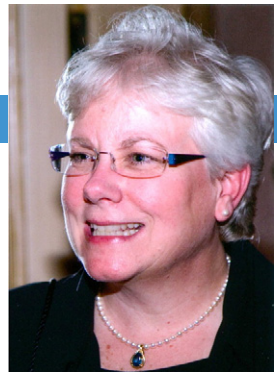
Journal of Pediatric Nursing (2016) **31**, 449–452



Becky J. Christian, PhD, RN, FNAP

RESEARCH COMMENTARY DEPARTMENT

Editor: Becky J. Christian, PhD, RN, FNAP

Translational Research – Balancing the Demands of Chronic Illness Caregiving and Self-Management for Children, Adolescents, and their Parents

Becky J. Christian PhD, RN, FNAP*

School of Nursing, University of Louisville, Louisville, KY

Received 16 May 2016; accepted 17 May 2016

Balancing the demands of chronic illness caregiving and self-management with the health and developmental needs of children and family members creates additional challenges for children and adolescents, their parents and families. Parents and children must meet their health and developmental needs, but the demands on parents and caregivers are magnified when a child has chronic illness and/or developmental and physical disability. Moreover, the shift in caregiving from hospital to home for children with chronic conditions and special healthcare needs has created increased demands on parents and their children to balance the chronic illness demands with the demands of everyday life (Christian, 2010). Parents and children are faced with the challenges of learning about caregiving associated with chronic conditions, teaching self-management to their children, and managing the child's chronic condition to promote functional ability for participation with other children in everyday activities at home and school (Christian, 2003). Balancing the demands of the child's chronic illness with their caregiving needs creates a burden on parent caregivers who may not have adequate support and resources available (Christian, 1993, 1998).

Moreover, as children and adolescents move from being dependent upon parent caregivers to becoming independent in self-management of their chronic conditions and special healthcare needs, new challenges emerge. Healthcare transitions of adolescents and emerging adults with chronic conditions and special healthcare needs create additional challenges for parents and adult healthcare providers (Nehring, Betz, & Lobo, 2015). Transition readiness from pediatric to adult healthcare providers requires that adolescents successfully manage their chronic conditions and special healthcare needs (Huang et al., 2011; Ryan & Sawin, 2009). Yet, barriers continue to exist for successful healthcare transitions by adolescents and young adults due to the lack of integration between pediatric and adult healthcare providers and systems (Betz, 2013). The health of children with chronic illness and special healthcare needs as well as the health of their parent caregivers is improved through translation of research into nursing practice (Christian, 2011, 2014; Hockenberry & Wilson, 2011; Melnyk & Fineout-Overholt, 2014; Polit & Beck, 2012). Thus, balancing the caregiving demands of children with chronic conditions with the needs of individual family members is integral to maintaining quality of life (Christian, 1993, 1998, 2010).

The challenges of balancing the caregiving demands of children with chronic conditions and special healthcare needs require translation of new caregiving strategies as children and adolescents progress to independent self-management and transition to adult healthcare.

In this issue of the *Journal of Pediatric Nursing*, eight articles address the challenges of balancing the caregiving demands of children with chronic conditions and special healthcare needs:

* Corresponding author: Becky J. Christian, PhD, RN, FNAP.
E-mail address: becky.christian@louisville.edu.

