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Research Commentary

Translational Research – Adolescents and Young Adults with Chronic Conditions and Disabilities Striving for Independence in Self-Management and Navigating Healthcare Transitions

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Adolescents and young adults with chronic conditions and disabilities strive for independence in self-management from their parents, while being challenged by healthcare transitions from pediatric to adult care. Parents and families are responsible for managing the challenges of their child's chronic conditions on a daily basis (Christian, 2016a, 2016b). Parents and their children manage the demands of the chronic conditions as a team with parents assuming the primary responsibility for management of the chronic condition. As children with chronic conditions and disabilities grow and develop, their developmental needs and the demands of chronic conditions create more vulnerability (Christian, 2016a, 2016b). Parents continue to share the responsibility for their child's chronic condition management, while providing oversight to prevent any health problems. As adolescents and young adults strive for independence assuming more responsibility for self-management of their chronic condition, parents are challenged by changes in their level of responsibility. Moreover, when adolescents and young adults "age out" of pediatric care, additional challenges emerge with respect to navigating healthcare transitions to adult healthcare.

Nursing research generates new knowledge and evidence designed to improve health outcomes for children and their families through the translation of research into evidence-based practice (Hockenberry, Wilson, & Rodgers, 2019; Melnyk & Fineout-Overholt, 2018; Polit & Beck, 2017). Thus, improvements in the quality of pediatric nursing care for children, adolescents, and their families are based on evidence generated from research and translated into practice through evidence-based practice projects and quality improvement projects (Christian, 2015). Moreover, these advancements enhance the quality of pediatric nursing care for children, adolescents, and their families, while improving nursing practice and contributing to nursing knowledge development.

In this issue of the *Journal of Pediatric Nursing,* a variety of research, quality improvement projects, and evidence-based practice articles present evidence focused on healthcare transition for adolescents and young adults with chronic conditions and disabilities, including: (a) implementation of a structured healthcare transition quality improvement project across seven large healthcare systems; (b) an interprofessional healthcare transition consultation program at a large tertiary children's hospital to coordinate care and facilitate healthcare transition of adolescents and young adults to adult care; (c) an exploration of parents' perspectives of their healthcare transition experiences for adolescents and young adults with intellectual disability; (d) an exploration of parent and adolescent perspectives about the transition to self-management of polycystic ovary syndrome; (e) an examination of mother-daughter dyadic communication about sexual behavior and reproductive health in adolescent females with a variety of chronic conditions; (f) development and implementation of an oncology child life program to educate, engage, and empower adolescents and young adults with cancer during diagnosis, treatment, and survivorship; (g) an exploration of perspectives of nurse practitioners and adolescents about school-based healthcare centers; (h) an examination of the effectiveness of a nurse-led cognitive skills building intervention on executive function and mood among young rural adolescents at a school-based health center; (i) an updated systematic review to identify knowledge translation strategies used by healthcare professionals in child health settings; (j) perspectives of low-income caregivers about the preferred method of education about common childhood illnesses to improve health literacy; (k) an exploration of parents' perspectives about the influence of the child's developmental disability on their weight-related behaviors; (l) development of an evidence-based practice decision tree to guide neurogenic bowel management for children with spina bifida; (m) a program evaluation of a camp designed for children with spina bifida, their siblings, and caregivers to promote self-confidence and independence in a family-centered camp environment; (n) an exploration of the influence of screen viewing duration and self-efficacy in limiting screen viewing with loneliness in a sample of adolescent-parent dyads; (o) an examination of caregiver burden and stress coping styles of parents of children with Autism Spectrum Disorder in Turkey; (p) an exploration of health-related quality of life among youth with inflammatory bowel disease and their parents; (q) a secondary analysis of longitudinal data about children and adolescents with cystic fibrosis and pancreatic insufficiency from 10 CF Centers to examine adherence to nutritional supplementation; (r) a systematic review and meta-analysis to determine the safety and efficacy of topical corticosteroids compared to vehicle/moisturizer in young children with atopic dermatitis; (s) a concept analysis and review of the literature to examine sleep in infancy to clarify the definition of age-appropriate

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sleep; (t) an exploration of mothers' perceptions of pain and pain treatment practices among hospitalized newborn infants in Kenya; (u) an exploration of parents' experiences associated with their child's resuscitation during hospitalization; and (v) an exploration of interprofessional healthcare providers' perceptions about pediatric death.

