



“Navigating the lived efficacies of Chagas treatment”

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ARTICLE INFO

Handling editor: Alexandra Brewis

Keywords:

Chagas
Treatment
Efficacy
Catalonia
Lay care
Living labyrinths

ABSTRACT

Drawing on an ethnographic study of Chagas treatment among migrant domestic workers in Catalonia, conducted between January 2014 and May 2016, and utilizing the concepts of “lay care” and “living labyrinths,” this paper explores how the efficacy of parasiticide treatments is experienced within relational and contextually situated frameworks. While pharmaceutical efficacy is often characterized by temporary and uncertain outcomes, the results indicate that lived efficacy is shaped by a complex interplay of embodied sociocultural, political, and historical processes, being continually negotiated and redefined within a broader context of global health values, biomedical technologies, migratory experiences and ethnicity, patient-doctor relationships, personal identities, daily demands, and care practices. The findings emphasize the reflexive management of the condition by those affected and highlight the role of pharmaceuticals as active agents that shape social and cultural dynamics, with significant impacts on social life and healthcare. By examining lived efficacy, the study suggests that limited access to healthcare services is not the sole process preventing treatment for Chagas, providing deeper insights into the logics behind actions related to Chagas pharmaceutical treatments. Incorporating “lay care” practices and perspectives into the therapeutic negotiation process not only acknowledges the complex “living labyrinths” navigated by social groups but also offers a foundation for reflecting on and reimagining alternative forms of care, recognizing their role in social and cultural reproduction.

1. Introduction

In recent decades, there has been increased focus on detecting and treating Chagas, driven by a new understanding of the parasite’s key role in the infection’s progression. This conceptual shift is crucial in the care of individuals in the “indeterminate chronic phase” of Chagas, who previously received neglected care. Now, the possibility of parasiticide treatment has become a key focus in biomedical and technical discourses and practices (Ventura Garcia, 2022, 2023; Ventura Garcia, 2018).

The two current treatments are effective in children and acute cases but have been controversial for chronic stages due to concerns over efficacy and severe side effects, especially in adults. While a cure is not possible, the concept of therapeutic efficacy has shifted, focusing on reducing the pathogen’s burden and decreasing the risk of developing chronic symptoms (Viotti et al., 2006). In this new preventive approach, diagnosis aims to detect the infection, treat the risk pharmacologically and follow-up (Ventura Garcia, 2022, 2023; Ventura-Garcia et al., 2021).

However, underdiagnosis and treatment rates remain exceptionally

high worldwide (Basile et al., 2011). This approach is shaped by “stratified biomedicalisation” (Clarke et al., 2010, in Mamo, 2024), where biomedicine’s advances lead to unequal outcomes, especially in “endemic” regions, where pharmaceutical solutions have been inadequate and access to diagnosis and treatment is critical (De Maio et al., 2014). In the international migratory context, undertreatment is linked to limited access to diagnosis. Treatment is often sought for its potential to extend life and achieve migratory goals but is frequently refused or abandoned due to perceived risks, side effects, and uncertain efficacy (Avaria and Gómez, 2008; Aguilar, 2009; Ventura Garcia et al., 2013; Ventura Garcia and Offenhenden, 2015; Forsyth, 2015, 2018, 2019, 2021; Navarro and de los Santos, 2017; Martínez-Parra et al., 2018; Castaldo et al., 2020; Mills, 2020; Avaria et al., 2021; Miranda-Arboleda et al., 2021; Valdez-Tah, 2021; Ventura Garcia, 2023; Offenhenden and Ventura Garcia, 2024; Ventura Garcia, 2018). Still, little is known about the experiences of those affected and even less about their experiences concerning its efficacy.

Based on an ethnographic study of Chagas treatment among migrant domestic workers in Catalonia, this paper draws on “lay care”

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<https://doi.org/10.1016/j.socscimed.2025.117709>

Received 12 August 2024; Received in revised form 8 January 2025; Accepted 13 January 2025

Available online 17 January 2025

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(Menéndez, 2003, 2016, 2018) and “living labyrinths” (Hardon and Sanabria, 2017) to advocate for critical, interpretative medical anthropology frameworks that explore how efficacy is experienced in these women’s daily lives, offering an alternative perspective on health approaches and practices related to current Chagas’ treatments.

