family caregivers in palliative care. Finally, a Swedish version of the CSNAT was chosen for validation. During the translation process, great care was taken to ensure that the translated version matched the original version of the CSNAT, and that linguistic differences and expressions were clarified. A direct translation was, on several occasions, not possible, and hence, some words needed to be changed and adapted to match the Swedish language.

Study context and participants for Stage II and Stage III

In Sweden, like in many other western countries, there has been a decrease in the number of hospital beds and an increased number of patients are cared for in their homes with the help of general or specialized home care teams. In Sweden all citizens are included in a social insurance system, ensuring salary also during a period of sick leave and economic support for deprived groups. Further it is possible to receive funding for a limited period from the government to care for a severely ill family member at home.

All data for Stages I and II were collected at two specialized palliative home care settings in two large cities in Sweden. Both settings provided care at home for patients who have complex palliative care needs and limited survival expectancy, regardless of diagnosis.

Patients in these settings have needs such as symptom management, emotional and existential support, as well as assistance with personal care. Both settings are staffed by multi-professional teams, including physicians, social workers, physical and occupational therapists, and nurses (who constituted the largest group of professionals in this study).

The director of departments and head nurses at each of the home care settings granted access to patient records for the identification of one family caregiver for each patient. Inclusion criteria for family caregivers were: being a spouse or partner to and living with a person who received specialized palliative home care at one of the two included settings; being 18 years

or older; and able to read and understand the Swedish language. Permission was also obtained to approach and invite employed nurses to participate. Inclusion criteria for nurses were not limited to anything other than being employed at one of the two settings. Altogether, the study had 132 participants, eight family caregivers and 10 nurses in Stage II and 114 family caregivers in Stage III.

Stage II – Content validity

Procedure

Family caregivers in Stage II were telephoned by one of the authors, given verbal information about the study, and invited to take part in an interview. They then received written information about the study, its aim, what to expect about the interview situation, and the principles of confidential and voluntary participation. At the time of the interview, all family caregivers who were approached gave their written informed consent. The same procedure was followed when nurses were approached and invited to participate, and all agreed to participate.

Data collection and data analyses

Cognitive interviews with a think-aloud approach (Willis, 2005) was used for data collection with both family caregivers and nurses. Participants were asked to reflect on the relevance, clarity and sensitivity of the wordings (upsetting or offending) as they went through the CSNAT. Family caregivers were interviewed individually, whereas data collection with nurses took place in the form of two group interviews with six and eight nurses, respectively, in each group. Group interviews were chosen as the data collection method with the nurses, as they provided the possibility for interactions between nurses and as they were asked to reflect on their situation as nurses working with the CSNAT as a tool in their clinical work. The interviews thus aimed to explore how the nurses perceived the CSNAT tool for their work in

supporting family caregivers. They were asked to consider whether the items were relevant, clear and understandable to them as nurses, and whether any of the items could be sensitive or difficult to discuss with family caregivers or could be upsetting to family caregivers. The goal was to gain an understanding about the CSNAT tool from the perspective of family caregivers living close to a patient who was receiving palliative home care, and from nurses as professional providers of care and support. All interviews were audio-recorded. Data were collected from October to December 2016, and the interviews lasted between 15 and 35 minutes. Comments from family caregivers and nurses on each of the CSNAT items were summarized according to each of the respective CSNAT items, and analyzed based on relevance, clarity, understanding, and sensitivity.

Results – stage II

Participants

Altogether, 10 family caregivers were asked to participate. One of them declined and another withdrew from the study after accepting because the patient's condition had unexpectedly been impaired. Altogether, eight family caregivers, five women and three men, aged 66 to 87, participated. Of them, five were caregivers to a patient with a cancer diagnosis and three to patients with COPD. Of the patients with COPD, one also had heart failure, and another also had cancer. The mean time since the patients had been diagnosed was 2.5 years. The sample also consisted of 10 registered nurses. All nurses were women aged 35 to 55, each with more than eight years of experience in palliative care nursing.

Relevance

Both family caregivers and nurses considered all the items were relevant for direct and comprehensive assessment of support needs among family caregivers in palliative care. They all believed that the use of CSNAT was a way to pay attention to the families' situation. The

family caregivers confirmed the relevance of the items in relation to their current situation. However, they found the item concerning their own health less relevant, as they still needed to cope with potential problems by themselves and visit a doctor or other health professionals. The nurses considered all the CSNAT items helpful to identify areas in which the family caregivers needed support. Both family caregivers and nurses believed that CSNAT could facilitate opportunities for family caregivers to express their needs and that it could be used repeatedly during the care. The nurses thought that it could be supportive when communicating with family caregivers.

