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National Testing of the Nursing-Kids Intensity of Care Survey for Pediatric Long-term Care

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ABSTRACT

Purpose: The purpose of this study is to test the Nursing–Kids Intensity of Care, a measure of the intensity of nursing care needs, defined as the quantity and type of direct and indirect care activities performed by caregivers in a national sample.
Design and Methods: A 40-item tool previously tested in a small sample was psychometrically tested on a sample of 116 children with complex medical conditions by 33 nurse raters across 11 pediatric sites.
Results: The Nursing-Kids Intensity of Care tool demonstrated components of usability, feasibility, inter-rater, test-retest and internal consistency reliability and construct validity in the national study sample.
Conclusions: Additional testing to further establish psychometric sufficiency and expanded use to quantify the intensity of nursing care needs of children with complex medical conditions in pediatric long-term care settings is recommended.
Practice Implications: This novel measure could assist the nursing administrators, educators and staff of pediatric long-term care facilities assess the intensity of care needs of their residents.

Purpose

The number of children with chronic, complex medical conditions (CMC) has increased substantially over the past decade due to medical advances and increased survival (Hall, 2011). In the United States (US), there are an estimated 11 million children with special needs of whom as many as 29,000 reside in a pediatric long-term care facility (Caicedo, 2015; Cohen et al., 2011; Friedman & Kalichman, 2014; Hall, 2011). There are an estimated 100 pediatric long term care facilities in the U.S. (Larson, Cohen, Murray, & Saiman, 2014). The care needs of these children are distinct and dependent on the nature of each child's physical, functional, and developmental status and need for invasive, supportive or assistive devices and care (Cohen et al., 2011; Friedman & Kalichman, 2014). For example, assistive orthotic devices, frequent respiratory suctioning, gastro-enteral feedings, behavioral therapy, or palliative care may be needed. Underlying medical diagnoses of children with CMC may include cystic fibrosis, oncologic diseases, congenital anomalies, multi-system disorders and other conditions that determine these special needs (Cohen et al., 2011; Friedman & Kalichman, 2014). Consequently, planning and providing sufficient care services and appropriate human and material resources are challenging and dependent on many factors, including the intensity of each child's care needs. Nursing intensity was defined as the direct and indirect patient care activities performed by caregivers and included factors that had an impact on the level of work required to perform those activities.

Unfortunately, nursing needs of the children with CMC are not well described, inconsistent definitions are used, and have been measured with tools designed for adults (Navarra et al., 2016). The development and testing of a measure to help quantify the characteristics and intensity of nursing care needs is an important precursor to care planning and appropriate allocation of resources. The Nursing-Kids Intensity of Care Survey (N-KICS) was designed to begin to address this gap and assess intensity of nursing care for pediatric residents of long-term care (LTC) facilities with CMC and its initial development, testing and use were recently reported (Navarra et al., 2016). In brief, in an iterative process pilot testing and item identification was performed followed by field testing and data collection at three sites. Results of testing the N-KICS at three pediatric LTC facilities confirmed an acceptable standard

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for limited reliability and validity and feasibility by interrater reliability and face validity when used for clinical and research purposes.

However, additional testing of the N-KICS with larger, varied samples was needed and a logical next step to confirm generalizability and determine whether expanded use is warranted and ascertain if the tool is useable and feasible for widespread clinical use. Therefore, the primary aim of this study was to assess components of validity and reliability of the N-KICS for children with CMC in a national sample of pediatric LTC settings and the secondary aim was to test the usability and feasibility of the instrument.

Methods and Procedures

Study Design and Setting

Testing of the N-KICS was conducted at clinical affiliates of the Pediatric Complex Care Association (PCCA, http://pediatriccomplexcare.org) by registered nurses (RNs) and nurse managers caring for children with CMC in pediatric LTC facilities. Facilities met the following criteria: minimum of 25 licensed beds, provision of care to children requiring long-term care (average stay of at least 2–3 months), willingness to collaborate, and commitment to have data collected by RNs who worked in a pediatric LTC facility for a minimum of one year. Recruitment of clinical sites occurred during the Annual PCCA Conference (2014) using focus group meetings to describe the nature and purpose of this study to potential participants. The annual PCCA educational conference includes presentations on evidence based practices, research, innovative programs, services and practices to improve care for the pediatric complex care population. Attendees include nurses, administrators, physicians, social workers, educators, and occupational, speech and physical therapists. Additionally, flyers describing the study were distributed during the PCAA meeting to recruit sites not participating in focus groups. PCCA attendees provided contact information to the research team if they were interested in volunteering to test the N-KICS tool. Word-of-mouth also yielded additional participants who contacted the study team after learning of the study through their personal and professional networks, including the PCCA's research committee. We sought to recruit a convenience sample for this exploratory study of 10–15 sites, or 10–15% of an estimated 100 such facilities in the US.

