

Reflections on sharing data from healthcare anthropological studies

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Abstract *This article discusses the topic of sharing the results of anthropological studies, such as disseminating research results to health professionals and to social movements. The starting point is a dialog with a number of successful and less successful publicizing experiences. This has allowed us to find negotiations and limits of this practice, and the different dimensions of which it is a part. We will use examples to develop two lines of questioning regarding “post-study requirements”. The first has to do with the ethical and political nature of the initiative, and the second problematizes the “interest” in the results on the part of the various subjects involved in the anthropologic investigation.*

Key words *Ethnography, Results disclosure, Research ethics, Qualitative survey*

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Introduction

Disclosing or sharing research data is an area that is not yet well developed within the scope of discussions about research ethics in Brazil. This topic is the focus of a recent review of the Helsinki Declaration by the World Medical Association. Specifically, a paragraph has been inserted ensuring access to the benefits following study closure¹. This amendment is motivated by the urgent demand to use successful medicines and therapeutic projects in those subjects originally involved in testing, and by a critical reflection on the extent to which science is responsible for the continued existence of certain structural inequalities and the particularly asymmetric conditions of knowledge development.

Among the main challenges one faces to advance in these discussions is the fact that conventionally, ethical reviews address the requirements to start a study, such as information about the conditions for participating, the anticipated risks and making sure there exists a suitable framework for data collection. All of these aspects (which are required for assessment), tend to be put into operation by demanding that one first obtain free and informed consent from the participants, and the content of such consent. Post-study obligations are less imperative, and normally correspond to assumed possibilities and not to concrete guarantees regarding the outcome.

The regulation of post-study obligations is fundamentally being discussed in the healthcare area, the purpose being access to the (successful) medicines by the subjects who helped test them. The main argument in favor of this commitment has to do with minimizing the presumed exploration when one compares the context in which drugs are tested, and the one in which they are marketed. The expectation of returns by the subjects who accept the risks and inconveniences of studies for scientific advancement is another important factor, as it places into question future possibilities for cooperation. However, there are a number of hurdles in terms of the length of pharmaceutical studies compared to the urgent demands of patients. Furthermore, to the extent that post-study obligations are viewed as compensation, the voluntary nature of study participation is questioned. The problem of inappropriate inducement emerges as one of the major challenges in this process, as do the emergence of unrealistic demands².

In social sciences in general, and in anthropology particularly, where the matter of research

ethics has been strongly problematized, there are few forums where this theme is discussed. At the national level, the right to access study results is one of the principles guiding the anthropologist's code of conduct, a document that traditionally governs research conduct. It is interesting to note that the Anthropology Code of Conduct dates back to 1986, meaning it pre-dates National Health Board (CNS) resolution 196/1996, which marked the start of ethics regulations in Brazil. Thus, questions such as the mismatch of power between the researcher and the researched have been debated since before there were regulations governing the ethics of research with human beings³. Although discussions about regulating research ethics in Brazil mostly center on health-related research – so much so that the National Research Ethics Committee (Conep) is linked to the Ministry of Health – people in the social sciences and humanities related to health have promoted debates to adjust the nation's regulations on research ethics to their research goals and methodologies⁴⁻⁹.

There is a consensus regarding the importance of disclosing results not only as a right linked to collaboration with the study, but also as the anthropologist's obligation to report. Here we highlight the rationale of reciprocity, which keeps the communication and exchange channel with the studied community open. However, mechanisms for sharing study results (when and how), to whom the results will be made public, and the expectations regarding the study results are not specifically addressed in the discussions that take place in the more general collective forums, nor are they part of methodological planning or the ethical review of studies.

We could use the distinction between research done “on” and “with” human beings to justify that the recently reviewed element of the Helsinki Declaration does not apply to anthropological research. Unlike experimental studies where human beings are involved as “guinea pigs”, social research is essentially inter-subjective. In ethnographic studies, participants are addressed as social actors¹⁰. Furthermore, the outcome of anthropological research has no clear practical application, nor does it have any intention of providing an absolute solution to the demands of the interlocutors. However, for clinical trial subjects, access to specific drugs is ultimately a matter of life or death. This does not mean that sharing results with the subjects of anthropological studies can do without more concrete guarantees.