The articles in this issue of the *Journal of Pediatric Nursing* predominantly focus on adolescents and young adults with chronic conditions and disabilities as they gain independence in self-management from their parents, as well as issues surrounding healthcare transition from pediatric to adult care, as follows:

- A pre-test, post-test design quality improvement (QI) project was conducted to evaluate the feasibility and effectiveness of implementation of a structured healthcare transition (HCT) improvement process over 12–18 months across the national HCT learning network in seven large health care systems that included 55 participating pediatric and adult practice sites (Jones et al., 2019). Using the *National Alliance to Advance Adolescent Health Got Transition – Six Core Elements of HCT*™ approach (2014), the healthcare transition program was evaluated at baseline and after implementation at 12–18 months. Comparison of pre- and post-implementation of HCT outcomes demonstrated statistically significant improvements in current assessment implementation mean scores from baseline to 12–18 months follow-up in both pediatric and adult sites as evidenced by 37.1% increase in mean scores across all 55 practice sites. With respect to the 47 pediatric sites, HCT mean scores improved by 37.1%; mean scores for the 8 adult practice sites improved by 40%. Thus, all healthcare systems reported success in implementing the structured healthcare transition QI process using the Six Core Element approach.
- An interprofessional transition consultation program was created at a large tertiary children's hospital with the team comprised of nurses, social workers, a community health worker, and physicians to coordinate care and facilitate healthcare transition (HCT) of adolescents and young adults (AYA) (18 years of age or older) with complex healthcare needs to adult care (Razon et al., 2019). The Adult Consult Team utilized a structured healthcare plan to address medical and psychosocial needs of AYA adapted from the *Got Transition*™ healthcare transition program (National Alliance to Advance Adolescent Health, 2014). During the one-year period from July 2017 through June 2018, the Adult Consult Team received 197 AYA referrals, including 79% ($n = 155$) outpatients and 21% ($n = 42$) inpatients with 15% of referrals ($n = 30$) transferred to adult care. Patient characteristics of those receiving consultation included 73% ($n = 144$) of patients being followed by two or more specialty care teams, 71% ($n = 139$) of patients diagnosed with intellectual or developmental disability, 48% ($n = 95$) with both, and 17% ($n = 34$) with technology dependence. Transition coordination of AYA with complex chronic healthcare needs although complicated was successful in using an interprofessional transition consultation program within a children's hospital and a tiered approach based on complexity of healthcare needs for HCT to adult care.
- A qualitative descriptive approach was employed to explore parents' perspectives of health care transition (HCT) experiences for adolescents and young adults (AYA) (ages 18 to 33 years) with intellectual disability (Franklin et al., 2019). Individual semi-structured interviews were conducted with parents ($N = 16$; 12 mothers, 4 fathers) of AYA with a variety of intellectual disabilities ($N = 14$) to describe parents' experiences with HCT to adult care, including barriers and facilitators. Three overarching themes were identified that represented parents' HCT experiences for their AYA with intellectual disability: (a) Inefficient and siloed systems; (b) “left out here floundering” in adulthood; and (c) hope despite uncertainty. These results highlight parents' perspectives of the ineffective preparation for HCT of AYA with intellectual disability to adult care, as well as the lack of coordination across health care, educational, community, and vocational systems. Moreover, the inadequacy of resources and infrastructure support were notable barriers to HCT. However, the value of parent peer support was emphasized as a critical resource for parents during the HCT of AYA with intellectual disability. Thus, the results of this study describe the simultaneous transitions that families experience during HCT of AYA with intellectual disability to adult care and the need for more effective integration of care across multiple systems, as well as the need for additional resources.
- A qualitative descriptive approach was used to explore parent and adolescent perspectives about transition to self-management of polycystic ovary syndrome (PCOS) (Young, Rew, & Monge, 2019). Focus groups (2 adolescent and 2 parent groups) were conducted with adolescents (ages 15 to 18 years) diagnosed with PCOS and their parents to explore the process of self-management guided by the *Individual and Family Self-Management Theory* (Ryan & Sawin, 2009). Adolescents ($n = 7$) and parents ($n = 8$) each participated in two focus groups. Thematic analysis of focus group transcripts was conducted using an essentialist/realist perspective. For parents, the primary theme was identified as *Concerns for Transitions to Self-Care* with subthemes: (a) facilitation versus direction; and (b) recognition of personal habits. The primary theme for adolescents was *Taking Control* with subthemes: (a) managing symptoms; (b) cognitive dissonance; (c) support; and (d) balance. These results emphasize the importance of adolescent transition from parental management to independent self-management of PCOS, as well as the need for healthcare providers to facilitate the transition to independence by providing guidance during adolescence.
- A descriptive correlational study was conducted to examine communication among mother-daughter dyads ($N = 100$) about sexual behavior and reproductive health in adolescent females (ages 14 to 19 years) diagnosed with a variety of chronic health conditions (Naftaly & Greenley, 2019). Adolescents and their mothers were recruited from outpatient clinics located in a children's hospital. Approximately 25% of the adolescents reported being sexually active. Results indicated that more frequent communication about sexual behavior and reproductive health with adolescent daughters was significantly associated with mothers being more comfortable communicating, earlier timing of communication, as well as mothers being more likely to talk to their daughters prior to onset of sexual activity. More frequent communication with adolescent daughters about sexual behavior and reproductive health was significantly associated with mothers not living with a partner, as well as mothers from racial or ethnic minorities. Regression analyses indicated that maternal outcome expectancy with respect to mother-daughter communication about sexual behavior and reproductive health accounted for 20% of the variance in frequency of communication, 11% of the variance in the timing of communication, and 21% of the variance in maternal comfort in communicating about sexual behavior and reproductive health with their adolescent daughters with chronic health conditions. Thus, these mother-daughter communication patterns about sexual behavior and reproductive health provide guidance for healthcare providers to enhance positive maternal outcome expectancy and improve the quality of care for adolescent females with chronic health conditions.
- The Oncology Child Life Program was designed to educate, engage, and empower adolescents and young adults (AYA) with cancer during diagnosis, treatment, and survivorship (Bergeron, Noskoff, Hayakawa, & Frediani, 2019). A multidisciplinary oncology team developed the comprehensive Oncology Child Life Program to meet the psychosocial support needs of AYA (ages 14 to 26 years) oncology patients through peer-supported social networking. Program outcomes indicate that the number of AYA participating in the program increased from 99 to 1312 (2018) since program inception (2015). Moreover, the number of AYA activities increased from 6 to 33 events per year. Patient and family satisfaction scores have consistently ranked above the 90th percentile on the NRC Picker survey item focused on involving teens in their care across all children's hospitals. Thus, the Oncology

