

Itinerary for patients with Acute Chagas Disease: From illness to coping in an Amazonian municipality

Victor Viana da Graça¹, Iací Proença Palmeira², Aline Silva O' de Almeida³, Ângela Maria Rodrigues Ferreira⁴, Sâmia Cristine Rabelo Borges⁵, Daniele Melo Sardinha⁶, Ana Caroline Guedes Souza Martins⁷, Antônia Margareth Moita Sá⁸

¹Nurse. Master in Nursing at Pará State University (UEPA), Belém, Pará, Brazil. E-mail: victorvianagraca@yahoo.com.br

²Nurse. Doctoral in Nursing. Adjunct professor at UEPA, Belém, Pará, Brazil.

³Nutritionist. Municipal Health Department of Abaetetuba, Pará, Brazil.

⁴Nurse, Doctoral in Biology of Infectious and Parasitic Agents from the Federal University of Pará (UFPA), Belém, Pará, Brazil.

⁵Nurse, Master at UEPA. Professor and Preceptor of the Multi-Professional Family Health Residence. Server Municipal Health Secretary of Ananindeua, Pará, Brazil.

⁶Nurse. Doctoral in Parasitic Biology in the Amazon (UEPA/IEC), Belém, Pará, Brazil.

⁷Nurse. Doctoral Student in Clinical Research in Infectious Diseases at National Institute of Infectious Diseases-INI-FIOCRUZ-RJ. Professor at UEPA, Belém, Pará, Brazil.

⁸Nurse. Doctoral in Nursing. Adjunct professor at UEPA, Belém, Pará, Brazil.

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Abstract— Objective: This study aims to understand the path from illness to coping with Acute Chagas Disease (ACD) by those who experience it. Method: Qualitative, descriptive study carried out in the city of Abaetetuba, Pará, Brazil. Twenty patients with Acute Chagas Disease followed at a health clinic in 2018 participated in the study. Home visits were made to collect information through a semi-structured interview script with open and closed questions. For data analysis, thematic content analysis was used. The research complied with Resolution No. 466/12 of the Brazil National Health Council. Results: Most participants are aged between 20 and 39 years (40%), 50% are female, 60% had no personal income, 50% declared themselves to be Catholics, 65% reported being under current treatment for ACD and 5% had complications. When analyzing the interviewees' statements, three categories and their approaches emerged: 1) The meaning of having and living with ACD (The knowledge of patients about the disease; the impact of the disease on the patient and religiosity as a form of hope); 2) The carrier's relationship with their social groups (The positive aspects; the negative aspects and the repercussions of the illness on the family); 3) The influence of food culture related to patients with ACD (Our açaí, daily health). Conclusion: It is concluded that this research not only demonstrates that ACD has a great biopsychosociocultural thickness, due to its significance for those who experience it, but also is fraught with stigmas for being inserted in a cultural environment of eating habits based on the consumption of açaí pulp.

I. INTRODUCTION

Chagas Disease (CD) is a human infection produced by the flagellate protozoan *Trypanosoma cruzi* (*T. cruzi*). It has a biphasic clinical course, consisting of an acute phase (clinically apparent or not) and a chronic phase, which can manifest in indeterminate, cardiac, digestive or cardiogestive forms [1].

The transmission cycle of the disease is based on the transmitter vector, the triatomine. However, after numerous national campaigns and multinational initiatives, transmission through this medium is partially controlled. In 2006, Brazil received from the World Health Organization (WHO) the certificate of eradication of transmission by the most relevant domiciled vector, *Triatoma infestans*. This, however, does not represent the eradication of the disease, which continues to happen through outbreaks mediated by other forms of transmission, such as the oral route [2].

CD in Latin America affects between 18 to 20 million people and more than 90 million who live in endemic areas are at risk of becoming infected, causing disabilities in infected individuals and death. For many decades, CD was a strictly rural disease. However, socioeconomic changes, rural exodus, deforestation and urbanization have transformed the epidemiological profile of the disease, making it a more urban and peri-urban phenomenon [3].

Were recorded 112 outbreaks in the national territory between 2005 and 2013, involving a total of 35 municipalities in the Amazon Region. The probable source of infection was the ingestion of foods contaminated with *T. cruzi*, including: açaí, bacaba, jaci (coquinho), sugarcane juice and babassu palm hearts. Most outbreaks occurred in the state of Pará with 75.9% and 12.5% of cases and, to a lesser extent, the states of Amazonas with 4.5%, Tocantins and Bahia with 1.8% each [4].

