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Perceptions of the population and health professionals regarding visceral leishmaniasis

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Abstract *Based on theoretical qualitative research reference methodology, this study sought to investigate the perception of visceral leishmaniasis (VL) by social actors directly involved in the prevention and control of the disease. Thirty-eight semi-structured interviews were conducted with residents, focus groups were staged with 18 health workers in an endemic VL area and depositions were collected, which after being processed by content analysis revealed shortcomings and challenges. The population associated VL with dogs, acknowledged their co-responsibility in tackling the disease and demanded information. Health workers identified environmental sanitation as an essential factor for VL prevention. Among the shortcomings, the lack of information about the disease and culpability of the individual because of non-adherence to prevention measures were observed, especially environmental management. Probably, approaches emphasizing the role of the environment as a health promotion agent and the timely definition of specific environmental measures against VL, constitute a prospect for overcoming these shortcomings. The consensus is that the main challenge for enhancing the prevention and control might be the participatory and dialogical construction of these approaches between health professionals and the population.*

Key words *Visceral leishmaniasis, Prevention and control*

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Introduction

Visceral Leishmaniasis (VL), characterized by the World Health Organization (WHO) as a neglected disease, represents an enormous public health problem in Brazil, where 70% of all registered cases in South America are concentrated[1]. This disease is widely disseminated within Brazil, with cases registered in the five main regions of the country and in twenty-one Federal States[2].

During the period between 1990 and 2012, the average incidence of this disease in Brazil, was equal to 1.8 cases/100.000 inhabitants (with a standard deviation equal to 0.4)[3]. Even though it was noted that the occurrence of these cases appeared to be stabilized as from 2004, with reduced numbers in the Northeastern region, one of the areas normally most affected, VL has already spread into the Northern, Southeastern and Mid-West regions of the country. In particular, this is the case of the State of Minas Gerais, which, in 1990-2001, had an average incidence of 0.8 cases/100,000 inhabitants (a standard deviation equal to 0.3); however, during the period from 2001-2012, these indicators rose to 2.3 cases /100,000 inhabitants (a standard deviation equal to 0.5)[4].

VL control in Brazil is focused on early diagnosis and treatment, reduction of the population of vectors and euthanasia of dogs that have been given a positive serological and/or parasitological diagnosis[5]. Choosing these strategies is based on the ecological and epidemiological fact that this disease is particularly complex, involving a vector that has a marked capacity to adapt to different environments, including urban areas, which facilitates the constant reactivation of the transmission cycle[6-9]. In the case of urban areas, this aspect is further enhanced by the continued presence of canine hosts, either through the prolonged condition of infection, irrespective of clinical symptomatology, or rapid replacement after euthanasia[10,11].

These multiple ecological and epidemiological factors, associated with disorganized urban occupation and other underlying issues involved in this process, such as insalubrious living conditions and lack of basic sanitation, as well as difficulties in access to and in the organization of health services, contribute towards establishing these heterogeneous scenarios for the transmission of VL[12,13]. In addition, with the implementation of the Brazilian Unified Health System, the management and operationalization of mechanisms for VL control and surveillance are now the responsibility of each municipality, which means that VL prevention and control activities have to be adapted to local conditions, which poses a challenge for the country's health care services.

Understanding more about the disease, going beyond its clinical and epidemiological characteristics and taking into account the views of the social actors directly involved in VL prevention and control, can help to ensure that these actions are more effective. This is the path recommended by authors like Lasker and Weiss[14] and Israel et al[15], who defend the idea that the local population should be involved in resolving collective problems and not only included as the scope of concern, or the source of data or the target of efforts to resolve these problems. Approaches such as these, which are participative and dialogic, find established theoretical support, especially in the area of health education, based on the Paulo Freire philosophical perspective[16,17].

The WHO, in its report of the last VL meeting held by specialists in 2010, share this view, highlighting the fact that social mobilization, in the sense of changing the behavior of the population, requires efficient communication strategies, with emphasis on permanent dialogue between the public and health professionals[10].

This same premise guided the development of this study, the aim of which is to understand the perception that health agents and the general public have about actions to prevent and control VL, seeking also to identify the lacunas, challenges and perspectives involved.

