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The rheumatic heart disease healthcare paradox: disease persistence in slums despite universal healthcare coverage—a provider perspective qualitative study

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ABSTRACT

Objectives: Rheumatic heart disease (RHD) is a preventable disease frequently recognized in urban slums. Disease rates in Brazilian slums are incommensurate with the country's economic status and the existence of its universal healthcare system. Our study aimed to investigate what system issues may allow for disease persistence, focusing on issues surrounding access and utilization of primary and specialized healthcare services.

Study design: This was a two-part (formative phase followed by implementation phase) qualitative study based on interviews and focus groups and analyzed via content analysis.

Methods: One focus group and 17 in-depth interviews with community health workers, primary care providers, and cardiologists who serve slum residents in Brazil and six interviews with key informants (community health researchers and cardiologists) were performed. Interviews with community health workers and primary care providers were from a single heath post in the neighborhood of Liberdade, a populous and previously unstudied slum in Salvador. Cardiologists were recruited from tertiary care referral hospitals in Salvador.

Results: Our findings revealed six major chronological categories/themes of issues and twenty subthemes that patients must overcome to avoid developing RHD or to have it successfully medically managed. Major themes include the effects of living in a slum (1), barriers to access and utilization of primary healthcare services (2), treatment in primary healthcare services (3), access/utilization of specialized healthcare services (4), treatment in specialized healthcare services (5), and certain systemic issues (6).

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Conclusion: Slums make residents sick in a manner of ways, and various bottlenecks impeding medical access to both primary care and specialty care exist, requiring multifaceted interventions. We detail major themes and finally suggest interventions that can allow for the health system to successfully eliminate RHD as a public health concern for slum residents.

Introduction

By 2030, nearly two of the planet's eight billion inhabitants will reside in slums.[1] Slums frequently experience violence, unemployment, limited access to public services, poverty, and increased health risks.[2,3] Despite the ongoing growth of slum communities worldwide, there is a paucity of health statistics on disease and access to healthcare within slums,[4–11] which limits capacity to address urgent health needs.[5,6,12]

Rheumatic heart disease (RHD) accounts for 15% of all patients with heart failure worldwide,[13,14] affecting 15 million people globally,[15] an estimate that rises to 62–78 million with echocardiography-based screening.[16] RHD is caused by group A streptococcal (GAS) infection and associated pharyngitis and/or acute rheumatic fever, either of which can lead to the cardiac sequelae of RHD and subsequent valvular dysfunction and heart failure. RHD is considered relatively rare in wealthy areas,[17] and prevalence is largely determined by socio-economic status (SES).[18,19] Known social risk factors include overcrowding and unemployment, while patients from low- and middle-income countries have a poorer disease prognosis.[20,21]

Universal healthcare access would presumably limit RHD prevalence and incidence by allowing primary care providers (PCPs) to identify and treat strep pharyngitis and cardiologists to manage active disease. Our study took place in Brazil, an upper middle-income country with a universal healthcare system, the *Sistema Único de Saúde* (SUS), since 1988.[22–28] Brazil also has one of the world's highest Gini coefficients[29] (a measure of income inequality) and extensive urban slums. As such, Brazil provides a unique setting to better understand healthcare access in urban slums and RHD in particular, providing a lens through which we can look at a wide swath of the health system spanning from primary to specialty care.

The burden of RHD in Brazilian slum populations has not been well described, but a study in the state of Minas Gerais screened school children from low SES neighborhoods and found a prevalence of 42 per 1000 children (37 borderline and five definite).[30] This compares to other echocardiography-based estimates in Cambodia (21.5), Mozambique (30.4), Nicaragua (48), and Kenya (62), all of which provide an average prevalence in developing countries of 40 per 1000.[16,31,32] Although there has yet to be an echocardiography-based study in the city of Salvador, Brazil's third largest city by population,[33] RHD was found to be the primary cause for valvular heart surgery there.[34]

Accordingly, the aim of this paper was to investigate why RHD persists at such high levels in Brazilian slums, despite universal healthcare access, focusing on barriers in accessing prevention and treatment for RHD in the Distrito Sanitário da Liberdade (DSL) neighborhood of Salvador, Brazil. By doing so, we hope to elucidate the dynamics of providing health care in slums for RHD worldwide and other acute and chronic illnesses from the perspective of healthcare professionals.

Methods

This study took place in Salvador, in the Brazilian Northeast, a region with 28% of Brazil's population but just 13.4% of its gross domestic product.[35] It therefore has a high concentration of Brazil's poverty, receiving more than 50% of total income transfer under Brazil's Bolsa Família program (a social welfare federal assistance program).

