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Hansen's disease knowledge among healthcare professionals working for the Estratégia Saúde da Família in the Sistema Único de Saúde, Vespasiano, MG, Brazil

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Abstract

Hansen's disease knowledge among healthcare professionals working for the Estratégia Saúde da Família in the Sistema Único de Saúde, Vespasiano, MG, Brazil

By Ana Isabel Balthazar Henao

Introduction: Hansen's disease, a neglected tropical disease, is commonly found in Brazil with reports upwards of 18,318 per year. A variety of reports have found that healthcare providers' knowledge of Hansen's disease is very limited, and only four of these have been conducted in Brazil.

Objective: To analyze the knowledge level of healthcare workers of the Estratégia Saúde da Família (ESF), in Vespasiano, MG, Brazil, about Hansen's disease.

Methods: The study was designed as a cross-sectional study, with an interview survey as the data collection mechanism, which was divided into a baseline knowledge section, and a clinical section. A total of 194 health workers were interviewed, 22 physicians, 17 nurses, 102 community health workers, 36 nurse technicians, and 17 other health professionals. For analysis, linear correlation, Pearson's correlation, and Student's t-tests, and descriptive statistics were used. Tables and graphs were utilized to display findings.

Results: It was found that most health workers had little knowledge of Hansen's disease diagnosis processes, treatment methods, transmission routes, and clinical presentations and held many of the popular Hansen's misconceptions. Physicians received the highest score averages for the baseline (65% of 14 points) and clinical sections (47.7% of 35 points). No correlation was found between sex and knowledge scores, or between who had previously received training and knowledge scores. Some correlation was found between profession and who received training, with a p-value of 0.009, leading to the rejection of the null hypothesis.

Conclusions: These gaps can result in mis- and underdiagnosis of the disease, inadequate treatment, and continued prevalence of Hansen's in communities. It is recommended that the Brazilian government invest in Hansen's disease educational programs to address the gaps.

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CHAPTER 1

INTRODUCTION

Hansen's disease, a neglected tropical disease previously referred to as leprosy, is caused by the bacteria *Mycobacterium leprae* and *Mycobacterium lepromatasis*.[1] Its existence and societal impact have long been documented, with records dating back to 600 BC.[2] From the time Hansen's disease was first identified, until recently, isolation was used as an infection control method, resulting in the exclusion and exile of individuals from society.[3] This preventative action was often taken due to lack of general understanding of the disease, misconceptions about how contagion occurs, and fear of disfigurement.[3]

The precise mode of transmission for Hansen's disease is still unknown, but experts believe that infection can occur through droplets during prolonged close contact or through environmental sources.[4] To this day, various misconceptions about transmission exist, including the idea that transmission can occur through casual skin contact, non-prolonged physical proximity, pregnancy, and sexual contact, all of which are untrue and contribute to the stigmatization of the disease.[4]

M. leprae replicates slowly, resulting in the need for very long periods of exposure to contract Hansen's disease and delayed symptoms for up to 20 years.[1] The delay in symptoms and diagnosis of the disease often generates difficulty in identifying the source of infection.[4] *M. leprae* bacteria targets the nerves, skin, eyes, and nasal lining.[1] The damage to the nerves can often result in loss of feeling and strength, subsequently leaving infected individuals more prone to injury.[1] When left untreated, nerve damage caused by Hansen's disease can result in paralysis of the extremities.[1] The skin of affected individuals may also lose feeling and change in color, or become dry and flaky.[1] Generally, early treatment of the disease can prevent disability, and once treatment begins, individuals are no longer contagious, highlighting the importance of early diagnosis.[1]

Overall, Hansen's disease is a very difficult disease to transmit and contract, which contradicts much of the public's knowledge about the disease.[1]

Hansen's disease is considered to have a spectrum, varying depending on the immune system of the infected individual and the stage of the disease.[2] The different classifications of the disease are lepromatous, borderline, and tuberculoid.[2] Lepromatous Hansen's disease refers to the disease's most aggressive form when there is a large number of bacilli and a very low immune response.[2] Individuals suffering from lepromatous Hansen's exhibit symptoms such as inflamed nodules, papules, and macules, as well as symmetrical plaques that appear on the face, knees, elbows, wrists, and buttocks.[2] They also display lesions and may have leonine facies, nose deformities, enlarged earlobes, and other visible symptoms.[2] Borderline Hansen's is the most common form of the disease, during which lesions vary greatly between infected individuals.[2] The borderline variant of Hansen's is considered extremely unstable and can transform into tuberculoid or lepromatous variants.[2] The last Hansen's variant, tuberculoid, refers to the form of the disease that results in skin patches or plaques that are not highly elevated and are hyper or hypopigmented.[2]

Diagnosis of Hansen's disease occurs based on the above clinical presentation of the disease and is confirmed through biopsy.[5] A biopsy is an essential step of diagnosis since Hansen's disease symptoms often resemble other conditions. [2] The classic hypopigmented patches found on many Hansen's disease patients can easily be confused with vitiligo or other skin diseases.[2] In the past, individuals with diseases such as psoriasis, eczema, and tinea have often been wrongfully diagnosed with Hansen's, further pointing to the importance of biopsy confirmation.[2] However, resources for biopsy evaluation are not universally available around the world .

The first drug treatment for Hansen's disease, dapsone, was developed in the 1940s and used as a monotherapy.[2] Patients were required to take the drug indefinitely, and several developed

resistance to the dapsone.[2] In the 1960s, two new drugs were introduced, clofazimine and rifampicin, and they began to be prescribed in combination with dapsone.[2] Today, it is standard to use a 12-month treatment with dapsone, clofazimine, and rifampicin, to cure patients of the disease.[2]

STIGMA

Stigma against individuals suffering from Hansen's disease has been prevalent since it was first identified, and before much was understood about the disease. However, a study recently found that attitudes toward Hansen's have improved when compared to previous research analyzing stigma.[6] A study of predominantly low-income, Brazilian participants, found that while Hansen's disease patients still face stigma, it is not as prevalent as before.[6] Additionally, the research participants reported that their family members and friends were supportive through the diagnosis and treatment process.[6]

HANSEN'S DISEASE IN BRAZIL

Hansen's disease was first identified in Brazil during the 17th century in the city of Rio de Janeiro and has remained endemic throughout the country.[7] Between the 1920s and 1960s, Brazil established state-sponsored and socially approved segregation of Hansen's patients as a control method for the disease, creating a multitude of Hansen's colonies across the country.[3] People often associated Hansen's disease with sin and filth, resulting in extensive stigma against those infected, their families, and communities.[3] The limited knowledge about Hansen's disease, its forms of transmission, and potential heredity, all contributed to the negative attitudes and segregation in Brazil.[3] Today, Brazil's population continues to be plagued with Hansen's disease in many

regions, and has the second-highest number of cases following India.[8] In 2021, the WHO reported 18,318 new cases in Brazil.[8]

BRAZILIAN HEALTHCARE SYSTEM

Brazil's public healthcare system is called Sistema Único de Saúde or SUS, and is one of the largest health systems in the world, it provides universal access to care for all individuals residing in the country.[9] SUS's governing principles are universalization, equity, and integration.[9] It is divided into three levels: national, state, and municipalities.[9] Each level has different co-responsibilities determined by the Federal Constitution and upholds the organization's four ideologies: regionality, hierarchy, decentralization, and popular participation.[9] SUS's services are organized by geography, following the hierarchy of care.[9] Power is further decentralized by distributing powers and responsibilities through the three levels of government.[9] Popular participation is also a pillar of SUS, meaning the Brazilian society must participate, and Health Councils and Conferences have been established for this purpose.[9]

Estratégia Saúde da Família

The Estratégia Saúde da Família, or ESF, is a primary care component of the Sistema Único de Saúde.[10] Its main goal is to expand, qualify and consolidate care for communities.[10] Estratégia Saúde da Família centers are found at community health centers, and are composed of a variety of health workers.[10] Each ESF is required to have at least one general practitioner or specialist in family care, a generalist nurse, a nursing assistant or technician, and community health workers, often referred to as ACS.[10] Oral and dental professionals may also be a part of these teams but are not required for the establishment of an ESF in a community health center.[10]

CHAPTER 2

LITERATURE REVIEW

PURPOSE

The purpose of this review was to analyze existing literature regarding the knowledge of healthcare professionals about Hansen's disease. It also informed the analysis of data collected in Vespasiano, MG, Brazil, about ESF health workers' knowledge of the disease.