Methodology

This study was developed between 2011 and 2014, in one of the municipalities belonging to the Belo Horizonte Metropolitan Region (BHMR), that, according to Ministry of Health reference criteria, has been classified as an intense VL transmission area. That is to say, over the last five years, this region has presented an average number of cases greater or equal to 4.4[5]. According to data made available by the Municipal Health Department, one hundred and thirty cases of human VL were registered within the municipality during the period from 2000 and 2010.

With a population of 637,961 inhabitants[18], the municipal health system is organized into seven regional administrations. During the period when this study was conducted, the municipality had four-hundred and forty-six community health workers (CHW) responsible for covering 40% of the population[3].

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Two regions were selected for the purpose of this study, named A and B. The reason these two regions were included was to observe heterogenic contexts related to the number of human cases registered between 2000 and 2010, in that Region A registered ten cases during this period, while Region B had thirty-seven cases.

The study was divided into two sections and, in both, the methodological and theoretical procedures were based on the assumptions of Qualitative Research related to the meaning and purpose of actions in their social structure contexts[19]. In the first stage, semi-structured interviews were conducted with local residents living in both regions and, in the second stage focus groups were conducted with health professionals.

Neighborhoods with the highest number of human VL cases notified between 2000 and 2010 were included in each regional group. Households selected for the survey were used as a basis to recruit participants, the total number of which was defined by using theoretical saturation criterion[19,20]. Thus, once it was seen that the inclusion of new individuals would not produce new elements to enhance or provide more in-depth theorizations, the process of gathering information was brought to a close. The interviews, which were conducted at the homes of the interviewees, dealt with perceptions and prevention and control of VL.

The findings obtained through an analysis of the interviews served as a guide to prepare the outline for the focus group. In this respect, the space/environment category was included in the discussions conducted in the focus group, which involved, more specifically, the relationship between the environment and VL occurrence/prevention/control. Two focus groups were conducted, one with community health workers (CHW) and the other with endemic disease combat agents (EDCA), which both belong to the same Basic Unit, located in Region B, which registered the greatest number of human VL cases during the period between 2000 and 2010. The municipal Primary Healthcare coordination indicated these Basic Units on the understanding that these health professional would be more readily available and have greater interest in taking part in the focus groups, participation on which being entirely on a voluntary basis.

All statements recorded were transcribed in full and processed by means of Content Analysis[21], based on two operational categories: VL prevention and control, so as to include the views of all social actors involved, namely members of the public and health agents, as regards how these actions affect their daily life and work.

The research protocol was approved by the Ethics and Research Committee at the René Rachou Research Center. All participants signed an Informed Consent Form (ICF).

Results

Interviews with local inhabitants of the regions

Twenty-four interviews were conducted in Region A, involving twenty-two women (91.7%) and two men (8.3%), with an average age of 45.6 years (with ages varying between twenty-two and eighty-five) who could read and write (95.8%). The average family income of seventeen of the interviewees (85%) who replied to this question was equal to 5.1 times the national minimum salary.

In Region B, which is characterized by the greatest number of notified cases of human VL, a total of thirteen interviews were conducted. Ten women (76.9%) and three men (23.1%) took part in this survey, with an average age equal to 47.9 years (between twenty-nine and seventy-four years old) who could read and write (100%). The average family income of six (46.1%) of those interviewed who responded to this question was equal to 4.5 times the minimum salary.

In both regions, participants had spent an average period of seventeen years living in the same home, which shows that those interviewed were long-term residents in these areas.

Perceptions of the interviewees on the prevention and control of VL

In general, the analysis revealed that the residents interviewed still had certain doubts about certain practices related to the prevention, control, transmission, signs and symptoms of VL. For example, we identified how VL was seen as a disease associated with dogs, in that many interviewees said they thought a dog's bite was responsible for, and often the only way of transmitting, this disease either through direct contact, with a bite, or through indirect contact, for instance, with secretions, urine and feces: *Ah, yes I believe that … if an infected animal bites a person… that is one way the disease can be transmitted.*

Ensuring cleanliness and hygiene was, repeatedly, cited by the interviewees as being the best method to employ to prevent leishmaniasis: …. *I am sure that it's a lot to do with cleanliness, right? You have to make sure you keep everything clean,*

maintain hygiene …? (Region B). In addition, among those interviewees who mentioned the role of the vector in the VL transmission cycle, it was clear that they associated this with dengue fever and, consequently, with measures used to control and prevent this particular disease: *Yes, I know … we have to make sure we don't have any stagnant water, right? This is what we have been doing in the dengue prevention campaign. We keep all receptacles clean...I think that's it* (Region A).

