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BRIEF COMMUNICATION

Period Prevalence of Rheumatic Heart Disease and the Need for a Centralized Patient Registry in American Samoa, 2016 to 2018

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BACKGROUND: Rheumatic heart disease (RHD) is a severe, chronic complication of acute rheumatic fever, triggered by group A streptococcal pharyngitis. Centralized patient registries are recommended for RHD prevention and control, but none exists in American Samoa. Using existing RHD tracking systems, we estimated RHD period prevalence and the proportion of people with RHD documented in the electronic health record.

METHODS AND RESULTS: RHD cases were identified from a centralized electronic health record system, which retrieved clinical encounters with RHD *International Classification of Diseases, Tenth Revision, Clinical Modification* (*ICD-10-CM*) codes, clinical problem lists referencing RHD, and antibiotic prophylaxis administration records; 3 RHD patient tracking spreadsheets; and an all-cause mortality database. RHD cases had ≥1 clinical encounter with RHD *ICD-10-CM* codes, a diagnostic echocardiogram, or RHD as a cause of death, or were included in RHD patient tracking spreadsheets. Period prevalence per 1000 population among children aged <18 years and adults aged ≥18 years from 2016 to 2018 and the proportion of people with RHD with ≥1 clinical encounter with an RHD *ICD-10-CM* code were estimated. From 2016 to 2018, RHD was documented in 327 people (57.2%: children aged <18 years). Overall RHD period prevalence was 6.3 cases per 1000 and varied by age (10.0 pediatric cases and 4.3 adult cases per 1000). Only 67% of people with RHD had ≥1 clinical encounter with an RHD *ICD-10-CM* code.

CONCLUSIONS: RHD remains a serious public health problem in American Samoa, and the existing electronic health record does not include all cases. A centralized patient registry could improve tracking people with RHD to ensure they receive necessary care.

Key Words: American Samoa ■ cardiovascular disease ■ epidemiology ■ registry ■ rheumatic heart disease

Rheumatic heart disease (RHD) is a severe and chronic complication of acute rheumatic fever (ARF), which is triggered by group A streptococcal pharyngitis.[1] Complications resulting from carditis during an ARF episode can permanently damage the heart valves, resulting in RHD.[1] RHD is a progressive disease, with complications including heart failure, stroke, and early death.[1] People with severe RHD often require surgery to repair or replace damaged heart valves.[2] RHD can be prevented from occurring among people with a history of ARF, or prevented from worsening among people with preexisting RHD, through routine prophylactic administration of benzathine benzylpenicillin G (BPG).[1,3]

Although RHD is now relatively rare in the United States, it remains a significant public health problem

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globally,[4] including in the US territory of American Samoa.[5,6] American Samoa's current RHD prevention and control activities focus on the pediatric population aged <18 years and include health education activities, intermittent echocardiographic mass-screening events at schools, free BPG prophylaxis clinics, and clinical management of pediatric patients with RHD through cardiology specialty clinics. Centralized ARF/RHD disease registries are a recommended component of comprehensive RHD prevention and control programs[7,8] that may improve uptake of and adherence to prophylaxis.[9,10] However, no centralized ARF/RHD registry currently exists in American Samoa.

We assessed multiple existing data systems to estimate the current burden of RHD in American Samoa and to assess the need for a centralized, comprehensive ARF/RHD registry that could be used to coordinate care and improve surveillance. The findings from this study can inform efforts within low-resource settings to use combinations of data systems and/or develop centralized registries to support disease monitoring and management activities and to inform resource allocation to meet both patient and programmatic needs.

METHODS

Because of the sensitive nature of the data collected for this study, requests to access the data set from qualified researchers trained in human subject confidentiality protocols may be sent to the American Samoa Department of Health (DOH) at ieliapo@doh.as.

