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Assessing Nursing Care Needs of Children with Complex Medical Conditions: The Nursing Kids Intensity of Care Survey (N-KICS)

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Abstract

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Background—Recent medical advances have resulted in increased survival of children with complex medical conditions (CMC), but there are no validated methods to measure their care needs.

Objectives/Methods—To design and test the Nursing-Kids Intensity of Care Survey (N-KICS) tool and describe intensity of nursing care for children with CMC.

Results—The psychometric evaluation confirmed an acceptable standard for reliability and validity and feasibility. Intensity scores were highest for nursing care related to infection control, medication administration, nutrition, diaper changes, hygiene, neurological and respiratory support, and standing program.

Conclusions—Development of a psychometrically sound measure of nursing intensity will help evaluate and plan nursing care for children with CMC.

Keywords

Instrument development; Nursing intensity; Pediatrics, complex medical conditions; Long-term care

Background

The number of children with complex medical conditions (CMC) has increased substantially over the past decade resulting in significant utilization of resources in acute inpatient and tertiary care centers (Adame, Rocha, Loudon, & Agrawal, 2011; Simon et al., 2010; Cohen et al., 2012; Jurgens et al., 2014). Although many of these children are cared for at home (Elias et al., 2012), it is estimated that there 100 pediatric long term care (LTC) facilities for children with CMC in the U.S. (Larson, Cohen, Murray, & Saiman, 2014). Nonetheless healthcare services for this population are complex and include frequent transitions across inpatient, outpatient, subspecialty and community settings with poor coordination of care, contributing to increased hospital use (Coller et al., 2014; Cohen et al., 2012). Hospitalization rates of children diagnosed with more than one complex chronic condition increased 100%, from 83 per 100,000 in 1991–1993 to 166 per 100,000 admissions during 2003–2005 (Burns et al., 2010). Additionally when comparing hospitalizations among children with and without a chronic illness during 2004–2009, the greatest cumulative increase was observed in children with two or more chronic conditions (Berry et al., 2013).

Children with CMC represent a diverse population likely to differ in service needs depending on multiple factors, including age, need for invasive or non-invasive mechanical ventilator support and other invasive therapies including feeding tubes (Benneyworth, Gebremariam, Clark, Shanley, & Davis, 2011; Peterson-Carmichael & Cheifetz, 2012). Yet severity of illness and intensity of service needs have been typically quantified using taxonomies designed for adult patients, i.e. Minimal Data Set (MDS). Inconsistencies in the operational definition of CMC have resulted in gaps in the current body of evidence describing the characteristics and needed healthcare resources for this population including intensity of nursing care. In adults, dimensions of nursing intensity include severity of illness, complexity of care, patient dependency, and the time needed to provide nursing care (Prescott et al., 1991), but these have not been described or quantified among children with

CMC in pediatric LTC facilities. These gaps extend to adolescents with special care needs as the inability to operationalize service needs during the transition process has resulted in a relative absence of models to support transfer of care from pediatric to adult healthcare providers (Betz, 2013). The ability to estimate nursing intensity for children with CMC using a psychometrically sound pediatric measure is needed to better predict allocation of nursing resources. The aims of this pilot study, therefore, were to: 1) design and test the psychometric properties of the *Nursing-Kids Intensity of Care Survey* (N-KICS) tool as a measure of nursing intensity for children with CMC in pediatric long term care, and 2) describe intensity of nursing care for a population of children with CMC using the N-KICS.

Methods

This study was part of a larger parent project, funded by the Agency for Healthcare Research and Quality (AHRQ), Keep it Clean for Kids (KICK), 1R01HS021470. This four year research study was designed to improve hand hygiene and patient safety climate in three New York area pediatric LTC residential facilities that care for children with CMC and disabilities.

Operational Definitions

Children with complex medical conditions (CMC)—Application of a uniform definition to characterize CMC is an important precursor to the development of a valid and reliable measure (Cohen et al., 2011). In this study, CMC is used to describe children with one or more diagnosed chronic conditions, severe functional limitations, distinct service needs, and substantial healthcare use (Cohen et al., 2011). More specifically within this definitional framework, chronic conditions may be diagnosed or unknown, and are associated with significant morbidity and mortality. Functional limitations are severe and often require technology assistance (i.e. wheelchair, feeding tube). Service needs are identified by the family, effect family functioning and include specialized healthcare and educational services. Projected healthcare use is high and typically involves extended hospital stays, subspecialty services with care from more than one healthcare provider (Cohen et al., 2011).

