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ORIGINAL ARTICLE

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Population-based surveillance of haemophilia and patient outcomes in Indiana using multiple data sources

Amanda I. Okolo[1] | John Michael Soucie[2] | Scott D. Grosse[2] | Christopher Roberson[1] | Isaac A. Janson[1] | Martha Allen[3] | Amy D. Shapiro[1]

[1]Indiana Hemophilia and Thrombosis Center, Indianapolis, Indiana

[2]Centers for Disease Control and Prevention, Atlanta, Georgia

[3]Indiana State Department of Health, Indianapolis, Indiana

Correspondence
Amanda Okolo, Indiana Hemophilia and Thrombosis Center, Indianapolis, IN.
Email: aokolo@ihtc.org

Introduction: Epidemiological surveillance of haemophilia through linkage of medical records within a US state has not been conducted in 20 years.

Aim: The Indiana Haemophilia Surveillance Project aims to identify all persons with haemophilia who resided in Indiana in 2011-2013 and to determine the percentage of patients in Indiana cared for at a federally recognized haemophilia treatment centre (HTC).

Methods: A retrospective review of medical charts was conducted to identify haemophilia cases during the surveillance years. Case-finding methods involved a variety of medical care resources including hospitals, administrative claims data and haematology/oncology clinic reports.

Results: In Indiana, 704 unique haemophilia cases were identified. Of those cases, 456 (64.8%) had factor VIII and 248 (35.2%) had factor IX deficiency. Among those with known severity levels (n = 685), 233 (34%) were severe, 185 (27%) were moderate, and 267 (39%) were mild. Overall, 81.7% of the haemophilia patients identified visited an HTC at least once during the three-year study period, which was the requirement for being considered an HTC patient. Age-adjusted prevalence for 2013 was 19.4 haemophilia cases per 100 000 males, 12.7 per 100 000 for factor VIII and 6.7 per 100 000 for factor IX. Incidence of haemophilia over the 10 years prior to the surveillance years was 1:3688 live male births in Indiana. During the surveillance years, 24 cases (3.4%) died.

Conclusion: We observed higher incidence and prevalence of haemophilia in Indiana compared to previous national estimates, as well as higher HTC utilization among persons with haemophilia.

KEYWORDS

epidemiology, haemophilia, haemophilia treatment centres, public health, surveillance

1 | INTRODUCTION

Haemophilia is a sex-linked bleeding disorder caused by deficiency or absence of coagulation factors VIII or IX.[1] Haemophilia A and haemophilia B result from mutations in factor VIII and IX genes, with a reported incidence of 1 in 5000 and 1 in 30 000 males, respectively.[2,3] The degree of severity is proportional to the reduction of the specific coagulation factor; severe, moderate and mild forms of

haemophilia are classified as <1%, 1 to 5% and >5% to <40%, respectively.[4,5] Complications of haemophilia, including severe, debilitating chronic joint disease, result in high healthcare resource utilization.[6]

Congress passed the Public Health Service Act in 1975 establishing comprehensive haemophilia treatment centres (HTCs) for haemophilia and bleeding disorder care,[3,7] and in the late 1980s, the Centers for Disease Control and Prevention (CDC) developed and implemented programs intended to ensure blood safety and to reduce complications from bleeding disorders.[8]

Public health surveillance is commonly defined as the ongoing, systematic collection, analysis and interpretation of data, along with the dissemination of findings to stakeholders capable of preventing or controlling disease progression.[9] The most comprehensive surveillance of the haemophilia population in the United States occurred over 20 years ago, when the CDC collaborated with health departments in six states (CO, GA, LA, MA, NY and OK) to launch a time-limited Haemophilia Surveillance System (HSS) project. During a 3-year study period, Soucie and colleagues identified and collected data on cases of patients with haemophilia from physicians, clinical laboratories, hospitals, state health departments and HTCs. Soucie et al reported the prevalence of haemophilia was 13.4 cases per 100 000 males in 1994. The incidence over the study period was 1 in 5032 live male births. Nearly, four out of five cases had haemophilia A (79%) and 43% of all cases were severe.[6] It was also discovered that HTCs reduce mortality in haemophilia patients by 40% and decrease healthcare resource utilization and cost of care.[10] The Indiana Haemophilia Surveillance System (IHSS) was modelled after the Soucie et al study and aimed to identify all persons with haemophilia, including those not served by an HTC, who resided in Indiana from 2011-2013.

