

***Cartas a Nora* from *Invisibles* (2007): Chagas Disease from a Bioethical Point of View**

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Summary

The story *Cartas a Nora*, the first in a series of five which make up the film *Invisibles* (2007) directed by Isabel Coixet serves as a reason to criticise the current situation of Chagas disease from the conceptual tools of bioethics. If we follow moral reasoning, we go from the individual case to the bioethical principle of justice (which is one of the four that make up the basic moral principles of this discipline). This approach takes us to a feedback situation: from the individual case to the strengthening of the criticism and condemnation of the injustice of the disease's present situation and vice versa. The analysis of the formal structure attempts to support the aforementioned, though introducing touches that are considered essential for a full understanding of the kind of narrative presented. It is explained that we are before a fake documentary, its formal structure is explained and it is made clear that it is not disrespectful towards the subject matter. The main purpose of the story, from a moral point of view, is to raise awareness, avoiding direct methods, in order to try to make the invisible visible or, to be more precise, to show us that which we do not want to see.

Keywords: Chagas disease, Bioethics, Justice, Documentary, Social Awareness.

Technical details

Title: *Letters to Nora* narration included in *Invisibles*

Original Title: *Cartas a Nora*

Country: Spain

Year: 2007

Director: Isabel Coixet

Photography: Emilio Guirao

Film editor: Arantxa Roca

Screenplay: Isabel Coixet

Cast: Lazmilla Castillo, Jakeline Vargas, Verónica Paladín, Montse Soler and Aran Blasco.

Color: Color

Runtime: 12 minutes

Genre: Documentary, Drama

Production companies: Médecins sans Frontière, Pinguin Films and Reposado.

Synopsis: View of Chagas disease through a Bolivian emigrant in Barcelona.

Awards: Goya Award for Best Documentary Film (2007).

<http://www.imdb.com/title/tt0871000>

Chagas disease has already been referred to in this journal from a mainly historiographic point of view¹. The intention of this article is to make a critical reading of the episode *Cartas a Nora* ("Letters to Nora") from *Invisibles* by means of conceptual bioethical tools and through an analysis of its film structure.

The episode *Letters to Nora* from *Invisibles*

Invisibles (2007) was produced by Javier Bardem with the participation of Médecins Sans Frontières. It tells five stories directed by as many film makers: namely, Isabel Coixet, Wim Wenders, Fernando León de Aranoa, Mariano Barroso and Javier Corchera, and it is presented as "the story of five forgotten conflicts".

The first of the five films is called Letters to Nora (Figure 1). It was directed by Isabel Coixet, based on a real story which takes place between Spain and Bolivia.

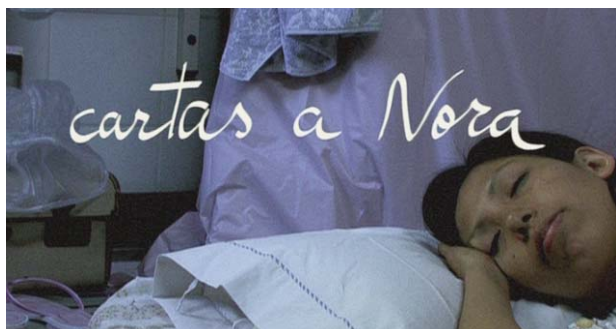


Figure 1: Nora (Lazmilla Castillo), the main character of *Letters to Nora*

It presents Chagas disease through the suffering and death of a man in Bolivia, captured in the correspondence Rosa sends to her sister Nora (Lazmilla Castillo). The narration is structured in three separate parts which correspond to letters that begin with the heading “Dear Nora”... While Rosa’s voice-over reads the contents of the letters the images match Nora’s everyday life (Figure 2), including images of her phone calls to her sister.



Figure 2: Nora’s everyday life has her sister’s letters as a background

In the first part Rosa, who is in Bolivia with her husband and children, tells Nora, an emigrant in Spain who is a domestic help, about the symptoms and signs that make her suspect that her husband, Walter, has Chagas disease. He is extremely tired, has lost a lot of strength, sweats at night, and complains about his chest - although he does not have a temperature -; in addition, he is serious and withdrawn, even fearful. Rosa says she has persuaded him to go to hospital. She uses the letter to thank Nora for sending her money, which has helped her to buy books and clothes for her children, as well as to remind her of Sarita, Nora’s daughter, who died of Chagas disease.

