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Transition to Adult Care: A Statewide Survey among Pediatric Hemoglobinopathy Specialty Centers in New York

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Abstract

Background: Transition from pediatric to adult medicine for young adults with special health care needs to be performed in an uninterrupted, patient-centered and comprehensive manner. In order to assess the health care status of children with hemoglobinopathies and identify plans and barriers in transition from pediatric to adult care, we conducted a statewide survey among hemoglobinopathy specialty care centers that receive newborn screening referrals.

Methods: An invitation via email with a link to the web-based survey containing 16 questions regarding transition to adult care was sent to center directors of all 33 hemoglobinopathy specialty care centers in New York State. Non-responders were contacted and asked to complete the survey over the phone.

Results: Overall, 28 (85%) of 33 centers completed the survey. Adult care was provided in all responding centers; 39% had transition plans/programs in place and 50% were in the process of developing a transition program. Current patient census figures ranged from 4 to 550 for sickle cell disease, and 1 to 130 for thalassemia. The maximum age of pediatric admission was from 18 to 28 years, and the transition occurred in between 18 and 25 years of age. With regard to the mode of transition, 75% of the transfers were initiated because of age or pregnancy and 57% of the transfers were based on the individualized transition plan. Financial difficulty, adolescent or family resistance, and differences between pediatric and adult centers were cited as the barriers to transition by more than 50% of the Centers.

Conclusions: In New York State, most transition is guided by an individualized and prepared transition plan. Financial support and assurance of adult care for patients and families are necessary.

Keywords: Sickle cell disease; Hemoglobinopathy; Thalassemia; Transition plan/program; Pediatric care; Adult health care

Introduction

Hemoglobinopathies, which include sickle cell disease and thalassemia, are genetic disorders that affect red blood cells. They are among the most prevalent hereditary disorders in humans; about 300,000-500,000 infants are born annually with major hemoglobinopathies worldwide. Using 2008 census data, it was estimated that approximately 100,000 people were living with sickle cell disease (SCD) in the United States (US) [1] Need a period. SCD, characterized by the severe pain due to vaso-occlusive complications, generally requires frequent hospitalization and long-term care [2,3]. With improved medical care and thus, increased survival and life expectancy of SCD patients [4,5], there is an increased need for greater support of transition of adolescents and young adults from pediatric to adult health care.

Over the past decade, many studies have characterized the experiences and practices of current pediatric specialty care programs [6-9]. Other studies have assessed the challenges faced when youth with special health care needs seek transition to adult-oriented care [8-13]. A recent survey was conducted among 45 large (≥100 pediatric patients) sickle cell centers in the US that care for pediatric patients to describe current transition practices and identify areas for improvement [14]. Thirty of 45 centers responded the survey. The majority of the centers are large, academic urban clinics associated with a free-standing children's hospital. The survey found that 77% of the respondents report having a transition program, although half have been in place for less than two years. Most centers (97%) identified an accepting adult provider; however, only 60% routinely transfer their patients to an adult hematologist specializing in SCD. Lack of an accepting adult hematologist with an interest in SCD emerged as a common barrier to transition.

In September 2010, the New York State Department of Health was awarded funds by the Centers for Disease Control and Prevention (CDC) and the National Heart, Lung and Blood Institute to develop a population-based surveillance for hemoglobinopathies in New York State (NYS). In November 2010, project staff contacted all 33 pediatric hemoglobinopathy specialty care centers across NYS and informed them

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about the launch of this project, in an effort to engage the collaboration with these physicians. Project staff also conducted a survey among these 33 pediatric centers to obtain information about the health care status and transition of patients with hemoglobinopathies from pediatric to adult care. The results of the survey are provided in this article.

Methods

Survey population - Hemoglobinopathy specialty care centers

Contact information (names and email addresses) for the directors of all 33 pediatric hemoglobinopathy specialty care centers was obtained from the Newborn Screening Program in the Wadsworth Center of the NYS Department of Health. The Newborn Screening Program consists of the laboratory and short-term follow-up components. For a newborn with screen positive results, the staff of the Newborn Screening follow-up unit informs the infant's primary care provider and the birth hospital of the results. The staff also refers the infant to a specialist in that particular disease area. Thus, the Newborn Screening Program is in constant contact with the pediatric specialty care centers/clinics for all screened disorders.