Intensity of nursing care—For this present study, intensity of nursing care is defined as the “amount of direct and indirect patient care activity required to carry out the nursing function and the factors that have an impact of the level of work required to perform that task” (Morris, et al., 2007, p. 468). Nursing care provided by and or supervised by a registered or licensed practical nurse is included in this definition for this present study.

Settings and Sample

Psychometric testing of the N-KICS and data collection was performed in three pediatric LTC facilities in New York State. All three facilities specialize in the care and treatment of children who require post-acute, rehabilitative services from birth to 21 years, Table 1.

Development and Pilot Testing of N-KICS

Following approval from the Institutional Review Boards at each facility and Columbia University Medical Center, development and psychometric testing of the N-KICS was conducted in partnership with content experts during an 18 month period (September 2012 – February 2014). Field testing with data collection proceeded psychometric evaluation and was conducted during a three month period (May 2014 – July 2014).

Literature review—The evaluation process was initiated with a comprehensive literature review of available intensity tools used for pediatric clinical and research purposes and was conducted using Medline. Search terms included were *intensity, nurse, nursing, pediatrics, measures, long term care, chronic illness, and complex medical care*. Search limits were English language in peer reviewed journals; no specific time limits were included. In this search we were not able to identify a psychometrically valid intensity measure for use in pediatric LTC facilities. However, content experts at one of the study sites identified two unpublished but relevant tools developed by pediatric nurses and designed to measure intensity of care needs. The first tool defined eight categories of patient needs including nursing care, medications, medical equipment, rehabilitation nursing, nutritional support, behavioral support, medical support, and palliative nursing care. A second tool was a worksheet containing 33 survey items in five categories of care (basic, skilled and restorative nursing care, medication administration and need for specialty care clinic visits). Neither of these clinical tools had been formally tested or implemented, but the worksheet was developed by a nursing leadership committee which had completed some preliminary testing. Since it was more current and less subjective, we adapted that tool for subsequent testing.

Psychometric testing—There were three recursive phases of psychometric evaluation leading to the development of the N-KICS (Figure 1) including testing of two earlier versions of an intensity measure (intensity worksheet, KICS). Reliability and validity, feasibility and acceptability were assessed during these phases equivalent to 18 months of testing. Statistical analyses were performed using SPSS 19.0 (SPSS Inc., Chicago, IL) with the level of significance set at $p < 0.05$. Descriptive statistics were computed for intensity scores and bivariate analyses were used to compare scores between nurse raters.

Phase I – Psychometric evaluation of the Intensity Worksheet: Initial psychometric testing was completed at Site A. Face validity included a cursory review of the measure by the research team. Three experts specializing in pediatric LTC judged the appropriateness of survey items to assess content validity. Construct validity was examined using content mapping to examine and compare the broad nursing care categories on the intensity worksheet with more specific clinical and psychosocial levels of care (e.g., nutrition, hydration, pain management). Inter-rater reliability testing was conducted by comparing intensity scores between two pediatric nurses with comparable education using data from the medical records of seven residents. Bivariate analyses using Spearman's rank correlation were computed and the level of significance was set to 0.05.

Results of face validity showed that the intensity worksheet was not easily understood by untrained judges, and content analysis confirmed that many of the survey items were repetitive across categories of care. Additionally, revisions to the intensity worksheet were recommended by the team of experts because some survey items did not reflect current care needs. Modifications to scoring and terminology on many items were also suggested to generate a measure consistent with the current healthcare environment. Although there were high correlations between raters for composite intensity scores and sub-categories of skilled and restorative nursing care, no statistically significant correlation was observed between raters for sub-categories of basic nursing care, medication administration, and specialty care clinic visits outside the facility. Based on the content mapping there were also inconsistencies between conceptual and operational definitions for these same subcategories (Navarra, Mosiello, Schneider, & Larson, 2013). Hence, this psychometric testing demonstrated unacceptable levels of validity and reliability.

Recommended changes to the intensity worksheet made by the content experts were integrated and redundant survey items were removed. The five general categories of care in the intensity worksheet were expanded. After review and approval of the revised measure by content experts, the intensity worksheet was renamed to the *Kids Intensity of Care Survey* (KICS) tool and included 35 items representing the physical and psychosocial needs of children with CMC. For each item on the survey, nurses select the number (range 1 through 4) that most accurately represents the care needs of the child during the previous 30 days. A description of the criteria for each numeric rating of survey items and a 'not applicable' option were provided with higher scores such as a 3 or 4 indicative of higher levels of care intensity for the survey item. At the completion of phase 3, pilot testing of the KICS tool was initiated at Site A and then expanded to the two additional long term care facilities, Sites B and C.