The second part begins with Rosa telling Nora that Walter has finally been admitted to hospital. The symptoms seem to worsen. She expresses again her strong suspicions that it may be the “damn *vinchu-*

ca” (damn kissing bug), the Chagas disease. As a result from this situation, Rosa begins to put two and two together and begins to think about the Chagas disease. Rosa remembers Nora from when they were children and played at being *invisible*, laughing gaily along the streets, thinking no one could see them. This process is like their childhood game and she feels that “*this disease is making us poor more and more invisible and nobody is interested*”. She summarises, in a chilling way, with “*It’s not that they don’t see us; it’s that they don’t want to see us*”. In a brief lapse of narrative time, Rosa manages to transmit images and sound, ranging from the innocence and tenderness of the children’s game to the tragedy of blind contempt that Chagas disease implies for the poor people of Latin America.

The third and last part of the narration focuses on the death of Walter, whose heart finally gave out to Chagas disease. Rosa writes to her sister to tell her he was buried three weeks before. The dramatic input increases when she explains to her son that his father is in Heaven with Sarita, Nora’s daughter, who also died from *vinchuca*. The doctors at the Hospital advise the family to get tested to see whether they have contracted the disease. But she doubts the usefulness of the diagnosis of a disease for which there is no treatment available: “*Doctor, so if we have it what are you going to do? Is there anything you can do? Doctor I’ve even read that the only medicine that stopped it has been discontinued. I read it in the newspaper.*”... “*Madam, there is something we can do. Bring them here and we’ll do the tests. Bring them in*”, “*But Doctor, my niece died in of Chagas disease in the patio of the school when she was jumping rope. She died doctor*”.

The narration comes to an end with Rosa’s resigned hope: “*I pray, I know not to what or whom, but I pray that they will eventually see us. So that they realise what’s happening because deep in my heart I know that something can be done*” (Figure 3).



Figure 3: “*I pray, I know not to what or whom, but I pray that they will eventually see us*”

Chagas disease

Chagas disease, or American trypanosomiasis, is an infection caused by a protozoan, *Trypanosoma cruzi*. The most common way of contracting the infection is through contact with the faeces of triatomine insects that feed on the blood of humans and animals². These insects belong to different species, commonly known by different names such as the one used in the film, “vinchuca” (Figure 4). Many of these bugs live within the adobe of shacks, from where they transmit the disease. It is estimated that around 16 -18 million people get infected by Chagas every year, of which around 50,000 die. When the insect that harbours the parasite bites, it leaves faeces on the victim’s skin. When the affected individual scratches the bite or touches his/her eyes or mouth, the parasite in the faeces enters his/her bloodstream. Chagas disease may also be transmitted through blood transfusions, from mother to child during pregnancy, or less frequently, through organ transplants or contaminated food. There is no vaccine against Chagas disease and those affected may get re-infected after receiving treatment³.



Figure 4: *Triatoma infestans* biting (source CDC)

“Chagas disease has an acute and a chronic stage. If it is not treated, the infection lasts for life. Acute Chagas disease debuts immediately after infection; it may last several weeks or months and parasites may be found in the circulating blood. The infection can be minor or asymptomatic. There may be fever and/or swelling around the place of inoculation (where the parasite penetrated the skin or the mucous membrane). Rarely, acute inflammation might lead to severe inflammation of the heart muscle or of the brain and the meninges. After the acute phase, most infected individuals enter a prolonged and asymptomatic stage of the disease (called “indeterminate

chronic”), during which very few parasites or none at all are found in the bloodstream. During this stage, most sufferers do not know that they are infected. Many people may spend their whole life without presenting any symptoms related to Chagas disease. However, it is estimated that 30% of infected people will develop debilitating medical problems, and these may occasionally become life threatening during their lifetime. The complications of chronic Chagas disease include heart rhythm abnormalities, which may lead to sudden death; dilation of the heart, which no longer pumps the blood properly, and dilation of the oesophagus or colon, which causes difficulties in eating and bowel movement”².

