Restitution of the research data in ethnographic health research: issues for debate based on field research conducted in Brazil and France

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Abstract *This study examines relevant aspects about the way anthropological research data restitution has been applied in the area of health, based on data obtained from ethnographic field research conducted in Brazil and France. These experiences show that data restitution has been part of the area of research, in different forms and time frames, making it possible to extend periods spent in the field and to interact with individual respondents. This also made it possible to interact with research interlocutors and compare different points of view, adding new information and thereby enriching the research. These aspects raise important questions that require reflection, from an ethical and epistemological standpoint. One is related to the demands made on health anthropologists when they begin their field research and how they deal with these questions: how will researchers use the data they collect without worrying that this may be wrongly interpreted or used in some way to reinforce normative patterns? So, how should an anthropological debate be "translated"? Conscientious researchers will seek to validate their analysis, to discover new points of view and provoke new lines of questioning. Thus, such data should provoke reflexivity about new avenues of research and interpretations.*

Key words *Ethnography, Interlocutor, Data return, Qualitative method, Reflexivity*

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Introduction

Anthropological knowledge is constructed through a series of processes of human interaction. Anthropologists need to assume a position among those who do not fully understand their role. Unlike those who conduct action-research, the aim of their research is not to directly interfere with the reality and the final results of their analysis (be this either through the written word of by audio visual means) and is, above all, knowledge that is *received* from their informants rather than *returned* to them. In other words, their research findings are more a source of information, rather than a matter to be discussed and debated with those they are investigating.

Anthropologists, and particularly those involved with health issues, are increasingly taking part in research work linked to national and international agencies, as well as NGOs and the health services, which involves conducting qualitative investigations to implement qualification and intervention projects. It is important to emphasis this, since dealing with issues involving health and disease requires certain social, cognitive and emotional qualifications that include issues involving both ontological and epistemological anthropology. Anthropologists often play the role of mediators between these institutions and their target population, who are the object of their research studies. Thus, the involvement of anthropologists in preparing and executing these projects is often intertwined with moral and ethical questions which paradoxically are not part of an anthropological analysis. One of these is the restitution of research data.

This study uses the concept of the restitution of research data according to the views expressed by Françoise Zonabend[1]: "ethnology is not a social "inventory" nor is it the registration of a society (…)." According to this author, the data restitution process is already an integral part of the initial stages of any field research. It will in some way be part of the implicit contract between researchers and their informants, which guarantees the veracity of the facts, and serves to control the research *a posteriori*. That is to say, to speak of data restitution *a posteriori* does not mean something that occurs after the research, but rather that it is part of the process, with variable modalities and temporalities.

Knowledge gained during field work is the result of human interaction, and is not extracted from the native peoples. As so well illustrated by Diego Zenobi[2], it is important to understand that ethnographically produced knowledge is part of human interaction, and not merely the extraction of information, and also influences the construction of ethnographic authority. This authority does not occur just by being in a certain place, as a witness to distant facts about the subject of an ethnographic study; nor as a mere rhetorical artifice, as is proposed by those who use a textualist approach. It should be seen as the participation of researchers in a context in which their actions and interactions have their place and make sense in relation to their role and position[2].

This means that research data is in a constant state of construction. Thus, there is continual enrichment to be gained in this process of ebb and flow. The greater or lesser moments of informality shape this exchange between the interlocutors and make it possible to compare different points of view. For example, it is usually the case that researchers need to continually explain and clarify the procedures and objectives of their research work, that is to say, from the time they begin their field work until the restitution of the same, researchers should reaffirm their interest in the object of their study and win over the trust of their informants.

