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Chagas disease is a low health priority among high-risk Latin American migrants in Geneva, a qualitative study

Marina Gold[a,*], Yves Jackson[b], David Parrat[c]

[a] Fundación Mundo Sano and Zurich University, Switzerland
[b] University of Geneva, Switzerland
[c] Geneva University Hospital, Switzerland

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ABSTRACT

This qualitative study of the situation of Latin American migrants with Chagas Disease in Geneva analyses how precarious migration-related socioeconomic conditions determine health priorities and disease perception. The study was conducted between 2016 and 2019 and is based on survey data collected in three Chagas-related community events, as well as on open-ended interviews with Bolivian migrants. This research contributes to more appropriate development of public health policies for migrants, as well as to a more nuanced and culturally sensitive understanding of how precarity affects the delivery of, and access to, healthcare in Western Europe. The significance of this research is to highlight how perceptions of Chagas Disease provide a lens to better understand the links between precarity and health among Bolivian migrants.

1. Introduction: Chagas disease and migration in Geneva

Chagas disease (CD), a neglected tropical disease, is a potentially fatal chronic parasitic infection that affects 6 to 7 million people mainly in endemic countries in Latin America (World Health Organization 2020). Given large migration movements from Latin America in recent decades, cases of CD have been documented in other regions such as the United States, Australia and various countries across Europe (Requena-Méndez et al., 2014; Gascon et al., 2010). The disease has a long clinically silent phase before organ damage occurs that frequently contributes to a delay in the diagnosis. In Switzerland CD was documented for the first time in 1979 (Jackson and Chappuis, 2011). However, it did not gain importance until after 2000, when Latin American immigration sharply increased (Jackson et al., 2011). With the high mobility of migrants within Europe especially after the Schengen area was established, the lack of epidemiological surveillance and transmission prevention measures, and low awareness among health professionals, the risk of undetected progressive organ damages and transmission is high in non-endemic countries such as Switzerland (Jackson et al., 2014). Indeed, it is estimated that roughly 90 % of cases have yet to be identified in Europe (Basile et al., 2011).

The population of the Canton of Geneva is around 500′000, 41 % of whom are foreigners. It is estimated that there are 10′000 to 15′000 undocumented immigrants in Geneva, mainly women from Latin America of child bearing age (Morlok et al., 2015). Most of them work in domestic service and in child care, while men tend to work in construction (Federal Statistics Office 2018).

Latin American migrants in Europe have a high prevalence of Chagas disease (Conners et al., 2016). Bolivians, who represent one of the largest Latin American group of migrants in Geneva, with a high predominance of people from rural areas endemic for CD, are the most vulnerable. A study conducted in the community and in healthcare setting in Geneva showed an overall prevalence of 12.8 % among all Latin American migrants and 26.2 % among Bolivians (Jackson et al., 2010).

In complex multi-steps migratory journeys, Switzerland is sometimes only a temporary location, and migrants move around Europe with the contingencies of work availability, as is revealed through the interviews and surveys of this research. In Switzerland, precarious migrants frequently lack the mandatory health insurance enabling access to medical care and the fear of denunciation and deportation lead them to avoid public healthcare institutions (World Health Organization 2017). These factors affect migrants' health-seeking behaviour and the capacity of the healthcare system to identify an often-silent (asymptomatic) infection, ultimately accounting for the low diagnosis rate (Jackson et al., 2014).

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* Corresponding author.
E-mail address: marina.gold@mundosano.org (M. Gold).

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A characteristic of the type of labour-motivated migration that brings Latin Americans to Europe is the movement of women on their own, initially leaving their husbands and children behind and sending back remittances, keeping only a minimum to live in precarious conditions (World Health Organization 2017; Wyssmüller and Efionayi-Mäder, 2011). Some women do not even rent an apartment, they rent a bed for part of the night and sleep in shifts, since they spend most of their time in their employers' houses. Those women who may have been in Europe for more than 20 years eventually manage to bring their families, often to Spain, where Spanish language makes settlement easier. However, for those whose children are living in their home country, the emotional stress permeates every aspect of their lives, including health-management practices, as is explored below (Jackson et al., 2022).

In economic migration focused on employment, migrants tend to pay little attention to their health, especially preventive health needs, which may further contribute to the low uptake of CD screening programs and frequent renunciation to medical care for economic reasons (Fakhoury et al., 2022). It is important, therefore, to analyse this phenomenon, in order to establish strategies to better diagnose and manage CD in a context of mobile and precarious migrant populations in non-endemic countries. Qualitative studies conducted in Madrid with the Bolivian population demonstrate the importance of considering the situation from an interdisciplinary perspective in order to develop more resilient health care structures that contemplate the reality of cyclical migratory movements in today's European context (Wyssmüller and Efionayi-Mäder, 2011; Ortí-Lucas et al., 2014).

The Geneva University Hospital (Hôpitaux Universitaires de Genève, HUG) has implemented since 2008 a CD screening and management strategy including activities both in the community and healthcare setting with an emphasis on undocumented migrants living in precarious conditions. The intention of community screening events was to raise awareness about Chagas disease among the larger population and within those most affected by it, as well as to encourage people to get screened, and for those who knew they were positive, to attend their regular check-ups. Community-based CD interventions have been shown to facilitate engagement with and foster trust among migrant groups in Europe (Navarro et al., 2017; Navarro et al., 2012). The *consultation ambulatoire mobile de soins communautaires* (CAMSCO, ambulatory consultation of community health) provides support to people without health insurance by establishing subsidising mechanisms of financial support, or the reduction of medical fees. HUG follow strict policies regarding personal data protection, allowing for a general high degree of trust among undocumented patients. In other locations throughout Switzerland this kind of social support is sometimes provided by the Red Cross or other Non-Government Organizations that help undocumented or precarious migrants.

The Argentinean non-governmental foundation Mundo Sano aims to collect scientific evidence about the negative impact of neglected tropical diseases on people's lives, in order to support the development of sustainable and efficient public policies. Chagas disease is a main focus of the foundation since its creation in 1993. It has programs covering all stages of the Chagas problematic: vector control, diagnosis and treatment, with a more recent focus on the interruption of vertical transmission. Mundo Sano has programs in multiple locations in Latin America (Argentina, Bolivia, Paraguay) as well as Spain and Switzerland.

