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Prevalence of and Disparities in Barriers to Care Experienced by Youth with Type 1 Diabetes

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Objective To describe the prevalence of access and process barriers to health care and to examine their relationship to sociodemographic and disease factors in a large and diverse cohort of US youth with type 1 diabetes.

Study design A cross-sectional analysis of 780 youth who participated in the SEARCH for Diabetes in Youth Study and were diagnosed with type 1 diabetes in 2002-2005. Experience of barriers to care was collected from parent report on questionnaires. Analyses included multivariate regression models to predict the presence of specific barriers to care.

Results Overall, 81.7% of participants reported at least one barrier; the 3 most common were costs (47.5%), communication (43.0%), and getting needed information (48.4%). Problems with access to care, not having a regular provider, and receiving contextual care (care that takes into account personal and family context) were associated with poorer glycated hemoglobin levels. Adjusted multivariate models indicated that barriers related to access (regular provider, cost) were most likely for youth with low family income and those without public health insurance. Barriers associated with the processes of quality care (contextual care, communication) were more likely for Hispanic youth and those whose parents had less education.

Conclusions This study indicates that a large proportion of youth with type 1 diabetes experience substantial barriers to care. Barriers to access and those associated with processes of quality care differed by sociodemographic characteristics. Future investigators should expand knowledge of the systemic processes that lead to disparate outcomes for some youth with diabetes and assess potential solutions. *(J Pediatr 2014;164:1369-75)*.

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Accessing high-quality care can be particularly complicated for children with special health care needs, such as those with diabetes, because they require more health care services than their healthy peers.[1] There is evidence, in fact, that the quality of care for US children with diabetes is less than ideal.[2] "Barriers to care" are factors that inhibit a patient or parent's ability to access, receive, and make use of care that is comprehensive, patient-centered, coordinated, accessible, and of high quality. Given the high burden of pediatric diabetes in children, including the early onset of complications increasingly identified in childhood,[3,4] an understanding of the prevalence of specific barriers to care is needed to better understand how to improve the quality of care and outcomes in this population. Barriers to care refer to both barriers accessing care (ie, getting care when needed and having a regular doctor) as well as barriers that affect the processes of care.[5-7] Process barriers affect family-provider interactions and include, for example, an appreciation of how a child's condition might affect other aspects of his/her or the family's life (contextual care), communication problems, and problems getting needed information.[7] Both types of barriers—access barriers and process barriers—could be a significant problem for youth with chronic conditions such as diabetes because they impede the receipt of high-quality care[8] necessary for good outcomes.[9]

HbA1c	Glycated hemoglobin
IPV	In-person visit
SEARCH	SEARCH for Diabetes in Youth Study
SES	Socioeconomic status

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Barriers have been shown to be especially problematic for children of minority race/ethnicity and low socioeconomic status (SES),[10] potentially contributing to health disparities.[11] In pediatric type 1 diabetes, disparities in glycemic control and other health outcomes are well documented.[12-14] However, there is limited research examining how sociodemographic characteristics are related to these poor outcomes in vulnerable youth with diabetes. Despite increasing recognition of the implications of barriers to care in children and adolescents, there are few studies describing the prevalence of such barriers in youth with diabetes, nor data to show whether these vary with sociodemographic characteristics. Filling this gap potentially could lead to interventions or policies that could reduce barriers and improve outcomes. This study fills existing gaps by describing barriers to care and the variables associated with them in a sample of children and youth with type 1 diabetes who participated in the SEARCH for Diabetes in Youth Study (SEARCH).