The North region contributed with the highest proportion of cases in the country (91.1%), having been registered in the state of Pará about 75% of all cases in Brazil, and more than 50% had symptoms onset between months from August and November for the years 2005 to 2013, a period that coincides with the açaí harvest in Pará [4].

In this context, the municipality of Abaetetuba is the most prevalent due to its epidemiological relevance, standing out in the national and international scenario for its hyperendemic profile, in which Acute Chagas Disease (ACD) is a serious public health problem. When comparing with the capital, Belém, which has an estimated population for 2018 of 1,485,732 people [5],

there is a greater burden of illness, however, the municipality of Abaetetuba, which has an estimated population for 2018 of 156,292 people, according to the demographic census of Brazilian Institute of Geography and Statistics (IBGE) 2010 [6], has greater magnitude due to proportionality. The municipality of Abaetetuba concentrates 14.8% of CD cases registered in the Amazon [7].

For the millions of patients with CD, there are still numerous challenges, such as living with a chronic, stigmatizing disease, with evolutionary potential to develop mega viscera and various complications, to which are added social problems, confirming the morbid potential of the association between human infection and the socioeconomic status of those infected. The population affected by this disease is predominantly composed of migrants from endemic rural areas, with little or no qualification for specialized work, particularly in the tertiary sector, and who cannot be held responsible or bear the burden of this disease alone entails to them [8].

In this sense, it is possible to say that the way of understanding ACD can support negative or positive attitudes towards the disease. Sudden death is an unusual event in these cases, but when patients are asked questions about the meaning of the disease, the answers differ from the available scientific knowledge. This event becomes the mark of the disease, the other clinical presentations lose importance and the ACD becomes the one “that kills suddenly” and becomes the icon and the stigma of the disease, that is, it starts to be represented as its worst consequence [9].

From this context, the following research question emerged: How is the path from falling ill to coping with Acute Chagas Disease by those who experience it? From this question, we sought to know the phenomena and categorize subjectivity, life stories, culture, myths and prejudices, similar to those that occur with other stigmatized diseases in different contexts (regional, social, etc.), as the imaginary of ACD is linked to death, the fear of not healing and cultural prejudice.

Thus, this study aims to understand the path from illness to coping with Acute Chagas Disease by those who experience it.

II. METHOD

The research complied with Resolution No. 466/12 of the National Health Council and the Declaration of Helsinki, which regulate and standardize research involving human beings, and was submitted to the

Research Ethics Committee of the Undergraduate Nursing Course at the Pará State University and approved under opinion 2,288.005.

This is a study with a qualitative, descriptive approach, in which 20 patients with ACD participated in a municipal clinic that cares for, treats and monitors patients with ACD in Abaetetuba, Pará, Brazil.

The following inclusion criteria were applied: Patients with ACD, being monitored at the municipal health service residing in Abaetetuba; Above 12 years of age. For the exclusion criteria: Person with cognitive deficit that makes it impossible to answer the interview questions.

Data collection took place between October 2017 and September 2018 through semi-structured interviews containing open and closed questions, organized in a script, which sought to know the sociodemographic profile and subjective questions for the apprehension of the object of study.

The approach and invitation to participate in the research took place during monitoring in the municipal health network. The interviews took place in the participants' homes, avoiding interrupting the institution's and patients' routine. The interviews were recorded in electronic media with consent. Subsequently, the information was transcribed in full, so that no information was lost.

The interview took place after participants over 18 had signed the Informed Consent Term or the Informed Consent Term by those responsible for the minors.

For data analysis, thematic Content Analysis was used, which consists of a set of techniques that analyze communication, describe the contents of the messages and provide, on the part of the researchers, the inference of the knowledge contained in the captured messages, according to the following steps: pre-analysis; exploration of the material; treatment of results, inference and interpretation [10].

The results were analyzed and organized into three analysis categories that emerged as a function of the 463 Record Units (RUs) found.

III. RESULTS

The results show that the most prevalent age group among the participants is between 20 and 39 years old (08/40%), 10 participants were female and 10 male, in terms of income, it was found that 12 (60%) participants had no personal income. With regard to religion, 10 (50%) declared themselves Catholic, 13 (65%) reported

being treated for CD and only 01 (5%) participant had complications.