Médecins Sans Frontières has portrayed the public health situation of the disease in Latin America with crystal clarity. “Chagas disease is more common among the poorest and most vulnerable populations. Often unaware of how the disease is contracted or the probabilities of recovery, people infected by *Trypanosoma cruzi* are almost certainly in no position to fight for their right to treatment. Regional health authorities have systematically neglected the treatment for the disease”³.

There are deficiencies in diagnosis of the condition, and a lack of appropriate medicines for the treatment of the disease. “Chagas is one of the most neglected diseases in the world. It has not yet been detected in millions of people who contracted it between ten and twenty years ago and who, as a consequence, remain untreated”³.

“Chagas disease is complicated to diagnose. Doctors must generally perform two-three blood tests before being able to declare whether a patient is infected or not. In adults, the disease often remains undetected or undiagnosed in its early stages because the carriers do not present clear symptoms”.

“When a patient has already entered the chronic phase of Chagas disease, treatment with current medicines is no longer effective. Greater efforts should therefore be made in order to develop active identification methods for the acute phase of the disease, which is when patients could really benefit from the treatment available”.

“Likewise, it is also difficult to establish whether a patient is totally healed or not. The only method available at present is to confirm a decrease in the amount of antibodies in the bloodstream”.

“The treatment may have severe side effects and should be taken under medical supervision. This is a challenge, since between 30 and 60 days are needed for the completion of a treatment course. There is no formula for younger children; currently, health workers must split the tablets in order to get the right dose and mothers must crush the pills and mix them with juice or the mother’s milk in the case of babies. None of the treatments can be prescribed for pregnant women who might pass the disease on to their newborn children”.

“The *market* constituted by Chagas patients is insufficient to motivate the private sector to invest in the development of medicines or therapeutic innovations, or even to register the existing medicines. But there is a pressing need for more research and development (R&D) of new molecules. An ideal and effective medicine should be developed to treat patients in the acute, indeterminate and chronic phases of the disease”³.

Bioethical point of view

The violation of the principles of justice is clearly expressed in *Letters to Nora*. In bioethics, the theory of the four basic principles, formulated by Beauchamp and Childress in 1979 in “Principles of Biomedical Ethics”, is vital (Figure 5)⁴. In their work the American authors develop and advocate four principles which are still supported nowadays, being of great use in the resolution of conflicts in this field: the principles of autonomy, beneficence, nonmaleficence and justice.

Diego Gracia distinguishes three levels in moral reasoning⁵: a formal one, which states absolute respect for all human beings; a second level, that of the material content of moral principles, such as the four principles of bioethics; and since these four principles are neither absolute nor without exception, the third level of moral reasoning is always the analysis of the circumstances and consequences of the particular case.

The moral reasoning that the cinematographic narrative analysed gives rise to stems from a specific case of Chagas; in it we can see its “invisible” nature. Rosa prays to “*to be seen*” because she is aware that this disease makes the poor become even more invisible. Médecins Sans Frontières state what is shown in the narration: infected people are in no situation to claim the bioethical principle of justice,

demanding an equal distribution of health resources in a globalised world³.

Following the levels of moral reasoning⁵, the violation of the principle of justice in health care can be criticised. Starting from the individual case portrayed in the narrative we are witness to a condemnation of the absence of equality in the share of health-care resources and the flagrant absence of research initiatives by the multinational pharmaceutical industry for diseases that are not “attractive” for the market, as is the case with Chagas; it only affects “*18 million people in Latin-America who live in poverty*”. The film suggests a surreal contrast in the sense that while “*at this moment no laboratory in the world is carrying out research to develop an efficient treatment for Chagas disease... there are 1800 patent pending drugs for slimming*” (Figure 6).

Beauchamp and Childress end the chapter devoted to the principles of justice in health care pointing out the following: “*Policies of just access to and financing of health care, together with strategies of efficiency in health care institutions, dwarf in social importance every other issue consid-*