METHODS

For this literature review, three databases were used to find academic articles about the knowledge of healthcare professionals about Hansen's disease. The databases selected were PubMed, CAB Direct, and EBSCO. The search terms selected for this review were "Hansen's disease" AND "knowledge," and "Leprosy" AND "knowledge." These terms were entered into the databases and various filters and criteria were used to select the articles. All articles had to: be published between 2012 and 2022, be peer-reviewed, have a primary source, have health workers as a population of interest, and the search terms had to be included in the title of the article. After applying these filters and criteria, the abstract of each article was read before selecting it for future inspection and review.

RESULTS

Following the methodology outlined above, a total of twelve articles were selected for analysis, five from PubMed, six from CAB Direct, and 1 from EBSCO. From these, four of the articles reported studies that had taken place in a region of Brazil. The other countries that were included in this analysis are India, Sri Lanka, Pakistan, Indonesia, Bangladesh, the Philippines, Thailand, and Nigeria.

Various categories of knowledge were identified throughout the articles, including general disease knowledge, knowledge of diagnosis, treatment, disease notification, and disease control and elimination. Furthermore, the confidence of providers in treating the disease, general education about the disease, attitudes or stigma, and knowledge following educational programs were also evaluated.

General Disease Knowledge: Symptoms, Pathology, and Transmission

An overarching theme through the articles in this review, was the widespread lack of general knowledge about Hansen's disease. A study conducted in India and Indonesia found that 88% of participants from India and 90% of Indonesian participants did not have adequate Hansen's disease knowledge.[11] They did not possess much knowledge on the cause of Hansen's, how it is transmitted, the early manifestations of the disease, or its contagiousness.[11] In a study that occurred in the state of São Paulo Brazil, only 9.54% of nurses who participated answered questions about Hansen's pathology.[12] When asked about the difference between paucibacillary and multibacillary Hansen's disease, 73.80% of nurses did not know.[12] In Nigeria, a study including medical interns found that only 29% had good knowledge of the disease.[13]

Researchers in the Philippines launched a study about the knowledge of health practitioners about Hansen's and found that only 36.2% had high levels of knowledge based on study standards, and 35.5% had a medium level of knowledge.[14] More specifically, it was found that only 18.5% of health workers who participated knew that inhalation is a mode of transmission, 52.8% believed that transmission occurred through body fluids and secretions, and 27.5% believed open wounds were a form of transmission.[14]

A study conducted in Sri Lanka required non-dermatological healthcare workers to evaluate common Hansen's disease symptoms.[15] Approximately 86% of participants were able to identify hyperpigmentation patches, 36% recognized skin nodules, and 20% of participants pointed to thickened nerves when asked to point to signs of Hansen's disease.[15] In this study, 20% of participants believed that Hansen's could be transmitted through skin-to-skin contact.[15] In a Pakistani study, high knowledge of the disease among medical staff was more prevalent.[16] Of the health workers who participated, 76.4% knew Hansen's disease symptoms.[16] It was also found that 77.3% know about the sources of infection for Hansen's disease.[16]

Diagnosis

Two studies analyzed the knowledge of Hansen's disease diagnosis practices. Researchers in Brazil found that only 45.23% of nurses who participated were aware that Hansen's disease requires clinical procedures for diagnosis.[12] In Thailand, practitioners were asked to complete Hansen's disease diagnosis.[17] A majority, 60.7%, were able to make a Hansen's disease diagnosis, but only 23.1% of participants could fully explain the medical examinations conducted.[17] Only a small percentage of participants used a slit-skin smear, a key procedure used for diagnosis and investigating the potential for disease.[17]

Treatment

The knowledge of Hansen's disease treatment was measured in an array of ways throughout different studies. An Indian and Bangladeshi study found that Hansen's disease treatment was the most well-known topic among their health workers.[11] Another study conducted in India with the medical intern population, found that 52% of participants had proper knowledge of Hansen's disease treatment.[18] In Brazil, researchers discovered that 69.4% of dental surgeons

are knowledgeable on the topic of Hansen's disease treatment efficacy.[19] However, 61.6% did not feel confident in their Hansen's treatment skills.[19] A study in the Philippines concluded that about half of the healthcare workers who participated correctly believed that a Hansen's disease patient who is being treated can no longer transmit the disease, does not need to be isolated and that individuals who completed the treatment series but continue to exhibit symptoms are not contagious.[14] Another study in Pakistan, found that only 45.2% of practitioners were sure about how and if the disease could be cured.[16]

Education

Researchers have also analyzed the level of Hansen's disease knowledge following training and educational programs, and individuals' access to educational programs. A study in Bangladesh found an increase in the knowledge of disease signs and treatment methods following the implementation of a course.[20] [20] In Brazil, when a Hansen's disease training program for health professionals was evaluated, researchers concluded it had low effectiveness and a small margin of knowledge gain.[21] In Mato Grosso, Brazil, only 8.3% of dental surgeons reported having previously received education about Hansen's disease at their workplace.[19]

Disease notification

Hansen's disease is categorized as a notifiable disease in Brazil, which has prompted several researchers to investigate whether health workers possess knowledge of this categorization and whether educational programs discuss the required notification of Hansen's. In Mato Grosso, Brazil, 47% of study participants were not aware of the requirement to notify Hansen's disease cases.[19] Another study in Brazil found that a training program about Hansen's disease did not mention notification of the disease.[22]

Attitudes and Stigma

Stigma has played a large role in the long history of Hansen's disease, and academics have attempted to learn about how it has shifted through the years and its status in different regions. A study that took place in India found that 33.3% of medical interns held stigma against Hansen's disease patients.[18] In the Philippines, 37.7%of healthcare professionals who participated in the study had negative attitudes towards Hansen's disease.[14] A Sri Lankan study reported that 34.3% of participating healthcare workers were fearful of Hansen's, and 43.3% would not want to tell friends if one of their family members was diagnosed with Hansen's disease.[15] This study also found that 27.5% of providers did not wish to share materials with patients, and 22.5% believed that individuals with Hansen's disease should be isolated from others.[15] A different study found that 49.9% of medical interns had a positive attitude towards Hansen's disease, and another found that myths about the disease were only prevalent among 6.7% of interns, portraying improved trends of attitudes and stigma. [13,18]

DISCUSSION

Research surrounding the knowledge of healthcare professionals about Hansen's disease is extremely limited. From the three databases that were used, all articles fitting the criteria were selected, which only yielded twelve academic articles. While there were numerous studies on population knowledge and attitudes toward Hansen's disease, there is a lack of literature focusing on healthcare providers was scarce, pointing to the importance of the research presented in this thesis. Furthermore, since only four of the articles found took place in Brazil, this gap highlights the continued need to explore the knowledge of professionals in Brazil since it has the second-highest number of cases in the world.[8]

While the countries where the studies analyzed took place, have some of the highest Hansen's disease rates in the world, the general knowledge of Hansen's disease is not widespread among practitioners.[11-13] Gaps in knowledge were common regarding the transmission, manifestations, contagiousness, and pathology of the disease.[11,12,14,15] Only a Pakistani study found high general knowledge by health care professionals.[16] With Pakistan being the sole outlier in general knowledge, there is a chance that Pakistan has more widely invested in Hansen's disease education, or that their practitioners may be required to have greater knowledge of the disease.

The diagnosis and treatment of Hansen's have more moderate levels of knowledge among practitioners. The knowledge of diagnosis and treatment methods fell between 40 and 70% in all studies.[11,12,14,16-19] The areas in which practitioners had lower confidence were: their perceived ability to treat an individual and the description of the medical examination.[17,19] It is likely that the topics of treatment methods and diagnosis had a higher emphasis during the training of practitioners, resulting in higher rates of knowledge of these topic areas. While treatment methodology and diagnosis techniques had more promising knowledge levels than other categories analyzed, they still presented important gaps to consider in providers' educations.

When a disease is deemed notifiable, it refers to the requirement that the disease be notified to public health authorities by practitioners if a case is identified, and is an essential measure in the control of infectious diseases. In Brazil, Hansen's disease is notifiable, however, almost half of the practitioners in a study did not know.[19] This generates concern because it could result in underreporting of Hansen's disease, and undermine surveillance measures, leaving the population at higher risk for disease spread. Another study in Brazil found that a training program did not include disease notification in its curriculum, pointing to a need for its inclusion in educational programs.[22]

Based on the literature review, a significant number of healthcare providers still hold stigma and negative attitudes against Hansen's disease patients, although their numbers continue to shrink. While most healthcare workers have positive attitudes in most studies, a large minority of stigmatizing providers pose a great threat to patients and the success of Hansen's disease programs. Practitioners with negative attitudes and stigma against Hansen's disease patients may not provide them with the best standard of care due to their biases. Another concerning finding in this review was the low effectiveness of educational programs and their lack of existence.[19-21] The decrease in knowledge of some subject areas, the small margin of knowledge gain, and the almost inexistent existence of Hansen's disease education in the literature indicate a need for educational investments in all Hansen's affected countries.