1.1. A new approach in Chagas management

In recent decades, a new approach to Chagas has emphasized the detection and treatment of affected individuals, shaped by broader social and medical processes. As De Maio et al. (2014) note, the concept of a “globalised Chagas” has highlighted a potential risk in nonendemic, industrialized nations since the turn of the 21st century, shifting attention from the global south to the global north and raising new solutions to a problem concerning health inequalities (De Maio et al., 2014). This new configuration aligns with Kreimer’s (2010) concept of the “purification process of the parasite”. Initially linked to poor living conditions, Chagas was reframed in the 1940s as a *vinchuca* (bug) problem requiring fumigation. Recent molecular approaches (see Mamo, 2024) have further redefined it as a parasite issue needing basic research, detaching it from affected populations and driving an unprecedented preventive approach in Chagas focused on treating individuals to mitigate “possible and potential risks” (Ventura Garcia, 2022, 2023).

This new configuration breaks with previous approaches focused on preventing new infections and treating symptoms only when they appeared (Magnani et al., 2009). It also challenges many dominant ideas about the disease, precisely the extent of the autoimmune theory and the ineffectiveness of pharmacological treatments during the “indeterminate chronic phase” (Zabala, 2010). The reformulation of the pathogenesis in the “indeterminate chronic phase” has shifted from autoimmunity to parasite persistence (Lescure et al., 2010), leading to a new risk model (Ventura Garcia, 2022, 2023; Ventura-Garcia et al., 2021; Ventura Garcia, 2018) that reframes Chagas’s progression: if treatments available under the autoimmune theory paradigm focused on alleviating effects in cases where the infection had damaged tissues, the rationale for medical intervention with parasitocidal drugs centres on the so-called etiological agent, thus opening the door to the administration of drugs during the chronic phase (Kreimer, 2010).

The two treatments for Chagas, Benznidazole and Nifurtimox, developed 60 years ago for veterinary use, have a wide range of toxic effects that may be severe among adults. Benznidazole may cause reactions like dermatitis, itching, and fever in 50% of patients, along with digestive issues (20%) and general symptoms like headaches and muscle pain (30%) (Molina et al., 2016). Since the harmful effects of these medicines can be severe, it is the main reason for treatment interruption or discontinuation (Pereira et al., 2013).

The criteria for a cure concerning these treatments have also been historically controversial (Kreimer and Zabala, 2007; Zabala, 2010). While both drugs are effective in children and acute cases, their efficacy in chronic cases has sparked a medical-scientific controversy around the disease conceptions and the notion of efficacy (Kreimer, 2010). The controversy arises because while a parasitological cure - the disappearance of parasites in the blood - is achievable, from the serological point of view, the antibodies remain in the blood, and drug effects can take decades to confirm, with efficacy decreasing over time since infection.

For decades, etiologic treatment was not recommended for chronic cases, but it is now advised for all acute and chronic Chagas patients, based on studies suggesting that Benznidazole and Nifurtimox may halt chronic symptom progression (Viotti et al., 2006, 2014). The therapeutic efficacy of the drug and potential treatment evaluation criteria have been reconsidered, and while the ultimate goal is the elimination of the pathogen, the control and reduction of its burden have also come to be considered as a reduction in the risk of developing pathologies.

1.2. Analytical notions

The use of medicines aimed at altering bodily conditions or functions (Geest and Whyte, 1988; Romaní, 1999) is a universal practice. Pharmaceuticals, as synthetic drugs produced and marketed globally, are a key category in biomedicine (Whyte et al., 2002). Efficacy, the final phase of their “life cycle”, defines their value: we use them because we expect them to benefit health or because society attributes that power to them (Geest and Whyte, 1988; Geest et al., 1996; Whyte et al., 2002).

Anthropological studies highlight the importance of context and the relationships between context, substances and individuals (Etkin, 1988; Romaní, 1999; Geest et al., 1996; Whyte et al., 2002; Jenkins, 2010). Since the mid-1990s, anthropology and Science and Technology Studies have shifted from separating the chemical properties of pharmaceuticals from sociocultural interpretations to viewing them as processual, relational, and situated entities. This approach views pharmaceuticals as flexible material objects shaped by social contexts, emphasising their understanding through practice rather than static outcomes. It also shifts the view of drugs from mere results of therapeutic practices to active agents in a network of relationships shaped by experimental, regulatory, and care environments (Hardon and Sanabria, 2017). Following this approach, the concept of “living labyrinths” (Hardon and Sanabria, 2017) emphasizes the complex, dynamic, and multifaceted contexts in which pharmaceutical efficacy is experienced. Rather than viewing efficacy as a matter of a drug’s inherent chemical properties, it highlights how efficacy emerges from local dynamics and social relationships, cultural meanings, individual experiences, and broader socio-political forces, being drug efficacy continuously negotiated and redefined in everyday life.

