Anthropology and Human Rights: Between Silence and Voice

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SUMMARY

This text deals with ethnographic research carried out for two years at Fraternidade Assistencial Lucas Evangelista (FALE), an institution that provides residence to 200 people diagnosed with HIV. At this institution, located on the outskirts of Brasilia, Brazil, ex-convicts, ex-prostitutes, abandoned children, transvestites, drug addicts, alcoholics, and those expelled from their homes by parents and relatives live together in a situation of confinement and terror. This text explores some of the possibilities and difficulties of anthropology at the forefront of the Human Rights debate. In particular, it emphasizes the dilemma of silence and voice—remaining silent or speaking out—for both anthropologists and their interlocutors. [Keywords: human rights, AIDS, institution, suffering, humanism]

This text deals with the ethnographic research carried out between 1998 and 2000 in the Fraternidade Assistencial Lucas Evangelista (FALE) institution in Brasilia, Brazil. Approximately 200 people reside at FALE, all of them infected with the HIV virus: ex-convicts, ex-prostitutes, abandoned children, transvestites, needle-abusing drug addicts, alcoholics, and HIV+ persons expelled from home by their parents or relatives. These residents live together in a situation of confinement and terror. After examining how persons survive in this institution and the processes through which terror inscribes itself on their bodies and in their consciousness, reducing their horizons of perception, I point to the tension between anthropological relativism and the universalism of human rights. My ethnographic research reveals the extraordinary appearance of the “other”—the emergence of people not considered human, and the fact that, in some way, anthropology can fight for their humanity. I propose that the findings themselves deny restrictive universalism. This text tries to understand the difficulties of anthropology in face of the human rights debate and seeks to emphasize the dilemmas of silence and the voice.

Writing about silence is a paradoxical task. The same literate act that seeks to enunciate also weakens the force of expression, as words fill the empty space otherwise filled by silence. This very statement, however, is an affirmation that resolves the conflict within the statement—its “aporia”—when we find
that silence is not measured in ambient noise or in emptiness. Writing produces silence, for every work that affirms, underlines, and highlights certain viewpoints also excludes and silences others. In fact, persistent silence reveals more than it hides. In other words, it reveals while hiding.

Silence is a dispositional, to use the expression of Michel Foucault, and we should seek to understand the different ways of “not saying,” finding out who can and cannot speak, and discovering who speaks for whom. Therefore, we should understand periods of silence as integral parts of speaking strategies. In this text, I will deal with only one of the variations of silence: the expropriation of language and the conditions under which speech occurs among a group of AIDS victims. The drama lived by these people is not limited to just the violence of the act that directly hinders their speech, but also the violence that continually censures those who speak in the name of those not authorized to do so. This story could indicate that the strategies of those in power, apart from compelling “undesirable” parts of the society to remain in extreme silence, also take away the voice—and thus the humanity—from the act of defending one’s rights. Would it be a paradox to state that the production of silence can tell us a lot about the way we choose to organize our lives, especially in situations involving suffering, pain, or disease?

The Production of Silence

This is the story of people carrying an infectious and contagious disease, immersed in a sea of pain and fear, parted from language; a group violently silenced. What methods were used to silence these AIDS sufferers? What does this silence mean? In this part of the text, I suggest that the production of silence is carried out simultaneously with the processes of exclusion and thereby construction of contaminated and abject beings.

At the beginning of the 1990s, an institution was set up on the outskirts of Brasilia, Brazil, called “Fraternidade Assistencial Lucas Evangelista—FALE.” It was located on an old farm near the highway that links the Federal District to Goiania. As soon as it was open, FALE changed the immediate neighborhood, presenting new problems to the local population. It quickly became a part of the social fabric of the city and country because of its unique condition: it was inhabited by people infected with HIV. Anyone who found they were infected with HIV and had no place to live went there. With spectacular speed, almost 200 people were living in a rural regional facility provided by the federal government. What began as an act of charity became a major institution, supported by both the government and private donations.

FALE became the center of attention for hospitals, clinics, health professionals, and everyone involved in helping and supporting HIV sufferers. The complexity of the HIV/AIDS epidemic has created social exclusion, poverty, and abandonment in such a concentrated manner that the problem has intrigued researchers and professionals. In August 1998, the population at FALE in Brasilia numbered 102 adults and 50 children. This number has been floating, although between 1998 and 1999 it never fell below 92, and at one point reached 200. All of the adults and some of the children carried the HIV virus. Most had
serious lifestyle diseases and required daily medical support. Tuberculosis, toxoplasmosis, and cytomegalovirus were among the most frequent diseases.

