RESEARCH COMMENTARY DEPARTMENT

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Translational Research—The Essential Interface Between Pediatric Nurses and Parents: Advancing Pediatric Nursing Practice



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TRANSLATING RESEARCH INTO practice provides evidence for enhancing the quality of pediatric nursing care and health outcomes for children, adolescents, and their families. The fundamental nature of pediatric nursing encompasses providing care for children, with nurses interfacing with parents and families, teaching parents to provide care for their child through health and illness, and how to cope with and manage chronic illness and disability, as well as providing anticipatory guidance to promote children's health, development, and well-being. Central to pediatric nursing practice is providing direct care to children and creating partnerships with parents to promote children's health (Hockenberry & Wilson, 2011). Creating partnerships with parents is essential for improving the quality of care for children and their families through the development and testing of new intervention strategies designed to address pediatric care management issues through research and the translation of evidence to practice (Christian, 2011b). Evidence from nursing research improves practice (Polit & Beck, 2012), and evidence-based practice improves the quality of health outcomes (Melnyk & Fineout-Overholt, 2011), thereby improving the quality of care for children and their families (Hockenberry & Wilson, 2011). In this way, translational research and evidence-based practice transforms pediatric nursing practice by enhancing the quality of care and health outcomes for children, adolescents, and their families (Christian, 2011a, 2013a, 2013b).

In this issue of the *Journal* of *Pediatric Nursing*, seven articles illustrate the essential interface between parents and pediatric nursing practice in providing quality nursing care to children and their families by: (a) evaluating the behavioral effects of a home-based intervention program for low birth weight (LBW) infants with post-traumatic feeding disorder (PTFD); (b) describ-

The essential interface between pediatric nurses and parents presents an extraordinary opportunity to improve the quality of care for children and their families.

ing parents' experiences and challenges associated with an unexpected newborn diagnosis of congenital adrenal hyperplasia (CAH); (c) evaluating the effectiveness of a quality improvement (QI) gastrostomy parent education program; (d) exploring the sleep-wake experiences of mothers of children with acute lymphocytic leukemia (ALL) hospitalized for maintenance treatment; (e) exploring uncertainty in parents of children with vascular anomalies (chronic orphan-illness) who were treated at a multidisciplinary vascular anomalies clinic; (f) examining a sense of coherence in parents of adolescents with type I diabetes with respect to adolescent health, emotional and behavioral adjustment; and (g) describing the process by which perinatally-acquired HIV infection and maternal loss impacts adolescent and young adult development as they learned to integrate HIV infection into their lives. Additionally, an observational study described the characteristics of blood samples collected from pre-existing peripheral intravenous (PIV) catheters from hospitalized pediatric patients; and a classical three-round Delphi survey

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of Society of Pediatric Nurses (SPN) members identified research priorities for pediatric nursing and challenges for pediatric nursing practice to provide future direction for research and guide practice.

The articles in this issue of the *Journal of Pediatric Nursing* highlight the interface between pediatric nurses and parents providing new evidence for translation into pediatric nursing practice to improve care and health outcomes of children, adolescents, and their families:

- A nested case-control design study was conducted to evaluate the behavioral effects of a home-based intervention program for low birth weight (LBW) infants with post-traumatic feeding disorder (PTFD) (n = 21; 15 male, 6 female), as compared to a matched control group of LBW infants (n = 21) post-intervention (Wilken & Bartmann, 2014). All infants with PTFD demonstrated total food refusal and fear or stress responses to food exposure. A significantly higher number of oral aversive procedures was reported for infants with PTFD as compared to the control group (p = .001), and there were significant differences between groups for ventilation (p = .006), recurrent intubation (p = .008), and changes in nasogastric tubes (p = .001). Higher food adversity (FAS) was moderately associated with greater number of total symptoms prior to intervention (p = .004). At 6-months post-intervention, symptoms of feeding disorders (e.g., FAS, food refusal, vomiting, swallowing resistance, gagging and total number of symptoms) significantly decreased for infants with PTFD who received the intervention, suggesting marked improvement in feeding. Findings from this study demonstrate the effectiveness of a brief, intensive intervention program for infants with PTFD with food aversion in a home-based setting.
- The experiences and needs of parents (n = 6 parents from 4 families; 4 mothers and 2 fathers) of newborn infants diagnosed with congenital adrenal hyperplasia (CAH) were explored in a descriptive qualitative study of parents who participated in the newborn screening program (Boyse, Gardner, Marvicsin, & Sandberg, 2014). Retrospective semi-structured telephone interviews were conducted with parents about their experiences associated with infant diagnosis of CAH and management. Content analysis was used to analyze interview data. Parents described their experiences and the challenges associated with an unexpected newborn diagnosis of CAH in three main themes: (a) communicating health information; (b) unmet needs; and (c) social support. Thus, findings provide health care providers methods of improving how health information is communicated and how health education is delivered to parents with an unexpected newborn diagnosis of CAH.
- A quality improvement (QI) educational project designed to standardize gastrostomy education and improve pediatric nurses' knowledge and skills in preparing parent caregivers of medically-fragile children for discharge from a

- Midwestern children's hospital (Kirk, Shelley, Battles, & Latty, 2014). Using the Plan, Do, Study, Act (PDSA) process, the standardized gastrostomy parent education program was developed and pilot tested on an infant unit; while a second pilot was conducted to test the trainthe-trainer method on a unit for children with complex medical and health needs. The effectiveness of the gastrostomy parent education program was evaluated through chart review (N = 30) resulting in significantly improved documentation of gastrostomy parent education $(\chi^2 = 5.455, p = .0196)$, improved documentation of parent responses to standardized gastrostomy parent education ($\chi^2 = 6.648$, p = .0099), as well as significantly improved frequency of parent education about specific actions to take if gastrostomy tubes fall out ($\chi^2 = 3.270$, p = .039). Based on these findings, pediatric nurses employed at this children's hospital now receive the standardized gastrostomy education program during nursing orientation to improve their quality of teaching and gastrostomy care with parents at discharge.
- Sleep—wake experiences of mothers (N = 20) of children hospitalized for maintenance treatment for acute lymphocytic leukemia (ALL) were explored in a descriptive qualitative study (Neu, Matthews, & King, 2014). Two main themes were identified through thematic analysis: (a) it's a whole new cancer world; and (b) I don't remember what it's like to have sleep. Mothers' perceptions of sleep quality were interrelated with issues that they had experienced throughout the child's illness and treatment. Lack of sleep associated with ALL management persisted from the initial treatment period and was related to sleep disruptions such as caregiving for their sick child at night, frequent awakenings, vomiting, medication administration, their child's steroid-induced hunger, and worrying that intensified at night. Mothers identified a variety of strategies for coping with lack of sleep and exhaustion associated with their child's hospitalization for maintenance treatment for ALL.
- Parental uncertainty in illness was explored using participant observations of physician-parent-child interactions (n = approximately 200) combined with open-ended questions responded to by parents (n = 55) of children (11 to 17 years) with vascular anomalies who were treated at a multidisciplinary vascular anomalies clinic (classified as a chronic orphan-illness) in a large Midwestern children's hospital (Kerr & Haas, 2014). Constant comparative method was used to analyze the qualitative data revealing five key themes and types of uncertainty: (a) normalization uncertainty, (b) information uncertainty, (c) orphan-illness uncertainty, (d) parental proxy uncertainty, and (e) social stigma uncertainty. Findings suggest that parents want multiple types of information from their child's multidisciplinary health care providers to reduce their uncertainty related to management of the child's vascular anomaly (chronic orphan-illness).

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