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"You will ask me: which am I?": the clinical practice of Chagas as a latent risk

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Abstract *Drawing on observation-based ethnography, interviews of health personnel and document review, this article describes and examines how, in clinical handling of Chagas disease, infection is treated as latent risk. It suggests that how this risk is managed has enabled a clinical practice to be conducted among people classified as at the indeterminate stage, by adding a dimension of possibility (Is it going to happen?) and potentiality (When and where?). This allows measures to be taken, including administration of medication or permanent monitoring. The reification of latent risk as a phenomenon that is manageable through a process of medicalisation engages, in turn, with other conceptions and specific experiences of risk among the affected groups. Framing the clinical practices deployed to address this risk as objects of study is a first step towards being able to describe and include them concretely in health system organisation.*

Key words *Risk, Chagas disease, Medical practice, Biomedicine, Public health*

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Introduction

In modern societies, science and technique are the preeminent social mechanisms through which the uncertain future is harnessed to the action of humankind. The notion of risk is one of the central constructs on the basis which discourses and practices relating to the body and health are articulated[1]. In present-day explanatory models, risk relates an imminent danger of contracting or developing a disease or health problem[2] and its purpose is the development of models and scenarios to guide action and enable measures to be taken to manage an uncertain future[3].

Historically, interventions directed to Chagas disease have focussed on controlling the vector insect and blood banks[4-6]. In recent decades, however, a series of movements in the biomedical field have led to a new scientific and technical configuration with regard to Chagas, framing the disease in a new model of risk in which diagnosis and treatment have taken on unprecedented importance. The redefinition of Chagas as a disease caused primarily by the action and persistence of *Tripanosoma cruzi* has played an important role in this change. *Zabala[6] argued that the 1980s marked a turning point in relations between the production of scientific knowledge and expectations for intervention regarding Chagas disease, in that they saw the emergence of a logic proper to the promotion of basic research as a legitimate intervention strategy. The new scenario paved the way for new conceptual paradigms and technical tools that enabled old questions to be revisited from new approaches. Until then, the autoimmunity paradigm – according to which Chagas is a parasitic disease at the acute stage and an autoimmune disease at the chronic stage – had been hegemonic in response to the eternal question of the mechanisms by which a percentage of people with the infection develop pathologies. From the mid-1990s onwards, however, the idea began to gain force that, despite the existence of autoimmune components, the disease is ultimately caused by the action and persistence of the parasite[7,8].*

Building on that redefinition, latent risk[9] is conceived here from a particular feature of the individual: an external agent – the parasite – enters the body, setting the carrier person to develop a disease that has not yet appeared or to die. While it is possible to find references to "risk of heart disease and sudden death" in the scientific literature since the 1990s, what is really novel about the notion of latent risk is precisely the discursive and practical potentialities granted it within the framework of the new scientific and technical configuration. By converting it into a clinical entity, it is possible to take actions no longer directed to preventing infection or to providing care for people who have already developed a pathology, but rather that include the majority classified as chronic and potentially ill, which to date had been relegated from clinical treatment.

Starting from an ethnography that included document analysis and literature review, participant observation and interviews of health personnel, this article (part of a more extensive doctoral thesis) explores in depth the biomedical discourses and practices relating to this new notion of risk, here termed latent risk[9].

Methods

The field work took place in Catalonia from early 2014 to mid-2016 in parallel processes of data collection and analysis. The ethnography was based on three main techniques[10] – review of the scientific and technical literature (including a non-systematic review of publications on risk and Chagas), participant observation and in-depth, semi-structured interviews – as described in a previous publication[11].

The literature analysis and interpretation was essential as written culture[12]. On the one hand, that analysis centred on learning about medical models relating to Chagas disease and how they have evolved over time in scientific and technical production. On the other hand, a non-systematic review of the literature relating to risk in the Chagas field was conducted by means of an advanced search of PubMed ("Chagas", "trypanosoma cruzi", "T.cruzi" (Limit to human) AND "risk") among articles accessible from 1961 to date.