FALE operates through a formal organization of the residents that holds periodic meetings to make small decisions. One resident who is designated as the leader coordinates these meetings as well as the rest of the residents. The leader, in turn, is subordinated to the top authority of the institution, president “Aunt Janaina.” Important events are reported to her, and she decides on a course of action. Central decisions are up to her. Aunt Janaina is greatly respected and feared, and this gives her substantial power over the lives and bodies of the people that live in the institution. This means that any self-determined activities and organizations of the people are assiduously put down, because everything they decide must be submitted for the president’s approval.

The inhabitants of the institution are required to call the president as well as some directors and volunteers “aunts” and “uncles.” The use of these terms are compulsory, and the beginners who do not know the FALE rules are penalized or admonished when they use different terms, such as “Ma’am.” The expressions “aunt” and “uncle” are, in fact, elements in a process that eventually turns adult people living at FALE into “children.”

FALE’s residents survive in brick and wood houses—generally with no tap water or sewage facilities. Single individuals live together, four or five to a house, with men sleeping apart from women. Families live together in one house. This division makes it easier to control the sex lives of unmarried residents’. Aunt Janaina forbids any intimate relations before marriage. This is not the application of a “safe sex” rule as practiced by hospitals and NGOs, but a ban on all sexual activities before marriage. Because the residents’ sexual activities are the subject of scrutiny by Aunt Janaina, many begin to adopt adolescent styles of interaction. They make love in secret and live in fear of reprisals if found out.

Aunt Janaina is the minister at weddings. With sexual relations forbidden before marriage, she pays special attention to weddings. The rule is one of the reasons for the high marriage turnover at FALE. The residents’ desire for love and sex leads to marriage, but because they only formalize their relationships to ensure small privileges and avoid punishment for dating in secret, such marriage results in frequent separations. Families form and break up easily and quickly. The lack of a constant family base, added to the frequent and compulsory change of house, make it difficult for those at FALE to create ties with each other. No one puts down roots, and residents feel little connection to the houses they live in, to the furniture or objects in them, or even to the institution.

Most of the residents are unemployed and only 10 of them receive a “Continuous Installment Benefit” from the government. FALE’s inhabitants are forbidden to take up paid activities. The only occupations are cooking, field clearing, answering the telephone, driving the ambulance, and so on. This work is linked to and directed toward the institution. There are no occupational or therapeutic activities—a situation that creates problems, given the number of alcoholics and illegal drug users. The AIDS sufferers carry out all of the tasks and chores at the institution. FALE does not have access to professionals to help perform tasks that require professional knowledge or personnel for basic tasks,
which means that people in serious condition who are not sent to hospital often receive little treatment or are completely abandoned.

Eighty percent of the male population and part of the female population have spent time in prison or rehabilitation clinics. Some AIDS sufferers who are in the prison system are “freed” to serve their sentences at FALE because of their bad health or as a result of Aunt Janaina’s intervention in court. None of the residents can leave FALE without Aunt Janaina’s authorization and consent. Trips outside the institution are mainly to public hospitals or to receive the “Continuous Installment Benefit” from the government. This means that the people live between two institutions: FALE and the hospital. FALE’s residents who leave without consent and do not carry out their daily activities are punished. Aunt Janaina hands down all the punishments.

