Project REENCONTRO: ethical aspects of genetic identification in families separated by the compulsory isolation of leprosy patients in Brazil

Claudia Lee Williams Fonseca, Flávia Costa Biondi, Glaucia Cristina Maricato & Lavínia Schuler-Faccini

Journal of Community Genetics

ISSN 1868-310X
Volume 6
Number 3

J Community Genet (2015) 6:215-222
DOI 10.1007/s12687-015-0227-3

Volume 6 • Number 3 • July 2015

Journal of Community Genetics

Special Issue: Genetics and Ethics in Latin America
Guest Editors: Jorge Sequeiros, Sahra Gibbon, Angus Clarke

Springer

Springer

J Community Genet (2015) 6:215–222
DOI 10.1007/s12687-015-0227-3

ORIGINAL ARTICLE

Project REENCONTRO: ethical aspects of genetic identification in families separated by the compulsory isolation of leprosy patients in Brazil

Claudia Lee Williams Fonseca[1] · **Flávia Costa Biondi**[2,3,4,5] ·
Glaucia Cristina Maricato[1] · **Lavínia Schuler-Faccini**[2,3,5]

Received: 11 December 2014 / Accepted: 9 April 2015 / Published online: 13 May 2015

Abstract In this paper, we discuss the experience of a team of geneticists, working in partnership with a Brazilian social movement aimed at promoting the rights of victims of Hansen's disease. These university researchers propose to use DNA test results to ascertain kinship connections and thereby reunite families that were sundered apart by draconian state policies of the mid-twentieth century that decreed the forced segregation of leprosy patients and the institutionalization of their children. The team's aim is to help revert stigma and reinforce positive group identity as well as to facilitate judicial claims to moral and financial reparation from the Brazilian state. We will discuss how, notwithstanding the voluntary nature of tests, mediated at all times through the social movement, the geneticists take care to follow clear ethical guidelines in the collection and stocking of DNA samples as well as in the devolution of test results. The subsequent inclusion of anthropologists in the team brings to the fore new ethical dilemmas ranging from procedures in field research to the possible consequences of research results.

Keywords Hansen's disease · Human rights · DNA · Kinship · Ethics · Leprosy

Introduction

Throughout the last century, in Brazil, as in other countries around the world, special establishments (hospital-colonies) were built to isolate patients affected by what was then known

---

This article is part of the special issue on "Genetics and Ethics in Latin America".

Claudia Lee Williams Fonseca and Flávia Costa Biondi contributed equally to this work.

✉ Flávia Costa Biondi
flavia_biondi@yahoo.com.br

✉ Lavínia Schuler-Faccini
lavinia.faccini@gmail.com

Claudia Lee Williams Fonseca
claudialwfonseca@gmail.com

[1] Postgraduate Program in Social Anthropology, Federal University of Rio Grande do Sul (UFRGS), Av. Bento Gonçalves, 9500 - Prédio 43311, Block AI, Sala 104A, Porto Alegre 91509-900, RS, Brazil

[2] National Institute of Population Medical Genetics - INAGEMP, Porto Alegre, Brazil

[3] Postgraduate Program in Genetics and Molecular Biology, Federal University of Rio Grande do Sul (UFRGS), Porto Alegre, Brazil

[4] College of Biological Sciences, University Campus of Altamira - Federal University of Pará (UFPA), Altamira, PA, Brazil

[5] Genetics Department - Biosciences Institute, Federal University of Rio Grande do Sul (UFRGS), Agronomy Campus, CP 15053, 91501-970 Porto Alegre, RS, Brazil

as leper.[1] Often, this legally mandated internment led to the patient's life-long withdrawal from society, as well as family disruption, with children being abruptly separated from parents. Internees' offspring were raised in "*preventorios*," specially supervised orphanages, or given—legally or informally—in adoption to relatives and even unrelated families. In the early 1980s, a Brazilian association was founded to promote the rights of people affected by Hansen's disease, Movement for the Reintegration of People Affected by Hansen's Disease (MORHAN). In 2010, this organization launched a nationwide campaign to identify and bring together siblings separated by the compulsory isolation of their parents. Through their energetic campaigns, the movement hopes not only to reunite families that have been sundered apart but also to help this generation of "separated children" to press legal claims for reparation against the Brazilian state.