Category I - The meaning of experiencing Acute Chagas Disease

As for the thematic categories, by analyzing the content of the respondents' answers, Category I was constructed, called "The meaning of living with Acute Chagas Disease", which has 197 RUs and corresponds to 42.54% of the RUs found. This category identifies Having and Living with ACD based on knowledge (Figure 1), limitations, fear of death and seeking refuge in their beliefs, listing the following sub-themes: Knowledge about the disease; the impact of the disease on daily life and religiosity as a form of hope.

Knowledge about the disease

In this analysis, it was possible to infer that there is a lack of information offered to patients with ACD by health professionals and/or when available, they are incomplete, as it was found that 75% of patients reported not knowing the disease or that the knowledge acquired comes from search other sources of information.

"I don't know anything about the disease, I had heard about it, that it gives people a lot of fever. I know about the barber too". (P1)

"Nothing, I don't know anything about the disease, I just heard comments, so-and-so has it." (P4)

"I don't have certain information to know about the problem of the disease, I don't know, I just heard the woman say that it's a problem with a barber that gives all this problem there". (P8)

This analysis showed that for 60% of patients, the knowledge acquired comes from lived or witnessed experiences. Knowledge based on common sense is ingrained in the daily lives of those who have and live with ACD and guides how the disease will be seen by the patient.

"[...] I was with a hospitalized sister-in-law, I saw one die with this Chagas disease, I put it in my head". (P4)

"[...] I looked for cases of people who had caught the disease, underwent treatment and now live normally, in this case I found people, friends of mine I didn't know they had and who undergo treatment and live normally". (P7)

Regarding their knowledge, it appears that patients had three basic knowledge about the disease, deeply rooted in social daily life: "the transmission of the disease through açaí or by the barber", the "disease that has no cure", and the "disease that kills".