This collaborative qualitative project between Mundo Sano and HUG emerged to address a relevant question that doctors at HUG asked themselves: why, when health seems to be the most important resource of labour-motivated migrants, and given the availability of free or low-cost health care support services, do Latin-American migrants not take a more proactive attitude towards their health in regards to CD? In the particular case of CD there is a cascade of patients lost from the moment of screening through to the long-term follow-up after treatment. An analysis of this cascade of loss to follow-up was conducted in Spain (Navarro et al., 2012) and showed that only 16,7 % of people underwent the complete process from diagnosis to treatment completion, between the years 2014–2017. While no systematic analysis was conducted for Switzerland, the experiential data taken from the Chagas consultations at HUG shows similar rates of loss of patients. This paper aims to address this issue through an analysis of health perceptions and health-seeking behaviour of Latin American migrants in Geneva. It explores the hypothesis that it is necessary to consider the interconnection between migration, labour and health, and its impact on Chagas-oriented screening and treatment programs to better understand this phaenomenon.

2. Theory

Migrants' health behaviour is often anything but rational. The health-migration relation is a complex one that can be approached through multiple perspectives, but it is essential to consider the socio-cultural elements surrounding precarious migrants in order understand their health-seeking behaviour. Many factors play key roles in determining the conditions and circumstances that surround access to health care, conceptions of health and agency of migrants. In order to unpack the factors affecting health and health-seeking behaviour for this particular cohort of precarious migrants in Geneva in relation to Chagas disease, we draw on theories of Social Determinants of Health, but with an additional critical contribution from theories of structural violence/vulnerability. These two theoretical lines, when taken critically, may complement each other in order to contextualise the entire situation, from the socio-cultural aspects of Chagas disease, the particularities of health within diasporic contexts and the structural features affecting dispossessed and precarious migrant groups in Geneva.

The theory of social determinants of health, supported by the World Health Organization, argues that there are

> Non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, development agendas, social norms, social policies and political systems (World Health Organization, 2008).

Some of the examples given by WHO as social determinants of health influencing equity to health include:

- Income and social protection
- Education
- Unemployment and job insecurity
- Working life conditions
- Food insecurity
- Housing, basic amenities and the environment
- Early childhood development
- Social inclusion and non-discrimination
- Structural conflict
- Access to affordable health services of decent quality.

The tradition of social medicine has discussed the importance of social factors influencing access to and quality of health since at least the 1970s (SOLAR and IRWIN, 2006). However, in 2009 the WHO has incorporated the theory of Social Determinants of Health (SDH) into many of its programs (Piñones-Rivera et al., 2021).

The contribution of the theory of SDH has been to highlight the socio-political and economic factors that affect people's health beyond purely biomedical knowledge. This theory is particularly relevant in research on Neglected Tropical Diseases since these are heavily determined by (and contribute to shaping) social, political, economic and environmental factors such as poverty, ecology, political neglect, colonial histories, etc. (Bardosh, 2014). SDH such as income, labour, education levels, housing, social inclusion and non-discrimination or access to health care are key factors in understanding the situation of precarious Latin American migrants in Geneva, as we demonstrate in the results below.

However, this theoretical approach does not contemplate the power play between the different structural forces that shape and order social determinants of health. By overlooking – or rather levelling – all determinants of health to a list, the power structures providing them hierarchical status are overlooked. That is, tacitly racist migration policies, the role of the capitalist system, the global structures of pharmaceutical companies, the workings of the market and other macro-level structural forces are key forces ordering and influencing how social determinants of health interact in each circumstance and location. Conversely, there are other, more mundane factors at the micro-level of social relations that also cut across the impact of SDH: personal animosities in local communities, contingencies affecting each person's migratory trajectory, friendships, contacts, social networks, personal and cultural preconceptions, etc. Therefore, it is crucial to consider that large-scale structural mechanisms and micro-scale personal contingencies are at play influencing the capacity of health care systems to provide health care, and shaping people's attitudes towards these health care systems.

Hence, pushing the theory of social determinants of health further, many researchers have alerted to macro structural determinants that extend beyond localised social issues and which account for much of the health inequity affecting, especially, precarious migrants (Marmot et al., 2008; Flynn and Wickramage, 2017). These scholars have pointed out the importance of hierarchising the factors that determine health, in order to understand that some factors are more easily transformed through programs of public health, and others are structurally embedded in global and historical processes that are harder to alter, such as the capitalist mode of production, neoliberal individualist conceptions of health and colonial histories identified as processes of structural violence or structural vulnerability (Farmer, 2004; Holmes, 2011; Piñones-Rivera et al., 2021). The important contribution of these theories has been to shed light on deeply ingrained power relations within the practice of medicine and the conceptions of health and healing. In precarious migratory contexts these forms of structural violence and vulnerability within which migrants find themselves can not be overlooked when developing public health strategies. Through the lens of social determinants of health, and the added critical edge of structural violence and vulnerability, we consider the situation of undocumented Latin American migrants with a neglected tropical disease in Geneva, Switzerland, in order to understand their health perceptions and priorities so as to better develop public health policies to the target population.

This qualitative research project was based on in-depth open-ended interviews, participant observation, and survey data. Qualitative methodology is appropriate in research intended to uncover the meaning of events or phenomena to research participants. The data collected, therefore, intends to capture how people hierarchize health concerns in precarious and adverse situations, in order to understand how situations of structural violence influence people's strategies of survival and their ability to reproduce social relations. Furthermore, since the categories used in health care are those provided by the health care system, it was important to understand the relationship and interaction between the categories important to the participants and those relevant to the research team. Qualitative interviewing intends to "gain access to the knowledge, experience and perspectives of research subjects" (Kelly, 2010) through the stories they tell about themselves and their migratory experience.

The importance of narratives (collected during these interviews in the form of notes and quotes taken by the team anthropologist) in qualitative research have been inspired by phenomenology (Ricoeur, 1984), a philosophical current represented by Husserl, Heidegger, Sartre and Merleau-Ponty, which focuses on the lived experiences of people and the strategies these employ to make sense of their circumstances. These narratives can be complemented with discourse analysis, which considers the use of language in the attempts to understand aspects of social life (Waitzkin, 1991), and grounded theory, useful in elucidating social processes in context (Morse et al., 2008). The latter aims to develop theoretical observations from the data (in this case, the experiences of participants, their narratives of illness and migration, and their attempts to make sense of the adversities they encounter), instead of hypothetically applying a theoretical perspective and using data to support of disprove it (Glaser and Strauss, 1967). The questionnaires and semi-structured interviews have yielded a complex picture of the adversities experienced by this particular cohort of Latin American migrants in their attempts to make sense of having Chagas disease in a precarious migratory context: a foreign language (French); irregular migratory circumstances, hostile social contexts and difficult to navigate bureaucratic institutions.

