



ORIGINAL RESEARCH

A qualitative exploration of knowledge of Chagas disease among adolescents in rural Ecuador

AUTHORS



Patricia Mora-Criollo¹



Majo Carrasco-Tenezaca²



Sharon Casapulla³ EdD, MPH, Assistant Professor



Benjamin R Bates⁴ PhD, Professor



Mario J Grijalva⁵ PhD, Professor *

CORRESPONDENCE

*Prof Mario J Grijalva grijalva@ohio.edu

AFFILIATIONS

¹ Infectious and Tropical Disease Institute, Department of Biomedical Sciences, Heritage College of Osteopathic Medicine, Ohio University, Athens, Ohio, USA

² Department of Biosciences and Department of Anthropology, Durham University, UK

³ Office of Rural and Underserved Programs, Heritage College of Osteopathic Medicine, Ohio University, Athens, Ohio, USA; and Department of Primary Care, Heritage College of Osteopathic Medicine, Ohio University, Athens, Ohio, USA

⁴ Infectious and Tropical Disease Institute, Department of Biomedical Sciences, Heritage College of Osteopathic Medicine, Ohio University, Athens, Ohio, USA; and School of Communication Studies, Scripps College of Communication, Ohio University, Athens, Ohio, USA

⁵ Infectious and Tropical Disease Institute, Department of Biomedical Sciences, Heritage College of Osteopathic Medicine, Ohio University, Athens, Ohio, USA; and Centro de Investigación para la Salud en America Latina (CISeAL), Escuela de Ciencias Biológicas, Facultad de Ciencias Exactas y Naturales, Pontificia Universidad Católica del Ecuador, Quito, Ecuador

PUBLISHED

3 January 2023 Volume 23 Issue 1

HISTORY

RECEIVED: 30 March 2021

REVISED: 22 February 2022

ACCEPTED: 5 September 2022

CITATION

Mora-Criollo P, Carrasco-Tenezaca M, Casapulla S, Bates BR, Grijalva MJ. A qualitative exploration of knowledge of Chagas disease among adolescents in rural Ecuador. *Rural and Remote Health* 2023; 23: 6796. <https://doi.org/10.22605/RRH6796>

This work is licensed under a Creative Commons Attribution 4.0 International Licence

ABSTRACT:

Introduction: Chagas disease (CD) is a neglected tropical disease that affects 6 to 7 million people worldwide. In South America, CD is a major health problem in several regions, causing more than 12 000 deaths per year. CD is caused by a parasite called *Trypanosoma cruzi*, mostly transmitted through the contaminated feces of certain species of triatomine bug, commonly known as the 'kissing bug'. CD is endemic in Loja province in the southern region of Ecuador, where triatomines have been found in 68% of communities. Previous promotion of healthy practices in Loja province have included educational programs directed toward youth to affirm cultural and social norms that support health and prevent CD transmission. The present study was designed to evaluate current knowledge related to CD among youth in the three communities of Loja province following previous intervention programs.

Methods: A descriptive, qualitative approach was applied using individual semi-structured interviews with 14 young people (eight females, six males) from three rural communities in Loja province. Interviews assessed knowledge about CD transmission, knowledge about the parasite–vector–disease pathway, and the role of youth

in preventing Chagas disease in their communities.

Results: Following a thematic analysis of the data, the study results showed there is cursory knowledge of the triatomine insect that can carry the causative parasite for CD. Participants were able to generally talk about the vector, habitat and prevention practices for triatomine infestation. Nevertheless, limited understanding of transmission dynamics in the parasite–vector–disease pathway itself was found. One major finding was that prevention practices were not correctly applied or followed, increasing the risk of exposure in the community. Youth also articulated that CD is stigmatized in their communities, which may be a barrier for prevention efforts.

Conclusion: Gaps in knowledge about the parasite–vector–disease pathway were identified among youth. Overall, youth responses indicated positive regard for prevention practices and a desire to be involved in prevention programs. Developing educational programs focusing on CD transmission may be needed to improve control and prevention of this parasitic disease. The implications of these findings are discussed for developing effective control programs in the region.

Keywords:

adolescents, Chagas disease, Ecuador, knowledge and attitudes, qualitative, stigma.

FULL ARTICLE:

Introduction

Chagas disease (CD) is caused by the protozoan parasite *Trypanosoma cruzi* (*T. cruzi*)¹. CD affects 6 to 7 million people worldwide, and 30 000 new cases are reported each year². The disease is endemic to 21 Latin American countries; however, in recent decades CD has spread globally to non-endemic areas such as Canada, the USA, Europe, Australia and Japan³. The most common way to be infected with *T. cruzi* is through the feces of certain species of triatomine bugs, also called 'kissing bugs'. Transmission to humans is associated with triatomine species adapted to live inside houses in rural areas. These insects hide during the day in the cracks of walls and roofs of precariously constructed houses and emerge at night to feed^{4–7}. Inadequate housing, and poor vector control within and around houses, have been identified as a risk factor for triatomine colonization⁸. Thus, prevention programs often focus on the interruption of household transmission as well as educational programs^{1,9}.