In each facility, the N-KICS tool was used by two nurse clinicians to score patient records and one nurse manager to provide a subjective rating. Inclusion criteria for the two nurse clinicians per site were RN staff members who provided direct clinical care to pediatric patients with CMC who had similar education (diploma, baccalaureate, masters) and duration of work experience (<5 years, 5–10 years, or >10 years).

Medical records selected to be scored by N-KICS included pediatric residents 21 years of age or younger with an expected length of stay in the pediatric LTC facility for ≥60 days and had not experienced a significant change in condition over the last 30 days. The sample size of pediatric residents at each site was determined using the following criteria: facilities with ≤100 beds included a sample of at least 10 residents and facilities with >100 beds sampled 10% of their total resident population. These criteria were chosen as the tool was designed to measure ongoing intensity representative of nursing care needs over the previous 30 days, rather than acute changes in care needs, in this long-term care population. Sites were instructed to randomly select records for review after establishing the record met inclusion criteria. Demographic information of children was not collected from medical records.

N-KICS Measures

Nursing intensity was defined as the direct and indirect care activities (such as administering medications, performing wound care and providing family education, coordination of services, respectively), performed by caregivers and included factors that had an impact on the level of work required to perform those activities. The theorized dimensions of nursing intensity included: severity of illness, complexity of care, patient dependency and time needed to provide care. The initial development and pilot testing of the tool has been described elsewhere (Navarra et al., 2016). Briefly, N-KICS is a 40 item pen and paper tool that asks nurses to select the number (range 1 through 4) best representing a pediatric resident's care needs during the past 30 days. Definitions for each care need and corresponding score values (including writing in "not applicable") were provided on the tool. The possible range follows content mapping and content expert review in which items were assigned different ranges; by example vital signs is scored 2–4, whereas escort for school attendance is scored 1–4 and stoma care is scored as 1 or 2, to enable quantification of unequal intensity (*Appendix* Nursing-Kids Intensity of Care Survey (N-KICS) Tool). For all items, higher scores suggest increased nursing care needs; the possible range of the composite score was 19–104. The time to complete each evaluation was estimated to be 15 to 20 min. In prior testing this tool demonstrated inter-rater reliability (Pearson's correlation coefficients ≥0.85), face, construct and content validity by content mapping, expert panel and statistical significant relationships between subjective and objective ratings ($p < 0.05$).

Data Collection and Procedures

The Institutional Review Board of Columbia University Medical Center approved this study. After identification of participating sites and completing any facility specific institutional review board approvals, the participants received one-on-one and small group training via teleconferences that included individualized sampling strategy clarification for sites. A tutorial for scoring the N-KICS tool, study logistics and data management was also provided. Participants reached 100% scoring reliability through training with the principal investigator using examples cases prior to use in the field. To characterize the study sites and participants each site completed an information sheet that included facility size; geographic location; and nurse clinicians' education and duration of experience in pediatric LTC.

The nurse raters were instructed to select the medical records as follows. To assure that there is no bias in which children are scored, we requested they be selected by sampling from an alphabetized list or by a list of their sequential medical record numbers. For example, if they needed to score 10 children and have 100 beds, select every 10th child from the list.

At each site, two nurse clinicians independently used N-KICS to assess the care needs of the same children. Each child's care needs were assessed twice by each nurse, with an approximate one-week interval between assessments. To establish translational construct validity, that is how well the construct is translated by face and content validity, the nurse manager also independently rated the intensity of care needs of the children (once) by using the N-KICS tool and subjectively categorizing each child's care needs into one of three groups: low, average, or high intensity of care needs (DeVon et al., 2007). All these data were collected between February and July of 2015.

In addition to the field testing, a follow up 1.5 h interactive session was conducted with conference participants during the PCCA Annual Conference in November 2015 to ascertain their perceptions on ease of use; applicability to them; duration to complete; and intent to use. Conference participants were provided with information on the study and informed if they choose to participate that would indicate consent and their information would be included as additional study data. To simulate the use of N-KICS for medical record review two case study vignettes were designed by two physicians trained in research and familiar with the pediatric LTC population. These case studies were pretested with the research team and following minor modifications to the case studies they were presented at PCCA and tested using the N-KICS by administrators, direct care providers and other staff from a variety of pediatric LTC, clinic, and care settings attending the session to

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