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

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ABSTRACT

Purpose: The Carer Support Needs Assessment Tool (CSNAT) was developed for use among family caregivers in palliative care for assessment of their support needs. The purpose of this study was to translate and evaluate the validity and reliability of the CSNAT in a sample of Swedish family caregivers and nurses in a palliative care context.

Methods: Data for this validation study was collected during 2016 in the context of palliative home care in two larger Swedish cities. The study was conducted in three stages to reach conceptual, semantic, operational and measurement equivalence between the original UK version and the Swedish version. Stage I consisted of translation to Swedish. In Stage II, cognitive interviews were performed with 8 family caregivers and 10 nurses. Data were analyzed based on relevance, clarity and sensitivity. In Stage III, the CSNAT and related self-rating measures (caregiver burden, preparedness for caregiving and quality of life) were completed by 118 family caregivers. Data quality, construct validity and test-retest reliability were evaluated.

Results: The CSNAT items were considered relevant and useful to identify areas of support needs. The Swedish CSNAT showed sound psychometric properties with satisfactory data quality and few problems with missing data across items (1.8%-6.1%). All items except one correlated as expected ($\text{rho} > 0.3$) with caregiver burden, supporting construct validity. All items had satisfactory test-retest reliability ($\kappa w = 0.45\text{-}0.75$).

Conclusions: 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 care.

1. 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; McIlfatrick 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

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assessing family caregiver needs and ensuring adequate support (Ewing et al., 2013a, 2013b).

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 might 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 might 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 might improve preparedness for caregiving and could 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 (Sarmento 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 (Sarmento 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, 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., 2015, 2016). 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.

2. Aim of the study

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.

3. 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.

3.1. *Ethical considerations*

Family caregivers of patients in palliative home care could 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 were 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).

3.2. *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