The observation focussed on contrasting the information compiled from different sources, as well as describing the practices related to the transformation of a population risk into a clinical entity and how that risk is managed in clinical practice. The author was present as an observer accompanying the medical team at 42 clinical visits to different patients, most of them women. She was also present at two other appointments accompanying five patients whom she monitored for longer, so as to gain a closer understanding of the risk as potentiality, as described in the results. The observation also took place at international scientific congresses and workshops, with a view to detecting the key scientific and technical discussions and controversies and how they were evolving.

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On the other hand, the author interviewed five clinicians and researchers and two technicians in order to explore in depth what was detected during observation or in the scientific literature, as well as to triangulate the information obtained. The interviewees were selected intentionally in line with the research objectives. The interviews, which were conducted at the workplace (except for one, by Skype), lasted from one and a half to two hours and were recorded. The informants' names were coded and replaced by pseudonyms. The notes from the field diary and the interviews were transcribed in Word using the pseudonyms to maintain participant confidentiality and were imported into the qualitative data analysis software, AtlasTi (version 8.2.4), where they were coded. The analysis, which followed the principles of inductive data analysis[13], identified distinct patterns, compared them with possible variations and established relations between codes. The interpretations were grounded in the interpretative approaches of medical anthropology, in dialogue with the human and collective health sciences.

The field work, centred on aspects of culture belonging to the researcher's everyday life, demanding an exercise of intense reflexivity towards the uses made of concepts and units of observation[10]. In that the researcher was part of the research process and embodied values, experiences and systems of knowledge, it was necessary to establish systems of control and systematisation, so that the categories deployed could be placed under constant surveillance through a field diary and discussions at congresses with the thesis director and peers.

The field work was carried out to the ethical standards set by the 1964 Declaration of Helsinki's consolidated criteria for reporting qualitative research *(COREQ). Approval was obtained from the Medical Anthropology Research Centre at Universitat Rovira i Virgili.*

Results

Chagas as risk culture

The literature review revealed that risk discourse emerged late and hesitantly in the scientific literature on Chagas, in view of the historical construction of risk in the health field described by Ayres[14]. In the late 1960s and the 70s the notion came to be associated with danger and vulnerability, but without including probability calculations to convert it into objective percentage data. It was not until the 1990s – and more particularly following the turn of the century – that the number of articles making reference to risk increased exponentially, coinciding with a generalised increase in research into Chagas disease[6,15]. These latter studies have made systematic use of serological and entomological surveys, whose findings are interpreted as indices of risk. In addition, rates have been extrapolated to produce estimates of populations infected and/or potentially infectable, while more sophisticated studies are appearing in which mathematics plays a central role in probabilistic quantification and takes on fundamental importance in arguments underlining the need for measures to control transmission of infection.

At least three main models of risk can be identified in the literature. Although they have gained diverse orientations, they articulate with each other, coexist and are expressed in a variety of forms. These models coincide with the different definitions that have been used to classify Chagas over the course of its history. First is exposure risk, which relates to Chagas as an infectious, noncommunicable disease. Second, transmission risk, connected with Chagas as a contagious infectious disease that can be passed on vertically in special circumstances, such as in blood transfusion and organ transplants, and where the healthy, asymptomatic carrier is of special importance. Such carriers are also important in the third model, which here is denominated latent risk, in which Chagas is conceived as a condition of chronic infection, contrasting with the idea of Chagas as a developed pathology and thus differentiating those people who are "at risk of" suffering from health problems from those already so suffering.

Historical approaches to risk

Exposure risk is connected with vector-borne transmission and assumes that there exists a population that is vulnerable because it is exposed to a danger connected with a specific ecological or social medium. In the American region where the insect vector is found, the characteristic response to that risk has included large-scale fumigation and improved housing, together with the institutionalisation of health education directed to modifying population behaviour and enabling social groups to manage specific risks by acquiring certain knowledge.