In some areas, due to the themes and populations that are the study subjects, anthropologists are called in to converse with social movements, institutions, stakeholders and policymakers. Indigenous ethnology, relationships between ethnicities, gender and sexuality studies, and body and health anthropology stand out in the development of this interface. As a rule, these themes also tend to involve ethical and political questions, which in turn refer to the expectations that the results will be applied, and their social and political implications. In healthcare specifically, healthcare professionals, social movements, the technical staff at institutions and even government administrators directly and indirectly demand that anthropologists provide them with research findings. In some cases, stakeholders, as part either of the study milieu or as a channel to facilitate access to the research subjects, agree to support the research effort only to the extent that there are explicit agreements regarding the sharing of study results.

In this context, this article proposes to use the experience of disseminating anthropological research results about health to reflect on the specificities unique to the discipline and the shared challenges regarding regulation of post-study commitments. Regarding the former, we present different ways of reporting data implied in ethnographic approaches, their problems and limitations. Here we call attention to the fact that research protocols are simply inadequate in terms of anticipating the terms under which results will be publicized. Regarding the challenges of regulation, we bring examples of the tensions implied in the dual ethical and political nature of the anthropologist's commitment to share the results of his or her work.

Experiences in sharing study results

There are many ways one can share the results of an anthropological study. Choosing a format generally depends on the theme and/or on the group investigated, the context in which the study was performed, and the political insertion of the researcher. There is no standard formula, and further experience in this theme can help deepen our reflections. This is why we have chosen to describe two experiences we believe to be positive, each one using a different format to publicize results, and to mention other experiences where problems of different types were faced during the post-study period.

The first experience portrays a situation in which the subject group had a political interest

in the study, and each step in the project was negotiated beforehand. This project was entitled *As faces da homofobia no campo da Saúde* (The Faces of Homophobia in Health). This study was performed following a public tender and was funded by the Ministry of Health National STD-AIDS Program. It was conducted in 2008 and 2009 by the Federal University of Rio Grande do Sul Medical Anthropology Research Group (NUPACS-UFRGS), together with the Brazilian League of Lesbians (LBL-SUL), and the National Collective of Autonomous and Independent Black Lesbians (CANDACE-RS). The aim of this study was to identify factors that make it harder for women who have sex with other women to access healthcare by analyzing the influence of sexuality on the doctor-patient relationship¹¹.

Although the study proposal and design were academic, the social movement was involved from the start of this project, including in the application for funding. The centrality assigned to the participation of these entities is that one of the study's intentions was to confront the healthcare professionals' views with those of the lesbian women seeking health services. Access to system users was enabled via the relationship network of two lesbian activists who were also involved in data collection (observations and interviews). More than privileged interlocutors, the activists were trained to work as research assistants. It is fair to say that this is where knowledge sharing started, in the study preparation phase, with the movement gaining familiarity with anthropological methods through training, and by qualifying the research tools by bringing issues raised from their own life experiences. During the actual fieldwork, there was almost constant tension between the movement's policy of visibility and the theoretical interest in mainly focusing on women who were not looking to make their sexual identity known, and thus were not engaged in the social movement. Despite all of the problems faced by the distance between the militants and the other women (systematically addressed while the fieldwork was being performed), this situation actually presented a unique reporting situation due to the profound understanding of where the other person was coming from.

There was also a more formal moment of disseminating research results, in this case a workshop about the health of women who have sex with other women. In addition to the research team, made up of researchers and activists, other people who investigate this theme took part of the workshop, along with lesbian activists from

other cities across the country, local activists and Ministry of Health representatives. During the workshop not only were study results presented, but one group of activists also drafted a proposal to design panties for women that could prevent Aids and other STDs. Another area of tension was the data submitted on the relationship between study subjects and men, and the recommendation that lesbian women should also become familiar with traditional methods of preventing pregnancy and STD/Aids. Many activists felt this was counter to their very “lesbianess”, and for this reason should not be part of the movement’s agenda. Discussions advanced however, towards a critique of the centrality assigned to the risk of STD/Aids transmission in relations between women. Rather than intervening directly in the sexual practices themselves, an agreement was made to prioritize a broader approach to making healthcare professionals and lesbian women aware of the importance of gynecological care.