FALE’s inhabitants do not question the validity or requirement for punishment. The economy of discipline stakes out the quantity and quality of punishments—which vary from simple punishments to expulsion. These punishments include going without food for a day, kitchen duties, washing dishes, and being banned from leaving FALE. Such disciplinary measures take on greater importance when infirmities start to appear. The punishment system is generalized and no one—not even the children—are exempt. It commands the daily life of residents. No one manages to escape punishment and almost all daily activities are the result of punishment. The economic policy of punishment is the result of and the source of Aunt Janaina’s power, as she dictates their implementation. When someone commits a “crime” and no one knows who is responsible, all take the blame. This creates a system of continuous vigilance and accusation. The result is either silence or lies, the latter an attempt to fight the punishment and relieve blame. As the activities are all the result of punishment, they make no sense for the inhabitants. Most of those punished see their work hours increase, and they always receive tasks they do not like. To increase their suffering, these tasks are chosen based on what each individual most dislikes. Under these circumstances, activity generally is undesirable and becomes nonsense. When people refuse to perform a task, they receive a more serious punishment or are expelled from the institution. For many, expulsion is unthinkable, as it means a return to prison or vagrancy. Expulsion leads to insecurity, as no one is sure where they will be the next day or if they will be able to survive. These insecurities further disrupt possible neighborly ties or friendships. When a resident of the institution is expelled, they wander the streets until their situation worsens dramatically. Their health condition becomes unbearable and they end up in the hospital for treatment, often becoming patients. When they recover, they still have no place to live and therefore must ask the hospital to speak to FALE. They generally spend two or three days begging to be let back in. Many times, after being abandoned by the hospital, which, according to health professionals, does not have the personnel or beds to look after them, the refugees find themselves at the barbwire fence surrounding FALE, begging to be let in.

Despite all of this, inhabitants of the institution do not show any resentment about their situation. Three distinct stages can be noted in people’s behavior. When people arrive at FALE, they are critical of Aunt Janaina and the workings of the establishment. This is the first stage. Commonly, during this time, they are upset about having “lost” a life. They want to stay there “until things get better”
or until their health conditions improve. During this stage they never consider FALE to be a final destination.

Later, at the second stage, although some of the residents’ criticisms persist, there is greater submission to Aunt Janaina’s orders and a certain identification with her ideas and values. During this period, even when acting against the decisions of Aunt Janaina, they still believe that they are “doing something wrong.” Aunt Janaina’s orders are no longer external to them but are seen as a positive force. When personal desires go against the institutional orders, FALE’s inhabitants leave or are expelled. The third stage is when subjects find themselves totally dominated by Aunt Janaina, with no prospect of ever leaving the institution, nor of changing their situation. These are the residents who have been at FALE the longest. Submission during this stage is so extreme that it could be described as servitude and is embarrassing for those who witness it and who are not part of the system. Not even the resident can explain this servitude. This context creates an infantile person, with no constant friendships, carrying out tasks that seem senseless, whose sexual activities are controlled, with no link to home, constantly at death’s door. Residents at this stage develop characteristics of regression, fragmentation, and loss of roots.

Despite having the characteristics of totalitarian institutions as formulated by Erving Goffman (1974), FALE has certain peculiarities that give it a different perspective: we are not talking about an institution born of modern bureaucracy but of total abandonment by the government. This is therefore a unique institution, created, and sustained by charity work, by a sense of pity for HIV carriers. How can we understand the appearance and existence of an institution such as FALE?

Despite the Brazilian government’s widely trumpeted success in the fight against AIDS, there still appears this example of a zone where the measures do not work: a zone of social abandonment.3 In this zone we find homo sacer: someone who does not deserve to live, who cannot be sacrificed, but who can be killed (Agamben 2002:13). If the acts of the Brazilian government seem for the most part to be questionable, it is because we can detect a complete absence of action with regard to FALE. FALE can be seen as the result of state disengagement and, simultaneously, as the desire to contain the “infectious” individuals and their “contamination.” FALE and AIDS become twined synonyms for contamination, signs of contagion, and indicators of the corruption of habits and the decomposition of flesh. This process generates pity and repugnance. What characterizes FALE is a metonymic web that presents a continuous relationship between exclusion, isolation, and contagion. This is not “a core of excluded people, temporarily isolated before future reintegration into society.” FALE’s inhabitants are destined for isolation and death.

Dilemmas of Voice

In Kafka’s story Before the Law, the action takes place between a guard and a man who asks questions, between the first of a series of representatives of the law and the outlaw. The outlaw wants Law, believing it to be a place to which he had a right of access. It is, however, an impossible place to access. This is because the Law has no place, and hence no means of access. It exists first and
foremost as a perception. Beyond this it is an empty space. Such emptiness allows the Law to be exploited by its representatives, extracting from it their persuasive and repressive powers, as well as a “tranquil and absolute violence” (Cixous 1995:69; Derrida 1993).

