ARTICLE

Descriptive Analysis and Profile of Health Care Transition Services Provided to Adolescents and Emerging Adults in the *Movin' On Up* Health Care Transition Program

Cecily L. Betz, PhD, RN, FAAN, Kathryn Smith, DrPH, RN, Alex Van Speybroeck, MD, MPH, Robert A. Jacobs, MD, MPH, Natalie Rivera, MA, Jeannie Lee, BS, Saba Saghhafi, BS, Benjamin Nguyen, BS, & Hao Tu, BS

ABSTRACT

Global efforts are underway to develop, implement and test health care transition (HCT) models of care. Most studies have focused on the transfer of care models. In contrast, the nurse-led interdisciplinary HCT model, *Movin' On Up*, provides comprehensive HCT services beginning in early adolescence. A retrospective analysis was conducted of data extracted from HCT records of 146 adolescents and emerging adults

Cecily L. Betz, Professor of Clinical Pediatrics, Keck School of Medicine, Department of Pediatrics; Director of Research/Director of Nursing Training, USC University Center of Excellence at CHLA; Director, Movin' On Up Health Care Transition Program, Children's Hospital Los Angeles Spina Bifida Program; and Editor-in-Chief, Journal of Pediatric Nursing, Los Angeles, CA.

Kathryn Smith, Associate Professor of Clinical Pediatrics, Keck School of Medicine, Department of Pediatrics; Associate Director of Nursing Training, USC University Center of Excellence at CHLA; and Co-Director, Children's Hospital Los Angeles Spina Bifida Program, Los Angeles, CA.

Alex Van Speybroeck, Assistant Professor of Clinical Pediatrics, Keck School of Medicine, Department of Pediatrics and Co-Director, Children's Hospital Los Angeles Spina Bifida Program, Los Angeles, CA.

Robert A. Jacobs, Professor of Clinical Pediatrics, Keck School of Medicine, Department of Pediatrics, and Division Head, General Pediatric Services, Children's Hospital Los Angeles.

Natalie Rivera, Research Assistant, Children's Hospital Los Angeles Spina Bifida Program, Los Angeles, CA.

Jeannie Lee, Research Assistant, Children's Hospital Los Angeles Spina Bifida Program, Los Angeles, CA.

Saba Saghhafi, Research Assistant, Children's Hospital Los Angeles Spina Bifida Program, Los Angeles, CA.

Benjamin Nguyen, Research Assistant, Children's Hospital Los Angeles Spina Bifida Program, Los Angeles, CA.

Hao Tu, Research Assistant, Children's Hospital Los Angeles Spina Bifida Program, Los Angeles, CA.

Conflicts of interest: None to report.

Correspondence: Cecily L. Betz, PhD, RN, FAAN, Department of Pediatrics, Keck School of Medicine, Los Angeles, CA 90027; e-mail: cbetz@chla.usc.edu

0891-5245/$36.00

https://doi.org/10.1016/j.pedhc.2017.11.006

with spina bifida (with a mean age of 13.91 years) who were provided services in the *Movin' On Up* HCT program. Data were categorized based on the Health Care Transition Research Consortium HCT model and the Omaha System framework and as to type of direct HCT services provided by the HCT Specialist and nurse-led interdisciplinary team conferences conducted. Findings revealed that the scope of services provided represented the scope of comprehensive needs beyond those associated with the transfer of care. J Pediatr Health Care. (2017) ■■, ■■-■■.

KEY WORDS

Adolescents and emerging adults, health care transition, nurse-led, spina bifida

INTRODUCTION

Acknowledgement of the health care transition (HCT) service needs of adolescents and emerging adults (AEAs) with special health care needs (SHCN) has generated considerable attention recently, as evidenced by the systematic reviews published in recent years (Bloom, Kuhlthau, Van Cleave, Knapp, Newacheck, & Perrin, 2012; Chu, Maslow, von Isenburg, & Chung, 2015; Wafa & Nakhla, 2015; Betz, O'Kane, Nehring, & Lobo, 2016; Coyne, Hallowell, & Thompson, 2017). There have been impressive achievements in the treatment of children with SHCN that have extended their life expectancies such that more than 90% survive into adulthood (Perrin, Anderson, & Van Cleave, 2014; Pinzon, Harvey, & Canadian Paediatric Society, Adolescent Health Committee, 2006). For example, among children born with spina bifida (SB), 60% are expected to survive into emerging adulthood (i.e., into their 20s; Roebroeck, Jahnsen, Carona, Kent, & Chamberlain, 2009).