In this paper, we discuss the experience of a team of researchers from the National Institute of Population Medical Genetics (INAGEMP) working in partnership with MORHAN. We consider how, through the Project "REENCONTRO," this team proposes to use the DNA test results in the promotion of human rights. Their aim is to help revert stigma and reinforce positive group identity as well as to facilitate claims to moral and financial reparation from the Brazilian state. We will discuss how, notwithstanding the voluntary nature of tests, mediated at all times through the social movement, the geneticists take care to follow clear ethical guidelines for the collection and stocking of saliva samples as well as the devolution of test results. The subsequent inclusion of anthropologists in the team brings to the fore new ethical dilemmas ranging from procedures in field research to the possible consequences of research results. We consider, in particular, the possible impact of test results not only for the family relations of the people tested but also for the judicial proceedings involved in reparation sought for human rights violations.

The ethical implications of genetic testing for family connections have been touched upon by diverse researchers. Perhaps the most debated subject is that of pre-symptomatic testing for late-onset genetic diseases such as Huntington's or Machado-Joseph and different forms of cancer (Gibbon 2004, 2013; Schuler-Faccini et al. 2014). There are, however, many other situations—and interesting ethical points of debate—involving the use of DNA technology to confirm or negate family relations. Leaving aside issues pertaining to the institutionally required testing of individuals—as in the case, for example, of family reunification for immigrants (Hautaniemi 2007), "loose-stringency" search for criminal offenders (Machado and Moniz 2014), or even paternity investigations (Fonseca 2009)—we consider in the present article the test's use in the promotion of human rights.

Here, we join many other contemporary anthropologists in the supposition that the ethical implications of our research cannot be separated from the political dimensions. This approach signifies that a discussion around ethics cannot be reduced to a set of fixed, abstract norms (as in certain forms of bioethics), nor can it be resumed in formal proceedings such as, for example, signed consent forms. We find inspiration here in thinkers such as Fassin (2012) who speak of the ethical imperative of researchers to think through the *effects* of their work not only for the people they are interviewing but also for those involved on a wider scale. And, in an attempt to adjust this perspective to our empirical universe, we follow the recommendations of researchers who underline the challenges of ethical discussions today. Schuch (2011), for example, citing the work of Abu-Lughod (2010), pleads for a "performative" definition of ethics, that takes into consideration the "active social life" of a research project, and underlines how—from start (fieldwork) to finish (publication and reception of results)— research passes through multiple social domains that require a constant rethinking of our ethical involvement.

A history of discrimination

The history of leprosy treatment around the world is associated with highly sensitive ethical issues. The isolation of leprosy patients in special hospitals was in evidence from early colonial times, but it was not until the end of the nineteenth century that this practice became a worldwide policy (White 2003). After a timid debate, isolation emerged as the consensual method to avoid spreading of the disease (Bechler 2009; Cunha 2010). By the early 1920s, the Brazilian government had adopted a model backed by a "sanitary police," but the full thrust of this policy emerged in the 1940s, under the presidency of Getulio Vargas. The Ministry of Health organized its actions around three interconnected institutions: the leper asylum (*leprosario*), dispensary (*dispensario*), and specialized orphanage (*preventorio*). Standing in for the previous lock-hospitals (asylums), "hospital-colonies"—little villages including church, cinema, and even jail—were built throughout Brazil in the country's hinterland. By 1943, 41 such institutions existed in 21 states, housing nearly 17,000 patients (Weaver 1944; Curi 2010). The dispensaries, located in the urban conglomerations, were designed to locate new patients and refer them for isolation. The *preventorio* was to receive the children of the colony's internees (Monteiro 2003), keeping them under close observation lest they themselves develop the disease.

As a result of this policy, the isolation of one or both parents many times led to the fragmentation of families (Monteiro 2003). Some of the healthy children of institutionalized

---

[1] In 1976, by international accord, the disease was renamed "Hansen's disease," to avoid the discriminatory connotations of the previous term (Oliveira et al. 2003).

parents were given into the care of relatives. However, prejudice linked to the disease and their relatives' fear of being contaminated or socially shunned led an increasing number of youngsters to the *preventorios*. Children born to patients in the colony were taken immediately after birth from their mothers and, when not handed over to relatives or taken to the orphanage, they were given in informal adoption to non-related families. Those who grew up in the orphanage were normally not allowed to leave the premises, attending primary school within the institution. Many of the children were put to work at a very early age (Monteiro 2003). By 1943, the country had 22 specialized orphanages, housing 2,500 children of leprosy patients (Weaver 1944). By 1960, their number of specialized orphanages had increased to 31 (Brazil, 1960). As a result of these policies, many people currently do not know how to find their parents and siblings. Some of the children have no proof of their original biological identity. And even those who have kept in touch with their relatives may have no formal proof of their relationship.