Interviews with people who had previous experience of VL, either from those close to them who had had the disease, which was less common, or via their own dogs or those of their neighbors who got the disease, which occurred more often, were longer and provided more details about the situations they had experienced and as regards their queries about the issues involved. In this respect, we should mention the fact that certain requests were made during various interviews, as regards finding a solution to the problems experienced in the daily life of the interviewees, such as finding rodents in their homes, stray dogs in the streets, the need for tree pruning, and so on: [...] *you see lots of dogs wandering through the streets in every neighborhood you visit* [...] *I'm not sure who is responsible, if it is the local city hall, the public prosecutor's office, the ministry of health, who knows anyway. However, someone should take measures to resolve this situation* (Region A).

Focus group with health professionals

Six EDCA took part in this stage of the study, including five women (83.3%) and one man (16.7%) with an average age equal to 36.8 years (varying between twenty-three and fifty-six years of age), all of whom had completed secondary education and had worked as a CHW in the region being studied for a period equal to seven years.

Thirteen women took part in the focus group involving EDCA, with an average age equal to 29.6 years old (varying from twenty-two to forty-five years old), all of whom had completed secondary education and four of whom (30.8%) were taking higher education courses. They had spent an average period of 5.8 years working as CHW in the region being studied.

Perceptions of health professionals regarding VL prevention and control

As was the case when analyzing interviews conducted with local residents, it was found that health professionals also mentioned their concerns regarding VL and also made requests for relevant training in the area.

With respect to actions for the prevention and control of the disease, it was clear that the actions taken by EDCA in combating dengue play a central role. Professional health workers mentioned that actions taken in relation to VL (collecting blood samples and the chemical treatment of the environment) come under the responsibility of four EDCA: *Just to give you an idea, we have one team of four responsible for covering leishmaniasis in the entire B Region.*

The EDCA generally show greater familiarity with VL and the measures used for its prevention and control than the CHW, which is to be expected, due to the different responsibilities of these professional groups.

Based on an analysis of the statements taken, it became clear that the environment is given two apparently unrelated meanings, one that is closer to or 'linked' to nature and the other related to the place where a person lives/works: *Nature … our homes; physical space;* which, in some way, may contribute towards the understanding that a relationship exists between the population, its living conditions and the environment which surrounds it. Nevertheless, it was found that, especially among the EDCA, there was a feeling that individuals were responsible or to blame for not taking the necessary actions for the prevention and control of this disease. The way these professionals labelled the population in derogatory terms was a constant issue, and is corroborated by the findings of Fraga[22] when he analyzed the educational practices conducted within a Regional Health zoonosis environment control district in Belo Horizonte, State of Minas Gerais.

Among the EDCA, it was possible to find a more comprehensive attitude towards the general public, probably because of the type of contact they have with local residents and the way they can identify with their living conditions and, very often, the difficulties that the general public faces. Nevertheless, these professionals do not deal with diseases such as VL, at least not in a systematic sense.

Discussion

These findings, which showed that residents had queries about certain aspects of the epidemiological components of the disease, its control and prevention, were also identified by Borges[23] in Belo Horizonte/MG; Luz et al.[24] in the BHMR and by Gama et al.[25] in the State of Maranhão.

The fact that most people believe that VL is solely transmitted by dogs can especially hamper the understanding that most people have and measures they take to prevent this disease as regards environmental management, which aims to change local conditions, to prevent the formation of immature vector breeding sites[5]. As highlighted by Alexander and Malori[26], their small size, silent flight and the fact that they do not hover, make it difficult for people to identify a vector, even in endemic areas, therefore most of the population may be largely unaware of the presence of phlebotomine sandflies (Diptera: Psychodidade) and their role in the epidemiology of the disease.

The fact that the local residents who were interviewed used dengue as a benchmark for information about vector-transmitted diseases such as leishmaniasis, may well be due to the fact that greater emphasis is given to the former, as can be seen in the concentrated activities of the ECDA in combating dengue, which involve intense and visible campaigns, with a regular cycle of activities carried out every two months and which involve home inspections to control vector focus points, as well as explaining the impact of mortality rate indicators for this disease. In addition, dengue is highly visible in the media, which, as discussed by Reis[27], generates a "storm of information" in the public mind as regards this disease.