CONCLUSION

The consensus is that most healthcare workers do not have enough knowledge to provide quality care to Hansen's patients. The reasons for this lack of knowledge are unclear based on the literature, but potential culprits are limited access to education on the disease in their initial health training, inadequate continued education programs, and overwhelming social misinformation and stigma. Providers may carry learned stigma from society into their practice, even. These findings imply a need for more robust educational programs for both providers and society.

The limited number of studies analyzing Hansen's disease knowledge of providers point to, points to the need for more research to be conducted, especially in countries with a high incidence of the disease, where providers are more likely to come across Hansen's. The lack of existing literature about providers' knowledge of Hansen's disease, prompted the research conducted in this thesis.

CHAPTER 3

METHODS

INTRODUCTION

We conducted a cross-sectional survey of healthcare workers of the Estratégia Saúde da Família (ESF), in Vespasiano, Minas Gerais, a city located in the southern interior of Brazil, to analyze their knowledge of Hansen's disease. The city of Vespasiano has a population of 127, 601, and between 2007 and 2014, had a total of 139 documented cases of Hansen's disease.[23]

POPULATION AND SAMPLE

Health workers of Vespasiano's Estratégia Saúde da Família (ESF) were the population of interest. This included physicians, nurses, nurse technicians, dentists, dental technicians, and community health agents (ACS). The study was conducted at community health centers across Vespasiano for easier access to the study population. We attempted to recruit all workers from the ESF of this municipality to have a representative sample of all primary care workers in the community. The inclusion of community health workers in this study was essential because they are the first line of care and have the most contact with community members. They visit homes in the community and are often the ones who recommend individuals visit the health center for checkups. While community health workers do not provide clinical care, they are still an essential group in ensuring the community accesses healthcare services. The initial goal was to recruit all health workers in the ESFs of Vespasiano, about 240 individuals. However, due to limitations such as time, vacation days, and lack of desire to participate, 194 individuals were interviewed.

RESEARCH DESIGN

All Estratégia Saúde da Família centers in the city of Vespasiano, MG, Brazil, were visited during the month of July 2022. Healthcare workers of the ESF voluntarily enrolled in the study and provided informed consent. Data were collected in the form of a survey, through individual interviews in Portuguese. The questionnaire included a baseline section for all participants and an additional section for nurses and physicians. Both sections aimed to capture the current knowledge of ESF healthcare workers about Hansen's disease.

PROCEDURES

The first step in the development of this study was to select the research questions that would best provide insight into Hansen's disease knowledge and Hansen's disease and education in the ESF.

Interviews were scheduled by the research coordinator based at each health center's convenience. Interviews were conducted individually and took place in a closed room to ensure confidentiality for participants. A consent form was signed by all participants, and each interview lasted between 10 and 20 minutes, and all responses were collected on paper and later transferred to Kobo Toolbox for digitization, and later downloaded to Excel for analysis. For several health centers the research team finalized all interviews in one visit, in cases where not all interested participants were able to participate, the research lead scheduled a follow-up visit.

INSTRUMENTS

The data collection instrument for this study was a quantitative survey delivered as an interview and recorded on paper. It began with demographic questions in order to better understand the study population. These were followed by a baseline and a clinical section. The baseline section

applied to all participants and focused on common misconceptions about Hansen's disease, and transmission routes. The clinical portion of the survey touched on the clinical presentation of the disease, diagnosis, and treatment procedures. Only nurses and physicians answered these questions since the clinical topics only applied to their capacities as healthcare providers. Questions were written as true or false questions and multiple-choice questions. The questions used in this study can be found in Appendix A.

DATA ANALYSIS

Demographic descriptive statistics were tabulated for each professional group by frequency or measures of central tendency as appropriate. The demographic statistics included numbers/counts and percentages for age categories, the highest level of education, sex, time working in the system, and whether Hansen's disease training was received. For the knowledge questions, values were awarded to the answers with each correct answer coded as 1 point, and incorrect answers coded as 0 points.

The baseline survey which every participant received, had a potential of 14 points. Since nurses and physicians had additional clinical questions, their total potential score was 35 points when the clinical portion of the survey was included. It was decided that participants would receive a passing score indicating good knowledge if they achieved a score of 70% or higher, based on commonly used grading criteria.

To compare the various professional groups, frequency and percentage were calculated. Data were displayed in tables and graphs for visualization and analysis. Linear regressions, Pearson's correlation coefficients, and T-tests were calculated to analyze the relationship between knowledge scores and numerical demographic variables. For qualitative variables, non-parametric analysis tests were conducted.

ETHICAL CONSIDERATIONS

This study was found approved by the FASEH IRB in Brazil, and found to be exempt by Emory's IRB. IRB paperwork can be found in Appendix B.

RESULTS

1. DEMOGRAPHICS

Table 1.1 Population Demographics

	Physician N (%)	**Nurse** N (%)	**ACS** N (%)	**Nurse technician** N (%)	**Other** N (%)	**TOTAL** N (%)
Age						
20-30	14 (63.3)	0 (0)	22 (21.6)	3 (8.3)	1 (5.9)	40 (20.6)
31-40	4 (18.2)	6 (35.3)	26 (25.5)	11 (30.6)	11 (64.7)	58 (29.9)
41-50	2 (9.1)	6 (35.3)	34 (33.3)	12 (33.3)	2 (11.8)	56 (28.9)
51-60	1 (4.5)	4 (23.5)	15 (14.7)	9 (25.0)	2 (11.8)	31 (16.0)
61-70	0 (0)	1 (5.9)	3 (2.9)	1 (2.8)	1 (5.9)	6 (3.1)
71-80	1 (4.5)	0 (0)	0 (0)	0 (0)	0 (0)	1 (0.5)
Highest level of education						
college	20 (90.9)	3 (17.7)	18 (17.7)	3 (8.3)	5 (29.4)	49 (25.3)
specialization	2 (9.1)	13 (76.5)	0 (0)	0 (0)	3 (17.6)	18 (9.3)
high school	0 (0)	0 (0)	75 (73.5)	17 (47.2)	7 (41.2)	99 (51)
other	0 (0)	1 (5.88)	9 (8.8)	16 (44.4)	2 (11.8)	28 (14.4)
Sex						
female	16 (72.7)	14 (82.4)	98 (96.1)	33 (91.7)	15 (88.2)	176 (90.7)
male	6 (27.3)	3 (17.6)	4 (3.9)	3 (8.3)	2 (11.8)	18 (9.3)
Time in system (years)						
<=1	14 (63.6)	0 (0)	29 (28.4)	4 (11.1)	2 (11.8)	49 (25.3)
1-5	4 (18.2)	2 (11.8)	8 (7.8)	6 (16.7)	4 (23.5)	24 (12.7)
5-10	1 (4.5)	3 (17.6)	23 (22.5)	13 (36.1)	5 (29.4)	45 (23.2)
10-15	0 (0)	6 (35.3)	26 (25.5)	6 (16.7)	2 (11.8)	40 (20.6)
15-20	1 (4.5)	2 (11.8)	10 (9.8)	1 (2.8)	1 (5.9)	15 (7.7)
20-25	1 (4.5)	3 (17.6)	6 (5.9)	3 (8.3)	0 (0)	13 (6.7)
25-30	1 (4.5)	1 (5.9)	0 (0)	2 (5.6)	1 (5.9)	5 (2.6)
>30	0 (0)	0 (0)	0 (0)	1 (2.8)	2 (11.8)	3 (1.5)
Received Hansen's disease training						
yes	4 (18.8)	6 (35.3)	30 (29.4)	1 (2.8)	0 (0)	41 (21.1)
no	18 (81.8)	11 (64.7)	66 (64.7)	34 (94.4)	16 (94.1)	145 (74.7)
I don't know	0 (0)	0 (0)	5 (4.9)	1 (2.8)	1 (5.9)	7 (3.6)
TOTAL N (%)	22 (11.3)	17 (8.8)	102 (52.6)	36 (18.6)	17 (8.8)	**194**

N=frequency
%=percentage of column (exceptions: last row (% of total participants), far right column (% of row))
Rounded to 1 decimal place

A total of 194 health providers participated in this study. ACS workers made up more than half of participants (n=102, 52.6%), followed in number by nurse technicians (n=36, 18.6%), physicians (n=22, 11.3%), nurses (n=17, 8.8%) and other healthcare professionals such as dentists (n=17, 8.8%). Most healthcare workers interviewed self-identified as women (W n=176, 90.7% | M n=18, 9.3%), and women made up much of every professional group in the study.