Child Life Program demonstrated success in meeting the psychosocial support needs of AYA oncology patients by empowering them to engage in their treatment and survivorship.

- An explanatory, sequential mixed methods design (QUANT/qual) study was conducted to explore perspectives of nurse practitioners (NPs) and adolescents (ages 13 to 19 years) about school-based healthcare centers (Daley, Polifroni, & Sadler, 2019). The first phase of the study employed a Delphi approach with an expert panel of NPs ($N = 21$) to identify essential elements of adolescent-friendly healthcare in school-based health centers (SBHC). After four rounds, consensus was achieved among the Delphi panel on 98-items resulting in six essential elements for adolescent-friendly healthcare in SBHC: (a) Confidentiality; (b) Accessibility; (c) Clinician/Staff; (d) SBHC Clinical Services; (e) SBHC Environment. The second qualitative phase employed six focus groups with adolescents ($N = 30$) stratified by age and gender who received care in five different SBHC located in five different counties to explore adolescent perspectives about their healthcare. Questions for focus groups were generated from the results of the Delphi expert panel. Results of the focus groups were congruent with the six essential elements and added two overarching themes: (a) Comfortable; and (b) trusted relationship. During the third phase of the study, themes from the Delphi expert panel were compared with themes identified in the adolescent focus groups. Thus, the results of the study indicate the importance of matching adolescent expectations for healthcare with the essential characteristics of SBHC and the care provided by NPs.
- A prospective, quasi-experimental design pilot feasibility study was conducted to examine the effectiveness of a nurse-led cognitive skills building intervention on executive function and mood among young rural adolescents (ages 12 to 15 years) receiving healthcare at a school-based health center located in a middle school (Carr & Stewart, 2019). Adolescents ($N = 15$; 93.3% African-American; 7 females, 8 males) with a positive annual screening for anxiety and/or depression participated in the 7-week cognitive behavioral therapy (CBT) intervention program conducted by a nurse practitioner. The Creating Opportunities for Personal Empowerment (COPE) intervention program developed by Melnyk et al. (2007) was evaluated to determine the effectiveness on rural adolescents' executive function, anxiety, and depression at baseline (T1), immediately post-intervention (T2), and at 3-months post-intervention (T3). Results indicate that executive function domains (e.g., behavioral regulation, metacognition, and global executive composite) among adolescents did not demonstrate significant improvements as a result of the intervention. However, adolescents improved significantly on domain of behavioral regulation executive function from immediate post-intervention (T2) to 3-month follow-up (T3), with a small effect size (Cohen's $d = 0.40$). Anxiety was found to decrease significantly from baseline (T1) to 3-month follow-up (T3), demonstrating a medium effect size (Cohen's $d = 0.50$). Although depression decreased from baseline (T1) to immediate post-intervention (T2) these changes were not statistically significant, nor were they sustained over time. Thus, the pilot feasibility study and novel use of the COPE intervention demonstrated significant improvements in anxiety and the behavioral regulation domain of executive function over time among predominantly African-American adolescents receiving healthcare at a rural school-based health center with potential for addressing substance abuse and mood disorders.