In this respect, there are two main lines to the risk exposure approach which, although articu-

lating with each other for a single purpose, differ substantially in their implicit assumptions and consequences. In keeping with the two major perspectives identified by Lupton[2] in the health field, risk is approached, on the one hand, as a danger to the health of populations exposed to certain external agents over which they have little control and, on the other, as the consequence of ways of life. Accordingly, risk comes to be conceived as externally imposed and to relate to what people or social groups do or do not do. While, in the former sense, the groups affected are seen as victims, health education and health promotion programmes have emphasised the connections between risks and the affected populations' lifestyles, beliefs and cultural habits, often disregarding underlying sociocultural and structural conditions.

As regards transmission risk, in the 1960s Chagas disease had been reported in all Latin American countries. It was in that context that the use of statistical methods became definitively established as an epidemiological fundamental that brought necessary objectivity to relations between knowledge of Chagas as a pathology and its public health dimensions, contributing more structural guidance by 1960s) way of estimations of global prevalence and incidence of infection. Calculations of the risk of blood-borne transmission by indirect contagion were an important influence in the introduction of control measures, which stabilised in the 1970s and later, in the 1990s, in the development of simultaneous screening programmes in different countries in the region, with a view to eliminating transmission of infection. These measures were also applied in regions where the insect vector is not found, but which were affected as a result of processes in which Chagas was urbanised and globalised. These made it possible for populations not directly exposed to vector-borne transmission to become infected indirectly through those groups identified as prone to infection.

Latent risk – the construct

From the biomedical standpoint, Chagas is associated with a parasitic infection that begins with an acute stage which, if not treated pharmacologically, progresses to a chronic stage[16]. The chronic stage of the infection, in the absence of detectable symptoms and signs, is known as the indeterminate form, while the development of lesions is considered to correspond, depending on the location of the disorders, to a chronic cardiac, digestive, mixed or neuro-autonomic stage. Both stages form part of a continuum. After a long (20- to 30-year) latency period after infection, between 20% and 40% – there is no consensus on the exact percentage[17] – of those infected develop clinical conditions[18]. However, there are no clinical or social indicators available to detect who will develop a pathology and who will not[17] and the fact that, among people who have suffered sudden death, a percentage are cases classified as at some indeterminate point in the chronic stage of Chagas disease has posed the need to reconsider the nosological framework[7]. As a result, the indeterminate form has come to be considered as potentially cardiac.

In current medical models, the presence of Tripanosoma cruzi is considered a necessary condition for the appearance of the disorders or sudden death. Nonetheless, although necessary, it is not a sufficient cause, because not all those infected develop pathologies. In addition to the role of the parasite and recognition for autoimmune components, the role of the population's economic and social conditions is also being considered, albeit timidly[19-21]. This latter aspect is rarely included in frames of reference and even more exceptionally in interventions. However, among health personnel such as David and Miguel, two of the researchers and clinicians interviewed, it is common to hear it said that: "it is impossible to find a mathematical model for a multifactorial situation" (David) or "at the moment we do not have the variables, we still do not have all the Xs to fill in" (Miguel). Accordingly, given the uncertainty as to why some patients develop the disease and others do not, risk has come to occupy the position of the missing link in the framework of a probabilistic model. Risk is selected as the scientifically significant piece among a plurality of causes involved in the specific situation, making it possible to intervene in the problem and take clinical action.

Clinical practice in view of latent risk

At the patient's appointment, the doctor will consider latent risk in two dimensions: the first, as the possibility that the person with the infection may develop a pathology; the second, that the pathology may potentially appear anywhere and at any time. In the event a positive case is detected and if the person diagnosed does not disappear from the care circuit, the clinical goal is to establish a baseline and anatomically detect the lesions that the parasite may have caused. In Spain, however, the greater percentage of people

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diagnosed are classified as at the indeterminate stage; that is, they present with no lesions that can be attributed to the infection. Thus, in the context of a conversation that took place during a clinical appointment between the doctor and a patient diagnosed with Chagas who had undergone an initial examination to detect possible lesions due to the infection, the doctor remarked:

There don't seem to be any conditions due to the Chagas [...]. However, you are going to ask me: which am I, one of those that nothing is going to happen to ever or one of those who is going to develop Chagas disease? We don't know, because there is no test we can do that will tell us. So, what we generally do is treat everybody.