Phase II – Psychometric evaluation of the Kids Intensity of Care Survey (KICS):

Psychometric evaluation of the KICS included face validity review by three untrained judges to assess whether the survey seemed to measure intensity of care needs. Then an expert panel of three registered nurses specializing in pediatric LTC and one nurse epidemiologist re-examined content validity, appropriateness and comprehensiveness of the revised survey items. Additionally, a brief survey was administered to two nurse raters at Site B to evaluate the utility of the KICS. The survey also included a five point Likert scale to quantify the relevance, time to completion and comparison of the KICS with an in-house data collection measure.

Inter-rater reliability testing using Pearson's correlation coefficients was performed by comparing completed composite KICS scores between pediatric nurses. Medical records of a convenience sample of 19 pediatric residents across the three clinical LTC facilities were used for the analysis, and 11 registered nurses participated in the inter-rater reliability testing. Two registered nurses from Sites A and B independently completed the KICS on seven and six pediatric residents, respectively. At Site C, six registered nurses from three different medical units and the nurse administrator independently extracted data from the same six medical records. Nurse raters at Site A were master's degree prepared with 25 years clinical experience. Nurses at Site B had Associate and Bachelor degrees with six and

23 years of clinical experience, respectively. At Site C, testing was completed by one Master's prepared nurse administrator with > 20 years' experience and six other registered nurses with various levels of education and clinical training, ranging from 5–15 years. Nurses participating in the psychometric testing were first given a brief introduction regarding the purpose and nature of the testing.

Face validity performed by the panel of non-experts confirmed that the KICS was easily understood, directions were clear to the reader, and that the attribute being measured appeared to be intensity of nursing care. Evaluation by content experts confirmed that the KICS was feasible for use in clinical practice and representative of care needs for children with CMC currently residing in a pediatric LTC facility. Based on the brief survey administered to evaluate the utility of the KICS at Site B, relevance and time to completion were rated as very good to excellent.

Results from the inter-rater reliability testing including the medical records of 19 children ($M=7.7$ years; $SD=1.7$ years) demonstrated a statistically significant correlation between the composite scores of nurse raters at all three sites. Pearson's correlation coefficients were uniformly 0.85.

Phase III – Psychometric evaluation of the Nursing-Kids Intensity of Care Survey (N-KICS): A series of focused discussions were conducted with content experts at Site C to review results of the pilot testing and to also offer an opportunity for the study team to gain additional feedback on categories of care, scoring, relevance, and wording. Feedback received resulted in additional modifications and included the following: 1) replacing greater than or less than symbols with words to describe frequency of care, 2) inclusion of condom catheter under elimination with criterion for scoring as a category 2 and 3) expansion of the measure to include five additional categories, namely weight, pulse oximetry, standing and positioning therapy and stoma care of the gastrostomy (GT) and jejunostomy (JT) tube sites. Criteria for scoring the additional categories were offered by content experts and included in the revisions.

The revised KICS was then re-examined for validity using a *Content Validity Index* developed by the study team and testing was completed at Site C. Six nurse managers participated and were asked to rate each survey item for its relevance to represent *intensity of nursing care needs for pediatric patients with chronic illness* in a skilled nursing facility. Each discrete survey item was ranked on a scale of 0 – 4 using the following criteria: 0=wording is unclear and unable to evaluate survey item, 1=not relevant to care needs, 2=somewhat relevant to care needs, 3=quite relevant to care needs, 4=very relevant to care needs. Descriptive statistics were computed and scoring of individual survey items reviewed by the study team. The mean composite score was 3.53 and a high level of validity was confirmed. There were no scores of 0 or 1 for any of the individual survey items.

The next phase of evaluation was conducted to examine construct validity of KICS. Subjective intensity ratings provided by nurse managers were compared with composite scores computed by nurses providing direct care. A convenience sample of residents receiving in-patient care at Site C (N=93) were included and comprised pediatric residents

from the nursery (n=23), toddler (n=25) and two school age units with stable (n= 21) and higher acuity (n=24) children and young adults. Each resident was independently scored once by the nurse manager of the unit and the primary care nurse providing care for the day, and this included either a registered or licensed practical nurse. Nurse managers' were instructed to provide a subjective rating of intensity of nursing care as low, standard, or high and coded as 1, 2 or 3, respectively by the study team. Nurses providing direct care were blinded to the subjective rating of the nurse manager and independently scored the patient, and the study team computed the composite KICS score.