Most of the individuals interviewed had only received a high school degree, however, this group was predominantly made up of ACS workers. About a quarter of participants had only worked in the health system for less than 1 year, and an overwhelming majority of healthcare providers interviewed had never received any Hansen's disease training at work (N=145, 74.7%).

2. KNOWLEDGE SCORES

Table 2.1 Baseline knowledge score statistics by profession, 14 possible points

statistic	ACS score (%)	nurse tech score (%)	other score (%)	nurse score (%)	physician score (%)	TOTAL score (%)
mean	6.3 (45.0)	6.9 (49.3)	5.1 (36.4)	8.4 (60.0)	9.1 (65.0)	6.8 (48.6)
median	7 (50.0)	8 (57.1)	6(42.9)	8 (57.1)	9 (64.3)	7 (50.0)
mode	7 (50.0)	8 (57.1)	0 (0.0)	8 (57.1)	9 (64.3)	7 (50.0)
min	0 (0.0)	0 (0.0)	0 (0.0)	1(7.1)	6 (42.9)	0 (0.0)
max	10 (71.4)	12 (85.7)	10 (71.4)	12 (85.7)	11 (78.6)	12 (85.7)

When the scores for the baseline questionnaire were analyzed (14 possible points), the average score in the study was 6.8 (48.6% of 14 points), which was not a passing score of 70%. Once stratified by profession, the highest average score was achieved by physicians (9.1 points, 65% of 14 points) followed by nurses (8.4 points, 60% of 14 points), nurse technicians (6.9 points, 49.3% of 14 points), ACS workers (6.3 points, 45% of 14 points), and other healthcare workers (5.1 points, 36.4% of 14 points), none of which were passing knowledge scores based on the 70% threshold. While on average, no group passed the questionnaire, all professions had at least one individual who received a passing score. The range of scores varied by profession, 0-10 for ACS

workers, 0-12 for nurse technicians, 0-10 for other health professionals, 1-12 for nurses, and 6-11 for physicians.

Table 2.2 Correct response count per question

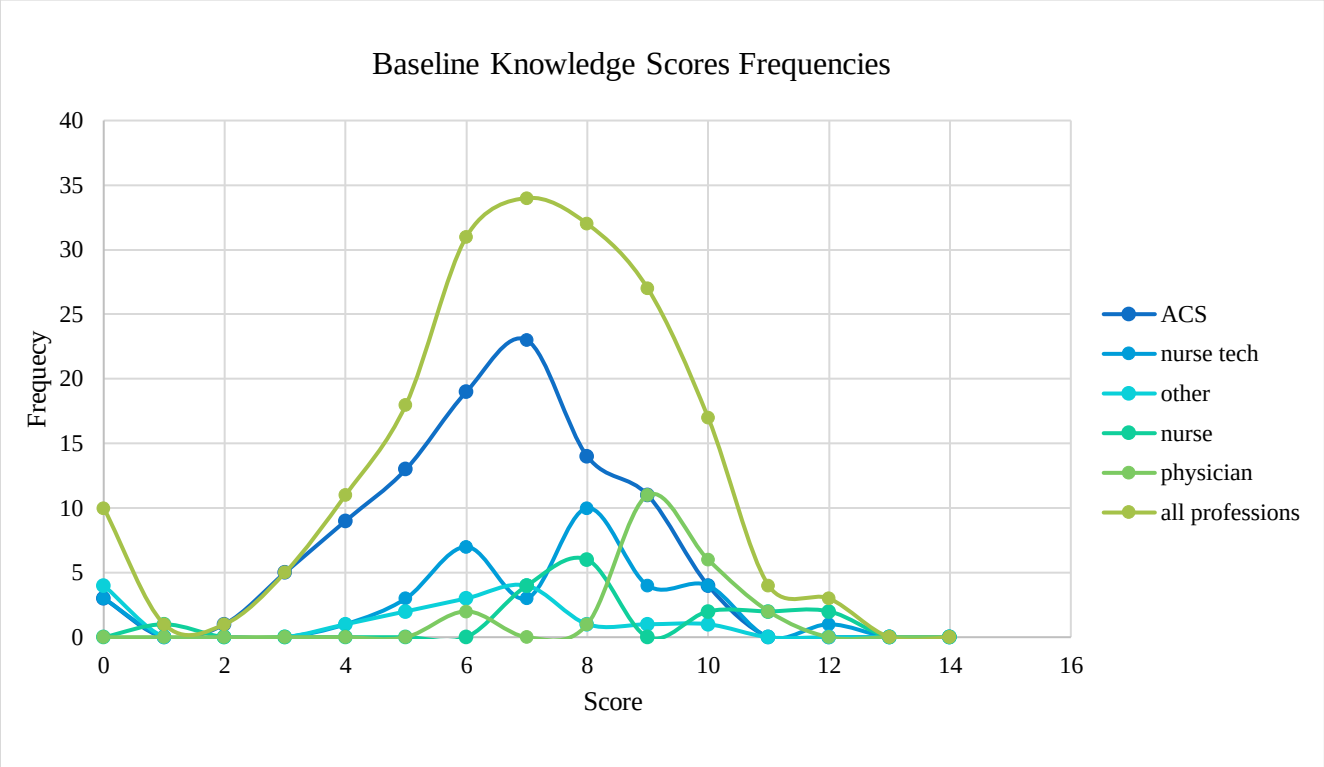
Question and answers	Correct answers count n (%)
What are the modes of transmission of Hansen's disease? Select all that apply Contact Respiratory Droplets Environment Contaminated water	 101 (52.1) 98 (50.5) 11 (5.6) 10 (0.52)
What country has the second highest incidence of Hansen's after India?	54 (27.8)
Hansen's disease is very contagious, true or false?	51 (26.3)
More than 95% of people have natural immunity to Hansen's disease, true or false?	53 (27.3)
Hansen's disease is not hereditary, true or false?	130 (67.0)
Hansen's disease is completely curable, true or false?	138 (71.1)
If Hansen's disease is not treated, it may result in deformities, true or false?	172 (88.7)
There is a vaccine for Hansen's disease, true or false?	102 (52.6)
A patient with Hansen's disease can have a normal life, true or false?	168 (86.6)
Hansen's disease is not contagious after starting treatment, true or false?	119 (61.3)
Disabilities related to Hansen's disease can improve, true or false?	118 (60.8)

The question with the highest number of correct responses was about deformities developed as a result of the disease (n=172, 88.7%). A total of 168 individuals also knew that individuals who have Hansen's disease can live normal lives. Surprisingly, only 54 individuals (27.8%) were aware that Brazil has the second-highest number of Hansen's cases in the world.

