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Research Commentary

Translational Research – Facilitating Transition of Adolescents With Chronic Conditions to Adult Healthcare and Improving the Quality of Pediatric Nursing Care for Hospitalized Children

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Independent self-management of chronic conditions by adolescents and young adults (AYA) is challenging (Christian, 2019) and intensified by adolescent developmental change and associated adolescent risk-taking behaviors. This interplay between adolescent developmental needs and the demands of chronic conditions increases the challenges of chronic condition management by adolescents and their parents (Christian, 2016a, 2016b). Moreover, the transition of adolescents with chronic conditions from pediatric to adult healthcare signifies a shift in relationships marking a change in the level of independence associated with adulthood, which may be difficult for both adolescents and their parents. As a result, this process of growth and development combined with the transition to adult healthcare may create additional stress for adolescents with chronic conditions and their parents.

New evidence generated from nursing research is essential for evidence-based practice (Melnyk & Fineout-Overholt, 2018; Polit & Beck, 2018) and results in improved quality of pediatric nursing care for children, adolescents, and their families (Hockenberry, Wilson, & Rodgers, 2019). In this way, new evidence and intervention strategies lead to changes in pediatric nursing practice, thereby improving the quality of care.

In this issue of the *Journal of Pediatric Nursing*, 8 of 14 articles present information about adolescents and young adults with chronic conditions with respect to transition from pediatric to adult healthcare, as well as the influence of adolescent risk-taking behaviors on health. Another article focuses on the concept of nurturing resilience as a protective mechanism to prevent distress and promote mental health. Additionally, four articles present new evidence and intervention strategies associated with hospitalization, including pain assessment of children in the PICU, interventions for opioid-exposed newborns with neonatal abstinence syndrome, the use of central line-associated bloodstream infections (CLABSI) bundles to improve quality of care, and the role of pediatric nurses in antimicrobial stewardship. Finally, the role of the school nurses in providing community-based care for children is explored from the perspective of student nurses. In this way, the articles in this issue provide new intervention strategies for adolescents with chronic conditions and for improving pediatric nursing care for hospitalized children:

- A systematic review of multiple systematic reviews ($N = 37$ reviews of 71 primary studies) focused on transition from pediatric to adult healthcare was conducted to create an evidence map for interventions (Hart, Patel-Nguyen, Merkley, & Jonas, 2019). A search of the literature published through February 2018 in PubMed, CINAHL, PsychInfo, and Cochrane Review databases, as well as the PROSPERO systematic review registry, yielded 431 articles with a final sample of 37 review articles met the inclusion criteria. The majority of systematic reviews were published in 2014 or later. The majority (54%; $n = 20$) of reviews included a variety of chronic conditions, with Type I diabetes as the most common condition ($n = 7$ reviews and 24 primary studies). Transition interventions for adolescents and young adults were described in 38% of the reviews ($n = 14$). Based on this review, gaps in the literature were identified with the need to conduct research on transition interventions for other common chronic conditions (e.g., asthma, ADHD, autism) among children and adolescents, and individual mental health disorders (e.g., depression), and transition interventions in primary care settings, as well as transition needs after transitioning to adult healthcare.
- A group-based, peer-mentor intervention was developed to promote disease self-management knowledge and behavioral skills among transition-age adolescents and young adults (AYA) with chronic conditions (i.e., inflammatory bowel disease, kidney disease, hypertension, lupus, and juvenile idiopathic arthritis) to facilitate transition to adult healthcare (Wiemann et al., 2019). The process included a needs assessment with AYA with chronic conditions ($n = 95$), their family members ($n = 49$), pediatric healthcare providers (HCP) ($n = 81$), and adult HCP ($n = 17$). Additionally, surveys were conducted in conjunction with participants at an annual transition conference to determine their views about essential skills necessary for transition. Findings from interviews and surveys were presented to the community advisory board that was comprised of transition-age AYA who had successfully transitioned to adult healthcare. Five specific needs were identified: (a) AYA were not prepared for healthcare transition; (b) Pediatric HCP were not prepared to assist AYA and their families in healthcare transition; (c) AYA and their families need to be prepared for differences between pediatric and adult HCP; (d) adult healthcare system is not adequately prepared to receive AYA with chronic conditions; and (e) Communication between pediatric and adult HCP is inadequate. Based on the findings from the needs assessment in

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conjunction with the community advisory board, the group-based, peer-mentor intervention was developed using principles of self-determination theory and motivational interviewing. Intervention program content about chronic condition self-management knowledge and behavioral skills necessary for transition focused on goal setting, understanding their diagnosis, insurance information, characteristics of good HCPs, refilling prescriptions, and mental well-being. The peer-mentor intervention program for transition-age adolescents and young adults (AYA) with chronic conditions was led by young adults with chronic conditions who have successfully transitioned to adult healthcare. The findings suggest that the group-based, peer-mentor intervention program has promise for improving transition of for adolescents and young adults (AYA) with chronic conditions to adult healthcare.