Descriptive statistics were computed for intensity scores and bivariate analyses using McNemar's Test were used to compare scores between nurse raters. The mean composite score of the sample was 53.0 (SD=13.4) with a range of 19 to 104. Composite KICS scores were dichotomized to define intensity as high or low/standard using the median score of the sample as a cutoff point (51/<51). Subjective ratings were similarly dichotomized to high or low/standard by collapsing subjective ratings of low and standard into one intensity category. Results of the bivariate analyses showed a statistically significant association between subjective ratings and composite scores, (McNemar's Test = 4.76, p = 0.029), thereby confirming construct validity.

Prior to implementing the measure for data collection and field testing at Site C, the title of *KICS* was modified to *Nursing-Kids Intensity of Care Survey* (N-KICS). The rationale for this change was to clarify that the intensity of care being assessed was direct and indirect nursing care and this decision was made in association with pediatric LTC content experts and administrative staff. Hence, the process leading to the current version of the N-KICS included extensive psychometric evaluation aligned with a coherent partnership involving administrative staff at each of the study sites.

Summary - Pilot Phase

At the completion of the pilot phase in February 2014, the N-KICS comprises a 40 item survey tool designed to measure intensity of nursing care for children with CMC in pediatric LTC facilities (See Appendix I for the final N-KICS tool). For each survey item, nurses are asked to select the number (range 1 through 4) best representing intensity of nursing care needs during the past 30 days. A score of 1 indicates the lowest possible level of care intensity and a score of 4 indicates the highest level. If the item has not applied to the child during the past 30 days, N/A (not applicable) is added to the scoring column. Possible range of composite score is 19–104, higher scores suggesting increased nursing care needs. It is important to note that score range will vary based on age, medical complexity and related nursing needs. The N-KICS meets a minimal standard for reliability and validity, is feasible for use in clinical practice, and is representative of care needs for children with CMC currently residing in a pediatric LTC facility. Average time to completion is approximately 10 minutes per pediatric resident, depending upon the comprehensiveness of the medical record, acuity level of the child, and length of stay in the facility.

Field Testing and Data Collection

Field testing of N-KICS was implemented at Site C in March 2014 to allow for staff and managers to gain familiarity with the tool, ask questions and receive training on scoring and use, Table 2. Nurse managers from each of the four clinical units were trained on the use of the N-KICS by the chief nursing officer (CNO); nurses providing direct care were trained by the nurse managers. Data collection for clinical and research purposes with the N-KICS was completed during a three month period (May 2014 -July 2014). In each of the four clinical units, the primary care nurse providing direct care completed the N-KICS using data extracted from the resident's medical record and from physical assessment during the nursing shift. Descriptive statistics were computed for each unit's average nursing intensity composite and individual survey item score, Table 3.

N-KICS and intensity of nursing care—Based on our preliminary findings, high intensity was defined as high or low using composite N-KICS scores of ≥ 51 or <51 , respectively. High intensity for individual survey items was defined as scores ≥ 2.7 or average survey item score across clinical units.

In all four units, high intensity (scores of ≥ 2.7) were consistently observed for survey items representing nursing care related to infection control, medication administration (orally, via a gastrostomy/nasogastric tube, or inhaled), nutritional interventions, elimination (diaper changes), bathing, mouth care, management of seizures, non-invasive respiratory support, pulse oximetry monitoring, respiratory care (chest therapy), and a standing program for older children. The average N-KICS composite scores for the nursery (n=23), toddler (n=25) and two school age units with stable (n= 21) and higher acuity (n=24) children and young adults were 48.7, 47.5, 58.9, and 59.3, respectively, Table 3.

Discussion

The findings of this study make several important contributions to the current body of evidence describing the needs for children with CMC in pediatric LTC facilities. First, to the best of our knowledge, we developed and tested one of the only survey instruments designed to measure intensity of nursing care for children with CMC. The N-KICS demonstrated an acceptable standard for reliability and validity and was feasible when used for clinical and research purposes.