3. Materials and methods

This objective of this qualitative research was to unpack health perceptions of undocumented Bolivian migrants about Chagas disease in the context of their precarious situation. It was a collaborative project between the Fundación Mundo Sano and HUG, with the collaboration of the patients' association Asswisschagas and HEKS/EPER (the aid organization of the Swiss Protestant churches). This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

The study received ethical clearance from the Geneva ethics board (project CCER 2017–00,197) under the title of *A qualitative study of health perceptions about Chagas disease among Latin American migrants in Geneva*. While Latin American migrants were the theoretical focus of the project application, during the research it became evident that the Bolivian population was predominant in the study group, and so became the focus of study.

The project took place between 2016 and 2019. Community CD screening events were held once a year (three events in total: 2016, 2017, 2018), during which survey data, participant observation and screenings were conducted. Moreover, during these events some participants were recruited for follow-up and open-ended interviews. Qualitative data was also collected during doctor-patient consultations with the Chagas disease specialists at HUG through participant observation of the team anthropologist during patient consultations, upon previous patient consent.

3.1. Setting

The Chagas disease events were celebrated each year in order to commemorate World Chagas Day, which falls on the 14th April. Since the date usually fell too close to Easter and the school holidays, the three events were organized in May, on a Sunday. They were mostly organized by Asswisschagas, the patients' association, and received support from the Geneva University Hospital and the Fundación Mundo Sano, as well as the World Health Organization NTD department.

The event began at midday and offered entertainment (dance, music and food) as well as information sessions on Chagas disease by diverse presenters. During the day, free on-site screening using a rapid diagnostic test was proposed to all participants. The immunochromatographic test (Chagas Stat-Pack, Chembio Inc.) was performed on capillary blood with a result available in 15 min. In case of positive result, participants were invited to undergo a free confirmatory serologic assay (ELISA Chagas, Biokit) at HUG. The extraction of blood outside the hospital setting was not logistically possible at the time. Upon confirmed infection, participants were proposed to undergo a full clinical assessment and a discussion about the risks and benefits of antiparasitic therapy.

Given the results of the survey conducted in 2016 (displayed in the Results section) the team observed that Chagas disease was low in the list of health priorities, competing with other health conditions such as hypertension and diabetes. In an exploratory procedure, and with the intention of placing Chagas concerns within other more general health concerns, in 2017 people were offered blood pressure measurement (seated for 10 min, using a well-calibrated arm-cuff) and capillary glucose testing (using Accu-Check Aviva glucometer). This was discontinued in 2018 because of the unreliable results obtained.

3.2. Qualitative data collection

The qualitative data collection for this study started in 2016 and was completed in 2019. Different types of data were collected:

1) Bibliographic data on Chagas in migratory settings was used as a background for understanding complex migratory movements of Latin Americans within Europe
2) A questionnaire collecting demographic details and knowledge of CD during yearly Chagas awareness community screening events (2016, 2017, 2018)
3) Open-ended interviews with selected participants (2017 – 2019)
4) Observations in clinical setting

3.2.1. Questionnaire

The questionnaires were only directed at adults. Children were not asked to complete the questionnaire. While children attended the event as it was a family-oriented activity on a Sunday, they did not form part of the research focus. The only information collected related to children was a question directed to adults about the number of children they had in Geneva and elsewhere. The age of the respondents was collected in age ranges, with the lowest being 10–19 in order to cover women in reproductive age. No respondents were underaged.

The questionnaire completed in the Chagas had three objectives: 1) to collect demographic data on participants; 2) to record people's knowledge on CD and 3) to understand their health priorities. The first section of the questionnaire collected people's demographic data:

- Gender
- Age range
- Country of Origin
- Employment status
- Year or arrival in Switzerland and other countries in the migratory chain
- Number of underaged children living in Geneva/back home

The second element of the questionnaire collected knowledge about CD:

- Knowledge of the vector
- Relatives with CD
- Previous screening for Chagas and completed treatment
- Understanding of means of transmission of CD

The third section of the questionnaire intended to reveal how people hierarchise health concerns. Informal conversations with Latin Americans in Geneva, and doctors' experiential knowledge working with this cohort, yielded a preliminary list of issues that concern the community in question: hypertension, diabetes, stress and depression. The team added other health issues related to Chagas in order to identify whether these symptoms were of concern even while people claimed that Chagas was not a priority: heart problems and digestive problems. The team added the general category of 'gynaecological problems' to contemplate women's health concerns and Chagas was established as a category to capture whether the disease itself was understood as a health concern. The health priorities also reflect the Social Determinants of Health established by the World Health Organization (WHO) as broader conceptualization of factors determining health and wellbeing.

Respondents were asked to prioritize different dimension of health from a list provided that aimed to cover a broad conception of health contemplated by the WHO (including social, psychological and physical elements): "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." The intention of this list was also to identify the factors affecting this migrant community that could influence their health perceptions. These included:

1. Absence of disease (no need to see a doctor)
2. Ability to take care of the family
3. Having private leisure time
4. Having a social life
5. Employment
6. Housing
7. Managing weight control
8. Doing exercise
9. Having money

The capacity of people to fulfil these dimensions of health, was not always under their control, as social determinants of health, and structural determinants have a strong influence upon these dimensions beyond people's own agency, as will be developed below.

People were asked to list the diseases and health problems that they perceived most affected their community; that is, the people they knew and those who were close to them in kinship terms (Fig. 3). The intention was to observe which medical conditions were perceived by people as the most serious and prevalent in their immediate social surroundings. A list was provided, with the option of adding other health conditions.