The doctor's explanation at the appointment forms part of a discourse common among health personnel and exemplifies the dimension of possibility associated with the uncertainty as to who will develop pathologies. That dimension rests on the *conversion of previously calculated epidemiological rates (the percentage of cases that have evolved and those that have not) and their reinterpretation as risk at the individual level*. As Samimian-Darash and Rabinow[22] argue, here calculating risks on the basis of past experience guides action, in a process that entails a conceptual jump in order to resignify an epidemiological measurement – which, by definition, cannot be attributed to any particular individual[23,24] – and convert it into a clinical entity. Although initially understood as possibility, when risk is selected as the medically significant cause, it is transformed into a causality in such a way that it ultimately excludes the possibility that the lesions may never appear. That is to say, what was possible but inherently uncertain ends up being treated as a certainty: if a percentage of patients – there is no way of knowing which ones – will develop pathology, then all will be considered as cardiac and will be treated pharmacologically with a view to reducing the risk of progression. Management of that risk is thus based on the assumption that decisions taken in the present with regard to the future favour certain possibilities to the detriment of others – although excluding the possibility that some may never happen[22].

From possible to potential

In the dimension of possibility, latent risk is managed in clinical practice by administering parasiticide drugs. That possibility was precluded on the autoimmunity paradigm, which did not contemplate any specific aetiology in progression towards pathologies, thus reducing the margin for medical manoeuvre to those patients who had already developed symptoms. Nonetheless, the efficacy of such drugs has been a historical source of controversy that it is worth revisiting in order to explain the dimension of potentiality.

The scientific community considers both Benznidazol and Nifurtimox effective at the acute stage. In chronic cases, however, findings have been controversial, because while the parasite disappears from the blood, antibodies continue to be detected even decades after taking the medication. Cure, understood as the state of seronegativity in a person previously diagnosed as positive, is impossible to evaluate with available technical instruments until ten or twenty years have passed after taking medication – and is also subject to the probability that only a percentage of patients treated will display negative serology[25,26] (to which must be added the drugs' broad and varied spectrum of toxicity[27,28]). The foregoing all leads to the practice of latent risk as potentiality, as shown by the explanation given by Juan, another of the doctors consulted:

For you, it's important to come in once a year or every six months to see if you haven't got worse. You've been coming in once a year, more or less, since 2013, when we diagnosed you. The results have been good and you did the treatment with Benznidazol in July. There are no disorders, your heart is perfect and we can't see too much in your digestive system, nothing. The lab results have been down since the treatment. But you have to come back every six or twelve months so that we can see you regularly, in spite of all that. We may find nothing now, but all the same, in two years that can change (Juan).

The dimension of potentiality appears in this scene as the consequence of a latent risk considered to be associated with the selection of a series of clinical variables that emerge from correlations between disorders and the development of severe pathologies at the population level, and which are reinterpreted as personalised risk factors in that they have to do with the appearance of "precursor lesions" or "markers of poor prognosis". These become a prognostic tool[17] that enables patients to be classified on a stratified scale, on the basis of which clinical decisions can be taken by identifying those subgroups that need more continuous follow-up. The purpose is that early detection of lesions is considered to be associated with a better prognosis.

Following Samimian-Darash and Rabinow[22], the question is no longer "whether" something

will happen, but "when" and "where" it will. That is why the action taken does not respond exclusively to a risk connected with the possibility that pathology will or will not appear, but rather the risk is conceived as a potential derived from the variety of lesions that may arise from the infection, where no known clinical tool is sufficient to counter it, beyond the drug circumscribed by its limitations. In this way, the dimension of potentiality answers for the space between what has already happened – which is seen reflected at the baseline of the initial diagnosis – and what is about to happen, where diverse realities may potentially manifest themselves.