In South America, CD is a major health problem in several regions, causing more than 12 000 deaths per annum, and placing more than 5 million people at risk of acquiring the disease³. Although

interventions in Brazil, Argentina, Ecuador and Colombia have been successfully implemented and the risk of transmission dramatically reduced, all vector control programs face limitations and challenges^{10–12}. For example, knowledge assessments from Peru, Mexico and Bolivia have found low levels of awareness of CD and a lack of knowledge about its transmission, symptoms or causative agent^{12,13}. In high-risk communities, this disconnect between triatomines and CD is also associated with low interest in prevention of CD and substantial underestimation of the risk of CD. For instance, in southern regions of Ecuador, triatomine infestations of houses reached up to 48% and are often associated with chickens and guinea pigs being kept inside the house¹⁴. Thus, developing educational programs around CD transmission (vector–parasite), risk and prevention may be needed to improve CD prevention programs.

New and alternative strategies such as holistic strategies that include health promotion focusing on improvement of living environment and system-based health promotions to prevent CD have been implemented in places such as Ecuador since 2013¹². In Ecuador the incidence of CD is high. The Ecuadorian Ministry of

Health estimates 36 new cases per 10 000 inhabitants per year, resulting in 4400 new cases each year¹⁵. The southern province of Loja in Ecuador is particularly vulnerable to this disease. Loja province has the highest poverty in the country, and a higher rate of inadequate housing environments has led to bug infestation rates of up to 48% in domiciliary units within the province^{6,7,14}. Strategies to combat CD in the country mainly focus on active searches for triatomines and insecticide-based spraying in homes, as well as educational programs for CD prevention¹⁴. Despite control efforts implemented in the country, CD remains highly prevalent among those aged over 5 years, while 25% of the total Ecuadorian population remains at risk¹⁵.

This study seeks to assess young people's knowledge and attitudes to CD in the three communities with previous intervention programs by the Healthy Living Initiative (HLI)¹⁶. Primarily, the initiative focuses on CD prevention through holistic health promotion⁷. Promotion of healthy practices includes educational programs directed toward youth to affirm cultural and social norms that support health and prevent CD transmission¹⁶. Since 2013, the HLI has implemented intervention programs directed toward youth and children with the purpose of implementing community-based research for CD prevention and control. For instance, entertainment education has been proven to serve as a powerful intervention among children in the studied communities¹⁷. Previous educational programs toward youth also included participatory research about Chagas prevention, participatory sketching, storytelling projects to promote awareness and song development to prevent CD^{18,19}. In the present study, secondary school children were reached in the community that had previously participated in educational programs from the HLI initiative since 2013. These secondary school students can serve as important informants for identifying gaps and successes from educational programs. The following two core research questions

were asked:

- What is the current state of knowledge about Chagas disease among youth in rural communities of southern Ecuador?
- What components of intervention programs do youth identify as motivating to participate in efforts to control CD?

Answering these questions is essential for the improvement of youth-directed intervention programs that have the goal to prevent CD transmission. They may also be transferable to programs that seek to improve health globally.

Methods

Study area

This study was conducted in Loja province in southern Ecuador (Fig1). Loja province, and specifically the southern mountains, is a region that experiences high rates of CD, endemic poverty and low access to human services in comparison to the rest of the country^{4,17}. All participants were recruited in Cariamanga, a city of approximately 14 000 residents. Cariamanga serves as an economic, health and educational center for residents of rural communities from across Calvas county. Youth between the ages of 14 and 18 years come to Cariamanga because it has secondary schools that serve the 840 km² county. These nearby communities face precarious socioeconomic conditions and have limited access to sanitation, health and education services²⁰. Three of these communities – Bellamaria, Chaquizhca and Guara – have experienced very high rates of triatomine infestation and were identified for economic, educational and sociocultural intervention by the HLI nearly two decades ago^{4,6}. Youth from these communities come to Cariamanga after finishing primary school if their families can afford the transportation costs, boarding costs and loss of labor on their subsistence farms.