- A quality improvement (QI) project was conducted to implement a portable medical summary for adolescents and young adults (AYA) ($N = 35$; ages 16 to 24 years) with chronc complex medical conditions to facilitate transition to adult healthcare (Chouteau & Allen, 2019). The Institute for Healthcare Improvement (IHI) model was used to plan and implement the QI project and a Key Driver Diagram was used to guide the development of portable medical summary intervention using the electronic health record. Project implementation process was guided by Plan-Do-Study-Act (PDSA) cycles. Results of the QI project demonstrated an increased use of portable medical summary for adolescents and young adults with chronic complex medical conditions from 0% to 100%. Thus, use of portable medical summary QI project was successful in improving the quality of care and facilitating the transition from pediatric to adult healthcare.
- A scoping review was conducted to examine the gap in literature with respect to risk-taking behavior among adolescents with chronic cardiac conditions as compared to health risk-taking behaviors identified in the national Youth Risk Behavior Survey (YRBS) (DiFusco, Schell, & Saylor, 2019). A search of six electronic databases (e.g., CINAHL, Plus Full Text, PubMed, Web of Knowledge, Scopus, ProQuest, and Grey Literature Report) of published literature from 1975 to 2018 yielded 17 articles that met the inclusion criteria. Studies included in the review reported wide variability in adolescent ages beyond standard definitions of adolescence (ranging from 7 years to 31 years of age), including children younger than 10 and young adults older than 25 years of age. Based on this review, the most prevalent types of risk-taking behaviors among adolescents with chronic cardiac conditions across studies corresponding with the six priority YRBS categories, including tobacco use, substance use (alcohol and/or drug use), and lack of physical activity. Additional self-reported risk-taking behaviors identified in these studies were poor oral hygiene, antisocial behavior, medication or treatment non-adherence, missed appointments, tattoos and piercings, excessive internet use, and gambling. The results indicate that risk-taking behaviors among adolescents with chronic cardiac conditions were found to be similar to those of adolescents with other chronic conditions. It is essential for pediatric healthcare providers to discuss risk-taking behaviors with adolescents with chronic cardiac conditions to minimize potential clinical complications.
- A secondary analysis of data from the Malaysian Adolescent Health Risk Behavior (MyAHRB) cross-sectional survey was conducted to explore the relationship between personal and family factors and high-risk behaviors among adolescents in Malaysia (Cheah, Lim, & Kee, 2019). Behaviors of adolescents ($N = 2991$; 13 to 17 years; 53% male) were classified according to degree of risk. The majority of adolescents were classified as participating in low-risk behaviors (53% of adolescents), 41% medium-risk, and 6% high-risk behaviors. The results of analyses indicated that the most frequent high-risk behaviors among adolescents were physical inactivity (36%), smoking (13%), and alcohol use (4%). Odds ratio analyses revealed that males were slightly more likely to engage in high-risk behaviors than females (OR: 1.28); older adolescents exhibited slightly more high-risk behaviors than younger adolescents (OR: 1.26); and adolescents with better academic performance demonstrated slightly more low-risk behaviors (OR: 0.41). In comparison to Malays adolescents, Chinese adolescents in the sample demonstrated greater odds of performing high-risk behaviors (OR: 1.71), while Indian adolescents demonstrated lower odds of high-risk behaviors (OR: 0.65). Thus, personal factors of age, gender, ethnicity, and academic performance were associated with high-risk behavior among adolescents in Malyasia.
- A descriptive qualitative study was conducted with adolescents to explore their perceptions and information sources about using electronic cigarettes (e-cigarettes) (Park, Kwon, Gaughan, Livingston, & Chang, 2019). The sample was comprised of both adolescents ($N = 34$) who self-identified as e-cigarette users ($n = 23.5\%$) or never/non-users ($n = 76.5\%$). Adolescents were between 10 and 18 years of age, 50% female, and from diverse race/ethnicity (44.1% Caucasian, 32.4% African American, 14.7% Asian American, and 8.8% Latino). Semi-structured interviews were conducted with adolescent participants and content analysis was used to identify major themes. Adolescents' perceptions about e-cigarette use identified by both users and never/non-users included popularity, coolness, healthier alternative, while e-cigarette users noted that e-cigarettes were pleasing and attractive due to unique features. Both adolescent e-cigarette users and never/non-users identified e-cigarettes as a healthy alternative that was more enjoyable and less harmful than smoking regular cigarettes. Reasons for not using e-cigarettes by both users and never/non-users included ambiguity, harm to health, and risk for addiction. Non-users added that e-cigarettes represented a gateway. Sources of information for adolescents about e-cigarettes included advertisement and marketing, family influence, peer influence, internet or social media, and school. The results of this study indicate that adolescents lack knowledge about e-cigarettes providing guidance to healthcare providers for adolescent health promotion interventions.
- An exploratory, descriptive qualitative study was conducted with children, adolescents, and young adults diagnosed with cancer ($N = 30$; ages 10 to 21 years; 22 males, 8 females; 63.3% Hispanic/Latino) to explore their cancer treatment experiences and the impact on lifestyle (Kuntz, Anazodo, Bowden, Sender, & Morgan, 2019). Semi-structured interviews were stratified by age groups, including interviews conducted with five school-age children (10 to 11 years), five adolescents 13 to 14 years, 10 adolescents 16 to 18 years of age, and 10 adolescents/young adults (19 to 21 years). Interviews were conducted in either English ($n = 18$, 60%) or Spanish. Narrative analysis revealed primary themes from interviews with children, adolescents, and young adults diagnosed with cancer described the meaning of their experiences as being difficult due to: (a) activity challenges associated with cancer treatment and hospitalization; and (b) disconnection from school, peers, and teachers while receiving treatment, as well as their need to attend school in alternative settings. Participants described the importance of storytelling as an important resource that facilitated their coping with the emotional and spiritual struggles associated with cancer diagnosis and treatment. Barriers that interfered with coping with cancer treatment were identified as: (a) the importance of building relationships with family and overcoming social isolation; (b) communication challenges that were not helpful in understanding of cancer and recovery; and (c) the value of altruism in helping others in the future. The findings from this study highlight the importance of exploring the meaning of cancer diagnosis and treatment for children, adolescents, and young adults to develop interventions that facilitate coping with cancer and treatment.
- An interpretive, descriptive design study was used to explore perceptions of methotrexate (MTX) intolerance and the impact on daily life in school-age children with juvenile idiopathic arthritis (JIA) (Khan, Mancini, Hopper, & Rennick, 2019). Semi-structured interviews using storyboard technique to elicit storytelling were conducted