At the beginning of the 1940s, sulfones were shown to be an effective treatment for leprosy. A few months after treatment, patients became non-contagious. However, depending on the region, the isolation of leprosy patients continued for decades to be public health policy. Despite a federal decree in 1962 advising against institutionalization (so as to avoid the "rupture of family ties, occupational disruptions, and other social problems"),[2] doctors and local authorities were still charged with the evaluation of each new case, thus explaining a system of selective internment with different versions in each of the federal states (Maciel 2007; Monteiro 1995). It was only in 1976 that compulsory isolation was legally abolished by a declaration from the Ministry of Health stating that, whatever the form and stage of the disease, patients should receive out-patient treatment in routine neighborhood health centers (Brasil 1976; Curi 2010). Nonetheless, in many states (particularly São Paulo where policies were generally more rigid), patients were subjected to mandatory internment up until the 1980s (Opromolla and Laurenti 2011).

As the colonies shut down, ex-internees banding together from colonies in different regions of Brazil founded MORHAN. Besides medical gains, the political efforts of this movement resulted in a 2007 federal law that awarded to ex-patients, sent to the colonies during the years of compulsory internment, reparation in the form of a life-long pension.[3] Soon after, MORHAN intensified its campaign to reunite family members who had been separated from one another because of the country's policy of mandatory segregation. In 2012, the Brazilian Ministry of Health appointed an Internal Working Group to determine the number of people separated from their families and to propose policies to repair the perpetrated harm.[4] Up to now, this Working Group, together with MORHAN, has registered 9000 individuals who were thus separated as children from their parents, but they are expecting a total of some 40,000.

Materials and methods

Projeto REENCONTRO

In 2011, INAGEMP collaborated with MORHAN to conduct DNA testing and to establish possible family links for those individuals identified by the organization but with no official documentation to prove their family belonging. One of the authors (LS-F), member of INAGEMP, had been doing volunteer work unrelated to her specialty in medical genetics with the social movement MORHAN long before she involved the genetics team of students and researchers. She had been involved, through other forums of discussion, with the geneticist Vitor Penchaszadeh (Penchaszadeh 2012; Penchaszadeh and Schuler-Faccini 2014), who had been a key player in the reuniting of children sequestered by the military during the Argentine dictatorship with their original families. The involvement of a geneticist in helping the children of leprosy patients to reunite with their original families seemed to be a logical extension of this "genetics activism." The project, registered at the Federal University of Rio Grande do Sul (UFRGS) as an "Extension activity," was named "REENCONTRO," and included other geneticists.

Upon formulating this project, each entity had its responsibilities clearly defined. The demand for tests was to stem directly from the different communities of ex-patients and their family members that sprang up around the previous hospital-colonies. MORHAN prepared and circulated through internet a form to be filled out by people who, in past decades, had been separated from their parents, brothers, or other relatives because of the mandatory segregation of patients suffering from Hansen's disease. This information, furnished on a voluntary basis, would be used exclusively for establishing data and preparing future actions or court cases in favor of the participants. In this preliminary phase of the project, the local chapters of MORHAN did a great deal of preparatory work, establishing a written registry of the cases and gathering documentation on each person involved in the case. Volunteers investigated available archives in the hospital-colonies and orphanages to gather proof of kinship ties between "separated children" and their parents, patients of Hansen's disease who had been confined in mandatory segregation.

---

[2] Decreto n° 968 (Brasil 1962).

[3] The movement's leaders present their political activism as a collective process as opposed to the judicial review of cases one-by-one, apparent in what scholars call the judicialization of patients' rights in Brazil (Biehl and Petryna 2013).

[4] WorkGroup: http://www.morhan.org.br/views/upload/relfilhossep.pdf. Acessed 03 November 2014.

INAGEMP's collaboration came in with the next phase of action—for the cases in which, despite the testimony of witnesses attesting to a certain kinship tie, there was no written documentation to prove it.[5] In this case, a positive DNA result, attesting to the genetic link between the supposed relatives could provide the missing proof.