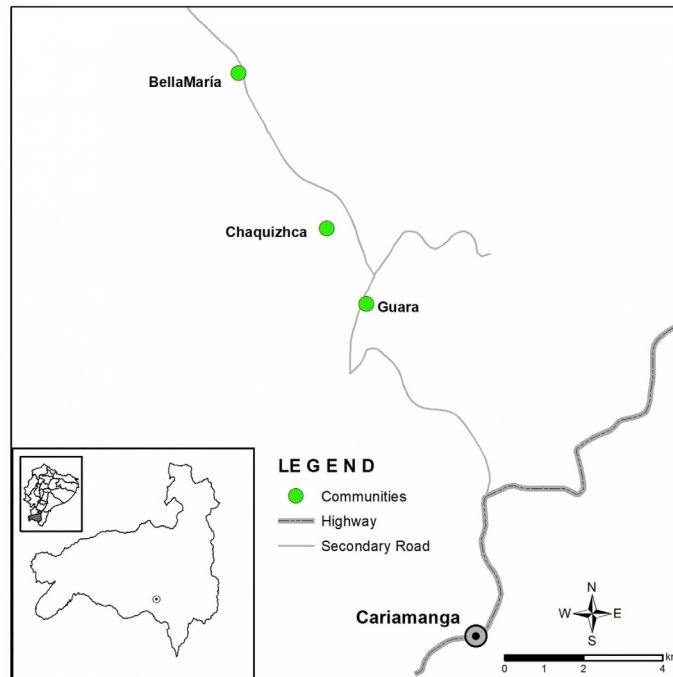


Figure 1: Map of the study area. Cariamanga, the county capital, is shown in relation to the locations of the three rural communities in which study participants lived.

Participants

Youth from Bellamaria, Chaquizhca and Guara attending secondary school in summer term 2018 in Cariamanga were invited to participate. Youth were recruited for two main reasons. First, adult perspectives on Chagas disease in these three communities have been accessed several times in the past^{16,21,22} and interviewing the youth could provide additional perspectives. Second, although the authors have reported on various projects carried out with youth in these three communities^{18,23}, these previous projects have not reported on how these interventions with the children may have a potential longer term influence on understandings of CD. To be included, a youth had to be aged between 14 and 18 years, born and raised in one of the three communities, and have participated in HLI programs at their primary school in 2013 or 2014. Secondary students who did not meet all three criteria were excluded from the study. School records indicated that there were 39 students from the three communities registered at the secondary school in Cariamanga. However, only 17 were in attendance during the study period owing to absenteeism for lack of funds for transportation, need to work on the family farm, illness, or other reasons. Three potential participants, after an initial screening for the three criteria, did not meet all inclusion criteria. Fourteen adolescents were included. All 14 participants (eight females and six males) lived in Cariamanga during the week to attend secondary school, returning home each weekend.

Study design, process and procedures

A descriptive, qualitative approach using individual interviews was used. Interviews were conducted in Spanish over 2 days in a private room by a member of the research team who is a native speaker from Ecuador. A semi-structured interview guide was used.

Questions were structured in a way that young people were able to comment on CD and triatomine bugs, their knowledge about the disease and their views of health intervention programs. All questions in the interview guide were developed in consultation with public health scholars, epidemiologists and employees of the Ecuadorian Ministry of Health to ensure that they addressed topics relevant to the transmission of Chagas disease. The questions were also reviewed by educators to ensure that the questions were age- and culturally appropriate. Each interview lasted between 20 and 30 minutes. Interviews were recorded on a digital recorder. Participants were asked not to discuss the topic or questions with other participants until all interviews had been completed.

Interviews were transcribed in Spanish using the transcribing software Transcribe Wreally (<https://transcribe.wreally.com>). After transcripts were reviewed for accuracy by comparing the transcript to the audio-recording, they were analyzed using principles of thematic analysis^{24,25} using ATLAS-TI qualitative data analysis software v7.1.0 (<https://atlasti.com>). Following Glaser's recommendations for emergent thematic analysis²⁶, constructs used to guide the HLI were employed as a sensitizing framework. Using the concepts of vectors, prevention, risk and intervention as the primary sensitizing concepts, participant talk was sorted into preliminary themes. This approach allows for theoretically informed categorization but does not force data into these categories, as additional ways of sorting and categorizing these themes was allowed to emerge.

Coding was performed by two independent reviewers. One coder conducted the interviews, and the other coder was not associated with data collection but was familiar with the work. If a new theme appeared to emerge for a coder they discussed it with the other

coder until consensus that a new theme had emerged. Coders, in sorting through participant talk, placed statements into a code family, and if there were discrepancies between coders they discussed the categorization until consensus was reached. The coders then revisited these code families to sort them into categories and subcategories. After finalizing the categories, the coders then named the themes to reflect the constructs contained within those themes. Finally, the articulated codes, categories and themes were fit with larger meaning structures for practical change.

Ethics approval

Written informed consent from each youth was obtained from their parents or legal guardians. Written consent was obtained during home visits as part of other research conducted in the communities during the summer. Each parent or guardian and

each participant was given a copy of the informed consent or assent for future reference. The study was approved by the Institutional Review Board at Ohio University (18-X-120) and the Ethics Committee at the partner university in Ecuador (2018-36-EO).