- An updated systematic review of the literature published since 2011 was conducted to identify knowledge translation strategies used by healthcare professionals in child health settings (Campbell, Louie-Poon, Slater, & Scott, 2019). Nine electronic databases (including Ovid MEDLINE, PubMed, Cochrane Library, Ovid EMBASE, CINAHL, Plus with full-text, Ovid PsychINFO, and ProQuest Sociologic Abstracts) were searched for the relevant literature that met the inclusion criteria of three robust research designs, specifically randomized controlled trials (RCTs), controlled clinical trials (CCTs), or controlled before-and after (CBA) studies published in English from 2011 through 2018. Methodologic quality of studies was appraised using the Quality Assessment Tool for Quantitative Studies and studies were analyzed by type of knowledge translation strategy using the Cochrane Effective Practice and Organization of Care data collection checklist. Of the 20,323 articles retrieved since the original review in 2011, 48 studies met the inclusion criteria (21 original review and 27 updated) with 30 RCTs, 3 CCTs, and 7 CBA. Of these studies, the majority (71%) used single interventions ($n = 34$) while 29% of studies ($n = 14$) employed multiple interventions. With respect to methodologic quality, studies were classified as either strong (16 RCTs), 18 studies as moderate (14 RCTs, 1 CCT, 3 CBA studies), or 14 studies classified as weak (8 RCTs, 2 CCTs, and 4 CBAs). Results of this review of the literature indicate that following knowledge translation intervention strategies were used in child health settings: education, reminders, computerized decision supports, multidisciplinary teams, and combined financial and education. Thus, the more effective knowledge translation intervention strategies in child health settings were online education, computerized decision supports, and reminders.
- Focus groups were conducted with low-income caregivers to identify the preferred method of education to learn about common childhood illnesses to improve health literacy (Ohns, 2019). Low-income caregivers ($N = 30$) were recruited from those who qualified for Women, Infants, and Children (WIC) Food and Nutritional Services with at least one child (≥10 years of age) and those participating in a monthly prenatal health education program for low-income pregnant women and their partners. The majority (83%) of caregivers reported receiving public insurance. Caregivers reported their education level as high school graduate ($n = 11$; 37%), some high school ($n = 5$; 17%), some college ($n = 9$; 30%), college graduate ($n = 3$; 10%), and no response ($n = 2$; 7%). Based on the Newest Vital Sign scale health literacy screening tool scores, caregivers demonstrated mean literacy scores of 3.57 (SD 1.48), indicating borderline limited reading and numeracy literacy skills. Focus group participants ranked their preferences for preferred educational method from five options. Results indicated that no statistically significant differences were found between literacy scores and preferred educational method, or educational level. The preferred educational method was the American Academy of Pediatrics, mobile app *Kids Doc*, followed by the book *My Child is Sick!* It is important to note that printed patient education diagnostic-specific handouts were the least preferred educational method. Caregivers' comments reflected their preferences for health education materials identifying the importance of immediate access to information as well as the comprehensiveness of information to improve health literacy among low-income caregivers.
- A descriptive qualitative approach was used to explore parents' perspectives of the influence of a developmental disability (spina bifida or Down syndrome) on the child's weight-related behaviors (Polfuss, Dobson, Sawin, & Klingbell, 2019). Parents were recruited from two national organizations, the NIH National Down Syndrome Registry and the Spina Bifida Association. Parents ($N = 15$; 13 mothers, 2 fathers) of children (ages 5 to 16 years) with physical or cognitive developmental disability [e.g., spina bifida ($n = 7$) or Down syndrome ($n = 8$)] participated in in-depth semi-structured interviews (average of 45 minute duration) via telephone. Thematic analysis of parent interviews yielded three overarching themes that described how their child's developmental disability diagnosis influenced weight-related behaviors: (a) Developmental characteristics or condition related factors; (b) social consequences; and (c) parenting influence on practices. Parents described the social and healthcare challenges related to the child's physical or cognitive developmental disability, which influenced the both child's physical and sedentary activities, as well as nutritional intake.
- An evidence-based practice decision tree was developed to guide neurogenic bowel management for children with spina bifida