The concept of “lay care” (Menéndez, 2003, 2018) provides a valuable lens to examine how health negotiations unfold within local care knowledge and practices, as well as the power dynamics between various medical and care models. Rather than viewing health models as separate, Menéndez’s emphasizes the dynamic interactions between health practices and power relations, synthesising different forms of care that result from religious, ethnic, economic, political, technical, or scientific conditions, which people intentionally navigate and adapt, often involving autonomous or semi-autonomous decisions about the use of treatments. Unlike biomedicine’s individualistic approach to self-care, these practices are shaped by sociocultural contexts (Müller et al., 2022) and facilitate the adaptation and reorganisation of care to support the group’s biosocial reproduction.

2. Methodological and contextual notes

The experiences of the parasitocidal drug discussed in this article occur within the context of international migration, a key aspect of globalization and its political and economic shifts. These processes involve labour exploitation in a transnational market, where migration plays a central role (Goldberg et al., 2021). In Catalonia, the “care crisis” (Comas d’Argemir, 2019) reflects the collapse of a welfare model reliant on the unpaid women’s domestic labor. This crisis is tied to increasing reliance on undervalued, poorly regulated domestic work, largely filled by migrant women in vulnerable, informal, and hierarchical employment, identified as stratified reproduction, structured globally based on gender, class, ethnicity, race, and migratory status (Offenhenden and Ventura Garcia, 2024).

Spain has no vector-borne transmission but bears the highest disease burden outside the Americas, with the largest affected group from Bolivia. Considering the heterogeneity between the different autonomous communities, in Catalonia – where the study took place - underdiagnosis is estimated at 60.5%, and undertreatment at 80.2% (Navarro et al., 2022). The Catalan health system is a decentralised model, publicly funded, with universal coverage for residents. During the fieldwork, legislative changes in Spain excluded undocumented individuals from healthcare, challenging the principle of universal care. While Catalonia

officially maintained healthcare access for undocumented immigrants this right was often violated (Morero and Ballesteros, 2014; Offenhenden and Ventura Garcia, 2024). However, participants in the research arrived in Catalonia between 2000 and 2006 and were diagnosed before the legislative changes took place. By the time of the interviews, all had regularised their legal status.

The study, based on ethnographic work, included semi-structured in-depth interviews, participant observation and analysis of the scientific literature (previously described in Offenhenden and Ventura Garcia, 2024; Ventura Garcia, 2022, 2023; Ventura-Garcia et al., 2021; Ventura Garcia, 2018). Fieldwork took place from January 2014 to May 2016 in two hospitals and two primary health centres, the latter being the point of access to formal health services for the Bolivian community in Catalonia (Romay-Barja et al., 2019). Other Chagas screening routes in Catalonia include blood banks and a protocol for screening pregnant women and their children since 2010. One of the hospitals and health centre were in Barcelona and within its metropolitan area, where pharmacological treatment and infection monitoring were carried out in centres specialising in emerging infectious diseases. While the others were in two medium-sized cities in southern Catalonia, where care is provided by internal medicine departments. Treatment is provided free of charge.

I interviewed twenty-three Bolivian women with a clinical diagnosis of Chagas at various stages, including some with and without children, and excluding those under 18. Seven were interviewed twice. They were primarily contacted through health services, as well as through a patient association and a snowball sampling strategy, based on the inclusion criteria. All had migrated from different parts of Bolivia and worked in domestic and care roles in Catalonia, with one working as a telephone operator at the time of the interview. The majority were diagnosed in the “indeterminate chronic phase”, estimated to comprise 42–100% of diagnosed cases in Spain (Vásquez, 2016). Seventeen had received or were receiving parasitocidal treatment, two declined it, and four were unknown. Additional interviews with five Chagas specialist clinicians-researchers and two policy technicians provided insights into the biomedical perspective on treatment and informed the analysis. Interviewees were intentionally selected based on the research objectives to explore issues from observations or literature and to triangulate data. All interviews lasted 1.5–2 h, were conducted in locations chosen by the informants - at work (except one via Skype with a technician), in the health service, at home or in a bar -. They were audio recorded, pseudonymised, and transcribed verbatim, except for two cases where women did not consent, and I took notes. Saturation (Guest et al., 2006) was reached when data became repetitive, redundant, or provided no new insights. At that point, 23 cases were deemed sufficient.

The observation contrasted information from various sources and described practices transforming a population risk into a clinical entity and managing it in medical practice and everyday life. I observed 42 clinical visits, mostly with women, and followed five patients more longitudinally to examine the lived experience of risk. Observation also included international conferences to track scientific debates, and daily life settings of women - work, family, and community - to understand the context of risk experience.

I systematically recorded observations and transcribed interviews, importing them into AtlasTi (v8.2.4) for coding. Using inductive analysis (Braun and Clarke, 2006), I identified patterns, compared variations, and established relationships between codes. I developed the coding framework, reviewed it with my thesis director, and conducted the coding. Coding units were typically paragraphs with distinct themes or meanings. Disputed codes were resolved through discussion, revisiting data, and examining context. This approach enabled a thorough exploration of themes emerging from participants’ experiences and the broader social context.