The different local chapters of MORHAN were responsible for organizing and maintaining the list of family members who desired to have a DNA test. INAGEMP gave heed only to those demands channeled through the social movement, discarding the inclusion of unaffiliated family groups or isolated individuals. It became evident early on that cases could be divided into two categories: those individuals who had been taken from their parents to grow up in the orphanage or given in (legal or informal) adoption to another family, and could find no legal documentation linking them to their original families, and those families in search of a child (generally a son/daughter or sibling) who, after having been taken away by authorities, had simply disappeared. In the first case, tests were run to confirm a "match" between two samples—that of the undocumented individual and that of a properly identified member of his or her biological family. In the second case, INAGEMP agreed to stock samples of the family members (generally siblings) who were hoping that one day their lost relative would turn up and confirm his or her identity thanks to the possibilities of the DNA profiles.[6]

Having confirmed the need to test certain individuals in the community, the local chapter of MORHAN and/or its national coordinators would contact INAGEMP to schedule a visit by the team of geneticists. Meanwhile, volunteers from the local chapter would organize the many details of the event: localization of and contact with "separated children" in need of the test, definition of a time and space for the meeting, and divulgation of the event in the local and national press. INAGEMP, through university research funds provided largely by the Ministry of Science and Technology, would provide plane travel and lodging for the geneticists, kits for the collection of saliva samples, and the other necessary laboratory materials and procedures.

In each region, the first meeting of the geneticists with the "separated families" would follow a ritual sequence. After an opening ceremony led by MORHAN's coordinators welcoming the audience, one of the geneticists would give a detailed explanation of Project REENCONTRO, describing the logic of the DNA test, the criteria of inclusion, the limitations of the test, and the risks involved. The next move was to read aloud the entire consent form, underlining the fact that the test was voluntary, that it would be used to establish the sought-after family link, and for nothing else. In general, whether taking place in a rustic community center or in more institutionalized spaces such as a town hall auditorium, after the initial opening, meetings would be conducted in an informal ambience that permitted ample dialogue between researchers and the audience.

After answering questions, the geneticists would receive the candidates one by one, filling out a specially prepared form stating place of birth, relevant hospital-colony and/or orphanage, circumstances of family separation, and names of known relatives and of adoptive family members. To satisfy the requirements of the genetics team responsible for the collection and identification of samples, candidates were required to present a certified photocopy of an ID document complete with photo and, preferably, proof of a residential address. The information would be transposed to a genogram for each case, including information on all family members.

Next, candidates would be invited to spit into a small plastic vial, part of a standard DNA collection kit (Oragene®), that would take anywhere from 5 to 15 min to fill properly.[7] Each sample would then receive a code number—according to the corresponding case—in order to guarantee total confidentiality of test results. A member of the genetics team would then organize the vials in a conditioned carry bag, and personally transport the samples back to the university lab in Porto Alegre (Laboratory of Medical Genetics and Evolution of UFRGS), where the material would be analyzed, and the final report emitted. The report, signed by three geneticists from INAGEMP, includes all the pertinent technical information together with a simplified explanation of the test results expressed in the form of a percentage possibility for a blood kin relationship.[8]

---

[5] The lack (or adulteration) of personal ID documents, common in Brazilian history, may have been exacerbated, here, by the question of stigma linked to leprosy (see Maricato 2014).

[6] Saliva samples were collected from 345 people in ten cities (Rio Branco, Cruzeiro do Sul, Manaus, Vitória, Betim, Três Corações, Belém, Natal, Porto Alegre e Santa Terezinha) from nine Brazilian states (Acre, Amazonas, Espírito Santo, Minas Gerais, Pará, Pernambuco, Rio Grande do Norte, Rio Grande do Sul e São Paulo). Of these 345 samples, 284 involve comparison with a possible relative (family groups with two or three samples) and 61 are destined to a "genetic bank" involving individuals who have not located their relatives. The DNA of these individuals remains in stock, awaiting the appearance of a possible relative with whom to run the test for biological relationship.

[7] In some cases, the other person to be tested is not present at the moment and the researchers have to schedule a new time and place to collect the corresponding sample.

[8] The tests were run with standard PCR-STR kits using 17 genetic markers. Samples were examined twice, through independent preparations on two separate days, according to international standards of quality control. Test results were interpreted by comparing samples from two individuals and determining, through the use of genetic population indexes, the probability of a biological link.

The biological material is to remain in INAGEMP freezers (available for revalidation if the legal necessity arises) until the project's termination. Since formal legal proceedings for the reparation of separated children have not yet begun, the present tests are not court-ordered, and so they do not yet count as official judicial documents. If and when the court requests the DNA test results, Project REENCONTRO will have the information on stock.