Methods

The SEARCH study is a multicenter observational study whose investigators, in 2001, began conducting population-based ascertainment of cases of nongestational diabetes in youth <20 years of age.[15] Youth with diagnosed diabetes were identified in geographically defined populations in Ohio (8 urban and suburban counties encompassing and surrounding Cincinnati); Washington (5 urban counties encompassing and surrounding Seattle); South Carolina and Colorado (selected counties in 2001, all counties in subsequent years); among health care plan enrollees in Hawaii and southern California; and among Indian Health Service beneficiaries in 4 American Indian populations. SEARCH sought to identify all existing (prevalent) cases of diabetes in 2001 and all newly diagnosed (incident) cases in subsequent calendar years. Ascertained cases were contacted and asked to complete an initial patient survey, and persons completing the initial patient survey were invited for an in-person visit (IPV) where, after informed parent consent and youth assent were obtained, anthropometric and clinical data and blood samples were collected. Youth with diabetes diagnosed in 2002-2005 who completed an IPV also were invited back for follow-up visits at 12, 24, and 60 months after their baseline IPV. A detailed description of SEARCH study methods has been published elsewhere.[15] Data for this cross-sectional study were obtained at the 24-month follow-up visit for participants diagnosed in 2002-2005.

Before implementation of the protocol, the study was reviewed and approved by the local institutional review boards that had jurisdiction over the local study populations, and compliance with Health Insurance Portability and Accountability Act regulations was ensured.

Parent-report on survey items was used to assess the presence or absence of several barriers to care, all of which can be organized into 2 categories associated with the quality of accessed care: (1) access barriers; and (2) process barriers. In terms of access barriers, general difficulty accessing care was measured by 2 items from the National Longitudinal Study of Adolescent Health.[16] In addition, lack of a regular health care provider and cost of care were each measured using items from the Consumer Assessment of Healthcare Providers and Systems survey. Process barriers were assessed with items from the Consumer Assessment of Healthcare Providers and Systems survey and included problems receiving care that takes into account personal and family context (contextual care), difficulty getting needed health information, and more general provider-family communication barriers. Table I shows all of the items for each barrier measured. Barriers were coded as present if parents endorsed the barrier or indicated that it was *ever* a problem (eg, that their provider "never," "sometimes," or "usually" showed respect for what they had to say). We used this relatively high cut-off score because of research suggesting ceiling effects in many parent and patient-reported provider satisfaction measures.[17]

Youths' race/ethnicity was reported by caregivers based on the 2000 census questions and categorized as Hispanic (regardless of race), non-Hispanic white, non-Hispanic black, American Indian, Asian, and Pacific Islander. Those who reported more than one race were placed into a single race category via the National Center for Health Statistics plurality approach.[18] Persons not classified into one race group using the plurality approach (0.5% of study visit cases) and those with missing race/ethnicity information (0.02% of cases) were classified as "other race/ethnicity" and "unknown race/ethnicity," respectively, and were excluded from analyses involving this variable.

Annual family income, parent education, health insurance status, and family composition were assessed based on caregiver report. Income was divided into four categories: <\$25 000, \$25 000-\$49 999, \$50 000-\$74 999, and ≥\$75 000. Parent education was classified as less than high school, high school graduate, some college, and bachelor's degree or beyond and was based on the highest education of either parent. Health insurance status was categorized as private, Medicaid/Medicare, none, and other (including military, tribe/Indian Health Service, school-based, or other type). Family composition was dichotomized as 2-parent household vs other (including 1 parent/1 household, 2 parent/2 households, and other).

Diabetes duration, defined as months since diagnosis, was measured by medical chart review. Blood samples were processed locally and shipped on ice to a central laboratory (Northwest Lipid Laboratory, University of Washington, Seattle, Washington) for analysis. A dedicated ion exchange unit, Variant II (Bio-Rad Diagnostics, Hercules, California), quantified glycated hemoglobin (HbA1c).

Statistical Analyses

Frequencies (and percentages) for presence of each barrier were calculated for the overall sample and by sociodemographic characteristics. χ^2 analyses were conducted to examine the distribution of barriers to care by sociodemographic factors and disease duration. Because of the large number of comparisons, we conservatively set $P \leq .01$ as