Luiz, a resident of FALE, told one of the most significant stories about the empty space between the Law and its representatives. His memories—that he chose as an important part of his life—tell us the story of contagion, the fear of contamination, and the construction of the contaminant being. He tells his story by highlighting violence and suggesting an intimate connection between violence and contagion. AIDS is the product of a messy life and the consequence of violence. Within the realm of disorder, he can also presage his own contagion. After years in prison, Luiz managed to obtain a transfer to FALE. Later, he left the FALE premises and was involved in drug dealing and robbery. When he ran the risk of being reincarcerated, he cut his body with a knife to stop his captors from nearing him. The spreading blood was both the sign of pestilence and at the same time protection against police violence. The AIDS sufferer’s force is encapsulated in the fear of contagion.

The police car comes up and we cut our arms (. . .) Cut our own arms and spread the blood over our bodies. Cut our arms and the police jump back, they won’t come near. The police are afraid and move away. Nobody wants AIDS. Then they can’t move us out of the area.

The act of cutting the body shows how the awareness of fear is a fundamental element of interpersonal relationships and the understanding he has of being a contaminant. The construction of the criminal—a synonym for violence—who contaminates is not simply a unilateral or external event. For the criminal, it also includes the slow, painful process of considering oneself abject: hopelessly subject to the natural processes of contagion. Between Luiz and the police—the first of the several representatives of the law—there is silence: no speech, no questions, no answers. The act of cutting flesh and spreading blood suggests it may be impossible to break the silence. The Indian anthropologist Veena Das (1995), in an attempt to understand the silence of people who suffer, questions whether pain destroys the capacity to communicate or creates a moral communication between sufferers. Evoking “critical events” that bring us closer to terror, Das finds, beyond bodily mutilation, the mutilation of language that is the “essential truth” of terror. In these circumstances, language is struck a blow, falling into silence. For the author, the fact that violence annihilates language indicates that terror begins in the region of the unutterable. This is where we find Luiz. That is why there is no voice that demands access to the Law. This silence creates a gap for the appearance of others who will try to defend the rights of those who cannot speak.

The Impossible to “Speak for”

Several professionals were indignant at the living conditions of FALE’s inhabitants. Criticisms of Aunt Janaina’s procedures, punishments, and conduct were drawn up and became commonplace, mostly coming from health
professionals working around Brasilia. The situation of FALE’s residents led some to compare it with concentration camps, and the discovery that no one was making efforts to change the situation drew parallels with the low sensitivity of German citizens who, during the WWII, would pass right by the concentration camps with disturbing indifference.

Change was required and everyone agreed that the rights of those in institutions’ should be observed. “After all,” said one doctor from the University Hospital of Brasilia (HUB) “human rights should benefit FALE’s inhabitants as well.” What should be called for, however, and how? What sort of rights would the FALE’s residents have, or at least should they have? One idea was to report its features as an asylum. Another was an attempt to establish conditions for the residents’ autonomy. The punishments were considered a form of torture, and many asked what could be done to stop them. Those involved in the discussion said that only with autonomy could AIDS therapies be conducted to reorganize lives. This meant that people should work, take courses, and do their best to maintain themselves. These activities, of course, were totally opposed to FALE’s guidelines. Conflict over such matters generated constant disagreements, and the level of confrontation can be seen in the positions taken by the HUB professionals. HUB members believed that their position and the activities performed at FALE were incompatible. The debates referred mainly to the different ways of looking at HIV sufferers. Health professionals pointed out that FALE deems all of its patients to be terminal, stating that Aunt Janaina does not encourage or support any step that could help FALE’s inhabitants to get their autonomy back. This meant that this institution was a place to go to await death. The concept of FALE as a place “where you go to die” justifies the striking growth of the institution. When residents are constantly dying, one could imagine a constant flow of people, although kept at manageable levels. This idea, as we have seen, is against the dynamics of the disease itself.

HUB guidelines and therapies are in constant opposition to FALE policy. FALE’s residents are not allowed to go for periodic consultations, a ban that places obstacles in the way treatments are given and, in some cases, cuts off access to AIDS drugs. The struggle for the patient’s’ autonomy and the search for how to “live with AIDS” is totally undermined by the fact that people who live in this institution are not allowed to work for remuneration and therefore have no means of getting beyond the stage of being “FALE inhabitants.” Because of their inability to develop and implement their policies, HUB professionals felt that they were hostages to FALE. The surprise that “everyone is going to FALE,” along with the dismay at seeing the inefficiency of the programs and activities developed there, led to disbelief that any measure or initiative could be taken. The weakening of HUB’s position in relation to FALE gave rise to constant questioning about the suitability of its policies in the fight against AIDS.