Discussion

In our societies, risk is a dominant manner of interpreting who gets ill and why[29] and is, at the same time, a central element in taking action. Chagas is defined as an infectious disease in which an aetiological agent is identified. The parasite stands as the natural cause in explaining the appearance of pathologies. However, as this is not sufficient to explain their appearance, it is complemented by the notion of risk, which makes the associated circumstances of probability clearer by using statistics and diagnostic, therapeutic or pharmacological technologies. In this way, biomedical practice redefines the relations between health and illness through this notion, enabling those patients classified as at the indeterminate stage to be included in clinical practice. In the doctor's surgery, latent risk is treated as the possibility of suffering health problems and is managed with parasiticide drugs that, nonetheless, cannot constitute grounds for disregarding the diagnosis once they are taken[30]. This leads latent risk to be treated also as potentiality and, consequently, to be managed by permanent health monitoring, which makes it possible to detect when and where lesions appear, and not just whether or not they appear.

The incorporation of biomedical models and practices into anthropological analysis since the late 1960s and the 70s assumed that it was possible to comprehend them as a cultural system interpretable in a position of symmetry with other medical systems and giving prominence to their sociocultural nature[31]. As argued by Good[32], the recognition of the historicity of that knowledge has enabled us to question the idea that it is a reflection of the natural order given through a progressive accumulation of experimental and scientific knowledge. In that those assumptions are what confers authority on medical knowledge, once that knowledge is related to its historical and sociocultural context – in this case, by positioning biomedical models and practices as just another object of study – the way is open to pose the need to reconsider the position occupied by the knowledge and logic of different groups and societies with regard to the risks associated with the infection that can cause Chagas disease.

Although the notion of risk is an abstract concept, in the medical model described here it becomes a concrete entity with a life of its own, a descriptive category more than an essentially cultural category. In that way, it is reified and made manageable by a process of medicalization and pharmaceuticalisation that forms part of a historical development of seeking technical and pragmatic solutions to health problems, which has occurred since the early twentieth century[4,14]. A constructivist and historicist perspective leads to the argument that risks arise from specific contexts and are rooted in different forms of knowledge, based on assumptions resting on shared values and symbols that are often taken for granted in the framework of belonging to a given social group[33]. This is precisely what was argued previously in another article[11], which explained how the instrumental rationality underlying the biomedical culture of risk contrasts with how risk is experienced by certain social groups affected by Chagas, among whom situated logics, experiences and biographical identities, emotions and intuitions play a key role, in contrast with the prevalence of a fundamentally cognitive understanding of risk in medical and technical terms. Moreover, clinical practices grounded in the notion of latent risk also have the potential to trigger concrete bodily experiences among the affected groups, as shown by the literature on the subject[1,23,33-44] and as described by Magnani[39] in relation to programmes to combat the vector in Brazil, and Ciannameo[45], in relation to screening policies in Europe, especially for whether people diagnosed are encouraged to take a medicine – which has multiple adverse effects and whose efficacy is contested to this day – and to undergo permanent monitoring of their bodies.

The need to inquire into the interrelations between expert and profane models, between biomedical or technical interventions and the practices, representations and bodily experiences of the groups affected, is one way of understanding the place that the latter occupy in the approach to Chagas and in the organisation of care for the

disease. It is also an invitation to leverage shared decision-making by using dialogical models that take account of lay or local forms of knowledge, and by participation from the affected groups. This means that the search for solutions or alternatives to current medical practices resides less in a top-down movement than in potential dialogues between these various actors and in meshing between the sociocultural models that they deploy in relation to Chagas, risk and care needs. For that purpose, situating biomedical practice as an object of study among others goes beyond understanding biomedical constructs and practices as cultural systems; it is a first step towards thinking about the interventions that are being performed through a different lens, which has potential for guiding changes in the development of health politics and services that can be more effective for the affected groups.

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