2 | MATERIALS AND METHODS

The IHSS was an active surveillance system adapted from the methods of the HSS project. The IHSS was a joint collaboration between the Indiana State Department of Health (ISDH), the Indiana Hemophilia and Thrombosis Center (IHTC), and the CDC conducted during February 2015 to February 2018. The CDC provided expert consultation but no personnel or funding. The surveillance period was from 1 January 2011 through 31 December 2013. The IHSS operated through the ISDH which provided the legal public health authority to collect and review medical records. A project coordinator was employed by the ISDH to identify patients and request medical records.

The IHSS defined a confirmed haemophilia case as a person with physician-diagnosed factor VIII or factor IX deficiency and a clotting factor activity level of < 50%. A probable case was defined as a person with either a physician diagnosis of factor VIII or factor IX deficiency, a clotting factor activity level of < 50%, or self-reported diagnosis with confirmed clotting factor product dispensation. Severity level was categorized as severe if the activity level was <1%, moderate, if the level was 1%-5%, and mild, if the level was 6%-49%. We excluded persons with a diagnosis of acquired haemophilia, women, carriers of the haemophilia gene mutation and non-resident visitors to Indiana, defined as living in Indiana for less than one month during the surveillance period.

Haemophilia cases were identified through various case-finding methods. Medical records were requested and obtained from the IHTC and from HTCs in states bordering Indiana. Indiana hospitals that had contact with potential cases were identified via hospital discharge data. Haematologists/Oncologists practicing in Indiana was identified through the ISDH Licensure Database. Medical records of persons with haemophilia were requested by the surveillance coordinator from identified hospitals and Haematologists/Oncologists. Cases were also acquired through the Indiana Birth Defects Registry, vital statistics, specialty pharmacies, laboratories, primary care physicians, and administrative claims records from Medicaid and the Regenstrief Institute, a healthcare research organization in Indianapolis. A modified version of the HSS data abstraction form was used for the IHSS. Materials with protected health information were maintained behind two locked doors in accordance with ISDH regulations. A secure online database was created by Inverse Square LLC to store data collected.

Data collection and abstraction began in February 2015. Patients who had contact with a medical facility during at least one of the surveillance years, either in person or via phone, and met inclusion criteria were eligible for inclusion in IHSS. Mortality rates and causes of death among identified haemophilia cases were assessed based on death certificate data. Death certificates were obtained for patients already identified via other methods and vital statistics were queried for haemophilia listed as a cause of death during the study period.

Prevalence rates were estimated by dividing the number of confirmed and probable cases by the estimated Indiana male population in 2011-2013 and multiplied by 100 000 to express the estimate as the number of cases per 100 000 males. Age-adjusted rates were calculated using US 2010 population estimates. Associations between demographic information and clinical characteristics were assessed for statistical significance using chi-square and Fisher's exact tests. To estimate incidence, the number of new cases, based on the dates of birth for prevalent cases, within the given year was used as the numerator and the number of live male births in Indiana during the given year was used as the denominator and multiplied by 100 000 to express the rate per 100 000 live male births. The years used to calculate incidence were the 10 years prior to the study period.

3 | RESULTS

During the study period, 599, 623, and 634 male cases of haemophilia were identified in 2011, 2012 and 2013, respectively, with a total of 704 unique male cases identified. Those 704 cases formed the study population, of which 662 (94.0%) cases were confirmed, meaning they had both physician and laboratory diagnoses, and 42 (6.0%) cases were probable, having either a physician, laboratory

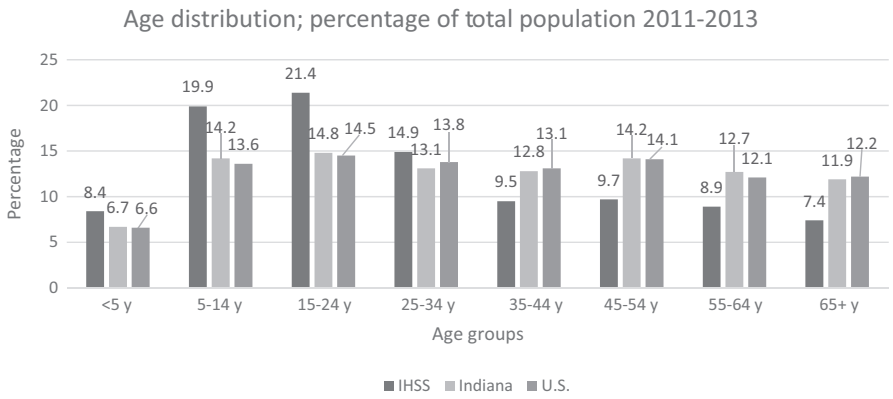

FIGURE 1 Age distribution of haemophilia patients by age and for all residents of Indiana and the United States

