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Research commentary column

Translational Research – Challenging Children and Their Families Throughout the World: Integrating Chronic Conditions Into Everyday Life

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Managing the demands of chronic conditions is challenging for children and their families throughout the world. Chronic conditions are stressful for children and their families and adaptation is required to integrate the demands of chronic conditions into their everyday lives (Christian, 2016a). Children and adolescents are challenged to integrate the demands of chronic conditions while meeting their developmental needs. Parents, families, and caregivers are challenged to balance the demands of their child's chronic condition on a daily basis (Christian, 1993, 2003, 2010, 2016b). When these factors are combined, the need for parents and families to balance the demands associated with chronic conditions contributes to their stress and ability to adapt, while challenging children, their parents, and families in their everyday lives (Christian, 2016a). Moreover, this challenge to adapt to chronic conditions and integrate the management of chronic conditions exists throughout the world across different cultures and societies.

Through nursing research, new evidence is generated and designed to improve the quality of nursing care and practice (Polit & Beck, 2017), as well as improve the health outcomes for children, their parents, and families (Hockenberry & Wilson, 2015; Melnyk & Fineout-Overholt, 2014). Translation of research evidence into pediatric nursing practice is essential for improving the quality of nursing care for children, their parents, and families, as well as advances in pediatric nursing practice (Christian, 2011, 2013a, 2013b, 2014a, 2014b).

In this issue of the *Journal of Pediatric Nursing*, the overwhelming majority of the articles focus on a range of chronic conditions in children and adolescents, as well as how parents, families, and caregivers manage the demands of chronic conditions and integrate the chronic condition into their everyday lives. Moreover, these articles present research focused on a broad range of chronic conditions affecting children and their families from countries throughout the world, including Canada, Denmark, Ethiopia, Iran, Israel, Italy, Mexico, Sweden, Turkey, the United Kingdom, and the United States. Additionally, five articles report studies focused on: (a) instrument development for the assessment of infant sleep safety survey; (b) a comparison of three non-invasive thermometers for temperature measurement in hospitalized children; (c) best practices to determine frequency of head-to-toe assessments in hospitalized children; (d) differences in non-interventional radiology sedation practices for children and unanticipated adverse events and type of provider; and (e) adolescent communication with parents about sexual risk-taking behavior and parental monitoring.

The articles in this issue of the *Journal of Pediatric Nursing* provide evidence for improving the management of chronic conditions for children, their parents and families, as well as advancing the pediatric nursing care of children throughout the world:

- A retrospective review of healthcare records of children with autism spectrum disorders (ASD) ($N = 385$) was conducted to determine whether or not maternal factors, perinatal or obstetrical complications, or neonatal birth characteristics were predictive of co-occurring neurodevelopmental disabilities (Zauche, Mahoney, & Higgins, 2017). The sample of children with ASD was 83% male and 18.2% born prematurely. Sixty-one percent ($n = 234$) of these children with ASD were identified as having at least one co-occurring neurodevelopmental disability, including 42% with language delay, 36% with cognitive delay, and 4% with ADHD. Mothers who experienced bleeding during pregnancy (OR: 2.233), mothers with less education (OR: 0.905), and those who were never married (OR: 1.803) were more likely to have children with ASD with at least one co-occurring neurodevelopmental disability. Although African American mothers were 7.7 times more likely to experience bleeding during pregnancy with premature birth (< 34 gestational weeks), maternal race was not found to be a significant predictor of co-occurrence of neurodevelopmental disabilities with logistic regression analysis.
- A comparative effectiveness, randomized clinical trial was conducted at 24 school-based health centers with four sites in each of six states (Arizona, Colorado, Michigan, New Mexico, New York, and North Carolina) to evaluate virtual training on obesity guidelines including motivational interviewing with and without technology decision support on healthcare providers' self-report of behavioral counseling for childhood obesity and parents' perceptions of care after training (Gance-Cleveland et al., 2017). The focus of this report is on the results of motivational interviewing training and virtual technology on healthcare provider satisfaction with training and overweight children's (5–12 years) parents' perceptions of technology-generated tailored patient education materials with surveys at three time points (baseline, immediately after training, and 6-months after training). Healthcare providers ($n = 31$) were highly satisfied with motivational interviewing training, demonstrating significant improvement in counseling proficiency ($p < 0.0007$)

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and psychological/emotional assessment ($p = 0.0004$). Parents ($n = 570$) were assigned to technology (59.5–63.4% Hispanic, T1-T3) and non-technology (46.5–66.7% non-Hispanic White, T1-T3) patient education groups and completed online surveys. Parents in the technology group reported significant improvement in healthcare provider support for healthy eating ($p = 0.04$). Thus, findings indicate that virtual training improved healthcare providers' ability to use motivational interviewing with parents to address childhood obesity and technology improved parent support for healthy eating.

