



Uncharted Territory: Systematic Review of Providers' Roles, Understanding, and Views Pertaining to Health Care Transition¹

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Background: Health care transition (HCT) for adolescents and emerging adults (AEA) with special health care needs is an emerging field of interdisciplinary field of practice and research that is based upon an intergenerational approach involving care coordination between pediatric and adult systems of health care. Informed understanding of the state of the HCT science pertaining to this group of providers is needed in order to develop and implement service programs that will meet the comprehensive needs of AEA with special health care needs.

Methods: The authors conducted a systematic review of the literature on the transition from child to adult care for adolescents and emerging adults (AEA) with special health care needs from 2004 to 2013. Fifty-five articles were selected for this review. An adaptation of the PRISMA guidelines was applied because all studies in this review used descriptive designs.

Results: Findings revealed lack of evidence due to the limitations of the research designs and methodology of the studies included in this systematic review. Study findings were categorized the following four types: adult provider competency, provider perspectives, provider attitudes, and HCT service models. The discipline of medicine was predominant; interdisciplinary frameworks based upon integrated care were not reported. Few studies included samples of adult providers.

Conclusions: Empirical-based data are lacking pertaining to the role of providers involved in this specialty area of practice. Evidence is hampered by the limitations of the lack of rigorous research designs and methodology.

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HEALTH CARE TRANSITION (HCT) is a specialty field of practice based on an interdisciplinary practice framework of care and is part of the care for individuals

with chronic, long-term, and intellectual disability conditions. Although transitions in care can cover different developmental periods, or movement between different levels of care, we focused on the transition from child to adult care for adolescents and emerging adults (AEA) with special health care needs (SCHN).

Specifically, HCT should be more appropriately conceptualized as a combined intergenerational practice specialty caring for this population, that is, those who work with children and AEA who are familiar with the

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developmental stages of early life. The professionals who specialize in adult care are conversant with the middle to final stages of life. This counterbalance of clinical practice has contributed, in part, to the continued challenges of transition specialty practice. HCT, although identified as a clinical need several decades ago, has faltered in its development as a practice specialty (Bloom et al., 2012; Freed & Hudson, 2006; Magrab & Millar, 1989; McPheeters et al., 2014).

The challenges in the developing field of HCT practice are formidable in that both pediatric and child health interdisciplinary professionals are expected to develop an additional repertoire of knowledge and skills that are firmly rooted in adult health care and the accompanying areas of adult development. Likewise, adult providers² are now faced with providing services to populations of adults for whom they have received scant, if any, professional training (American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians-American Society of Internal Medicine, 2002; Freed & Hudson, 2006; McPheeters et al., 2014; Okumura et al., 2010; Patel & O'Hare, 2010). The convergence of an integrated system of care between these two very different spheres of practice has been difficult to achieve, with no clear pathway to adult care (Betz, 2013; DeBaun & Telfair, 2012; Gleeson & Turner, 2012; Harden et al., 2012). Typically, transition systems of health care have been developed based on the individual efforts of single pediatric and adult institutions. To date, templates of best practice and training standards have not been developed. The recently published report by the Transitions Clinical Report Authoring Group (American Academy of Pediatrics, American Academy of Family Physicians, & American College Physicians, Transitions Clinical Report Authoring Group, 2011) is the most reasonable template that approximates identification of an algorithm that prescribes areas of practice. This field continues to remain elusive (Bloom et al., 2012; Bryant & Walsh, 2009; Crowley, Wolfe, Lock, & McKee, 2011; McPheeters et al., 2014).

This systematic review is designed to answer the following questions pertaining to HCT of AEA-SHCN: 1) What is the state of the HCT science pertaining to the role of providers involved in this specialty area of practice? 2) What research problems or questions have been investigated pertaining to providers involved with HCT? 3) What evidence has been generated that can be applied to improve the HCT training or service competencies of pediatric and adult health care professionals? and 4) What evidence can be applied to the provision of HCT services for AEA-SHCN?

Method

The articles included in this systematic review covered the period of 2004 to 2013 and were taken from the PsycINFO, MEDLINE (OVID), and EBSCO databases. These databases were selected because articles published in the field are primarily listed in these three databases; however, the preponderance of articles was located in MEDLINE (OVID). The following search terms were used: *disability* or *chronic* or *special health care needs* and *transition*. In addition, the research team reviewed the reference lists of all research articles obtained from the databases searched and retrieved additional HCT-related publications. The third component of the search involved reviewing and retrieving other articles from previously published systematic reviews and reviews of literature (Bloom et al., 2012; Bryant & Walsh, 2009; Christie & Viner, 2009; Crowley et al., 2011; Jalkut & Allen, 2009; Pai & Ostendorf, 2011; Rapley & Davidson, 2010; Sawyer & Macnee, 2010; Wang, McGrath, & Watts, 2010; Watson, Parr, Joyce, May, & Le Couteur, 2011). The search process, based on PRISMA guidelines (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009), is detailed in Box 1. A total of 55 studies were included in this systematic review of literature (Table 1).

The search resulted in a total of 745 full-text articles or complete reference abstracts if the full text article was not available. Two members of the research team separately reviewed all articles and excluded those using the following criteria: a) clinical topics; b) conference abstracts; c) not published within the review timeframe; d) inadequate description of the research; and e) published in a language other than English. Studies included in this systematic review were those that met the following inclusion criteria: a) published from January 2004 to December 2013; b) sufficient description of the research design and methodology provided; c) written in English; and d) findings about health care providers could be clearly identified. If team members differed in their appraisal of whether an article should be included, they re-reviewed their appraisal until consensus was achieved. At the conclusion of this vetting process, the number of articles was reduced to 260. Articles were then selected by the primary author with the consensus of the other two team members, to narrow the number of articles to include only studies whose samples were composed of providers, resulting in a total of 64 articles. Next, studies were excluded if the findings generated from providers could not be critically reviewed. A total of nine studies were eliminated from the review for the following reasons: a) subjects were not HCT professionals (Bhaumik et al., 2011); b) subsample groups were merged (Pickler, Kellar-Guenther, & Goldson, 2011; Reiss, Gibson, & Walker, 2005; Repetto, Gibson, Lubbers, Gritz, & Reiss, 2008; van Staa, Jedeloo, van Meeteren, & Latour, 2011; Vijayan, Benin, Wagner, Romano, & Andiman, 2009); c) merger of age groupings (Darrach, Wiart, Magill-Evans, Ray, & Anderson, 2010); and d) parents/AEA-SHCN responded to questions about providers (Nishikawa, Daaleman, & Nageswaran, 2011; Sawicki et al., 2011). A total of 55 studies were included in this review of literature (Table 1).

² For the purposes of this paper, the meaning of the term *provider* is used interchangeably to refer to a specific discipline or several disciplines. The context of its meaning is dependent upon its use in this paper. This term was used to be inclusive rather than denote one discipline to avoid circumstances of undue wordiness.

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