It is important to stress the importance of having the activists directly involved in the study to achieve this type of dialog. A demonstration of how vulnerable lesbian women are to STDs and Aids was a core demand the movement placed on the study, as it would legitimize its involvement and its share of prevention resources. However, the study itself made the activists aware of other issues, such as the problems faced by the more butch women with the dynamics of gynecological exams, and the unwillingness of healthcare professionals and the women themselves to discuss their sexuality in the context of basic healthcare.

A third moment of sharing had to do with researcher involvement in planning and implementing the intervention strategies themselves. In this case, we would call attention to two: 1) Involvement in forums organized by the social movement, to which government administrators, healthcare professionals and lesbian women were invited; 2) The development of visual communication materials (campaigns with billboards and TV spots) to educate women who have sex with other women on the importance of taking care of their health. The campaign design and models were the researchers, research assistants and women of the lesbian movement.

The second experience we bring, explores a situation where there was limited knowledge on the topic being researched, and the survey revealed previously unknown directions. This was a study conducted as part of the requirements for a Ph.D., on the impact of a diagnosis of HIV/AIDS

on the daily lives of women¹². At the time, there were very few studies on this issue and there was an urgent need to focus on this topic, as healthcare services had recently implemented a protocol to prevent vertical transmission of HIV (from mother to fetus). It was essential to understand the impact of such a diagnosis on women, and to get them to adhere to pre-natal care, use medication and not breast-feed. The study results were initially presented only to the healthcare services where the women who participated in the study had been recruited, however they were later presented to managers of different levels (city, state and federal).

Another strategy used to publicize the findings as to have a more direct impact on the women themselves, was to engage the researcher in training events geared towards healthcare professionals serving this population in different services, both within and outside the state. The scarcity of data on the theme and the context of these services were both factors that, in our view, created significant demand that the study results be shared beyond the merely academic environment.

Study results were disclosed individually and differently to women who live with HIV Aids. Once the study ended, the researcher visited all of the participants. The visit took place almost two years after the data had been collected. The goal was to inform participants of the study conclusion and talk about the results. The experience with this sharing varied quite a bit. Two of the interviewees had died during this period, however their family members felt valued with the visit and the contribution made to the study. Others were found in the healthcare service and followed a course revealed during the study (as in a new gestation, in the case of a new partner). Some participants could not be located as they had changed address or moved to another city.

During these post-study meetings, the sharing of findings was not linked to any upcoming thesis or any other published text. On these occasions, results were shared only verbally and with a certain amount of affection, as there is no denying that anthropological work involves a give-and-take relationship¹³. The post-study period is also a time to “give back” the contributions received during the fieldwork, when not only data was exchanged, but also affection and other feelings. Therein lies one of the problems faced by the researchers when trying to share their results with participant groups, as this requires picking up a level of emotional involvement that in gen-

eral has already been somewhat effaced by the time elapsed between the end of the field work and the analysis of the data collected.

Both of these situations express what we believe are successful examples of sharing and disclosing research data, and are by many standards quite exceptional. Not only because anthropologists are not always aware of the group's expectations, but also because the researcher does not always have full control of the publicizing conditions. At this point, we would like to list a number of research projects we undertook involving public healthcare services, where it was impossible to share the results with the participants for a variety of reasons. Either there was no manifest interest on the part of the healthcare team in being told of the results, or the group did not deem the study relevant, did not have confidence in the methodology employed or simply did not care for the strategy the researcher devised to share these results. There were also situations in which the healthcare team coordinators informed us they would rather the results not be submitted to the larger group, as they could be interpreted as a failure of or criticism of the service. On rare occasions, the material produced by the anthropologists describes a service that is precarious, illustrates specific situations where there was discrimination, or shows how tired the professionals involved are in light of the demands and limitations of the service itself. Other times, the difficulty came in mobilizing any interest on the part of city or state administrators, and the results of the study were considered of value outside the context in which they were produced.

