

# *The medicine is the least of the problems:* following networks in adherence to AIDS treatment

*O remédio é o menor dos problemas: seguindo redes  
na adesão ao tratamento de aids*

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## **Abstract**

This essay intends to question Bruno Latour's methodological proposal. In research on people living with HIV and their adherence dilemmas, using Latour's proposal, we sought to address the following issues: how does one bring the universes of people living with HIV closer, without fractioning their lives? How does one understand the relationship established between PLHIV (People living with HIV) and their medication without setting aside the issue of medication management from other experiences? Despite the obstacles, common to those who decide to follow certain itineraries (the dangers of the journey, as Brazilian author Guimarães Rosa would say), the research guided by the methodology proposed by Latour - the ethnographic methodology of the "Actor-Network Theory" - allowed us to follow the actors' steps, although timidly and initially, without fractioning their lives and without making isolated cutouts, monitoring what happens in a network and is interconnected, interfering and suffering interference. The ethnography carried out led us through tortuous paths, forcing us to venture into confusing itineraries, networks of humans and non-humans, medications, swimming pools, NGOs, health care, and a network of relationships among people living with HIV, through the difficult paths that our interlocutors developed.

**Keywords:** AIDS; Addiction to the Treatment; Ethnography; NGO.

## Resumo

Este texto buscou problematizar a proposta metodológica de Bruno Latour. Numa pesquisa sobre pessoas vivendo com HIV (Vírus da imunodeficiência humana) e seus dilemas de adesão, valendo-nos da proposta de Latour, buscamos trabalhar com as seguintes questões: como efetuar uma aproximação aos universos das pessoas vivendo com HIV sem fracionar a vida das pessoas? Como compreender as relações que a PVHIV (Pessoas vivendo com HIV) estabelece com a medicação sem separar a questão da administração medicamentosa do restante das experiências? Apesar dos percalços, comuns àqueles que se dedicam a seguir itinerários (os perigos da travessia, diria Guimarães Rosa), a pesquisa guiada pela metodologia proposta por Latour - a metodologia etnográfica da “Teoria Ator-Rede” - permitiu, ainda que tímida e inicialmente, seguir os passos de atores, sem fracionar as suas vidas, sem fazer recortes isolados, acompanhando o que acontece em rede e está interligado, interferindo e sofrendo interferências. A etnografia realizada nos levou por caminhos tortuosos, fazendo-nos embrenhar em itinerários confusos, em redes de humanos e não humanos, de remédios, piscinas, Organização Não Governamental (ONG), serviços de saúde, uma rede de relações de pessoas vivendo com HIV nos caminhos difíceis que nossos interlocutores elaboraram. **Palavras-chave:** Aids; Adesão ao tratamento; Etnografia; ONG.

## Introduction

The number of individuals living with the human immunodeficiency virus (HIV) is growing, and it is necessary to know what their lives are like. At the beginning of the acquired immunodeficiency syndrome (AIDS), in the 1980s, diagnosis was a prophecy of imminent death, and it was said that survival was up to six months after diagnosis. After the advent of triple antiretroviral therapy, in the 1990s, life expectancies increased to five years survival. In the first decade of the 21<sup>st</sup> century, the question is no longer survival but rather the quality of life of those living with HIV (PLHIV). There are no more predictions of imminent death and health care professionals have begun to classify AIDS as a chronic disease, due to the increased life expectancy of PLHIV. Their lives, however, are anchored on permanent dependency on specific medicines; TARV.

The number of PLHIV grows by approximately thirty thousand new cases, who will go on to be patients using TARV, annually, added to the two hundred and fifty thousand already living with the disease in 2010. It should also be taken into account that it was in 2012 that the Ministry of Health issued a technical note altering its recommendations for starting medicalization of PLHIV. Before this, it was recommended to start the treatment after tests showed CD4 + lymphocytes below 350 units/milligram serum, this parameter has now changed to 500 cells/mm<sup>3</sup>; a factor which greatly increases the number of people taking TARV.

