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Awareness of Sickle Cell among People of Reproductive Age: Dominicans and African Americans in Northern Manhattan

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ABSTRACT *Sickle cell disease is a chronic condition that is characterized by severe anemia, painful crises, and organ dysfunction. In the USA, sickle cell is a health burden typically associated with African Americans. Dominicans constitute the largest Latino group in New York City (NYC) and have the second overall highest prevalence of sickle trait—one in 20 births, compared to one in 12 African American births. We aimed to document the prevalence of sickle within the largely Dominican and African American community of Northern Manhattan (Washington Heights, Inwood, Harlem), assess and compare knowledge about sickle disease and carrier status in young adults of reproductive age between African Americans and Dominicans, and elicit preferred sources of health information. NY State Newborn Screening data in Northern Manhattan were analyzed by zip code. A brief oral survey was administered to 208 parents of young children—150 Dominicans and 58 African Americans. Significant differences were seen in knowledge about sickle—27% of Dominican parents surveyed correctly defined sickle cell disease as an inherited blood disorder, compared to 76% of African Americans ($p<0.001$). Only 7% of African Americans did not know their own trait status, compared to 43% of Dominicans ($p<0.001$). Parents were better informed if they or family members were affected by sickle conditions. Participants from both groups prefer receiving information from doctors and online. A separate group of 168 predominantly Dominican youth, ages 14–24, demonstrated knowledge levels similar to that of Dominican parents. These results suggest that many of reproductive age in a NYC community affected by sickle conditions frequently lack basic relevant information, with larger information gaps among Dominicans. Expanded efforts are warranted to inform young adults of diverse affected communities.*

KEYWORDS *Health literacy, Hemaglobinopathy, Ethnicity and health, Health education, Health disparities*

INTRODUCTION

Sickle cell disease is a chronic condition that is characterized by severe anemia, painful crises and organ dysfunction. As an autosomal recessive disorder, a sickle

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hemoglobin gene is inherited from each parent with asymptomatic sickle trait. In the USA, sickle cell disease is a health burden typically associated with African Americans, affecting 1:350 births.[1] Latinos have the second highest incidence among US populations, with 1:1,100 affected births in the eastern USA.[1] In New York City (NYC), sickle trait affects 1 in 12 African Americans and 1 in 35 Latino births. Of approximately 200 newborns diagnosed with sickle cell disease in NY in 2008, 36 (8%) were Hispanic.[2] In NYC, Latinos constitute one fourth of the population, with Dominicans constituting the largest group of foreign-born adults.[3,4] The highest proportion of Dominicans live in Northern Manhattan, an area described by Washington Heights, Inwood, and Harlem combined, representing one third of Manhattan's total population of over 1.5 million people.[4–6] A high birth rate, coupled with a sickle trait incidence as high as 1 in 20 Dominican and other Caribbean Latino births, results in many Dominican children affected by sickle conditions.[2] Many of the children with sickle cell disease receiving their specialty care in Columbia's Pediatric Hematology clinic in Northern Manhattan are of Dominican descent.

Public awareness efforts and outreach to affected families about sickle cell has largely targeted African Americans.[7,8] Adding to the common challenges to sickle awareness of low education and health literacy levels, high rates of poverty, limited access to insured health benefits and health information, Latino barriers may also include language and a perception that sickle cell is an "African" disease.[9]

This study aimed to assess and compare knowledge of sickle disease and trait among people of reproductive age in two groups affected by sickle in Northern Manhattan—Dominicans and African Americans—and to identify strategies for relevant health education. Parents of children under 5 years of age were surveyed because of their reproductive age and likely recent experience with newborn and/or prenatal screening. To further document awareness of sickle among Dominicans, a separate group of predominately Dominican youth, ages 14–24, was also surveyed.

METHODS

Newborn screening results from the NY State Newborn Screening program for Northern Manhattan were obtained by zip code of birth residence. Screening data included 13 zip codes: 10025, 10026, 10027, 10029, 10030, 10031, 10032, 10033, 10034, 10035, 10037, 10039, 10040, with a combined population of over 530,000.[5,6] Sickle cell disease was defined as a newborn bloodspot screen detecting only sickle (S)—HbSS or HbSC. Sickle trait included screens reported for S or C trait—HbAS or HbAC.