I have translated the quotes in this article from Spanish to English. Ethical approval was obtained from the Medical Anthropology Research Center and the University Rovira i Virgili.

Lastly, as the researcher is part of the process, bringing values, experiences, and knowledge systems, it was essential to implement a robust reflexive approach to both the investigation and the use of concepts and units of observation to properly address the phenomenon (Ventura Garcia, 2018). This included continuously monitoring categories through a field diary, discussions at conferences, and exchanges with the thesis advisor and peers.

3. Results

These women’s migration stories are shaped by economic hardships driven by the late 20th-century neoliberal policies in Latin America (see Offenhenden and Ventura Garcia, 2024; Ventura Garcia, 2023; Ventura Garcia and Offenhenden, 2015; Ventura-Garcia et al., 2021; Ventura Garcia, 2018). Despite shared backgrounds of poverty and loss of loved ones to the disease, their experiences with parasitocidal treatment vary greatly. These range from relief and confidence to hope, trust in medical advice, uncertainty, and scepticism, as well as feelings of empowerment or vulnerability. These issues are explored in the following subsections.

3.1. When identity matters

Roxana was around her 40s when I interviewed her. She identified herself as Quechua and was raised in one of the departments with the highest rates of Chagas in Bolivia, “in a community far away from the city. My parents are very, very poor, and they have not been able to have that comfort to live in proper houses”. She pursued a teaching career with a scholarship for Indigenous people, married, and had a son. Shortly after his birth, she and her husband migrated to Spain to support their family financially. Half her family, including her deceased father, had suffered from Chagas “due to poverty”. She embodied the fact that sudden death may come at any moment, something preventing her from considering having another child or pushing her to travel each year to visit the family in Bolivia, as she does not have insurance for the repatriation of her body in case she dies. She took the medication “just in case”. However, the idea that death might come without warning was very present and taking the drug did not mean any reassurance for her: “I don’t believe in it. You can think one thing and then find yourself in trouble”.

Rosalba, who was in her 50s and originally from the Cochabamba region, also attributed her suffering to the rural poverty and “antiquated” living conditions she endured. However, her experience with the treatment was markedly different: “I always said: I’m going to die of Chagas, just like my father, when my heart was pounding” or when “skin rashes” or “shortness of breath” appeared. According to biomedical models, one of the characteristics attributed to Chagas is the “asymptomatic nature” of the so-called chronic indeterminate phase. However, at an *emic* level, discomfort may appear before or after a formal diagnosis, even disappear after stage classified. These discomforts are central to defining the experience and assessing the efficacy of the treatment. As exemplified in Rosalba’s narrative, discomforts ceased after treatment: “I no longer suffer (...). I am now treated, and I feel cured because I no longer have what I had (...). It has lengthened my life because I feel better and safer”.

Efficacy is evidenced by the disappearance of discomforts, restored daily functioning, and her newfound ability to envision herself in the distant future. This transformation followed what she described as a “new” and “valuable” treatment, provided in a context where such treatment is accessible. However, it is essential to note that while Rosalba felt cured, her idea of cure included periodic follow-ups, associated to a particular idea of “ironclad health” (Taranilla, 2015), aligned with medical narratives emphasising check-ups and practices aimed at maintaining the body in an almost invulnerable state through constant control and surveillance.

3.2. What's at stake

As mentioned in the previous section, discomforts are central to assessing efficacy, whether felt before or after the treatment, as we will see in this section. In the migratory context, treatment negative effects are critical as they can jeopardise work ability (Forsyth, 2015; Ventura Garcia, 2023; Offenhenden and Ventura Garcia, 2024). This was the case of Noelia, who arrived in Catalonia in 2001 and worked caring for older adults since then. She took the medicine fearing disease progression, but she experienced burning, numbness, and itching in her legs and hands for over a year, persisting at the time of the interview. Despite these symptoms, she continued working as a carer:

"I couldn't stand the itching, with this swollen hand, all red (...). I can't do anything! I put on a cotton glove and another one to work. I must work! I take care of an old lady (...). I can't stop washing her; I don't get paid if I do. What am I going to live on!?"

As noted in Offenhenden and Ventura Garcia, 2024, domestic workers, particularly women, face a discriminatory legal framework with fewer social benefits compared to other sectors, including no unemployment benefits. Informal recruitment is common, even for those with valid residence and work permits, and limited work history in Spain makes it challenging to qualify for benefits. Health issues further complicate matters, raising fears of income loss and undermining their ability to support their families. Many women are solely responsible for family maintenance, as many men disengage from parental duties.

