



Research Commentary

Translational Research – Family Management and Parenting Stress Associated with Chronic Conditions in Children

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Chronic conditions in children impact children, their parents, and families as they navigate the challenges of adapting to and managing the child's chronic condition at home. The multiple dimensions of caregiving and management of children's chronic conditions affect all aspects of life, including the impact of the chronic condition on the child, parenting stress associated with learning skills to provide care at home, the impact on families as they manage the chronic condition, as well as the effects of the chronic condition on school performance and absenteeism. Transactions between parents, children, and their families are central to successful adaptation to and management of their child's chronic condition. As children grow and develop, they learn self-management of their chronic condition and become more independent from parents as they transition to adolescence. Improving quality of life of children with chronic conditions, as well as their parents and family is dependent upon balancing the demands of the chronic condition, and integrating effective interventions for managing the chronic condition (Christian, 2010, 2016a, 2016b). In this way, quality of life is influenced by the ability of children, their parents, and families to successfully adapt to and manage their child's chronic condition by incorporating it into their everyday lives.

Evidence generated through nursing research and translated into pediatric nursing practice improves outcomes for children, their parents, and families (Hockenberry, Wilson, & Rodgers, 2019; Melnyk & Fineout-Overholt, 2018; Polit & Beck, 2017). Thus, evidence of best practices is essential for improving adaptation to and management of children's chronic conditions by children, their parents, and families.

In this issue of the *Journal of Pediatric Nursing*, the articles present research focused on children with chronic conditions, parenting stress associated with home care, and family management of children's chronic conditions as demonstrated by: (a) an adaptation of the *Family Management Styles Framework* to expand the framework to include the perspectives of children about their chronic condition and family management; (b) an exploration of the mediating effects of family management style on parenting stress and quality of life in children with epilepsy; (c) an evaluation of family-centered care and empathic communication among undergraduate nursing students during pediatric simulation using standardized actors; (d) a descriptive qualitative study of home care experiences of parents of children with tracheostomies; (e) a systematic review of the literature to examine the impact of childhood

disabilities on educational outcomes for school-age children and adolescents with chronic conditions; (f) a secondary analysis of outcome data from an early intervention program for overweight and obese for children and their families; (g) an integrative review of the literature to identify screening and clinical practice guidelines, or recommendations for Vitamin D deficiency for children and adolescents; and (h) an evaluation of a peer-led asthma self-management group intervention program day camp for urban adolescents. In addition, a correlational study was conducted to explore pediatric staff nurses' views about professional development in an acute care setting.

The majority of articles in this issue of the *Journal of Pediatric Nursing* describe research focused on family management of children's chronic conditions, parenting stress associated with home care, and the impact of the chronic condition on children, as follows:

- An adaptation of the *Family Management Styles Framework* (FMSF) was conducted to expand the framework to include the perspectives of children about their chronic condition and family management, as well as to incorporate transactions between parents, children, and their families (Beacham & Deatrck, 2019). Interview data ($N = 32$) from the authors' previous study of school-age (ages 8 to 13 years) children's perspectives about family management of their chronic health conditions (Beacham & Deatrck, 2015) were analyzed to inductively develop and expand the framework to incorporate the perspectives of children. Based on this analysis, the framework was adapted to expand major components, including contextual influences, definition of situation, management behaviors, and perceived consequences, as illustrated by exemplars of the children's views of family management and self-management of the chronic health condition. Thus, the adapted framework provides a more comprehensive picture of how families manage and incorporate children's chronic conditions into their everyday lives by integrating the perspectives of children with those of their parents, as well as capturing children's developing understanding of their chronic condition and increasing responsibility for self-management.
- A descriptive exploratory study was conducted to examine the mediating effects of family management style on the relationship between parenting stress and quality of life in children with epilepsy in Korea (Im, Cho, & Kim, 2019). Parents ($N = 93$; 97% mothers, 3% fathers) of children with epilepsy (ages 6 months to 17 years) were surveyed using the Korean versions of self-report measures of parenting stress, quality of life, and family management style. Results of path analysis