or self-reported diagnosis. Confirmed and probable cases were included in the analysis.

Mean age (±SD) of the study population was 29.7 (±21.0) years, and the median age was 25 years. Figure 1 compares the percentage of the total population by age ranges for the haemophilia population and the general populations of Indiana and the United States. The study population overall was younger than the Indiana (median age 35.9 years) and US (median age 36.1 years) populations. Adult patients (≥18 years) were 64.3% of cases (453); the remaining 35.7% of cases (251) were paediatric patients under 18 years.

Nearly, two-thirds of cases (64.8%; 456) had factor VIII deficiency and 35.2% (248 cases) had factor IX deficiency. Among those with known severity levels (685), 233 (34.0%) were severe, 185 (27.0%) moderate, and 267 (39.0%) mild. Nineteen (2.7%) cases had unknown severity levels (Table 1). Statistical analysis showed a significant association between type of haemophilia and severity ($P < 0.0001$) and cases identifying as Amish and type of haemophilia ($P < 0.0001$) and severity ($P < 0.0001$). Despite representing about 7% of the study population, the Amish population accounted for 17.7% of all factor IX cases. A majority of all our haemophilia cases (85.5%) were non-Hispanic white, 8.5% were non-Hispanic Black, 1.7% were Hispanic, and 2.0% were listed as other races or multiracial. The remaining 2.3% of cases had an undetermined race.

Overall, 575 (81.7%) cases were seen at an HTC at least once during the three-year study period. Of those not seen at an HTC during the study period (129), 27.9% (36) received haemophilia care primarily from an emergency department, 23.3% (30) were seen by a private haematologist, 4.6% (6) were cared for by a primary care provider, 4.6% (6) had either no care provider or were incarcerated during the study period, and 39.5% (51) had an unknown source of haemophilia care. The proportion of severe cases was significantly higher at HTCs ($P < 0.0001$); 40.7% (234) of cases seen at an HTC were severe compared to only 9.4% (12) of cases not seen at HTC facilities, and 95.1% of all severe cases were seen at an HTC.

Most (75%) of the study population with severe haemophilia was on prophylaxis at some point during the study period. Prophylaxis utilization among patients with severe haemophilia seen at an HTC was 30% higher compared to severe patients seen outside of the HTC network. Sixteen (2.3%) had an inhibitor during the study period, 75% of whom were severe patients. Most (81%) of the patients with an inhibitor were seen within the HTC network, similar to the overall distribution of cases. Thirty-eight (5.4%) patients suffered from an intracranial haemorrhage during the surveillance period. With respect to infectious disease, 4.1% (28) had a diagnosis of HIV infection and 19% (134) had hepatitis C. Of the patients receiving care at an HTC, only 17.6% utilized ED services compared to a third of the non-HTC patients (33.3%).

Most, 89.2% (n = 628) of the study population had insurance during the study period. The primary insurance for 39.3% (247) of our population was private insurance, 27.2% (171) had Medicaid, 13.1% (82) had Medicare, 2.2% (14) had either CHAMPUS or ICHIA, state-sponsored insurance, and 18.2% (114) had an unknown insurance type. The majority of cases without insurance, 57%, were Amish, and 94.7% of all haemophilia patients without insurance were cared for at an HTC.

There were 634 identified cases of haemophilia in 2013. The age-adjusted prevalence of haemophilia in 2013 was 19.4 cases per 100 000 males, 12.7 per 100 000 for factor VIII and 6.7 per 100 000 for factor IX. The mean incidence of haemophilia over the 10 years before the study began (2001-2010) was 30.1 per 100 000 or 1:3688 live male births in Indiana. The average incidence for factor VIII and factor IX patients was 1:5433 and 1:15252, respectively.