Setting

American Samoa, a US territory located in the remote Pacific region, is composed of 5 inhabited islands with a total population of 55 689 in 2018. People with ARF and RHD receive care and routine BPG prophylaxis at 5 federally funded community health centers administered by the American Samoa DOH and the Lyndon B. Johnson Tropical Medical Center (LBJ), the only acute care hospital in the territory. As there are no pediatric cardiologists currently based in American Samoa, children with RHD receive specialist cardiology care during biannual visits by pediatric cardiologists from the US mainland. Heart valve surgery is not available in American Samoa; people who require heart valve surgery obtain care overseas. Patients who have heart valve surgery are then managed postoperatively by local healthcare providers. Many residents of American Samoa are insured through the Medicaid program, which provides 100% fee-for-service coverage for all healthcare services obtained at the LBJ hospital based on a system of presumed eligibility and can be used to cover heart valve surgeries overseas.

Procedures and Data Sources

In 2019, staff from the Centers for Disease Control and Prevention, the American Samoa DOH, and LBJ identified RHD cases from 5 data sources: the electronic health record (EHR) system, 3 patient tracking spreadsheets, and an all-cause mortality database. The EHR system (CareVue EHR from Medsphere Systems Corporation, Carlsbad, CA), which is based on the VistA EHR system developed by the Department of Veteran Affairs and the Indian Health Service, was used by all healthcare providers in the territory, including DOH-operated primary care clinics and LBJ. Queries of the EHR retrieved information from 2016 to 2018 to identify patient encounters with *International Classification of Diseases, Tenth Revision, Clinical Modification* (*ICD-10-CM*) codes indicative of RHD (codes I01.0–I01.2, I01.8, I02.0, I02.9, I05.0–I05.2, I05.8–I05.9, I07.0–I07.2, I07.8–I07.9, I09.0–I09.2, I09.81, I09.89, and I09.9); patient clinical problem lists containing ARF- or RHD-related keywords (eg, rheumatic, RHD, ARF, RF, bicillin, and bici); and nursing notes documenting ARF- or RHD-related BPG prophylaxis administrations. The 3 RHD tracking spreadsheets were developed by identifying patients with RHD from the EHR and were independently used and maintained by the DOH's RHD Prevention and Control Program, the LBJ Pediatrics Department, and the visiting pediatric cardiologists to coordinate care. The purpose and structure of the spreadsheets vary: LBJ uses its spreadsheet to track patient information not easily accessible in the EHR, the DOH uses its spreadsheet to track newly identified children with RHD to link them to care, and the pediatric cardiologists use their spreadsheet to coordinate patient care. The all-cause mortality database is maintained by LBJ's Vital Statistics Department and includes deaths that occur inside and outside of the hospital from 2016 to 2018. This investigation was reviewed by the Centers for Disease Control and Prevention and was determined to be nonresearch.

RHD Case Definition

RHD was defined as follows: (1) ≥1 inpatient or outpatient clinical encounter with *ICD-10-CM* codes indicative of RHD, (2) RHD *ICD-10-CM* codes or RHD-related keywords indicating RHD as the cause of death, (3) an echocardiogram diagnosing RHD according to the World Heart Federation criteria,[11] or (4) being listed in one of the RHD patient tracking spreadsheets. Medical record numbers, unique patient-level identifiers common to all data sources,

were used to merge the data sources and avoid duplication. Average projected population counts for American Samoa from 2016 to 2018, derived from the US decennial census, served as population denominators.

Statistical Analysis

We used Pearson χ^2 and Fisher exact tests to assess the independence of the distribution of cases by sex, age group, and race among children aged <18 years and adults aged ≥18 years using a type I error rate of 5%. We also assessed the independence of distributions in healthcare payer, which included commercial or private insurance, Medicaid, or Medicare, 2 US federal healthcare coverage programs. We then calculated age-stratified RHD period prevalence per 1000 population overall and by subgroup from 2016 to 2018. To assess the degree of fragmentation of the existing data systems, we also calculated the percentage of known people with RHD who were identified from each data source.