The way pathogenic vectors have adapted to urban areas and domestic environments, is one aspect that should be considered. Due to the complexity of transmission, one of the essential measures of prevention is territorial organization, where residents can implement significant actions in conjunction with health professionals. It is important that residents and health professions take charge of the cycle of this disease so that, together, they can find ways to take the most effect and sustainable actions within these territorial areas. The association between both diseases (dengue and leishmaniasis) and references made to other problems experienced in daily life (stray dogs, rodents, tree pruning) illustrate both the cultural construction of the disease, bringing together ideas and practices that have been elaborated/re-elaborated by individuals and groups over a lifetime[28,29], as well as the evaluation of possibly more urgent and complicated issues experienced by people in their daily lives. In fact, this last aspect shows the need to reflect on the adequacy of health practices as regards maintaining a balance between the priorities of health teams/professionals and those of the community, which is a weak point that is often mentioned in the literature[30]. Specifically, in respect to VL, the document prepared during the last WHO meeting of specialists, emphasized that the aims of a prevention and control program have to be clear and in keeping with day-to-day requirements so that these make sense to the public, as well as showing that the prevention and control programs designed exclusively for a single disease have little effect[10].

In this respect, environmental management measures, such as cleaning yards, the correct elimination of solid organic waste and sources of humidity, not allowing domestic animals inside the house, and so on, can help avoid or reduce the proliferation, not only of the VL[5] vector, but also of other diseases, such as dengue. In addition, these measures will also help prevent and control other non-vector-borne transmitted diseases, such as leptospirosis, for instance.

Environmental hygiene was repeatedly mentioned by the interviewees, probably because this refers to all that is healthy and part of daily life, especially as the relationship between hygiene and health is something that is impressed on everyone from an early age; we should brush our teeth, wash our hands, and so on[31]. The perception that hygiene, not only in a personal sense but also on an environmental level, is a means of preventing diseases was identified in a study conducted by Roma et al.[32], in a region in the outskirts of Marília, State of São Paulo.

Even though the impact that methods of hygiene have on the incidence of VL in humans and dogs has not yet been scientifically proven, eliminating the favorite micro habitats where vectors develop (such as fissures and cracks in the walls, damp earth and shaded areas) is considered to be one of the few examples of effective measures to combat phlebotominae not involving the use of insecticides[26,31].

Apart from queries related to the epidemiological aspects of VL control/prevention, the statements made by both residents and health professionals indicate the complexity of existing environmental problems in urban areas and the need to "find someone to blame' and to hold responsible for the misfortunes experienced in daily life, as well as 'a party responsible for resolving these issues.'

In order to understand and to deal with this complex situation, we feel it is important to start with the concept of space proposed by Milton Santos, which he defines as: "[...] an inseparable group of components of a system of natural or manufactured objects and systems of actions, deliberate or otherwise"[33]. In this sense, a constructed natural environment is historic, temporal and mediated by technique, and is differentiated by a greater or lesser input of science, technology and

information, in that these differences are the way that cities are able to resist this same rationality while, at the same time, present a portrait of the diversity of social classes, of differences in income and of cultural models. In addition, a constructed environment represents a heritage that cannot be ignored and is one that, depending on the way it is remodeled and transformed, determines the actions that will be imposed upon it[33]. Thus, the individual and society are joint partners in the historic construction of space and are heirs, not only of the space constructed, but also, and more importantly, of the different problems and issues that result from the appropriation of space and which are materialized, for instance, in that which causes sickness and death.

The approach that tries to make individuals (residents) feel responsible and to blame for not performing recommended actions to prevent and control disease can be analyzed based on an understanding that the process to incorporate knowledge of a scientific technique, which is inherent in the training of a professional and, as debated by Fraga[22] and Oliveira[34], leads to the deconstruction of the community identity of CHW and EDCA and the construction of another which incorporates subjectivity, which, according to Rocha et al.[35] (re)affirm "non-egalitarian relations in the interrelated scope of daily relationships," legitimizing a professional practice that is, to a certain degree, one of surveillance. If, on the one hand, this deconstruction process and distancing from a community identity make it possible to "see" the environment from an investigative standpoint, making it possible to identify situations of risk, on the other hand, it may also elicit prescriptive and punitive attitudes on the part of these professionals.