However, the negative effects of the treatment can go further. For Laura, who was 35 and, unusually, had a work contract at the time of taking medicine, the treatment's negative effects triggered a chain reaction in her daily life, leading to an endless succession of visits to various specialists, including psychiatry, where she was diagnosed with depression. The treatment worsened her existing issues, causing her to miss a university course and taking time off work. She also faced stigma from colleagues who linked her condition to something contagious, associated to her origin and ethnicity. Before the treatment, she felt healthy, but now, she questioned whether the drug was worsening her condition: "Am I getting better or am I getting worse with this?"

While Laura is highly critical of the medication, questioning its efficacy and safety, Imelda, in her 40s with two children, had a very different perspective despite experiencing an extreme allergic reaction that required over two weeks in intensive care: "I had no skin, I was in red meat (...), and I couldn't swallow through my mouth, it hurt me, and I complained a lot (...). I thought I was going to die". After some time, Imelda resumed treatment with Nifurtimox, "because her doctor told her to" and in hopes of healing or at least being able to raise her children if something happened. But also with the argument that she was low in defences the first time she took it. After a week of retaking it, and in the face of an early allergy, she abandoned it definitively. The idea that each body responds differently to disease and treatments was common among interviewees. This suggests that the effects of the drug are influenced by individual components in which the attributes of the person taking it - as the attitude or constitution, among others - and the vital moment-linked to strength or weakness, and stress levels - contribute to having one effect or another.

3.3. Medical pluralism

In contexts of medical pluralism, lay and traditional conceptions about the body's functioning and health are key to understanding treatment use and experienced (Etkin, 1988). The efficacy of medicines is often assessed by how well they align with traditional healing practices and understandings of health while articulated with clinical practices. Another example is identifying emotions like worry, anxiety or anger as contributing to illness and the progression of the parasitic infection (Ventura-Garcia et al., 2021).

Diana was 53 years old when I met her in early 2015. She came from

a severely impoverished region in Bolivia, where she was all too familiar with *vinchucas* and had witnessed many relatives, including her father, suffer or die from Chagas. At the clinic in Barcelona, the doctor repeatedly assured her that "the results were all fine". However, despite being told that her heart was in perfect condition, Diana would often say: "My cousin had a heart attack, but it was Chagas too. She was healthy; the doctors said her heart was fine, and yet she died".

At the time of the interview, she was employed as a live-in caregiver for a 95-year-old woman diagnosed with dementia. This role required her to reside in the woman's home, managing all domestic tasks and providing essential care. The emotional toll on Diana was profound: "I just don't feel like doing anything, I don't feel like going out; sometimes I feel like crying ... Or desperation, or nerves ... I've never been nervous. Never. But here ...". When she began the parasiticide treatment, her symptoms temporarily subsided: "It stopped for a while. It was good; I was feeling more animated". However, they eventually returned. Diana considered that her health had deteriorated over the past three years due to the stress, irritability, and anxiety caused by her work situation. And she felt that these conditions had reawakened the "beasts" [parasites]: "The most important thing he [the doctor] recommended to him [her father] was not to get nervous or complain because the bugs could get angry, and once they get angry, they won't stop".

This cultural model, documented among Spanish-speaking and Indigenous groups in the Andean region and Bolivia (Tapias, 2006; Escandell and Tapias, 2010) and among people diagnosed with Chagas in Bolivia (Forsyth, 2017), aligns with the therapeutic pluralism practised by these women in the migratory context. According to this, preventive emotional management practices aim to "keep Chagas asleep", preventing disease progression - a nearly impossible goal for Diana due to her challenging working and living conditions -. Emotional stress compromised her treatment's efficacy. At the time of the interview, she was awaiting the blood test results and considering retaking the drug if the tests revealed a significant parasite load. Meanwhile, she used onion juice to cleanse her blood of parasites, a traditional self-care practice that she was using alongside pharmaceutical treatment.

3.4. Reactualizing efficacy in the clinical setting

Those administering the drug also navigate the meanings and expectations in clinical interactions (Helman, 1984; Whyte et al., 2002), which can potentially influence the lived efficacy of the treatment. This complexity extends beyond patients and their families to clinicians, who must manage the ambiguities and paradoxes of treatment efficacy when translating population-based probabilities of "cure" into individual, often relying on hope or follow-up.

In these cases, patients may have reservations and opt for follow-ups without pursuing treatment, a preference that can be overlooked in clinical settings focused on instilling hope.