Our study findings help to identify many of the primary care needs for residents of pediatric LTC facilities. Although care needs among pediatric residents of LTCs facilities have not been previously described, a retrospective cohort analysis (2004–2009) including twenty-eight children's hospitals in the US was conducted to compare trends in resource use for healthy children and children with chronic health conditions (Berry et al., 2013). Resource use and growth in number of patients was highest in children with chronic conditions affecting two or more body systems. Common diagnoses among these children included cerebral palsy, complex chromosomal anomalies, major congenital heart diseases, respiratory disease (bronchiopulmonary dysplasia and respiratory anomalies) and hydrocephalus (Berry et al., 2013). These findings are congruent with other recently reported evidence describing increased numbers of hospitalized children with CMC (Burns

et al., 2010). Moreover considering that diagnoses of children with CMC typically are associated with significant developmental delay and/or physical limitations (Kuo, Cohen, Agrawal, Berry, & Casey, 2011), it is not surprising that higher intensity ratings were found for some basic care categories such as bathing, elimination (diaper changes), nutritional interventions, standing program, and mouth care.

Intensity of nursing care related to infection control scored as the highest individual survey item for two of the four units, nursery and one of the two children's unit providing care for more medically complex patients. This is not surprising considering that residents of LTC facilities are at increased risk for healthcare associated infections (HAI) (Castle, Wagner, Ferguson-Rome, Men, & Handler, 2011; Larson, Cohen, Murray, & Saiman, 2014). Specifically in children, increased acuity level and indwelling devices (e.g., urinary catheters, tracheostomies, feeding tubes) with subsequent delivery of care from multiple healthcare professionals are among the many factors associated with HAI-related morbidity and mortality (Kopel et al., 2010; Immergluck, 2007; James et al., 2007). Additionally children often remain in extended care facilities for months and sometimes years involving daily contact with other residents and caregivers (Buet et al., 2013). Yet hand hygiene in pediatric LTC facilities has been reported to range from 27.0% - 65.0%, adding to transmission risk of infectious agents (Buet et al., 2013).

Medication administration was another survey item with higher intensity ranking and may be explained by the practice of polypharmacy in this population (Schwantes & Wells O'Brien, 2014). Scores of 2 and 3 on the N-KICS for medication administration indicated the need for three to six daily medications, a commonly observed pattern in children with CMC (Feudtner et al., 2011).

Composite N-KICS scores for the nursery did not meet the numeric ranking of high nursing intensity, a composite N-KICS score 51. Moreover the intensity scores in the nursery were lower than expected when compared to toddlers and older children, likely related to the inclusion of survey items with little or no relevance to the care of infants and children 2 years (e.g., escort to school or clinic, monitoring of mobility devices or urinary catheters, and assistance with ambulation/mobility). We recommend that the operational definitions of high and low intensity among residents in pediatric LTC facilities to be interpreted with an appreciation of developmental diversity.

These data contribute to a better understanding of the healthcare needs for this population in LTC facilities. Considering that a large proportion of this population is discharged to home from acute care settings (Berry et al., 2013), with reported caregiver burden of 11–20 hours weekly (Kuo et al., 2011), future testing of the N-KICS could include evaluation of service needs for families that would be helpful for discharge planning. Among the current gaps in the literature is the need for demographic data describing the specific characteristics of children with complex chronic conditions including the types of technologies and healthcare services being used in healthcare facilities and at home (Rehm, 2013). The scarcity of valid and reliable tools to assess care needs for these children and families is a contributing factor and adds support for further testing of the N-KICS.

Psychometric and field testing was conducted during an 18- month period and our experience provides evidence for the importance of collaboration with senior administrators and active staff participation when conducting research in pediatric LTC facilities (Larson et al., 2014). Productive partnerships were initiated and maintained with staff at each of three long term care facilities, and included processes for consistent communication and shared decision making.

Limitations

Our results represent preliminary testing using the N-KICS, but additional psychometric testing with larger and varied samples is needed. Additionally, as with any data extracted from medical records, information may be inaccurate or missing.