(Beierwaltes, Chinarian, Muñoz, & Suson, 2019). A step-by-step approach for individualized bowel management was based on evidence from the literature and clinical experience to improve outcomes. A comparison of bowel continence outcome data from the clinic with the National Spina Bifida Patient Registry (2011) database indicated outcomes of bowel continence for 42.1% of children ($n = 898$), as compared to 72.1% children with spina bifida ($n = 43$) who were managed at the clinic with the bowel management decision tree. Thus, the decision tree guidelines demonstrate promise for improved individualized bowel management for children with spina bifida.

- A program evaluation of Camp V.I.P. designed for children with spina bifida, their siblings, and caregivers to promote self-confidence and independence in a family-centered camp environment was conducted to evaluate outcomes (Zimmerman et al., 2019). Since inception in 2012, camp participants have included 63 children with spina bifida (ages 6 to 17 years), 81 siblings, and over 100 caregivers have attended the camp. An online survey was administered via SurveyMonkey to parents ($N = 32$) to evaluate self-confidence and independence of children with spina bifida. Parents reported that with camp attendance, 93% of children's self-confidence increased and 86% of children demonstrated increased independence. Additionally, parents of children with spina bifida reported making strong connections with other families and that communication and friendship with other families continued after camp ended. Thus, the camp was successful in supporting comprehensive family-centered care for children with spina bifida and their families.
- A secondary analysis of data obtained from the 2014 nationally representative study, *Family Life, Activity, Sun, Health, and Eating* (FLASHE), designed to monitor cancer-related risk factors in the U.S. was employed to explore the influence of screen viewing duration and self-efficacy in limiting screen viewing with loneliness in a sample of adolescent-parent dyads ($N = 1573$ dyads; adolescents ages 12 to 17 years) (Yang, Tracy, Jensen, Jiang, & Linder, 2019). Using the actor-partner interdependence model to predict loneliness from screen viewing duration, no statistically significant actor-partner effects were found for either adolescents or their parents. Results indicate that adolescents' self-efficacy in limiting screen viewing was significantly associated with less loneliness, as well as less loneliness in their parents. Parents' self-efficacy in limiting screen viewing was negatively associated with their loneliness, but not with their adolescents' loneliness. Thus, among adolescent-parent dyads, adolescents' self-efficacy in limiting screen viewing significantly influenced their parents' loneliness, but this association was not reciprocal. That is, parents' self-efficacy in limiting screen viewing did not influence adolescents' loneliness.
- A descriptive cross-sectional design study was employed to examine caregiver burden and stress coping styles of parents ($N = 131$; 72.5% mothers) of children with Autism Spectrum Disorder enrolled in a private education center in Istanbul, Turkey (Bozkurt, Uysal, & Düzkaya, 2019). Parents of children with Autism Spectrum Disorder (ages 3 to 6 years; 63.4% male) demonstrated high caregiver burden. Significantly greater caregiver burden was found for parents with one child compared to those with multiple children, as well as for parents of daughters as compared to those with sons. Parents with self-confident and optimistic coping styles predicted less caregiver burden; while parents with helpless and social support-seeking coping predicted greater caregiver burden associated with children with Autism Spectrum Disorder. Thus, the results of this study highlight the importance of assessing caregiver burden in parents of children with Autism Spectrum Disorder, as well as providing positive coping strategies.