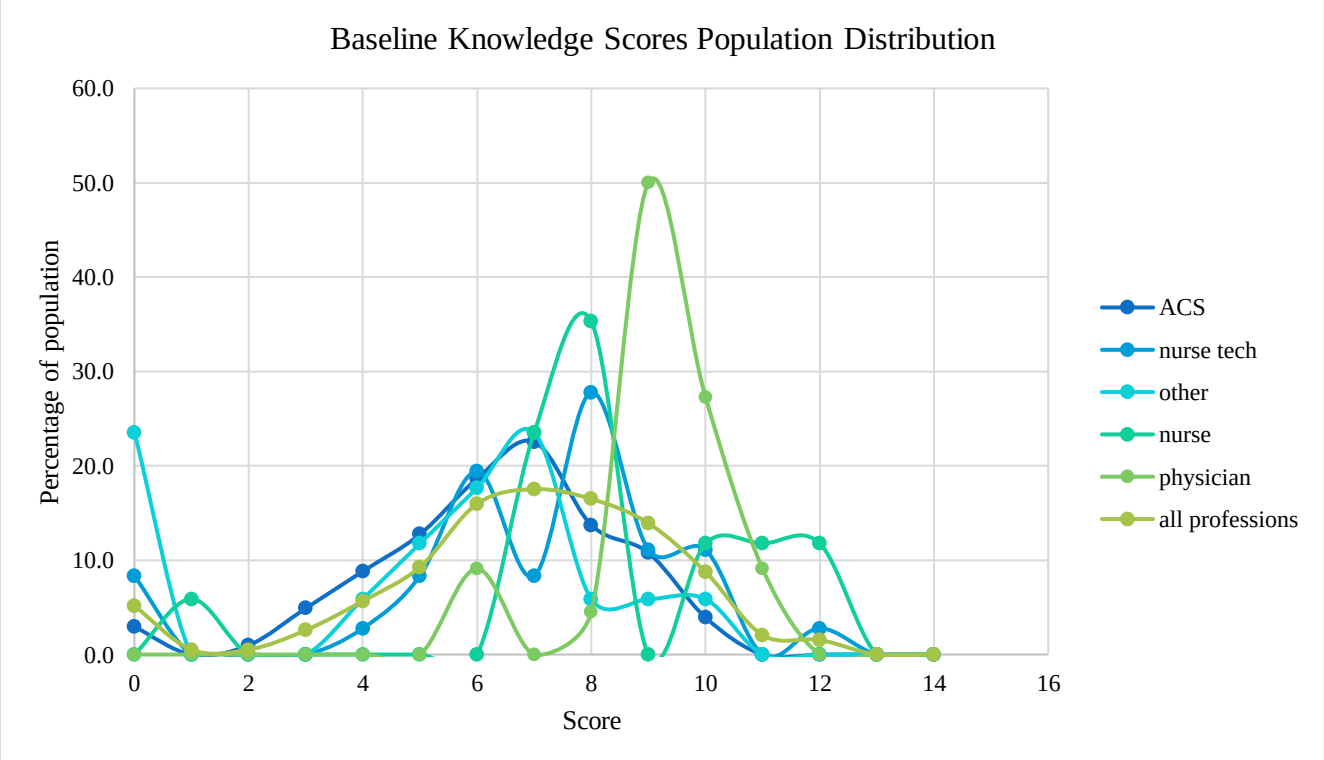
Table 2.3 Baseline Knowledge Score Frequencies and Frequency Percentage From Each Population

Frequency and Population Distribution of Scores												
score	ACS		Nurse techs		Other		Nurse		Physician		TOTAL	
	frequency	% of population	frequency	% of population	frequency	% of population	frequency	% of population	frequency	% of population	frequency	% of population
0	3	2.9	3	8.3	4	23.5	0	0.0	0	0.0	10	5.2
1	0	0.0	0	0.0	0	0.0	1	5.9	0	0.0	1	0.5
2	1	1.0	0	0.0	0	0.0	0	0.0	0	0.0	1	0.5
3	5	4.9	0	0.0	0	0.0	0	0.0	0	0.0	5	2.6
4	9	8.8	1	2.8	1	5.9	0	0.0	0	0.0	11	5.7
5	13	12.7	3	8.3	2	11.8	0	0.0	0	0.0	18	9.3
6	19	18.6	7	19.4	3	17.6	0	0.0	2	9.1	31	16.0
7	23	22.5	3	8.3	4	23.5	4	23.5	0	0.0	34	17.5
8	14	13.7	10	27.8	1	5.9	6	35.3	1	4.5	32	16.5
9	11	10.8	4	11.1	1	5.9	0	0.0	11	50.0	27	13.9
10	4	3.9	4	11.1	1	5.9	2	11.8	6	27.3	17	8.8
11	0	0.0	0	0.0	0	0.0	2	11.8	2	9.1	4	2.1
12	0	0.0	1	2.8	0	0.0	2	11.8	0	0.0	3	1.5
13	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
14	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0

Graph 2.1 Frequency of Baseline Knowledge Score



Graph 2.2 Baseline Knowledge Score Population Distribution (percentage of population)



The distribution of scores was observed in two manners: frequency of scores, and percentage of the population that attained each score. They exemplified the same concept, but percentages, unlike frequency counts, allowed for the data to be analyzed on the same scale for all professions. The frequency of scores for the study population was normally distributed with a few outliers. When stratified by profession, there were several variations in the distribution of score frequencies. Most professions showed a normal or close to a normal distribution, except for nurse technicians, whose frequency of scores had two peaks. The distribution of scores by the percentage of the population that reached them showed very similar trends to the frequency analysis. Physicians achieved higher scores more consistently than any other group, with 50% of its population scoring 11 points out of 14, a passing score.

Table 2.4 Total Knowledge Scores of Physicians, and Nurses, 35 possible points

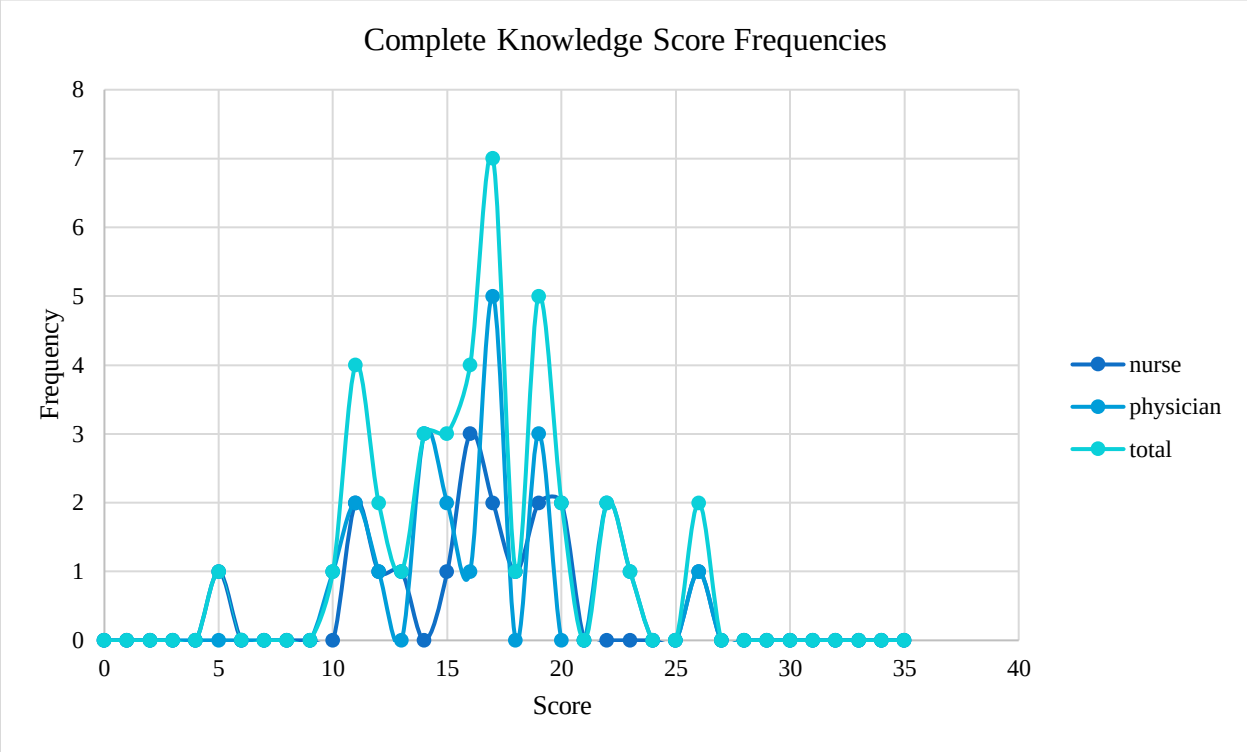
	physician score (%)	nurse score (%)
mean	16.7 (47.7)	15.9 (45.4)
median	17 (48.5)	16 (45.7)
mode	17 (48.5)	16 (45.7)
min	10 (28.6)	5 (14.3)
max	26 (74.3)	26 (74.3)

When the questions for nurses and physicians only were included (35 potential points), the results displayed similar trends as the baseline scores. The mean scores for both groups fell below the 70% threshold, indicating that most participants did not achieve a passing score. However, the range included some passing scores with a high of 26 points (74.3%). Furthermore, the low score for both groups was higher than their lowest baseline score, showing that all participants received at least one point or more from the additional questions.

