Georgia PHRESH Findings

Public Health Research, Epidemiology, and Surveillance for Hemoglobinopathies

June 2014

Survey of Provider Information Needs

Healthy People 2020 includes three developmental objectives related to sickle cell disease (SCD) that Georgia's Public Health Research, Epidemiology, and Surveillance in Hemoglobinopathies (PHRESH) project seeks to address. These are to increase the proportion of persons with hemoglobinopathies who receive 1) appropriate immunizations (BDBS-1), 2) early and continuous screening (BDBS-4), and 3) disease-modifying therapies (BDBS-5). In order to inform health promotion efforts in these areas, we conducted a survey to assess medical providers' needs for educational materials on appropriate immunizations, the use of a chemotherapy medication named hydroxyurea as a disease-modifying therapy, and the need for early and annual Trans-Cranial Doppler (TCD) screening to identify stroke risk in children starting at age two. This brief describes the survey population and responses, and discusses possible implications of the results.

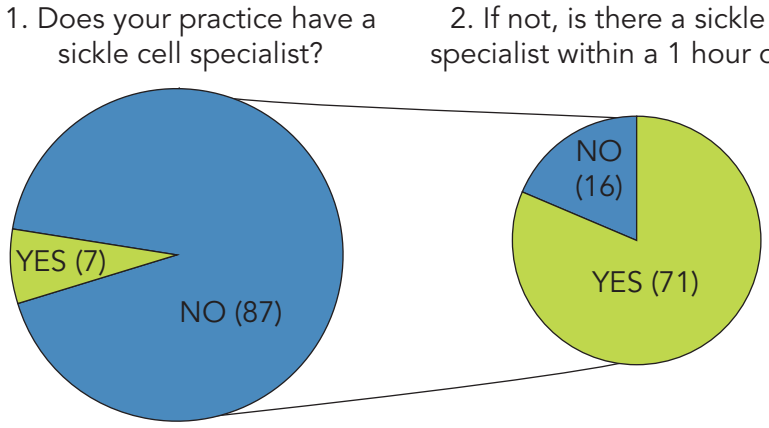
Survey Population

During the month of August 2013, the Sickle Cell Foundation of Georgia, Inc. (SCFG) and the Georgia Department of Public Health (GDPH) conducted scripted telephone interviews with provider representatives across the state and recorded responses in a standardized log. We targeted pediatric and family practices because surveillance through the Registry and Surveillance System for Hemoglobinopathies (RuSH) project indicated that sickle cell patients in Georgia have most of their medical provider interactions with pediatricians, family physicians, and other health care providers.

Surveys were completed with 100 practices in 48 counties that, according to RuSH data, contain 85 percent of all confirmed SCD cases in Georgia. The large majority of respondents represented pediatric-only practices. The remainder included family physicians, clinics, health departments, and Federally Qualified Health Centers. Forty-five of the practices reported serving mainly black patient populations; 10 served black and one other race/ethnicity; 10 served mainly white patient populations; and 28 served patients from all races and ethnicities.

Eighty-four percent of surveyed practices reported seeing sickle cell patients. Only seven practices had a sickle cell specialist on staff; however, another 71 said there was a sickle cell specialist within a one-hour drive. This leaves 16 providers and their patients lacking practical access to a sickle cell specialist (See Figure 1). A large majority of respondents reported ease in making specialist referrals for their sickle cell patients.