The restitution of the research data implies placing the interlocutors face to face in situations they experience on a daily basis. On the other hand, all researchers fear possible reactions, especially since their informants may feel they are misusing, distorting or over simplifying this research data, so that a lack of trust, doubts and suspicion can and should be treated as part of their data material and examples of knowledge. Questions that frequently arise are: At what point is an anthropological discussion translatable? … How can the restitution of research data affect the data or the relationships between researchers and their research subjects? … What sort of misunderstandings might occur? … What can this research work offer the researcher? As already mentioned, data restitution preparation already begins when researchers initiate their field research: the way that a group reacts to the presence of a researcher is already a valuable piece of information for the purpose of the research itself, indicating the expectations that the research subjects have about the researcher. In this connection, the question arises about researchers' sense of responsibility and commitment, that is to say, the degree of involvement anthropologists have in their field of research. Researchers can be seen as collaborators, and that is where their fears lie: the way their research will be applied,

and anthropological research, above all, sees itself as being free from objectives of this type. Health anthropologists, especially in Brazil, are committed to their field of research and often work with familiar themes[3]. This involves not only an investment in national issues, but also a more integrated concept of nationhood, as described by Leibing[4].

I would like to pause here to reflect on the restitution of the research data based on anthropological health research conducted with low-income groups in Brazil and my own doctoral theses, which resulted from fieldwork I conducted centered on health assistance services provided by the humanitarian medical group *Médecins du Monde* (MDM – Doctors of the World).

Research data restitution in different contexts

In 2012, I worked on a project based on the reasons why people did not adhere to or abandoned treatment for tuberculosis in the shanty town complex of Manguinhos, which is where the activities of the Germano Sinval Faria Healthcare School Center, which is part of the Fiocruz National School of Public Health[5]. I was responsible for coordinating the qualitative side of the research study, which was based on interviews with local inhabitants and target groups and with professional health workers.

When conducting research into health care, health professionals are often included as actors to be investigated. This means that health professionals are often on the defensive in relation to researchers, since they are seen as people who think they know it all, who are inconvenient and spend all their time questioning practices and making people feel uneasy. As a result, health professionals are often not that keen to take part in a survey, since they are unwilling to be treated as "research objects."

This was certainly the case in this study: health professionals were very unwilling to take part in the focus groups. As well as the afore-mentioned reasons, we believe their unwillingness was also partly due to relevant questions involving the demands imposed by the type of work they do: too many things to do, difficulties in programming agendas, conflicts within their teams and the fact that TB does not represent a particular priority among the innumerable other health problems they have to treat. However, one question in particular drew our attention: many complained that, on previous occasions, once researchers had completed their work, they offered no follow-up to the health team. So great was their resistance to participate in our research, that it was impossible to use focus groups as originally planned, so this technique was replaced with individual interviews with those health workers who were willing to participate in our study. Anthropological analysis should take into account the reasons why potential informants might show resistance and boycott such interviews. Thus, readapting research techniques, so as to respect informants, involves methodological as well as ontological questions, involving the restitution of the research data.

However, with regards to TB patients, many agreed to give an interview in the expectation of obtaining treatment from Fiocruz, even though we explained we were researchers and not health professionals. One such comment is a good example: "Feel free to record, you can record me – and you know why, because my medical tests, they are all there with Dr. G. They are all there, in that file of his. I have proof to show why I need to be admitted to hospital."

The fact that a researcher is seen as a health worker is not unusual for an ethnographer working in this field. This became even more regarding ethnography at the MDM center. I always used this space to explain that my role was exclusively as a researcher, but, depending on the situation, professional health workers and others used to see me in a different light, as will be explained more fully below. These considerations need to be incorporated into one's research data and analysis, taking into account the system to which these actors belong, the different hierarchical levels that characterize their social relationships and the conflicts that arise as a result. .

With regards to research conducted at Manguinhos, in some situations, the interviewers found TB patients who were not receiving treatment and who were in a very bad state of health. These cases were drawn to the attention of the health workers. Meanwhile, our survey showed that patients who adhered to the treatment were those who had a close relationship with one of the health workers. We therefore talked to the team about the need to value the work of the health workers who encouraged these links so as to ensure the success of the TB treatment. This is an important detail, since it shows how the views of an outside researcher can make an important contribution to issues related to health care. In other words, researchers should bear in mind their own social responsibility as citizens

when faced with the needs and rights of users to adequate medical treatment, as outlined by Jean-Pierre O. de Sardam[6], which does not mean however, that their research work is being applied in any way. Researchers should, however, take care not to assume the role of a welfare worker, taking the side of the health care users against the professionals and, thereby, lose sight of the complexity and ambiguity of health care issues. To overcome such conflicts, Paul Farmer[7] suggests an attitude of pragmatic solidarity, to reinforce the trust and proximity that a researcher and the participants construct between them during a period of research. According to this author, this is also a way of constructing scientific knowledge.