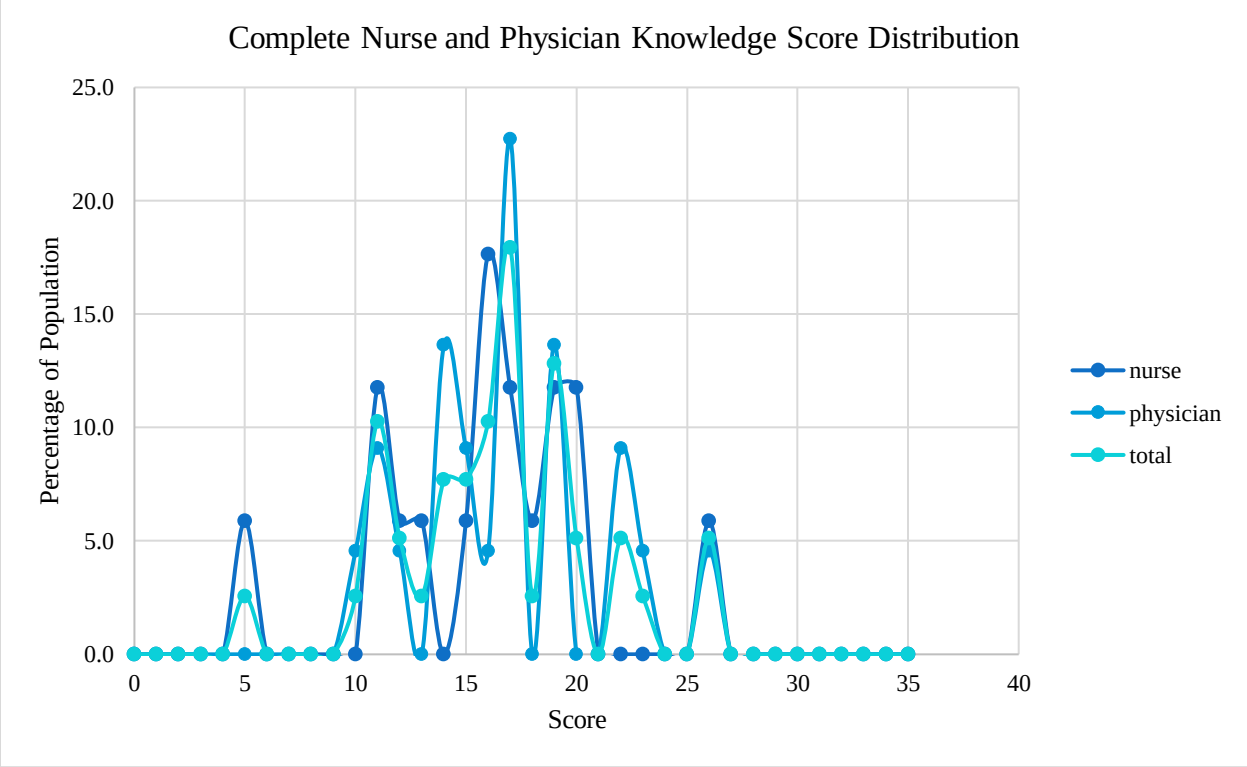
Table 2.5 Complete Nurse and Physician Knowledge Score Frequencies and Frequency Percentage From Each Population

Frequency and Population Distribution of Scores						
Score	nurse		physician		TOTAL	
	frequency	% population	frequency	% population	frequency	% population
0	0	0.0	0	0.0	0	0.0
1	0	0.0	0	0.0	0	0.0
2	0	0.0	0	0.0	0	0.0
3	0	0.0	0	0.0	0	0.0
4	0	0.0	0	0.0	0	0.0
5	1	5.9	0	0.0	1	2.6
6	0	0.0	0	0.0	0	0.0
7	0	0.0	0	0.0	0	0.0
8	0	0.0	0	0.0	0	0.0
9	0	0.0	0	0.0	0	0.0
10	0	0.0	1	4.5	1	2.6
11	2	11.8	2	9.1	4	10.3
12	1	5.9	1	4.5	2	5.1
13	1	5.9	0	0.0	1	2.6
14	0	0.0	3	13.6	3	7.7
15	1	5.9	2	9.1	3	7.7
16	3	17.6	1	4.5	4	10.3
17	2	11.8	5	22.7	7	17.9
18	1	5.9	0	0.0	1	2.6
19	2	11.8	3	13.6	5	12.8
20	2	11.8	0	0.0	2	5.1
21	0	0.0	0	0.0	0	0.0
22	0	0.0	2	9.1	2	5.1
23	0	0.0	1	4.5	1	2.6
24	0	0.0	0	0.0	0	0.0
25	0	0.0	0	0.0	0	0.0
26	1	5.9	1	4.5	2	5.1
27	0	0.0	0	0.0	0	0.0
28	0	0.0	0	0.0	0	0.0
29	0	0.0	0	0.0	0	0.0
30	0	0.0	0	0.0	0	0.0
31	0	0.0	0	0.0	0	0.0
32	0	0.0	0	0.0	0	0.0
33	0	0.0	0	0.0	0	0.0
34	0	0.0	0	0.0	0	0.0
35	0	0.0	0	0.0	0	0.0

Graph 2.3 Complete Knowledge Score Frequencies



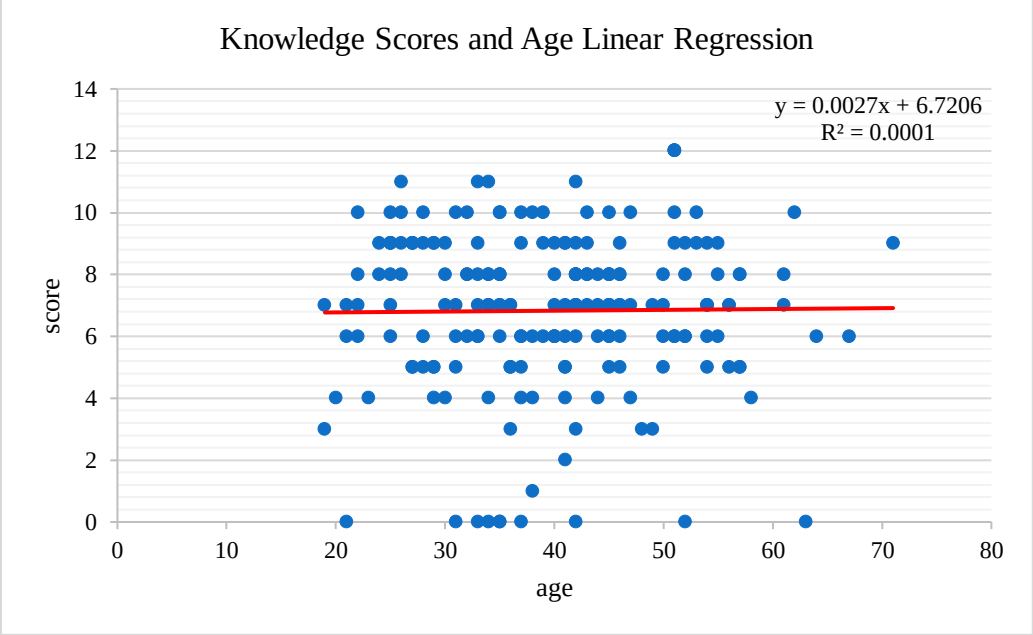
Graph 2.4 Complete Nurse and Physician Knowledge Score Distribution (population %)



The frequency and population distributions of physicians' and nurses' complete scores (35 potential points), demonstrated the symmetry of a normal distribution to some extent. While there are several peaks in the data, they follow a bell-shaped pattern. Most scores fell between 10 and 20 points.

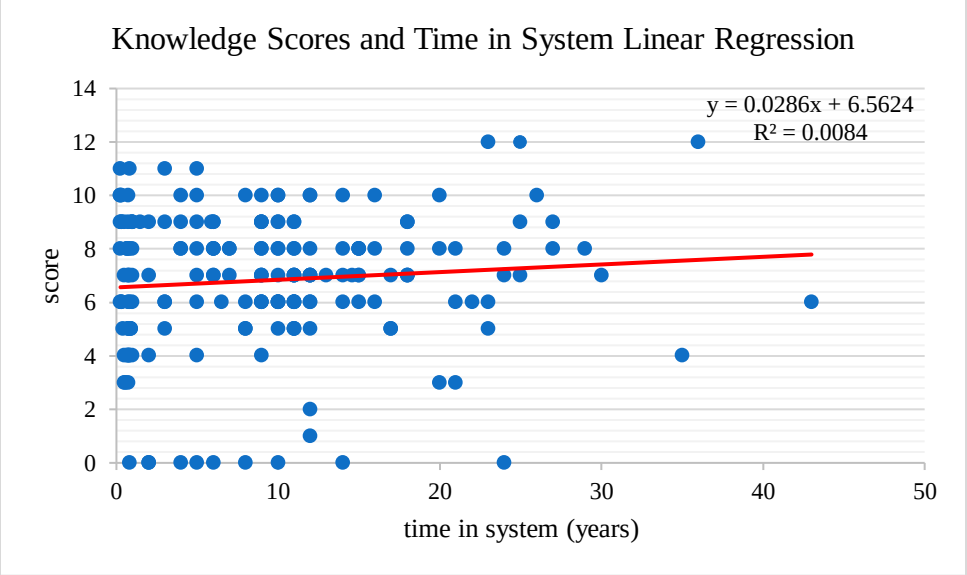
3. NUMERICAL CORRELATION

Graph 3.1 All Professionals Age and Baseline Knowledge Scores Linear Regression



The age and knowledge correlation graph showed a slight upward slope indicating a slightly positive correlation. As age increases, the knowledge score somewhat increases as well. The Pearson correlation coefficient for age and baseline knowledge scores was 0.012, signifying an extremely weak positive correlation.

