Translational Research: The Multidimensional Scope of Pediatric Nursing

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BY NATURE, THE scope of pediatric nursing is broad and includes multiple dimensions with respect to developmental age group of children and adolescents, and a focus on promoting health, growth and development; care and management of pediatric acute and chronic conditions and disabilities in hospital, home, and the community; as well as parenting and family functioning. Additionally, children and adolescents and their families reflect diverse characteristics that vary by culture, race and ethnicity, geographic region, and country. Caring for children and working with parents and families provide pediatric nurses a broad range of intervention points for improving the quality of child health outcomes. Nursing research generates evidence to improves nursing practice (Polit & Beck, 2012), and evidence-based practice improves health outcomes (Melnyk & Fineout-Overholt, 2014), ultimately resulting in higher quality of pediatric nursing care and the health of children, adolescents, and their families. In this way, translational research and evidence-based practice provide the opportunity to improve the quality of health outcomes.

In this issue of the Journal of Pediatric Nursing, 23 articles illustrate the multidimensional scope of pediatric nursing practice through the translation of evidence to improve the care of children, adolescents, and their families obtained through a wide variety of methods:

- A secondary analysis of five cases of infants with CHARGE syndrome in Sweden was conducted using the medical record database from the National Resource Center for Deafblindness to determine health care consumption during the first year of life (Carlsson, 2015). Health care resource utilization by five cases of infants diagnosed with CHARGE syndrome reflected complex health care needs with multiple health care contacts. During the first year of life, all infants were hospitalized from 26 to 230 days, underwent 10 to 34 different diagnostic procedures, and were prescribed 10 to 28 different medications.

- A phenomenological approach with a hermeneutic orientation was employed to explore the feelings of mothers (N = 16) of children (6 months to 17 years of age) with a rare disease, Alagille syndrome, and the use of online health communication to manage their feelings of chronic sorrow (Glenn, 2015). However, only half of these mothers experienced chronic sorrow, while the remainder experienced “unpleasant feelings” of fright, anger or being overwhelmed. Four essential themes reflected these mothers’ psychosocial reactions and lived experiences associated with having a child with a rare disease: (a) connectedness, (b) online triggers, (c) empowerment, and (d) seasons of online communication.

- A descriptive, qualitative study of school-age children (N = 32; 8 to 13 years of age) with various chronic conditions was conducted to describe children’s perspectives and understanding of chronic condition management (non-categorical approach) using the family management style framework (FMSF) (Beacham & Deatrick, 2015). Additionally, parents provided demographic and survey information about the child’s chronic condition. Three dimensions from the FMSF explained the children’s perspectives of their chronic condition.
management supporting the applicability of the FMSF framework: (a) definition of the situation; (b) management behaviors; and (c) perceived consequences.

- Best measurement practices with respect to biophysical and fitness variables among overweight or obese, transition-aged youth and young adults with intellectual disabilities (N = 30, 18 to 35 years) are presented based on a community-based health promotion intervention research study conducted 1 year (Cardell, Clarke, & Pett, 2015). Evaluation of the successes and unique challenges of measuring biophysical and fitness variables are reported with suggestions for adapting measures to improve the accuracy of measurement of health promotion variables in transition-aged youth with intellectual disabilities. Thus, health promotion research can be designed to address these measurement challenges, resulting in research that is more inclusive with better access to research participation by people with disabilities.

- A descriptive qualitative study was conducted to explore the perceived met and unmet palliative care needs of life-limiting and life-threatening conditions in children and young adults (birth to 25 years of age), and their families (N = 59 adults from 51 families) in the UK (Coad et al., 2015). From a combination of individual interviews and focus groups, two categories of palliative care needs of children and young adults with life-limiting and life-threatening conditions were identified related to family perspectives, services, professional staff issues, and communication issues as: (a) met needs; and (b) unmet needs. Unmet needs were identified as the need for broader financial, social, and emotional support with more responsive healthcare specialists.

