

Developing a Transition Care Coordination Program for Youth With Spina Bifida

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ABSTRACT

Introduction: This quality improvement pilot study focused on developing and facilitating readiness for transition in youth with spina bifida. The results contribute to a broader institution-wide initiative at a subspecialty pediatric organization.

Methods: The clinical roles of six nurse care coordinators were restructured to add responsibility for transition care coordination. Together, parents, youth, and nurse transition care coordinators created and implemented individualized family-centered care plans focused on improving self-management and readiness for transition to adulthood. The Transition Readiness Assessment Questionnaire was administered before and after intervention initiation.

Results: Fourteen youth–parent pairs participated in this study. Postintervention Transition Readiness Assessment Questionnaire results indicated that both parents and youth perceived improvement in transition readiness. Youth perceived more improvement than did parents.

Discussion: This pilot study showed that budget-neutral processes can be systematically implemented to facilitate transition preparation from pediatric to adult health care services for youth with spina bifida and their families. *J Pediatr Health Care.* (2017) ■, ■-■.

KEY WORDS

Adolescence, care coordination, children with medical complexity, spina bifida, transition

BACKGROUND

Spina Bifida

Spina bifida is the most complex congenital disorder with which infants are expected to survive long term (Bowman, McLone, Grant, Tomita, & Ito, 2001; Liptak & Samra, 2010). Spina bifida is a complex neuroembryologic disorder resulting from incomplete closure of the posterior neural tube. Most of these children live with hydrocephalus, neuromuscular scoliosis, neurogenic bowel and bladder, and limited mobility (Bowman et al., 2001; Liptak & Samra, 2010). They typically need ongoing subspecialty care that ideally includes neurosurgery, urology, physical medicine and rehabilitation, and orthopedic care. Some patients may also need neurology, sleep medicine, pulmonology, or psychiatry care. Additionally, many children require rehabilitation therapy services, psychology, neuropsychology, and assistive technology services.

Children with spina bifida are considered *medically complex*, defined as medically fragile and having the most intensive health care needs (Cohen et al., 2011). Hampton et al. (2011) and

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O'Hara and Holmbeck (2013) explain that children with spina bifida often have executive functioning problems, specifically difficulty with planning, organization, and processing. In particular, those with spina bifida combined with hydrocephalus have more cognitive challenges compared with those without hydrocephalus (Iddon, Morgan, Loveday, Sahakian, & Pickard, 2004). A study by Beal et al. (2016) examined health care transition readiness for groups of adolescents with varying chronic conditions. The subjects with spina bifida scored significantly lower than other groups in readiness measures, thought to be related to their executive functioning difficulties. The authors suggest that their findings support the need for additional transition services for adolescents with spina bifida (Beal et al., 2016).

In addition to physical and cognitive challenges, young adults with spina bifida report a poorer quality of life and lower rates of employment and independent living. They are vulnerable to lagging behind developmentally when entering adulthood and are at risk for isolation in their communities (Bellin et al., 2011). A study by Zuckerman, Devine, and Holmbeck (2010) found that compared with typically developing peers, adolescents with spina bifida were less likely to achieve adult milestones of leaving home, attending college, obtaining employment, having romantic relationships, and maintaining friendships. Evidence-based interventions are critical to support youth with spina bifida and their families through their developmental stages and facilitate achievement of milestones and good quality of life. Children with medical complexity require focused, coordinated care by experienced providers who excel with this population (Cohen et al., 2011).

Transition

The focus of transition is preparing youth for adult life, helping them gain autonomy and independence, and creating plans for their futures (financial, living, and care assistance). Transitioning from pediatric to adult services requires numerous intentional processes over time for children with spina bifida. Multiple medical, psychosocial, educational, and vocational needs must be addressed (White, McManus, McAllister, & Cooley, 2012). During the transition process, youth with special health care needs must gain the knowledge, skills, and experience necessary to gradually take responsibility for their own health-related tasks (White et al., 2012). Failure to appropriately transition can slow the typical developmental process of gaining independence and can lead to adult health-related problems or lack of anticipatory guidance (Shah & Boudos, 2012). Gaps in care during the transition period are common and may result in increased hospitalizations and poor health outcomes (White et al., 2012). Heath, Farre, and Shaw (2017) caution providers that transition cannot involve only youth. Parents and adolescents together create

the emotional environment necessary for successful adaptation to the transition process, which requires parents to gradually relinquish control and support adolescent autonomy appropriately (Heath et al., 2017).

Tools are available to measure the tasks and skills necessary for transition from pediatric to adulthood and adult health care. The Transition Readiness Assessment Questionnaire (TRAQ) is a widely used validated 20-item instrument, a patient-report assessment of health and self-management skills (Wood et al., 2014). According to Zhang, Ho, and Kennedy's 2014 systematic review of 10 transition readiness tools, TRAQ was the best tool, and it showed appropriate content validity, construct validity, and internal consistency.

Creating programs to support patients' and families' achievement of developmentally appropriate transition into adulthood not only leads to improved health outcomes but also increases youth self-worth and independence. With advances in health care and medical technology, children with medical complexity are surviving longer, highlighting the importance of effective transition (Grant & Pan, 2011). The American Academy of Pediatrics (2011) stressed the importance of transition for children and youth with special health care needs and explained that both primary care and subspecialty care providers have roles in this process. Unfortunately, of all Medical Home goals, moving transition forward is the only goal that made minimal progress between 2005 and 2010 (McManus et al., 2013). Barriers to transition planning include limited staff training, financial barriers, and a lack of identified staff members responsible for transition planning. Delays may also be related to provider, parental, and adolescent anxiety regarding the transition process (McManus, Fox, O'Connor, Chapman, & MacKinnon, 2008).

Despite poor progress achieving transition goals and numerous barriers for implementation, work continues to develop effective transition care programs.

Kaufmann Rauen et al.

(2013) stressed the importance of communication between team members when developing transition programs. Effective collaboration between pediatric and adult care providers is especially important. Reiss (2012) developed the Transition Oriented Health Supervision framework to facilitate active involvement of adolescents in their own health care. Transition Oriented Health Supervision has eight steps: (a) build an alliance

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