The study sites were located in the DSL at the Santa Monica Family Health Unit (USF-SM) and the Hospital Ana Nery, as well as at the Hospital Universitário Edgar Santos, which is not part of the DSL. Both hospitals are tertiary hospitals with statewide catchment areas and specializations in cardiology. The USF-SM serves a section of the DSL, a community housing one of the largest communities of Afro-descendent Brazilians in the country.[36]

The study used semistructured interviews to collect data from 17 participants in addition to one focus group. A convenience sample of clinicians and community health workers (CHWs) working in the study setting were recruited as follows: six cardiologists via snowball sampling, with nine CHWs and two PCPs via research contact (family health post manager). Informed consent was obtained in Portuguese. The focus group was conducted prior to the in-depth interviews. Interviews were audio recorded and transcribed in Portuguese, and a thematic analysis was performed using MAXQDA software. Thematic analysis, a method for identifying, analyzing, and reporting patterns (themes) within data,[37] was chosen in order to search for and identify the common threads that spread across the entire set of interviews,[38] helping to identify major agreed-upon barriers or issues. Memos were written according to code/theme to clarify scope, content, and interrelationship. Selected quotes were translated into English.

The University of California, San Francisco ethics committee provided an exemption, and in Brazil, the study received approval from the Research Ethics Committee of the ISC – UFBA Institute of Public Health, approval no. 2,245,779, HAN Ethics Committee no. 2,839,303, and HUPES Ethics

Committee no. 2,598,267. Funding for this research was provided by the Center for Global Public Health at the University of California, Berkeley.

Results

Our findings revealed six major obstacles that must be overcome in the prevention and treatment of RHD. These include the effects of living in a slum (1a and 1b), barriers to access and utilization of primary healthcare services (2), treatment in primary healthcare services (3), access/utilization of specialized healthcare services (4), treatment in specialized healthcare services (5), and systemic issues (6) (Fig. 1).

Slum risk factors

Overcrowding

Poor sanitation was considered a major contributor that leads to enhanced infection and spread of GAS. CHWs emphasized that resident inability to adequately maintain a healthy living space was due to structural vulnerabilities and resultant poverty. This is consistent with research that poverty-associated risk factors such as unhygienic living conditions lead to persistent GAS in the environment and that overcrowding leads to repeated GAS infection.[40–42]

Diet and exercise

Malnutrition in children is potentially linked to susceptibility to acute rheumatic fever[43] via a decreased immune response.[44] Maintaining an adequate diet can be difficult, and despite nutrition recommendations being communicated to patients, providers note that these instructions may be impossible to follow, again demonstrating poverty as inhibiting an individual's ability to stay healthy.

> Sometimes… they're very thin… You counsel them about diet, it's just that they won't always manage, but for financial reasons. You'll say "you have to eat every three hours" but sometimes they can only eat twice a day. How are they going to eat more? (PCP 1).

Research has shown that exercise improves health outcomes and reduces the risk of both cardiovascular disease[45] and rheumatic fever.[46] However, access to this preventive measure was made difficult because of violence in the community.

Community outreach

CHWs and PCPs are able to communicate with patients the need for a healthy diet and exercise but lamented challenges in providing health education to the community. In addition to space and material, community violence was seen as hindering education and outreach by the clinic, limiting participation and possible educational topics. Liberdade is described by residents of Salvador as being one of the most violent neighborhoods in the city. All study participants discussed gang-related violence, specifically in terms of territorial conflicts related to the trafficking of narcotics, as affecting health.

> There is always violence… oh is it here. It can explode at any moment, ok? Sometimes we're afraid to enter a community because we don't know what will be there. We're waiting for a bomb to go off. (CHW 4).

For CHWs, the violence not only made outreach more difficult, but they spoke in visceral terms about both the scale of violence and the psychological effects it had on the community and on the CHWs themselves. While it is possible that violence and associated stress affects pathogenic susceptibility, here we see community violence