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indicated that the direct effects of parenting stress on quality of life were not significant. However, parents with higher parenting stress scores had significantly lower easy family management styles and significantly higher difficult family management styles. Parents classified as having easy family management styles demonstrated significant indirect effects on parenting stress and quality of life. Family management style was found to be a significant mediator of parenting stress on quality of life. Thus, for Korean parents of children with epilepsy, easy family management styles were the most important predictor of quality of life.

- A convergent parallel mixed-methods design was used to examine undergraduate nursing students' ($N = 146$; 87% female) performance in providing family-centered care and empathic communication with pediatric simulation using standardized actors (Fitzgerald & Ward, 2019). Two pediatric scenarios with family caregivers (e.g., child hospitalized with asthma; unvaccinated infant with high fever) were developed for the simulations. Standardized actors and student peers evaluated student performance; faculty observers provided debriefing immediately after the simulation. Results indicated significant differences between simulation performance evaluations by student peers and standardized actors, with student peers perceiving more empathic communication as compared to perceptions of standardized actors. Content analysis of debriefing session notes was conducted based on Kolb's experiential learning theory with four predetermined categories of students' responses: (a) Doing, *demonstrating empathy*; (b) Watching, *explaining observations*; (c) Feeling, *helping people*; and (d) Thinking, *understanding the situation*. Thus, the use of standardized actors in family-centered care simulation scenarios was effective in teaching empathic communication to undergraduate pediatric nursing students.
- A descriptive qualitative approach was used to explore the home care experiences of parents of children with tracheostomies during transition from hospital to home in China (Gong et al., 2019). Semi-structured interviews were conducted with parents ($N = 13$; 11 mothers, 2 fathers) who had been providing care at home for less than one month. Content analysis of interviews yielded three categories with subcategories describing parents' experiences with caregiving for their children with tracheostomies at home: (a) Direct care overload (parental role change, from helplessness to skillfulness, lack of professional support); (b) Psychological overload (anxiety and depression, social isolation); and (c) Personal growth (changing their perspectives, developing potential). Results suggest that parents in China face many challenges providing home care for children with tracheostomies including direct physical and psychological overload particularly after discharge from hospital. However, the stress of home caregiving is compounded by the additional stress associated with the one-child policy in China and the demands of providing care for four grandparents as well as their child with tracheostomy. Thus, the findings of this study highlight the importance of discharge preparation and education for parents of children with tracheostomies in China for the transition from hospital to home.
- A systematic review of the quantitative literature was conducted to examine the effect of childhood disabilities on educational outcomes for school-age children and adolescents (ages 5 to 21 years) (Yoder & Cantrell, 2019). Using multiple databases, a search of the relevant literature published from 1990 through mid-2018 was conducted using CINAHL, MEDLINE, ERIC, Teachers Reference Center, Psychology & Behavioral Science Collection, and Academic Search Elite databases, including ancestry searches yielding 1106 articles with 184 additional records identified, resulting in 43 articles that met the inclusion criteria. Results indicated that chronic conditions among children and adolescents are significantly associated with increased school absenteeism, grade repetition, and almost two times greater risk of not graduating from high school. It is important to note that children and adolescents with mental, emotional, and cognitive delays were at greater risk for not graduating from school. Moreover, the greater severity of the disability with respect to the chronic condition, the poorer educational outcomes. This review highlights the impact of chronic conditions on educational outcomes, as well as the importance of assessing educational functioning among children and adolescents with chronic conditions.
