

**Development of a “what matters to family carers” assessment tool for evaluation of care and support at end of life care (Phase 2)
Executive Summary**

This study aimed to develop a Carer Support Needs Assessment Tool (CSNAT) and test its validity and psychometric properties.

The CSNAT was developed from support needs identified from focus groups and interviews with carers and health professionals and reviews of the literature and existing measures that were conducted in Phase 1. CSNAT consists of 7 items covering support to help the carer look after their relative and 7 items covering support for carers themselves. Minor amendments were made to the CSNAT and study procedures after initial piloting in one Hospice at Home (H@H).

The CSNAT was tested with current carers whose friend or relative had been referred to H@H. Carers completed the CSNAT alongside standard measures of health related quality of life, caregiver strain, stress, positive appraisals and preparedness, measures of patient functional status and symptoms. These were completed at baseline and at four weeks' follow up. Demographic information was also collected at baseline.

Carers were recruited through six participating H@Hs. Valid data were obtained from 225 carers at baseline and from 141 carers both at baseline and follow up.

CSNAT responses showed that the majority of carers wanted more support with knowing what to expect in the future and dealing with their feelings and worries. More than a third wanted more support with having time for themselves in the day, understanding their relative's illness and knowing who to contact. A fifth or more would have liked support with looking after their own health, practical help in the home, managing symptoms, talking to their relative about their illness, financial, legal or work matters, overnight respite or providing personal care. Fourteen carers wanted more support with spiritual concerns. Only five carers identified an additional need not covered by the CSNAT items, yet additional needs were closely related to items already covered. CSNAT responses therefore indicate that none of its items was superfluous and that the existing items covered the vast majority of carer support needs, suggesting that the CSNAT has good content validity.

CSNAT scores underwent Factor Analysis and three factors were extracted. Factor 1 represents items related to “protecting self”, associated with daytime respite, night time respite, looking after own health and offloading practical tasks in the home. Factor 2 appears to represent “dealing with uncertainty and anxiety”, associated with concerns over what to expect in the future, understanding the illness, talking to their relative about the illness, dealing with own feelings and worries and knowing who to contact if concerned. Factor 3 is associated with “managing practical care giving tasks”, relating to personal care, equipment to aid care and managing symptoms. The factors account for 46.5% of the variance and show good internal reliability (Cronbach's Alpha 0.67-0.80). While individual items rather than summative scores will be of relevance in H@H practice, the factor and reliability analyses nevertheless suggest that the CSNAT has a meaningful underlying structure and internal consistency.

CSNAT scores showed clear and consistent correlations with preparedness for care giving, health related quality of life, caregiver strain and stress, and also showed clear correlations with patients' need for help with Activities of Daily Living. There was also some correlation with positive care giving appraisals and patients' symptoms, but these patterns were less consistent. These results suggest that CSNAT has good criterion validity.

The CSNAT picked up changes in support needs between baseline and follow up consistent with parallel changes in patients' need for help with ADL and caregiver strain, suggesting it is sensitive to change over time. The CSNAT was also able to identify significant differences in support needs between different groups of carers, including carers of patients with cancer versus longer term conditions; carers who did or did not have additional care responsibilities; and carers of different ages, suggesting that the CSNAT is sensitive to care giving context.

Testing of the CSNAT has therefore shown that it is a comprehensive, valid and sensitive measure of carer support needs with a meaningful underlying structure and internal consistency. We are currently disseminating results and undertaking a feasibility study of its implementation in H@H practice.