A frustrated research findings dissemination experience took place in a study we conducted to investigate healthcare services for people living with HIV/Aids in three Brazilian cities. As this study dealt with healthcare professionals and services, we felt that the results should be reported to system managers and the professionals themselves. However, in one of the cities included in the study, despite numerous suggestions that we divulge the results at a seminar designed specifically for this audience, city administrators showed absolutely no interest. It was only after the results had been presented at a seminar for healthcare professionals and managers of another city included in the study, and the intermediation of an international agency interested in the theme, that we were able to get any interest from city and state administrators in the results of the study, and this only happened two years after completion.

From this set of experiences, we must remember that one of the peculiarities of anthropological research is that sharing results is not only about using the data; furthermore the format in which results will be shared or reported cannot be predicted at the onset of the study. This is something that must be negotiated while the process is underway, and depends on the social groups involved, the context of the study itself, the expectations arising from the presence of the researcher in the field, and the conditions for maintaining the link once the study is over. Making any sort of commitment before the study starts has the risk of being profoundly unilateral, as it will not have taken into consideration the expectations of the participants. It will also become anachronistic, as the context is dynamic, something inevitable in any ethnographic insertion.

Results disclosure as an ethical and political commitment

For a variety of reasons, disclosing results to the group that has taken part of a study is always a tense step in the research process. First, one must point out that the outcome of anthropological studies is not expressed as tables or numbers, but as interpretations. It is harder to question numbers than interpretations, as the latter are considered "subjective". Another point to consider is that the purpose of social research is to go beyond the common sense and the very "consciousness" of the study participants. Thus, anthropological reasons are easily perceived as "untrue". However, when there is a better fit between the political intentions of the group being researched and the results obtained, the group will often expect the anthropologist to take direct and resolute action on the problems of the community in question. In other words, they expect that result of the study will be that the researcher him or herself takes a militant stance and direct action on the situations that could produce effective change in the situation under study. It is in this context that we find the numerous complaints of failure of anthropological studies to disclose or share data. It is not unusual that, because of this, these very communities are unwilling to collaborate in future studies.

On the other hand, one must admit that the training anthropologists receive does little to actually resolve this problem. The absence of any objective and operational response leads to frustration on the part of study participants. We do not have a new treatment to offer against disease, nor any recipe for how to proceed in all of the sit-

uations. However, most anthropological studies in the area of healthcare produce a detailed analysis of the problem, identify the hurdles hampering communication between professionals and patients, reveal situations of suffering, stigma and discrimination that come with disease, and help understand the interactions inside healthcare institutions, among other important points.

The problem lies not in the knowledge produced, but in how this knowledge is, or quite often is not, shared with the stakeholders. In other words, anthropologists are not trained to transform knowledge into a format and language that can provide answers to the questions raised by research participants, institutions, professionals and other stakeholders.

This problem in reporting the results of anthropological studies is perhaps due to the distance from, and limited adherence to what is commonly known as “applied anthropology”. Unlike other countries such as the United States and Argentina, Brazil has no tradition of inserting anthropologists in government agencies and public (and much less private) institutions. With the exception of native Indian studies, where the interface with institutional uses, in particular legal, is much closer, very little anthropological research has been used as subsidy for public policy or management. Furthermore, it is only recently that anthropology has been a university course in Brazil, and the profession is not yet regulated. We train our students almost exclusively for academic work that, in our area, has very little to do with social problems and demands. We research what is academically interesting but this does not necessarily relate to urgent societal matters.

Sharing study findings with the populations researched, and with the institutions and social movements involved, implies in a dialog that is not at all evident, as the view of an anthropologists may cause a displacement that questions day-to-day demands and practices, and questions values and assumptions implicit in certain processes. In this context, publicizing study results is not only an ethical commitment; it is also a political position.

