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Caregiving Demands in Parents of Children With Cancer: Psychometric Validation of the Care of My Child With Cancer Questionnaire☆

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A comprehensive evaluation of the psychometric properties of Care of My Child With Cancer (CMCC) was performed in a sample of 411 parents of children undergoing treatment of cancer at five Canadian pediatric oncology centers. Psychometric tests used to assess data quality, targeting, reliability, and construct validity demonstrated that the CMCC is a scientific sound measure. The CMCC will be helpful for assessing increasing parental responsibility for caregiving tasks associated with cancer care.

IN THE PAST two decades, changes in the health care system have exerted a shift from inpatient care toward outpatient community- and home-based settings that, in turn, have increased the responsibilities of family caregivers. Children with cancer now receive a large part of their treatment at home, placing extra demands on parents who must perform a variety of tasks including administering medication, monitoring for toxicity, and communicating with health care professionals. Children with cancer may experience a range of symptoms that all require parental attention, including fever and infections, mouth ulcers, constipation, nausea and vomiting, anorexia, pain, fatigue, anxiety, and depression. The intensive and often prolonged treatment can pose problems for family organization, especially if the hospital is far from home. Logistically, it can be difficult for siblings and extended family members to visit and participate in the care of a child, and often, one parent shoulders most of the day-to-day demands of caregiving.

To properly assess increasing parental responsibility for caregiving tasks associated with cancer care, Keegan-Wells et al. (2002) developed Care of My Child With Cancer (CMCC), a questionnaire that can be used in research to measure the amount of time required and the effort or difficulty associated with parental caring for a child with cancer. According to Keegan-Wells et al., CMCC was developed for use in research to further investigate and understand caregiving demand and ultimately to develop and test nursing interventions that aim to support parents in their caregiving roles and maximize family functioning during a

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child's treatment of cancer. We performed a comprehensive evaluation of the psychometric properties of CMCC in a large independent sample of parents of children undergoing treatment of cancer at five pediatric oncology centers in Canada. We used recommended psychometric tests and criteria for the development and validation of health outcome measures by the Scientific Advisory Committee (SAC) of the Medical Outcomes Trust (2002). Psychometric tests and criteria for the rigorous, three-stage, gold-standard methodology set out by the SAC were helpfully summarized by Cano et al. (2004) in a publication outlining the development of a patient-reported outcome measure.

Methods

Participants

This study was a subset of a larger study designed to evaluate quality of life (QL) of parents of children with cancer (Klassen et al., 2008). Parents were recruited into this study over a 28-month period (November 2004 to February 2007) from five Canadian pediatric oncology centers: BC Children's Hospital (Vancouver), CancerCare Manitoba (Winnipeg), Children's Hospital of Eastern Ontario (Ottawa), The Hospital for Sick Children (Toronto), and McMaster Children's Hospital (Hamilton). We included parents of children with any type of cancer who met the following inclusion criteria: The child was in active treatment, the child was at least 2 months postdiagnosis, the child was not considered palliative, the parent (one per family) was the child's primary caregiver (person most responsible for the day-to-day decision making), and the parent could read English.

Procedure

Ethical approval was obtained from each participating center. Written informed consent was obtained from all participants. Consenting parents completed a questionnaire booklet that included the CMCC (Keegan-Wells et al., 2002), the PedsQL 4.0 Generic Core scale (Varni, Seid, & Rode, 1999), and questions about the child's cancer and family demographics.

Care of My Child With Cancer

Care of My Child With Cancer (Keegan-Wells et al., 2002) measures time and effort associated with 28 caregiving tasks. Items were generated through expert opinion and literature review but not parental input. Instructions ask parents to complete the scale in response to the past month. Each item is scored separately for time and effort on a 5-point Likert scale. Scores for time range from 1 (*no time*) to 5 (*more than 5 hours per week*). Effort scores range from 1 (*no effort*) to 5 (*a great deal of effort*). Item scores are computed by multiplying the raw time score by the raw effort score and taking the square root of the product. The total score represents the sum of item scores and can range from 28 to 140.

Limited evaluation of the psychometric properties of CMCC has been published. Keegan-Wells et al. (2002) showed that internal consistency and test–retest reliability were acceptable for the total score. Exploratory factor analysis yielded a four-factor solution accounting for 52.5% of the variance. Tasks associated with meeting the family's emotional, information, and communication needs and maintaining family function in the face of illness and treatment accounted for 13 items; the most common tasks associated with physical caregiving across the various pediatric cancer diagnoses accounted for 7 items; catheter care accounted for 2 items; child care for the ill child and siblings accounted for 2 items. Four items were unclassifiable and include giving intramuscular and intravenous medications, arranging medical services, and traveling to and from the treatment facility. Given that best practice guidelines in exploratory factor analysis published by Costello and Osborne (2005) described that a factor with fewer than 3 items is generally weak and unstable, we focused the analysis in our article on their total score and two strong factors. We refer to these factors as *emotional caregiving* and *physical caregiving*. Scores can range from 13 to 140 (emotional caregiving) and from 7 to 35 (physical caregiving).

For this study, we modified the instructions asking parents to think about the most demanding week in the past month and to indicate the amount of time and effort each task required. This modification was meant to ensure that we did not underestimate the impact of caregiving due to variation in treatment intensity that can happen within a 1-month period.

Data Analysis

To determine whether CMCC fulfills fundamental prerequisites for rigorous measurement as defined by traditional psychometric methods, we used guidelines outlined by the SAC of the Medical Outcomes Trust (2002), which were helpfully summarized by Cano et al. (2004).

Data Quality

Data quality is the completeness of item- and scale-level data. It is determined by computing the percentage of missing data for each item and the percentage for whom a scale score can be computed. Criteria for item- and scale-level data quality are less than 5% missing data (Cano et al., 2004; Smith et al., 2005).

Targeting

Targeting is the extent to which the range of the construct measured by the item or scale matches the range of that construct in the study sample. Targeting can be studied at both the item and scale level. At the item level, it is