The afore-mentioned attitude may be thought of as a paradigm of risk, which – as from the 1970s – became a main explicative (and predictive) theoretical benchmark of the unwelcome events that occur in the lives of the population, such as sickness and death, that also created refined techniques of risk analysis. From an anthropological viewpoint, Mary Douglas[36] discusses the purist approach adopted in contemporary analyses about perceptions of risk that are based on the assumption that this is an individual and rational choice, disregarding the influence of social factors, of inter-subjectivity or the construction of a consensus in decisions made by individuals. This supposed objectivity is incorporated and constructs a 'language of risk' that aims to be purely scientific. Thus, scientific language transfers the responsibility to individuals for making decisions about exposure and danger, eliminating the need for a consensus of opinion. In addition, Douglas[36,37] indicates that objectivity that one aims to give to a perception of danger in the present precludes the possibility of understanding this as being part of a process that is representative of guilt, which helps to maintain an ideal order of society, to the extent that dangers threaten those who transgress. According to this author, the cultural systems of constructing guilt in a society organize how and what information will be used in the cognitive risk perception process[36]. In this sense, in order that new information is accepted as being truthful it must be faithful to the particular political organization of the individual/group concerned; the rest will be treated with suspicion, deliberately censured or unconsciously ignored[36].

If we consider, therefore, that risk perception is the result of a cognitive process where guilt and atonement are present, and where cultural elements guide choices, recognizing insalubrious spaces may not just follow methods of hygiene resulting from traditional medical knowledge. Thus, blaming local residents for not following guidelines that organize and establish these areas in order to make them healthier is not only normative, but also perverse, since it is more commonly and effectively implemented, taking into account basic health care actions, in peripheral neighborhoods, where sectors of the community, that have always lived in areas that are habitually built in unhealthy environments, are usually settled. In this way, the responsibility for creating conditions that lead to disease/death is transferred to the individual, which provides objectivity, scientific discourse, to make decisions about what risk(s) to take and how to transform these spaces, which effectively expunges the historical records of these events in order to understand and transform them.

Using an approach that is based on the environment as a historically constructed space and promotor of health, for the prevention and control of VL, as well as other endemic diseases that require environmental interventions, instead of employing specifically prescribed actions for one or several diseases, may help the public recognize "their problems" in issues that are covered by the proposed prevention and control measures, and ensure that these actions will eventually be seen to "make sense." This "view" is supported by the precepts of health promotion that embrace a broader concept of the health-sickness process and its causes, and propose the articulation of technical and popular knowledge in conjunction

with the mobilization of institutional, community and public and private resources to face and resolve same[38].

The major challenge is that emerges is the operationalization of these concepts in the daily and working life of the population. In this sense, the reorganization of the work process based on the main health surveillance, territorial guidelines and health problems and practices seem to offer a real possibility in overcoming these issues. Adopting territoriality as a guiding principle for health practices makes it possible to attain a wider view of the environment, in both a geographic as well as social and political sense, and will thereby help promote actions that are planned and impartial to meet existing problems and health requirements[30].

Final Considerations

The prerogative of qualitative research, to "construct new approaches, review and recreate new concepts and categories during the investigation"[19] was enriching and made it possible to include in this study a discussion about the environment and the need to view this from a broader perspective.

Some limitations should be considered as, for example, the fact that only health professionals from only one BHU were included in the study. By including other professionals, who have experience of different situations, even if they are from the same municipal region, would greatly enhance our understanding of local realities.

From the analysis of the statements given it was possible to see that both the public and professionals still raise many queries about VL, as well as about the issue of blaming individuals for not complying with required measures, above all those involving environmental management, which in the regions studied are seen as failings in the prevention and control of VL. As discussed in the text of this article, approaches that highlight the role that the environment plays as a promoter of health, rather than a specific provision for environmental measures to combat VL, represent ways to overcome the lacunas encountered. The situation presents a clear challenge to establish participative dialogue, involving both health professionals and members of the general public, to discuss these different approaches.

Collaborators

RF Carmo, ZMP da Luz and PD Bevilacqua participated equally in all stages of the elaboration of this article.

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