All discussions refer to two possibilities: either HUB should work harder to understand FALE and take the necessary steps to accept—as FALE does—the special circumstances of its residents; or it should treat the residents as normal patients, without any consideration of their institutional ties. According to the first possibility, no matter how much HUB seeks to understand the residents, Aunt Janaina’s orders end up getting in the way. Concerning the second, taking the institution away from the patients would lead to their further isolation.
Penha, one of HUB’s leading psychologists, who defends the first idea, said: “I think this objective is extremely important, and that is why we must cut the connection between the patient and FALE. We work with individuals.” This does not mean that the efforts of HUB are only directed at caring for “reasonable” and autonomous people, nor that autonomy is only a way of making treatment easier, but mainly that a person should be autonomous, individual, and rational. Once people become FALE inhabitants, life is possible only if they become individuals—which is a value or set of values alien to them. The inhabitants’ dilemma is that their survival does depend on the acceptance of these values. Ironically, associating autonomy with existence means that those people who do not adapt or do not accept a “rational” lifestyle do not deserve to, or cannot, live. The failure of HUB’s professional activities is that they see the human beings, FALE’s residents, surrounded by differentiated conceptions of “relationship” and “person” they do not want to accept or understand. The health professionals speak for and on behalf of the FALE inhabitants’ rights, taking for granted that people who live in FALE need to be able to look after themselves and lead a healthy life. The irony of speaking for is based on the desire to represent FALE’s inhabitants’ and fight for their rights and for their humanity, based on a claim to humanity that is simultaneously not perceived to exist.

The situation of the FALE residents needs a solution. HUB professionals empathize with the suffering of the residents, but because their attempt to speak for them is inefficient, this creates a situation that not only fails to relieve the patient’s pain but permits further suffering. The drama of these so-called contaminated people—who have serious diseases and no practical therapy, who live in an institution that submits them to a policy of punishment, and who have no way of changing their condition from within their institution—cries out for measures that can change the situation and, at the very least, minimize the pain. In other words, it is necessary to fight for their rights. It was based on this point of view that the HUB professionals set up a meeting with professionals from the Federal District in 1999.

The Impossible Meeting

The meeting was supposed to focus on FALE’s residents. The idea was to centralize the debate on “health problems” because the HUB doctors thought that a nontreatable form of tuberculosis was developing at FALE, causing a serious problem for public health. There was also the expectation that “all of the problems at FALE would be discussed,” as shown by psychologist José. With this in mind, various professionals from other hospitals and clinics who worked with FALE inhabitants were invited. At the meeting that was to take place, the HUB professionals wanted to propose a series of actions that would be implemented at FALE to improve the living conditions of the inhabitants. The HUB members drew up a basic platform for their demands, which included: (1) guaranteed schooling for the children; (2) a check on the situation of the orphans living at the institution; (3) a provision of therapies for drug addicts; (4) the setting up of hygiene and food standards compatible with the patients’ requirements; (5) an end to the punishment system; (6) and certain others.
News spread about the meeting and information about the basis for these changes reached all the different hospitals. The meeting’s original format changed so much that many thought it was a meeting to demand human rights at FALE. The general idea was that, after this meeting, the professionals would start a claim against the government requesting immediate implementation of human rights for the FALE’s residents. Despite the fact that the situation was extremely serious, only one person, a FALE volunteer, turned up at the date and time set. After talking to the meeting organizer, he said:

If you criticize FALE, we will take our own steps. . . . We will not go along with this human rights story at FALE. . . . You are good at criticizing, but I want to see what you’ll do if Aunt Janaina closes FALE! Are you going to take them [FALE’s residents] home with you?

The meeting never took place. The health workers who did not come justified their absence by claiming they had conflicting appointments or full agendas. At HUB, they came to the conclusion that FALE was a “‘wasp’s nest’ nobody wanted to touch.” According to the psychologist Jose, this meeting would have been “impossible,” as “no one wants to stand up against Aunt Janaina.” The importance of this critical event stems from the fact that the dramatic actions of the social actors’ created a spectacle that was based on fear and the desire for human rights. It would seem that the mere expression “human rights” evokes feelings and sensitivities that incite people to take sides and take action. The mere possibility of talking about human rights led to three results: (1) Aunt Janaina took a highly aggressive position against any changes at FALE; (2) health professionals asked which steps should be taken; and (3) FALE’s residents started to talk about rights among themselves.