When thinking about parameters for developing public health programs, we understand that it is necessary to study factors which could interfere in the quality of life of those taking TARV. We sought to understand the daily procedures of taking the medications, doses and times, always with an eye to the different possibilities which could interfere with life as a whole in all the paths, whether chosen by PLHIV or not. Over time, the scientific literature has begun to discuss AIDS treatment as something more than “taking medicine” or, in other words, as something more than administering antiretroviral drugs - but it has always been difficult to research this “something more”. The question is, then, how to become closer to the universes of those living with HIV, without fractioning their lives? How can

the relationships which PLHIV establish with the medication be understood without separating this from the daily issues of administering the drugs from the rest of the experiences?

The aim of this research on adherence to treatment (for a doctoral thesis) ceased to be about the reaction to medication reported by PLHIV and came to consider the individuals' relationships with their environment and how circumstances can alter procedures concerning adherence to treatment. The research was conducted in Francisco Morato (SP), accompanying daily activities concerning adherence to treatment. The overall objective was to describe PLHIVs' intricate networks of relationships, recording the movements concerning the disease, day-to-day experiences, seeking the diverse ways along which an individual goes and always avoiding field observation concentrating only on aspects of the disease. More specifically, we wanted to discover how certain factors interfere in the life and health of those individuals, such as the network of relationships formed by attending a health care service; participation, or lack of it, in support groups with peers and, also, the adaptation processes when faced with the confrontations of life as a whole.

In this article, we aim to present the ethnographic methodology used in the research conducted with PLHIV in PVHIV in Francisco Morato, a poor suburb in the north of Greater São Paulo, some 40 km from Praça da Sé. The need to describe the actions of the interlocutors in a specific reality (socio-economic, political and geographic) led us to the work of Bruno Latour - "Actor Network Theory" - which recommends accompanying the actors along their tangled paths. In the following sections we will seek to: describe the context of the research, give a quick overview of conditions where our actors live; present the work of Bruno Latour, the author of the theoretical framework used in the methodology, and report some of the research procedures which led us to unusual paths in the bibliography dealing with adherence to antiretroviral treatment.

## The context of the epidemic

Between 1980 and 2010, 608,230 notifications of HIV infection were reported; in the same period,

there were 241,469 deaths from AIDS, leaving 366,761 individuals living with HIV. In 2010, the national incidence rate was 17.9/100,000 inhabitants (34,218 notifications), while the death rate was 6.3/100,000 inhabitants (11,965 deaths) (Brasil, 2012a). As this trend shows, there is a significant increase in the number of individuals living with HIV beginning antiretroviral treatment. In February 2012, the Brazilian Ministry of Health reported 254,000 individuals receiving antiretroviral treatment in 2011 - in the state of São Paulo alone, this figure was more than 76,000 individuals. With the Ministry of Health 2012 recommendation to raise T - CD4+ lymphocyte count for starting treatment from 350 to 500, an immediate 15% increase in the number of antiretroviral users was estimated. One of the factors considered by the authorities dealing with the issue is the cost of the medication. In 2011, the Ministry of Health expenditure per person on sexually transmitted diseases was more than two thousand *reais* on medication alone, with expenditure on the rest of population being 20 *reais* per person.

**Table 1 - Federal Government Spending on Medication in 2011**

Program 1,293 - Pharmaceutical Care and Strategic Materials:	R\$ 4,089,465,376.42
Action 4,370 - Medication for the Care of HIV/AIDS and other Sexually Transmitted Diseases	R\$ 565,276,704.84

Source: Brasil, 2012b.

In addition to the financial question, there is also discussion on treatment complications when the patients do not adhere properly to the recommended techniques. Brazilian literature (Brasil, 2007a, 2007b, 2008a; Caraciolo and Shimma, 2007; Diaz-Bermúdez and Hamann, 2011; Rego and Rego, 2010; among others) indicates that, for better results for new treatment procedures, new combinations are needed which decrease adverse factors, as are better living conditions for those undergoing treatment; on the other hand, one of the most commonly reported problems in unsuccessful treatment is not following all of the requirements for taking the medication.

