Journal of Pediatric Nursing (2015) **30**, 834–841

Type 1 Diabetes Among East African Immigrant and Nonimmigrant Black Youth in the U.S.

M. Rebecca O'Connor PhD, RN [a,b,*], Adrian Dobra PhD [a], Joachim Voss PhD, RN, FAAN [a], Catherine Pihoker MD [b,c], Ardith Doorenbos PhD, RN, FAAN [a]

[a] *University of Washington, School of Nursing, Seattle, WA*
[b] *Seattle Children's Hospital, Division of Endocrinology, Seattle, WA*
[c] *University of Washington, School of Medicine, Department of Pediatrics, Seattle, WA*

Received 17 November 2014; revised 1 June 2015; accepted 2 June 2015

Key words:
Type 1 diabetes mellitus;
Immigrants;
Africa;
Pediatrics;
Ethnicity;
Youth

Type 1 diabetes has not previously been described in East African immigrant youth in the United States. The purpose of this study was to compare East African immigrant and nonimmigrant Black youth with type 1 diabetes. Among other clinical and demographic differences, estimated prevalence of type 1 diabetes was nearly four times higher among East African youth in King County, Washington (6.20/1000, 95% confidence interval (CI) [4.49, 7.91] vs. 1.56/1000, 95% CI [1.03, 2.09]) compared to nonimmigrant Black youth. These observations are lost within the Black/African American race classification and additional work is needed to confirm and further explore these findings.

THE PURPOSE OF this study was to compare clinical characteristics of type 1 diabetes in East African immigrant youth to those of other non-immigrant youth in the larger Black/African-American race classification. The first step in ensuring high-quality health care and addressing potential health disparities is to provide an accurate description of the population(s) served, including rich data on race and ethnicity. However, as the Institute of Medicine's (IOM) Subcommittee on Standardized Collection of Race/Ethnicity Data points out, the health care system in the United States (U.S.) "does not provide the necessary level of detail to understand which groups are experiencing health care disparities or would benefit from targeted quality improvement efforts" (Ulmer, McFadden, Nerenz, & for the Institute of Medicine, 2009, p. 13). Based on Census Bureau classifications, all organizations that receive federal funds in the U.S. must use five race classifications (Black/African American, White, Asian, American Indian or Alaska Native, and Native Hawaiian or Other Pacific Islander) and two ethnicity classifications (Hispanic or Latino, and Not Hispanic or Latino) (Ulmer et al., 2009). Within each of these race and ethnicity classifications are many heterogeneous ethnic groups whose distinct characteristics are lost to categories that are too broad. Results from this study suggest that type 1 diabetes-related differences exist between two distinct ethnic groups within the Black/African American race classification in the U.S. These differences are lost within the larger category of race, exemplifying the IOM's stance that U.S. health care data are insufficient to identify specific health disparities.

Previous studies have highlighted differences in a population's risk for developing disease or poor health outcomes based on race or general immigrant status. In the case of type 1 diabetes in the U.S., 2009 prevalence rates are higher for non-Hispanic White (NHW) youth than for Black youth 0-19 years of age (2.55 per 1000 NHW youth, 95% confidence interval (CI) [2.48, 2.62], vs. 1.63 per 1000 non-Hispanic Black youth, 95% CI [1.51, 1.77]) (Pettitt et al., 2013). However, a registry study in the Philadelphia area reported that

* Corresponding author: M. Rebecca O'Connor, PhD, RN.
E-mail address: rebeccao@uw.edu.

http://dx.doi.org/10.1016/j.pedn.2015.06.002
0882-5963/

type 1 diabetes incidence rates in the late 1990s were higher for Black youth (15.2/100,000) than for NHW youth (12.8/100,000) (Lipman et al., 2006). Black youth in the U.S. aged 0–19 have higher rates of diabetic ketoacidosis (DKA) at the time of type 1 diabetes diagnosis compared to NHW youth of the same age (25.5% vs. 10.3%) (Bell et al., 2009; Mayer-Davis et al., 2009). Higher rates of DKA at type 1 diabetes diagnosis have also been reported for mixed immigrant groups elsewhere, such as among non-Western immigrant youth in the Netherlands when compared to Dutch and Western immigrant youth populations (17.4% vs. 9.6% and 7.3%, respectively; $p < 0.05$) (van Laar, Grishchenko, van Wouwe, & Stronks, 2007). Two studies from Scandinavia have recently suggested an increased risk for type 1 diabetes in East African youth; however, the Finnish study was small (n = 10 Somali children) and the Swedish study used an insulin registry as an indirect measure of type 1 diabetes cases (Hjern, Soderstrom, & Aman, 2012; Oilinki, Otonkoski, Ilonen, Knip, & Miettinen, 2012). Additional studies have also characterized type 1 diabetes in mixed immigrant youth and African immigrant youth in Europe and Israel, but with conflicting results (Delli et al., 2010; Neu et al., 2001; Raymond et al., 2001; Zung et al., 2004). Limited data is available on type 1 diabetes in youth in Africa, and the data that are available are widely described as incomplete and unreliable (Majaliwa et al., 2008; Mbanya, Motala, Sobngwi, Assah, & Enoru, 2010; Oilinki et al., 2012).