In summary, medical advances for children with formerly fatal conditions have resulted in long-term survival of a growing population of children with CMC (Hall, 2011), and increased numbers of children with CMC accessing health care services (Berry et. al, 2013; Burns et al., 2010) . A distinguishing feature of this population is the exceptionally high care demands placed on the healthcare system, families and other care providers (Kuo et al., 2011). To our knowledge, the N-KICS is one of the first published survey instruments designed to measure intensity of nursing care needs for children with CMC, and has met a satisfactory standard for reliability and validity. The development of a measure to help quantify patient characteristics and intensity of nursing care needs is an important precursor to appropriate allocation of healthcare resources for this growing population. Delineation of nursing intensity for children and adolescents with CMC is an important component of discharge planning when transitioning from a pediatric LTC facility to the home setting. Additionally quantifying nursing needs for this cohort may potentially facilitate a more seamless transition when aging out of pediatric services, and transferring to an adult care setting. The next steps for future research include additional psychometric testing of the N-KICS with a larger and more diverse population and qualitative data collection with nurses and caregivers to learn more about patient care needs and related intensity of nursing care.

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Appendix A

Nursing-Kids Intensity of Care Survey (N-KICS)					
Patient Name _____					Date _____
Scoring Instructions:	For each item on the survey, select the number that BEST represents the care needs of the child during the past 30 days. If the item has not applied to the child during the past 30 days, please indicate N/A (not applicable) in the scoring column. Total scores will be added by the KICS study team. Thank you for your participation.				
	Definition and Score 1	Definition and Score 2	Definition and Score 3	Definition and Score 4	Score
Vital Signs		Vital Signs daily	Vital Signs 2–3 times daily	Vital Signs 4 or more times daily	
Weight	Every 3 months	Monthly	Weekly	Daily	
Observation	Child observed every 15 minutes	Child observed every 15 minutes <i>and</i> caregiver is assigned to only 3 residents	Child must remain in direct visualization of staff member at all times	Child is within arm's reach of staff member at all times	
Bathing		Assist with bathing set up	Bathing with 1 person assistance	Bathing with 2 person assistance	
Mouth Care		Assist with mouth care set up	Mouth care provided with 1 person assistance	Mouth care provided with 2 person assistance	
Functional Status - Ambulation/Mobility	1 person assistance with ambulation, transfers, and mobility 4 or less times per day	1 person assistance with ambulation, transfers, and mobility more than 4 times per day	2 person assistance with ambulation, transfers, and mobility 4 or less times per day	2 person assistance with ambulation, transfers, and mobility more than 4 times per day	
Escort for School Attendance	Escort 1–2 days per week	Escort 3 days per week	Escort 4 days per week	Escort 5 days per week	
Escort for Clinic Visits		Once weekly or less	2 times per week	3 or more times per week	
Nutritional Support with meals		Assist with feeding set up only	Resident fed with 1 person assistance	Resident fed with 2 person assistance	
Nutritional Support with bottle feeds			Bottle feeding provided every 4 hours or less frequently (i.e. q6h or 8h)	Bottle feeding provided more frequently than every 4 hours (i.e. q 3 or q 2h)	

	Definition and Score 1	Definition and Score 2	Definition and Score 3	Definition and Score 4	Score
Nutritional Interventions			Initiation and maintenance of continuous enteral feed	Initiation and observation of bolus enteral feed (GT or NG) OR Initiation and maintenance of total parenteral nutrition from central line catheter	
Intake and Output		Monitoring of Intake and output	Monitoring of Intake and output with oral/enteral fluid replacement	Monitoring of Intake and output with fluid replacement via intravenous/central line catheter	
Elimination – diapers			Diapers changes every 4 hours or less frequently (i.e. q6h or 8h)	Diaper changes more frequently than every 4 hours (i.e. q 3 or q 2h)	

	Definition and Score 1	Definition and Score 2	Definition and Score 3	Definition and Score 4	Score
Elimination – urinary catheter		Condom catheter	Indwelling urinary catheter	Intermittent urinary catheterization one or more times/day	
Stoma care (GT/JT- Gastrostomy/Jejunostomy)	Routine care of site once daily	Care of site needed more frequently than once daily			
Ostomy Care (<i>check stoma skin condition, fecal matter, adherence of pouch</i>)			Ostomy care twice daily	Ostomy Care two or more times per day with 1 person assistance	
Pulse Oximetry monitoring			Intermittent monitoring	Continuous monitoring	
Respiratory Support-Non-invasive: CPAP, BIPAP, Q2 therapy			Non-invasive support 12 hours or less daily	Non-invasive support more than 12 hours daily	
Respiratory Support-Invasive Ventilator with endotracheal tube or tracheotomy				Invasive ventilator support	