Figure 1. Access to Sickle Cell Specialists



Georgia Department of Public Health

404.413.0314
www.gsu.edu/ghpc
ghpc@gsu.edu

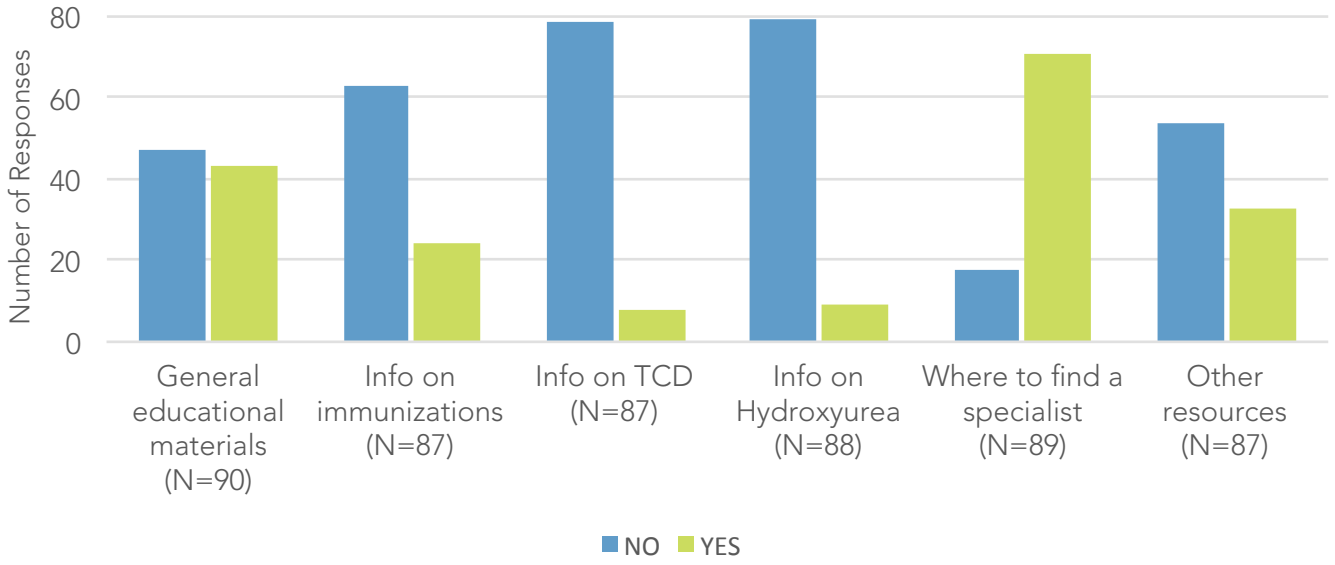
Georgia State University | Andrew Young School of Policy Studies

Georgia Health Policy Center

Provider Access to Sickle Cell Educational Materials

Survey respondents were asked whether they had educational literature available for sickle cell patients and their families. While almost half of the practices reported having general materials on SCD, only about one-fourth had literature on appropriate immunizations, and even fewer had literature on TCD (9 percent) and hydroxyurea (10 percent) (See Table 1). Over half of the respondents reported not having the information they need to appropriately prescribe TCD and hydroxyurea for sickle cell patients; almost one-third said they did not have enough information to appropriately prescribe immunizations for sickle cell patients. Over one-third of respondents revealed that they do not talk to sickle cell patients about immunizations, TCD, and hydroxyurea, nor do they give out materials on the topics. However, almost 60 percent of respondents indicated that they, their office, or their patients could use more information on these subjects.

Figure 2. Availability of Sickle Cell Educational Materials for Patients & Families



Discussion

Most pediatric and primary care practices taking part in the survey refer their patients with SCD to specialists. They tend to rely on those specialists to manage all aspects of sickle cell care, not keeping educational materials on hand and only seeking them out as needed. This is likely a reflection of the small number of providers surveyed who have patients with SCD and their perception of having specialists within a one hour drive. Nevertheless, RuSH findings indicate that primary care providers, particularly in counties of high sickle cell prevalence, should be on alert for and prepared to interact with, advise, and provide optimal care to sickle cell patients. Primary care practitioners serving sickle cell patients should be in regular consultation with a hematologist. Additionally, pediatricians can play a particularly significant role in recommending immunizations and other early treatment options to parents of children with SCD. As a result of this survey, and the clear need among primary care providers for sickle cell educational materials, the Georgia PHRESH team is now working to distribute hard copy educational materials on immunizations, TCD, and hydroxyurea to survey participants so that they are better prepared for future interactions with sickle cell patients.

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