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Health literacy & Chagas disease knowledge: A cross-sectional study in Southern Loja Province, Ecuador

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ABSTRACT

Objective: Health literacy is associated with many patient outcomes. This study sought to determine the association between a person's level of health literacy and their knowledge about Chagas disease.
Methods: A cross-sectional survey was conducted with people living in two counties in rural Loja Province, Ecuador who attended a mobile health clinic. The communities in which the study was conducted are at high risk of Chagas disease and have limited access to both health care and educational resources. The Spanish version of Short Assessment for Health Literacy measured health literacy. The Chagas Disease Knowledge questionnaire measured knowledge of Chagas disease. T-tests and correlational analysis were used to assess associations.
Results: Overall 85 people participated in this study. A majority of the respondents were female (64.1%), and a plurality were married (40.7%) and had education less than secondary (40.7%). The average age of the sample was 44.31 ± 18.85. Health literacy levels and Chagas disease knowledge in the communities were low. About half of people had inadequate health literacy. No association between health literacy and Chagas knowledge was found.
Conclusion: Health literacy levels and Chagas disease knowledge were not found to be correlated. Explanations for the lack of association may include common causes of inadequate investment in Chagas disease education as well as neglect of health systems in rural Ecuador. Efforts to improve both health literacy and Chagas disease knowledge in poorer, rural areas of Ecuador are needed.
Innovation: This is the first study to assess relationships between health literacy and knowledge of Chagas disease in an uninfected population. For novel conditions, relationships between health literacy and disease knowledge should be investigated before communication campaigns are adapted.

1. Introduction

Chagas disease (CD), also called American trypanosomiasis, is a neglected tropical disease that affects about 7 to 8 million people around the world [1]. An additional 70 million people are at risk of acquiring this disease [2]. Most of these people live in rural areas of Latin America where poverty is widespread, access to healthcare is limited, and educational opportunities are constrained [3]. Because the parasite (*Trypasnoma cruzi*) that causes CD is usually spread through the feces of a triatomine bug (where an infected bug bites and opens a wound, the bug defecates as it takes a blood meal, and then the bitten person accidentally pushes feces containing *T. cruzi* into the wound or nearby mucosa), vector control programs have been implemented to limit the bug's presence in people's homes. These control programs include spraying of insecticides such as deltamethrin to kill bugs and their larvae in homes already infested [4] and the construction of new and improved

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homes to prevent the intrusion of bugs before infestation occurs [5,6]. Although these programs are effective, they also face significant limitations. Specifically, improved housing is a relatively expensive solution and may take months to years to initiate with a family, and spraying insecticides, while cheaper, requires regular technical application to remain effective and uses dangerous chemicals that can create other health problems for families [7,8].

These challenges for sustainable control of CD indicate that we must try to do more than eliminate bugs; rather, to control CD we must account for social and environmental factors that help drive this disease [9,10]. To address social and environmental factors, communication campaigns to teach people about CD and inexpensive and easy practices they can immediately adopt to reduce their risk are often proposed as cost-effective ways for governments and NGOs to address CD [11]. Communication campaigns are suggested because CD risk is associated with knowledge of CD and attitudes related to the disease, and, moreover, it is believed that, if knowledge and attitudes can be shifted, so too can the risk of contracting CD [12-15].

For a communication campaign to be successful, however, recipients of the campaign's message must be health literate enough. Although health literacy is broadly defined, health literacy can usually be summarized as the ability of an individual or group to comprehend, internalize, and apply new medical knowledge. The World Health Organization defines health literacy as, "the ability of individuals to gain access to, understand and use information in ways which promote and maintain good health for themselves, their families and their communities" [16]. Health literacy was identified as a cognitive barrier to access health care in Ecuador [17]. Thus, if we seek to address a population at risk of CD, in this case rural populations in Latin America, it may be necessary to assess both health literacy and current knowledge of CD to design a successful campaign.