- A descriptive correlational study was conducted to explore health-related quality of life among youth ($N = 92$; ages 8 to 18 years, 51% male) with inflammatory bowel disease (IBD) (74% Crohn's disease; 26% ulcerative colitis) and their parents (87% mothers) (Goldstein-Leever, Bass, Goyal, & Maddux, 2019). Significant differences were found between emotional and school health-related quality of life for youth with active IBD, as compared to those with quiescent disease. Moreover, significant differences were found between youth and parent-proxy ratings of emotional health-related quality of life. Youth and parents demonstrated moderate to good agreement on health-related quality of life domains. Youth and parent reports of emotional difficulties, parent reports of school difficulties, and youth report of physical difficulties were significant predictors of psychology referrals for youth with IBD. Thus, routine assessment of health-related quality of life for youth with IBD is an important indicator of psychosocial adjustment.
- A secondary analysis was conducted with data from a placebo controlled, double-blind randomized controlled trial (RCT) study of children and adolescents ($N = 109$; ages 5 to 17.9 years) with cystic fibrosis (CF) and pancreatic insufficiency who were recruited from 10 CF Centers to examine adherence to nutritional supplementation (Lym-X-Sorb) over 12-months (Hommel et al., 2019). No significant differences were found between youth who received the nutritional supplement and those who received the placebo. When both groups were combined to identify patterns of trajectories, no significant differences were found. However, four distinct patterns were identified, including approximately 60% of participants who adhered well (18% of these near perfect adherence) and 42% at or above 80% adherence; while two patterns evidenced poor adherence by 40% of participants, including one pattern that demonstrated consistently low adherence (24%) and another pattern that declined over time (16%). Thus, the results indicate the importance of identifying specific adherence patterns to nutritional supplementation for children and adolescents with CF to tailor interventions and improve health outcomes.
- A systematic review and meta-analysis was conducted to determine the safety and efficacy of topical corticosteroids compared to vehicle/moisturizer in childhood atopic dermatitis (<2 years of age) (Fishbein et al., 2019). Following PRISMA guidelines, a search of the relevant literature for randomized controlled trials (RCTs) published from inception to February 15, 2017 was conducted using multiple databases, including PubMed, MEDLINE, EMBASE, Web of Science, Cochrane Database of Controlled Trials, Cochrane Database of Systematic Reviews, DARE, NHS Economic Evaluation, CINAHL, GREAT, and clinicaltrials.gov. The search yielded 636 studies (original age range was expanded after only one article met the inclusion criteria < 2 years of age) with 12 RCT studies that met the revised inclusion criteria. Results across studies indicate that the proportion of children who responded to topical corticosteroids was found to be greater (0.65 at 95% CI, 0.54–0.74) in treating childhood atopic dermatitis as compared to the proportion of responders to vehicle/moisturizer (0.32 at 95% CI, 0.20–0.48). Adverse effects were low and similar between groups. Mild adrenal suppression was reported in 3% of children treated with topical corticosteroids. Although few RCTs have examined the use of topical corticosteroids in children younger than 2 years of age, the results of this review suggest that topical corticosteroids are safe and effective in treating childhood atopic dermatitis with minimal risk of side effects.
- A concept analysis and review of the literature was conducted to examine sleep in infancy (ages birth to 12 months) and to clarify the definition of age-appropriate sleep (Shimko, 2019). The relevant literature was searched for published peer-reviewed articles from 2007 to December 31, 2018 using PubMed, CINAHL, and PsycINFO databases. The search yielded 647 articles with 348 articles that were reviewed for eligibility resulting in 20 studies that met the inclusion criteria. Using the Walker and Avant (2011) approach to concept analysis, a conceptual definition was formulated based on the evidence from the scientific literature. Thus, the refined definition of sleep during the first year of life is that sleep in infancy reflects a dynamic physiologic process that is essential for neurodevelopment characterized by intense neural activity, developing sleep architecture, and sleep consolidation which is different from sleep in adulthood. Thus, the