Clarity

Most of the items were considered easy to understand by both family caregivers and nurses. Some of the nurses, as well as some of the family caregivers, reacted to the use of the word “care”. The expression “to care for” in English is a broad term that includes caring about someone but was initially translated into a Swedish expression denoting “to deliver care to”, which was perceived as implying an expectation that family caregivers should fulfil the role of a care worker. This was perceived as being rather demanding, both by family caregivers and nurses, and resulted in a change of wording in the CSNAT items that related to “care”. Some family caregivers and nurses experienced that the structure was disorganized, because questions about practical matters and psychosocial matters were mixed. Family caregivers considered it difficult to understand the item about “what to expect in the future”, and wondered whether the item concerned physical, emotional, or economic aspects. The nurses thought that the response categories were quite clear, while some family members would have preferred just ‘Yes’ or ‘No’ alternatives as they found it difficult to grade their needs.

Sensitivity of the wordings

Neither family caregivers nor nurses considered any of the items upsetting or offensive, or that they awakened emotions that were difficult to cope with. Some of the nurses, however, believed that it would be difficult to ask questions that identified certain family caregivers' support needs with which they might not be able to help. This can be compared with the reflections among family caregivers that they would be surprised that the home care unit had the resources to respond to some emerging support needs. The nurses perceived that the items assumed that family caregivers should and do want to provide practical care. This was confirmed by one family caregiver who experienced the CSNAT items as almost insinuating that family caregivers were obliged to provide practical care. This again relates to the issue of the translation of the term 'care for' and contributed as a reason for changing the wording in the CSNAT to avoid this interpretation.

Stage III - Measurements properties

Procedure and data collection

Based on the results from the cognitive interviews, the Swedish CSNAT was revised and Stage III of the study was initiated. All eligible family caregivers ($n=342$) in the two palliative home care settings were approached by the authors. They were sent a letter by post including information about the study, a request for their participation, as well as a questionnaire, including CSNAT-related validated self-rating measures (caregiver burden, preparedness for caregiving, and quality of life) and demographic questions, such as gender, age, and relation to the patient. Family caregivers consented to participation by completing and returning the questionnaire in a pre-paid stamped envelope for direct return to the researchers. On the last page of the questionnaire, family caregivers were asked whether they would consider answering the CSNAT items again in one week's time. An explanation was made about the

aim of testing reliability. For those who agreed to participate in the retest ($n=88$), a questionnaire, including the CSNAT, was again sent by post.

Measures other than CSNAT

The Caregiver Burden Scale (Elmstahl et al., 1996) consists of 22 items divided into five subscales. For the present study, only the general strain subscale was used. The items are answered on a 4-point Likert-type scale, ranging from ‘not at all’ (1) to ‘often’ (4), where higher scores indicate greater caregiver burden. The item scores of each subscale are summed, and a mean value for each subscale is calculated, with scores ranging from 1 to 4. Cronbach’s alpha for the general strain subscale was 0.91 in the present study.

The Preparedness for Caregiving Scale measures family caregivers’ perceived readiness to provide care and is valid for use in palliative care (Archbold et al., 1990, Henriksson et al., 2012, Henriksson et al., 2015). It consists of eight items answered on a 5-point Likert-type response scale ranging from ‘not at all prepared’ (0) to ‘very well prepared’ (4), with a total score ranging from 0 to 32. Cronbach’s alpha was 0.94 in the present study.

The *Quality of Life in Life-Threatening Illness – Family carer/caregiver version* (QOLLTI-F) tool measures QoL in eight dimensions. The present study used QOLLTI-F’s single-item indicator for overall quality of life. Responses are made on 11-point numerical rating scales (0–10), with a descriptive anchor at each end.

Statistical analysis

Descriptive statistics were used to present the sample and study variables.

The evaluation of data quality was based on descriptive statistics and included item score distribution (ceiling and floor effects) and missing data patterns. Ceiling and floor effects

occur when a considerable proportion of subjects score the lowest or highest possible score. There is no consensus on how to define the limit of these effects, but previous research has commonly used >15% as a criterion (McHorney and Tarlov, 1995).

To evaluate construct validity, the CSNAT items were correlated with external constructs expected to be related to support needs (caregiver burden, preparedness for caregiving, and quality of life) using polyserial correlation coefficients (ρ). To support construct validity, it was hypothesized that lower levels of support needs should correlate moderately or stronger with lower levels of caregiver burden ($\rho > 0.3$) and higher levels of preparedness for caregiving and quality of life ($\rho > -0.3$).

Test-retest reliability was examined using weighted quadratic kappa statistics (κ_w), $1 - ((i-j)/(k-1))^2$. The kappa statistics were interpreted according to (Altman, 1991): <0.20 poor, 0.21–0.40 fair, 0.41–0.60 moderate, 0.61–0.80 good, and 0.81–1.00 very good.