Given the complexity of the surveys, and to address circumstances where participants had low levels of literacy, different members of the research team assisted participants in the completion of the surveys. Crucial in the completion of the questionnaires was the conversations held with the interviewers. This allowed for the collection of personal explanations provided by participants during the completion of the survey – such as family histories related to CD, adverse experiences during migration, perceptions related to the Latin American community in the diaspora – all relevant in the contextualization of the socio-political determinants of health in situations of precarious migration. This was done intentionally, merging the two qualitative methodologies of structured interviews – amenable to producing quantifiable data (Green and Thorogood, 2004) – and informal, semi-structured or 'open-ended' interview methods, which aim to produce a 'thick description' (Geertz, 1973) of the complex health-related perceptions of participants.

The questionnaire was completed separately and independently to the screening process. This was done to prevent people from declining to get screened for not wanting to answer the questionnaire. The main purpose of the event was to encourage people to get screened, so the research team decided to prioritize that. It is evident in the results that people were more willing to get screened than to be subjected to the tedious process of completing the questionnaire. Therefore, it is not possible to correlate the answers in the questionnaire to the Chagas screening results. This means that some people agreed to answer the questionnaire, but did not get screened, and some were screened but did not answer the questionnaire. Generally, people were approach by the research team with the questionnaire and while they were providing the answers they were also informed about the possibility of getting tested at the event.

The qualitative data from the three surveys (2016, 2017, 2018) was first reported individually for the discussion of the research team, and aggregated and analysed as a single data set for the purpose of the paper analysis. The numbers are not significant, as the community of Bolivians is small, but they reveal certain trends, and contributed to contextualize the experiential data provided by the in-depth interviews. Besides the completion of the surveys at the Chagas day event, in subsequent months the team anthropologist conducted nine open-ended interviews with people who were willing to talk in more detail about their health and their experiences with Chagas. Eight Bolivian participants were female and one was male. None of them were related, in order to avoid autocorrelation of data. The mean age of the interviewees was 45. The sampling was random, emerging from willing participants that had attended the Chagas Day events as well as snowball sampling technique resulting from these initial participants. The phone numbers of those who were willing to participate in open-ended interviews at a later stage were taken and they were contacted and interviewed in person (8 cases) or by phone (1 case) by the team anthropologist.

The open-ended interviews allowed for further exploration of people's health perceptions in the context of precarious migratory status: oppressive working conditions, psychological stress given the importance of their labour to the family in Bolivia, loneliness, lack of social support, etc. People were encouraged to talk about their experiences with the health care system in Geneva, and to contextualise their migratory experience. In the cases where participants had Chagas, they were asked to specifically narrate their experiences of Chagas disease in Geneva. In all cases participants talked freely and needed little coaxing from the interviewer. The interviews were carried out in Spanish, the language of the participants, by an interviewer from Latin America (native Spanish speaker). The guiding questions used by the interviewer as prompts included:

1. Can you tell me how you have ended up in Geneva? (Migratory context)
2. Can you tell me a little about your family in your home country? (Family history and socio-cultural background)
3. Do you have Chagas? /What do you know about it? /What has been your experience with Chagas in Geneva? (narratives of health and illness).

The data was anonymised and depersonalized in order to protect the identity of the participants. The open-ended interviews, which lasted between 20 and 30 min, were not tape recorded given the undocumented status of patients and their uncertainty with official authorities. Participants felt more comfortable meeting in neutral spaces like cafes, instead of the hospital, and they were reluctant to give personal details that would identify them to the authorities, which they feared could deport them. The interviewer took short notes and then kept an interview journal where she took extensive notes from interviews as soon as the interview was over to preserve as much as possible veratim quotes, impression and observations.

Open-ended interviews were categorised using thematic analysis to organize the key themes emerging from the interviews, following Green and Thorogood (Green and Thorogood, 2004). The key concerns of the research team were broad enough (health and migration) to allow for the particularities of the participants to emerge from the interviews. The key themes, further developed in the results, included: precarity of migratory status, family rupture, oppressive labour relations, mistrust in local institutions, lack of social support network or the existence of weak ones and language barriers.

Additionally, Chagas-specific consultations between patients and the Chagas expert were observed by the team anthropologist. The patients were informed beforehand (often by phone) about the research study and the possibility of an observer accompanying them throughout the consultation. All patients, except one, agreed to the presence of the team anthropologist. She spoke Spanish, which made the patients feel more comfortable. She explained the purpose of the research again, before the consultation, and gave the patients the option of asking the observing anthropologist to leave the room whenever they desired. The anthropologist sat in a corner, and did not interfere with the consultation. After the consultation the anthropologist asked the participants whether they would agree to being interviewed further and their details were taken for further contact.

Lastly, a private room was set up where people were able to get CD screening. It was a small room, separate from the main event area, so that people had more privacy and could have a conversation with the medical staff. In the case they were tested positive, their details were taken in order to invite them to have a confirmatory blood test at the hospital, and a consultation with a doctor.

4. Results

4.1. Demographic data

A total of 132 (41.3 %) people out of an estimated 320 participants completed the survey in the three consecutive events. In 2016, 42 people completed the survey, in 2017, 57 people and in 2018, 33 people. People were more willing to get screened than to complete the questionnaires, which becomes evident in the lower numbers of questionnaire responses compared to screenings. One hundred people (75.6 %) were of Bolivian origin, especially from the regions of Santa Cruz and El Beni. There was a predominance of female respondents ($n = 106$, 80 %) and most ($n = 79$, 74.5 %) were of child-bearing age (15–49 years old). A majority of respondents ($n = 105$, 79.5 %) had children, with similar numbers of children living in Switzerland and Bolivia. Overall, 70 % were employed. Nine open-ended interviews were carried out in total during or after the events.

4.2. Rapid diagnostic testing

The proportion of participants that underwent voluntarily screening was comparable over the three yearly events: 48 % in 2016; 47 % in 2017; and 49 % in 2018. All people tested were asked their gender, age, place of origin. The results of the rapid diagnostic tests are displayed in Table 1. Those tested under 18 years of age were done so with the

Table 1
Results from the rapid diagnostic tests.