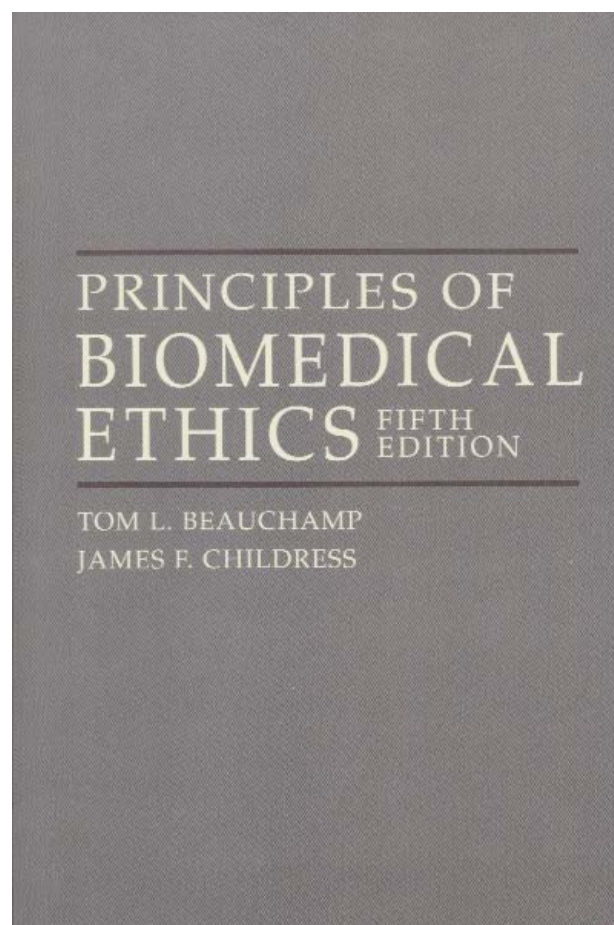


Figure 5: Cover of the fifth edition of *Principles of Biomedical Ethics* by Beauchamp and Childress

ered in this book. Many barriers exist to achieving access to health care. For millions who encounter those barriers, a just health care system remains a distant goal⁴. It is Rosa's distant ideal when she prays for them "to take notice of her".

As an unjust counterpoint to the narrative directed by Coixet (the *invisible* of Chagas disease) we find the developed world, characterised by a progressive and unlimited development in the field of health care, giving way to the phenomenon of the "medicalisation" of life, a situation in which every aspect of human life is under the influence of health concerns, in which non-medical problems are treated in terms of illness. This enormous and unjustified health-care expense situation was reported in an editorial in the *British Medical Journal* (2002) which bore the meaningful title: *Too much medicine?*⁶.

As in similar cases in the history of humanity, justice in health care is closely linked to social justice. Illness and its healing are closely related to poverty. The improvement in hygienic-sanitary social conditions would imply an improvement in the incidence index of the disease. Jörg Blech places this improvement in relation to other infectious diseases: "In the reduction of mortality, the general improvement in the living conditions of the people was definitively the most important aspect. After studying the death registers in Wales and England, the social-minded English doctor McKeown discovered the following: the deaths caused by many diseases, among them cholera, typhoid fever, tuberculosis, measles, scarlet fever and whooping cough, dropped dramatically in the 19th century, well before the epidemiological agents responsible for the disease had been identified and drugs against them were available. From the example of tuberculosis, McKeown calculated that approximately 90% of the decreases in disease rates were due to improvement in living conditions and only 8% to the availability of antibiotics⁷".

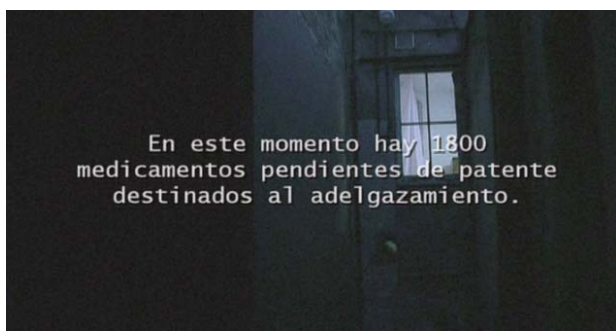


Figure 6: The surrealism of pharmaceutical research shown in *Letters to Nora* ("at this moment no laboratory in the world is carrying out research to develop an efficient treatment remedy for Chagas disease... there are 1800 patented Patent Pending drugs for slimming")

The proximity to the world of "the invisibles", illustrated in the narrative based on a true story portrayed in *Letters to Nora*, allows us to go from the sad complicity with the characters to the moral judgement that condemns a huge injustice. This condemnation is both at health-care level in groups of millions of human beings (the "invisibles" for multinational pharmaceutical companies), and at the level of social justice (for millions of "invisible" people who would not die if their life conditions were to improve: decent housing, sewage systems, drinking water...).