results of this analysis highlight the importance of sleep for neurodevelopment in infancy and the need for healthcare providers to assess the sleep quality of infants during the first year of life.

- A qualitative descriptive study was employed to explore mothers' perceptions of pain and pain treatment practices among hospitalized newborn infants in level I and II neonatal units in Kenya (Kyololo, Stevens, & Songok, 2019). As part of a large mixed-methods study of mothers' perceptions of pain and pain treatment practices in neonatal units in a low-income country, the qualitative component of the study employed semi-structured interviews with mothers ($N = 15$) using photo-elicitation techniques to describe mothers' perceptions of witnessing their hospitalized newborn infants undergoing painful procedures. Inductive content analysis was used to identify themes describing these mothers' experiences with their newborn infant's hospitalization, resulting in three broad themes: (a) Pain defining the hospitalization experience; (b) Pain-relieving interventions; and (c) Improving pain practices. The results indicate that infant hospitalization was stressful for their mothers when their newborns experienced unexpected painful procedures without adequate comfort measures. Further, the results highlight the importance of healthcare providers involving mothers in comforting their newborn infants during painful procedures.
- A qualitative descriptive approach was used to explore parents' experiences during their child's resuscitation in the hospital (Stewart, 2019). Parents and/or caregivers ($N = 21$; 14 mothers, 6 fathers, 1 grandmother) were interviewed between 1 and 12 months after being present for their child's (ages newborn to 17 years) resuscitation and the majority (81%) of children survived. Thematic analysis of interviews yielded four overarching themes describing the parents' experiences during child resuscitation: (a) Overwhelming chaos; (b) getting through it; (c) cognitive presence; and (d) joy mixed with heartache. Results indicate that although parents experienced overwhelming chaos during their child's resuscitation, being present during their resuscitation, receiving real-time clinical information about their child, and knowing that the healthcare team was invested in their child helped parents cope with the stressful experience. Moreover, these parents' experiences may be useful in guiding healthcare providers' interactions with parents during child resuscitation.
- An electronic survey was administered to interprofessional healthcare providers to explore their perceptions about pediatric death to improve end-of-life care (Kukora, Keefer, Pituch, & Firn, 2019) with the survey ($N = 880$) results reported elsewhere. The focus of this report is responses to one qualitative open-ended question (included in the quantitative survey) about healthcare providers' ($n = 306$; 35% survey participants) experiences surrounding neonatal and pediatric death ($n = 138$ patients). Thematic analysis of the free-text comments yielded three themes describing end-of-life care experiences among neonatal and pediatric patients: (a) Favorable aspects of the death experience; (b) unfavorable aspects of the death experience; and (c) combined favorable and unfavorable aspects. The majority (63%) of comments described aspects of the child's death favorably, while 43% of the comments described negative aspects of the experience. Thus, these qualitative comments by interprofessional healthcare providers offer guidance for improving end-of-life care experiences associated with neonatal and pediatric death.

Striving for independence in self-management of chronic conditions is a developmental challenge for adolescents, young adults, and their parents. Moreover, navigating healthcare transitions from pediatric to adult healthcare represents an additional challenge. In this way, the articles in this issue highlight these challenges while providing new evidence-based intervention strategies to facilitate adaptation to and management of chronic conditions by adolescents, young adults, and parents. As a result, this evidence provides the foundation upon which to change practice, as well as improve health outcomes for adolescents, young adults, and their parents.

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