**Table 2 - Growth in the number of individuals living with HIV in Brazil (until 2010)**

Year	Until 2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
New cases	251,291	31,064	35,430	35,428	34,194	33,166	32,280	34,128	36,523	35,980	34,218
Deaths	127,744	10,730	10,948	11,055	11,283	11,020	11,100	11,046	11,372	11,839	11,965
Difference	123,547	20,334	24,482	24,373	22,911	22,146	21,180	23,082	25,151	24,141	22,253
Contingent	123,547	143,881	168,363	192,736	215,647	237,793	258,973	282,055	307,206	331,347	353,600

Source: Brasil, 2011.

At the beginning of the epidemic, in the 1980s, the sick individual's situation was such that legislation was passed on retirement of those undergoing treatment as they could no longer work and death was imminent. With the introduction of antiretrovirals, in the 1990s, the lives of those living with HIV were prolonged, by the beginning of the 21st century life expectancy (or survival), after diagnosis, was around six years. It was then that health care services began to become concerned about "adherence to medication" which, on the one hand, increased life expectancy and, on the other, created a series of difficulties, from the need to rigorously control doses and time of administering medications to their unwanted side effects. In the literature on AIDS, most of the studies are on the effects of the medications which, from 1998 onwards, in Brazil, began to provide longer life (Guibu et al., 2011), to the point where survival is no longer the issue, but, rather, quality of life.

Faced with the contingent of individuals living with HIV and with forecasts of growth in this population, it becomes necessary to understand how they live and deal with the technical procedures required in the recommendations for administering the medications. Treatment results do not depend on the pharmacological potential of the drugs prescribed alone, as government literature on the subject shows (Brasil, 2007a, 2007b, 2008a, 2008b), treatment is affected by a series of factors which intervene in administering the medication and in the difficulties of adhering properly, resulting in the harmful effects of partial or deficient adherence.

## Contextualizing adherence

Diverse national and international studies (Caraciolo and Shimma, 2007; Vitória, 2004; Rossi and

Batista, 2006) indicate that adherence to treatment for chronic disease (for example, hypertension, diabetes, obesity etc.) is around 50% of individuals correctly using 80% of medication. When other recommended factors, such as changing lifestyle habits, doing physical activity and nutrition re-education are considered, adherence falls to around 22% (Teixeira et al., 2000); in practice, only around one in five individuals follow their prescribed treatment completely. In antiretroviral treatment, 95% correct use of medication is required of those living with HIV, in addition to other factors recommended for dealing with the disease, at risk of compromising the desired result, using up precious stages and making continuity of the procedure in question unviable. This level of requirement in itself, justifies research into the factors which can interfere with adherence to treatment (Brasil, 2008b).

Moreover, it is argued that adherence to treatment decreases still further as the complexity and duration increase, as the proposed regime interferes with lifestyles, activities and eating habits, in addition to inconvenient side effects. In other words, it is a requirement which the average person finds difficult to meet, there are so many factors going against adequate adherence to the technical recommendations. Only one third of those undergoing treatment are even close to the desired rates (Rego and Rego, 2010), which makes the implementation of an antiretroviral monitoring scheme urgent, due to the possibilities of treatment failure. However, there is no safe and easy way to monitor adherence, with diverse efforts and measures resorted to in order to achieve any plausible result for analysis (Rocha et al., 2011). And there is also the issue of service provision, as, according to Ministry of Health reports (Nemes et al., 2011, p. 65), "the health care services do not yet provide a structure which facilitates user

participation, be that in the way they are listened to, or be it in the way their complaints are dealt with”.

Although recent studies show that those undergoing ARV (Antiretroviral) treatment have decreased viral loads, which decreases the possibility of transmitting the disease it should be remembered, as Souza Jr. et al. (2011) point out, that, beyond technical requirements, there is an individual who, among other things, is living with HIV: psychological issues such as anxiety and mood are obstacles to be overcome in improving these individuals' quality of life. Whereas the doctor, the specialist, focuses on pathology, HIV and its consequences, the individual undergoing treatment has, in addition to medication, many other things to worry about, which can interfere in the treatment results.