	2016	2017	2018
No. of Participants in the event	80	140	100
Number of people screened, n	39	66	49
Women, n (%)	$n = 31$; 79.5%	$n = 49$; 74.2 %	$n = 39$; 79.5 %
Bolivian origin, n (%)	$n = 34$; 87.2 %	$n = 49$; 87.5 %	$n = 42$; 85.7 %
Mean age (SD); and age range	41; 11–68	45; 5–76	43; 20–70
Positive screening, n (%)	$n = 2$; 5.1 %	$n = 10$; 15.2 %	$n = 4$; 8.1 %
Comments	Both participants with a positive test were from Bolivia and subsequently followed-up at HUG. The infection was confirmed by a second serological test. Both underwent a complete clinical assessment. One was pregnant and could not receive therapy so she had to contact the hospital after terminating lactation but failed to do so. The other was too old to receive treatment.	All 10 positive tests were Bolivian, 2 of them being males. One had already been diagnosed and treated in 2008. Eight new cases to be contacted. None reached treatment.	Three of the four cases were women. Two women and one man were from Bolivian origin, and there was a woman who did not provide personal details about her origin.

consent of their parents, who were present and signed a consent form.

The rapid diagnostic test provides an almost immediate result, although positive results need subsequent confirmation by traditional blood test. However, many patients did not make it to their first doctor's appointment to confirm their rapid test and to undergo full clinical assessment to decide upon the need to undergo antiparasitic therapy. The loss of patients from community event to the ideally regularly controlled patient reached nearly 85 % over the whole program.

As for the blood pressure measurement (seated for 10 min, using a well-calibrated arm-cuff) and capillary glucose testing (using Accu-Check Aviva glucometer) the results showed that from the 66 people testes, 4 people, (6.1 %) showed a Glycemic level that could potentially indicate the presence of diabetes (Glycémie $>$ 11 mmol/l); and 12.2 % (8 people) who meet high blood pressure criteria (TA $>$ 140/90 mmHg). Given that these tests were conducted during a party with dance and food, they could not be taken as definitive, but rather as general indicators.

4.3. *Knowledge about transmission routes*

Fig. 1 reveals people's knowledge of Chagas transmission. It demonstrates that people generally understand the vector as main source of transmission, and blood transfusions as another mode of contagion, but there are various areas of uncertainty: the relationship between Chagas and sexual transmission, kissing, and cohabitation, and the possibility of congenital transmission (important in non-endemic countries). There is a generally poor knowledge about CD transmission, but particularly about the risk related to transfusion and congenital routes.

During the survey people were encouraged to get tested in the free community event, but they initially showed reticence to do so, arguing that they did not have health insurance, and "there is really nothing you can do about Chagas anyways" (Bolivian woman, 70 years old).

Women in childbearing age showed a change in attitude when they learnt, in the process of answering the questionnaire, that Chagas infection can be transmitted congenitally and that it can be cured in young children. In the event held in 2017, the medical team also offered blood pressure tests and blood sugar tests with the intention of placing Chagas in a general bill of health, destigmatizing the test.

4.4. *Health priorities*

Fig. 2 reveals the top priorities for respondents which included being able to take care of their family, having time for leisure activities, having secure employment and housing and not having to see a doctor. Respondents also perceived nutrition and exercise as important elements of good health, but stressed in open-ended interviews that they were unable to achieve these due to the constraints from their precarious employment conditions. Women in domestic service told repeatedly of how their employers did not allow them to eat during working hours, so they had to buy a slice of pizza on the way into or out of work at odd hours. They were unable to have a steady eating routine or prepare fresh, home-made meals, and since they worked sometimes 12 h a day, they were unable to do exercise, beyond the physical work demanded by cleaning and taking care of children. On Sundays, their day off, they would go to church and do their house work. They had little time left for a social life, but considered church one of the few social spaces in their lives.

Diabetes and cardiac problems were perceived as the most prominent issues affecting their immediate social relations. Chagas, importantly, was not seen as a relevant health problem, however, in extended interviews people explained their concern over Chagas as a condition without cure, and their anxiety at being diagnosed positive in a situation of precarity – as undocumented migrants in a place where they did not understand the health care system.

4.5. *Semi-structured interviews*

The following table displays the thematic categories emerging from the interviews and illustrates them with direct quotes from the interviews. In most cases Chagas did not emerge as a main concern of the interviewees, even while 8 out of the 9 people interviewed had tested positive for Chagas. The interviewees were all Bolivian, from Santa Cruz or El Beni, both endemic regions for the CD vector. As evident through the in vivo descriptions, people's comments and views can often fall within more than one theme, as themes are interrelated. For example, lack of trust of local public institutions is closely associated with irregular migratory status and lack of proficiency in the local language (Table 2).

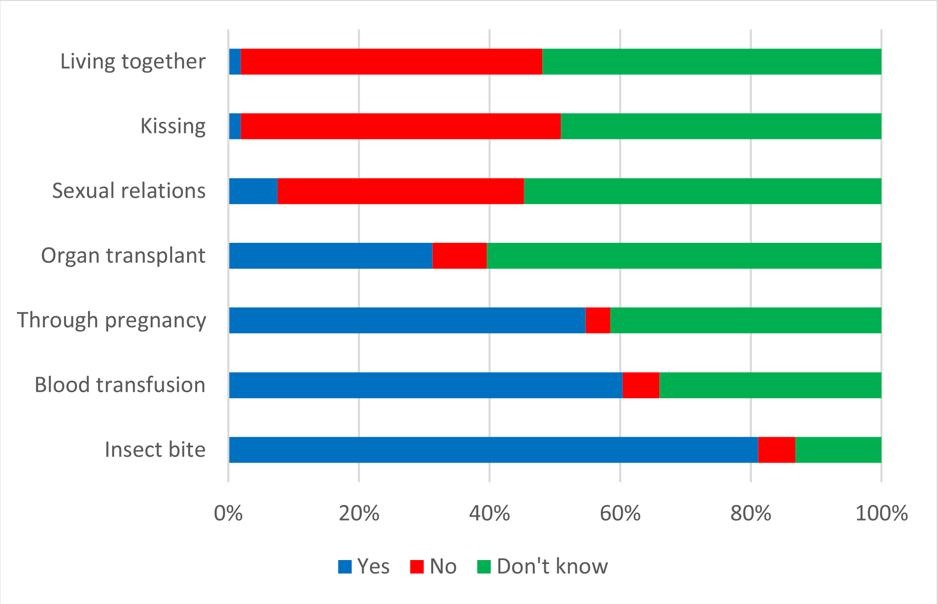

Fig. 1. Routes of CD transmission reported by participants ($n = 132$).