Widespread international efforts are underway to develop, implement, and test the effectiveness of HCT service models based on the recommendations of pediatric and adult professional associations and experts (Cadario et al., 2009; Hankins et al., 2012; Pyatak et al., 2017; Vanelli et al., 2004). HCT service recommendations have been primarily generated by the medical community, with a heavy emphasis on the transfer of care from pediatric primary and specialty care to their adult counterparts (American Academy of Pediatrics American Academy of Family Practice, & American College of Physicians–American Society of Internal Medicine, 2002; American Academy of Pediatrics et al, 2011; Baldassano et al., 2002; Geerlings et al., 2015; Rosen, Blum, Britto, Sawyer, & Siegel, 2003).

These HCT models of care also emphasize enrollment in adult insurance coverage and the corresponding logistical processing (i.e., medical records; Cadario et al., 2009; Hankins et al., 2012; Pyatak et al., 2017; Steinbeck et al., 2015). Although the HCT models of care are comparable in focus, their implementation is varied. Different models included joint pediatric/adult provider clinic appointments with medical record summary (Cadario et al., 2009); tour of the adult clinic with introduction to adult providers, with follow-up debriefing by pediatric providers (Hankins et al., 2012); transfer to specialty clinic for a defined age range of AEAs before transfer to adult services (Pyatak et al., 2017); and scheduling adult provider appointments with follow-up calls, electronic listings of adult health care, and community-based resources (Steinbeck et al., 2015).

Comprehensive models of care are based on a broad range of activities, including self-management instruction, service coordination, and referrals, that are more extensive than those provided in transfer-of-care models, which focus only on health care programs. Referrals within comprehensive care models include resource information and access to community-based programs/services for education, training, employment, recreation, and community living/housing purposes (Betz, O'Kane, Nehring, & Lobo, 2016; Geerlings et al., 2015; Sheehan, While, & Coyne, 2015).

More recently, the Society of Pediatric Nurses issued a position statement on health care transition, entitled "Transition of Pediatric Patients Into Adult Care," with guidelines based on an inclusive model of care for all adolescents, including those with SHCN (Betz, 2017). The framework of HCT services is based on a comprehensive model of care addressing the biopsychosocial needs of AEAs as their care is transferred to the adult health care system and as they transition to emerging adulthood (Arnett, 2000; Betz et al., 2014).

Given the emerging development of this field of practice and science, efforts are currently underway by advanced practice interdisciplinary (ID) specialty clinicians and researchers to develop, implement, and test HCT models of care. Recently published systematic reviews of HCT service models provide scant evidence to guide the development of intervention services or models of care (Betz, O'Kane, Nehring, & Lobo, 2016; Bloom et al., 2012; Chu et al., 2015; Coyne et al., 2017; Embrett, Randall, Longo, Nguyen, & Mulvale, 2016; Le Roux et al., 2017; Prior, McManus, White, & Davidson, 2014). As these reviews indicate, there are significant methodologic and design limitations that are associated with the studies published to date. Of particular interest is the lack of information provided on the HCT intervention services/models themselves, posing challenges with model replication and development. Furthermore, reliable and valid measurements of HCT outcomes from which to draw conclusions about the effectiveness of models are scarce (Betz & Smith, 2010; Coyne, Hallowell, & Thompson, 2017). The HCT models investigated have focused on the transfer of care rather than on more comprehensive, longer-term HCT service beyond the circumscribed period of the transfer of care (Betz, O'Kane, Nehring, & Lobo, 2016; Chu, Maslow, von Isenburg, & Chung, 2015; Coyne et al., 2017). A longitudinal HCT model of care is predicated on the acknowledgement that AEAs with SHCN have complex biopsychosocial and developmental needs requiring