A p -value of <0.05 was considered statistically significant. All statistical analyses were conducted using Stata 15.1 (StataCorp, College Station, TX, USA).

Results – stage III

Participants

Altogether, 114 family caregivers participated (response rate 33%), and 63 completed the retest (72%) within two weeks. Ninety percent of participants were born in Sweden, 61% were women, and the mean age was 67.5 (SD=10.9, range=33–90) years. In general, the participants were well educated, and 42% had a university degree. A majority was retired (61%), while 27% worked full-time, and 12% had children in their household. One-fifth

(20%) reported receiving care benefits, i.e., they were paid by the Swedish government to provide care for the patient at home. Most of the patients had a cancer diagnosis (84%) (Table 1).

More than 60% of the family caregivers reported that they needed more support concerning knowing what to expect in the future, having time for themselves in the day, and dealing with their feelings and worries. Less than 30% needed support with financial, legal, or work issues, or with their beliefs or spiritual concerns (Figure 1).

Data quality

The distribution of the item scores was positively skewed and floor effects were observed in all CSNAT items, with the most prominent found in the item concerning spiritual beliefs and the item about financial, legal, or work issues. However, all response categories were used (Table 2).

Problems with missing data were, overall, low, however, in the last question that asked family caregivers to provide information about additional support needs that are not included in the CSNAT, missing data exceeded 25% (Table 2). This is, however, to be expected, as this is a final ‘catch-all’ question that many may see as optional. There were 9 participants who had indicated that there were other issues for which they needed more support that were not included in the CSNAT. Not everyone had specified their issues of concern, but issues mentioned were weekend respite, financial support to be able to afford a larger apartment, help with the children, information about the illness, and coordinated care.

Construct validity

Overall, the construct validity was supported, as all CSNAT items except “understanding your relative’s illness” correlated to a rho-value above 0.3, with one or more of the three external constructs expected to be related to support needs (Table 3). Regarding caregiver burden, all items except one correlated as hypothesized, i.e., lower levels of needs correlated with lower burden ($\rho > 0.3$). Regarding preparedness for caregiving and quality of life, six and nine items respectively correlated as hypothesized, i.e., lower levels of needs correlated with higher levels of preparedness for caregiving and quality of life.

Test-retest reliability

All CSNAT items had satisfactory stability, with eight showing moderate ($\kappa_w = 0.45\text{--}0.59$) and seven good ($\kappa_w = 0.61\text{--}0.75$) test-retest reliability (Table 4).

DISCUSSION

This study includes a translation and validation of a Swedish version of the Caregiver Support Needs Assessment Tool (CSNAT). The results suggest that the Swedish version of the CSNAT has sound psychometric properties with satisfactory data quality, construct validity and stability.

The results from the cognitive interviews allowed for valuable qualitative feedback and suggest that the items of the CSNAT were considered relevant both to family caregivers and nurses. However, it also provided the opportunity for corrections in the translation of the tool, as some questions were formulated in a way that was received less well by the participants. It became obvious that the word “care” could be interpreted differently in Swedish compared to English, hence the necessity to change the wording for a Swedish context. It has previously

been stated that, in addition to translation, it is important to make a cultural adaption of an instrument (Carvajal et al., 2011).

Some of the nurses in the present study believed it would be distressing to identify support needs that they were not able to help with, even though the CSNAT-approach would not necessarily demand this from them. However, this may perhaps reflect a misunderstanding; not so much of the items and the tool itself, but of the CSNAT Approach. This points towards the need for training to ensure the CSNAT and the person-centered CSNAT approach are fully understood by those who administer and adopt them.

Some family members in the present study would have preferred 'Yes' or 'No' alternatives to the items. However, it is well known that family caregivers are reluctant to accept support for themselves as they favor the patient receiving support, rather than themselves (Harding and Higginson, 2001). In relation to this, it might be that the existing CSNAT response categories enable them to indicate whether they need more support – even if it is only 'a little more'. In the present study, the family caregivers found the item relating to their own health to be less relevant. This could be compared with the results obtained from interviews when the CSNAT was first developed, in which the section on physical health concerns were found to be very relevant by the participants (Ewing et al., 2013b). However, those interviews were completed with bereaved family caregivers. It could be that family caregivers during ongoing care are so concerned with caregiving that the item becomes less relevant to them then, but it is a hidden issue and remains a key issue in relation to the effects of caring on their health that only becomes evident during bereavement.