It is very likely that campaigns that understand and address their audience's level of health literacy will be more successful. This is because there are strong relationships between health literacy and health outcomes. Reviews and meta-analyses show that for many common conditions, including heart disease [18,19], HIV [20,21], diabetes [22-24], cancer [25,26], and COPD [27-29], there are strong relationships between health literacy, patient readiness for prevention, and improved patient outcomes. Only one study, however, has assessed the relationship between health literacy and CD, and that study was conducted only among people already diagnosed with the disease [30]. This study, of 379 Brazilians living with Chagas disease found that 85% had inadequate health literacy and that patients with inadequate health literacy were more likely to take medications beyond prescription and report poor self-perceived health as compared to patients with adequate HL. Although these findings are important to understanding treatment adherence after diagnosis, if health literacy can be associated with CD prevention factors, such as better knowledge of the disease, it is possible that we can adapt patient education objectives to better address an uninfected population. Thus, persons at risk, but not yet diagnosed, are an essential population to engage. If a relationship is found between health literacy and knowledge of Chagas disease in a naïve population, then we can better design interventions with approaches that use adaptations to levels of health literacy as well as the knowledge level of the population. Because we are unaware of any research on people who are at risk of Chagas' disease and associations between of their level of health literacy and knowledge of Chagas disease, we ask:

RQ1: What differences, if any, are there in different demographic grouping's levels of health literacy and knowledge of Chagas disease?

RQ 2: What association, if any, is there between a person's level of health literacy and their knowledge of Chagas disease?

2. Methods

2.1. Ethics statement

All procedures for this study were approved by the Committee on Ethical Research with Human Subjects at the Pontifical Catholic University Ecuador (EO-107-2023) and the Ohio University Institutional Review Board (23-D-103). All participants were adults. Consent documents were in Spanish. Participants either read the informed consent form or had it read to them and indicated their consent by signing the form. Participation was voluntary and confidential, and all participants were assured of their right to withdraw from study without penalty.

2.2. Study site

As part of a larger research and service learning project, this study was conducted in small cities and their surrounding rural communities in Calvas and Gonzanama counties in Loja Province, Ecuador in July 2023. Loja province, in the southern highlands of Ecuador, was chosen because this province is particularly vulnerable to CD. The Ministry of Health believes that Loja has the highest rate of new cases in the country [7], and the province experiences both the highest rate of poverty in the nation and among the most limited access to human services [31]. Within Loja, Calvas and Gonzanama counties have some of the highest rates of home infestation (up to 48% of homes) by triatomine bugs within the country [8].

2.3. Participants

Participants for this study were recruited through traveling health clinics that visited small towns throughout the two counties. Researchers approached all individuals waiting for the traveling health clinic. After greeting a potential participant, a brief explanation of the research was provided. Participants were informed that they would receive treatment from the traveling clinic independent of their choice to participate in this study. After obtaining informed consent, a demographic questionnaire, a measure of health literacy and a questionnaire about Chagas disease knowledge were applied to the participants.

Eighty-five people participated in this study. This sample size, assuming statistical significance set at $a = 0.05$ and power at 0.90 would allow us to detect medium effects or greater. Given that health literacy has been generally found to have a large effect on health-related outcomes, this sample size was judged sufficient. Overall, the sample obtained was more female and slightly older than the general populations of Calvas and Gonzanama counties. More women ($n = 55$, 64.0%) participated than did men ($n = 30$, 34.9%). Participants ranged in age from 18 to 87 years of age ($M = 44.31 \pm 18.85$). Full demographics are reported in Table 1.

2.4. Measures

To assess relationships between health literacy and knowledge of Chagas disease two measures were employed: the Short Assessment of Health Literacy - Spanish version (SAHL-S) (Cronbach alpha = 0.90) and the Chagas Level of Knowledge Scale (ChaLKS) (Cronbach Alpha = 0.75). Both questionnaires were administered orally at the various study sites.

The SAHL-S questionnaire [32] was used to assess health literacy among Ecuadorians. The SAHL-S is comprised of 18 items where the participants must read and pronounce a word correctly and then correctly associate that word with one of two other words (e.g., the participant reads and pronounces the word "pregnancy" and then should correctly associate pregnancy with "birth" and not with "childhood"). Incorrect pronunciations, incorrect associations, or a participant responding "I don't know" were counted as incorrect. Acceptable health literacy scores were those greater than or equal to 15 and poor health

Table 1
Summary of demographics and mean differences in health literacy and Chagas disease knowledge scores by demographic variable.