Technically, what counts is the response to treatment, the objective of improving health perceived through tests measuring viral load and CD4 lymphocytes, but test results do not always reflect adherence; some individuals, although swearing they accurately adhere to administering medication, continue to have a high viral load and low CD4, due to factors other than the medication used, whereas others, with adherence which is only reasonable, have better results (Caraciolo and Shimma, 2007). In the Virtual Health Library (VHL), adherence to medication is defined as the patient's voluntary cooperation in taking medication or remedies according to the prescription, including duration, dose and frequency. For cooperation to occur, communication and conviction are necessary, as it is not easy to put all the required procedures into practice. In research on adherence to treatment in Brasília, Diaz-Bermúdez and Hamann conclude that “adherence to treatment is a complex and dynamic social process in which the individual is obliged to rethink and restructure their life trajectory in a process of re-socialization and constructing a new identity” (Diaz-Bermúdez and Hamann, 2011, p. 117).

Researching adherence, however, has operational limitations, as variables cannot be limited or excluded as occurs in a laboratory, as it deals with multiple and complex procedures of the lives of individuals living with HIV. It is not just a question of the technique of administering and reacting to medication, as explained above. Researching ad-

herence involves various social, economic, cultural and political factors; thus, the need to specify the location of our study.

## Contextualizing the research field

Our research was conducted in one of the poorest regions of São Paulo, in the municipality of Francisco Morato, a suburb to the north of the state capital, around 40 km from *Praça da Sé*. More than 180,000 people live in an area of less than 50 km<sup>2</sup>. Half of the population are aged under twenty and only 10% are over fifty years old. The concentration of poverty per square meter is high in this municipality, with the poorest human development index in the region (the third worst in the state of São Paulo). In this context, we shared the lives of PLHIV for more than two years, amidst privations, difficulties, want and suffering; always bearing in mind the issue of adherence to treatment.

Based on this reality, we had to find a method to aid us in responding to the following questions: How do we conduct research without fractioning our interlocutors' experience? If Public Health Research assumes that the reality to be investigated requires that a problem be considered in all its multiplicity, how can the investigation be carried out without design or direction? How are we to respond to “How do those infected with HIV live?” without the “life” itself being dissected? And without the multi-faceted networks through which our interlocutors pass representing only pale reflections or statistical portraits or a rich and fluid reality? These were the questions which led us to the work of Bruno Latour. We will give a short introduction to the author later, before discussing his method in more detail. This is not an attempt to cover all of the nuances of Latour's theoretical-methodological proposal exhaustively. For us, it seems sufficient to focus on the aspects which were productive in our investigation.

## Introducing Bruno Latour

Bruno Latour was born in France, in 1947. He studied philosophy and, according to him, became interested in anthropology by chance: taking advantage of an opportunity to do a “collaboration” instead of mili-

tary service, between 1973 and 1975. It was at this time, according to Latour, that he was confronted with the anthropological issue of understanding difference, with an anthropology directed at “primitive tribes” and with “whites” conducting anthropology of blacks, of the “black soul”, of “African mentalities”. It was a polarized relationship which Latour called asymmetrical and against which he would later argue: what would anthropology be like if it were directed at the center and took upon itself the task of growing closer to science, law, the State? (Latour, 2012).

Thus, in 1975, with the inauguration of the *Jonas Salk Institute for Biological Studies* in San Diego, California, Latour managed - through the mediation of an old family friend, the renowned neurologist Roger Guillemin - to have a project approved to undertake an ethnography of science - to study scientists producing science. It was no longer “primitive tribes” being studied, but renowned scientists, researchers who became famous through publications on TRF (*thyrotropin-releasing factor*) and TSH (*thyroid-stimulating hormone*) (which underwent the scrutiny of the “anthropological gaze”). It was in this piece of research that he noted the importance of non-human agents interfering in social relationships<sup>1</sup>. From this research in the laboratory, the book “Laboratory Life” was published, relating the procedures of the human, the action exercised by the location of the printer, the cupboard, the air conditioning unit and by the article published by another scientist - items which, *a priori* did not interfere in the research into hormones (Latour and Woolgar, 1997). This is what Latour called symmetrical anthropology.