Maybe this meeting was impossible because it was an event that required answers to questions about humanity itself. In this case, however, the subject was a group of abject, contaminated people who have been excluded and isolated from any ideal of humanity. So questions arise: What kind of humanity? What is human? Does not the act itself of talking about a universal human being or the universality of humanity create the inhuman? Does not the same act that ensures the human being’s rights create those that are not human and who do not, therefore, have rights? Does not the act of talking about human rights create the inhuman, and at the same time offer, in an act of pity, to ensure their rights? Would we not therefore be able to state that human rights only exist under the condition whereby the human rights themselves have denied rights to a certain part of humanity?

Human rights can be interpreted as ethnocentric. This is because the very purpose of their advocates, which is to insert the precepts everywhere, presumes a lack or absence of such rights in the places the advocates deem to be without them and thus seek to insert them. Supported by a structure of nation-states, the advocates attempt to impose Western ideas on the whole world. The rights are, in fact, political tools for global imposition and homogenization. Notwithstanding this ethnocentric and reactionary characteristic, the demand to bring human rights to the FALE’s residents offers a chance to question their effectiveness and reality. The demand requires an agreement: it forces a
negotiation of the differences between the representative parties about what it is to be human and what should be desired. This process weakens any preconceived idea of “humanity” and discourages concepts that presuppose that the work would involve simply molding discordant bodies to a structure of knowledge and power that has been constructed beforehand. To say, merely, that “human rights exclude the following, that ‘universal man is European, white, heterosexual, and that the rights are exclusively for him,’ ” in other words, to criticize only the universality aspect of human rights, seems as unequivocal and dogmatic as the a priori acceptance of the rights themselves. What is worse, such a limited statement immobilizes discussion, ending the possibility of working on the contradictions, loopholes, and unexplored spaces of hegemony.

But, if the intention to speak for leads to silence, what should we do? How do we deal with the silence between the FALE’s inhabitants and the Law? Can we talk about the universal rights of man for people so marginalized? How can one be a voice and represent a person with no rights without becoming a form of oppression by exercising the tranquil and absolute violence about which Cixous warns us? The desire to speak for shown by the HUB professionals is an example of the construction of the universal human being as an individual (Dumont 1985, 1992). FALE’s inhabitants, however, organize their lives around other ideas and values. If the situation that they are submitted to is perverse and degrading, the options that they are offered do not appear to relieve their pain.

In FALE’s case, if a naive and uncritical application of human rights can lead to prior and fictitious suppositions, and FALE’s residents want these suppositions, skepticism will make it impossible to give value to any demand for rights. If the idea that the universality of human rights is contested by local interpretations and, thus, we cannot speak in terms of universality nor of human rights, would this not be a reification of the opposition between international and local? Is there any connection between those who presuppose knowledge of the needs of others and those who make the prior assumption that any communication will fail?

The Impossible Invention

Many anthropologists have sought answers to the dilemmas of human rights. Some state that anthropologists can contribute by mediating between different cultures and their concepts of human rights. Others argue that it is possible to reconcile some of the postulates of universality with relativism. All of these positions seem to have a common point, that talking about human rights cannot mean the weakening of anthropological criticism. Our critical posture must be one that provides a distance from ideas that demand human rights. In FALE’s case, for example, the noncritical posture of the health professionals who demanded human rights for FALE was liable to lead to the defense of the ideals of individual autonomy, of therapeutic practices, and of a whole range of values that, in fact, would add to the FALE’s residents’ suffering, as I tried to show throughout the text. Could it be that a more critical approach and the fear of naturalizing concepts could lead to views that weaken or stop contributions from a more political anthropology? How should we keep our distance when the situation requires us to take a position, with the consequent
defense of rights for FALE’s residents? How can we keep a distance when
human rights, for instance, could be an effective tool in the fight against
extreme forms of oppression? Again, given the propensity of anthropologists to
work alone, aren’t these the least suitable people to talk about human rights?