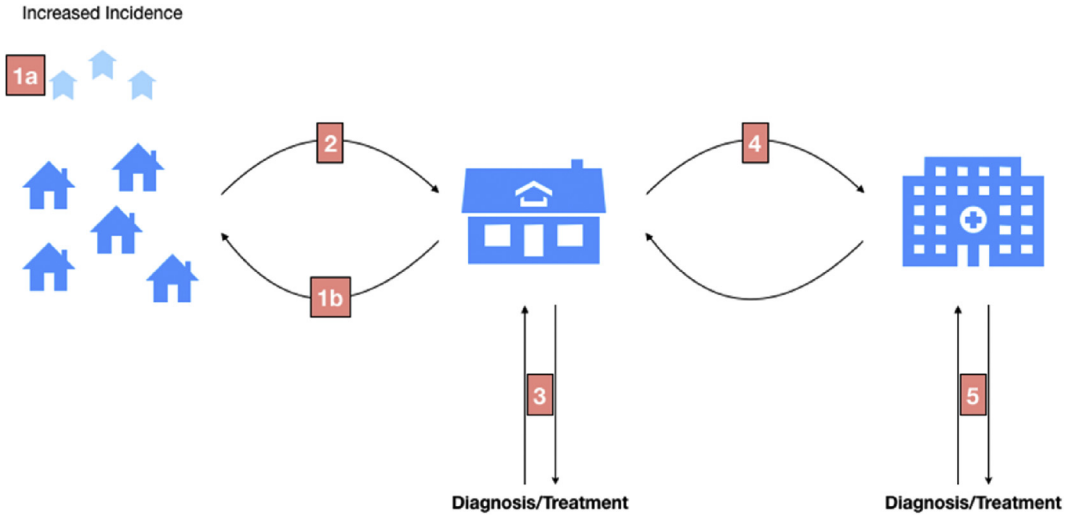

Fig. 1 – The referral system and barriers leading to progression (adapted with permission from Meara et al.).[39]

concretely limiting outreach and community contact by CHWs.

Barriers to access/utilization of primary healthcare services

Trust and awareness

Prior studies show lack of awareness of the clinic and/or a lack of trust in the clinic might be a barrier to accessing health care,[47] but we found that CHWs believed residents to be both informed and trusting of USF-SM.

> They're well informed. They have our day-to-day information… and the doctors are really helpful. (CHW 8).

Resident ambivalence

A major reason CHWs believed residents did not utilize the USF-SM was that the services did not seem useful. They frequently spoke of community members perceiving that the treatments offered by the USF-SM to be ineffective. Individuals in poverty in Brazil have been found to show higher incidences of fatalism and pessimism.[48] Accordingly, for the segment of the community that is reticent to use the clinic, poverty and associated feelings of fatalism and pessimism may be an explanation. The majority of residents were reported to use the USF-SM. However, it was often stated that their health-seeking behaviors were determined by the severity of the illness, that they would wait until symptoms deteriorated before interfacing with the healthcare system, often skipping the clinic entirely. In the context of developing RHD, this is a concerning finding, as streptococcal pharyngitis is usually self-limiting, but the lack of treatment allows for the development of postinfectious sequelae.[49]

Similarly, PCPs noted that their process of differential diagnosis often required a child to be brought back by their parents as a diagnosis was made clinically and without a rapid strep test. Thus, in addition to known USF-SM utilization difficulties related to a lack of resources and/or inability to take off work,[28] a lack of overt symptoms in this instance may also contribute to loss to follow-up and allow for continued RHD progression.

> We ask some children, when we have a presentation that is suggestive of a throat infection or a viral pharyngitis, to be brought back in 48 hours. The responsible parents bring them back. The ones who are not bring them back only if they get worse. (PCP 2).

Lack of providers

All providers spoke of the lack of doctors or nurses who could attend to residents. The lack of primary care physicians in particular has been described in the literature[50,51] and was seen by providers as the major impediment to slum residents getting medical attention. CHWs believed the lack of regular healthcare providers to be a source of dissatisfaction felt by the community as well.

> Our team went without a doctor for a year, the nurse moved away. Later they sent two nurses, one stayed for a time, one for another time, but neither came regularly. (CHW 7).

Alternative care

The perceptions that going to a USF is not useful, either because the treatment is ineffective or because there is no healthcare provider, resulted in community members seeking out alternative healthcare options, namely the direct use of pharmacies. In Brazil, availability of over-the-counter antibiotics decreased in 2010 after new national restrictions, yet the practice is known to persist both anecdotally and from evidence in the literature.[52,53] Additionally, various studies focusing on either antibiotics or pharmacist recommended over-the-counter medications show this practice may indeed be harmful.[54–56]

> So, being without a doctor… they (the residents) will look for other ways. There's no nurse, so they look for other solutions. They'll just go directly to the pharmacy instead. (CHW – focus group).

Furthermore, the use of traditional medicines in the region has a long history related to the Afro-Brazilian religious tradition Candomblé.[57] While traditional remedies were seen as an alternative care modality, CHWs saw people who used teas as an exclusive replacement for healthcare as a minority. Instead, they were more concerned with the use of traditional medications as prolonging the time between the appearance of symptoms and seeking medical attention.