Latour proposes breaking down the boundaries between society and nature, human and non-human, objective and subjective; as, for him, everything depends on the “agency”, that is, the capacity to act, to provoke reactions, to interfere, provoke changes in course, whatever the agent may be. A question of linguistics, Latour denominated the human who moves and acts the *actor*; and, the non-human who

acts, influences, connects and interferes in the social the *actant* when an active role is attributed to something which is not human as, in English, *actor* is attributed exclusively to humans. In “Pandora’s Hope”, Latour highlights the action of yeast on Pasteur, even questioning whether it was Pasteur who made the yeasts famous or whether the yeasts created Pasteur’s fame. Where the text states: “yeast led Pasteur’s reasoning” (Latour, 2001, p. 171) it is not merely a figure of speech, but rather an exact description of what happened in the laboratory when the agent, the actor of the action, in this case actant, is the microbe and not the scientist.

In 1987 he published “Science in Action”. In contrast to the image of the idealistic scientist recluse in his laboratory through love of science and truth, Latour shows a man and an organization in full social functioning, rewarded by politics, by economics and by marketing. He highlights that scientific output is a production of the times, of the reigning interests, both vested and declared (Latour, 2000).

In “We have never been modern”, from 1991, he draws up a type of manifesto. While discussing the concepts of modernism and post-modernism, Latour states bluntly that “we have never been modern”, as in modernism the social and nature, human and non-human are separated. Latour demonstrates that everything is so hybrid and interlinked that it is not possible to study nature separately from society, nor humans without non-humans. It is enough to look at a newspaper on any given day to see that things occur forming networks of interconnections, with analysis restricted to one discipline being non-productive as everything is interlinked in a complex, multi-disciplinary universe. Humans and non-humans, society and nature need to be treated symmetrically (Latour, 1994). For those who accuse idealists of not believing in reality, Latour published “Pandora’s Hope” in 1999. Based on, an apparently absurd, question he was asked by a psychologist at a meeting of scientists in Rio de Janeiro: “*Do you believe in reality?*”, Bruno Latour created a book of essays discussing the relationship between subject

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<sup>1</sup> Although the term “social” would be re-discussed by Latour (2008) we could not discuss all aspects of his work here. We sought to give only an initial outline to demonstrate how our attempt to not fragment life and experience of our interlocutors led us to Latour.

and object, so dear to philosophy and other areas of knowledge, in an original manner, inserting a human and non-human aspect into this dichotomy (Latour, 2001).

In Brazil, in August 2012 at the Universidade de São Paulo (USP), in a lecture at the FAU (Faculty of Architecture and Urbanism) auditorium, Latour reaffirmed a series of items of his theoretical proposal as the introduction to a new project for studying scientific production (Latour, 2012). He told how he had learned an interesting word which had no translation in French: “gambiarra”. He adopted this term as the “unlikely assembly of multiplicity, not only the verification of the truth, but also in ways of extending the truth”. Most of the interlocutors in our research lived by *gambiarra*, that is, from unlikely assemblies, doing what they can with what they have, as we will see later. At that meeting, outlining his theory, Latour stated that the ethnography of the modern, despite the concept of modern (object of discussion throughout his work), assumes the multiplicity of ways of verifying the truth. He declared that this is nothing to do with relativism, but with relationism, in the sense of ability to speak the different languages of the modern, in their various languages, those of law, of religion and politics.

This quick overview of Latour’s work is a mere sketch of a much greater contribution. Latour’s discussion was essential to our analyses of adherence to antiretroviral treatment. For us, Latour provided a path, beyond mere theoretical discussions of the status of reality, the limits of constructionism, the importance of symmetrical anthropology, the agency between actors and actants; or, at the very least, a direction to escape from what seemed non-productive for those with HIV (and to understand adherence to antiretroviral treatment): fragmenting the lives and experiences of those taking antiretrovirals.

## Ethnographic method based on Latour

In “*Reassembling the social*”, an introduction to the actor-network theory, Latour revises and broadens his concepts on the methodology of social research, starting from the criticism of what is social. He also takes up the issue of non-human actors’ participa-

tion affecting the production of knowledge (Latour, 2008).

For Latour, it does not make sense to give explanations about the social but, rather, to outline connections as there are so many elements in flux that it is not possible to list all the ingredients which affect a social situation, the researcher should merely describe each connection which is established when some movement is made. Something which is inert, which does not affect anything nor respond to interference from anything, simply does not exist in the social context. Social is the relationship which is established and promoted diverse connections, the movement of inter-relations, associations; these social connections occur between human beings, influencing and being influenced by the other. Social connections also occur between human beings and non-humans, when non-human objects interfere in the life of a human being. The actor in action interacts with other actors, forming a network of connections, multiple connections which make the social into the science of living together. Everything which acts, which moves or leaves a trace, which modifies the scene in which it moves. It is down to the researcher to follow the traces, describe the marks left by the actor or actant.