RESULTS

We identified 327 people with RHD (57.2% children and 42.8% adults; Table) from 2016 to 2018. Most were female sex (61.8%), of Samoan race (93.6%), and receiving Medicaid (87.8%). Adults with RHD were more likely to be women compared with children with RHD, and less likely to be on Medicaid (P<0.0001 for both comparisons).

Overall RHD period prevalence was 6.3 per 1000 population and varied by age. Among children aged <18 years, RHD prevalence was 10.0 per 1000 population (Figure 1), and within this age group, prevalence was highest among those aged 10 to 17 years (17.8 per 1000 population), followed by those aged 5 to 9 years (6.5 per 1000 population) and those aged <5 years (0.2 per 1000 population).

Table 1. Characteristics of People With RHD Overall and by Age Group: American Samoa, 2016 to 2018

Characteristic	Total (N=327)	Children Aged <18 y (n=187 [57.2%])	Adults Aged ≥18 y (n=140 [42.8%])	*P* Value*
Age, y, n (%)				…
<5	1 (0.3)	1 (0.5)	…	
5–9	33 (10.1)	33 (17.7)	…	
10–17	153 (46.8)	153 (81.8)	…	
18–25	51 (15.6)	…	51 (36.4)	
26–35	35 (10.7)	…	35 (25.0)	
>35	54 (16.5)	…	54 (38.6)	
Sex, n (%)				<0.0001
Women	202 (61.8)	90 (48.1)	112 (80.0)	
Men	125 (38.2)	97 (51.9)	28 (20.0)	
Race group, n (%)				0.67
Samoan	306 (93.6)	176 (94.1)	130 (92.9)	
Other Pacific Islander†	17 (5.2)	10 (5.4)	7 (5.0)	
Other	2 (0.6)	0 (0.0)	2 (1.4)	
Missing	2 (0.6)	1 (0.5)	1 (0.7)	
Payer, n (%)				<0.0001
Medicaid	287 (87.8)	177 (94.7)	110 (78.6)	
Medicare	8 (2.5)	0 (0.0)	8 (5.7)	
Other‡	30 (9.2)	9 (4.8)	21 (15.0)	
Missing	2 (0.6)	1 (0.5)	1 (0.7)	
District, n (%)				0.70
Eastern and Manu'a	141 (43.1)	75 (40.1)	66 (47.1)	
Western	166 (50.8)	92 (49.2)	74 (52.9)	
Missing	20 (6.1)	20 (10.7)	0 (0.0)	

The Table includes people with RHD who were alive or died from 2016 to 2018. RHD indicates rheumatic heart disease.

*Pearson χ^2 and Fisher exact tests were used to compare the distribution of the case status, sex, race group (Samoan vs other), payer (Medicaid vs other), district, and data source variables for the RHD patient population aged <18 and ≥18 years.

†Responses include Polynesian, Fijian, and Tongan.

‡Responses include commercial and self-pay.