Twenty-four patients (3.4%) died during the study period, all but one of whom were adults. The median age of death was 57.5 years, which was younger than median age of death of males in the United States of 79 years.[11] The majority of patients who died (20) were of mild and moderate severity. There was no significant association between mortality and the setting where patients received care; 25% of deaths (n = 6) occurred in cases outside of the HTC network. The mortality rate was 13 per 1000 person-years. Primary causes of death included haemophilia-related causes such as non-traumatic intracranial haemorrhage and GI haemorrhage and non-haemophilia-related causes including cirrhosis, cancer, heart disease, respiratory failure and HIV (Table 2).

4 | DISCUSSION

We report the first assessment of the prevalence and incidence of haemophilia within Indiana. The average incidence of haemophilia

TABLE 1 Demographic and clinical characteristics of haemophilia patients

Characteristic	N	%
Patient type		
Paediatric (<18 years)	251	35.7
Adult	453	64.3
Race/Ethnicity		
Non-hispanic white	602	85.5
Non-hispanic black	60	8.5
Hispanic	12	1.7
All other races	14	2.0
Unknown	16	2.3
Amish	46	6.5
Deficiency		
Factor VIII	456	64.8
Factor IX	248	35.2
Severity		
Mild	267	37.9
Moderate	185	26.3
Severe	233	33.1
Unknown	19	2.7
Primary insurance		
Private	247	35.1
Medicare	82	11.7
Medicaid	171	24.3
ICHIA/CHAMPUS	14	2.0
None	76	10.8
Unknown	114	16.2
Primary care source		
HTC	575	81.7
Non-HTC	129	18.3
Current inhibitor	16	2.3
Hepatitis C	134	19.0
HIV	28	4.1
Home infusions	366	52.0
Treatment		
Episodic	390	55.6
Prophylaxis	201	28.7
Immune tolerance	8	1.1
Unknown	102	14.6
ICH	38	5.4
Mortality	24	3.4

during the study period was roughly 1:3700 live male births, which is higher than the generally accepted frequency of haemophilia of roughly 1 in 5000 live male births. The estimated haemophilia prevalence in Indiana was 45% higher than previously reported in the United States.[6] Figure 1 depicts the larger proportion of patients in older strata compared to Soucie et al and the increased mean

TABLE 2 Cause of death for patients who died during study period

Cause of death	Number (n = 24)	%
Respiratory disease	3	12.5
Cardiovascular disease	4	16.7
HIV	1	4.2
Haemorrhage	6	25
Malignant neoplasm	4	16.7
Cirrhosis	2	8.3
Trauma	1	4.2
Sepsis	1	4.2
Cerebral palsy	1	4.2
Hepatorenal syndrome	1	4.2

(29.7 years versus 25.4 years) and median (25 years versus 23 years) ages. The higher prevalence in part reflects improvements in haemophilia care, including the widespread adoption of prophylaxis, which contributed to increased longevity. The most important explanations, though, for the higher prevalence are the dramatic reduction in HIV infections in younger cohorts and the impact of HIV treatments in decreasing mortality from HIV in the haemophilia population. Early mortality for many patients exposed to HIV and hepatitis from plasma-derived blood products in the early 1980s greatly contributed to decreased prevalence of haemophilia in the older strata. The largest percentage of patients in our study were in an age range (15-24 years) that had little to no exposure to contaminated blood products. Figure 2 illustrates differences in prevalence by age and by severity, highlighting a marked decline in prevalence in patients with severe haemophilia older than 35 compared to mild and moderate patients. Overall, we observed that haemophilia patients are living longer compared to 20 years ago. The prevalence of haemophilia in men ages 65 and over was 9.8 per 100 000 males compared to a rate of approximately 5 per 100 000 males in the Soucie study at ages 65-74.