While type 1 diabetes -related differences between racial groups and broad immigrant and non-immigrant populations have been identified, there is a lack of research that describes characteristics of type 1 diabetes between two ethnic groups within the same race classification, such as immigrant and nonimmigrant Black youth in the U.S. Current classifications of ethnicity in the U.S. hinder the ability to characterize differences between these two populations. The specific aims of this retrospective study are (a) to describe and compare demographic and clinical characteristics between U.S. immigrant and nonimmigrant Black youth with type 1 diabetes at time of diagnosis, and (b) to estimate the prevalence of type 1 diabetes among these two populations in King County, Washington.

Potential clinical implications that follow from this and future related research are of great importance to nurses caring for children, adolescents, and their families. The knowledge that type 1 diabetes affects groups differently is critical for a nurse's ability to provide optimal care for diverse patient populations. For instance, nurses taking care of East African immigrant families (a group which may be at increased risk for developing type 1 diabetes) might educate them on the signs and symptoms of type 1 diabetes in an effort to decrease the presence and severity of DKA at diagnosis. Given that it is almost exclusively nurses who conduct patient and family education at and after type 1 diabetes diagnosis, it is also absolutely crucial for nurses to recognize how difficult a skill like carbohydrate counting may be for East African immigrants for numerous reasons based on our clinical experience [primary language other than English, lack of math skills, primary grain is teff (which is a whole grain indigenous to East Africa and not widely known in the U.S.), majority of meals are cooked at home, etc.] and extra care should be taken to meet the needs of this and other vulnerable populations affected by the disease.

Methods

Study Design

After obtaining permission from the Institutional Review Board at XX Children's Hospital (XCH), de-identified data were obtained from existing electronic medical records. Once East African immigrant and nonimmigrant Black youth were identified as described below, each case was assigned a unique study number and all identifiable data were removed (medical record number, name, date of birth). All pediatric patients diagnosed with type 1 diabetes and seen at XCH on at least one occasion between January 1, 2000, and July 31, 2011, were identified by primary or secondary ICD-9 codes. This query resulted in 2929 patients identified. From this population, all individual medical records for each patient whose race was classified as Black/African American, Other, or Patient Refused/Missing ($N = 760$) were reviewed by the Principal Investigator; 129 patients in these three categories were identified as NHW (17.0%). Race/ethnicity information could not be obtained for 86 patients (4.4% of all patients identified).

Sample

Cases of type 1 diabetes were initially identified through primary and secondary ICD-9 codes and confirmed by providers in the medical record, an approach also used by the on-going SEARCH for Diabetes in Youth study (SEARCH), the largest U.S. study to date to describe diabetes in children and adolescents (SEARCH for Diabetes in Youth, 2004). East African immigrants represented 94% of Black immigrant youth with type 1 diabetes at XCH and as a result, inclusion in the immigrant sample for the study was restricted to this group. Patients were classified as East African immigrant if their race was listed as Black/African American and (a) notation in the medical record of patient or their parents' birth in an East African country (Kenya, Uganda, Ethiopia, Eritrea, or Somalia), or (b) interpreter requests were made for an East African language (Amharic, Somali, Tigrinya, Oromo, or other). While there are many definitions of 'immigrant', we have chosen to include patients or youth of parents born in East Africa because previous data suggests that parents' immigration status may affect diabetes outcomes (Jaacks et al., 2012).

Patients were classified as nonimmigrant Black if their race was listed as Black/African American and (a) their language was listed as English, (b) ethnicity was listed as 'not Hispanic', and (c) no reference to any other race or country of birth outside the U.S. was noted for the patient or their parents. All of the patients who met these criteria and whose diagnosis with type 1 diabetes before the age of 20