Graph 3.2 All Professionals' Time in System and Baseline Knowledge Score Linear Regression



The correlation graph for baseline knowledge scores and the time working in the system also shows a slight upward slope, indicating some positive correlation. The slope for this regression is steeper than that of age and knowledge scores, signifying that the correlation between time in the system and knowledge scores is stronger. Also, the Pearson correlation coefficient is 0.092, which shows a stronger relationship than the coefficient for age and knowledge scores. However, a correlation coefficient of 0.09 still does not demonstrate strong correlation.

Knowledge scores were stratified by self-identified sex and a T-test was conducted. Based on a Student's t-test, the two-tailed p-value is 0.244, which is larger than the significance value of 0.05, and therefore we fail to reject the null hypothesis that there is no difference between scores of the two sexes. This means there was no correlation between scores and sex. The knowledge scores were also stratified by whether individuals had received training or not. Following a Student's t-test, the two-tailed p-value was found to be 0.145. This p-value was larger than the

predetermined confidence value of 0.05, and therefore the null failed to be rejected, meaning there was no correlation between previous training and knowledge scores.

4. SELF IDENTIFIED KNOWLEDGE PERCEPTIONS

All nurses and physicians were asked whether they felt qualified to treat individuals diagnosed with Hansen's disease. Out of 39 practitioners, 1 (2.6%) relayed that they did not know if they were qualified, 15 (38.5%) said they were qualified, and 23 (59%) answered that they were not. Another question where nurses and doctors were asked to determine their knowledge on a subject, was about the difference between type 1 and 2 of Hansen's disease. For this question 18 (46.2%) self-identified as knowing the difference, and 21 (53.8%) participants answered that they did not know the difference between the two types of Hansen's disease.

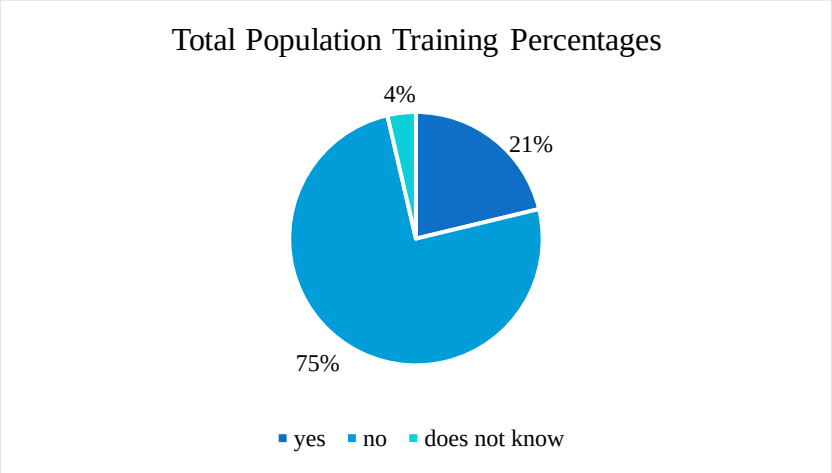
5. TRAINING

Out of the 194 participants, only 41 (21.1%) had previously received Hansen's disease training. A staggering 145 (74.7%) had never received training about the disease, and 7 (3.6%) were not sure that they had. Even when separated by profession, most of each professional group had never received training. Nurses had the highest proportion of Hansen's disease-trained individuals, followed by ACS workers, and physicians. A p-value of 0.009 was found when a T-test was performed to determine the correlation of trained and untrained individuals between professions. Since the p-value is less than the confidence interval of 0.05, the null is rejected, indicating a difference in training based on profession.

Table 5.2 Training Counts by Profession

Training Received	physician N (%)	nurse N (%)	ACS N (%)	nurse tech N (%)	other N (%)	TOTAL
yes	4 (18.2)	6 (35.3)	30 (29.4)	1 (2.8)	0 (0)	41 (21.1)
no	18 (81.8)	11 (64.7)	66 (64.7)	34 (94.4)	16 (94.1)	145 (74.7)
I don't know	0 (0)	0 (0)	5 (4.9)	1 (2.8)	1 (5.9)	7 (3.6)
No response	0 (0)	0 (0)	1 (1)	0 (0)	0 (0)	1 (0.5)

Graph 5.1 Total Population Training Percentages



CHAPTER 4

DISCUSSION

Through this study, the common trend of low Hansen's disease knowledge rates was furthered. On average, participants did not achieve passing scores of 70% or higher. Low training rates were common among all professions. No strong correlations were found between different variables, except for those who received training and their profession.

Comparing the participants' knowledge from the literature to this study is difficult due to a lack of standardization. The populations of interest, Hansen's topics that were asked about, and analysis methods were different between most of the studies analyzed. However, based on the standards each study set, including this one, it can be concluded that the healthcare providers targeted across these various studies had overall low levels of knowledge of Hansen's disease, and that this is more than likely representative of healthcare workers in general.

For Brazil, this is an especially alarming problem, since it has the second highest number of Hansen's disease cases in the world.[8] Knowledge gap areas that appeared in the studies conducted in Brazil included knowledge of disease pathology, the need for clinical diagnosis, and disease notification.[12,19] Poor knowledge on these topics also came to light in this study, most participants were only aware that infection could occur through prolonged contact and droplets. Physicians and nurses in this study were highly aware of the need for clinical diagnosis through physical exam, but as aware of the need for blood work, skin biopsy, and skin smear. The ignorance of diagnosis methods is concerning due to the potential for incorrect diagnoses, resulting in delayed treatment for patients and subsequent increased risk of permanent nerve damage.

In a previous study in Brazil, only 8.3% of dental surgeons had received Hansen's disease training at their place of employment.[19] Similarly, low rates were seen in our study, where only

21.1% of participants reported having previously received training. These low rates are a potential explanation for the low knowledge scores.

Regarding the knowledge scores of this study, the trends in scores when stratified by profession show various unexpected results. Based on the 16-point questionnaire, the highest scores were achieved by nurses and nurse technicians, however, physicians had the highest mean score. It was surprising to see this result due to the lengthier and more strenuous educational requirements for physicians. Even when the scores of the clinical questionnaire were added in for analysis, nurses and physicians had the same high scores.

The combination of poor Hansen's disease knowledge and low training rates points to both the potential problem and solution. It was especially concerning that physicians had lower Hansen's disease training rates than nurses and ACS workers. If healthcare workers have not received training on Hansen's it greatly hinders their ability to identify, diagnose and treat the disease. While the state of Minas Gerais (MG) where this study was conducted has cases of Hansen's disease and several endemic areas, the region with the highest number of cases is the north of the country .[24] In the future, it would be important to analyze the level of Hansen's disease knowledge in endemic regions of MG, but also expand this study to states with a higher incidence of disease, such as ES. Comparing knowledge levels between endemic and non-endemic regions could aid in the development of educational programs if there are clear differences in the knowledge of providers. Future research could help solidify where most practitioners' knowledge gaps are, to create a standard training that may be used across the universal healthcare system of Brazil, SUS.

Limitations

Factors that were outside of the research team's control and resulted in limitations included: gaps in the literature on the subject, and the unwillingness of some individuals and health centers to participate. Since this was a cross-sectional study, the data collected can show correlation but not causation and only informs us bout one moment in time.

The scope of this study was limited to Estratégia Saúde da Família health workers in the city of Vespasiano, Minas Gerais, Brazil. The decision to conduct this study in one city prevents the findings from being generalizable to other cities, and even to other health workers within Vespasiano that are not part of the ESF. Findings only describe a very specific subset of the healthcare workforce. Furthermore, since some of the questions were considered self-reporting questions, they may not have provided the most accurate information.