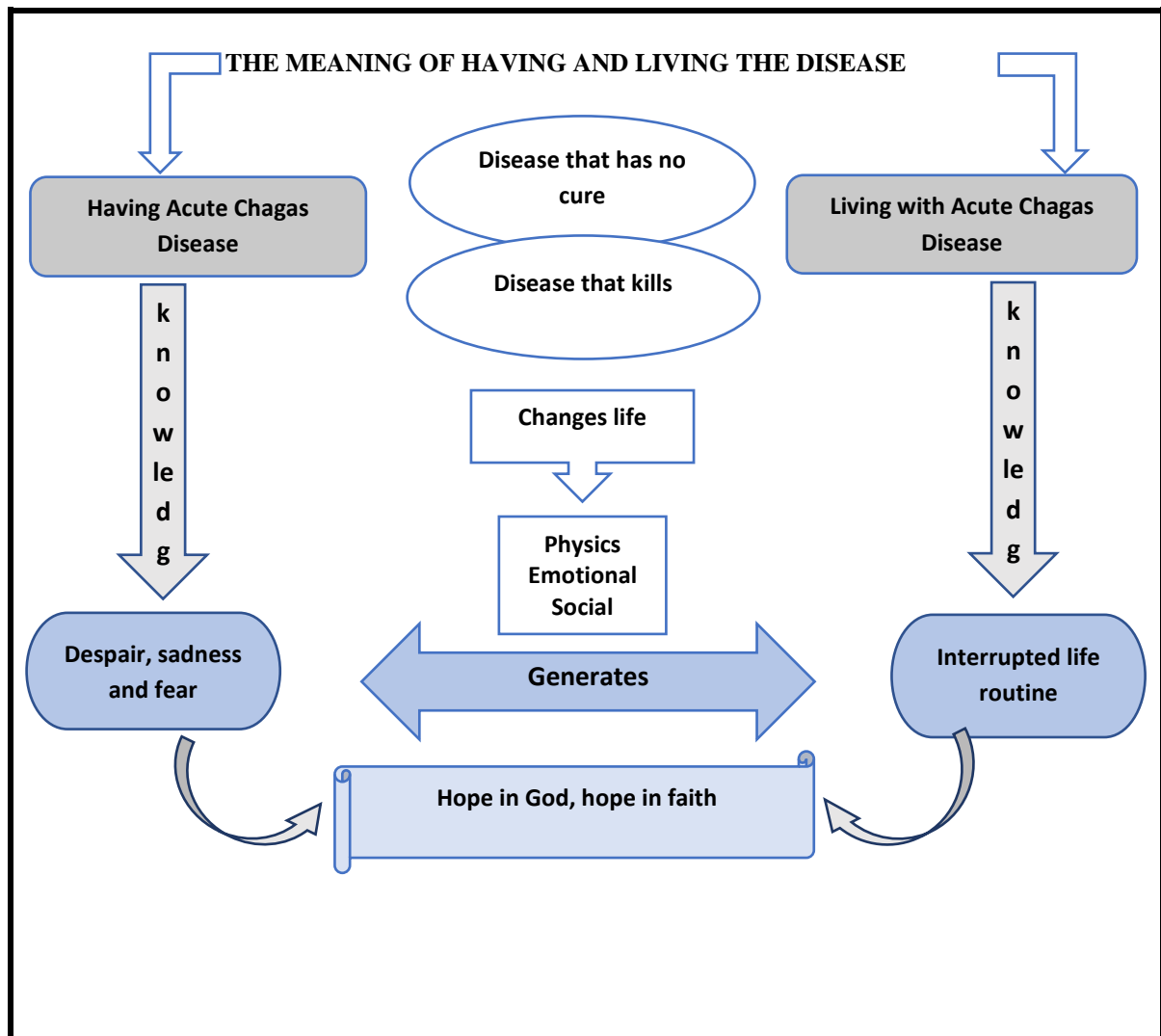


Fig.1: Diagram representing the meaning of Having and Living with Acute Chagas Disease.

Source: Prepared by the author.

The impact of the disease on daily life

Now, participants' testimonies are addressed from the diagnosis of the disease, the changes and the impact on their daily lives. Regarding the diagnosis, 70% of patients say they did not suspect the disease.

"[...] it didn't cross my mind that it was Chagas Disease". (P3)

"I didn't suspect it, I thought it was a fever, that it wasn't going away". (P6)

As for the reaction to the positive result for DCA, patients experience various feelings that resulted from the news. The emotional impact is evident in the testimonies of patients, such as fear, sadness, concern, among others.

"[...] it's all over for me, it made me very sad to know that I had it, really sad. This sadness came

that I was already starting to become depressed, now with this disease it made me sadder". (P4)

"[...] I was very scared because it was a very big psychological reaction[...] The shock didn't just come to me, it came to the whole family". (P9)

It is evidenced in the reports of 40% of patients with ACD that during the course of the disease, the concern with the possibility of no cure is very significant.

"[...] I heard that this disease has no cure... This disease has a cure"? (P1)

"[...] I knew that CD had treatment, I just didn't know that it had no cure". (P7)

The analyzes reveal the existence of a network of meanings associated with ACD that is associated with ideas about manifestations, repercussions and treatment, and configures the representation of a disease that

imposes progressive limitations, “the wanting to do and not being able to”.

“It changed my routine, because he said I can't walk, play soccer and do anything that makes my heart race. He spoke to me. It's bad, for now I'm adapting. The person can't stay still, because it makes me want to work, because I used to work on a motorcycle taxi, then he said I couldn't push anything, so I stay”. (P2)

“[...] I went to try to work and I couldn't do it anymore [...] I went to wash clothes, but I have to stop for a while because of the arrhythmia when I go over my limit and I get tired and I get short of breath [...] When I was feeling really bad, I knelt on the bed and started crying and I said that I couldn't stand the despair anymore, I even told God to take my life”. (P11)

Religiosity as a form of hope

In the narratives, it was identified that 50% use the belief in God and the practice of faith to cherish their fears and uncertainties, in addition to the hope of a cure. The term “God” within the URs found was expressed 57 times.

“[...] God gives us strength, courage for us to overcome, stay in that faith, and I thank God I have a lot of faith in God [...] I can do it as I have it, every time it's good, I say it's okay, thanks to God [...] I have a God up there, who takes care of everything, he solves all the problems, he gives the cure, he does everything, so I believe in God that I'll get out of this and get well”. (P3)

“[...] But first act faith in God and fight to win”. (P4)

Category II - Relation of the bearer with his social group

This category has 150 RUs which corresponds to 32.39% of the RUs found. It discusses how ACD patients report social interaction and social interaction with their family, friends and society in general (Figure 2).

The participation of this network of social groups presents itself as a source of positive as well as negative events, which translate to the patient a reading of stimuli and support for the search for quality of life or attitudes that interfere in the course of illness.