- A secondary analysis of free-text comments from children and adolescents (7 to 15 years of age), with type 1 diabetes, and their caregivers (N = 693) who participated in the DEPICTED study, a cluster randomized clinical trial to determine the effectiveness of a training program for pediatric diabetes teams in the UK (Lowes et al., 2015). Although the intervention training program had no statistically significant effect on glycemic control, the perceptions of children, adolescents, and their caregivers were obtained through free-text comments at baseline (n = 523 total comments from caregivers, n = 448 total comments from children) and at 1-year follow-up baseline (n = 271 total comments from caregivers, n = 228 total comments from children). Four key themes were identified and categorized as follows: (a) attending clinic, (b) communication skills, (c) emotional responses to type 1 diabetes, and (d) emotional support in clinic.

- A review of the qualitative research literature focused on children, adolescents, and young adults (3 to 24 years of age), and their experiences living with chronic conditions of diabetes, asthma or epilepsy were conducted with 18 studies that met the inclusion criteria (Lambert & Kcogh, 2015). Three common themes were identified that described their experiences of "feeling different": (a) participation in everyday life restrictions and adjustments, (b) treatment regimens—constraining and enabling, and (c) communication—disclosure, stigma, and support.

- An ethnographic study was conducted with children, adolescents, and young adults with learning disability and their parents, as well as the hospital staff to explore their needs during hospitalization in the UK (Oulton, Sell, Kerry, & Gibson, 2015). Only the perceptions of hospital staff (N = 27) are presented in this report. Hospital staff identified six factors that are important when providing an individualized approach to care for children, adolescents, and young adults with learning disability during hospitalization: (a) gaining appropriate knowledge and experience; (b) identifying children and young people with learning disability; (c) focusing on the “little things”; (d) creating a safe, familiar environment; (e) using appropriate resources; and (f) developing a partnership with parents.

- A critical review of the literature reporting the use of interventions employing electronic media technology to provide psychosocial support for children and adolescents (birth to 19 years of age) with long-term chronic conditions was conducted (Aldiss, Baggott, Gibson, Mobbs, & Taylor, 2015). Of the 664 studies published and retrieved over 25 years, 40 studies met the inclusion criteria; however, only 27 of the 40 studies met the quality criteria (>50% quality criteria achieved). Findings were summarized in five overarching categories: (a) knowledge; (b) psychosocial outcomes; (c) quality of life (generic or disease-specific), (d) service use (reduced number of hospital appointments); and (e) school absenteeism. However, poor methodological quality of the research evidence and the lack of involvement of children and adolescents in the development of technology contributed to uncertainty about the benefits of using supportive technology for providing psychosocial support for children and adolescents with chronic conditions.

- A review of the published literature (1995 to 2012) on perspectives of siblings of children and adolescents with chronic illness (non-categorical approach) was conducted (Knaecht, Hellmers, & Metzing, 2015). A search of the literature retrieved 238 studies that met the initial inclusion criteria; however, only a few studies solely described siblings’ experiences from their perspectives, and none of these studies met the inclusion criteria. Thus, the authors revised their methodological approach and determined that nine studies met the revised criteria for inclusion in the review. Six themes were identified that described the perspectives of siblings of children with chronic illness as follows: (a) emotional experiences, (b) somatic complaints as bodily experiences, (c) developmental experiences, (d) family life experiences, (e) everyday life experiences, and (f) experiences in the context of the siblings’ illness. It is important to note that some of the studies reported parent-proxy data that may not accurately reflect the perspectives of siblings of children and adolescents with chronic illness.

- A mixed-methods, qualitative-dominant design using a narrative life story method was employed to explore the perceptions of body image in childhood burn survivors’ and their non-injured siblings (N = 21 participants representing 13 cases of childhood burn survivors) (Lehna, 2015). Qualitative findings were reported reflecting two primary themes with respect to perceptions of body image: (a) internal perceptions of body image, including self-esteem and personality type; and (b) perceptions of body image that were external to the person, including social environment of family and community, as well as interpersonal experiences of siblings.

- A descriptive qualitative study was conducted with physicians (N = 22) of young adult patients with pediatric-onset chronic conditions to explore healthcare system practice supports and barriers to care (Szalda et al., 2015). Major practice supports or facilitators included: (a) formalizing intake processes for new patient transfers, (b) interoperable medical records and use of patient portals, and (c) leveraging care coordination infrastructure within the patient-centered medical home. Barriers to care were identified by five major themes: (a) definition of the patient’s medical team, (b) lack of appropriate medical records, (c) time constraints and administrative burden, (d) lack of training and comfort of healthcare providers and support staff in adult healthcare system, and (e) financial constraints.