Latour redefines the social not as a domain in space, a specific reality or anything in particular, but as a very singular movement of re-association or re-grouping. He says that the social is not a visible thing, but hidden by the traces left by movements in the direction of new relationships, both those aim to dominate not only sociology but sociology of associations or sociology of innovations (Latour, 2008). The *slogan* of actor-network theory is “follow the actors themselves”, learn from the actors, as those being researched always know more about their life and conditions than the researcher. Report new associations the actors make to follow their paths, new connections, new webs in the network being formed. Without trying to explain anything and without leading the actors down any paths, simply following their traces.

Latour (1994, p. 8) stated: “The AIDS virus takes us from sex to the unconscious, to Africa, to cell cultures to DNA to San Francisco”. He continues, this path is perceived and investigated in a fragmented

way and analytically cuts through an extensive “network” in small, specific compartments. On various occasions, Latour has suggested that it would, on the contrary, be more interesting to follow heterogeneous series of elements connected through the networks which carry them, seeking to describe their plots, going along with the multiplicity of agencies, flows and movements. Latour proposes describing associations, recording the group’s movements, arguing that the group only exists when in a movement of grouping together or changing, when the process of the group being formed affects the lives of those in the group and those related to them. The action of grouping together provokes changes in the course and the procedures worthy of the researcher’s attention. It falls to the researcher to follow the actors and actants; follow their steps and the paths forged by them, as an ant forges its path (Latour, 2008). Latour proposes following them as Shirley Strum did, monitoring baboons in Africa, always behind them, not interfering in the group’s movement, merely noting the complexity of the relationships they established (Latour, 2012). It was in this way we sought to study the field in which those living with HIV circulate, using techniques developed to deal with the problem, whether to solve it or for adaptation or refusal in the issue of adhering to treatment. As Latour states, “human beings are characterized not by the emergence of the social, but by deviation, translation, the inflection of all courses of action in increasingly complicated (but not necessarily more complex) technical devices)” (Latour, 2012, p. 15).

Regarding adherence to antiretroviral treatment, for example, there is no rigid template of right and wrong actions in which the procedures of the individual with regards adherence to the medication can be evaluated and verified. They are multiple actions, linked by strands, and it is us who are interconnected. The technical devices which the actors of the research present as a solution or adaptation to their problems are interesting objects in discovering the group’s procedures. These devices may be simple things which appear in day-to-day life, something intuitive, procedures without theoretical/philosophical discussion but which take on a relevant role in people’s lives and in the course of their lives. Latour identified this in Rio de Janeiro, with the use of the

word *gambiarra*. The researcher then becomes the target of the recording, describing and transforming in text - describing the network of relationships. Latour’s theory thus seeks to avoid fragmenting the subjects’ experiences with pre-defined questions, but follows them in their intricate connections, their unusual networks, recording the solutions they find for themselves. With these objectives, we seek to accompany the movement of individuals being treated in the Testing and Counselling Center (CTA) and who, at that moment, sought to create an NGO called the Instituto Novo Tempo, as we will see.

## Medicines, NGOs and swimming pools

This research was conducted between 2009 and 2012. The idea was to follow our interlocutors, as taught by Latour, letting them guide us through the unusual paths of the actors and actants, avoiding becoming bogged down in medicinal aspects linked to the disease. It was at that moment we came across the mobilization of certain people creating an NGO which, among other aims, intended to develop a space for those living with HIV/AIDS

We sought to follow the formation of the NGO which would work together with local prevention and care services in Francisco Morato. The NGO would be an imaginative way for the residents of Francisco Morato to deal with AIDS and promote conditions for those with the disease to develop better adherence to treatment. We imagined being able to monitor the actors and facts linked to the procedures and conditions to improve adherence to treatment. The group being formed promised intervention actions together with the local community.