Meanwhile, the "separated children" are handed their test results. In personal and private encounters scheduled with a member of the genetics team, they receive a sealed envelope together with verbal clarifications in answer to any questions that may arise. In some cases, and always with the previous permission of the participants, the devolution of test results is integrated into a public ceremony aimed at giving visibility, and thus political leverage, to the cause of the "separated children."

Anthropological approximations

The ethical issues involved in the anthropologist's collaboration in Project REENCONTRO, although overlapping with some of those raised by geneticists, introduce considerations of still a different nature. The interest of the genetics team in the project stemmed from the coordinator's longstanding role as a volunteer activist working alongside other participants in MORHAN. The anthropologists, on the other hand, were first drawn in by the desire to do an ethnographic study of the varied uses of DNA technology, finding the partnership between INAGEMP and MORHAN a particularly rich case for reflection. They had been absorbed into the INAGEMP research team on entirely open terms, i.e., with an as-yet vaguely defined agenda. However, the loose collaboration carried expectations on all sides of some sort of helpful feedback (Víctora 2004).

The participation of anthropologists in Project REEN CONTRO began at the end of 2012, at a politically sensitive moment. After a great deal of hard work, MORHAN had persuaded federal authorities to form a Working Group to study the possibility of state reparation for the violation of the rights of "separated children." Guidelines had been put down on paper, and the movement was hoping any moment for a solid political advance in the form of a presidential decree or congressional bill. Although the anthropologists were given complete liberty as to the objectives and procedures of their research design, once involved, they were soon convinced that their research would not make sense (to either their "natives" or themselves), were they not ready to embrace the group's cause. Thus, ethical concerns ended up coinciding with those voiced by other anthropologists who occupy a "hybrid" space between research and activism (see Fleischer 2007; Schuch 2011).

Results

Multidisciplinary pitfalls: avoiding false pretenses

A first ethical concern for the anthropologists was to make sure "informants" understood the difference between the saliva test (geared exclusively toward advancing their rights to reparation through judicial channels) and the detailed narration of their life stories (geared toward the more academic objectives of anthropological research). We thought it important for them to understand that they could refuse contact with the anthropologists without damaging their cause. As is in the case of many other Brazilian anthropologists (Víctora 2004; Schuch 2011), we had ruled out establishing a separate term of consent, preferring instead to rely on direct, oral clarification of our objectives. But ultimately, as illustrated in the following description of our fieldwork procedures, our explanations appeared to be of little interest to our interlocutors.

Our first foray into the field was when Glaucia Maricato (then an undergraduate student of anthropology) was invited to accompany the team of geneticists to Acre, a largely rural state in the far North of Brazil. The idea was for her to observe the collection of saliva samples, organized by the local chapter of MORHAN during two distinct events—one in the state capital, the other in a smaller town in the hinterland. The anthropologist decided to arrive in the region a little earlier, 2 weeks before the first event. Her aim was to explore the social networks of families connected with MORHAN in an attempt to understand how the DNA test might fit into people's lives. During those 15 days, nearly a hundred people came by the movement's local headquarters to sign up for the test, and, while volunteers were busy helping to fill out forms, many visitors would wonder over to chat with "the girl collecting stories." From there, the anthropologist soon branched out into the surrounding area, a neighborhood that sprung up on the outer limits of the ex-hospital-colony. Passed on, with friendly recommendations, from one family to the next, she was generally received with hot coffee and affable, informal conversation.

The major event for the collection of saliva samples was held in the auditorium of a local community center. During the opening ceremony, the anthropologist sat on the podium and, alongside MORHAN's local coordinator, local political authorities, and the geneticist, she too was called on to speak a few words, explaining her interest as "student of anthropology" in the family histories. However, as things moved on, the distinction between the different university specialists blurred. People, anxious to get back to their jobs and homes, expressed their impatience with long waits. Hence, following a previously agreed-upon protocol, Glaucia Maricato donned plastic gloves to collaborate alongside the two other geneticists in the register and collection of saliva samples. As oriented by the members of INAGEMP, before asking people to sign the consent form, she would read the document out loud, underlining the confidentiality of the data; then, she would explain the amount of saliva needed and hand over the recipient. Only then would she remove her gloves, pick up her notepad, and, once again, emphasize her role as "student of anthropology" interested in people's stories.