A brief anonymous oral survey was developed with Columbia's Community Pediatrics for culturally and literacy appropriate translations, and was piloted with young adults in Northern Manhattan. The survey was administered from June–August 2010, and was offered in English or Spanish. The survey queried respondents' race/ethnicity using questions similar to those used by the 2010 census.[10] Based on self-identification, respondents were categorized by Latino vs. non-Latino and Dominican vs. African American or Black. Country of birth was identified. The survey assessed sickle status of the participant and their family, knowledge about sickle trait and sickle cell disease, and preferred methods for receiving relevant health information. Verbal consent was obtained for administering the survey. This study was performed under formal approval and policies of the Institutional Review Board of Columbia University. Chi-squared test was used to compare differences between ethnic groups.

All 208 survey participants confirmed that they were parents of children under 5 years of age, with 150 self-identified Dominicans and 58 African Americans. Most participants, 195 (94%), were recruited from the waiting room of general pediatric clinics at the NYP Ambulatory Care Network in Northern Manhattan, including all of the Dominican parents. Thirteen parents also were recruited from the Northern Manhattan Perinatal Partnership health education site in Central Harlem.

A similar written survey was administered anonymously to 168 teenagers and young adults, ages 14–24, in collaboration with the community-based organization Alianza Dominicana in Northern Manhattan. None revealed themselves as parents. The survey was performed at Alianza's Annual Youth Conference in May 2010. In total, 91% of participants identified themselves as Dominican (71%) or Hispanic/Latino (20%). Eighty-three percent (83%) of youth survey participants stated that they were born in the USA. No comparable African American group was available to survey.

RESULTS

Newborn Screening Results

NY Newborn Screening results of all infants born in Northern Manhattan were analyzed for a 2-year period of 2006–2007, by ethnicity and zip code of birth residence (Table 1). Of 19,206 infants, 45.3% were identified as Hispanic and 24.1% as Black. Overall, 1,113 infants (5.8% of the total) were identified with S or C trait—4.8% of all Hispanic and 11.7% of all Black newborns (Table 1). Of those with trait, 37.6% infants were Hispanic and 48.5% were Black. Of those diagnosed with disease, 7 (25.9%) were identified as Hispanic and 18 (66.7%) were Black.

Survey Results

A total of 208 parents of young children responded to the survey from either target group—150 Dominicans and 58 African Americans. The majority of Dominican parents (68%) were born in the Dominican Republic, while all of the African Americans were born in the USA. Only 27% of Dominicans properly defined sickle cell disease as an "inherited blood disorder," compared to 76% of African Americans ($p<0.001$). Of the 73% percent of Dominican parents who could not define sickle cell disease, 27% defined it as a "blood infection" and 45% admitted that they did not know. In contrast, 10% of African Americans incorrectly defined the disease and 14% admitted that they did not know (data not shown).

TABLE 1 NY State Newborn Screening for sickle cell: results for Northern Manhattan (2006–2007)

	Hispanic		Black		Asian		White		Other/unknown		Total	
	N	%[a]	*N*	%[a]	*N*	%[a]	*N*	%[a]	*N*	%[a]	*N*	%[a]
Sickle trait	419	4.8	540	11.7%	4	0.7	27	1.0	123	4.9	1,113	5.8
Sickle cell disease	7	0.1	18	0.4%	0	0.0	0	0.0	2	0.1	27	0.1
Total births	8,706		4,621		552		2,807		2,520		19,206	

Data provided by New York State Newborn Screening Program [2]

[a]Percentage of total births, by ethnicity

Of the two groups of parents surveyed, 5% of both groups reported that they have sickle trait. At the same time, 9% of Dominican parents reported having one or more family members with sickle trait and 8% reported having family affected by sickle cell disease (Figure 1). A larger proportion of African American parents reported having one or more family members with trait (23%) or affected by sickle cell disease (21%).

Over 43% of Dominican parents reported not knowing their sickle trait status, as compared to only 7% of African Americans ($p<0.001$) (Figure 1). Similar results were obtained regarding knowledge of family members' sickle trait status—37% of Dominicans versus 21% of African Americans ($p<0.001$), and disease status—28% and 2% respectively, ($p<0.001$) (Figure 1). Results from the largely Dominican youth survey were similar to those from Dominican parents, with one third of respondents not knowing their sickle carrier status and many not knowing if their family carried trait (Figure 1) or anyone with disease (data not shown).

Of parents who reported having a family member with sickle trait, most (11 of 13 in each group) correctly defined sickle cell disease as an "inherited blood disorder." In contrast, of parents who did not have a family member with trait, 29 of 137 (21%) Dominicans versus 32 of 44 (73%) African Americans were able to correctly define disease ($p<0.001$).