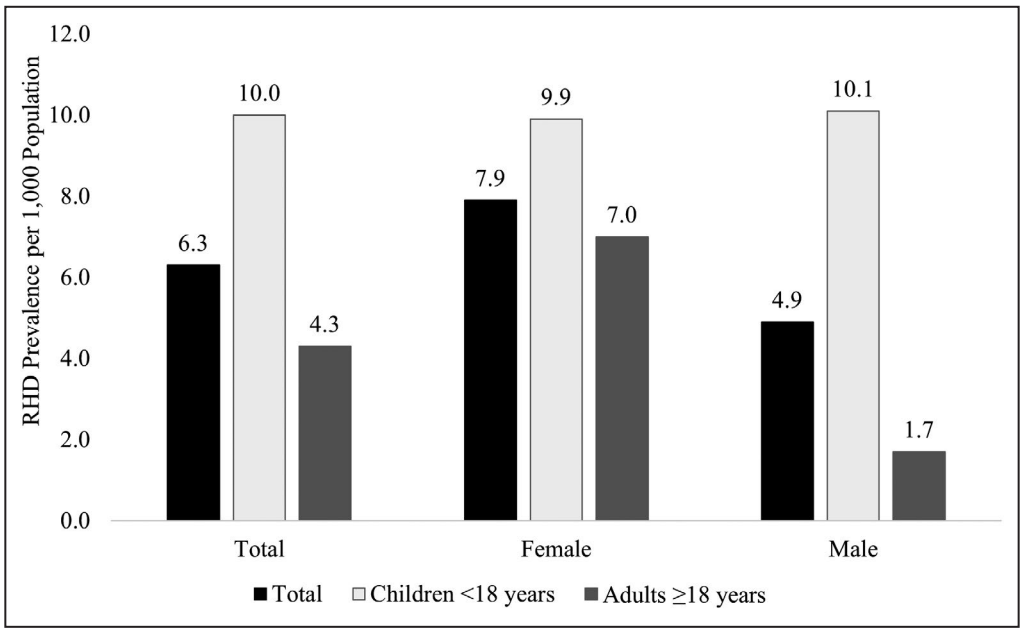

Figure 1. Period prevalence per 1000 population of rheumatic heart disease (RHD) overall and by age group and sex: American Samoa, 2016 to 2018.

Compared with children aged <18 years, RHD prevalence was markedly lower among adults aged ≥18 years (4.3 per 1000 population). Among adults, RHD period prevalence was highest among those aged 18 to 25 years (6.8 per 1000 population), followed by those aged 26 to 35 years (5.5 per 1000 population) and those aged >35 years (2.9 per 1000 population).

RHD period prevalence was higher among female patients (7.9 per 1000 population) compared with male patients (4.9 per 1000 population) in all age groups (Figure 1). However, sex differences varied by age group. Men aged ≥18 years had the lowest period prevalence of all age-sex groups (1.7 per 1000 population).

No single data source contained all people with known RHD. Among all people with known RHD, 92.7% had any documentation in the EHR (66.7% had clinical encounters coded with *ICD-10-CM* codes indicative of RHD, 50.8% had a note recording BPG prophylaxis administration, and 23.2% had an RHD-related keyword in the clinical problem list). Of all people with known RHD, 60.9% were listed in the RHD patient tracking spreadsheets.

The proportion of people with RHD in each data source varied by age group (Figure 2). Consistent with the program's focus on the pediatric population, children aged <18 years were more likely than adults aged ≥18 years to have a record of RHD-related antibiotic prophylaxis administration, to have RHD-related keywords in the patient clinical problem list, and to be listed on a tracking spreadsheet (P<0.01 for all comparisons). Adults aged ≥18 years were more likely to have a clinical encounter coded with an *ICD-10-CM* code indicative of RHD and be included in the all-cause mortality database (P<0.01 for all comparisons).

DISCUSSION

Using multiple data sources, we documented an overall RHD period prevalence of 6.3 cases per 1000 among people in American Samoa from 2016 to 2018, with markedly higher period prevalence among children than adults. Our RHD period prevalence estimates represent the most current data available for children and are the first known estimates among adults in American Samoa. The current RHD period prevalence estimates among children (10.0 cases per 1000 population) are notably higher than those reported in a 2013 study, which found the RHD point prevalence to be 3.2 cases per 1000 population among children aged <18 years.[5] However, these estimates are not directly comparable or indicative of temporal trends in RHD prevalence because of methodologic and contextual differences between the 2 studies. For example, the 2013 study identified cases using a single clinical encounter coded with RHD-related *ICD-9-CM* codes.[5] In addition, increased school-based echocardiographic screenings conducted since the 2013 study might have resulted in increased detection of children with RHD, contributing to the higher prevalence reported in this study. Results from this analysis leverage multiple data sources and use a comprehensive case definition to