Armed with a theoretical-methodological reading of Latour, attentive to the issue of human and non-human in the network of relationships, we move on to the group’s activities. We accompanied the organization and events such as the Christmas party for children of those living with HIV, in 2010 and 2011. We participated in a series of “Chá Positivo” events, a project consisting of meetings of those living with HIV with public health care service agents in an effort to find integration and facilitate social and technical relationships. As the



NGO president (Johnny) said, when you get to know someone outside of the service environment, the relationship within the service becomes easier. He was speaking of the advantages of getting to know people outside of the roles of “health care service worker” or “patient undergoing treatment”.

We also participated in an artisanal soap making course, promoted by individuals who had proposed forming an NGO with the aim of providing increased income from producing and selling personalized soap. However, the group which proposed to be the basis of the NGO did not maintain itself in the way it had expected and broke up. The project did not last long. The president and vice president got work and began to look after their own subsistence first. As the NGO had no budget, there was no need for a treasurer, nor did the secretary have anything to report. A small contingent tried to maintain the “institution” as they called their NGO which was never registered, or legally recognized.

We can follow the steps of the individuals from the appearance of the intention to form an NGO and after the collapse of the venture, as well as recording the care movement actions which remained. It was as part of this process that the story of the swimming pool emerged. In a conversation in a waiting room, Almerinda, one of the main interlocutors, invited “everyone” to use her swimming pool, an actant which altered the whole routine of Almerinda’s life and of which more will be said later.

We began to accompany Almerinda’s day-to-day life. A 47 year old woman weighing 43 kilos, she had been living with HIV for twenty three years, and at that time was concerned about financial limitations due to investing in a swimming pool for the use of all her colleagues in misfortune - those affected by HIV and poverty. Her gross monthly income, two minimum wages (one from her AIDS pension, the other a pension from her husband, who had died of AIDS), did not amount to more than a thousand reais, but she managed to raise R\$ 17,800.00 in loans to construct the swimming pool. Around 85% of her monthly income went on paying the loan. To avoid the limitations on the loans she was allowed, she resorted to financing and even to store credit where, loans are sold and paid back in installments with interest. Meanwhile, she went without her false

left eye which would have cost around six hundred reais.

During the first stages of research, the story of the swimming pool made no sense. Almerinda had very little and had difficulty paying her R\$ 150.00, rent, and yet she was constructing a swimming pool on another piece of land. The first time we heard an invitation to use the pool was during a conversation in the CTA waiting room; she invited all the patients there to come to the swimming pool at the weekend. Later, we learned that the pool was fulfilling a promise made to a friend who looked after her in a difficult situation, one of the health complications to which PLHIV are subject.

As the research continued, there was, among other things, a jealous fight between members of the family who owned the land on which the pool was constructed and Almerinda was excluded from participation, she could no longer visit the house where the swimming pool, which became a pool of disagreement, was built. It was, in truth, a four by five meter tank, with a depth of half to one and a half meters, without filter or water treatment. It was filled weekly by siphoning water from the pipes in the street.

We continued to follow Almerinda, who continued to provide assistance in the name of the NGO, her time was used in taking people to and from medical appointments in both Francisco Morato and Franco da Rocha and in São Paulo. Sometimes she just accompanied them on the train or the bus, sometimes she managed to get lifts through political or business favors. One time, when Almerinda had severe toothache and needed a dentist, she lost her right canine as the professional in the municipality was not qualified to treat, just to extract. Another time, when an Herpes Zoster attack affected her entire left arm, she was caught in the crossfire of two doctors, one demanding she continued with the antiretroviral AIDS treatment, the other that she suspended it until the Herpes was treated.

Diverse actors who, without knowing each other, affected the life of this person who suffered contradictory interference in her network of relationships with health care service doctors. After 23 years of living with HIV, no solution had been found for her inability to swallow the medicine capsules, she still

had to dilute it in water in order to take the medicine. For a time she was treated with liquid medicine for children, but the viral load increased, meaning new attempts at treatment, which only existed in capsule form, were made. We were able to accompany the ritual of placing the capsule in a cup of water, mixing and pressing until fully diluted, which took around fifteen minutes. Next to the cup, something sweet to counterbalance the bitter medicine.