- A qualitative, grounded theory study was conducted to identify best practices in parent/nurse interactions in the pediatric intensive care unit (PICU) for parents and children with complex chronic conditions (N = 19 participants, including 7 parents of different children [5 mothers and 2 fathers]; and 12 nurses) (Baird, Davies, Hinds, Baggott, & Rehm, 2015). Parents and nurses identified two types of rules in the PICU which negatively affected the family’s ability to receive care that was attentive to their needs. Two types of rules in the PICU included: (a) explicit rules or the basic rules of the unit; and (b) implicit rules, the “unspoken rules” or social norms in the hospital setting. Moreover, the PICU nurse assumed the conflicting roles of rule enforcer and facilitator of patient and family-centered care which, in turn, influenced the relationship
A concept synthesis of empirical evidence from the published literature (N = 30) was conducted to examine family-centered care and partnership-in-care models with respect to parents managing their child’s long-term chronic condition (Smith, Swallow, & Coyne, 2015). Findings suggest that although the concepts of family-centered care and partnership-in-care for children with chronic conditions are well established in the healthcare literature, implementation continues to be problematic in everyday practice.

A descriptive correlational study was conducted in two sites (Beijing, Shanghai) in China to identify predictors of family management in families of children (6 to 16 years of age) with chronic conditions (e.g., rheumatic diseases, renal disorders, endocrine conditions, and genetic diseases) (N = 399 caregivers) using the family management style (FMS) framework (Zhang, Wei, Shen, & Zhang, 2015). Chinese versions of the quantitative measures were developed and tested with acceptable psychometric data. Hierarchical regression models were statistically significant explaining 29 to 48% of the variance for all aspects of family management among families of children with chronic conditions in China, thereby supporting the FMS framework.

A longitudinal, descriptive correlational study was used to examine compassion fatigue mediated associations between stress exposure among novice pediatric nurses (N = 251) and compassion satisfaction, burnout, and job satisfaction at 3-months and 6-months (Meyer, Li, Klarsenfeld, & Gold, 2015). Findings suggest that stress exposure after 3-months of bedside pediatric nursing significantly predicted lower compassion satisfaction and more burnout in novice pediatric nurses, after controlling for pre-existing stress; compassion fatigue was found to partially mediate these associations.

An integrative review of the literature published between 1995 and 2013 was conducted to identify the tasks and communication involved in the parenting of young children (birth to 5 years of age) (Mooney-Doyle, Deatrick, & Horowitz, 2015). Of the 716 abstracts that were retrieved, 38 research articles (26 quantitative, 2 qualitative, 5 mixed-methods, and 5 integrative reviews or concept analysis articles) met the inclusion criteria and were included in the analysis. Findings suggested both task-oriented and communication-oriented themes of parenting of young children. The three task-oriented themes of parenting included: (a) tasks for parental self-efficacy and confidence; (b) hands-on work, as well as the intangible work of behavior and emotion regulation; and (c) distribution and allocation of child care work and influences on role development. Three communication-oriented themes of parenting were identified: (a) parental influence on child development and behavior through communication and interaction; (b) crying and non-verbal means of expression as powerful means of communication within the family; and (c) improvement of parenting communication through positive communication skills.

A mixed-methods, sequential, quantitative dominant (qual → QUAN) explanatory study and instrument development was conducted to determine the psychometric properties of the Chinese version of the Caregiver Burden Index (CBI) for parents of children with allergies in China (Liu, Gau, & Hung, 2015). The instrument development process included two phases: development of the CBI and validation of the instrument. In-depth interviews with mothers (N = 7) caring for children with allergies were conducted and a critical review of the literature in English and Chinese was done. Next, a panel of experts (N = 5) examined the scale for content validity with a Content Validity Index (CVI) of 0.89. Six items were excluded from the original scale, resulting in a 24-item version of the CBI. Then, a focus group of 20 parents was conducted to obtain feedback and review the content of the instrument. Validation of the CBI instrument included a field test of the measure through the conduct of a cross-sectional study with mothers (N = 97) caring for children with allergies. Psychometric evaluation of the CBI instrument included item analysis, internal consistency calculation, and factor analysis with principal axis and Varimax rotation resulting in three factors with 20-items. Thus, findings suggest that the 20-item CBI has sufficient reliability and validity to measure caregiver burden parents of children with allergies in China.