Results

Two main categories were identified for how youth in Cariamanga articulate their understandings of CD and related topics. These categories are (1) determining the state of scientific, actionable knowledge related to CD among youth and (2) exploring ways in which youth can become agents of change for control of vectors associated with CD. Within each category, subcategories were articulated. A summary of themes, categories and codes is provided in Table 1.

Table 1: Summary of themes, categories and subcategories of the coding process

Themes	Category	Subcategories
Limited knowledge regarding the vectors for CD Limited knowledge of the etiology of CD Stigmatization of the disease	Determining the state of scientific, actionable knowledge related to CD among youth	Lack of knowledge Inconclusive prevention practices Intervention programs Prevention practices Preconception Assertiveness Knowledge of vector
Willingness of youth to become involved Identifying best strategies	Exploring ways in which youth can become agents of change for control of vectors associated with CD	Agency Role of youth Transference of knowledge

CD, Chagas disease.

State of scientific, actionable knowledge

The first category, 'determining the state of scientific, actionable knowledge', comprised three themes: limited knowledge regarding the vectors for CD, limited knowledge of the etiology of CD, and stigma associated with CD. Each theme represents an opportunity for better scientific communication toward the prevention of CD.

Limited knowledge related to CD vectors: Overall, contradictions were found between the knowledge of the vector and its relationship to CD. For example, participants showed high concerns about having a 'deadly disease' or a 'serious disease'. Surprisingly, this disease was not identified as CD. However, while participants were aware that having the *chinchorro* (the local name used to identify the triatomine) living inside the house was risky in some way, they did not connect the presence of the bug with the risk of contracting CD. For instance, a 15-year-old male from Bellamaria said he was not afraid of the bug 'because they are too small, and they can't do anything'. Similarly, a 17-year-old participant said, 'I'm not afraid, I mean they don't look aggressive, they are small, harmless, but when you sleep ... that's a different thing, it's a danger'. In contrast, a 17-year-old female from Bellamaria said: 'I usually run when I see one ... because the disease they can transmit', but she did not name the 'disease'.

These contradictory reactions led to one of the study's major findings associated with prevention practices. It was found that

prevention practices were not correctly applied or followed. For example, a 14-year-old boy from Bellamaria described how he reacted after he sees a *chinchorro* inside the house: 'I grab a plastic bag, I collect the 'chinchorro' and put it inside a flask ... later, I throw it away and bury it'. A 16-year-old participant also mentioned that she killed the bug with a shoe or anything in hand. Although these actions kill the bug, they are dangerous because a person could come in contact with the feces and get infected with the parasite *T. cruzi*. Not following the proper protocol represents a risk of contamination to the population. Good prevention practices include collecting the bug safely using a bag, placing the kissing bug in a flask and reporting to local authorities. Based on that data, the study identified a lack of proper implementation prevention practices among participants as representing a major gap in knowledge regarding CD.

Limited knowledge about the dangers of finding triatomines inside the house and how the disease is transmitted were also identified. For example, even though participants were aware that having animals inside the house could attract triatomines, the presence of dogs, guinea pigs, and chickens co-habiting with the family were often mentioned. This is a problematic because domestic animals can serve as intermediate hosts for the *T. cruzi* parasite²⁷. Triatomines can colonize chicken nests, guinea pig pens, rodent nests and places where domestic animals live, and serve as a reservoir for parasite transmission²⁷. In the specific area of the

present study, it is not uncommon for animals such as dogs, chickens or guinea pigs to be kept inside the house to protect them from predators¹⁷. Such relocation results in an increased risk of CD transmission. However, even though participants were aware of the presence of kissing bugs, they still did not know that the insects can transmit the parasite that causes CD.

Limited knowledge regarding the etiology of CD: The authors found an unfamiliarity among participants with the parasite (*T. cruzi*) that causes the disease. Youth indicated incorrect transmission pathways, creating a complex chain of scientific inaccuracies that make it difficult to address vector control among the population. The disease was often confused with a virus among participants. For example, when a 15-year-old participant from Bellamaria referred to CD as a virus:

... the 'chinchorro' and depending on the 'chinchorro', they often bite us and there is that disease ... those viruses that they have can go to the body and give us diseases.

A 15-year-old participant explained Chagas:

... from what I understand ... it's a virus, it is transmitted through an insect that when you sleep ... it bites you in the way it can infect you and then ... it affects more and more ... from there you have some symptom like fever ...

Misinformation and stigmatization about contact from person to person through false routes such as kissing or touching were also mentioned. For example, some youth believed CD is transmitted through kissing and person-to-person infection (like the common cold). For instance, a 16-year-old female from Bellamaria mentioned:

... if one person has the disease and we imagine this disease goes to another person, they don't get contagious just because of the bug bites you, but because it transmits through physical contact ... and if that person touches another one it can contaminate all the population ... so, yes, I think is alarming.