As stressed in the case cited above, this research study was not requested by the health workers. Even so, in the case of anthropological health studies, they make many demands on an anthropologist with a view "to understand the culture" of those they want to treat. This sort of demand has already been questioned by several actors who have drawn attention to the danger of viewing this sector of the population as being 'exotic'[8]. In such cases, it is important that an anthropologist considers such demands as a research and cultural factor. This is what happened which I conducted my research in France.

When I met the MDM health center coordinator for the first time, to present my research project, both she and the other professionals showed a good deal of interest in my proposal. The idea of having an anthropologist present could help them understand why African women were so keen to receive treatment to help them become pregnant, a factor they associated with the importance of motherhood in African culture. I agreed to observe these events with special attention, though I sought to analysis these as a form of interaction between health workers and their African patients. At the same time, the concern shown by these professionals in relation to "the value that maternity has in African culture" is a viewpoint that also reflects the cultural values of French society and, thus, is a factor which I included in my research[9]. I therefore decided to learn more about the historical aspects of the values associated with a smaller family unit and its medicalization process within French society, which could be dated to the period between the two World Wars.

Thus, aspects related to the culture or the *sans papiers* illegal immigrant status of African women make their desire to have children unlawful, since this was seen as their inability to conform to Western values, and therefore made

their social inclusion in the country impossible. However, it would be a mistake to argue that African women wanted to have more children because this was closely linked to their own cultural values. Reducing this fact to a cultural condition incurs running the risk of reifying these women for their differences and negates the fact that, even in Western societies, the value given to motherhood is also a product of culture. If the medical-hygienist and pedagogic discussions related to a reduced family unit has not yet been integrated into African societies, that is because these do not adhere to such regulatory concepts. Undoubtedly, for African women, having children is perfectly coherent with the principles of their culture, since this confers prestige on them as women and as mothers. On the other hand, having children is one of the elements of social inclusion, both in Africa and in France, since this implies material advantages provided by the family in the first case, and by the State in the second. The fact that French doctors working at the center were similarly surprised that French women living in precarious socio-economic situations should want to have children makes it necessary for us to conduct investigations into class values. Thus, the desire to have children is only considered a legitimate one if this is based on models that conform to the values of a dominant class.

In fact, the intermediators tend to think that only the target populations are bearers of "culture"[10]. However, by reducing these population groups to a cultural etiquette, incurs the risk of reifying them for their differences and assuming that it will be impossible for them to integrate into society, underlining their biomedical legitimacy and thereby justifying their failings, which further reinforces the exclusion of vulnerable population groups. On the other hand, there is also the risk of denying the fact that the interventions themselves are a cultural product. Following this line of reasoning, we should take care with the definition of an anthropologist's role as a cultural "interpreter."

The use and disuse of research

Research activities in a health context often involves taking part in team meetings, internal training courses, consultations and discussions involving clinical cases and being invited to give an opinion about different matters. These matters should be included as research data, bearing in mind that a researcher is never simply an observer, but also an actor[11].

During my research at the French humanitarian center, I often had to "adopt a position": by simply "taking notes" in a waiting room or during medical consultations, "my silence" in these situations put my identity in doubt, from the viewpoint of health workers and users alike. Was I a researcher or a doctor? It is worth underlining that, in order to participate in consultations, I was introduced by the doctors as a "colleague." However, since I did not take an active part in these, did that mean I was an intern? And, as an anthropologist, what was my role during a medical consultation? [12, 13]. This meant that, in some situations, I was called upon to give an opinion about a diagnosis and offer advice to patients. Immigrant patients, in turn, felt more at ease when describing their afflictions with someone who was also a foreigner. These situations, far from underlining my "neutrality" in the research study, actually gave me a wide range of opportunities to interact and introduced elements that were relevant to my research. In fact, the relationship between a researcher, health users and health workers involved differences in gender, nationality, ethnicity, culture and social class. I therefore sought to use all these factors so as to better understand the construct of the different spectrums of otherness and seeing these as situations of interpersonal communications that produced data that became an integral part of the anthropological analyses.