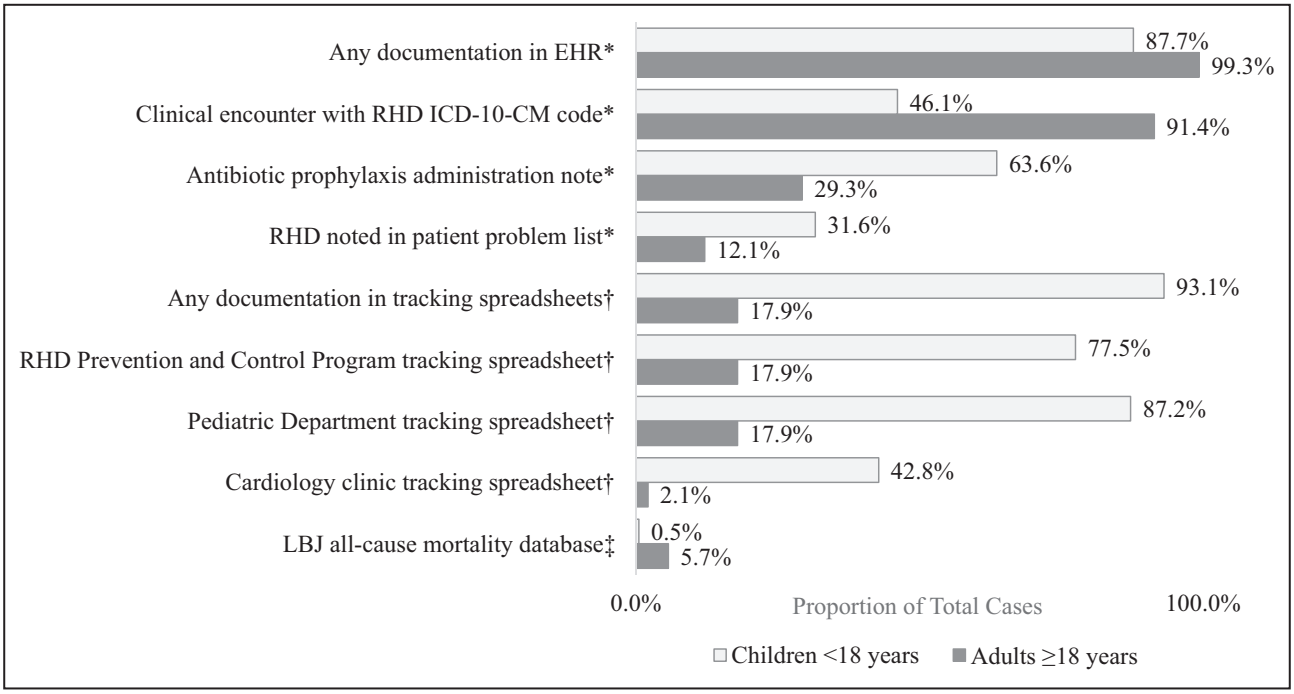

Figure 2. Proportion of patients with rheumatic heart disease (RHD) included in data sources, by age group: American Samoa, 2016 to 2018.
EHR indicates electronic health record; *ICD-10-CM*, *International Classification of Diseases, Tenth Revision, Clinical Modification*; and LBJ, Lyndon B. Johnson Tropical Medical Center.

estimate RHD prevalence following the initiation of mass screening activities.

The true RHD prevalence in American Samoa is likely higher than the current estimate.[6] An echocardiographic screening study conducted in 2012 among a convenience sample of 4 schools in American Samoa estimated a prevalence of 35 cases per 1000 that met the World Heart Federation criteria for definite RHD among children aged 5 to 18 years.[6] However, results from this echocardiographic screening study were not representative of schools and may overestimate or underestimate true RHD prevalence in the territory. A recent systematic review and meta-analysis of 37 populations in areas endemic for RHD reported a pooled prevalence of RHD detected by echocardiography of 12.9 per 1000 population, with substantially higher clinically silent disease compared with clinically manifest disease.[12]