The fact that participants mentioned person-to-person physical contact as a route of transmission could be associated with the limited knowledge of the participants regarding Chagas disease transmission. Moreover, when participants were asked about the symptoms and treatment commonly associated with CD, several gaps in knowledge were identified. For instance, participants often confused the chronic- and acute-phase symptoms, as they often refer to a 'deathly disease'. However, they seem to believe that home remedies can be used to treat the symptoms. Misinformation between the two phases (chronic versus acute phase) of CD was clearly identified. A participant mentioned:

... if it's not that bad ... you can treat them with a home remedy like we always do here. Well in my house we do it like this ... when we have some kind of disease, they gave us plant remedies but if it is very bad ... we will have to go to the hospital or inject you with an antidote.

Special attention should be given to this limitation regarding progression, symptoms and treatment of CD. Together this data also identified limited knowledge about CD transmission as a barrier to the implementation of health promotions.

Stigmatization of the disease: Participants were ashamed to admit that they had seen a *chinchorro*, especially if it had been present inside the house. Some participants, for instance, mentioned that they had never seen a bug before. However, as the interview advanced, they admitted they had killed one. Additionally, they often saw the presence of the bug as a sign of a lack of hygiene and poverty. For instance, a 14-year-old said:

... people with low incomes that still live in mud houses of adobe ... some places don't even have water or electricity. They live like that. They accumulate things, materials, garbage ... That's where I think you mostly find the bug.

This repeated use of 'them' and 'they' separated people at risk of home infestation as an 'other' divided from the regular portion of the community. Participants directly connected poverty and economic status to the presence of the triatomine bug. Moreover, this connection may stigmatize the disease or exposure to its risk factors. A higher risk of having the disease was also associated with age, as older people and children were seen as more at risk. The youth, however, did not consider themselves at risk. Together these misconceptions represent a limitation for the implementation of prevention practices; they also represent a limitation to accessing health treatment. Stigmatization of the disease could also limit participation in surveillance. Thus, it is critical to acknowledge stigmatization among the studied population.

Youth as agents of change

The second category was exploring ways in which youth can become agents of change. Within this category, two themes were identified. First, youth were interested in being agents of change, both by learning more about CD and by adopting practices to limit infestation. Second, they recalled play-based strategies as meaningful strategies that prompted them to desire change. The first theme indicates a willingness of youth to become involved; the second suggests the best way to encourage this involvement.

Youth are interested in becoming agents of change: Overall, participants were willing to learn about CD. Participants also expressed their interest in sharing information with other members of the community. For instance, participants mentioned their eagerness to transfer such information to other members, especially to 'the most vulnerable members like children'. Special interest in projects where they can 'feel empowered' was constantly mentioned. For instance, an 18-year-old from Bellamaria mentioned, 'last year we participated ... we did a video clip, about the student life, how is it living here and coming from the city, I liked that'. This kind of interest from youth in learning about CD as well as being part of prevention projects represents an opportunity for intervention. More importantly, the inclusion of this targeted population could not only incentivize youth but also

empower them.

Identifying best strategies: Participants mentioned the importance of cleaning the house and surroundings, chicken nests, and avoiding the accumulation of materials such as wood or brick. A 15-year-old youth mentioned his active participation in prevention practices:

... changing the chicken nest often, avoiding the accumulation of wood, bricks around the house. We have to cover the holes, clean the house in depth and clean the beds and the mattress.

When participants were asked about where they had learned prevention practices, they mentioned that the knowledge came from their parents and grandparents or external agents. An 18-year-old female from Bellamaria said:

... we were taught by people from the university, when they came the first time, they teach us little by little and we were learning ... we should not allow animals inside the house and that we should keep our bed tidy, otherwise the little animal, the 'chinchorro' could come and bite us.

Participants were also invited to discuss previous intervention programs and the impact they had had on their lives. Vivid memories were present regarding the *chinchorro* and association with the disease. Overall, games organized by external agents during their visit were the most memorable for the participants. For instance, a participant from Bellamaria said:

... they gave us activities on how to prevent the bite of the 'chinchorro' ... they taught us that we have to have our house clean and holes on the walls had to be covered.

... we used to play a game with a ball ... and the one that has the ball and put it on the arch ... and there the new ones become the 'chinchorro' ... they covered your eyes ... you have to put a ball 'chinchorro' in the hand and if you won, they gave you a prize.

Overall, ludic activities for learning about CD prevention practices were impactful. More importantly, participant recollection of learning games was constantly mentioned, especially the played-based strategies, which not only bring good memories to participants, but they also remain over time¹⁷⁻¹⁹. Future intervention programs should adopt this type of play-based strategies in youth populations. Together these results highlight some of the positive impacts of intervention programs and the importance of entertainment education to promote community-based disease prevention.

The authors also found some limitations among participants such as lack of knowledge about CD transmission, symptoms, and treatment or stigmatization of the disease. Perhaps future entertainment education programs should emphasize the importance of learning about CD transmission.