On the other hand, I often worried that my data, once published, would produce negative reactions. I also did not want to be misunderstood for "using consultation data," often involving sensitive situations, for the purpose of my research. I therefore decided to use a strategy, during my fieldwork, which was to deliver short extracts taken from my observations together with a preliminary analysis. I would then see how the health professionals reacted, though was always fearful that this would produce a negative response. To my surprise, this was very well received, which clarified my position as a researcher and especially what Anthropology involved.

After this, they were even more willing to help me, inviting me to discuss "interesting cases." They also felt their work was being valued: here was someone who was paying attention to their work and was writing a thesis about them. I also received a good response to the two paragraphs I wrote for an internal MDM bulletin, where I simply discussed how important it was to assess the relative cultural aspects of patients who were not of French origin, which they told me

was a "wonderful article." This showed that this approach also positively affected data collection and the questioning of methodological aspects of research. Perhaps we could think about using this type of approach more often in the dynamics of gift and countergift?

On another occasion, I was invited by the organization's managers to talk about my research. This was another difficult situation, since the managers were in conflict with the team at their central base. I presented a few facts, among which I mentioned that some health professionals had called into question the "humanitarian role" that they were developing and how they valued this type of reflection as a critical analysis of their work. However, this was understood by the managers to mean "don't they know the role they are meant to play yet?" In other words, it was clear that an anthropologist not only makes a second to third hand interpretation[14], but that, in much the same way, their research data will be read and interpreted according to a person's particular point of view, and that a researcher has no control at all over how this data will be used and interpreted by third parties. Nevertheless, one of the goals that anthropologists should have is that their impartial outsider's view as a researcher can highlight factors that will enable health workers to think about the way they carry out their work.

It is more complicated to restitute research data *a posteriori* to healthcare users than it is to health professionals. In such cases, perhaps we should think about the restitution of data to users during the period of research, rather than afterwards, through personal interaction and the possibility of establishing less hierarchical relationships at the time these contacts are made. For example, my presence at the MDM center was often a source of comfort to immigrant patients since, as previously mentioned, they felt closer to someone who was also a foreigner. This close relationship was obviously more apparent with patients from Latin America, who were obviously delighted to find someone they could speak to in Spanish. My presence was also requested on many occasions to help with translations during medical consultations. This enabled me to establish a much closer relationship and proximity with these patients.

Thus, In France, my nationality, or the fact that I was a foreigner, my accent and my friendly approach, enabled me to have fruitful exchanges with patients at the MDM center. Some of the immigrants later returned to talk to me about their difficulties and I established close relationships,

which have continued until the present day, with homeless people living on the streets known as *habitués*. Thus, an anthropologist can and should develop ties with their native informants by listening to them, thereby incorporating one of the methods used to promote care that is so widely encouraged by health programs and policies.

When a "native" informant reads the research data

In research, we can think of data restitution as also being a way to prolong our fieldwork, our interactions and relationship with our native informants. In this case, research receptivity and data restitution blend together as regards established interactions, engagement and responsibility in relation to the field of research. The dual end product of an investigation, be it about the way to draw up a report for a funding project or for an article for a scientific magazine, underlines the distinction between two roles: 'pure' science versus 'applied' science. Nevertheless, this is an ideal distinction. In real situations, it may be observed that there is ambiguity between these two roles, depending on when one or the other is claimed and one or another argument is used, depending on the context. Publishing articles and books is an important way to promote research within the academic community, but these publications tend to have little repercussion for those surveyed.

In the case of my doctoral research, the fact that this was published in book form in the language of the research location and launched at the center where I conducted my research meant that practically all of the health workers had the opportunity to read my work. As they became aware of and recognized themselves through the ethnographic data, they felt valued, and this led to several meetings after the research was completed, which offered a rich interchange of information that was imbued with feelings of affection on both sides. One patient, who lived on the streets, whose letters to one of the volunteers and poems on alcoholism, I quoted extracts from in my work (obviously with his permission), after reading my book, immediately sent me some more of his poems and the letters he held. I keep in touch with him to this day.

Once they had read my book, the health workers also gave me feedback on their thoughts. I include a letter below from a nurse, who at the time was 92 years old, and who had worked as a volunteer at the MDM center since it first opened.