A descriptive quantitative design was employed to explore the challenges associated with breastfeeding infants with phenylketonuria (PKU) as experienced by mothers (N = 75) (Banta-Wright, Kodadek, Steiner, & Houck, 2015). Mothers responded to an Internet survey, identifying three primary categories of challenges with respect to breastfeeding: (a) common breastfeeding issues (n = 56, 78%); (b) breastfeeding and PKU (n = 49, 65%); and (c) no challenges (n = 10, 13%). Results suggest that breastfeeding issues are increased for mothers of infants with PKU primarily due to frequent phenylalanine monitoring.

A cross-sectional analysis of electronic medical encounter-level data obtained from four community pediatric clinics through the child health improvement through computer automation (CHICA) system was conducted to explore the associations among secondhand smoke exposure, parental depressive symptoms and behavioral outcomes in preschool children (N = 2,441; birth to 6 years of age) (Bauer, Anand, Carroll, & Downs, 2015). Of the 2,441 children’s records examined, 27% were exposed to secondhand smoke which was significantly associated with a diagnosis of attention deficit-hyperactivity disorder (ADHD) and/or disruptive behavior disorder (DBD) among preschool-age children. Parental depression was significantly associated with a greater likelihood of the preschooler having been prescribed psychotropic medication.

A quality improvement program designed to facilitate transition from pediatric to adult-based health care services for adolescent patients (17.5 to 18 years of age) with cystic fibrosis (CF) (N = 22) in Canada was evaluated (Gravelle, Paone, Davidson, & Chulvers, 2015). Three transition interventions were sequentally implemented and evaluated: (a) patient transition clinical pathway, (b) collaboration with adult CF clinic, and (c) measurement of transition readiness. Employing a retrospective chart review approach, the CF patient transition clinical pathway usage was conducted identifying that 73% indicators were recorded over 4 years. Collaboration with adult CF clinic included a CF pre-graduation workshop led to adolescents having a better understanding of the expectations of adult CF care as well as improved continuity of care. Transition readiness was assessed through a questionnaire resulting in 75% of adolescents with CF (n = 12) scoring greater than 75% although they needed more education about medications, filling prescriptions, and insurance. Based on this evaluation, guidelines for best practices for transition from pediatric to adult-based CF care were established and implemented.

A time-motion study was conducted over a 12-month period to determine the time needed to support the educational needs of hospitalized school-age children (N = 419) with hematologic or oncologic diagnosis with respect to coordination between healthcare and school systems (Irwin, Flum, & Mertian, 2015). Findings suggest that hospital educational liaisons spent their time, on average, participating in the following specific tasks: (a) 28% of time on consultation to patients, (b) 26% of time in preparatory work for meeting with school teams and families, (c) 17% of time traveling to and from schools, (d) 14% of time on documentation, (e) 8% of time facilitating and participating in school meetings, and (f) 7% of time facilitating traditional in-service education with school personnel and students. More time was spent with children who were diagnosed with leukemia or lymphoma than other diagnostic categories included in the sample of children with hematologic or oncologic diagnoses.

A cross-sectional, descriptive correlational study was conducted in Turkey to determine the relationship between the needs of mothers (N = 87) who have children and adolescents (7 to 18 years of age) with hearing impairment and maternal state-trait anxiety levels (Bilsin, Çuhadar, & Gök, 2015). Statistically significant positive associations were found between the mothers’ state-trait...
With the multidimensional scope of pediatric nursing, it is essential to translate research evidence into pediatric nursing practice to improve the quality of care and health outcomes for children, adolescents, and their families. As highlighted by these articles, multiple methods were employed to gain a better understanding of the health challenges faced by children, adolescents, and their families across a variety of settings and cultures throughout the world. To that end, new evidence and more effective intervention strategies translated into pediatric nursing practice facilitate advances in care and ultimately improve the health of children and their families.

References