Discussion

This study aimed to understand the knowledge regarding some

aspects of Chagas disease and how intervention programs for the youth population living in the southern region of Ecuador are remembered. The aim of the first research question was to assess the current state of CD knowledge among youth in rural communities of southern Ecuador. Results showed that there is cursory knowledge about the triatomine, prevention practices and vector transmission, yet there is a disconnection with CD and its transmission. Additionally, the authors found that there were substantive gaps in knowledge about CD symptoms and treatment. Although participants seem to recognize the kissing bug or how to prevent colonization in their homes, they did not know that the kissing bug can transmit CD. Furthermore, participants did not have a clear concept of what CD is and the consequences of living with it. The study results identified this as an important gap when implementing intervention programs, which could contribute to an underestimation of communities' risk of CD.

The authors also identified a lack of proper implementation of prevention practices among participants. Participants' improper handling of the bug if encountered inside the house, maintenance of domestic animals inside the house, and failure to report the presence of the bug to the authorities further reflect a lack of association of triatomine bugs with disease risks. These behaviors have been associated by other authors with a lack of knowledge about Chagas disease and its transmission²⁸. In agreement with other authors, the present study's results showed that greater knowledge of CD could have the potential to drive communities to enact new preventive health-related behaviors^{29,30}.

Youth from the communities also articulated a stigma associated with the presence of the bugs inside the house. Overall, participants were ashamed to confirm the presence of the bug inside their houses. They associated the kissing bug with lower socioeconomic status. These associations may limit the implementation of prevention practices because people are ashamed to ask for help, for fear of being stigmatized in their communities³¹. Stigmatization of CD has become a major psychological barrier for accessing health treatment for this disease³². In addition, previous studies have found that the public associates CD with filth, neglect and misery, leading at-risk populations to ignore possible infections²⁸. It may also be a psychological barrier to primary prevention practices. Future education programs should be encouraged to address and counter stigma in CD prevention.

Previous research has found that effectively disseminating information about the vector and the disease to the population at risk has helped prevention programs to be more effective¹¹. Therefore, education campaigns linking the vector with the disease and parasite may be a promising strategy to adopt in rural southern Ecuador.

The aim of the second research question was to identify which components of an intervention program youth identify as motivating to participate in control programs. Results showed that youth participants identified external agents as an important

source of information that could motivate prevention and control efforts toward CD. Participants stressed the importance of programs for children and how they would like these interventions to be performed for future generations. Additionally, participants repeatedly commented on how prevention practices were encouraged and taught by parents, grandparents and external agents. The generational transfer of information appears to play an essential role in replicating behaviors, but improved behaviors can also result from the efforts of external agents that engage youth in the communities.

This study confirms the importance of children and youth being involved in educational vector control programs¹⁹. More importantly, information is retained and transferred over the years. Youth can play an essential role in intervention programs because household activities can shape actions throughout adult life³⁰. The present results confirm findings from work with youth in Mompós, Colombia³³ and Córdoba, Argentina³⁴ that young people are willing to participate in surveillance and control programs for CD, as well as their findings that there are significant shortcomings in understandings of CD vectors and etiology that should be addressed to make this surveillance and control most effective. Thus, active participation and empowerment of youth populations may be a promising approach when developing effective CD control programs in the Andean Ecuador region.

Conclusion

Overall, the authors conclude that intervention programs like that of the HLI have had a positive effect on youth in the communities by delivering information regarding the parasite vector and supporting general prevention practices. Nevertheless, several limitations and gaps of the HLI intervention program were identified. For instance, the study found that there is still a disconnect between the risk of having the kissing bug living inside houses and knowledge about CD transmission. Thus, these results support findings that community members underestimate their risk of CD¹⁰. This lack of knowledge regarding Chagas disease

should be considered as a significant barrier for successful vector control programs. Even though knowledge is not enough to change behaviors²⁹, addressing these gaps could be a starting point for improving intervention programs. Understanding CD and the social context that influences people's living conditions is an important factor in explaining the prevalence of the disease and increasing public awareness of it²⁸. Gathering further information from other members of the communities can confirm or deny these claims about general community knowledge surrounding CD.

Finally, the authors addressed the importance of improving and revisiting intervention programs such as that of the HLI when working with youth in the communities. Messages should focus not only on preventing disease transmission or evoking fear of the kissing bug, but on preventing further stigmatization of the disease in the communities. Acknowledging barriers such as misinformation, and limited knowledge about transmission or stigmatization of the disease, could help design better campaigns for prevention behaviors that tailored to the targeted communities.

Limitations of the study

Limitations during the development of this study were identified. The researchers in this study are affiliated with the HLI, providing them with insight and access to the processes and outcomes of these efforts. At the same time, knowledge of participants who had been previously involved with HLI may have led some participants to provide overly positive responses regarding HLI's efforts. Because of the logistical organization of the study, some participants might have discussed their answers beforehand on the topics of the interview. However, the compressed 2-day timeframe made this sharing unlikely. Finally, this study only included youth who had been involved in previous education programs. Thus, these findings should not be generalized to all youth or other members in the communities but instead considered as potentially transferable lessons.