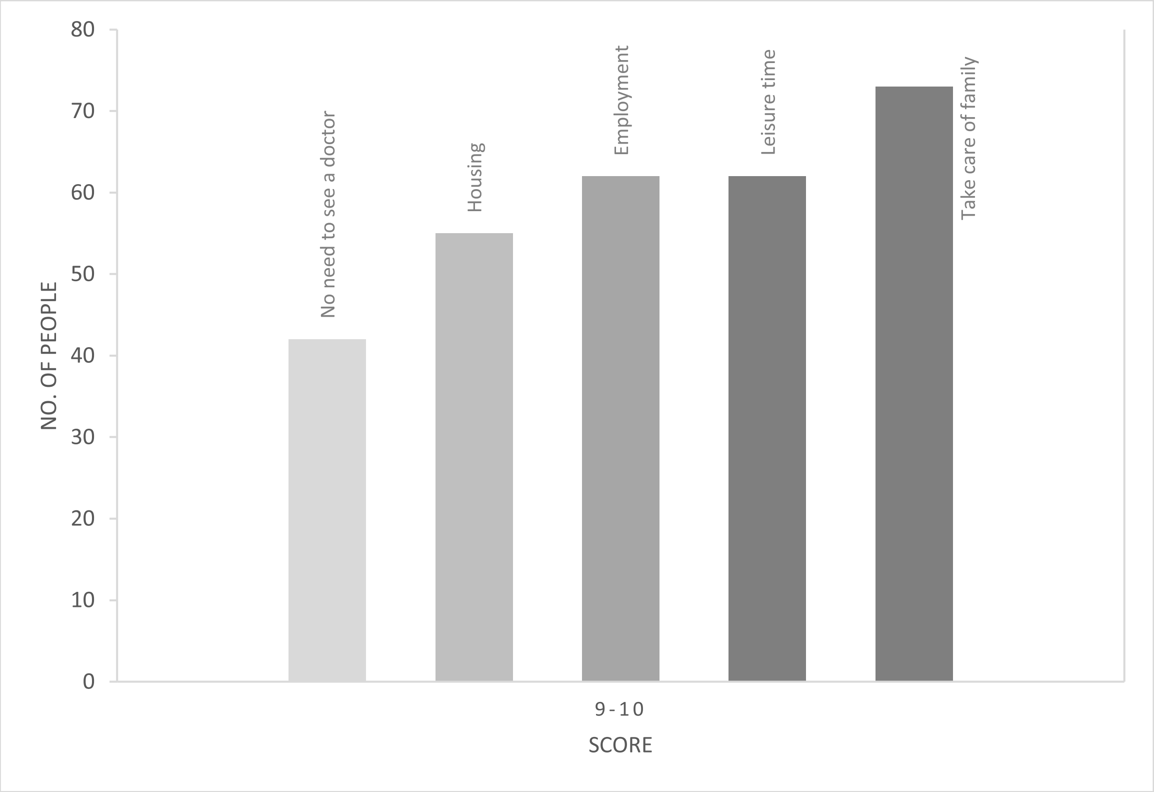

Fig. 2. Health priorities among participants to the survey ($n = 132$).

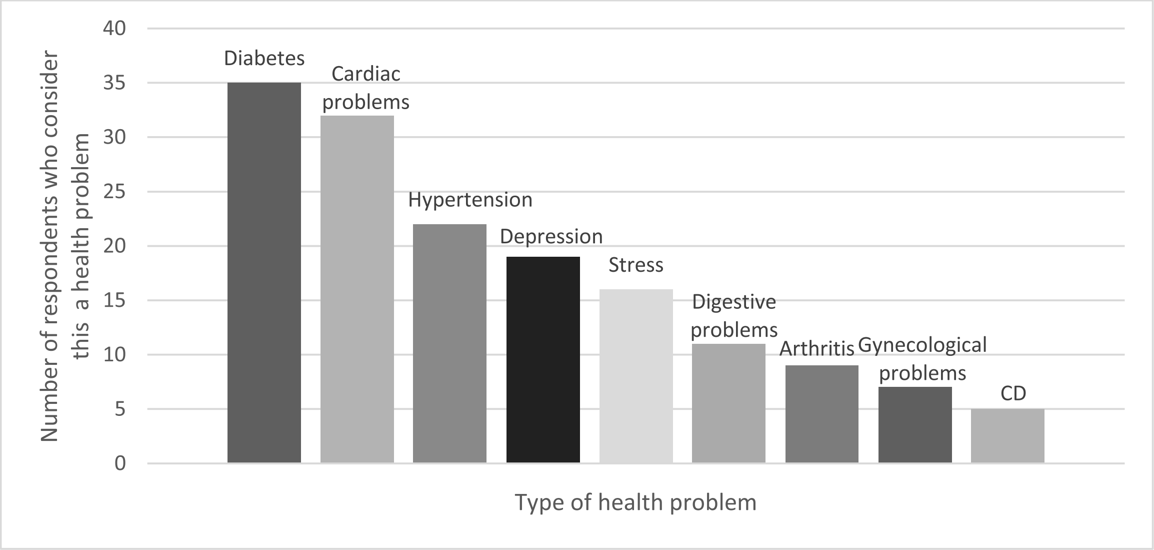

Fig. 3. Perceptions of prevalent health problems among participants in the survey ($n = 132$).

5. Discussion

It was an achievement of the Patients' Association and the Geneva University Hospital that a community screening was held in Geneva outside of hospital space. This was key in order to make Chagas testing accessible to a community that feels very suspicious of official spaces, (given their undocumented status), and for whom Sunday is the only day off (given the prevalence of employment in care and domestic work). The patients' association had worked relentlessly with the staff at the Geneva University Hospital in order to be able to organize a screening event in the community. The importance of this in a context of precarious undocumented migration is central, given that many undocumented migrants mistrusted official institutions (including healthcare) for fear of denunciation. Therefore, bringing the Chagas screening option into the community space, in an easily accessible venue close to the main train station, and on a Sunday when they were given a free day, was a great step towards overcoming barriers of access to screening. However, unfortunately, the loss of patients between the initial diagnosis, the confirmatory blood test and further clinical follow up has been of 85 %, for the same reasons that people do not go to the hospital for screening in the first place (undocumented status, language barriers, lack of time, lack of prioritization of Chagas). In Spain Mundo Sano aims

Table 2

Thematic categories from the semi-structured interviews ($n = 8$).