	Definition and Score 1	Definition and Score 2	Definition and Score 3	Definition and Score 4	Score
Respiratory Care – Suctioning (oral, nasal and orotrachea)	Suctioning 1–2 times/day	Suctioning 3–4 times/day	Suctioning 5–8 times/day	Suctioning more than 8 times/day	
Respiratory – Trachea Care		Trachea care once daily	Trachea care twice daily	Trachea care twice daily or more frequently with 1 person assistance	
Respiratory Care –Chest therapy			Chest pulmonary therapy with ABI machine every 4 hours or less frequently (i.e. q6h)	Chest pulmonary therapy with ABI machine more frequently than every 4 hours (i.e. q 2 h)	
Neurologic – Seizure Disorder			1 or more seizures during past 30 days with NO change in therapy	1 or more seizures during past 30 days with change in therapy	
Infection Control				Droplet and or contact isolation	
Pain Management			Pain assessment and intervention every 4 hours or less frequently (i.e. q6h)	Pain assessment and intervention more frequently than every 4 hours (i.e. q 2 h)	
Family/Resident Education	Education 2–3 times per month	Education once weekly	Education 2 to 4 times weekly	Education 5 to 7 times weekly	

	Definition and Score 1	Definition and Score 2	Definition and Score 3	Definition and Score 4	Score
Medications (given PO, GT, NG)	1 – 2 meds per day	3 – 4 meds per day	5–6 meds per day	More than 6 meds per day	
Medications (given via IV/central line)	1 med per day	2 meds per day	3 meds per day	4 or more meds per day	
Medications - inhaled	Nebulizer treatments 1–2 times/day OR MDI every 12–24 hours	Nebulizer treatments 3–4 times/day OR MDI every 6–8 hours	Nebulizer treatments 5–8 times/day	Nebulizer treatments more than 8 times/day	
Mobility Devices	Orthotics - 1 device	Orthotics - 2 devices	Orthotics - 3 devices	Orthotics – 4 or more devices	
Standing Program (older children)		1 time weekly	3 times weekly	5 times weekly	
Positioning Therapy (infants)			Once daily	Twice daily	
Skin Care – Pressure Ulcers	Wound care for Stage 1 pressure ulcer	Wound care for Stage 2 pressure ulcer	Wound care for Stage 3 pressure ulcer	Wound care for Stage 4 pressure ulcer	

	Definition and Score 1	Definition and Score 2	Definition and Score 3	Definition and Score 4	Score
Diabetes/Glucose Monitoring				Glucose monitoring 4 or more times daily	
Hearing, Speech & Vision		Child with one limitation	Child with two limitations	Child with three limitations	
Behavior				Exhibits physically aggressive behavior toward self or others daily - requires active supervision to prevent harm	
Palliative Support		Chronic illness with progression - may include residents with DNR and/or DNI orders	Terminal illness, anticipated death within 6 months	End-stage terminal illness, anticipated death within 2 weeks	
TOTAL SCORE					

Comments: Please add any comments and or suggested changes/additions. Thank you!

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Highlights

- The N-KICS is designed to measure intensity of nursing care for children with CMC.
- Psychometric testing of N-KICS confirmed acceptable reliability and validity.
- Intensity scores were highest for N-KICS survey items related to primary nursing care.
- Infection control is an important component of nursing intensity.

Figure 1.
Flowchart illustrating process leading to development of the Nursing - Kids Intensity of Care Survey (N-KICS)

Table 1

Characteristics of participating study sites

Study Site	Site A	Site B	Site C
Number of beds	54	137	97 ^b
Number of children's rooms	14	63	52
Number of classrooms	5	14	4
Length of stay (mean days)	1022	477	243
Length of stay (range)	7 days – 10 years	1 day – 20 years	1 day – 21 years
Age range of children	birth - 20 years	2 months – 14 years	12 days - 27 years
Children with: (%)			
Tracheostomy	30.0	51.0	39.0
Central venous catheter	2.0	0	9.0
Feeding tubes ^a	79.0	85.0	85.0
Ventilator dependent	7.0	12.0	0
Admissions per month	2.6	6.9	9.6
Total Nursing Staff^c			
Nurse Practitioners	2	4	5
Registered Nurses	33	98	94
Licensed Practical Nurse	3	15	12
Nursing Assistants	34	59	118

Note. Categories are not mutually exclusive and children may be represented in more than one category

^aNGT=nasogastric tube; GT=gastrostomy tube; JT=jejunostomy tube; GJT=gastrostomy-jejunostomy tube.