Survey questionnaire

The 16-question survey asked pediatric hemoglobinopathy specialty care centers about 1) characteristics of their pediatric patients with hemoglobinopathies; 2) the status of transition program/plans; 3) the elements included in the transition program/plan/policy; 4) the mode of transition to adult care; and 5) the barriers and obstacles to transition to adult care.

Survey data collection

A link to the web-based survey was sent to 33 pediatric hemoglobinopathy specialty care centers in NYS via email in late February 2011. Non-responders to the web-based survey were contacted by telephone in early April 2011 and were asked to complete the survey over the phone.

Data analysis

Responses to the survey were collected, downloaded, and converted into a dataset for analysis. Summary statistics, simple and stratified, were generated using SAS (SAS Institute, Cary, North Carolina).

Results

In total, 28 (85%) of 33 pediatric centers completed the survey. Responses regarding patient characteristics are summarized in (Table 1). The number of patients with sickle cell disease and thalassemia varied by survey site and ranged 4 to 550 patients with sickle cell disease and 1 to 130 patients with thalassemia. Most pediatric care centers allow admission of patients of 21 years old, but some centers accept patients up to 28 years of age. Planning for transition to adult care starts when patients are in adolescence; the actual transition occurs at around 20 years of age. All centers participating in the survey provide adult care. Most centers either have (39%) or are developing (50%) a transition program/plan. On average, 13% of the patients are within transition age (data not shown).

Characteristics	Median	Minimum	Maximum
Number of patients with sickle cell disease	110	4	550
Number of patients with thalassemia[a]	4	1	130
Maximum age of pediatric care admission (years)	21	16	28
Minimum age of planning for transition to adult care (years)	17	12	21
Minimum age of transition to adult care (years)	20	18	23
Percent of patients who are currently within the transition age	9%	0%	50%
Percent of patients within the transition age transferred in 2010	10%	0%	100%

[a]N=24, 4 centers do not have thalassemia patients

Table 1: Summary of the responses of the pediatric hemoglobinopathy specialty care centers in New York State to the questions about patient information and about transition to adult care program (N=28).

In 2010, the percent of patients who were within transition age and actually transferred to adult care centers ranged from 0 to 100; nearly one-third of the centers had more than 40% of the patients within transition age transferred to adult care centers. One third of the centers do not confirm that their patients continue on after their first visit to adult care center (data not shown).

Responses regarding those elements that are (or will be) included in the transition program/plan are shown in Figure 1. Nearly half of the transition programs have designated staff to coordinate transition activities (48%) and procedures to support transition (48%); about 59% of the programs discuss legal healthcare decision making for youth; but only 22% included assent forms by youth for treatments. The majorities of the pediatric centers provide care coordination for youth with complex conditions (78%), provide educational information on transition (67%), create a portable medical summary (67%) and develop a management plan for youth staying healthy (67%) through their program. Most centers do not use the Current Procedural Terminology codes for reimbursement of transition services, but 52% of the centers reported preparing medical documentation for program eligibility for the Supplemental Security Income or Vocational Rehabilitation.

Figure 2 shows the responses on the mode of transition to adult care. In general, transfer to adult care is initiated according to an individualized transition plan (57%), and begins because of either the patient's age or pregnancy (75%). Most transitions (93%) were planned ahead.

Responses regarding barriers and obstacles to transition to adult care are summarized in Figure 3. The responding centers identified financial difficulty (52%), adolescent (56%) or family (52%) resistance and the differences between pediatric and adult centers (56%) as the major barriers to transition to adult care. Less than half of the centers found lack of coordination between pediatric and adult centers (33%), transition program (37%) and institutional support (41%) as barriers. Many centers have difficulty in finding adult providers/specialists (41%) as well.

Discussion

Transition from the pediatric to adult care system is a dynamic and critical process for patients with special health needs. Transition should occur uninterrupted and comprehensively [15]. This study found that in NYS, 39% of pediatric hemoglobinopathy specialty care centers we surveyed have a program/plan for transition to adult care and 50% are in the process of developing a program/plan. Most transition programs/plans contain health care coordination, health management and educational components. Transition is generally initiated based on the age of the patient or pregnancy. In terms of barriers, financial difficulty, adolescent and family resistance, and differences between pediatric and adult centers have been identified as potential obstacles to transition to adult care. Although individual pain management and