Barriers to treatment in the primary healthcare services

Health literacy

CHWs universally expressed that patients had a poor understanding of how to take medications, stating that they frequently would use a medication only while experiencing acute symptoms and then stop. Residents were also noted to seek medication from a neighbor who had previously had similar symptoms instead of from a clinician. Overall, low health literacy was seen to necessitate an extended time period with the patient, which was difficult for the PCPs, and required constant follow-up and outreach by CHWs.

> The level of understanding is low. There's the issue of literacy as well. There are a lot of functionally illiterate people, you write things and explain it to them, but when they look at the prescription they don't understand what it is they're holding. (PCP 2).

Availability of medications

Medications are not ubiquitous in Brazil,[58] and antibiotic access in particular is often limited by low SES.[59] CHWs and PCPs identified a lack of basic medications as a barrier. Poor access to penicillin for streptococcal pharyngitis is a missed opportunity to prevent future RHD.

> I will tell you that this is the greatest difficulty, because people end up not buying the medication and then they get worse. Man, there have been some terrible, terrible throat problems and days where the mom says, 'I don't have money, I didn't buy any (medicine).' (CHW 9).

Diagnostic testing

In addition to lacking a rapid strep test, PCPs reported difficulty ordering an antistreptolysin O (ASO) titer, both of which likely contribute to an underestimation of streptococcal disease prevalence in Brazil.[17]

Barriers to access/utilization of specialized healthcare services

Screening and diagnosis

In the state of Bahia, there is no screening program for RHD, and the PCPs at the clinic noted that they would not send a patient for an echocardiogram unless the patient demonstrated symptoms.

> In fact, there's a grading, because we in family medicine think of SUS as an economy. So, it's no use me asking for an echocardiogram if there are no changes to the physical exam or ECG. So, for screening we do cardiac auscultation, a clinical exam, and when there's some alteration suggestive of a morphological change to the heart or valvular change we order an echocardiogram. (PCP 2).

Regrettably, auscultation as the primary method of screening can often miss subclinical RHD.[17,60–62]

Referral to specialists

Difficulty with referral was noted by all providers to be a long and arduous ordeal. Referrals are sent to a central regulation system (*regulação*) that determines which of the various public hospitals in the city of Salvador the patients will be referred to for specialty care. Heathcare providers also pointed to an insufficient number of specialists, making the system fundamentally inept in providing for the population.[26] As noted in the literature,[63,64] health workers pointed to the lack of coordination of referrals within the system, and cardiologists especially were frustrated with the lack of appropriate triage. Studies have shown this waiting period to be longer for low SES individuals in Brazil.[65]

> Triage used to exist… but these days it doesn't. Now, when they enter into the regulation they enter into a blender that mixes everyone up and spits them out randomly. (Cardiologist 2).

Communication with physicians

As previously described,[64,66] we also found poor communication to hamper patient care. The majority of cardiologists found this detrimental to patients, a complaint echoed by CHWs. Differences in SES affect communication between the doctor and patient[67,68] and in this case may result in poor adherence, understanding, and therefore poorer outcomes.

> The physician needs to know the patient in their entirety. The patient is not the disease. The patient… is inserted in a reality, and if you don't perceive this reality and you treat that patient, they'll tell you they're taking the medication and when they get home they won't. (CHW 1).

Treatment in the specialized healthcare services

Health literacy

CHWs, PCPs, and cardiologists noted patients often had a poor understanding of their condition. This was seen as a major difficulty in terms of understanding the need to see a physician regularly and the need to adhere to medical treatment.

> What we see most… is the patient not wanting to return. So, sometimes it's because either the family itself doesn't understand, doesn't realize the severity of the disease, or doesn't understand the need for prophylaxis and the importance of taking benzathine every 21 days… It's this question of understanding… that I think is the biggest problem. (Cardiologist 4).

Prophylaxis

More than half of the cardiologists noted structural barriers that patients can face in adhering to long-term penicillin injections. The first of these being the requirement that the medication be injected in a medical facility. Cardiologists viewed the risk of anaphylactic shock not worth the resultant limiting access that occurs with the transport, financial, and logistical barriers. In addition, a lack of access to prophylactic medication increases the changes for RHD in patients with previous ARF.[17,69–72]

Diagnostic testing

Echocardiography referrals also run through the central regulation (*regulação*). Similar to barriers expressed earlier, providers believed that the supply is not enough for the demand, that there should be a triage system, and that the time needed for a patient to get an examination is a significant barrier.

> There is no certain date in the… system for (echocardiogram) vacancies to appear, the vacancies are random. The patient isn't always available to be forever waiting at the desk for the form or vacancy they need. (Cardiologist 1).