This nurse had always worked in the social area, and had taken an active part in the French Resistance. This nurse's work consisted mainly in treating skin disorders among homeless people living on the streets, and this is what she refers to in her letter, which I have translated as follows:

Dear Jaqueline

I begin this by saying how happy I was to see you again and to spend some agreeable moments with you. I would like to thank you for so kindly offering me a copy of your book, which I read with great interest, since I have in one way or another been involved in the healthcare that you describe as a "Lack of care." Reading your book, for which I must congratulate you, I learned many things, bearing in mind that I did not have contact with all the patients. Those that came into the infirmary were in desperate need of treatment, which we gave with the valuable assistance of Dr. H, a dermatologist. Thus, there was a very good level of contact between ourselves and our patients, and this often helped them to talk to us about their problems, while we were treating them. But there were others who only came in to talk to us, to tell us they were feeling unwell, and we listened to them. I also had the satisfaction of overseeing student nurses who, at the end of their internship, told me how their views about these people had also changed and that they now realized that, the majority at least, were very amiable people. I too, was often surprised by their behavior. I will cite one example: we once had a patient who was very anti-social and lived alone and was mentally unbalanced. Once, they tried to steal his bag and he fought off the thieves. He was injured as a result and, when he came to us, his arms and half of his back were badly burned. After treating him, we made him go to hospital. At that time, he had long hair. Two months later, he came to the center and we asked him if the hospital treatment had been painful. He replied: "It wasn't that treatment that hurt, but the fact that they cut off my hair." This was not exactly the answer I had been expecting! All this is to tell you that because these people lead very hard lives, they are able to accept without complaint the often very painful treatments we give them.

I now have the time to think about all that I witnessed during the sixteen years I worked at the MDM, of which I have very fond memories. I feel rather useless now, but know we cannot dwell on such thoughts about all that is now in the past.

I wish you continued success in your work in the city of Rio de Janeiro and many thanks again.

Warm regards,

M. L.

The reflections that the anthropological data provoked in its readers, as in the case of the *a posteriori* testimony from nurse M.L., were essential, not only because these opened up possibilities to deepen the interchange and strengthen the ties I had with my informants, but also because this meant I could harvest the fruits of my research. The health professionals I had worked with had abandoned the center some time after my research due to conflicts with the central coordination. But they frequently met up among themselves and with the old *habitués* from the center. When I go to France, I am invited to join these meetings and they register this event in a book as a reminder of their experiences at the MSM center.

The subjectivity and affection involved in this research should be considered as an integral part of the anthropological study. The text *Encontrando Taso, me descobrindo* ('Finding Taso, discovering myself') by Sidney Mintz[15] is an example of how co-existence and proximity make it possible to understand and give new meaning to aspects that had, until then, been perceived as natural by the researcher and by the research subject.

General Conclusions

Ethnographic texts are produced and interpreted within the relationships established between the researcher and the subject of their research. In accordance with James Clifford[16], at the same time that ethnographic experiences are being textualized, the ethnographic text is imbued with all the experiences involved during the research study. Thus, allowing the research subjects to play an active and direct role in the process of research data restitution makes it possible to attain more advanced levels of research.

The field of anthropology is emblematic: it can establish both a geographical space as well as the group with whom anthropological activities are developed. However, this is where anthropologists establish their identity, namely an identity that always seeks to give legitimacy to anthropology in practice. On the other hand, there is no symmetry between the position occupied by an anthropologist and the 'native' informants. An understanding of another always goes through a rhetoric of otherness, in which categories and aims are in permanent construction. In short, this is a situation involving personal communication, which produces and restores data. It is therefore important to include as an integral part of anthropological interpretations the intellectual and emotional route that gave rise to these constructs and to reconsider the position of the anthropologist as being part of their own research data. Conscientious researchers aim to validate their analysis, seeking new points of view and provoking new lines of questioning. Maria Cecília de S. Minayo and Iara Coelho Z. Guerriero have also given thought to the need to integrate ethical issues as part of the process to construct and analyze research data[17]. Thus, research data restitution provokes new uncertainties and interpretations as a form of reflection.

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