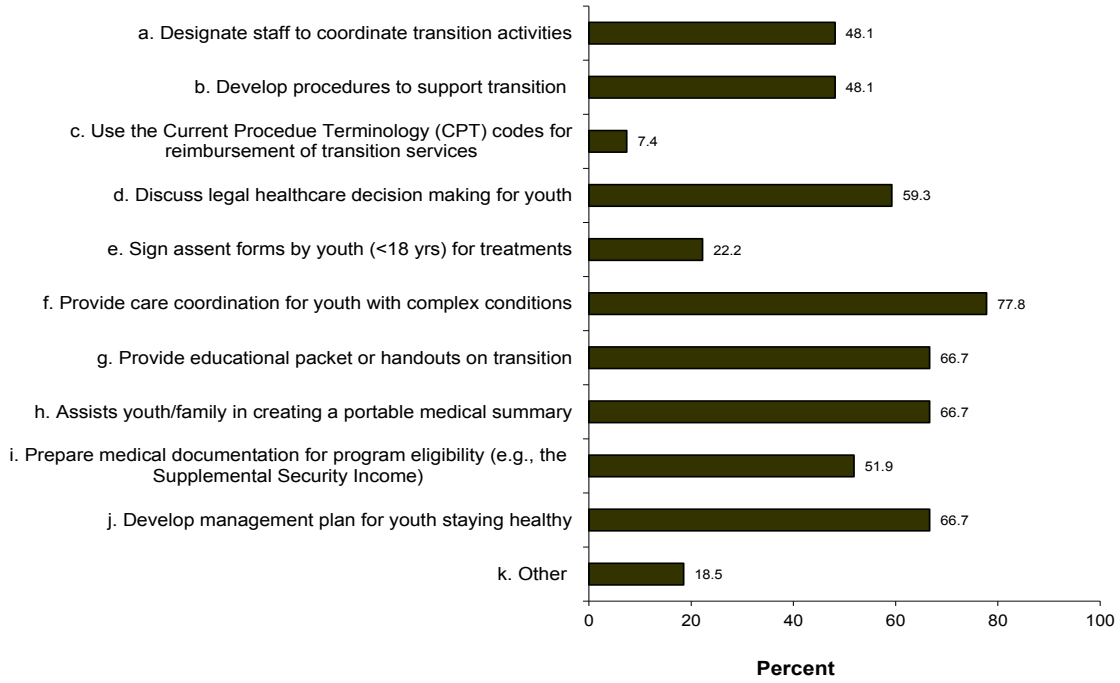

Figure 1: Responses to the question: "What are the elements included (or will be included if you are developing a program) in your transition program/plan/policy (Please check all that apply)?" (N=28).

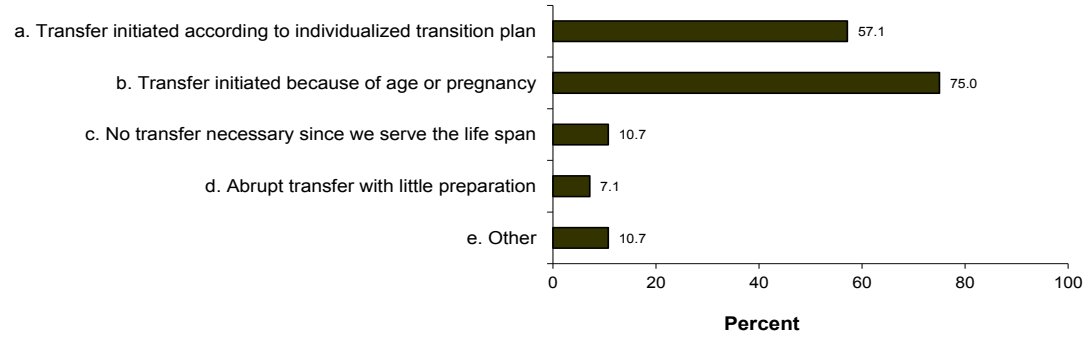

Figure 2: Responses to the question: : "What is the mode of transition to adult care (Please check all that apply)?" (N=28).

educational components have been considered and included as major components in plans, designated staff to coordinate transition activities and assist with financial aid would enhance the process.

As young patients gain autonomy regarding their own health care status, most of the transition programs should provide information on how to handle complex conditions. In addition, programs provide a management plan for youth to stay healthy and a portable medical summary. Our survey found that 32% of the centers who transfer their patients to adult care centers do not follow-up and confirm with their patients who just had a first visit to adult care center. Without timely follow-up to check whether the patient experienced complications or problems with the transition, patients might become lost in the health care system. Studies have shown that patients with long-term special healthcare needs are more vulnerable to abrupt environmental changes, including changes in the healthcare setting [16] and concern about building new relationships with adult health care providers [17]. When patients are not transferred appropriately or are transferred abruptly, they may experience discontinuation of medical care and emotional care which may exacerbate preexisting health conditions. Therefore, patients undergoing transition should be followed up until they become familiar with the new healthcare system.