REFERENCES:

- 1 Pan American Health Organization. *Chagas disease*. Available: [web link](#) (Accessed 11 December 2018).
- 2 World Health Organization. *Chagas disease (American trypanosomiasis)*. Available: [web link](#) (Accessed 11 December 2018).
- 3 Lidani KCF, Andrade FA, Bavia L, Damasceno FS, Beltrame MH, Messias-Reason IJ, et al. Chagas disease: from discovery to a worldwide health problem. *Frontiers in Public Health* 2019; **7**: 166. DOI link, PMID:31312626
- 4 Grijalva MJ, Palomeque-Rodríguez FS, Costales JA, Davila S, Arcos-Teran L. High household infestation rates by synanthropic vectors of Chagas disease in southern Ecuador. *Journal of Medical Entomology* 2005; **42(1)**: 68-74. DOI link, PMID:15691011
- 5 Grijalva MJ, Villacis AG. Presence of *Rhodnius ecuadoriensis* in sylvatic habitats in the southern highlands (Loja Province) of Ecuador. *Journal of Medical Entomology* 2009; **46(3)**: 708-711. DOI link, PMID:19496445
- 6 Grijalva MJ, Suarez-Davalos V, Villacis AG, Ocaña-Mayorga S, Dangles O. Ecological factors related to the widespread distribution of sylvatic *Rhodnius ecuadoriensis* populations in southern Ecuador. *Parasites & Vectors* 2012; **5(1)**: 17. DOI link, PMID:22243930
- 7 Nieto-Sanchez C, Baus EG, Guerrero D, Grijalva MJ. Positive deviance study to inform a Chagas disease control program in southern Ecuador. *Memórias do Instituto Oswaldo Cruz* 2015; **110(3)**: 299-309. PMID:25807468
- 8 Schofield CJ, Lehane MJ, McEwen P, Catala SS, Gorla DE. Dispersive flight by *Triatoma infestans* under natural climatic conditions in Argentina. *Medical & Veterinary Entomology* **6(1)**:

51-56. DOI link, PMID:1600228

9 Report of the WHO informal consultation on the 'evaluation and testing of insecticides', WHO/HQ, Geneva, 7 to 11 October 1996. Available: [web link](#) (Accessed 22 June 2018).

10 Rosecrans K, Cruz-Martin G, King A, Dumonteil E. Opportunities for improved Chagas disease vector control based on knowledge, attitudes and practices of communities in the Yucatan Peninsula, Mexico. *PLoS Neglected Tropical Diseases* 2014; **8(3)**: e2763. DOI link, PMID:24676038

11 Williams-Blangero S, VandeBerg JL, Teixeira ARL. Attitudes towards Chagas' disease in an endemic Brazilian community. *Cadernos de Saúde Pública* 1999; **15(1)**: 7-14. PMID:10203442

12 Blasco-Hernández T, Miguel LG-S, Navaza B, Navarro M, Benito A. Knowledge and experiences of Chagas disease in Bolivian women living in Spain: a qualitative study. *Global Health Action* 2016 Dec; **9(1)**: 30201. DOI link, PMID:26976265

13 Cabrera R, Mayo C, Suárez N, Infante C, Náquira C, García-Zapata MTA. Cabrera R, Mayo C, Suárez N, Infante C, Náquira C, García-Zapata MTA. Knowledge, attitudes and practices concerning Chagas disease in schoolchildren from an endemic area in Peru. [In Spanish] *Cadernos de Saúde Pública* 2003; **19(1)**: 147-154. DOI link, PMID:12700793

14 Grijalva MJ, Villacis AG, Ocaña-Mayorga S, Yumiseva CA, Moncayo AL, Baus EG. Comprehensive survey of domiciliary triatomine species capable of transmitting Chagas disease in southern Ecuador. *PLoS Neglected Tropical Diseases* 2015; **9(10)**: e0004142. DOI link, PMID:26441260

15 Dumonteil E, Herrera C, Martini L, Grijalva MJ, Guevara AG, Costales JA, et al. Chagas disease has not been controlled in Ecuador. *PLoS ONE* 2016; **11(6)**: e0158145. DOI link, PMID:27351178

16 Nieto-Sanchez C, Bates BR, Guerrero D, Jimenez S, Baus EG, Peeters Grietens K, et al. Home improvement and system-based health promotion for sustainable prevention of Chagas disease: a qualitative study. *PLoS Neglected Tropical Diseases* 2019; **13(6)**: e0007472. DOI link, PMID:31194754