with school-age children ($N = 12$; 9 female, 3 male; ages 6 to 12 years). Inductive content analysis was employed to identify themes. Children with JIA described MTX intolerance as extremely challenging and distressing with three overarching themes were identified: (a) *"No kid likes taking MTX"* with two subthemes, including associative MTX intolerance and anticipatory MTX intolerance; (b) *The importance of strategies and routines*; and (c) *Working hard to live with MTX intolerance*. The results highlight the importance of early identification of MTX intolerance among school-age children with JIA, as well as the need for intervention strategies to manage MTX intolerance.
- A concept building process was conducted to explore the phenomenon of nurturing resilience and clarify the meaning with respect to children and adolescents to prevent distress resulting in mental health disorders (Martinez & Opalinski, 2019). Using the concept building process as described by Liehr and Smith (2018) to develop an emerging concept, the meaning of nurturing resilience was defined and illustrated through critical incidents in a practice story and identification of core qualities. Thus, through this process of concept building, the phenomenon of nurturing resilience was explored as a protective mechanism for promoting mental health and defined as *developing secure connections with another to support self-acceptance that aids in tempering reactivity when faced with environmental hardships*. In this way, nurturing resilience allows healthcare providers to assist children and adolescents faced with difficult situations to change their responses and develop protective mechanisms, resulting in positive mental health outcomes.
- Based on a larger cross-sectional, multi-site descriptive study, current pain assessment practices across 15 pediatric intensive care units (PICUs) from 12 children's hospitals in the U.S. are described (Laures et al., 2019). The electronic health records of 220 children hospitalized in 15 PICUs were obtained over a 24-h period. Pain assessments were performed on children (ages <1 month to 21 years) an average of 11.5 times (SD 5.8, range 1–28 times) during a 24-h period. Fifty percent ($n = 110$) of the children were <2 years of age; 50% of the children were receiving mechanical ventilation. Most children ($n = 117$; 54%) were able to communicate about their pain, although nurses reported multiple communication barriers, with 34% of parents or guardians ($n = 74$) helping nurses understand their children's pain. Twelve different pain assessment scales were used across the 15 PICUs, including five self-report pain scales and seven behavioral scales. Most commonly, pain assessment was performed using numeric self-report pain scales (12 hospitals) and the FLACC behavioral pain scale (10 hospitals). Based on the results of this study, recommendations for pain assessment when the child is able to communicate are for PICU nurses to use self-report pain scales, followed by the appropriate use of behavioral pain scales.
- A quality improvement (QI) project using a retrospective chart review was performed to determine whether a non-pharmacologic, rooming-in strategy for opioid-exposed newborns at-risk for developing neonatal abstinence syndrome (NAS) would reduce total length of stay and the need for pharmacologic interventions (Cree, Jairath, & May, 2019). Opioid-exposed newborn infants at-risk for NAS in the pre-intervention group ($n = 48$) were compared with opioid-exposed newborns that received the rooming-in intervention ($n = 40$). Results indicated that total length of stay was significantly reduced from 14 days to 10.1 days ($p = 0.014$) for infants in the rooming-in group. Duration of pharmacologic treatment for newborn infants in the rooming-in group significantly decreased from 15.68 days to 9.71 days ($p = 0.023$). Thus, the rooming-in intervention was successful in reducing length of stay and the duration of pharmacologic treatment for opioid-exposed newborn infants at-risk for developing NAS.