- A secondary analysis of a dataset from the ProActive Kids (PAK) Foundation 8-week early intervention program focused on lifestyle behavioral change, physical activity, and nutrition to improve body composition, physical strength, body image and self-esteem among overweight and obese for children and adolescents ($N = 884$; 5 to 17 years of age; 48.4% Caucasian, 29.6% Hispanic, 22% Black) and their families, using a three-tier, quasi-experimental, pre-test/post-test design study conducted from 2010 to 2017 (Moxley et al., 2019). Children in the sample were stratified into three age groups (<8.9 years, 9–12.9 years, >13 years), and subdivided by gender ($n = 440$ female, $n = 446$ male). The focus of this secondary analysis was to determine changes in body composition among overweight and obese children and adolescents from baseline (week 1) to completion of the PAK intervention program at 8 weeks. Results of the analysis demonstrated significant improvements in body composition, including weight, percentage body fat, fat free mass (FFM), and BMI. Significant differences in weight and BMI were found by age and county of residence, but were not significant by gender. Significant differences in percentage body fat and FFM were found for gender, age, and county of residence. Thus, consistent improvement in body composition was demonstrated among all overweight and obese children and adolescents who participated in the 8-week PAK intervention program.
- An integrative review was conducted to identify existing screening and clinical practice guidelines, or recommendations for Vitamin D deficiency for children and adolescents (Davis, Aksornsrri, & Papachrisanthou, 2019). A search of literature published from September 2017 through December 2018 was conducted through searches of CINAHL, PubMed, and SCOPUS databases, yielding 310 articles with two additional records, resulting in 8 articles that met the inclusion criteria. Results of the review identified that screening recommendations and guidelines for Vitamin D deficiency are available, although there was insufficient evidence and variation about which risk factors should be screened. Vitamin D deficiency screening was recommended for children and adolescents who are at-risk.
- An evaluation was conducted to determine the acceptability and generalizability of a peer-led asthma self-management group intervention program in a one-day camp setting for urban adolescents (Grape, Rhee, & Sanchez, 2019). Adolescents diagnosed with persistent asthma ($N = 259$; ages 12 to 17 years) from three urban cities participated in a one-day camp asthma self-management group led by trained peer leaders ($n = 35$; ages 16 to 20 years) (intervention group), or by asthma educators or nurse practitioners (control group). Adolescent participants evaluated the intervention program as having high acceptability and satisfaction (92–94% positive ratings for all items); however, no significant differences were found between type of group leader (peer or professional). Peer group leaders were evaluated positively ($n = 119$). Thus, the program evaluation supports the acceptability and generalizability of a peer-led asthma self-management group one-day camp intervention program for urban adolescents.
- A correlational design study was conducted to examine views about professional development among pediatric staff nurses ($N = 74$; 96% female, ages 21 to 61 years) employed in an acute care pediatric hospital (Horn, Pilkington, & Hooten, 2019). Education preparation of pediatric staff nurses included: MSN (4%), BSN (64%), ADN (29%), and Diploma (3%). The highest ranked components of professional development by pediatric staff nurses were continuing nursing education (96%) and nursing specialty certification (90%). Motivators for professional development among pediatric staff nurses included increased knowledge to improve patient care (98%), personnel

fulfillment (93%), and extended clinical role (93%). Barriers to professional development included family commitments (70%) and finances (68%). Significant associations were found with younger pediatric staff nurses identifying greater importance of professional development; pediatric staff nurses with MSN or BSN valued continuing education as important for professional development; improved self-confidence motivated pediatric staff nurses with lower levels of educational preparation; and younger pediatric staff nurses identified improving job opportunities as motivation for professional development. Thus, the findings suggest that pediatric staff nurses' rationale for professional development is motivated by improving the quality of patient care.

These articles highlight the multidimensional impact of children's chronic conditions on the lives of children, their parents, and families. As families adapt to and manage the child's chronic condition, they learn to balance the demands of the chronic condition and integrate management of the child's chronic condition into their everyday lives. In this way, management of the chronic condition is enhanced, while improving the quality of life of children with chronic conditions, their parents, and families.

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