	N (%)	Health Literacy Mean (SD)	Chagas Knowledge Mean (SD)
Overall		12.28 ± 5.21	2.94 ± 2.25
		t, d, sig	**t, d, sig**
Sex		1.69, 0.36, ***p* = 0.048**	−0.32, 0.07, $p = 0.38$
Female	55 (64.1)	13.03_a (4.36)	2.91 (2.37)
Male	30 (34.9)	11.07_b (6.36)	3.07 (2.07)
		Chi Square (df, N), η^2, sig.	**Chi Square (df, N), η^2, sig.**
Civil Status		$\chi2$ (2, 81) = 9.31, $\eta^2 = 0.11$, ***p* < 0.01**	$\chi2$ (2, 81) = 6.77, $\eta^2 = 0.08$, ***p* = 0.03**
Single	25 (29.1)	49.96_a (25)	40.24_a (25)
Married	35 (40.7)	32.17_b (35)	47.54_b (35)
Cohabitating	21 (24.4)	45.05_{ab} (21)	45.05_{ab} (21)
Separated*	1 (1.2)	17.00 (0.00)	5.00 (0.00)
Widowed*	3 (3.5)	8.00 (1.73)	2.94 (2.25)
Education Level		$\chi2$ (2, 86) = 36.07, $\eta^2 = 0.43$, **p < 0.01**	$\chi2$ (2, 86) = 0.89, η^2, $p = 0.64$
Less than Secondary	38 (44.2)	25.83_a (38)	41.55 (38)
Secondary	32 (37.2)	54.41_b (32)	43.34 (32)
More than Secondary	16 (18.6)	63.33_b (16)	48.44 (16)
# of Children (Range 0–14)	3.06 ± 2.80	$\chi2(4, 85) = 23.26$, η^2, = 0.28, **p < 0.01**	$\chi2(4, 85) = 2.05$, $\eta^2 = 0.02$, $p = 0.72$
0	14 (16.5)	46.32_{ab} (14)	46.89 (14)
1	12 (14.1)	57.54_{ab} (12)	39.17 (12)
2	19 (22.1)	58.16_{ab} (19)	46.55 (19)
3	14 (16.3)	34.75_{ab} (14)	36.64 (14)
4 or more	26 (30.2)	27.87_b (26)	43.50 (26)
		r, sig.	**r, sig**
Age (Range 18–87)	44.31 ± 18.85	−0.52, **p < 0.01**	0.21, $p = 0.08$

NOTE: Participants who declined to answer a demographic question not included; * = excluded from Kruskall Wallis analysis because $n < 5$; 4 or more children includes 4–14 children. Within demographic categories, significant differences marked with **bold** and Mean Rank and sample size of group variable mentioned for Kruskal Walis t-tests with more than two grouping variables, significant differences between grouping variables marked with differeing subscripts at $p < 0.05$.

literacy scores were those less than or equal to 14. The SAHL-S was developed in Spanish. All items were reviewed by native Ecuadorian health scholars not affiliated with this specific study for cultural appropriateness; these reviewers recommended no changes to the items.

The ChaLKS is an 8-item questionnaire and grading scale developed by Ramos-Rincón et al. [33]. It consists of yes/no items, with a "I don't know" option. An answer earns one point if the correct answer is chosen. "I don't know" responses were counted as incorrect. The ChaLKS was developed in Spanish. All questions were reviewed by native Ecuadorian health scholars not affiliated with this specific study for cultural appropriateness; these reviewers recommended that the local term for the triatomine bugs – *chinchorro* – be used in the question that asked about the insect vector.

2.5. Statistical procedures

We began by assessing the mean levels of health literacy and knowledge of Chagas disease among members of the community. e the data was not normally distributed (Shapiro Wilk = p-value <0.05). we applied non-parametric Kruskal Walis t-test to assess differences in health literacy and Chagas disease knowledge among demographic variables and reported Mean Rank values as appropriate. Then, to assess relationships between health literacy and knowledge of Chagas disease, two procedures were employed. First, to assess whether there was a general relationship between the two variables, we ran a Pearson's correlation. Then, we compared the level of Chagas disease knowledge among individuals with low health literacy as compared to those with high health literacy using a t-test. Both procedures were performed as some studies measuring health literacy employ a t-test grouping subjects with a standardized cut-off score while other studies perform a correlational analysis. Using both procedures provides the fullest insight into potential relationships between health literacy and CD knowledge. All procedures were performed in SPSS. The significance level for all tests was $p < 0.05$.

3. Results

Overall, both levels of health literacy and knowledge of Chagas disease were low in the study population. Adequate health literacy is defined as scoring 15 or greater on the SAHL-S; the mean score for members of the community was below the cutoff for adequate health literacy (M = 12.28, s.d. = 5.21). Knowledge of CD was also poor; individuals answered correctly less than half the questions posed (M = 2.94, s.d. = 2.25).