- A multi-level quality improvement project was implemented to evaluate adherence to a central line-associated bloodstream infections (CLABSIs) bundle protocol in the pediatric acute care and hematology/oncology units of a quaternary healthcare setting over five years (Santos, Husain, Torres, Huang, & Jacob, 2019). Development of a CLABSI bundle by the "Bug Buster" hospital committee was based on the evidence and was comprised of five components, including hand hygiene, personal protective equipment (PPE) and aseptic technique, catheter type selection and site selection, sterile dressing and line maintenance, and ongoing education and monitoring of adherence to CLABSI prevention. Adherence to the CLABSI bundle intervention quality improvement project was measured over a five-year period. Prior to implementation of the program, a total of 41 incidents of hospital-acquired CLABSIs were reported during the year as compared to 9 incidents of CLABSIs post-implementation. When comparing pre-and post-CLABSI intervention implementation, quarterly CLABSI rates decreased in pediatric acute care units from 2.8 to 6.6/1000 catheter days pre-implementation to 1.31/1000 catheter days post-implementation, and decreased in pediatric hematology/oncology units with pre-implementation rates of 2.1 to 4.3/1000 catheter days to 0.54/1000 catheter days post-implementation. Although staff adherence (92.6%) to using PPE increased, adherence rates to wearing PPE by family and visitors remained low (36.8%). Thus, the CLABSI quality improvement project was successful in decreasing rates of CLABSI of children in pediatric acute care units and in pediatric hematology/oncology units, as well as increasing staff adherence to wearing PPE, but not family and visitor adherence.
- Focus groups were conducted with pediatric nurses ($N = 90$) across a range of clinical units and settings within a freestanding children's hospital to explore pediatric nurses' perceptions of their role in antimicrobial stewardship (Hamdy, Neal, Nicholson, Ansusinha, & King, 2019). A total of 12 focus group discussions were conducted with 10 focus groups of clinical bedside pediatric nurses and an additional two focus groups with members of system-level nurse leadership councils, practice council, and resource council. Five themes with respect to nurses' roles in antimicrobial stewardship were identified from the perspectives of pediatric nurses during focus groups: (a) advocating for the patient; (b) communicating with the team; (c) administering medications safely; (d) educating caregivers; and (e) educating themselves. Barriers that prevented nurses from their antimicrobial stewardship role included deference to physicians, overlapping roles, inconsistent inclusion on rounds, inconsistent relationships with physicians, and lack of institutional protocols for antibiotic use. Thus, pediatric nurses confirmed their multiple roles in antimicrobial stewardship and the importance of using a standardized approach for antibiotic use.
- A qualitative analysis of undergraduate pre-licensure nursing students' reflections ($N = 38$) about a two-day school nursing pediatric clinical experience working with school nurses in public K-12 schools was conducted (Quinn & McAuliffe, 2019). Content analysis of students' reflective journals revealed three major themes: (a) benefits of the clinical experience; (b) suggestions for improvement; and (c) an appreciation for the school nurse role. Three subthemes included greater responsibility than anticipated, resource constraints, and lack of support. Thus, the community-based school nursing experience provided pediatric nursing students the opportunity to interact with a variety of children of different ages, abilities, socioeconomic status, and health conditions, as well as learning about the social determinants of health and the role of school nurses.

As highlighted by the articles in this issue, transition from pediatric to adult healthcare is challenging for adolescents with chronic conditions and their parents. Adolescent risk-taking behaviors contribute to poor outcomes among adolescents and may have a negative impact on health. Additionally, new evidence provides intervention strategies designed to improve the quality of pediatric nursing care for hospitalized children. To that end, translation of new intervention strategies into pediatric nursing practice improves the quality of care for children, adolescents, and their parents.

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