



Systematic Review of the Impact of Transition Interventions for Adolescents With Chronic Illness on Transfer From Pediatric to Adult Healthcare¹

Patricia Y. Chu AB^{a,*}, Gary R. Maslow MD, MPH^{b,c}, Megan von Isenburg MSLS^d, Richard J. Chung MD^{b,e}

^aDuke University School of Medicine, Durham, NC

^bDepartment of Pediatrics, Duke University School of Medicine, Durham, NC

^cDepartment of Psychiatry, Duke University School of Medicine, Durham, NC

^dDuke University Medical Center Library

^eDepartment of Medicine, Duke University School of Medicine, Durham, NC

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Transfer from pediatric to adult care is a critical component of a high-quality transition experience for adolescents and young adults (AYA) with chronic illness. To examine the current evidence regarding the effect of transition interventions on care transfer, we performed a systematic review of studies that evaluated the effect of transition interventions on the specific health services outcome of transfer. The Medline, CINAHL, and PsycINFO databases were searched for studies that evaluated 1) a discrete transition intervention for AYA, 2) included a comparison group, and 3) reported on the outcome of transfer from pediatric to adult healthcare. References were screened and reviewed separately by authors, and relevant study details were abstracted during the review process. Five studies from five different countries were included in the final analysis. All five studies were conducted in specialty care clinics, with three interventions involving a nurse practitioner or systems navigator and two interventions involving physicians. Four studies were retrospective observational studies, and one was a pilot randomized controlled trial. Three of the five studies found that the transition intervention was associated with increased rates of transfer while the other two showed no statistically significant effects. Overall, evaluation of transfer appears to be hindered by methodological challenges. Establishing clearer definitions and metrics of transfer and creating the infrastructure needed to monitor the transfer of patients more consistently are important goals.

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Background

OVER THE PAST decade, the transition from pediatric to adult health care of adolescents and young adults (AYA)

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* Corresponding author: Patricia Y. Chu, AB.

E-mail address: patricia.chu@duke.edu.

with a variety of chronic health conditions has garnered increasing attention (Baldassano et al., 2002; Committee on Pediatric Aids, 2013; Crowley, Wolfe, Lock, & McKee, 2011; DeBaun & Telfair, 2012; Freyer, 2010; Jurasek, Ray, & Quigley, 2010; Peters & Laffel, 2011; Prior, McManus, White, & Davidson, 2014; Reiss & Gibson, 2002; Sable et al., 2011; Tuchman, Schwartz, Sawicki, & Britto, 2010). The increased attention is due, in part, to a growing body of

evidence that shows that AYA access to and use of healthcare services decline significantly during the transitional period and that this decline in health service utilization is associated with worse health outcomes (Blinder et al., 2013; Camfield & Camfield, 2011; Hemker, Brousseau, Yan, Hoffmann, & Panepinto, 2011; Lotstein et al., 2013; Sawyer, Drew, Yeo, & Britto, 2007; Sheehan, While, & Coyne, 2015). Recent systematic reviews of the transition experiences of young adults with type 1 diabetes and congenital heart disease have shown that young adults have a much lower clinic attendance rate after transferring to adult care (Heery, Sheehan, While, & Coyne, 2015; Sheehan et al., 2015). For example, one Canadian study of AYA with complex congenital heart disease found that less than half of the young adults studied successfully transferred to the adult heart center within a 2 year period and that patients who did not transfer reported significantly more comorbidities than those who did (Reid et al., 2004). The low transfer rate is striking given that clinical guidelines advise follow-up at least every 6 months. The root causes of such gaps in care and suboptimal transfers are varied, and may be related to loss of health insurance in the United States or to a number of other provider-, patient-, and family-related barriers to health care transition articulated elsewhere (Fair, Sullivan, Dizney, & Stackpole, 2012; Okumura et al., 2010; Peter, Forke, Ginsburg, & Schwarz, 2009; Reiss, Gibson, & Walker, 2005).

To improve the quality of care of AYA during this critical transitional period, the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians released a joint clinical report in 2011 that provided detailed guidance for transitioning all youth, including those with special healthcare needs (Cooley & Sagerman, 2011). Based on this guidance, the Got Transition/National Center for Healthcare Transition developed several tools to promote quality improvement efforts within practices and health systems, and enumerated the six core elements of health care transition clinical practice: 1) establishment of a transition policy; 2) transition tracking and monitoring; 3) assessment of transition readiness; 4) transition planning; 5) transfer of care; and 6) transfer completion (Got Transition/Center for Health Care Transition Improvement, 2014).

The joint clinical report on transitions and the Got Transition guidelines have spurred increased investigation of various aspects of health care transition including transition readiness assessment, transition planning, and biomedical outcomes such as disease status following transition (Fernandes et al., 2012; Fredericks et al., 2010; Gurvitz et al., 2013; McPherson, Thaniel, & Minniti, 2009; Moynihan, Saewyc, Whitehouse, Paone, & McPherson, 2013; Nakhla, Daneman, To, Paradis, & Guttmann, 2009; Reid et al., 2004; Sawicki et al., 2011; Wiener, Zobel, Battles, & Ryder, 2007; Wray, Frigiola, & Bull, 2013; Yeung, Kay, Roosevelt, Brandon, & Yetman, 2008). However, to date, the rigorous criteria for evaluating intervention studies in other areas of pediatric research have not been broadly applied to the evaluation of transition

interventions. Transfer of care, one of the six Got Transition core principles, is an important health services measure that may reflect on an individual patient's transition preparation and may predict future outcomes.

The present study aims to systematically review the current health care transition literature to identify studies that evaluated the effect of a transition intervention on the discrete outcome of transfer from pediatric to adult care.

Methods

Framework and Definitions

In order to evaluate the impact of transition programs on transfer from pediatric to adult care, the population of interest chosen for this review included adolescents and young adults ages 14 to 25 years with chronic medical illness since transfer is most likely to occur in this age group. The interventions of interest were any discrete transition interventions that were formal hospital or clinic-affiliated programs that aimed to fulfill at least one of the six Got Transitions core elements. The comparisons of interest were between patients who participated in transition programs and others who did not. The outcome of interest was transfer, which was defined as attending at least one appointment with an adult healthcare provider. Transfer was chosen because it is one of the Got Transitions core principles, and it is an important health services process measure associated with future health outcomes that is discretely measurable.

Literature Search

The PubMed, Embase, and PsycInfo databases were searched using a strategy developed by a medical librarian (MvI) in collaboration with the other authors. The search combined a comprehensive list of relevant subject headings and textwords for chronic illness (both in general and including specific chronic illnesses), healthcare transitions, and the adolescent and young adult age group. No date limits were applied, and results were limited to English language publications. Additional articles were identified through review of the reference lists of relevant review articles. The full search strategy is included as on-line supplement Appendix 1.

Study Selection

Two reviewers (PC and RC) independently reviewed the titles of all publications produced by the initial search using the framework outlined in Figure 1. Titles that were definitively unrelated to the review focus were excluded. The abstracts of the remaining articles were reviewed with reference to the following criteria: (1) the publication was an evaluative study of a discrete transition intervention and included a comparison group; (2) the population studied included adolescents and/or young adults; and (3) the publication included outcomes data on transfer from pediatric to adult care. Abstracts that definitively did not meet these criteria were excluded. Using the aforementioned criteria, the remaining articles were then reviewed in full by three authors (RC, PC, and GM) to determine final inclusion or exclusion from analysis.

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