- The psychometric properties of the Turkish version of the Caregiver Burden Index (CBI) were examined in a study of mothers ($N = 213$) of children (6 to 12 years) diagnosed with allergies for at least six months (Ekim, Hecan, & Oren, 2017). Internal consistency reliability was determined to be 0.85 (Cronbach's alpha) with item-total correlation ranging from 0.63 to 0.84. An exploratory factor analysis with varimax rotation was conducted to examine construct validity, resulting in three factors: constraints on personal and family life accounting for 30% of the variance, physical health complaints explaining 25.6% of the variance, and psychological distress explaining 18% of the variance. Findings were comparable to the original English version of the CBI, thus supporting that the CBI is a reliable and valid instrument to measure caregiving burden in Turkish mothers of children with allergies.
- An exploratory, mixed-methods approach was used to develop and pre-pilot test the Parent Learning Needs and Preferences Assessment Tool (PLAnT) to diagnose and support parents' learning needs in managing their child's chronic condition (Nightingale, Wirz, Cook, & Swallow, 2017). In phase I, an online survey was conducted with parents/caregivers ($n = 4$) to assess their experiences in obtaining information and learning needs in caring for their child's chronic condition, as well as the views of healthcare professionals ($n = 4$) about their role in the learning process. Following the survey, qualitative interviews were conducted with parents/caregivers ($n = 10$) and healthcare professionals ($n = 13$) to obtain their perspectives about the parents' learning needs and preferences. These survey data and interviews were used to develop and further refine the PLAnT components of the diagnostic tool. In phase II, pre-pilot evaluation of the PLAnT included administration of the tool followed by individual interviews and focus groups with parent/caregivers ($n = 13$) of children with chronic renal conditions from six children's kidney units in the UK, and interviews with healthcare professionals ($n = 9$). Findings suggest the importance of healthcare professionals identifying parents' learning needs and preferences by *asking parents directly*. Moreover, by collaborating with parents and using their self-identified learning needs and preferences as assessed by the PLAnT, this information provides a guide for supporting parents as they learn to manage their child's chronic renal condition.
- A descriptive study was used to assess the perceptions of adolescents [$N = 153$; $n = 85$ females (55.5%), $n = 68$ males (45.5%); ages 14 to 15 years] to explore parental monitoring and sexual communication for prevention of sexual risk behavior among adolescents from public high school in Monterrey, Nuevo Leon, Mexico (Davilá, Champion, Monsiváis, Tovar, & Arias, 2017). Differences in sociodemographic characteristics were explored by sexual activity, gender, and age. Of the sample of Mexican adolescents, 11.1% ($n = 17$) reported being sexually active (11.8% males; 10.6% females). Adolescents who were sexually active reported significant differences in parental monitoring, with less monitoring of older adolescents, more monitoring of females than males, and less monitoring of adolescents who were sexually active. Moreover, sexually active adolescents received more information from their parents about prevention of sexually transmitted infections (STI) and HPV, but significant gender differences were found. Fewer sexually active females received information about HPV than males. All sexually active males received information about HPV, while only 50% of non-sexually active males received information about HPV prevention. Thus, these findings suggest areas to assist Mexican adolescents and parents in improving sexual communication and parental monitoring for preventing STI.
- A longitudinal, non-concurrent, multiple baseline design across subjects pilot study was conducted to evaluate the impact, feasibility, and acceptability of an oral medication adherence-promoting intervention (including electronic digital pillbox) among non-adherent adolescents ($N = 12$; 11 to 17 years) with inflammatory bowel disease and their caregivers (Maddux, Ricks, Delurgio, & Hommel, 2017). Adolescent–Caregiver dyads were randomized to either a 3-, 5-, or 7-week baseline phase followed by the 4-week intervention tailored to each family's adherence needs and barriers. Mean adherence by adolescents significantly increased by 12% from baseline to post-intervention ($p < 0.01$), and by 6% from baseline to 1-month follow up ($p < 0.025$). Eighty-two percent of adolescents and 100% of caregivers reported that the use of an electronic digital pillbox changed how adolescents took their medication. Generalized linear models yielded statistically significant differences over time with improved adherence from baseline to post-intervention ($p < 0.001$), and from baseline to 1-month follow up ($p < 0.01$). Logistic regression analysis indicated almost two times greater adherence during post-intervention when compared to baseline (OR 1.97, $p < 0.001$). Thus, the findings suggest that the intervention was feasible and significantly improved oral medication adherence among non-adherent adolescents with inflammatory bowel disease.
- A school-based, cross-sectional study was conducted to assess the emerging nutritional problems associated with overweight/obesity among adolescents ($N = 546$, mean age 15.37 ± 1.88) attending eight schools in Jimma Town, Ethiopia (Gali, Tamiru, & Tamrat, 2017). Adolescents' dietary intake was composed of predominantly cereal-based diets (99.6%) and vegetables (73.9%). The majority of adolescents walked to school (83.7%) and were involved in moderate to vigorous sports activities (62.7%). The prevalence of overweight/obesity was found to be 13.3%. Logistic regression analysis identified factors that were significantly associated with being more at-risk for overweight, including: being female, attending private schools, being from wealthy households, and lack of parental education. Additionally, adolescents who did not consume vegetables were nine times more likely to be overweight, those who did not consume fruit were five times more likely to be overweight, and those who were not physically active were almost four times more likely to be overweight, as compared to their peers. Findings provide support for the importance of nutritional intake and physical activity in preventing the emerging problem of overweight among adolescents in Jimma Town, Ethiopia.
- A qualitative, focused ethnographic study was conducted to explore parental experiences of how healthcare practices and healthcare professionals influence everyday life of parents with a child ($N = 15$) (ages 5 to 12 years; 10 boys and 5 girls) with ADHD in Denmark (Laugesen et al., 2017). Brief participant observations ($n = 16$) were conducted at pediatric or mental health clinics with parents and/or caregivers of children with ADHD; individual interviews ($n = 15$) were conducted with parents and/or caregivers 1 to 14 days following the observations at the clinic or in the parents' homes. Three main themes emerged from the everyday experiences of the parents and/or caregivers: (a) when the house of cards collapses in everyday life; (b) treading water before and after receiving the ADHD diagnosis; (c) healthcare as a significant lifeline. Findings suggest the importance of developing a trusting relationship with healthcare providers as a significant lifeline for parents and families managing their child's ADHD, as well as recognition by healthcare providers that ADHD influences all aspects of the family's everyday life.

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