Analysis of the film

The analysis of the film is carried out, beyond the aforementioned elements, with the purpose of explaining how this problem is taken to the screens. The first striking fact is that this, like the rest of the stories that make up the film - and to a greater or lesser extent - is what is technically called a *fake documentary* (in fact, *Letters to Nora* was entirely filmed in Barcelona). However, and this should be stressed, this does not imply that the film deals with fictitious or unimportant topics, or that such topics are treated in a disrespectful way. It is only due to formal reasons. This point must be explained to avoid misunderstandings. As an introductory note it must be pointed out that the documentary is closer to works such as *Moi, un Noir* (1958) by Jean Rouch than to others in the style of *Vérités et mensonges* (1973) by Orson Welles (Figure 7), where both form and content refer to what is announced in the title itself. The same trend will be followed by many of the other extracts from the "documentary". This element, which at first sight might seem outrageous or even immoral, is far from being so. Following a growing trend, and echoing the mechanisms of the so-called "cinematographic modernity", this new style of documentary has assumed its share of guilt. That is, the impossibility of absolute neutrality or objectivity. Thus the choice is taken, in cases like the one we are dealing with, to make use of the "fictionality" of the medium to tell very real stories. Let us analyse some elements that illustrate this statement.

The story begins with a reference to its veracity, the well-known announcement: "Based on a true story". Nevertheless, the first element of fiction is already shown in this still. "Based on" means that there is neither the intention to perform a follow-up, nor the intention to carry out fieldwork in the strict sense of the word. The elements are the typical ones of a documentary film: a hand-held camera, "low technical quality" - in an attempt to keep in tune with

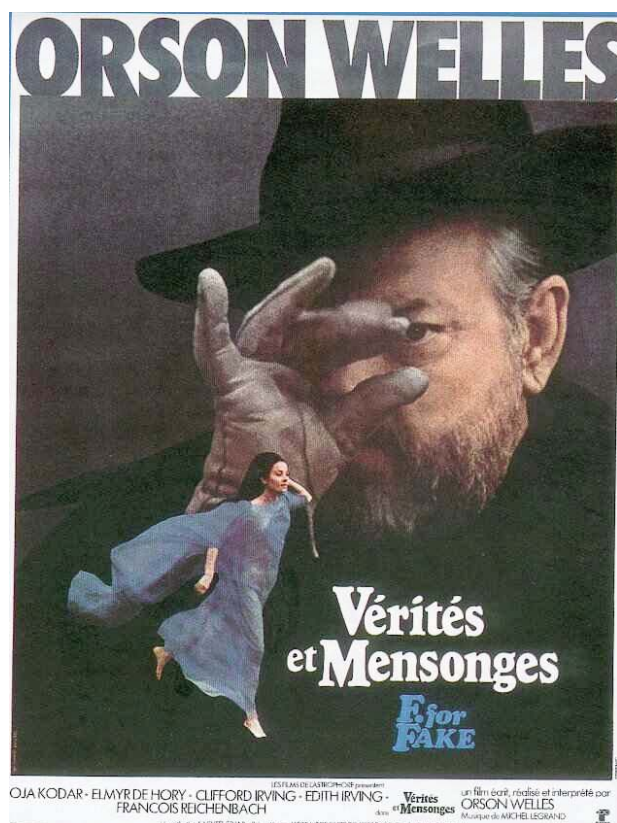


Figure 7: French poster of *Vérités et mensonges* (1973) by Orson Welles

the dynamism of reality, a reality which is reluctant to “sit” for us -, a different setup from that of film (for the same reasons), etc. The spectator only needs to pay a little attention to notice that all these elements are artificial. The “low quality” does not respond to a lack of budget or a lack of knowledge of the cinematographic environment; it is indeed something deliberate, since the expertise of Coixet, who in the caption confesses herself the director of the chapter - in almost childish letters (Figure 8), hardly appropriate for a supposedly “realistic” documentary -, is unquestionable. A domestic look is chosen, like that of an amateur, even with *retro* touches (the occasional sound of the reels which remind us of 8-millimetre cameras and the use of colour filters that intend to prove that it is an antique film-story). It is clear that this work has neither been recorded with an 8-millimetre camera, nor with a low-cost video camera. The aspect of the photo bears no similarity with that of the old cameras mentioned, so that the sound of the reel would respond to the other intention we have just mentioned. And, even though it was filmed in digital format, it was certainly not made with an “amateur’s” camera, at least not all of it. The reason is simple. Even though the image is sometimes “unconnected”, the film plays with the depth of field. This, as anyone who is familiar with the technical aspects of video

