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RESEARCH COMMENTARY DEPARTMENT

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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 for children, adolescents, and their families (Hockenberry & Wilson, 2011). With the multidimensional scope of pediatric nursing, multiple avenues of study exist for generating evidence to enhance 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 of children, adolescents, and their families on multiple dimensions (Christian, 2011, 2013a, 2013b, 2014).

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.

> *With translational research, the complex health challenges faced by children, adolescents, and their families exemplify the multidimensional scope of pediatric nursing and provide direction for interventions to improve the quality of care and health outcomes.*

- 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

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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 & Keogh, 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 (Knecht, 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 representing13 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