PUBLIC HEALTH IMPLICATIONS

The findings of this study indicate a large gap in knowledge of Hansen's disease, similarly to existing literature. Hansen's is a disease often forgotten by the world due to its waning incidence and most common presence at the seams of society, leaving endemic pockets extremely vulnerable. Many of the individuals and communities affected by Hansen's are already vulnerable populations because of poverty and poor infrastructure, which in turn increase their risk of contracting Hansen's.

Healthcare is universally provided in Brazil, which provides a facilitated avenue for Hansen's disease patients to be diagnosed since cost is not a large barrier. However, as seen in this study, most healthcare providers do not have sufficient knowledge to give a diagnosis or treatment. This can result in widespread underdiagnosis, lack of or mistreatment. Hansen's is degenerative, meaning that the longer individuals go without treatment, the worse their symptoms and damage to their bodies will be. Underdiagnosis could result in many individuals

developing disabilities due to their physician's inability to diagnose them. Furthermore, since individuals could go years without *M. leprae* being identified in their systems, they could infect individuals who have prolonged close contact with them such as spouses or individuals who live in the same household.

Regarding poor treatment knowledge, it poses the threat of antibacterial resistance. Inappropriate treatment of a bacterial disease can lead to individuals developing bacteria resistant to the drug being used, which could make a drug obsolete. It could also result in individuals not being cured of Hansen's, even though it is completely curable with treatment. Antibiotic resistance is a public health issue because it can result in the infection of more individuals, and the spread of bacteria that cannot be treated. This in turn can increase the burden of disease in populations.

RECOMMENDATIONS

While current knowledge levels may seem bleak and can result in a variety of negative consequences, knowledge can be increased through a multitude of programs. Brazil should invest in more extensive Hansen's disease training during medical, dental, and nursing school, as well as during the training programs for community health workers and nurse technicians. Especially in endemic areas, Hansen's disease should be reviewed as part of onboarding training for individuals who are starting to work at ESFs. Continued education programs should also be made available for all ESF workers. Hansen's disease information could further be disseminated alongside that of other neglected tropical diseases that are also prevalent in Brazil. The city of Vespasiano should also provide online and in-person trainings for those interested in learning more about Hansen's disease. Overall, increased funding for Hansen's disease programs is necessary.

CONCLUSION

The overarching theme across literature and this study of healthcare providers' inadequate knowledge of Hansen's disease points to their unpreparedness to identify, diagnose and treat infected individuals on an international scale. From doctors to nurses to community health workers, most health professionals in the city of Vespasiano, MG, Brazil, are unprepared to face cases of Hansen's disease. It is essential that educational programs be developed to bridge gaps in knowledge to improve care.

APPENDIX A

SURVEY QUESTIONS USED FOR ANALYSIS

Question	Answer
Sex	Masculine Feminine non-binary Other _____ Refused to answer
Age	_____
What is your highest level of education?	High school College Specialization Other _____ Refused to answer
What kind of professional are you?	Physician Nurse Nurse Technician ACS (community health worker) Other _____ Refused to answer
How long have you worked in the health system?	
Have you received training about Hansen's disease?	Yes No I don't Know Refused to answer
What are the modes of transmission of Hansen's disease? Select all that apply	Contact Respiratory droplets Environmental Contaminated water consumption I don't know Refused to answer

Question	Answer
What country has the second highest incidence of Hansen's after India?	Colombia Russia Brazil United States All None I don't know Refused to answer
Hansen's disease is very contagious, true or false?	True False I don't know Refused to answer
More than 95% of people have natural immunity to Hansen's disease, true or false?	True False I don't know Refused to answer
Hansen's disease is not hereditary, true or false?	True False I don't know Refused to answer
Hansen's disease is completely curable, true or false?	True False I don't know Refused to answer
If Hansen's disease is not treated, it may result in deformities, true or false?	True False I don't know Refused to answer
There is a vaccine for Hansen's disease, true or false?	True False I don't know Refused to answer
A patient with Hansen's disease can have a normal life, true or false?	True False I don't know Refused to answer

Question	Answer
Hansen's disease is not contagious after starting treatment, true or false?	True False I don't know Refused to answer
Disabilities related to Hansen's disease can improve, true or false?	True False I don't know Refused to answer

Clinical Question	Answer
Do you consider yourself qualified to perform a complete health evaluation of a potential Hansen's disease carrier?	Yes No I don't know Refused to answer
How is a Hansen's disease diagnosis made? Circle all that apply	Physical exam Blood test Biopsy Skin smear I don't know Refused to answer
Do you know what type 1 and type 2 Hansen's diseases are?	Yes No I don't know Refused to answer
What drugs are administered to a Hansen's disease patient? Circle all that apply	Rifampicin Clofazimine Dapsone Other I don't know Refused to answer
What symptoms do you consider necessary to make a referral for a patient with Hansen's disease to a specialized healthcare unit? Circle all that apply	Numbness in hands and feet Tingling Numbness in the skin Body cramps Pricking and needle sensation on skin Spots on the skin Body and nerve pain Swollen hands and feet Swollen face Weakness in the hands Weakness in the feet Loss of eyelashes and eyebrow hairs Other I don't know Refused to answer

APPENDIX B

Code	Question
trans_contact trans_droplet trans_env trans_water	What are the modes of transmission of Hansen's disease? Select all that apply
country_cases	What country has the second highest incidence of Hansen's after India?
TF_contagious	Hansen's disease is very contagious, true or false?
TF_immunity	More than 95% of people have natural immunity to Hansen's disease, true or false?
TF_hereditary	Hansen's disease is not hereditary, true or false?
TF_curable	Hansen's disease is completely curable, true or false?
TF deform	If Hansen's disease is not treated, it may result in deformities, true or false?
TF_vax	There is a vaccine for Hansen's disease, true or false?
TF_norm	A patient with Hansen's disease can have a normal life, true or false?
TF_contag_treat	Hansen's disease is not contagious after starting treatment, true or false?
TF_disability	Disabilities related to Hansen's disease can improve, true or false?

APPENDIX C

July 15, 2022

Jessica Fairley

jkfairl@emory.edu

IRB EXEMPT REVIEW

Title:	Perceptions Of Health Professionals About Leprosy Care in the Family Health Clinics in Brazil
Principal Investigator: Jessica Fairley	
IRB ID: STUDY00004818	
Funding: None	
Documents Reviewed:	EnglishHealth ProfessionalsSurvey.pdf, Category: Surveys, Questionnaires, Interview Guides; • FINAL FHP Health Professionals.portuguese.pdf, Category: Surveys, Questionnaires, Interview Guides; • HD.Perceptions.consent.English.pdf, Category: Consent Form; • HIPAA.waiver.docx, Category: Other; • Perceptions.backtranslated.pdf, Category: Consent Form; • Portuguese.consent.pdf, Category: Consent Form; • Provider.perception.IRB.pdf, Category: IRB Protocol;

Dear Jessica Fairley:

Thank you for submitting an application to the Emory IRB for the above-referenced project. Based on the information you have provided, we have determined on 7/15/2022 that although it is human subjects research, it is exempt from further IRB review and approval. This project meets the criteria for exemption under 45 CFR 46.104(d)(2)(ii). Specifically, you will survey healthcare providers in Brazil on the topic of leprosy.

Please note the following in association with this exemption:

• Attached are stamped approved consent documents. Use copies of these documents to document consent.

This determination is good indefinitely unless substantive revisions to the study design (e.g., population or type of data to be obtained) occur which alter our analysis. Please consult the Emory IRB for clarification in case of such a change. Exempt projects do not require continuing renewal applications.

Please note that the Belmont Report principles apply to this research: respect for persons, beneficence, and justice. You should use the informed consent materials reviewed by the IRB, if applicable. Similarly, if HIPAA applies to this project, you should use the HIPAA patient authorization and revocation materials reviewed by the IRB unless a waiver was granted. CITI certification is required of all personnel conducting this research.

Unanticipated problems involving risk to subjects or others or violations of the HIPAA Privacy Rule must be reported promptly to the Emory IRB and the sponsoring agency (if any).

Sincerely,

Mike Bingham, JD Consultant

Now that your submission has been approved, please take a few moments to complete the Emory IRB Satisfaction Survey*. We will use your responses to improve our service to the Emory research community. We appreciate your feedback!*

EMORY UNIVERSITY | Institutional Review Board
Research Administration

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