cameras will know, is not possible with an “amateur’s” camera. Therefore, why choose a photography that is far from preciosity? Here we could mention the words of the French film maker Robert Bresson: “*The beauty of your film shall not lie in the images (postcardism) but in the ineffable that they will release*”⁸. In fact, everyday images, hardly polished like reality itself, speak, dialogues being non-existent. Little by little they build a parallel story to that told by the voice-over, amplifying and multiplying sensations. In other words, the overlapping of images and text duplicates the story, turning it into several (even though they are the same one) and turning it into a closer text, of the kind that could be recorded by anyone’s video camera. Nevertheless, the choice of correspondence as the main axis of the story still emphasises its fictional nature.



Figure 8: Childish letters in the film credits of *Letters to Nora*

Sound plays a very important role in this work. Far from its conventional use - mainly in the form of dialogue - it assumes other functions. In fact, there is no dialogue, neither fictional nor in the form of interviews (a common resource in documentaries). The little sound there is, apart from the voice-over and the soundtrack, is direct, that is, not “masterised” or subjected to any kind of postproduction process. Undoubtedly, the intention is to suggest that underlying this narrated fictitious story is a true story, much more moving than what the film itself might show. In the same way, this film plays with the depth of sound, especially in the song which accompanies the tale. Yet again, this aspect is far from the traditional approach of the documentary and, as a consequence, from the strictly realistic approach. The sound, sometimes near and sometimes far away, reproduces the distance and proximity to reality and, perhaps, the spectators own attitude towards the problem dealt with.

In *Letters to Nora* there are many elements that suggest “autoreferentiality” and that play a guiding role, not only for this section, but for the work as a whole. Of the first type we find the children’s song

at the end that refers us to the kind of characters in the heading. The reason for this is to try to emphasise that Chagas disease is common in Latin America - something also referred to by the use of everyday language (“la vinchuca”)-, or more to the point, that it affects a poor and rural sector of the population. But the intention is also to make people aware of the problem, which, as we will see, is the main purpose of the chapter, beyond any desire to document or to outline a chronicle. Of the second type is the already mentioned sentence “*when we were invisible*”, a detail which connects this part with the rest of the film. The chapter it bears the most similarities with is obviously *Bianca’s dream*, directed by Mariano Barroso. Nevertheless, the differences are also clear. In this latter film, although the fictional element is also clear, the fieldwork or approach to reality is greater. Curiously, both condemn the proceedings of the pharmaceutical industry. And also curiously, they both criticise the Western world, more concerned with aesthetic matters (slimming, eradication of unwanted hair) than with the horror implied by the absence of health for an ample majority of the world’s population. Curiously again, in short, both parts stress how one part dies of hunger and disease, while the other dies of the disease caused by indigestion, as another way to express the “death of the soul”.

The story ends with a reference to real facts of the Chagas disease. An inclusion of text provides enough information of a more technical nature without completely giving up the awareness element (the folk song that also tackles the problem from a point of view which is not clinical, but human) (Figure 9).

If we accept that both *Letters to Nora* and the rest of the episodes that make up *Invisibles* display a great quantity of elements which are far from what might be considered typical of the classic documentary, we can ask the key question: what is their purpose? What is their basic tool? It must be said, or repeated, in plain words that the intention is to awaken the population’s awareness. Although it is also done, it is not so important to show the images of the problem as to appeal to people’s hearts. In this case there is an important display of resources intended for such purpose: scenes of grief, images of children, children’s folk songs, nursing homes crammed with elderly people under conditions that if not unhealthy are indeed pitiful, desperation, the ghost of feeling separated from one’s roots and that of poverty, the death of a daughter, etc. The openly sensitizing elements are elegantly rejected, such as images of patients suffering the advanced phase of Chagas.