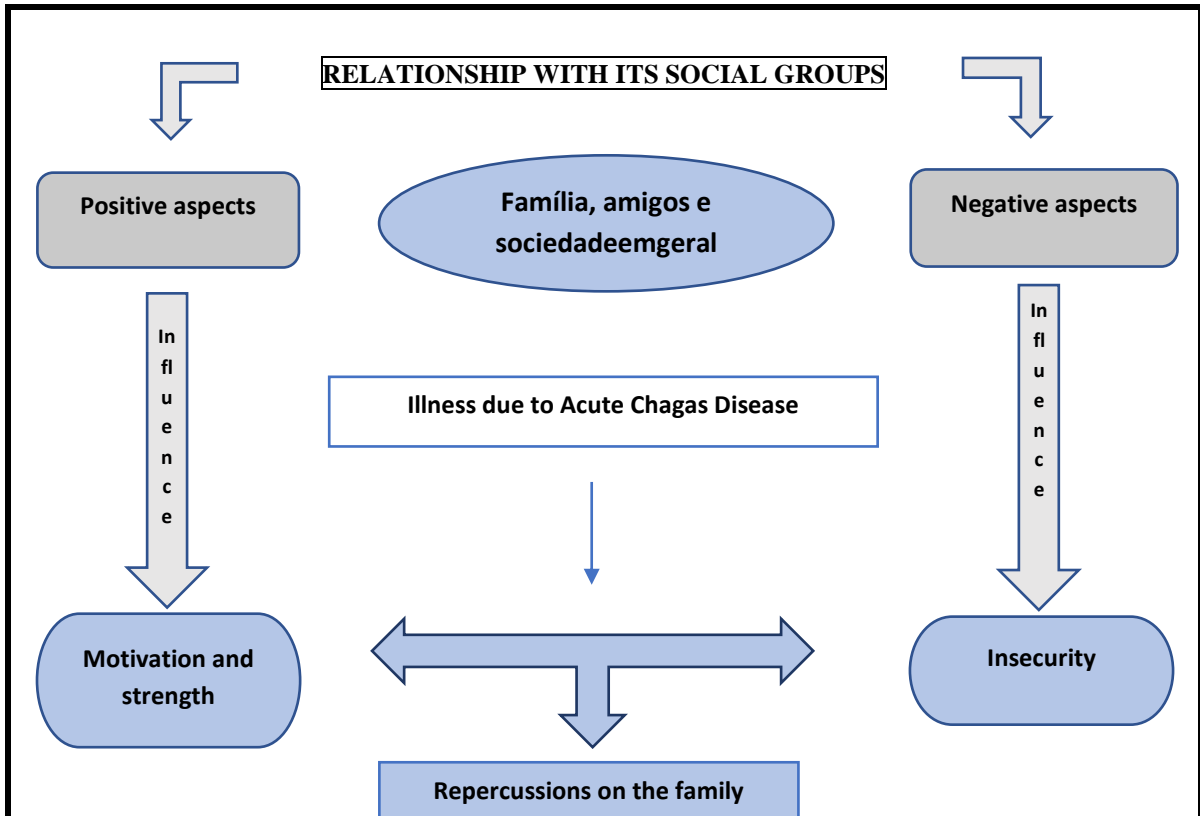


Fig.2: Representative scheme of the bearer's relationship with his Social Groups.

Source: Prepared by the author.

The repercussion and the affect network

Family and friends not only form a support network but also play a very important role in this process. The strength and encouragement that patients receive from this support network makes them stronger in the face of illness, however, in this nucleus, the family is the most important element to overcome the challenges, as seen in the following statements:

"[...] my family says that I have to take the medicine, be in this care, that I have to take the medicine every eight hours, a lot of concern". (P6)

"My family and friends are taking it normally, they are always giving strength to follow the treatment and do everything right, it won't be a problem, in that sense, but the relationship really became normal, for those close to me I said and there was the support from all". (P12)

Coping and social stigma

It is understood that CD is, from this point of view, a social disease experienced with stigma and prejudice that seem to be rooted in society, as seen in the statements.

"[...] I went to the office and sat in the chair and people didn't want to sit next to me, because I was transformed, I was completely unknown, it was full of red plaques, so much so that my body was all covered up". (P13)

"CD for me is, today, since when it hit me it has a kind of prejudice for me, CD and HIV hardly some want to accept." (P19)

Repercussions of the illness on the family

In this research, the term "family" has a frequency of 50 citations in the identified URs.