While patients actively seeking a diagnosis are eager for treatment, which may be unavailable or costly in Bolivia, this is not always the case for those with incidental diagnoses, where treatment is usually offered by the doctor. In these cases, patients may have reservations and might opt for follow-ups without pursuing treatment, a preference that may be overlooked in clinical settings focused on instilling hope:

"I've never heard that there is a treatment or a cure for Chagas (...). It's a minimal probability for me to take a medication that I'm not sure will cure me. And then he [the doctor] told me: but what if you are this 0.0001% that you will be cured? So you have hope (...). It was with that he convinced me (...). In the end, you hold on to anything" (Laura).

Laura's experience underscores the complexities of the doctor-patient relationship and the uncertainties surrounding parasitic treatment. Doubting the drug's efficacy and safety, she questions its value and stresses the need for better information, community discussions, and follow-up without clinician pressure. However, she

acknowledges that clinical power dynamics may deter patients from challenging doctors, making them more likely to accept treatment if recommended:

“Are we being tested? Are we laboratory rats? (...). We would like to know! (...). They [doctors] should explain it to you clearly, don't treat us like fools who don't know anything, that they tell you something and you have to believe it (...). This [Chagas] is typically contracted in the countryside, and people from rural areas often haven't had the opportunity to pursue education. So, they can likely take it as fact when you tell them something.” (Laura).

While not all the clinicians were fully convinced by the use of these pharmaceuticals, the fact that they did not have another option to offer to the patient was often crucial to prescribing it as an “*act of faith*”, as a “*consolation for the patient*” and even as a consolation for themselves, as proof that they can do something: “*I think it is crucial to try it because it is the only weapon we have to fight*” (Magda, clinician). The complexity deepens when the chances of “cure” overlap with the idea of Chagas as a chronic condition requiring lifelong clinical follow-up: “*In the chronic phase, only a peak of 20 per cent is cured, counting as a cure that the antibodies descend (...); that is why it is so important that a follow-up is made every year or every six months to see if the disease has worsened*” (Martin, clinician). Despite the results of the analytics may be clinically meaningless immediately after treatment, the drug's efficacy was shaped by the doctor's interpretation and the follow-ups in the context of the medicine's attributes, origin, and symbolic value - new, modern, scientifically proven -.

The variations on the lived efficacies described, understood as processual, relational and situated (Hardon and Sanabria, 2017), shed light on the complexities of social and gender inequities and identities and the meanings and expectations of lived treatment outcomes. I will reflect on it further in the discussion.

4. Discussion

Hardon and Sanabria (2017) point out that anthropological views on pharmaceuticals have evolved from seeing drugs as static objects with distinct chemical properties and sociocultural meanings to understanding them as dynamic entities shaped by context. Rather than existing as purely “discovered” substances, pharmaceuticals are continuously redefined through processes of extraction, purification, and modification in laboratories, influenced by cultural, social, and scientific practices. Once these substances leave controlled settings, their effects are further shaped by the unpredictable and interconnected realities where social, cultural, and environmental processes interact in complex ways.

From a process-centred perspective, the efficacy of parasiticide treatments for Chagas, initially defined in laboratory settings, has been redefined by the evolving context of the disease's globalisation and the growing focus on its molecularization. The transition from eradicating pathogens to reducing disease burden - framed as lowering the risk of developing related pathologies - has paved the way for a new prevention and care model that perpetuates social inequities. In addition, the pharmacological efficacy and effectiveness of these treatments are marked by “biomedical ambiguities” (Whitmarsh, 2008), with outcomes remaining uncertain and provisional. From this, we could infer that the experience of healing for those who have taken them would similarly be placed in a temporary state. Nevertheless, these ambiguities multiply in the “lay care” settings, where treatment efficacy becomes a dynamic, negotiated aspect of everyday life, rather than a static attribute of the pharmaceutical.

In this article, I have explored the lived efficacies of Chagas treatments from the perspective of migrant women employed in Catalonia's domestic and care sector. Through their stories, I highlight how efficacies emerge within relational and context-specific frameworks of “living labyrinths”, reflecting embodied sociocultural, political, and

historical processes. By framing these experiences through “lay care”, the analysis extends beyond therapeutic practices' outcomes, connecting them to the broader conditions these women navigate and sustain their lives.

In the migratory context, parasitic treatments often represent a technology of hope (Jansen, 2021), offering these women a chance to extend life and pursue their goals while balancing work and familial responsibilities. Yet, their precarious domestic and care work - marked by informality, lack of contracts, and exclusion from social benefits (Offenhenden and Ventura Garcia, 2024) - makes preserving the ability to work vital, shaping their identities as women and migrant workers, materialising care for their families, and influencing the lived efficacy of treatments, either challenging or reinforcing it. This occurs alongside the medicalisation of the condition within a broader global health framework, where the biopolitical management of risk, poor health, and suffering often fails to address profound social, political, economic, and historical issues, despite its potential role in treating or preventing diseases (Jenkins, 2010). Within this framework, hope may become blurred by a deep embodied scepticism that eventually challenges the hegemonic biopolitics of risk concerning Chagas.