^bIncludes 2 respite beds

^cNumbers do not include per diem nursing staff

Table 2

Characteristics of clinical units at Site C

Clinical Unit	Nursery	Toddler	Children's A	Children's B
# Beds	25	24	24	24
Staffing (n)				
Physicians	1	1	1	1
Nurse Practitioners	1	1		
Registered Nurses	5	3 – 5	3 – 5	4
Licensed Practical Nurse	----	1 – 2	1 – 2	
Nursing Assistants	4–5	5	4 – 5	4 – 5
# of child life rooms	1	1	1	1
Age of children (range)	1 month - 2 years	2 years - 6 years	5 y ears - 21years	5 years - 27 years
Children with: n (%)				
<i>Tracheostomy</i>	8 (32.0)	8 (33.0)	11 (46.0)	11 (46.0)
<i>Central venous catheter</i>	3 (12.0)	4 (17.0)	0 (0.0)	2 (8.0)
<i>Feeding tubes (NGT, GT, JT GJT)</i>	21 (84.0)	21 (88.0)	22 (92.0)	18 (75.0)

Note. Each unit is equipped with a child life room. Classrooms for education of residents are located on a separate unit.

Table 3

Summary of N-KICS' survey item and composite scores at Site C (N=93)

Clinical Unit	Nursery (n=23)	Toddler (n=25)	School age A (n=24)	School age B (n=21)
KICS Discreet Survey Items (possible score range 1- 4)	<i>M</i>	<i>M</i>	<i>M</i>	<i>M</i>
Vital Signs	2.36	1.94	2.36	2.06
Weight	3.47	3.24	2.56	2.51
Observation	1.28	1.05	1.28	1.14
Bathing	2.96	3.07	3.07	3.30
Mouth care	2.89	2.99	2.91	2.88
Functional Status - Ambulation/Mobility	1.73	1.69	2.42	2.73
Escort - School	N/A	N/A	3.95	3.95
Escort - Clinic	2.02	1.98	1.97	1.90
Nutritional Support with Meals	2.81	2.76	2.89	2.60
Nutritional Support with Bottle Feeds	3.48	3.33	N/A	N/A
Nutritional Interventions	3.91	3.56	3.76	3.61
Intake and Output	2.47	2.40	2.04	2.68
Elimination - Diaper	3.86	3.73	3.80	3.82
Elimination - Urinary Catheter	N/A	N/A	N/A	2.00
Stoma Care	1.45	1.29	1.42	1.38
Ostomy Care	N/A	N/A	N/A	3.50
Pulse Oximetry Monitoring	3.73	3.47	3.63	3.75
Respiratory Support (non-invasive)	3.94	3.40	3.56	3.59
Respiratory Support - invasive	2.36	1.94	2.36	2.06
Respiratory Care - Suctioning	3.51	2.62	3.29	3.25
Respiratory Care - Trachea Care	2.53	2.20	2.45	3.25
Respiratory Care - Chest Therapy	3.36	3.07	3.03	3.08
Neurologic - Seizure Disorder	3.75	N/A	3.03	3.09
Infection Control	4.00	3.20	3.85	4.00
Pain Management	3.16	2.69	2.98	3.11
Family/Resident Education	2.13	2.06	1.55	2.59
Medications - PO/GT/NG	3.05	3.21	3.65	3.76
Medications - Central Line/IV	N/A	N/A	N/A	N/A
Medications - inhaled	3.47	3.24	2.56	2.51
Mobility Devices	1.56	1.23	2.39	2.28
Standing Program (older children)	4.00	2.96	3.94	3.87
Positioning Therapy (infants)	3.42	3.75	N/A	3.17
Skin Care - Pressure Ulcer	N/A	N/A	N/A	N/A
Skin Care - Cast Care	N/A	N/A	N/A	N/A

Clinical Unit	Nursery (n=23)	Toddler (n=25)	School age A (n=24)	School age B (n=21)
Skin Care - Burns	N/A	N/A	N/A	N/A
Laboratory Collection and monitoring	1.18	1.12	1.02	1.11
Diabetes Glucose Monitoring	N/A	N/A	N/A	N/A
Hearing, Speech & Vision	2.52	2.13	2.88	2.48
Behavior	1.28	1.05	1.28	1.14
Palliative Care	1.91	1.77	2.00	2.00
KICS Composite Scores <i>(possible score range 3–140)</i>	48.7	47.5	59.3	58.9

Note. *M*=mean. N/A=not applicable to patients at time of testing on clinical unit Data collected May – July 2014

School age unit A with higher acuity patients. School age unit B with more stable patients.