



Poster # 18

Title of poster: Development of a longitudinal outcome measurement questionnaire for family caregiver quality of life as addressed by their support needs.

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Abstract

One component of our study consists of a clustered randomized control trial (RCT) to determine whether the use of the Carer Support Needs Assessment Tool (CSNAT) by home care nurses with the family caregivers of their patients improves the quality of life of said family caregivers. We will be testing the following 2 hypotheses in our RCT: The use of the CSNAT as a practice support tool intervention will 1) lead to improved family caregiver quality of life during the time prior to patients' death and in bereavement and 2) contribute to the following secondary outcomes in family caregivers during the time prior to patients' death: enhanced perceived social support, improved preparedness to provide care and reduced caregiver burden.

We have adapted a model of caregiver burden to hypothesize the various concepts by which addressing support needs may contribute to family caregivers' quality of life. Due to the complex nature of quantifying quality of life and the factors that contribute to quality of life for family caregivers, we needed to create a questionnaire that would address each concept in our hypothesized model, for example, burden, preparedness, overall quality of life, patient functionality and symptoms, etc...

Developing an appropriate questionnaire for our outcomes measurement took considerable foresight and required that we address the following concerns:

1. **Constructs:** We had to define the constructs within our model as they relate to family caregiver support needs and the quality of life of family caregivers.
2. **Measurement Tools:** We had to investigate and select a number of appropriate, validated measures to use in order to measure our constructs, e.g., to address general quality of life we selected the Quality of Life in Life Threatening Illness - Family Carer Version (QOLLTI-F). Appropriate authorization was obtained to utilize each of the measurement scales we had deemed most appropriate.
3. **Order of Tools:** Considering the length of the final questionnaire we needed to determine the most appropriate order for the measurement tools so as to ensure that we would obtain our primary outcome measures near the beginning while still maintaining a natural flow between topics.
4. **Mode of Administration:** As is the case with longitudinal outcome measures we needed to assess what would be the best course of action to ensure that our data collection was as complete as possible over the entire data collection period.

Our final measurement tool consists of various established family caregiver tools incorporated into one questionnaire. As this questionnaire will be longitudinal, we will be using an in-person interviewer administration mode with response cards to help with retention and data integrity. In some cases we have adapted the family caregiver tools slightly to accommodate a change from the original self-administration mode to an interview administration.