The cognitive interviews revealed that family caregivers considered that the item about knowing what to expect in the future was a bit unclear and they wondered whether it

concerned physical, emotional, or economic aspects. Their confusion could also be related to what diagnosis the patient suffered from. The trajectory of heart failure or COPD for example could be extremely difficult to predict in comparison to malign diseases and physicians may find it difficult to communicate the patient's survival time (Green et al., 2011, Gore et al., 2000). Still, more than 60% of the family caregivers participating in Stage III, when examining the measurement properties, reported that they were in need of more support in relation to this item, a finding which is also congruent with those found in studies from the UK (Ewing et al., 2013a) and Australia (Aoun et al., 2015). Based on the results from the present study, it may, however, be appropriate to reflect on what issues about the future that family caregivers actually meant that they needed support with. This question underlines the importance of having a conversation with the family caregiver about their needs.

Data from the participants were skewed with floor effects seen in all items, although all response categories were used. It should be noted, however, that the tool is designed to comprehensively capture the full range of domains with which family caregivers may need support. Therefore, it is to be expected that most will only select a set of items that reflect their situation and will not express a need for support with the remainder.

Few missing values were observed for CSNAT, which implies that the tool was regarded as easy to complete. The final item asks the participant to identify any additional needs for support and the number of missing values were $>5\%$, which is set as a recommended limit. However, in this tool, this number of missing values in the final item could be regarded a strength. It may be that many people did not respond because they had no additional support needs and did not think they needed to respond. Because many family caregivers were unable to identify any further needs, the CSNAT seems to have most areas of support covered. There is also a need to acknowledge that the issues raised as additional support needs, for example,

financial support or understanding the illness, are actually covered in the CSNAT, but the participants may have wanted to highlight them again. This phenomenon was also seen in the original validation (Ewing et al., 2013a). For example, in both studies, family caregivers wanted more support with weekend respite, which could be considered a part of getting time for yourself or a break from caring overnight.

The construct validity of the Swedish version of CSNAT was good, as significant correlations above 0.3 were found between the items and other instruments that are often used in the context of palliative care and family caregiving. In addition, the test-retest showed acceptable stability for all items in CSNAT. Very strong kappa values were not expected as support needs can change rapidly in family caregivers to patients in palliative home care settings.

METHODOLOGICAL CONSIDERATIONS

The sample size of 114 family caregivers is sufficiently large for the statistical analyses that were used, as well as for the test-retest (Hair, 1998). The sample seems to have included family caregivers who coped rather well with their situation as they, in general, reported low needs for further support. In addition, a great number of family caregivers had higher education, and few were born outside of Sweden. Because a large population in Sweden has a background in other countries, this indicates that the sample might not be representative of Swedish family caregivers. The bias may also be due to the setting chosen for the study. Specialist palliative home care settings usually provide high quality support for family caregivers as part of their standard care. A limitation to the study is the lack of information on whether and how family caregivers who did not respond differed from those who did. The fact that those family caregivers who are already coping well or are well-supported are more

likely to take part in research than those who are more vulnerable is a problem that has been demonstrated in earlier studies and that could affect the results (Holm et al., 2017, Schildmann and Higginson, 2011)

The CSNAT has not previously been tested for its internal consistency, such as determining the Cronbach's alpha value, which is the traditional way of testing the reliability of an instrument. The authors of CSNAT have deemed that it would be inappropriate to perform such tests on CSNAT, as it seeks to capture the range of family caregivers' support needs rather than a single underlying construct or set of constructs, and that it should not be summed into a total score, which is standard for most other instruments (Ewing et al., 2013a).

Any test-retest of the CSNAT domains should, however, be interpreted with caution. The need for more support with any domain is a trigger for further discussion to explore what the underlying problem and associated solution may be. This will be different for different family caregivers. For example, 'knowing what to expect' may for one family caregiver be about knowing what to expect when the patient becomes bedbound, and for another how the illness will develop over time. The need for more support within a particular domain may also change over time. This stresses the importance of exploring the underlying issue and reviewing support needs over time when using the CSNAT. It also highlights that test-retest results for CSNAT domains in general should be treated with care. The initial underlying problem within a domain may improve, but family caregivers may still indicate the need for more support within that domain because a new problem has emerged. However, a test-retest may be meaningful in this study as there was a short time between responses, there had been no known intervention by nurses in between measurements, and the test-retest simply sought

to establish whether the CSNAT seemed consistent in eliciting whether family caregivers have concerns within a domain over a short space of time.

CONCLUSION

This study further adds to the validity of the CSNAT and shows in addition that it is reliable and stable for use among family caregivers in palliative home care. The CSNAT has been developed for use in a palliative care context and it highlights family caregivers' situation and support needs. Used as part of The CSNAT Approach, it enables a comprehensive, person-centered approach to family caregiver assessment and support, which is facilitated by practitioners but led by family caregivers. The CSNAT Approach can be repeated during the care, enabling family caregivers to express their changing needs and to support nurses when communicating with family caregivers. In conclusion, this study establishes the validity of the CSNAT for use among family caregivers in palliative care in Sweden.

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