http://dx.doi.org/10.1016/j.pedn.2016.05.002

- An integrative review was conducted to explore the role of hope for adolescents with chronic conditions of the peer-reviewed literature published from 1995 to 2015 (Griggs & Walker, 2016). However, the review was expanded to include studies that included both adolescents (11 to 20 years of age) and children (<11 years of age) in their samples. Of the 197 articles retrieved from four databases that met the inclusion criteria, 54 articles were retrieved, including 27 quantitative studies, 9 qualitative studies, and 17 theoretical articles. A synthesis of the literature yielded seven themes with respect to hope among adolescents and children with chronic conditions: (a) *promotes health,* (b) *facilitates coping and emotional adjustment*, (c) *enhances quality of life,* (d) *essential in spirituality/ purpose in life and illness,* (e) *improves self-esteem*, (f) *an important factor in resilience*, and (g) *affects maturation*. Importantly, the role of hope among adolescents with chronic conditions was central to being better able to identify multiple pathways for achieving goals, being more resilient, viewing setbacks as challenges, and managing psychological symptoms associated with chronic conditions.
- A quantitative cross-sectional design study was used to determine the accuracy of nicotine content in electronic cigarette (e-cigarettes) and refill liquids (e-liquids) sold in unlicensed vape stores, as well as child-resistant packaging and sales to minors in North Dakota ($N = 93$ e-liquid samples from 16 vape stores) (Buettner-Schmidt, Miller, & Balasubramanian, 2016). Of the 93 e-liquid samples analyzed for nicotine content, 70 samples were labeled as containing nicotine and 23 labeled as no nicotine. Of the 70 samples with nicotine, 51% were mislabeled, with 17% containing more than the labeled nicotine content, and 34% containing less than the labeled content. Of those remaining 23 samples labeled as being nicotine-free, chemical analysis revealed that 43% of the samples contained nicotine. Moreover, only 35% of the e-liquid refills had child-resistant packaging of the potentially toxic substance. Importantly, mislabeling of e-cigarettes and e-liquids and the lack of child-resistant packaging were identified as potential risks associated with toxic substances for children and adolescents, with key implications for healthcare providers.
- A mixed-methods pilot feasibility study was employed to test the effectiveness and feasibility of a tailored video intervention for teaching inhaler technique to children and adolescents ($N = 25$; ages 7 to 17 years) with asthma by school nurses in a school-based setting (Carpenter et al., 2016). At baseline, only 22% of children demonstrated correct inhaler technique. For the children ($n = 9$, 36%) who used a spacer for metered-dose inhaler (MDI), improvement in technique was demonstrated after watching the video with an increased mean number of steps performed correctly from 6.4 steps to 7.6 steps (8 steps total)($p = .03$), with 100% correct technique demonstrated at 1-month follow-up ($p = .01$). Similarly, for children who did not use a spacer ($n = 16$, 64%), children demonstrated improvement in technique with the mean number of steps performed correctly after watching the video, increasing from 4.5 steps to 7.6 steps (8 steps total)($p < .01$), with sustained improvement (7.3 steps) at 1-month follow-up ($p < .01$). Additionally, focus groups conducted with school nurses ($n = 7$) indicated that use of the tailored video intervention to improve children's inhaler technique was feasible for implementation in a school-based setting.
- A descriptive qualitative study was conducted to describe parent perceptions ($N = 18$ parents; 16 mothers, 2 fathers) of family caregiving during transition from hospital to home for their child (infants to adolescents) with a tracheostomy (Callans, Bleiler, Flanagan, & Carroll, 2016). Focus groups were conducted to obtain parents' perspectives associated with the transitional experiences from hospital to home caregiving for a child with a tracheostomy. Four key themes were identified by parents caring for their child with a tracheostomy: (a) *This is not the life I had planned: Coming to accept the new reality;* (b) *Don't make the hospital your home; don't make your home a hospital;* (c) *Caregivers engage with providers that demonstrate competence, confidence, attentiveness, and patience;* and (d) *Participants value the opportunity to give back and help others.* Importantly, parents' perspectives about caregiving and the transition from hospital to home provided valuable insight and information for nurses to improve family members' ability to care for their child with a tracheostomy.
- A descriptive qualitative study was conducted to describe the perceptions of adolescents ($N = 15$; 12 to 18 years) with Type I diabetes and their parents ($N = 25$ parents; 15 mothers, 10 fathers) with respect to stressors associated with transition to self-management (Ersig, Tsalikian, Coffey, & Williams, 2016). Telephone interviews were conducted with adolescents with Type I diabetes (T1DM) and their parents. For adolescents, the primary stressors focused on ineffective self-management and anticipatory worry. Parents' perspectives of stressors associated with transition to self-management of their adolescents with T1DM were focused on four themes: (a) *control of management responsibility*, (b) *anticipatory worry*, (c) *health care transition with changes in health insurance,* and (d) *resources for Type I diabetes management.* Thus, both adolescents and their parents identified stressors focused on the process of shifting self-management responsibilities associated with T1DM from parents to adolescents.
- The effects of kangaroo care in the Neonatal Intensive Care Unit (NICU) on the physiological functions of preterm infants ($N = 40$), maternal–infant attachment, and maternal stress was determined in a quasi-