Most of current anthropology states that our values are part of our culture.
Thus, anthropology itself remains subject to its own historical and social condi-
tions. Relativist criticism turns against the discipline, revealing the historic,
dated, and culturally limited character of anthropology and of relativism (Soares
2001). The movement to recognize the relativity of relativism is salutary as it
shows the limits of absolute relativism, which would deny any possibility of
human rights, justifying that any presupposed universality would violate local
interpretations. In fact, absolute relativism would not support a project to con-
struct a wider universality with more plurality. There is an “agonistic, tragic,
aporian” feature to this issue that, instead of blocking practical and discursive
positions, says Soares (2001), merely affirms the inexorably value-based, prag-
matic, and political character of the positions. Anyway, this aporetic situation has
led to the idea that the political, moral, and ethical areas that are created by
human rights would be an area where the anthropologist is most frail, and would
not provide enough security for adequate work. Contrary to a “position,” only
solitude itself as a vocation would be an antidote to the dangers of noncriticism.

The fear, doubt, anguish, and pain of anthropologists themselves, in my
point of view, signal a process of continuing self-questioning and blocking—
or making it hard—for anthropological discourse to become one with the
normalizing discourses. The undecided aspect could mark a meeting with
“otherness”—to use the terms of Jacques Derrida (1991)—and, because of this,
build the scope of responsibility. This, it is suggested, makes it less likely that our
preconceived ideas will neutralize the new situation, being the inaudible charac-
ter of the other. The anthropologist can particularly emerge in the space in
which we question what is human, suggesting many interpretations—and
using a number of cultural experiences for answering—this question. The chal-
lenging of an a priori definition of humanity negates exclusive universalism
and opens up space for various points of view of what it means to be human.
Thus, anthropology would examine essential categories, freeing them for criti-
cal analysis, arguing as to their ability to include.

How can we include people not known as human in humanity? When a
group of AIDS sufferers gain national attention, as in the case of the FALE
residents, they help to create the link between anthropology and human rights.
This extraordinary appearance of the other, the emergence of people not con-
sidered human and the fact that, in some way, anthropology can fight for their
humanity, deny restrictive universalism.

This is an attempt to take back lost humanity, carried out simultaneously by
ethnographic writing and by an anthropologist’s defense of human rights and
the validity of these rights for these people. This novel claim opens up loopholes
in the law. When the first AIDS sufferers requested laws that protected them
from homophobia and racism and what could safeguard them against being
abandoned by the state, they called for laws that did not take into account any
previous law (Butler 2001). In the same way, the demand for reasonable living
conditions and laws to support them, in short, the demand for humanity for
people as lost as those at FALE, presents possibilities for confronting the law and reshaping what is human. This sudden emergence of FALE inhabitants who are “the other” comes about alongside the fight to undermine the conditions that have contributed to the silence of FALE’s inhabitants. The anthropologist arises in this breaking away, this breaking of silence, like a voice, among others, among various others. But what voice? Is not this voice just another way of speaking for? If the role of anthropologists resides in their voices, their solitude would be something absolutely immediate and provisional. Here, we come back to the issues of representation. Anthropologists’ political activities and their efforts to break up the supposed ethnographic neutrality face another aporia: how to construct a voice without eradicating the complexity of the other? And in a fragile and vulnerable situation such as the one at FALE, how can this voice be built without delving into the misery of others? How can an anthropologist be a voice without silencing others, and without being silent on their silence? The doubt about which path to take, the fear that a position may become critical, the pain of living with suffering; all these situations may give form to the agonistic, tragic, and aporetic combat that Luis Eduardo Soares describes. What should we do? The positive intention to provide a definitive answer to these questions—either to solve dilemmas or to solve doubts—is a fragile chimera. Maybe what is left is to try and live out this experience of the possibility of the impossible.

The Voice

Lying on a bed in the HUB, Carlos stares at the wall. His physical condition is worsening daily, and visibly. His eyes have that yellowish hue that I—maybe naively—see as the approach of death. He is alone, and the size of his sadness haunts me. I try to talk about FALE, about his life, but nothing seems to hold his attention beyond the next shot of morphine. Carlos had his legs amputated; his family cannot stand to hear his name. He is blind. He is addicted to morphine, initially used to relieve his pain. No one visits Carlos, only social workers and HUB psychologists. While a doctor looks after him, I think about my fieldwork, about Carlos, about what I could do to help him, what I should say. Suddenly Carlos starts to cry. Not knowing what to do, I gently put my hand on his shoulder. I help him into a more comfortable position. Carlos said—or was it my imagination, I don’t know—“life was bad but death will be worse.” I stuttered something. I went home with the feeling of the monumental uselessness of everything I did.11

Reading in retrospect, Carlos’s story seems to fall into a sort of Kafka area of magical reality. How can someone be in this condition? Doesn’t the style show exaggerated sentimentalism? Isn’t the absurd and simple act of placing a hand on his body also a way of building silence? Is there any way to reduce this feeling of uselessness?