In addition, treatment negative effects can inadvertently reveal one's condition at work, jeopardising their ability to work or maintain employment. Additionally, these women may face discrimination based on ethnicity and origin within the migration context, where certain infectious diseases are often linked to processes of “othering” (Sánchez Arteaga et al., 2015), further intensifying the stigma they may already be facing within their community, where Chagas is highly stigmatised. However, this study did not find that stigma led to avoiding treatment out of fear of disclosing the condition, as has been noted with other illnesses such as asthma, mental health diagnoses, or HIV, where the desire for deidentification can influence the decision to seek or avoid treatment (Dowell and Hudson, 1997; Adams et al., 1997; Barton Laws et al., 2000; Usher, 2001). In this ethnography, access to treatment in this migratory context - contrasted with the limited options in Bolivia - may lead to a reinterpretation process where lived efficacies are reshaped, associating them to a “newest, modern, and “best” parasiticide available for Chagas. Negative effects after treatment are common and often fuel scepticism about its efficacy and safety, as noted in other anthropological studies (see Whyte et al., 2002). This scepticism is shaped by personal experiences shared within personal networks, where trust in medicines is negotiated. For these women, negative effects are often seen as proof the medication is “strong”, but also, consistent with popular understandings of the body, as the result of personal or situational factors, making them not generalisable to others or oneself at different times.

These popular models of health also intersect with working conditions and lived efficacies, as domestic work is physically and emotionally demanding. Caring for elderly members or the employers adds an emotional dimension that extends traditional gender roles assigned to women, reinforcing a gendered division of labour (Offenhenden and Ventura Garcia, 2024). The way these emotional demands intersect with the conceptions of health and illness often leads to suffering concerning the condition, particularly for older workers with limited opportunities for social mobility.

The results also highlight how pharmaceutical effects are constantly updated, modified, and redefined within care settings (Hardon and Sanabria, 2017), shaped by power dynamics and patient-doctor interactions. These dynamics explain why some individuals diagnosed with Chagas adhere to treatments with uncertain efficacy and potential adverse effects, and how these lived efficacies are reinforced or challenged during follow-up visits. Treatment can alleviate patients' anxiety and provide hope - particularly for women feeling guilty if their children are infected (Garrido and Avaria, 2022) or fearing they may die before their children can care for themselves -, while reinforcing the doctor's confidence in their competence and that action has been taken (Whyte et al., 2002). However, while patients diagnosed with Chagas may often

avoid confronting doctors and appear compliant during consultations (Pound et al., 2005; Ventura Garcia, 2018), these micropolitics can challenge medical authority and clinical guidelines, the reduction of care to the strictly bio-pharmacological, and paternalistic practices within clinical contexts, associated to ethnicity and gender. Patients may ultimately reject the prescribed treatment, turn to alternative care, or integrate multiple approaches to reinforce the management of their condition, including the role developed by religious values on health choices, with many women identifying as Evangelical, an area for further exploration.

Finally, recent ethnographies show that doctors also reflect on their practices (Hardon and Sanabria, 2017). While this ethnography captures some doctor experiences, further research is needed to explore how dominant discourses on parasiticide treatment during Chagas' "indeterminate phase" are challenged by practitioners in clinical practice.

Building on Craig (2012) and Hsu (2012), lived efficacies should be understood through the actual practices and contexts in which people use, experience, and engage with a treatment in everyday settings, which in this case is a continuum of the everyday life conditions associated to migration, gender and ethnicity. Examining these women's experiences and practices reveals how they navigate the "living labyrinths" of managing Chagas, balancing discomforts and the effects of treatment with the demands of precarious jobs and lives in a migratory context (Forsyth et al., 2021; Valdez-Tah, 2021; Martínez-Parra et al., 2018; Offenhenden and Ventura Garcia, 2024; Ventura Garcia, 2023; Ventura Garcia and Offenhenden, 2015; Ventura-Garcia et al., 2021). This highlights how lived efficacy is dynamically unfolding and permanently redefined, influencing their sense of self, emotional well-being, hopes, and everyday functioning, and allowing for a broader interpretation that suggests that limited healthcare access is not the only aspect preventing those affected by Chagas from being treated. Emphasising these lived efficacies, the value placed on biomedical technologies, and broader power relations and structural violence reveals how those affected manage the condition reflexively (Menéndez, 1998, 2003; Whyte et al., 2002; Müller et al., 2022) and underscores the role of pharmaceuticals as active agents that shape social and cultural worlds with significant impacts on social life and health care.