Notwithstanding worries that people might feel obliged to collaborate in the anthropological research, telling their stories as though in payment of INAGEMP's genetic services, it soon became clear that many individuals not only understood the specific nature of our research but also took evident pleasure in participating. For example, the morning of the first event, Glaucia Maricato reencountered a young woman (around 30) whom she had interviewed a few days earlier. The woman had returned, now accompanied by her six brothers and sisters, for a saliva test. Her husband—a young man with a university diploma in history—had come along as well, but for other reasons. He was there exactly because he had heard about the anthropologist's research and thought it would be interesting to find out more, ask questions, and see if he could help with his own knowledge on dates and policies of internment. In a climate of open curiosity, his wife and in-laws also chimed in, alternating between laughter and tears, as they went into the details of the family saga. It would seem that it was precisely the understanding that Glaucia was not a geneticist that made people feel free to chat.

In fact, eliciting narratives has been a fundamental part of MORHAN's activities since the founding of the organization. Vividly told stories about the forced segregation of times past and the lasting damage wrought by this "state violation of human rights" had shown to be effective in moving vast audiences and urging legislators to offer reparation. On the other hand, people's dramatic stories, when told during a community meeting, create a feeling of solidarity among those who have shared similar tribulations, enhancing the spirit of collectivity (Fonseca and Maricato 2013). Considering the number of times people have given their highly emotional accounts at the microphone of public events or even during television interviews, one might hazard that the anthropologist, far from invading people's intimacy, is furnishing an added opportunity for public recognition. There still remained the open question of what the anthropologist would do with these interviews—how the family histories might harm or help in the pursuit of collective rights.

Following through on the consequences

The standing members of the project (from INAGEMP and MORHAN) were already thinking about the possible effects that a DNA test, proving family links, would have for members of the community. Their hypothesis was that the genetic test helped to activate memories and to reconfigure identities. By giving people an opportunity for a concrete approximation to biological relatives, it reshaped familial relationships and extended the kin network. In fact, it was evident to all of us that the DNA test did exert a force for bringing together people. It also had a great mediatic appeal, enhancing "visibility" of "separated children" in the local press, considered fundamental for their political cause. However, this original hypothesis carried distinctly positive connotations—with the idea of "extending the kin network." And the anthropologists were somewhat less sanguine about this matter.

Most tests were being run on people who already knew or were firmly convinced of the family relationship, but had no way of legally proving it. The impact of biological confirmation of already strongly supposed facts remained to be seen. At any rate, to evaluate such changes beyond the level of a first ritual hug between the tested individuals (upon receiving the positive DNA results), would require the observation *over time* of family interactions. It was not the sort of "diagnostic" that anthropologists could furnish—not, at least, at the moment.

In this first phase of research, the anthropologists found another sort of collaboration that would be coherent with their ethical and political involvement. The genetic test was geared toward a hoped-for reparation of the "separated children," but it took place within a more general social movement involved in promoting the quality of life for entire communities. MORHAN's thrust, since the early 1980s, had never been narrowed to a few isolated individuals. The movement had a way of expanding its demands for decent health facilities, preventive campaigns, and rehabilitation centers to include an array of different categories (including, for example, various forms of deficiencies, old age, etc.), always targeted toward the lower-income peripheral populations where so many of the families "affected by" Hansen's disease lived. Certainly, activists had no intention of using the DNA tests to *limit* the potential pool of internees' descendants to blood relatives.

And yet, thinking through the "active social life" of the genetic tests—destined to go through a judicial wringer to sort out who would have and not have the right to reparations—the social scientists foresaw the possibility of certain confusion. Given the judicial world's essentializing proclivities—the thirst in that arena for clear, "objective" standards—analysts have commented how in recent years, with the availability of DNA exams, courts judging family disputes have tended to simplify their decisions by leaning toward the "fact" of biological rather than social connections (Jasanoff 1995; Dolgin 2008). This trend does not always give the hoped-for results. In cases of contested paternity, the legal use of DNA technology is just as likely to cut a child's ties with his or her socially established yet non-biological dad as "provide a father to a fatherless child" (Fonseca 2009).

To outline some of these ambiguous results, helping specialists to see that biological truth does not necessarily fortify family ties would be a way for the anthropologists to maintain an ethical and political coherence. By using the habitual arms of the anthropologist's trade—extended narratives that convey something of the lived experience of their "natives"—combined with the analytical tools provided by contemporary anthropology, they could underline the dynamic nature of family formation in these communities, urging the legal world to adopt an inclusive perspective to judge exactly who could be classified as a "separated child."