"The shock didn't just come to me, it came to the whole family, there was despair in the family [...] my family members see me as an act of faith, of me remaining strong". (P9)

"[...], I'm not really worried about things, about suffering, I know that suffering exists, but the concern now that it's killing my family". (P15)

Category III - Influence of food culture associated with the transmission of Acute Chagas Disease

With regard to the food issue associated with oral transmission of the disease, the regional Amazonian context in which the illness due to ACD occurs, influencing the transmission, is discussed. This category has 116 RUs, which corresponds to 25.05% of the RUs found, and describes how the influence of food culture in the daily carrier is presented, characterized by the reports

in the interviews, demonstrating how the insertion of contaminated food and illness.

In the speech of the carriers, it is possible to identify that there are references to food, which in their understanding can be a vehicle for oral transmission of ACD and mention foods such as sugarcane juice, flour, mango and açai.

"[...] it could be from the sugarcane juice, it could be from his shoe, it could be from the flour too". (P2)

"We start to worry more about what we're going to buy on the streets, after I had the disease I didn't drink sugarcane juice anymore, because it's also transmitted by it, I get a little suspicious." (P16)

Our açai, the health of every day

This unit addresses with greater focus the cultural issue of oral transmission of ACD as a result of the contamination of the açai fruit by *T. cruzi*, as the cultural representation of the consumption of this fruit is evidenced in the participants' narratives. The term "açai" within the listed RUs was the most cited by all interviewed participants, with a frequency of 114 citations.

Açai is a ubiquitous food in Abaetetuba, sold at every corner by artisan scouts and consumed at any time of the day, constituting the main dish of the residents, which is the municipality's cultural identity. For 95% of the participants, the consumption of açai pulp is characterized as the main form of contamination.

"[...] Açai, which could have been açai, we drink açai, at lunch, at dinner and sometimes we make porridge in the morning with rice, then we drink that porridge". (P3)

"It could have been through açai, it's the only explanation there is." (P6)

For some of the participants, the fear of not being able to consume açai anymore leads them to apprehension and means the break of a daily routine of eating. However, the concern to look for a place that offers the necessary hygienic care, which uses fruit whitening as a control for the protozoan *T. cruzi*, is noticeable.

"[...] the first time I went to the doctor and came back worried, so I thought – am I going to continue taking açai? [...] that doubt, where did it go? Where did I go wrong? Since then, the only thing I didn't cut was only the açai that I couldn't cut, but I policed it to go to a place that has a more adequate sanitation to the açai manufacturing process". (P7)

"[...] The doctor said I wouldn't be able to take açai for a while, then the day I went to Belém, the

nutritionist told me that I had to take the açai, then I said Dr. take it all away but don't take my açai, because we are so used to having lunch and having açai dinner. (P14)

The consumption of açai pulp with the guarantee of proper cleaning of the fruit should be encouraged, as it is a nutrient-rich food. However, CD is addressed in groups and in the social environment, published in the regional media as having its main form of contamination in the consumption of açai, and consequently, it is related to the appearance of cases. However, for many, the strength of the eating habit overwhelms any other concern, which thus favors the emergence of cases of the disease, even if somehow these groups have contact with information about the possible transmission of CD through the pulp of the açai contaminated by *T. cruzi*.

It is known that CD is linked to social, historical and cultural aspects, aimed at understanding the social interaction of people who experience them as a disease present in the environment, considering that it is inserted and belongs to social groups with identity and close cultures, share the same cultural eating habits, and even though they are aware of the possibility of oral transmission of the disease when adequate hygienic-sanitary conditions are not offered, the force of habit prevails.

IV. DISCUSSION

The knowledge of ACD patients about their condition, both in terms of biomedical knowledge and common sense, influences the course of illness and coping with the disease. Health professionals have a specific perception, and not necessarily similar to that of ACD patients, of what is relevant and problematic, what causes or prevents a problem, and the type of action that this problem requires. This view is determined by your body of biomedical knowledge. As for patients, lay people of a community or group, this perception is determined by networks of symbols that articulate biomedical and cultural concepts, the latter based on knowledge acquired through observation, and the exchange of experiences, which determines characteristic forms of thinking and acting in the face of a health problem [11].

