

Transition of the Chronically Ill Youth With Hemoglobinopathy to Adult Health Care: An Integrative Review of the Literature

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ABSTRACT

With the advent of innovative technologies and medical advances, more than a half million chronically ill youth (CIY) cross the threshold into adulthood yearly. Successful transition of the CIY with hemoglobinopathy (e.g., sickle cell, thalassemia) from pediatrics to adult care continues to be an inconsistent process. The purpose of undertaking a comprehensive empirical review was to synthesize the transition literature focusing on CIY with hemoglobinopathy and clinical recommendations. Among 17 studies critically reviewed and summarized, five studies focused on the CIY with hemoglobinopathy, and the remainder on youth with other

chronic conditions. Further research on transition, especially for CIY with hemoglobinopathy, is needed. *J Pediatr Health Care.* (2009) 23, 37-48.

Key words: Young adult, adolescent, transition to adult care, chronically ill youth, hemoglobinopathy

More than 30 years ago, the majority of chronically ill children did not survive into adulthood. With the advent of innovative technologies and medical advances, approximately 750,000 chronically ill adolescents cross the threshold yearly into adulthood (Scal & Ireland, 2005). Successful transition of chronically ill youth (CIY) from pediatric to adult care continues to be a challenging process. Often, the transitioning experience consists of an abrupt transfer, which leaves the youth unprepared for the movement to adult health care (Hauser & Dorn, 1999; Scott, 2006; Wojciechowski, Hurtig, & Dorn, 2002). Consequently, the adolescent may not keep follow-up appointments with the new provider and may return to the pediatric provider or the emergency department for health care (Hauser & Dorn). Because CIY with hemoglobinopathy are at risk of having severe medical complications develop (e.g., sepsis and severe anemia), obstacles that impede transition to adult care must be identified to promote an uninterrupted transfer to adult health care. This comprehensive literature review on the transition of the CIY to adult health care was undertaken to synthesize the transition literature focusing on youth with hemoglobinopathy (e.g., sickle cell disease [SCD], thalassemia, and severe hereditary spherocytosis) and identify related clinical recommendations.

METHOD OF REVIEW

A comprehensive exhaustive literature search on the transition to

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adult health care was conducted by using MEDLINE, Cumulative Index of Nursing and Allied Health Literature (CINAHL), PsycINFO, UpToDate, the Agency for Healthcare Research and Quality (AHRQ), MD Consult, Cochrane Database of Systemic Reviews, ProQuest, National Guideline Clearinghouse, Web of Science, and several organizational Web sites such as the American Academy of Pediatrics (AAP), the American Heart Association, and Sigma Theta Tau International. The search limitations included children to young adult age bracket, the English language, and publication dates from 1980 to 2007. The search strategies also included searching the names of authors who had published more than one article on transition to adult health care. The search terms and phrases utilized were: adolescent, young adult, chronically ill youth and hemoglobinopathy, pediatric-oriented care, adult-oriented care, children and special health care needs, transition program, transfer program, continuity of care, transitional strategy, transitional barriers, transition to adult care, and transfer to adult care.

Initially, the inclusion criteria consisted of transition search terms, age range, and the English language, with the only exclusion criteria being middle to older age individuals. However, after sorting through a plethora of nonempirical literature published on chronically ill youth's transition to adult health care, the exclusion criteria were broadened to include commentaries, editorials, and case studies on transition. The reference lists of each research study were perused to identify other related studies. A hand search of nursing, medical, and psychological journals, books, position papers, and conference proceedings was performed until the references became repetitive in the literature.

HISTORICAL ASPECTS

Expert panels, publications, conferences, and policy statements

have discussed facilitating an organized, coordinated transition for young people with chronic conditions from the child to the adult health care system (Blum, 1995; McGrab & Millar, 1989; Rosen, 1995). In 1984, the United States Surgeon General co-hosted a national invitational conference with the Under Secretary of Education, focusing on the needs of older adolescents with chronic and disabling conditions. This conference provided the first national focus on health care transition issues (McGrab & Millar). The Society for Adolescent Medicine addressed the problem of transition in a position paper delineating recommendations for transition funding, research on outcomes of transition programs, investigation of multiple transition models, and education concerning transition issues among health care trainees and providers (Blum et al., 1993). The American Academy of Pediatrics (AAP) (1996; 2002) published policy statements describing the importance of the health care provider role to educate and advocate for youth and family in promoting transition to adult health care.

Since the 1980s, a limited number of empirical studies have been published on transition of the CIY to adult care, especially for youth with hemoglobinopathies. To compile a comprehensive review of the transition literature, it was necessary to supplement the paucity of hemoglobinopathy studies with transition studies on a variety of chronic illnesses (e.g., cystic fibrosis [CF], diabetes, and disabilities). The literature review identified 17 empirical studies that met the inclusion criteria, with only five of the studies focusing on hemoglobinopathies (Tables 1-3). All of the transition studies were published in peer-reviewed journals. The studies are listed in Tables 1, 2, and 3, which are divided into five areas: author and date, design and purpose, subjects, key findings, and clinical recommendations. In reviewing the 17 studies, three

main transitional obstacles consistently emerged from the literature: (a) five studies focused on the lack of transitional support (Table 1); (b) six studies focused on limited transitional programs (Table 2); and (c) the remaining six studies focused on transitional resistance toward adult health care (Table 3).

TRANSITIONAL OBSTACLE: LACK OF TRANSITIONAL SUPPORT

Lack of transitional support was described in the following five studies that focused on the lack of available resources to support transitional programs for the CIY. Scal (2002) surveyed 13 out of 36 health care providers who were nominated by CIY's caretakers. After receiving a mailed investigator-developed survey, the health care providers identified lack of transitional support (e.g., no time for transition planning, no resources, and no personnel) and difficulty in finding or communicating with an adult subspecialist medical provider as factors that interfered with the transfer of the CIY (e.g., CF and epilepsy) to adult health care (Scal). Scal's study identified other factors such as lack of time to address transition issues, lack of additional training for the health care provider in relation to adolescent developmental and emotional issues, lack of utilization of transition services (e.g., insurance coverage, employment and/or school guidance) and limited community based resources, which was a factor supported in another study by Scal & Ireland (2005).

The lack of transitional support was identified in a cross-sectional study using a random digit-dial method. The study surveyed a sample of 4332 out of 4426 eligible parents of youth aged 14 to 17 years obtained from 2000-2001 National Survey of Children with Special Health Care Needs (Scal & Ireland, 2005). The Health Care Transition (HCT) survey asked the parents if the health care provider (HCP) addressed transition issues during

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