Code/Themes	Definition	Purpose/ Meaning	In vivo description
Precarious migration: - Undocumented status - Fear of deportation - Lack of health insurance	Participants describe their migratory experiences and trajectory	Identify the stress factors caused by irregular migratory status	"Sometimes they ask too many questions at the hospital, I'm worried because I don't have papers. I am scared that the police will take me" (Female, 47 years old).
Family: - Unified/separate family groups - Number of children, their location and their age	Participants describe their social context	Identify the social and kinship networks that define participants' experiences in Geneva	"My daughter is married and has papers (residency permit). She wants to stay here (Geneva) because she has her little girl. I want to go back (to Bolivia)" (Female, 49). "I worry about my children, they are in Bolivia. If I lose my job here I can not send money to them" (Female, 47). "The medication is expensive. If I have to pay for it, I would rather send money to my family. They say it doesn't really cure you anyways" (Female, 49).
Labour: - Labour relations with employer - Regular/ irregular employment status	Participants describe their educational levels and labour conditions	Identify levels of personal development, satisfaction and capacity for economic wellbeing	"I was brought to Geneva by my Spanish employer, as a nanny for the children. They pay me according to Spanish salaries, and it is cheaper for them, but I am ok because I wanted to leave Spain for personal reasons" (Female, 45). "I am thankful about my employer. You hear horrible stories about mean people who do not pay properly, or don't give their employees free time. My family is nice with me, I don't complain." (Female, 49). "Good nutrition is important to stay healthy, but I'm too busy to cook properly or exercise. Sometimes I dance around just to move the body, you know?" (Female, 45). "I have lost so much weight since I came to Switzerland. Meat is expensive and work hours are long and hard" (Female, 49). "I'm not sure I want to take the medication (for Chagas). If it stops me from working I will have to stop taking it" (Female, 47).
Language: (French/Italian/ German) vs Spanish	Proficiency in locally used language	Determine the level of autonomy that language proficiency allows in the development of labour and personal relations	"I wish to return to Spain one day, where I understand the language, and I understand when doctors talk to me" (Female, 42).
Local structures: - HUG (doctors) - CAMSCO (social workers) - Pharmacy	Participants identify and describe their relations with local bureaucratic and organizational structures	Understand the degree of structural violence and the ability of participant to navigate local institutions. Determine participants' views of local institutions	"I try not to take too many medications, in the Portuguese shops I can find some herbs that my grandmother used to take for some ailments" (Female, 42). "I thank God I am in good health" (Female, 49, domestic service). "Sometimes you feel that doctors are experimenting on you, I don't want to get tested in Switzerland because I don't know what they are saying" (Female, 42). "The doctor is nice, he calls me to make sure I'm OK, and he helped me so that CAMSCO doesn't charge me" (Female, 47).
Social Networks: - Facebook - Local community - Digital information support - Religious groups - Cultural activities	Participants describe their social connections developed in Geneva (and other locations in Europe) beyond their immediate family.	Identify the existence/lack-there-of social support structures in Geneva that can assist in the management of health and wellbeing in	"My employers are nice because they paid for my visit to Geneva so I can see my Bolivian friends. There are no Bolivians in Aarau (a Canton in the Swiss-German part) and

(continued on next page)

Table 2 (*continued*)

Code/Themes	Definition	Purpose/ Meaning	In vivo description
		precarious circumstances.	I feel very lonely. If it weren't for the girls (the children she takes care of) I would leave" (Female, 49). "I don't really participate in community events. Many people are not nice, why would I want to spend time with them?" (Female, 45). "Social life is important, I join community events to make new friends" (Female, 35). "I don't go to community activities because it's a matter of social class. I don't want to mix with them…" (Male, 48).

to address this major barrier by facilitating a community worker to follow up on the patients between screening and treatment and is conducting a project to evaluate the impact of this action in reducing the loss of patients from screening to treatment or regular control.

Community screening events of the type held in Geneva during this research have also been carried out in other locations in Europe, such as Spain (Navarro et al., 2012; Blasco-Hernández et al., 2016), Germany (Navarro et al., 2017), and Italy (Di Girolamo et al., 2016). These have the objective of eliminating barriers of access to diagnosis in populations that are often either geographically marginalised (with limited access to hospitals), or have difficult employment conditions that complicate their visit to hospitals during working hours. Community events held on weekends in easily accessible neighbourhoods aim to enable diagnosis and access to care. However, in Switzerland, people attending the community event were not all interested in a Chagas screening, and declared sometimes being very reluctant to consult at the Hospital, given their fear of deportation. There is in fact no risk of deportation (given the stringent levels of data protection), but the divergence may be due to preconceived ideas, or extrapolatory fears from other experiences. This was also reflected in the lower level of questionnaires answered in relation to screening tests. People were very suspicious of providing details about their personal life, or expressed the desire to just have fun at the party. Those who accepted to being interviewed at a later appointment were much more willing to provide information, after establishing a rapport with the team anthropologist.

Community screening events complement traditional points of access into the health care system, and bring together different organizations working on CD so that people understand the services and support groups available in their community. The main objective of the event was to destigmatize CD and disseminate tailored information in a culturally-sensitive way. The underlying intention was to address the structural determinants of health for precarious migrants who were often suspicious of institutional clinical settings and had oppressive working conditions that did not enable them to take time off work to attend to their health. Each year we encountered participants who had never been screened and still chose not to take the test even when it was free and accessible. This highlighted the resistance to CD awareness, and people's view that "it is better not to know," a perception closely linked to the historic misconception that nothing can be done about CD.

Contextualizing Chagas within a broader concern with preventative health was the point of the exploratory measure to offer other health tests during the community screening event in 2017. Participants were extremely receptive to this tactic and were eager to get their blood pressure measured (as many of them reported suffering from hypertension). The increase in people taking the Chagas test in 2017 (66 people, against 39 in 2016 and 49 in 2018) could be a result of this strategy. The presence of cardiovascular and metabolic risk factors within the target population supports the idea of combining Chagas disease testing with other more general preventative health measures.