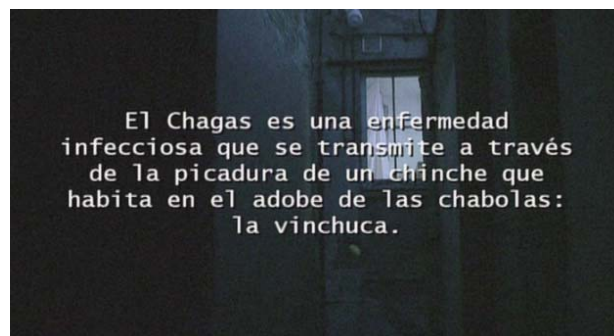
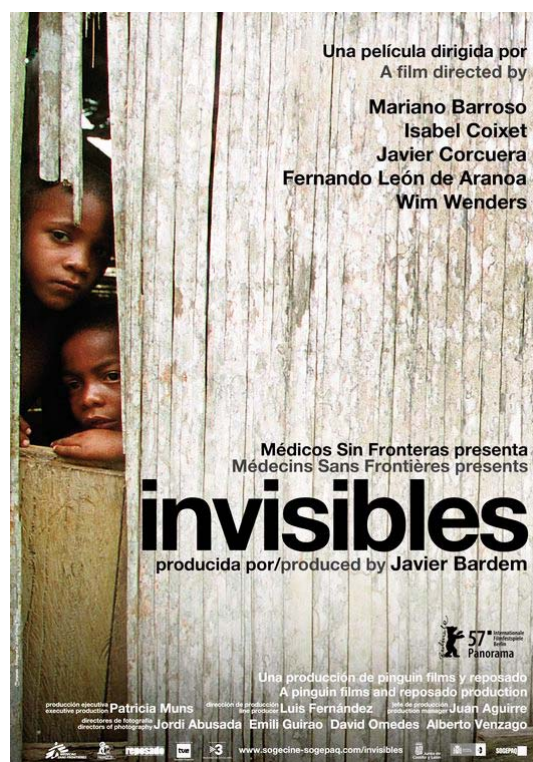


Figure 9: Information about the disease in *Letters to Nora* (Chagas disease is a parasitic disease resulting from the bite of a bug that lives in the mud walls of the slums: the kissing bug)

Unfortunately, and the different authors who sign each of the works are well aware of this, the spectator is highly immunised to the picture. Images like these are commonplace: they are in newspapers, on TV, and this stirs people into action. The real problem is known by everyone. Therefore, the new matter lies in beginning to gain awareness and, as far as possible, in taking action. *Letters to Nora* and the rest of these films strive to make visible the invisible, or more precisely, as an extract from one of the letters harshly reveals: “*that which we simply do not want to see*”.

Translation by the team of the Languages Service of the University of Salamanca.



Spanish poster of *Invisibles* (design by RedPixel)

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Some diseases have an animal reservoir, meaning they can infect other species besides humans. Yellow fever, for example, infects humans, but can also infect monkeys. If a mosquito capable of spreading yellow fever bites an infected monkey, the mosquito can then give the disease to humans. So even if the entire population of the planet could somehow be vaccinated against yellow fever, its eradication could not be guaranteed. The disease could still be circulating among monkeys, and it could re-emerge if human immunity ever waned. (The discovery of an animal reservoir for yellow fever was in fact The Presidential Commission for the Study of Bioethical Issues (the Bioethics Commission) was created by Executive Order 13521 on November 24, 2009. The Bioethics Commission advised President Barack Obama on bioethical issues arising from advances in biomedicine and related areas of science and technology. It replaces The President's Council on Bioethics appointed by United States President George W. Bush to advise his administration on bioethics, and the National Bioethics Advisory Commission (1996)

Disease is a dynamic process and it is just opposite to health. Health denotes perfect harmony and normal functioning of all the body system or state of complete wellness, whereas disease denotes disharmony and deviation from normal functioning of various bodies functioning system. What's the difference between infectious and non communicable diseases? According to its creators disease never depends upon single isolated cause rather it develops from a chain of causation in which each link itself is a result of complex interaction of preceding events these chain of causation which may be the fraction of the whole complex is known as web of causation.