The higher prevalence in Indiana is especially pronounced for haemophilia B. In comparison with the six-state study, factor IX deficiency was more common as a proportion of all haemophilia cases in Indiana by a factor of 1.6 (35.2% vs 21.5%). Although data from the CDC Surveillance Project showed state-by-state variability, Indiana's proportion of haemophilia patients with factor IX deficiency (35.2%) was 22.6% higher than the state with the highest percentage of factor IX deficiency (Louisiana, 28.7%). The higher rates are partially attributable to the Amish population that resides in Indiana and also to founder effect with individuals from the Amish community who leave and carry the mutation into the non-Amish community. The Amish community in Indiana was estimated to be 45 000 in 2010.[12] Of 46 cases of haemophilia within the Amish community, 44 had moderate factor IX deficiency and two had severe factor VIII deficiency. Even excluding the Amish population, however, the prevalence of haemophilia B was 6.2 cases per 100 000 males, which is considerably higher than the rate reported by Soucie et al (2.9 cases

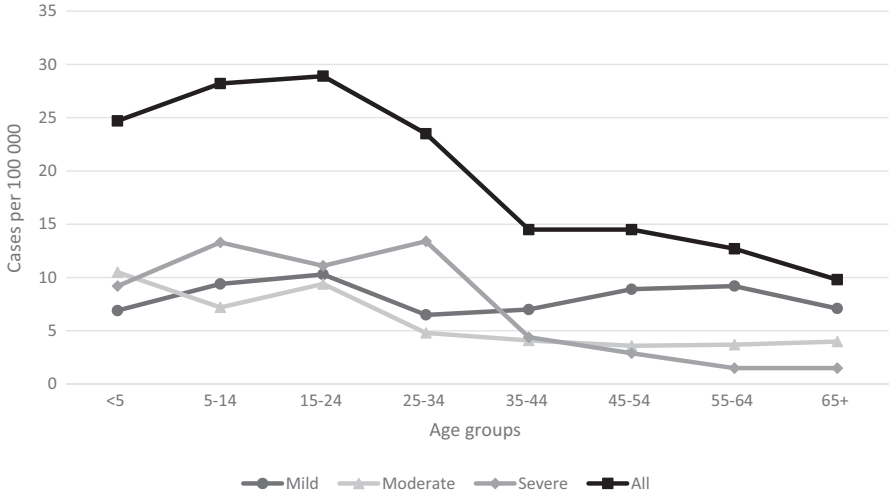

FIGURE 2 Age-specific prevalence of haemophilia by severity level in 2013

TABLE 3 Distribution of haemophilia patients by race/ethnicity, haemophilia type and severity

	VIII		IX		VIII & IX[a]							
					Severe		Moderate		Mild			
Race	N	%	N	%	N	%	N	%	N	%	Total	Prevalence
Non-hispanic white	374	62.2	228	37.8	186	30.9	170	28.2	233	38.8	602	22.8
Non-hispanic black	50	83.3	10	16.7	32	53.3	12	20.0	16	26.7	60	19.5
Hispanic	11	91.7	1	8.3	6	50	0	0	5	41.7	12	5.7
All other races	10	71.4	4	28.6	8	57.1	2	14.3	4	28.6	14	16.9
Unknown	11	68.7	5	31.3	1	6.2	1	6.2	9	56.2	16	-

[a]Does not equal total sum because unknown severity data were not included

per 100 000). Three of the six states surveilled (CO, OK, and NY) have Amish populations although Indiana's estimated Amish population (~45 000) is about 3.7 times larger than New York's (~12 000) and more than 75 fold larger than Oklahoma and Colorado (<600, <350, respectively).[12] This report is thus the largest known surveillance of haemophilia prevalence among an Amish population.

Disease severity has implications for the care required to prevent and limit haemophilia-related complications. In our cohort, 34%, 27% and 39% of patients had severe, moderate and mild haemophilia, respectively, compared with 31%, 26% and 43% reported by Soucie et al 20 years before. The decreased percentage of patients with mild haemophilia occurred despite a reclassification of disease severity that now includes factor activity levels of up to 40% as having mild haemophilia (compared to < 30% during the CDC Surveillance Project).[4,5] Fewer deaths among patients with severe haemophilia likely account for this shift in the proportion of haemophilia severities. Similar to Soucie et al, we observed higher rates of severe haemophilia in non-Hispanic (NH) Black patients compared to NH White patients and observed higher rates in Hispanic patients as well (Table 3). Rates of severe haemophilia in NH Whites and Hispanics in Indiana were similar to the US data previously reported. This could be due to possible underdiagnoses of minorities with moderate or mild disease. With a shift in population demographics projected in the future,[13] the proportions of patients with severe disease may shift as well.