In NYS, transfer from pediatric to adult care for patients with hemoglobinopathies was initiated based on individualized transition plan and only 7% of the patients were transferred without preparation. The most common reason for transition was age or pregnancy (75%). This is consistent with a study among pediatric care providers regarding transition, which identified age (100%) and pregnancy (74%) as the most common criteria of transferring to adult care [14]. In general, pregnancy among adolescents and young people is not planned ahead, and this may imply insufficient preparation for smooth transition. Physical age and pregnancy often do not fully reflect whether patients are ready to transfer to adult care, particularly young people with

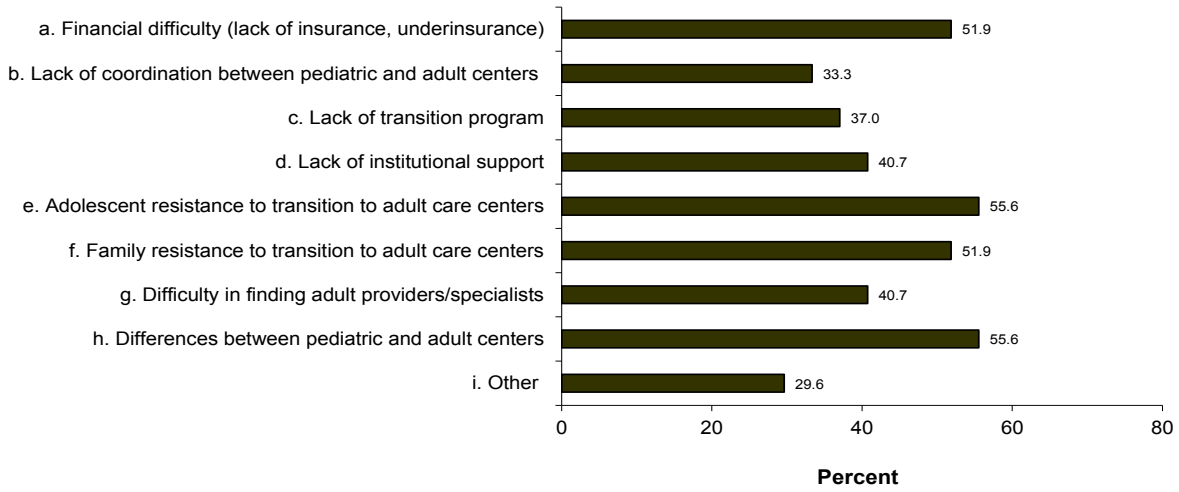

Figure 3: Responses to the question: "What are the barriers and obstacles to transition to adult care (Please check all that apply)?" (N=28).

chronic conditions, and individual readiness may vary regardless of age. Therefore, these factors should not be major driving forces for transition to adult care.

Financial difficulty, adolescent and family resistance and differences between pediatric and adult centers were identified as the barriers and obstacles to transition from pediatric to adult care. The primary concern of young adults regarded their ability to pay and acceptance by adult care providers [18]. Studies have identified a lack of information on transition, fear of departing from their familiar healthcare provider [13] and embarking on a relationship with a new provider [17] as major concerns on transition to adult care. Once young patients were moved to adult care successfully, they acknowledged benefits of the adult-oriented system even though most young patients were concerned about adaptation prior to transition [17]. The relatively high proportion of providers experiencing adolescent and family resistance to transition and similar responses observed in other studies suggest the importance of using individualized transition programs, allowing for sufficient time for young patients to adjust and become comfortable.

This is the first statewide survey assessing healthcare transition status of patients with hemoglobinopathy in NYS. While patients and their families were not surveyed, we were able to collect information from the majority of the hemoglobinopathy pediatric specialty care centers in NYS who have had close relationship with their patients over many years. Future step for this project includes ascertainment of adult care centers, physicians and specialists in NYS who treat and care for adult patients with hemoglobinopathies to explore the possibility of collecting clinical data on adults with hemoglobinopathies. The surveillance data collected through the project will aid to a better understanding of the health status of people living with sickle cell disease and thalassemia and help raise public awareness about these diseases.

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