The knowledge of health professionals is based on scientifically proven aspects, what the literature affirms as true, often being the opposite or despising common sense, starting to deny or treat as wrong the way common people, popular knowledge, understand and explain the world [12].

For CD patients, the result is almost always a limited view, possibly due to the lack or scarcity of material, cultural and symbolic resources, in which knowledge is passed on to the patient following the informative model, restricted to diagnosis and therapy [11].

The approximation with the ACD patient must be based on experience and subjectivity, which requires the possibility of dialogical relationships and socialization of knowledge, within the possibilities and limits of the subjects at each moment, favoring greater interaction between professional and patient to better deal with the disease by those who experience it and who cares for it. Thus, the health education process of CD patients is their social relationships, whose social support is a way of dealing with the health issue, understanding the problems in the field of the community itself and also enabling the socialization of the notion of individual autonomy and collective [11].

It is noticed in the speeches a very great fear of dying (60%), as for the vast majority it is the “disease that kills suddenly”. However, in an 11-year historical series of positive cases in the state of Pará, 26 patients with ACD (1.3% of positive cases) died.13. These data, however, do not reflect the popular imagination about the fear of death, hence the need and importance of the health professional's participation to act in this reality.

Corroborating the findings of this research, studies show a picture of anxiety related to death, due to situational factors evidenced by fear of loss of physical and/or mental capacities and fear related to loss of control and unpredictable results secondary to the lack of knowledge of the evidenced pathology by the patient's verbal reports [14].

Regarding cure, cases of ACD are indicated for immediate specific treatment and long-term follow-up in order to identify a serological cure. In a study considering 179 patients treated with Benznidazole in the acute phase of CD by oral transmission and who had a follow-up under a research protocol for an average period of 5 to 6 years, there was serologic cure in 26.3%, more evident during the fourth year after treatment. Another 2.7% evolved with mild to moderate chronic heart disease, and 73.7% persisted with reactive serology, but with a significant decrease in antibody levels [15].

The high persistence of reagent serology demonstrated in the study indicated above in an average period of 5.6 years, leads to interpreting how long it can take to discharge according to serological criteria, since the cure is serological negative and can be understood by the patient as a disease that has no cure. The results presented are in line with the representativeness of the research

participants' narratives, which are evidenced with scientific evidence, configuring the representation of a serious disease that cannot be cured [15].

For ACD sufferers, the burden of having and living with the disease is similar to diseases considered "incurable", such as cancer and acquired immunodeficiency syndrome (AIDS). For the limitations in daily life, conditions that make it impossible for them to follow their daily routine of activities, and these changes in the daily lives of patients are not always related to effectively installed limitation, as sometimes it results from projections of possibilities of existing in the present and in the future. The existence of limitations, whether they are work, leisure, home activities, among others [11].

As can be seen, patients with ACD, in addition to living with the threat of a possible death, still face limitations imposed not only by the disease, but also by physical limitations, but also limitations arising from society, which causes them even greater social suffering, and because of that, they end up being labeled as vulnerable and professionally limited. The disease is accompanied by an idea of vulnerability that can trigger discriminatory attitudes and behaviors that hinder the social and professional insertion of patients [16].

Despite the emotional impact caused by the diagnosis, it was then observed that each person has a unique way of dealing with the disease and treatment, as well as the impact on their lives, due to the discovery. In this study, many of them showed that they use religion and faith as coping strategies for the disease. For some participants, the traditional drug treatment, alone, is unable to respond to their desires and, therefore, they seek spiritual treatments and religious practices, to the point of abdicating the medicines because they believe they are cured. Others, however, extol the importance of drug treatment.

It is necessary to undergo treatment when diagnosed with CD and not abandon it, even if faith and belief are added to the treatment, in addition to continuing with monitoring by health professionals. Religion and belief in God through faith allow the carriers' personal experiences to become intelligible and bearable. Religion and belief symbolically handled as a supporting pillar for coping, given the elements derived from it insecurities, fears and risk of death, ensure the understanding of having and living with a disease and fostering confidence in the cure of the disease [17].

Faith can be a great ally in coping with illnesses, it is good for immunity, improves the response to treatment processes, and can even help fight depression and anxiety. In religion, if the belief is in God or in any other entity, the

ultimate purpose is to face the disease, seek strength to win, strength to fight for life [18].

The support and care of family and friends, even though they are also shaken and weakened, is of essential importance for the adaptation to the new condition experienced by patients with ACD [19].