Nearly, 82% of patients with haemophilia visited an HTC; that is, approximately a 15 percentage point difference compared to the national estimate reported 20 years ago. Factors contributing to this difference likely include providers increased awareness of specialized care for patients with haemophilia and the case finding and outreach efforts of the IHTC. The difference may also be due to the different methods of case ascertainment used in this study to discover patients outside of the HTC network. Our data confirm that patients cared for at HTCs are more likely to have severe haemophilia, are three times more likely to have HIV and are two times more likely to have hepatitis than patients seen outside of the HTC network (Table 4). Despite larger proportions of patients with severe disease and comorbidities, patients receiving care at HTCs in the 1990s were reported to have improved outcomes.[6] Similarly, the present study found very limited evidence of patients outside the HTC network receiving comprehensive joint health assessments or demonstrating the ability to self-infuse. HTC patients with severe haemophilia were 30% more likely to be treated with prophylaxis than patients outside of the HTC network. There was a 47.1% lower frequency of ED use among patients being cared for at an HTC compared to patients cared for outside of the HTC network, suggesting

TABLE 4 Demographic and clinical characteristics of haemophilia patients by source of care

	HTC		Non-HTC		Total
Characteristic	N (total = 575)	%	N (total = 129)	%	N
Deficiency					
Factor VIII	361	62.8	95	73.6	456
Factor IX	214	37.2	34	26.4	248
Severity					
Mild	194	33.7	73	56.6	267
Moderate	163	28.4	22	17.1	185
Severe	218	37.9	15	11.6	233
Unknown	0	0	19	14.7	19
Insurance					
Private	209	36.4	38	29.5	247
Medicare	65	11.3	17	13.2	82
Medicaid	145	25.2	26	20.2	171
ICHIA/ CHAMPUS	14	2.4	0	0.0	14
None	72	12.5	4	3.1	76
Unknown	70	12.2	44	34.1	114
Treatment					
Episodic	354	61.9	36	27.9	390
Prophylaxis	190	33.2	11	8.5	201
Immune Tolerance	7	1.2	1	0.8	8
Unknown	21	3.7	81	62.8	102
Home Infusions	350	60.9	16	12.4	366
Hepatitis C	122	17.3	12	9.3	134
HIV	26	4.6	2	1.7	28
Haemophilic Arthropathy	126	21.9	2	1.6	128
Target Joint	65	11.3	4	3.1	69
ICH	27	4.7	11	8.5	38
ED Visits	101	17.6	43	33.3	144
Hospitalizations	105	18.3	45	34.9	150

that even with greater severity of disease, HTC patients are better equipped to manage their care and avoid ED visits. The multidisciplinary integrated care model of HTCs is used throughout the world for the care of patients with haemophilia; our results may be relevant to other countries where the HTC model is utilized.

4.1 | Limitations

This study has limitations. First, the clinical data for patients seen outside of the HTC setting were less complete than for patients seen at HTCs. The missing data could result in underestimation of the occurrence of certain clinical characteristics. In addition, lack of participation from several physicians and clinics may have resulted in a failure to identify some patients not captured by the administrative data sets and hospital discharge data. Finally, probable patients (n = 42) were included in the analysis, which may have led to a slight overestimation of prevalence. These patients are likely true haemophilia patients but not all criteria for confirmation were met. Exclusion of these cases would not appreciably affect estimated prevalence.

5 | CONCLUSION

In conclusion, Indiana has observed higher prevalence estimates and HTC utilization among persons with haemophilia than previously reported. Although those served by HTCs are more likely to have severe illness, they have a reduced rate of ED utilization and an increased rate of prophylaxis and self-infusion compared to haemophilia patients receiving care outside of the HTC network. This type of surveillance, while time consuming, may be one of the better ways to collect population-level data on patients with haemophilia so as to

track the impact of new therapies for haemophilia and give a more complete estimate of disease frequency.

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DISCLAIMER

The findings and conclusions in this study are those of the authors and do not necessarily represent the official position of the CDC.

DISCLOSURES

The authors stated that they had no interests which might be perceived as posing a conflict or bias.

AUTHOR CONTRIBUTIONS

AIO collected the data, performed data analysis, and wrote the manuscript. ADS, CR, JMS, and SDG designed the study, provided expert consultation, critically reviewed and edited the manuscript, and had final approval of manuscript. MA assisted in data collection. IAJ contributed in writing and editing of the manuscript.

ORCID

Amanda I. Okolo https://orcid.org/0000-0002-2328-2085

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