Given that RHD is a chronic condition,[1] results from this study indicating markedly lower RHD period prevalence among adults compared with children are unexpected. One potential explanation for this finding is underdiagnosis or undertreatment of RHD among adults, given that mass echocardiography screenings and coordinated clinical services have focused on the pediatric population as opposed to adults. Alternatively, lower RHD prevalence among adults could also be explained by increased detection of children with RHD through population screening activities and linkages to care, which could result in less clinically meaningful RHD in adulthood through improvements in BPG initiation and adherence. The marked sex differences among adults may be explained by women's more frequent healthcare seeking behavior or contact with the healthcare system during the reproductive years, especially given the serious adverse sequelae among pregnant women with RHD.[13]

A major finding from this investigation is that none of the existing patient tracking systems can be used to easily identify all people with RHD using the case ascertainment methods described in this study. Although most (92.7%) individuals with known RHD had documentation of RHD in the EHR, the information is currently stored in several different locations that cannot be easily reconciled to create a comprehensive list of patients or clinical indicators. Developing a centralized ARF/RHD registry by modifying the existing EHR to enable the compilation of patients and key clinical indicators or by establishing a new data system external to the EHR could resolve this problem. More important, any centralized ARF/RHD registry would need to be created using all available data systems given the degree of fragmentation identified in this study. Such fragmentation is not unique to American Samoa and has been documented elsewhere: a recent analysis from Australia found that ARF/RHD disease registries,

hospital records, and death databases were all missing substantial numbers of people with ARF and RHD because of resource and administrative constraints.[14]

Centralized ARF/RHD disease registries are recommended components of comprehensive RHD prevention and control programs,[7,8] and may improve uptake of and adherence to prophylaxis when used as part of a coordinated service delivery model.[9,10] Maintaining and using existing data systems to create a centralized ARF/RHD registry could improve health outcomes in American Samoa in a variety of ways. For example, a centralized registry could facilitate follow-up of people identified through population-screening activities; facilitate case management activities designed to minimize loss to follow-up and improve BPG prophylaxis delivery; improve coordination of care and services provided by clinical and public health partners; help transition young adults from pediatric to adult care; and improve care among women of reproductive age to ensure they receive prophylaxis and active clinical monitoring. When used as part of a broader, multidisciplinary healthcare approach, centralized registries have been shown to improve patient management and treatment delivery at primary, secondary, and tertiary levels, ultimately improving the rates of disease and collection of surveillance information for epidemiologic reporting.[7,9,14] However, establishing a centralized registry alone may not reduce RHD in endemic regions; increasing population-based echocardiographic screening is needed to identify new cases of RHD, link them to care, and improve the accuracy and value of the registry.

A strength of this analysis is that it used multiple data sources to identify RHD cases, especially given that exclusive use of *ICD-10-CM* coded clinical encounters from hospital administrative databases have limited positive predictive value for identifying true cases of RHD.[15] Limitations of this analysis include that RHD period prevalence estimates likely underestimate the true burden of RHD in American Samoa, as people with undetected RHD and those who did not seek care from 2016 to 2018 would not have been included. In addition, the data sources used for case ascertainment methods may have been more likely to identify children with RHD, given that the existing RHD prevention and control program focuses on the pediatric population and the younger age distribution of ARF and populations receiving BPG prophylaxis overall. In addition, we were unable to validate RHD diagnoses for identified cases by examining echocardiograms, which may have affected the sensitivity and specificity of case ascertainment.

This study highlights RHD as a persisting population health problem in American Samoa. Although a combination of existing data systems could be used to support disease monitoring and management activities, establishing a centralized ARF/RHD registry could improve multiple aspects of American Samoa's RHD prevention and control program, and inform the resource allocation to meet patient (and programmatic) needs. Centralized ARF/RHD disease registries are recommended components of comprehensive RHD prevention and control programs,[7,8] as they can improve surveillance and coordination of care to ensure people with RHD receive the care necessary to manage the disease and reduce adverse sequelae and mortality.

ARTICLE INFORMATION

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