3.1. Demographic associations

In terms of demographic differences (see Table 1), higher health literacy was positively associated with being female and with not being married, individuals who have 1 or 2 children, whereas it was negatively associated with participants who had 3 or more children. These effect sizes, however, were very small to small [34]. Persons living without children did not differ from other groups. Higher health literacy was, unsurprisingly, positively associated with people with secondary school education or greater as compared to those with a primary school education; the effect size indicates a medium effect [34]. Age was negatively associated with health literacy, meaning that older people are less health literate than younger people; the effect size was medium. This association may be because compulsory schooling was not mandated and federal support for education through the ninth year not supported in Ecuador until the late 1990s, meaning that older people may not have had access to basic education that was guaranteed to younger people. Although cohabiting individuals have lower CD knowledge than married individuals, neither differ significantly from singletons, and we are unable to identify a causal mechanism for why this could be so.

3.2. Associations of health literacy and Chagas disease knowledge

The Pearson's correlation test revealed a very weak correlation and no statistically significant association between level of health literacy and knowledge of Chagas disease ($r = 0.07, p = 0.35$). The t-test revealed that individuals with adequate health literacy did not report higher levels of Chagas disease knowledge (n = 44, M = 2.82 ± 2.21) as compared to individuals with low levels of health literacy (n = 42, M = 3.07 ± 2.31). Differences between the two groups were not statistically significant ($p = 0.30$) and the effect size was very small (d = 0.11). Both the correlation and the difference test indicate there is little practical utility of using health literacy to predict Chagas disease knowledge.

4. Discussion and conclusion

4.1. Discussion

Overall, levels of health literacy and knowledge of Chagas Disease were low in the study population. Health literacy and Chagas disease knowledge were not associated with one another in terms of statistical significance or practical utility.

About half of people living in these communities had inadequate health literacy. Moreover, the mean health literacy score for members of

the community was below the cutoff for adequate health literacy. These findings reflect general trends of lower health literacy among people who live in rural areas [35-37] or impoverished communities [38-40] found in other national contexts. Given that the rural areas in Calvas and Gonzanama counties are characterized by widespread poverty and low access to healthcare (17), this trend is likely to manifest in this context as well. Independent of any discussion of CD, since health literacy is associated with many health outcomes [16], the low level of health literacy in these counties indicates a need for a general intervention to improve health outcomes more broadly.

Knowledge of CD was also poor. This finding of low knowledge level of Chagas disease is consistent with previous studies conducted in Latin America and Latin American diaspora populations [13,41-43]. Low knowledge of CD is also common among practitioners in Latin America [14,33]. The finding of low knowledge indicates that educational campaigns about CD are needed. Several advocates for CD prevention believe that greater knowledge is needed [12-15], and our study supports their findings. The finding of low knowledge indicates that educational campaigns about CD are needed.

Although overall health literacy and knowledge of CD in these communities were poor, some demographic associations may indicate targets for communication interventions. Men, older people, people with lower educational attainment, and people with three or more children are less likely to be health literate. This finding is similar to other disease contexts showing similar demographic patterns [44,45]. These audiences may be good targets for health literacy education campaigns. However, because there were few differences in levels of CD knowledge, community-wide interventions may be appropriate. For both health literacy and Chagas disease knowledge, no subpopulation had high scores, also indicating the need to have community-wide, rather than demographically-targeted, communication campaigns.

The findings from the *t*-test and correlational analyses indicate that health literacy and knowledge of CD were not associated. That is, we cannot assume that adapting an intervention to express lower complexity will lead to greater knowledge of CD, nor that providing current CD educational materials to a community will increase their health literacy. Previous research has found associations between health literacy and knowledge of health conditions in familiar contexts such as heart disease (18, 19, 20, 21, 22, 23, 24, 25, 26). However, for novel conditions, such as COVID-19 during the early pandemic [46,47], or for conditions unfamiliar to a specific population [48-50], the relationships between health literacy and disease knowledge are less clear. Because our sample was an undiagnosed population, they may not have familiarity with the disease, explaining in part why we found no relationship. Quintino et al.'s study [30], which did find relationships among health literacy and Chagas disease-related outcomes was in an infected population, and this may mean that health literacy only becomes significant when a disease becomes known to a person.