The ideal use of the DNA test would involve blood siblings, one of them with documentation that demonstrates filiation from at least one forcibly segregated parent with Hansen's disease, and the other with no such proof of family belonging. There are indeed many such cases. During the mid-twentieth century, children, generally born at home, were often informally scattered among relatives, and their birth certificates, taken out years later, included data (date of birth, name of parents) that, at the time, was virtually impossible to check. Now, with DNA technology, mis-registered persons need but one close relative to reestablish official family links. Problems arise when neither of the siblings has the correct filiation registered on his or her documents (as, for example, in the case of two full-blood sisters who were never declared by their forcibly interned father). Equally complicated are the cases in which a child's institutionalized parent was, in fact, a foster parent—with no blood relationship, as illustrated in the following case.

Born in Santa Catarina state, Amélia was around 2 years old when, in the early 1950s, her mother was interned for leprosy. At first, the girl and her older brother went to the local *preventorio*. However, her mother, in an advanced stage of illness, died soon afterwards: "When Mom died, they told my dad we had no right to stay on at the orphanage." At first, the children were placed with their elderly maternal grandparents, but these new guardians soon became too old to manage a household. "That's when my aunt (mother's sister) took me in. I was six or seven, old enough to help raise my cousins. So, my father gave me to her. I was supposed to stay until I got married." But the aunt was also ill with Hansen's disease and when, twice, the woman was interned for long periods, her three children, together with Amélia, once again ended up in the *preventorio*.

As we see, Amélia qualifies in a number of ways as a "*filha separada*"—separated child. The problem is she has no proof of this status. The orphanage records have been lost, and she has only vague memories of her mother. The memories she has are of her "foster" family—aunt and cousins—with whom she has maintained close contact throughout life. It is through them that she learned about the meetings of MORHAN and the movement of "*filhos separados*"—separated children. Amélia's aunt is already drawing her special pension as a victim of compulsory internment and activists calculate that her children, legally declared in their mother's name, will have no difficulty claiming benefits as separated children. But what of Amélia? Her situation sets her apart from the family she grew up with and, in her anxiety, Amélia has started paying a lawyer who promises to "do his best" to help.

Stories such as this are designed to collaborate with the objectives of Project REENCONTRO, pointing out the limits of the genetic tests. In this Brazilian setting, we note, on the one hand, how the parentage registered on a person's official documents historically had no guaranteed connection with biological facts. On the other hand, kinship arrangements were highly inventive and heterogeneous and real-life family attachments, in many situations, had little or nothing to do with biology. It is imperative that judicial operators recognize the hybrid nature of kinship relations—recognizing social as well as biological indicators—in order to fashion broad and inclusive criteria for the evaluation of the hurt caused by the forced fragmentation of families.

Discussion

During the past few years, there has been much debate in Brazil about the ethics involved in genetic research among indigenous peoples. Just as elsewhere in the Americas, indigenous peoples have questioned the ethics of blood samples collected as much as 50 years earlier (Santos and Maio 2004; Kowal et al. 2013), and researchers are thinking through the various social, scientific, and ethical problems involved. However, the particular way the INAGEMP team introduced the DNA test for family ties has helped to avoid the sort of touchy ethical issues that plague other forms of genetic research. First, participants are not chosen by researchers, or arranged according to pre-existing criteria of some research design. Tests are run as a sort of service-on-demand, offered to individuals who have actively sought them. Furthermore, the constant presence and steady consultancy of the social movement's leaders represent a mediation that enhances the political leverage of those being tested. People are not treated as isolated individuals, but rather as members of a historically constituted and politically engaged collectivity. Nonetheless, the geneticists are still obliged to ensure that a series of precautions have been taken—both in the technical handling of the tests and in the person-to-person negotiations involved in collecting samples and giving final test results.

Ethical preoccupations lead the geneticists to carefully control the procedures linked to the collection and preservation of saliva samples as well as to the confidentiality of test results. The anthropologists, arriving belatedly on the scene, and with an initial interest that placed research above activism, were confronted with somewhat distinct ethical worries. On the one hand, they were careful to clarify their particular objectives—so that they would not be confused with the geneticists. On the other hand, they sought to think through the "active social life" of the DNA tests—a reflection that would take their research results beyond the genetic laboratory to the possible consequences—specifically, in the judicial sphere—of new information provided by the tests. This multidisciplinary collaborative effort is, however, relatively recent, and the full complexity of planning and carrying through on solidly ethical practices will no doubt be subject, in the future, to ever more probing debate.

Acknowledgments We thank Hugo Bock and Maria Luiza-Saraiva Pereira (University Federal of Rio Grande do Sul - UFRGS) for their invaluable collaboration in the laboratory analysis; to *Movimento de Reintegração das Pessoas Atingidas pela Hanseníase* (MORHAN) for the logistic support during field trips.