Systemic issues and neglect

Cardiologists, in particular, were concerned with the lack of public investment and general low government attention to the disease. The perceived non-acknowledgment of the existence of RHD was often phrased in terms of the economic and political centers of the south ignoring problems in the Northeast, a regional tension with deep historical roots[73] still felt by participants in our study. Health post providers in Liberdade voiced forceful concerns that their community was

indeed ignored and attributed a large part of this to racial discrimination.

> The whole social structure is set up so that blacks and the poor stay in the same place, and their descendants stay there, not seeing possibilities for getting out. (PCP 2).

Discussion

The intent of this study was to investigate health providers' perspective on RHD in slum areas. The results support the need for continued economic and educational development of slum areas to both empower residents to better care for their health and productively manage their own homes and neighborhoods to address overcrowding and sanitation.[5] Understanding that community violence prevents outreach implies an increased need for advocacy to decrease community violence.

Primary prevention

Active surveillance of children at risk for GAS pharyngitis is an option that has found success in New Zealand.[74] It would be necessary, however, to better understand the viewpoint of residents in Liberdade and other slums to explore motivations, health-seeking behaviors, and why they might choose not to seek treatment and/or not to adhere to treatment. Notably, as health care in Liberdade is already underresourced, proposed cuts to public services amidst current political turmoil will likely exacerbate the already tenuous healthcare coverage.[75]

Secondary prevention

The irregular supply of penicillin G benzathine must be addressed,[76] and it is likely necessary to ease restrictions on where the injections can be administered in order to facilitate access. Brazil could consider decreasing injection dosing to once every four weeks instead of three.[77] This is the schedule in New Zealand, and recurrence rates for ARF have remained low.[71,78–80] Further research into improving prophylactic adherence should be performed to identify ideal targets for intervention.[81] According to our research, however, retention in care is a major issue, as seen elsewhere.[82] To mitigate causative factors, RHD care should be decentralized, as advocated in the Addis Ababa communiqué on how to eliminate RHD in Africa.[82,83] Alongside this, we should note, are increased PCP training programs regarding the diagnosis and referral necessity of ARF and RHD.[76]

Ameliorating systemic issues

Investments should be directed toward public health campaigns aimed at educating the public about RHD, provider training for RHD, and research to discover the disease burden. An echocardiography-based study should be conducted to provide a quantitative value for the burden of RHD and inform the potential need for a wider screening program using telehealth, task-shifting, and/or handheld echocardiography as needed to improve feasibility,[84,85] especially considering recent development of cost-effective models.[86] Finally, medications such as penicillin need to be consistently stocked and available.

Communication between the referring physician and specialist should be prioritized. This would likely allow for better treatment for the patient by both physicians, improve adherence, and help bridge the cultural and communication divide that exists in a highly economically stratified society.[87,88] Training diverse physicians from slum communities should continue to be prioritized,[89] or gaps in the quality of care will likely continue.[90,91]

The major limitation of this study was the relatively small sample size of 17. We chose to focus on one health post in particular to get a thorough understanding of one clinic's issues. Thus, despite reaching saturation with the providers at this clinic, the study details the experience of one slum in Salvador, which, while instructive, should not be overgeneralized.

While many of the barriers aforementioned could relate to any disease and therefore inform slum health in general, the issues that affect RHD development more uniquely include RHD-related health literacy (not returning to clinic, not using medications as prescribed), a lack of screening, difficulty obtaining imaging, availability of appropriate diagnostic tests or medications (rapid strep test, ASO titer), difficulty referring to specialists, and systemic neglect. Policy makers should prioritize these. In terms of future research, at the very least we should know the disease prevalence and must continue to study barriers to care in this and other slum communities in Salvador. Importantly, a further understanding of the etiology of the lapses in the healthcare system should be investigated, looking more specifically at aforementioned themes from the resident perspective. This can further validate findings from this paper and look for further heretofore unmentioned barriers and therefore eventually lead to better recommendations.

If a quarter of the world will be living in slums in 2030, action should be immediate. Studying RHD in Brazilian slums is an important case study that points out ways in which we can improve the healthcare system to appropriately address healthcare in slums. RHD is preventable and should be eliminated in a country with universal healthcare. Learning from Brazil's experience can help us generalize best practices for tackling healthcare in slums globally for afflictions both infectious and chronic.

Author statements

Ethical approval

The study received approval from the Research Ethics Committee of the ISC – UFBA Institute of Public Health, approval no. 2,245,779. HAN Ethics Committee no. 2,839,303, and HUPES Ethics Committee no. 2,598,267.

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Competing interests

None declared

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