Parents of both racial/ethnic backgrounds stated their preference for learning about sickle trait by either talking to a doctor (55%) or using online resources (40%), rather than by meeting with a health educator (17%).

DISCUSSION

Despite high prevalence of sickle in both groups, our surveys reveal substantial knowledge gaps about sickle cell in people of reproductive age surveyed from Dominican and African American communities in Northern Manhattan, with Dominicans substantially less knowledgeable about both sickle trait and sickle disease. Comparable survey results between Dominican parents and young adults

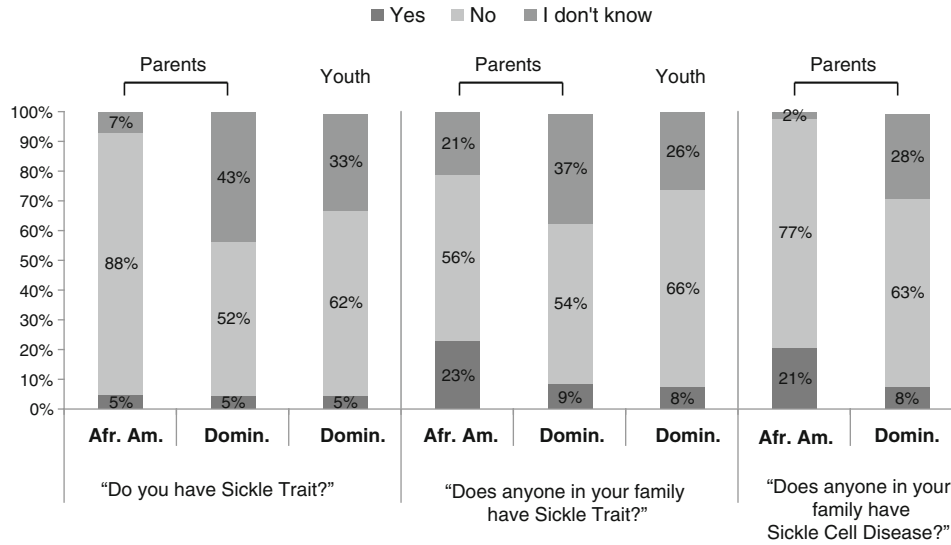

FIGURE 1. Parents' and youth's knowledge about sickle for themselves and their family by ethnicity. Parents $N=150$, Dominicans; 58 African Americans; Youth $N=168$, predominately Dominican.

from the same community suggest that recent obstetric and/or newborn screening medical services received by parents did not improve their sickle cell knowledge.

Despite the lower level of knowledge about sickle cell among Dominicans, those with a family member with sickle trait appear to be as knowledgeable as their African American counterparts. In contrast, African American parents without affected family members are much more knowledgeable than Dominicans. Lower prevalence of sickle disease and carrier rates among Dominicans may contribute to their lower level of awareness.

Health outreach staff at Alianza Dominicana described a variety of Spanish terms used for sickle cell disease ("anemia," "anemia falciforme," or "sickle cell") and sickle trait ("portador"or "rasgo"; unpublished data). This apparent lack of standardized terminology may contribute to the knowledge gap. Sickle-focused health materials or messages for the public in print or online may be less readily available or effective in Spanish. High prevalence of foreign birth among Dominicans may also contribute to these lower knowledge levels. Moreover, several Dominicans from the Alianza staff described a perceived stigma associated with sickle cell as an "African" disease (unpublished data), and that family members had requested that they not reveal their sickle trait status outside of the family. Images and language used by health education materials may fortify the perception of sickle as limited to those of traditionally "African" origin. Others interviewed had thought the disease to be a form of leukemia or acquired HIV infection, possibly a generalization about contemporary public health disease messages.

Participants expressed preference for counseling from their doctors or internet materials, rather than receiving telephone calls from health care providers or counseling from health educators, suggesting that responsibility for educating patients includes primary care providers. Our recent survey of Northern Manhattan primary care providers revealed that many do not routinely check newborn screening results for sickle trait or perform recommended follow-up.[11] Educational challenges exist at multiple levels.

Despite a high prevalence of sickle trait, most Dominicans surveyed here demonstrated low levels of knowledge about sickle cell. These results suggest that targeted education could be beneficial for this and perhaps other non-traditional communities bearing sickle trait. Such education is especially important for teens/youth, parents of young children, and others of reproductive age.

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