Inter-observer agreement of a comprehensive health status classification system for pre-school children among patients with Wilms’ tumor or advanced neuroblastoma

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Abstract

We assessed inter-observer agreement on a new comprehensive health status classification system for pre-school children (CHSCS-PS). Prospective assessments of children aged 2–4.9 years at the time of diagnosis of neuroblastoma (stages 3–4, excluding 4S) or Wilms’ tumor (stages II–V) were collected independently from a parent and nurse by self-report during therapy. Responses were used to determine functional status on 10 health domains, as well as an overall disability score. Inter-observer agreement was evaluated by a kappa statistic for agreement about levels within individual domains, and by an intraclass correlation coefficient (ICC) for agreement of overall disability scores. Twenty-four parent/nurse pairs of assessments were collected. Agreement was almost perfect for mobility and self-care, substantial for emotion and pain, and slight for speech. There was high percent agreement for vision, hearing, dexterity, learning and remembering, and thinking and problem solving, but insufficient variability in responses to calculate a kappa statistic. The ICC for overall disability scores between observers was 0.86, indicating strong agreement. Given the need for, and paucity of, instruments for the measurement of health-related quality of life in very young children, these results strongly support further evaluation of the CHSCS-PS.

Key words: Health status classification, Inter-observer agreement, Neuroblastoma, Pre-school children, Wilms’ tumor

Introduction

Improvements in the long-term survival rates of children with cancer have prompted an increased focus on the acute and chronic morbidity associated with both the disease and its therapy [1–3]. Measures of health-related quality of life (HRQL) provide a method for quantifying this morbidity, and inform decisions by caregivers regarding therapeutic alternatives [4]. However, the paucity of validated HRQL instruments for children younger than 5 years of age [5] has limited the assessment of HRQL in this age-group, which comprises more than 30% of children with cancer [6]. Challenges to the development of an HRQL instrument for pre-school children include difficulties with designing a standard instrument for a population in which the definition of ‘normal’ changes substantially as children develop, and the need to collect data from proxy assessors because
pre-school children typically cannot complete these assessments independently [7].

The Comprehensive Health Status Classification System for Pre-school Children (CHSCS-PS) is a recently developed multi-dimensional tool for measuring comprehensive health status in young children [8]. This tool evolved from the Health Utilities Index (HUI) Mark 2 (HUI2) and Mark 3 (HUI3) for use in children aged 2–5 years. The HUI has been used in a wide variety of clinical settings, including pediatric oncology [9–11], and is one of the best instruments for assessing health status and HRQL in children with cancer [3]. Although it has been used in children younger than 5 years of age [3, 12], reliability and validity have not been established in this age-group. In its current form, the CHSCS-PS provides measures of health status on 10 separate domains. The CHSCS-PS has been described in an unpublished report to the Medical Research Council of Canada [8] and in presentations at major scientific meetings [13, 14], but this is the first published peer-reviewed paper assessing its measurement properties.

In the current study, the CHSCS-PS was used to assess the health status of pre-school children undergoing therapy for one of two tumors, Wilms’ tumor or advanced neuroblastoma. We focused on these malignancies because they are two common childhood cancers that portend excellent and poor prognoses, respectively, and were expected to be associated with relatively large variability in health status among patients. Such variability is important for establishing the reliability of an instrument [15]. Because proxy observers are necessary for the completion of CHSCS-PS assessment questionnaires, we were particularly interested in the agreement between parents and nurses on assessments using this instrument. Here, we describe the inter-observer agreement of the CHSCS-PS.

Methods

Subjects

Eligible subjects were all patients who were aged 2.0 through 4.9 years (inclusive) at the time of diagnosis of either Wilms’ tumor or neuroblastoma [16], who were receiving active therapy at the Hospital for Sick Children (HSC) in Toronto or the McMaster Children’s Hospital (MCH) in Hamilton, and who were enrolled on a prospective study that assessed HRQL at various time points during therapy using the CHSCS-PS. In order to be included in this analysis of inter-observer agreement, patients were required to have at least one pair of CHSCS-PS assessments completed by both a parent and a nurse.

Study design

The study was approved by the research ethics boards of both institutions. Parental consent was obtained for all participants. Patients whose parents did not speak English were excluded. For each assessment completed in hospital or at a clinic visit, a parent and the nurse responsible for the child’s care were each asked to complete a self-administered questionnaire independently.

CHSCS-PS

Data for the 10 domain CHSCS-PS (Table 1) were collected using separate 12-question multiple-choice questionnaires for parent (Health Status Classification System Parent Questionnaire) and nurse (Health Status Classification System Clinician Questionnaire) observers. Observers were asked to choose one response option for each of the 12 questions. Two questions were used to determine a level of function for each of the vision and hearing domains. Responses to the eight remaining questions provided the level of function for the remaining eight domains: speech, mobility, dexterity, self-care, emotion, learning and remembering, thinking and problem solving, and pain. There are 3–5 levels in each domain. For each question, observers were instructed to select the response option which best described the child’s level of functioning during the week prior to the assessment.

In addition to reporting functional levels for individual domains, we calculated an overall disability score for each assessment. The overall disability scores were calculated as the sum of the level code for each of the 10 domains. The scale for overall disability scores is defined such that the minimum score is 10 (no disability on any domain) and the maximum score is 41 (maximum disability on all 10 domains).