Who is interested in the outcome of anthropological studies

Although recent changes in the Declaration of Helsinki have to do with “shared benefits” as one of the products of scientific studies, it is important to consider the source of this type of demand. It helps us reflect on the interests at

play, on the disclosure and use of the results of anthropological studies, and the role of the anthropologist not only as a researcher, but also as a social actor, as a subject who is politically implicated in ethnographic situations¹⁴. As an ethical problem, sharing study results could be thought of as individual exchanges and, based on sensitive strategies, and on the dynamics of reciprocity established during the interaction. However, when we consider the political nature of the anthropological commitment, one must also consider other questions: who has an interest in the study outcome? To whom does the researcher have a commitment to report these results? To the direct study participants? To the professionals involved in the care of these subjects? To the managers in charge of planning and implementing public policy? What is the best way of reporting study results so that they have the desired impact? What is the desired impact in this case?

The definition of “target audience” for reporting data is, as shown in the experiences above, variable and even multiple. One principle that we believe should guide this definition is that study results always be shared with the subjects who are directly involved. The question is, who are these subjects? Those who participated directly in the study, giving us their time and opening their homes and lives to us? Those who circulate in the locations where we were conducting our observations? Are they the subjects in a position to intervene in the reality under study? Is it society in general?

This question is always difficult to address and there are multiple positions. Researchers who work with audiovisual means, such as ethnographic videos, have shown that this is an interesting way to share the data with those directly involved. Using photographs and videos to disseminate research findings is certainly not only a way to share the data, but may also be a lever to discuss it with the participants. As stated by Claudia Fonseca¹⁴ when discussing her experience producing an ethnographic video:

It is inherent to the anthropologist's ethos to believe our research will, in one way or another, benefit those we work with. We want to see our efforts strengthening group identities, reinforcing collective memories or at least fighting discrimination and prejudice. In this regard, our written products, which primarily reach social agents and planners, have an indirect (if any) impact on the groups researched. A video on the other hand, offers the possibility of continuing not only the field research, but also a direct dialog with our informants.

As not all studies use audiovisual resources, we must seek other ways to share the study results with those directly involved. Experience shows us that often this takes place subjectively, through the relationship established in the field. In other words, more effective sharing may not be limited to the actual presenting of the results, but the effect that field in anthropology has on those who participate in the research and on the researcher. Meetings in the field are opportunities for reflection and dialog on themes and situations that are not part of day-to-day reflections. For instance, this is a very common experience in works about Aids and sexuality. Listing and being listened to, obtaining important information in a qualified manner, reflecting on past experiences and discussing them with the researcher are other ways to share a study in a manner that goes beyond the results themselves.

The outcome of anthropological research on the other hand, is of no value on an individual basis, as its goal is to capture a culture, a worldview that goes beyond the individual. It is something akin to epidemiology, where the results are collectively valid but cannot be directly transposed to individual cases. Thus, disclosing the overall study results often makes little sense for those directly involved.

Strategies that enable expanding the impact of the study beyond those who participated in it directly seem to be a good option for sharing the results more effectively or, in other words, in a way that the findings may actually improve the lives of those involved. Thus, healthcare studies should invest in disseminating their results with

the healthcare services, professionals and managers involved, as they are the agents with the power to change the practices and policies that interfere directly in the day-to-day lives of the subject groups.

The media is another resource one should not discard, be it for its power to quantitatively expand the number of people who learn of the study outcome, be it because the media is replete with hegemonic discourses about the body, health and disease. It is interesting how the prestige of the media gives credibility to the study and the researchers themselves. Including material that the media or social media may use as source material can today be a broader and more democratic way of sharing these findings, and can be incorporated into our strategies for publicizing research results.

Certainly there is no single way of disclosing research results. What is essential is that this be an ethical and moral commitment of all anthropological studies. To believe that an academic publication will solve the problem is to run away from this responsibility towards the research subjects. Anthropological studies, and especially those involving “vulnerable” groups, play an important ethical and political role. Sharing successful and unsuccessful experiences of publicizing research findings will help to not only deepen this reflection, but also raise this as a concern of students and future anthropologists. Perhaps in the coming years our methodology courses will include the discussion of the ethical questions regarding anthropological research, and the ethical imperative of sharing the study results.

Collaborations

DR Knauth and NE Meinerz helped draft the article. [conferir tradução]

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