4.2. Limitations and directions for future research

Chagas disease knowledge may not be associated with health literacy for many reasons, and each of these reasons may indicate a limitation to the present study. First, it is possible that the two variables are simply orthogonal phenomena. Second, it could be that, although a priori we had a sufficient sample size to detect a correlation between the variables of interest [52], a larger sample could be more sensitive to detect these differences. It is also possible that our population was somehow unique owing to its specific location or historical experiences that it does not represent the psychographics of rural Ecuador. Since we did not measure socioeconomic status or access to healthcare at the individual level, it is also possible that our participants differ from the overall population. Future researchers may wish to engage larger samples from a broader array of communities to assess these possibilities. Alternatively, because we found that both health literacy and CD knowledge were quite low, it could be that there is a common cause beyond both phenomena. Endemic poverty in the region or general neglect of this region by the central government in Ecuador, for example, could drive both phenomena and mask any association [53,54]. The lack of relationship may also be due to the lack of communication about CD to people living in this region; as a neglected tropical disease, it is possible that the failure of government or health institutions to message about CD explains why there is little knowledge [55,56]. Endemic poverty, limited educational opportunities, and lack of communication each provide social and structural reasons for low HL and CD knowledge that should be explored in future research. Finally, it is possible that people in this region do hold knowledge about CD, but the instrument that we used – the ChaLKS – assesses knowledge different from that which community members find useful in understanding the disease [3,57]. Future research should consider accounting for these cultural influences that may inform the relationship between health literacy and knowledge of CD.

4.3. Innovation

Despite these limitations, this is the first study that we are aware of to assess potential relationships between health literacy and knowledge of Chagas disease in an uninfected population. Previous research has found associations between health literacy and knowledge of health conditions in familiar contexts such as heart disease [18,19], HIV [20,21], diabetes [22-24], and cancer [25,26]. However, for novel conditions, such as COVID-19 during the early pandemic [46,47], or for conditions unfamiliar to a specific population [48-50], the relationships between health literacy and disease knowledge are less clear. CD, for this sample, and perhaps more broadly, may be a novel condition where there are different relationships among health literacy, knowledge, and disease outcomes.

In infectious disease research, generally, the associations of health literacy with knowledge and with preventive practices are not consistent [51]. The common recommendation to meet the reader's health literacy level so that they can read, understand, and use the information must be carefully considered for each infectious disease in context. Although communication interventions are often suggested as a cost-effective and efficient way to encourage disease knowledge and promote practices that reduce exposure to the insect vector that carries *t. cruzi* [11], our findings suggest simply changing the health literacy level in communication materials will be insufficient to raise knowledge of CD. It may be necessary to address systemic causes for both low levels of health literacy and low levels of CD knowledge in these communities before seeking to adapt communication campaign materials.

4.4. Conclusion

The current study found poor knowledge of Chagas disease in the community and inadequate health literacy. Although we sought to determine what differences, if any, there were in different demographic grouping's levels of health literacy and knowledge of Chagas disease, we found that there is a community-wide need for interventions aimed at improving the level of health literacy and improving levels of CD knowledge. Rather than designing messages targeted based on demographics, generalized educational interventions employing universal design principles are more likely to address the needs in these two counties. We also sought to determine what association, if any, there was between a person's level of health literacy and their knowledge of Chagas disease. Since we did not find a simple association between higher levels of CD knowledge and health literacy, adaptation of communication campaigns may be delayed until overall health literacy in these communities is improved or a campaign could be implemented that addresses both health literacy and CD knowledge simultaneously. If we can find a way to improve the level of health literacy and the knowledge of Chagas disease in these two rural counties in Ecuador, we may better be able to prevent the spread of this deadly neglected tropical disease.

CRediT authorship contribution statement

Talia L. Caridi: Writing – review & editing, Methodology, Investigation, Funding acquisition, Data curation, Conceptualization. **Fernanda Mariño-Polo:** Writing – review & editing, Methodology, Investigation, Data curation, Conceptualization. **Cora G. Farra:** Writing – review & editing, Writing – original draft, Data curation. **Alison M. Mingus:** Writing – review & editing, Writing – original draft, Investigation. **Athar Memon:** Writing – review & editing, Writing – original draft, Formal analysis. **Mario J. Grijalva:** Writing – review & editing, Supervision, Project administration. **Benjamin R. Bates:** Writing – review & editing, Writing – original draft, Supervision, Project administration, Methodology, Funding acquisition, Formal analysis, Conceptualization.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

Talia Caridi reports financial support was provided by the Research and Scholarly Advancement Fellowship and the Medical Student Research Seed Funding Grants from the Heritage College of Osteopathic Medicine Benjamin R Bates reports financial support was provided by The Urban Communication Foundation. Cora G. Farra reports financial support was provided by Ohio University, Provost's Undergraduate Research Fund. Cora G. Farra reports financial support was provided by Ohio University, Barbara Geralds Schoonover Professorship Fund. Athar Memon reports financial support was provided by Ohio University, Barbara Geralds Schoonover Professorship Fund. Mario J. Grijalva reports financial support was provided by Pontifical Catholic University of Ecuador. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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