Another crucial issue for Almerinda was the steep dirt road, which became impassable in the rain. The first meeting to record her narrative could not take place in her home as it was impossible to reach because of the rain. During the research, between one conversation and another, the fear of the rain always appeared, when the need for emergency help would make it impossible for an ambulance to reach her home. During the field research, there was a day on which the car could not get through, obliging us to cut through the woods, climbing a steep embankment. This was one of the factors which provoked a change in course, in this case, Almerinda moving to another place where, if necessary, an ambulance could reach her. This resulted in sacrifice on many fronts: she moved to a place which was half the size for double the price, far from her closest friend and well known neighbors. And far from the swimming pool.

Almerinda was just one of more than thirty individuals with whom we conversed during the research. In more than two years of field work and systematic accompanying of actions and activities of PLHIV, many actors and actants appeared and posed questions and inquiries. We could descend to specific details characterizing socio-political or socio-economic conditions in the municipality, factors which directly affect taking medication; we could detail the limitations of the medical and pharmaceutical services which make it more difficult to manage administering the medication, facts which are general knowledge when talking about the quality of health services provided in poor suburbs such as Francisco Morato; we could enumerate countless problems, as the network of PLHIV is not simply the connection between the patient and their medicine and health care service provision, nor does it consist solely of initiatives such as forming the NGO, but

of all the other things. And it was this very methodological proposal of Latour which led us to steep hills and swimming pools.

It was this methodology which led us to Almerinda's dilemmas and to those of other inhabitants of Francisco Morato, who told us of diverse aspects of the problems of adherence. These actors seem to insist that the issue of adherence passes through diverse paths (as shown in the story of Almerinda) and itineraries. This can be synthesized in the statement of one of our interlocutors, with whom we conversed in the doctor's waiting room; on being asked about the problems of adhering to the medication, after a litany of problems, finished with the significant statement that *the medicine is the least of the problems*. It seems that, after following Almerinda's paths, this was exactly the case: in addition to the many medications they have to take, these people's networks also deal with death, illness, politics, NGOs etc.

In this research on the illness and treatment, our actors led us to an NGO which did not work and, then, to an unexpected swimming pool. What does this have to do with adherence? What does the story of the swimming pool mean? Why do people so afflicted, on one of the poorest municipalities in São Paulo end up building a swimming pool? Latour's methodology was important in continuing ahead following the only traces of the NGO, the care work developed by those who did not abandon the proposed venture. Almerinda, a woman less than five feet tall, weighing forty-three kilos, and forty seven years old, twenty three of those years living with AIDS.

## Final considerations

The methodology proposed by Latour led us along different paths. The most productive of these torturous routes was perceiving that, for our interlocutors, dilemmas in adherence are not exclusively related to the medications, or even to biomedicine. Due largely to improvements in medication, those infected with HIV are now living longer, dependent on those medications, but the actors in the research conducted insist that they do not live by the drugs alone. The story we narrated - about swimming pools and hills,

poverty and seeking forms of organization - appears to signal that it is not productive to view adherence as simply connected to correct use of medication; it is not only the quality of the drug, nor availability in the pharmacy, the health care provided, nor even the patients will which guarantee adherence to treatment, everything depends on a number of paths of which, as the interlocutors pointed out, “the medicine is the least of the problems”. This is the relevance of Latour’s methodology: making us embroil ourselves in these confused itineraries, these human and non-human networks, medication, swimming pools, NGOs, health care services, a network of relationships of those living with HIV, in the difficult paths which our interlocutors traced.

Of course, this is only a part of a rich reality. And, throughout the research, many problems appeared: for example, we were not able to follow the paths of the medications (from production to the hands of PLHIV) and we went from a more general concept of the network to a Latourian concept (Strathern, 1996). However, despite the setbacks, common to those who dedicate themselves to following itineraries (the dangers of the journey, as Guimarães Rosa would say), this adventure provided by the methodology proposed by Latour - the ethnographic methodology of “Actor-Network Theory” - permitted us, although timidly and initially, to follow the steps of the actor without fractioning their life, without isolating anything, as everything occurs in a network and is interconnected, interfering and suffering interference.

P S. Almerinda passed away in January 2013.

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