For patients with ACD, the family support network has made a great contribution to seeking care and motivates them in the face of illness, with the family being a symbolic and cultural framework that helps them to build their conception of the disease [16].

ACD patients, in addition to suffering an abrupt change in their health status, both physical and psychological, suffer the repercussions of the disease in their life context, in social life. After the initial impact of knowledge about the diagnosis, indifference and marginalization from society and family members can occur. CD is surrounded by prejudice and stigmas and popular cultural domains that condition the social relationships of its patients [11].

In a study with 308 patients with CD, it was found that the social stigma is still very evident, since the lack of knowledge about the pathology causes prejudiced behavior towards the patient, and also highlights that health promotion and education practices minimized this situation, affecting their quality of life [20].

It can be seen, then, when observing the interviewees' statements, that there has been little evolution so far, with regard to prejudice against patients, so it is understood that it is necessary to take even more care and, even better, of people who develop CD, facing physical aspects and those related to the stigma and prejudice experienced.

Care must include the patient and their family members, understanding that directing eyes only to the individual who is sick is to fail to notice the whole family, in which each individual has a way of understanding the disease and facing the problem. In general, the family feels responsible for the care and they are sensitive to reactions of adaptation and recognition of the impact of the illness, which also change the relationship with each other and with the social environment [21].

Family members and patients use mechanisms to react to threats arising from real and imaginary situations resulting from the illness, creating ways to cope with the disease [21].

The fear of death and the arrival of a disease popularly known as incurable lead the family to a threshold of feelings and attitudes that denote the repercussions of the disease. Because of this, in the course of illness, there is emotional instability with psychological changes to the

family and the patient in the way of thinking and relating, leading to changes in behavior patterns [11].

Corroborating the results of this study, CD has a strong impact on the family aspect, as it affects their daily lives, but it emphasized that the patient reflected the importance of family support at this time, which has a positive impact on the treatment [16].

According to the SUS Informatics Department of Brazil (DATASUS) of the Ministry of Health, in the State of Pará, in a historical series from 2007 to 2017, there were 1,388 cases of CD by oral transmission, which corresponds to 98.16% of all cases that occurred and in the city of Abaetetuba there were 232 cases in the city, corresponding to 73.41% of the total cases in the period, demonstrating the high incidence of cases of ACD by oral transmission [13].

Nowadays, oral transmission is one of the main forms of the disease in Brazil, particularly in the Amazon region. The consumption of raw or undercooked meat from wild animals infected with *T. cruzi* is mentioned as one of the forms of transmission, being proven in experimental studies with animals [22].

Practices are constituted through various habits and are influenced by social determinants such as low education, few financial and housing conditions [23], in addition to cultural factors, linked to meanings and values of a set of sociocultural relationships that link people and groups to each other [17].

The pulp of the açaí fruit is the daily food for thousands of people in the North of Brazil and, especially in the State of Pará, especially in the municipality of Abaetetuba, whose price is affordable and due to its high nutritional value²⁴. In this region, sales and consumption are carried out immediately after processing, almost always without any heat treatment or hygiene [25].

In the North region, oral transmission predominates, which mainly involves açaí, however the contamination occurs due to lack of hygiene, and the correct handling of food prevents the transmission of the disease and its consumption should be normal on a daily basis day [26]. In the process called “bleaching”, the açaí fruits must be submitted to thermal treatment with water at a temperature of 80°C for 10 seconds and, soon after cooled to room temperature, in order to guarantee the quality of the product [27].

V. CONCLUSION

The results demonstrate that ACD has biopsychosociocultural thickness, as it has significance for those who experience it, in which they trace a painful path and often without perspectives, which, in the initial view

of the patient, is an illness based on a path of no return. The disease is accompanied by stigmas and cultural values that condition the carrier's social relationships, based on the perception of their health status in physical, psychological and social aspects.

The disease has shown to have great limiting power in the quality of life of patients by adding misconceptions, especially about death, causing anticipated suffering, in addition to generating physical and psychological repercussions. This understanding is built on common sense knowledge, shared by their peers.

Furthermore, the research shows the impact of ACD on public health in the North region and the challenges in coping with the disease, since it recognizes the need to include the theme in the community system and social groups, reinforcing the need for professionals healthcare professionals pay more attention to the changes that ACD brings about in the socio-psychological scope of the patient.

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