In the third year (2018) the team decided not to repeat this, despite its success as incentive to increase CD screening, because people were getting their blood pressure and sugar levels tested after eating, drinking and dancing and the tests gave erratic results. However, the brief exploratory tactic carried out in 2017 showed that while Chagas does not constitute a main health concern, people are nonetheless health-conscious and will take the necessary precautions to take care of their health regarding the medical conditions they deem important. Furthermore, by placing Chagas disease strategies within other more general health concerns, it may be possible to address the low priority of Chagas for both patients and medical practitioners.

The interviews and surveys revealed child-bearing age women's openness to Chagas testing and treatment at the realization that it can affect their future children. Young mothers then bring in the rest of their family to get tested once they are diagnosed as positive. This highlights the importance of understanding kinship relations in the development of Chagas 'test and treat' strategies (Zulantay et al., 2013). In Geneva, Bolivian migration is predominantly female, therefore there is an over representation of women in the sample, and this places men in a more silenced position. Men are sometimes described by women of the Bolivian community as neglecting their health for not wanting to appear weak. Furthermore, as Heckert (Heckert, 2017) has shown in research on HIV in Santa Cruz, the construction of masculinities in Bolivia impacts on how health is perceived and addressed by both people and health practitioners. In campaigns around Chagas, in the context of a predominantly female undocumented and precarious migration, this research should serve as caution not to reproduce these tendencies within Chagas policies.

A crucial finding of this project is that family (its proximity and integrity) in the context of Bolivian migration in Geneva is a key determinant of health and how it is prioritised by migrants. Despite people's awareness of the importance of preventative health, and of a broad understanding of health and wellbeing including social, physical and psychological factors, the absence of family (specifically children) reverts all health priorities and positions employment as the only relevant activity that grants purpose to the migratory project. Health priorities are subordinated to the main purpose of migration, ie. to send money to family in Bolivia which confirms previous studies (Benach et al., 2011).

When viewing Chagas through the lens of global health, a multidisciplinary approach is crucial, particularly a focus on global migration movements (Chapter 2 – Migration and migrants: A global overview 2018) (Flynn and Wickramage, 2017), which are social and political phenomena that escape the constraints of national borders and are determined not only by social factors but more importantly by macro structural processes. Undocumented migration is not equally precarious throughout Europe. In Spain with a universal health coverage and the common language, access to health is easier, but lack of public transport to public hospitals can become a barrier to access (Pérez-Ayala et al., 2011; Essadek et al., 2017). Therefore, it is important to take each non-endemic location in its particularities, and contextualize it with the experiences of other European countries in order to learn from, but not replicate, these experiences.

Furthermore, Forsyth (Forsyth, 2015) has argued that in the case of Chagas in Bolivia, different explanatory models are employed – structural and experiential – to understand how people manage the disease. This is relevant in migratory contexts where structural precarity and experiential alienation are key determinants of how people manage their health. Therefore, in the development of Chagas programs in Geneva, it is necessary to take into account multiple issues, which pertain to structural, experiential and socio-cultural explanatory models of health. People's undocumented status determines their health-seeking behaviour as they are fearful of official institutions and of providing their personal details. Furthermore, even though the hospital is easily accessible through public transport, reducing barriers of access to care present in other European locations such as Spain, the office hours of doctors and social workers clash with patients' inflexible working conditions making it difficult for them to access consultations.

People's personal situations also affect their health-seeking behaviour. Those who have disaggregated families (that is, most of their children and spouse/parents living in Bolivia) are less likely to give Chagas a high priority. Conversely, people who have managed to bring their children to Europe, or have started new young families in Geneva have a more proactive attitude towards their health and are more likely to bring their family members to get Chagas tests.

Lastly, while socio-cultural ties can sometimes help contain people in precarious migratory situations, in Geneva, the 'Bolivian community' is not a unified entity. It is important to understand that it can not be relied upon as the only actor to support state-run programs because it often reproduces exclusions and stereotypes of Chagas, poverty and indigeneity.

6. Limitations

There are multiple limitations to this study that were given by the particular circumstances of the research subjects. Firstly, the research project was designed to be carried out during the Chagas Day events, which were community-organized and had as their main intention providing entertainment to (particularly) the Bolivian community, and included the information and screening as a secondary element. That is, many people attended the event because it was a Bolivian gathering and not because they were interested in Chagas.

Secondly, because it was organized by the AsswisChagas patients association, which represented mostly the Bolivian community, the participants tended to be the same each year, which also explains the reduced interest in the questionnaires by the third year, as participants had completed them in previous events. This also generates a small sample of research subjects and conditions the experiences to a single community.

Thirdly, and related to the previous point, the predominance of a single community also resulted in the exclusion of other communities (Bolivians from different regions, and other Latin Americans) that did not feel represented within this group. This is a potential of all patients'associations, where animosities between people and regional enmities can become enmeshed with the work of the association.

Fourthly, the third year the research team did not count with as many volunteers in the process of completing the questionnaires, and this was evident in the reduced number of questionnaires completed.

Lastly, but not exhaustively, the testing outside the hospital raised multiple issues, begging with the large number of people lost, the inability to extract blood for confirmatory tests (which is not the case in other locations that do out-of-hospital screenings, such as in Spain), and the less-than-ideal context of conducting medical examinations during a party where people dance, eat fatty, friend food and drink alcohol. However, in spite of these complications, the possibility of providing access to health care outside hospital settings has more benefits than setbacks.

7. Conclusion

The situation of precarity given by an undocumented status in Switzerland is complicated by a complex health care system. Additionally, the coexistence of three national languages (French, German and Italian) and a public discourse somewhat hostile to foreigners in general makes Switzerland a difficult host country for (undocumented) migrants (See https://www.mipex.eu/switzerland). The objective of this paper has been to raise issues about CD that reveal the importance of thinking about precarity and migration in relation to health. The case of CD, as a neglected tropical disease in a non-endemic country, opens a broader discussion about the importance of wellbeing in the construction of health in migrant settings. In the context of Bolivian undocumented migrants in Geneva, the disaggregation of family and the subordination of life to the need to work subverts all other elements of a holistic notion of health (as wellbeing). What is a neglected condition in the first place, becomes exposed to additional levels of neglect determined by social conditions (undocumented status, lack of social support, hostile host society, lack of understanding of local language, oppressive employment circumstances, etc.). The case of Chagas in non-endemic contexts illustrates the complexities of health in migration, and enables us to consider more creative ways of addressing complex social and medical issues.

Declaration of competing interest

The authors 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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