5. Conclusion

Biomedical treatments for neglected tropical diseases are often outdated and harmful, with pharmaceutical companies lacking incentives to develop new drugs due to the limited profitability from impoverished patients. As a result, advancements rely on philanthropic and public sector efforts, and new treatments remain years away (Forsyth, 2018). Thus, it is crucial to recognise that the same structural violence that perpetuates social inequities, exposing the most vulnerable groups from endemic regions to the infection and placing them in precarious living and working conditions in the context of migration, also limits their access to prevention and care. This is due not only to a lack of effective treatments and "market failure" (Trouiller et al., 2002, in De Maio et al., 2014) but also to "stratified biomedicalisation" (Clarke et al., 2010, in Mamo, 2024) of global health and the insufficient solutions provided through its pharmaceuticalisation, which risks reducing broader contextual processes to mere biological problems, prioritising pharmaceutical solutions over other forms of care and intervention (Menéndez, 1998; Jenkins, 2010; De Maio et al., 2014). Examining the lived efficacies of potentially harmful pharmaceuticals with uncertain effects in the Catalan context underscores a pressing issue of social justice that goes further: the urgent need for structural preventive approaches in global health, along with the development, availability of and access to diagnosis and more safe and effective treatments.

While a comprehensive discussion of these implications, especially in the so-called endemic countries, is beyond this paper's scope, I want to highlight one issue that emerges from the findings, being relevant to the current discussion. In his ethnographic study in India, Ecks (2005)

illustrates how pharmacological treatment is framed as a human right and a means of restoring citizenship by reintegrating disadvantaged or stigmatised individuals into society. This paper supports that view but also aligns with Persson et al. (2016), who argue that the pharmaceuticalisation of public health can result in new forms of exclusion tied to normative expectations, particularly when individuals opt not to adhere to prescribed pharmaceutical treatments, especially in resource-rich settings, where medications for conditions like HIV are readily accessible and widely used, creating moral pressures to conform to medicalised standards of care.

From a biomedical perspective, not using available medical resources is often seen as irrational resistance to therapy or neglect of the responsibilities as citizens by failing to care for their health, implying a moral obligation and disciplining patients to adhere to prescribed treatments (Persson et al., 2016). As a result, literature frequently discusses non-adherence by focusing on patient failures and deficits or within the framework of the doctor-patient relationship (Menéndez, 2003; Persson et al., 2016; Jenkins and Kozelka, 2017; Müller et al., 2022). However, medical anthropology and other social sciences highlight that treatment adherence is complex, often overlooked by biomedical views that fail to consider the sociocultural aspects shaping health, disease, and care-seeking processes (Kleinman, 1980; Donovan and Blake, 1992; Menéndez, 2003; Pound et al., 2005; Jenkins and Kozelka, 2017).

While ensuring access to diagnosis and treatment is undoubtedly fundamental, considering the lived efficacies of those affected helps us understand the logic behind the actions carried out concerning the treatment that encompass a whole series of aspects that go far beyond the biochemical properties of the drugs. This approach does not reduce pharmaceutical efficacy to these social groups' experiences; instead, it serves as a starting point to reflect on biomedical regimes, and the complex "living labyrinths" in action that are navigated and engaged in the "lay care" practices for social and cultural reproduction, including processes related to broader regulatory, research, and care environments. Examining and incorporating "lay care" practices into the therapeutic negotiation would enhance our understanding of how affected individuals, practitioners, and health services actively navigate the complexities of assessing efficacies, avoiding patronising dynamics that frame parasiticide treatment prescriptions within moral imperatives related to the governmentalities of risk.

While not radically new, this suggestion aligns with anthropological literature advocating for considering and integrating the knowledge and practices of those affected, acknowledging that these arise from complex sociocultural and structural inequities impacting their health and health-seeking processes. Applying this approach to parasiticide treatments in Chagas care could be valuable to reflect and reimagine other multiple forms of care practices.

Ethics approval

The project was approved by the Ethics Committee of the Department of Anthropology, Philosophy, and Social Work at Universitat Rovira i Virgili in October 2013.

Declaration of generative AI and AI-assisted technologies in the writing process

During the preparation of this work, the author utilized DeepL, ChatGPT, and Grammarly for translation and English language correction. Following the use of these tools, the author thoroughly reviewed and edited the content as necessary and assume full responsibility for the final publication.

Declaration of competing interest

No conflicts of interest.

Acknowledgements

I thank Martyn Pickersgill, Àngel Martínez-Hernaez, Oriol Romaní and Jorge Crespo for their comments on a first draft of the manuscript. PMF-PIPF-DAFITS-URV funded the work as a predoctoral grant. The writing has been supported by UK Research and Innovation (EP/Y023617/1), following a MSCA.

Data availability

The authors do not have permission to share data.

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