17 Bates BR, Sharma D, Baus EG, Grijalva MJ. En nuestra casa no hay chinchorros: a youth-oriented, participatory approach to chagas prevention in Guara, Loja Province, Ecuador. *Frontiers in Communication* 2020; **5**: 18. DOI link

18 Bates BR, Marvel DL, Nieto-Sanchez C, Grijalva MJ. Painting a community-based definition of health: a culture-centered approach to listening to rural voice in Chaquizhca, Ecuador. *Frontiers in Communication* 2019; **4**: 37. DOI link

19 Marco-Crespo B, Casapulla S, Nieto-Sanchez C, Urrego JGG, Grijalva MJ. Youth participatory research and evaluation to inform a Chagas disease prevention program in Ecuador. *Evaluation and Program Planning* 2018; **69**: 99-108. DOI link, PMID:29753193

20 Castillo R, Abraham IJ, Cuevas F, Sharman MA. General technical coordination of metric innovation and analyses of information. [In Spanish] *Quito: National Institute Of Statistics and Census, Government of Ecuador* 2014; **267**.

21 Patterson NM, Bates BR, Chadwick AE, Nieto-Sanchez C, Grijalva MJ. Using the health belief model to identify communication opportunities to prevent Chagas disease in Southern Ecuador. *PLoS Neglected Tropical Diseases* 2018; **12(9)**: e0006841. DOI link, PMID:30260961

22 Bates BR, Villacís AG, Mendez-Trivino A, Mendoza LE, Grijalva MJ. Determinants of intentions to prevent triatomine infestation based on the health belief model: an application in rural southern Ecuador. *PLoS Neglected Tropical Diseases* 2020; **14(1)**: e0007987. DOI link, PMID:31999721

23 Bates BR, Grijalva DA, Grijalva MJ. A culture-centered, participatory approach to defining 'development' in rural Ecuador. *Qualitative Research Reports in Communication* 2020; **21(1)**: 45-58. DOI link

24 Nowell LS, Norris JM, White DE, Moules NJ. Thematic analysis: striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods* 2017; **16(1)**: 160940691773384. DOI link

25 Sandelowski M, Leeman J. Writing usable qualitative health research findings. *Qualitative Health Research* 2012; **22(10)**: 1404-1413. DOI link, PMID:22745362

26 Glaser BG. *Emergence vs forcing: basics of grounded theory analysis*. California: Sociology Press. 1992.

27 Gürtler RE, Cecere MC, Vázquez-Prokopec GM, Ceballos LA, Gurevitz JM, Fernández M del P, et al. Domestic animal hosts strongly influence human-feeding rates of the Chagas disease vector *Triatoma infestans* in Argentina. *PLoS Neglected Tropical Diseases* 2014; **8(5)**: e2894. DOI link, PMID:24852606

28 Ventura-García L, Roura M, Pell C, Posada E, Gascón J, Aldasoro E, et al. Socio-cultural aspects of Chagas disease: a systematic review of qualitative research. *PLoS Neglected Tropical Diseases* 2013; **7(9)**: e2410. DOI link, PMID:24069473

29 Sanmartino M, Crocco L. Knowledge about Chagas' disease and risk factors in Argentina communities with different epidemiological trends. [In Spanish] *Pan American Journal of Public Health* 2000; **7(3)**: March. PMID:10808751

30 Waleckx E, Gourbière S, Dumonteil E. Intrusive versus domiciliated triatomines and the challenge of adapting vector control practices against Chagas disease. *Memórias do Instituto Oswaldo Cruz* 2015; **110(3)**: 324-338. PMID:25993504

31 Gómez LJ, van Wijk R, van Selm L, Rivera A, Barbosa MC, Parisi S, et al. Stigma, participation restriction and mental distress in patients affected by leprosy, cutaneous leishmaniasis and Chagas disease: a pilot study in two co-endemic regions of eastern Colombia. *Transactions of The Royal Society of Tropical Medicine and Hygiene* 2020; 13 February: trz132. DOI link, PMID:32052043

32 Forsyth C, Meymandi S, Moss I, Cone J, Cohen R, Batista C. Proposed multidimensional framework for understanding Chagas disease healthcare barriers in the United States. *PLoS Neglected Tropical Diseases* 2019; **13(9)**: e0007447. DOI link, PMID:31557155

33 Cantillo-Barraza O, Sanmartino M, Chica Vasco J, Triana Chávez O. Towards development of a local scientific culture to deal with Chagas problems. [In Spanish] *Revista Ibero Americana Educacion*

2012; **58**: 119-133. DOI link

34 Rodriguez C, Capdevilla V, Crocco LB, Dujé N, Lazarte CY, Lopez

AG, et al. *Peer education, a strategy to work on Chagas from school*.
Cordoba: Imprenta Ingreso, 2012.

This PDF has been produced for your convenience. Always refer to the live site <https://www.rrh.org.au/journal/article/6796> for the Version of Record.