The solutions for overcoming silence and blunted language caused by pain may lie in the continual attempt to speak to rather than the speak for attitude. This search for voice cannot be done without considering an other’s pain. On the contrary, as suggested by Veena Das (1995, 1997) who appropriated Wittgenstein’s analysis, we should remember that the pain is located in another body and, conversely, in one’s own, because the curative force of anthropology should be those without pain sharing the pain of the others and experiencing
their suffering. In Wittgenstein’s opinion (2003), compassion shows proximity between people, leading to the conviction that the other feels pain and that it can be shared. Wittgenstein shows how pain can be shared. Compassion toward my friend leads to the question of what I can do for him. Hold his hand, offer words of comfort, bring food, tidy the bed. These simple actions show that I am giving my motor capacity, guided by the desire of another. If he is weak and sedentary, my hand will fetch water. If he is weak, my limbs will provide energy. We act as if we were one body. My body acts to relieve suffering. Sharing will relieve pain, as pain is anchored in isolation. Pain and disease break the link with the natural and social world, marked by solipsism.

When bodies interconnect, when they share a communion, when my compassionate body touches the sick body, we can act as a force for cure. The sharing does not seek to legitimize discipline and the specialists, but to form one single body, via narratives, and by creating converging voices. As far as possible in such a difficult area we should be attempting such a cure for the pain and suffering experienced in other bodies. Perhaps it is this sharing that offers a certain meaning to the simple—and now not so absurd!—act of touching a sick body, showing that communication is possible. The agonistic, tragic, and aporetic relationship between solitude and such a position make it impossible, which paradoxically in turn makes it possible for the conditions to arise where the anthropologist can become a “wounded doctor” (Gadamer 1994), who is sensitive to the pain of others. It is this experience of pain, suffering, and compassion that constructs the point from which the anthropologist can speak of rights and humanity, in their axiological and practical aspects, without becoming just another normalizing line of thought.

At the end of the day, this ethnography of FALE may not only provide a considerable amount of information and conclusions on the habits, torments, and the social activities of AIDS sufferers, but allows the reader to better sense the pain of and with the other. Where anthropologists can be wounded doctors, perhaps we can use our therapeutic powers to evoke emotions and sensations that expose our fears and doubts. Anthropology should not use the representations of suffering or terror to build its authority, but rather try and make it possible for the pain felt by others to be humanly imagined and understood. This is not about speaking for, which would make it more impossible or difficult for the subalterns to speak, as suggested by Gayatri C. Spivak (1994), but about sharing speech or the lack of it, and causing others to share this experience.

Notes

1. Dispositive is one mesh of speeches, institutions, and rumors that answers to the exercise of power at a specific historical moment. See Michel Foucault (1981, 1985, and 1986). With reference to silence, see Foucault (1981); for an anthropological approach to silence, see David Le Breton (1997).

2. From now on, all references to the Fraternidade Assistencial Lucas Evangelista (Assistencial Fraternity Lucas Evangelista) will use the abbreviation FALE. All names in this text are fictitious.

3. For an interesting analysis on zones of social abandonment in Brazil, in the context of AIDS, see João Biehl (1999).

5. Supposition that every AIDS sufferer is about to die and the only thing left is to give him or her a “comfortable death.”

6. I use the notion of human rights in its wider meaning that covers the group of laws that deal with the right to life, protection from psychological and physical abuse, and so forth.


10. On expounding about misery in general, see the work of Angela McHobbie (1982).

11. A section from my field diary, written in October 1998.

12. The analysis of Stanley Cavell (1997) points out pain as the main topic in Wittgenstein. *Philosophical Investigations*, in this direction, “is the great work of philosophy of this century whose central topic may be said to be a pain” (Cavell 1997:95).

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