Compliance with ethical standards The research complies with the current Brazilian Ethics Guideline in Genetics and Anthropology. Participation in the study was entirely voluntary and the confidentiality of data was respected at all times.

Conflict of interest Claudia Lee Williams Fonseca, Flávia Costa Biondi, Glaucia Cristina Maricato, and Lavínia Schuler-Faccini declare that they have no conflict of interest. This project was funded by the Brazilian Research Council (CNPq)—National Institute of Population Medical Genetics (INAGEMP)—process 573993/2008-4.

References

Abu-Lughod L (2010) The active social life of Muslim human rights. A plea for ethnography, not polemic, with cases from Egypt and Palestine. J Middle East Women's Studies 6(1):1–45

Bechler R (2009) Muito mais do que isolamento em questão: ciência, poder e interesses em uma análise das duas primeiras Conferências Internacionais de Lepra – Berlim 1897 e Bergen 1909. Belo Horizonte Temporalidades 2:175–201

Biehl J, Petryna A (2013) Legal remedies: therapeutic markets and the judicialization of the right to health. In: Biehl J, Petryna A (eds) When people come first: critical studies in global health. Princeton University Press, Princeton

Brasil, Ministério da Saúde (1960) Manual de Leprologia. Rio de Janeiro: Departamento Nacional de Saúde, Serviço Nacional de Lepra. http://bvsms.saude.gov.br/bvs/publicacoes/manual_leprologia.pdf. Acessed 03 November 2014

Brasil, Ministério da Saúde. Portaria n°165 de 14 de maio de 1976

Brasil. Decreto Federal n° 968, de 7 de maio de 1962

Cunha V (2010) Isolated 'like us' or isolated 'among us'?: the controversy within the National Academy of Medicine over compulsory isolation of leprosy sufferers. Rio de Janeiro, História, Ciências, Saúde - Manguinhos 17(4):939–954

Curi L (2010) Excluir, isolar e conviver: um estudo sobre a lepra e a hanseníase no Brasil. Ph.D. Dissertation in History, Federal University of Minas Gerais (UFMG)

Dolgin J (2008) Biological evaluations: blood, genes, and family. Akron Law Rev 41:347–398

Fassin D (2012) Introduction: toward a critical moral anthropology. In: Fassin D (ed) A companion to moral anthropology. Wiley-Blackwell, Oxford

Fleischer S (2007) Antropólogos 'anfíbios'? Alguns comentários sobre a relação entre Antropologia e intervenção no Brasil. Revista Anthropológicas 18(1):37–70

Fonseca C (2009) Doubt is the mother of all invention: DNA and paternity in a Brazilian setting. In: Birenbaum-Carmeli D, Inhorn M (eds) Assisting reproduction, testing genes: global encounters with new biotechnologies. Berghahn Books, London, pp 258–284

Fonseca C, Maricato G (2013) Criando comunidade: emoção, reconhecimento e depoimentos de sofrimento, vol 15. Interseções (UERJ), Rio de Janeiro, pp 252–274

Gibbon S (2004) Re-examinando a 'genetização': árvores familiares na genética do câncer de mama. Política e trabalho 20:35–60

Gibbon S (2013) Ancestry, temporality, and potentiality: engaging cancer genetics in Southern Brazil. Curr Anthropol 54(7):107–117

Hautaniemi P (2007) Conectando famílias de construções genéticas: testes de DNA na reunificação da família somali na Finlândia, vol 29. Cadernos Pagu, Campinas, pp 285–303

Jasanoff S (1995) Science at the bar: law, science, and technology in America. Harvard University Press, Cambridge

Kowal E, Radin J, Reardon J (2013) Indigenous body parts, mutating temporalities, and the half-lives of postcolonial techno science. Soc Stud Sci 43:465–483

Machado H, Moniz H (2014) Bases de dados genéticos forenses: Tecnologias de controlo e ordem social. Coimbra Editora, Coimbra

Maciel L (2007) Em defesa dos sãos perde Lázaro a liberdade: uma história das políticas públicas de combate à lepra no Brasil (1941-1962). PhD Tesis in History, Federal University of Fluminense (UFF)

Maricato G (2014) Direitos Humanos, papéis e hanseníase: múltiplos testemunhos na produção de provas da internação compulsória. Natal, Anais da 29ª RBA

Monteiro Y (1995) Da maldição divina a exclusão social: um estudo da hanseníase em São Paulo. Ph.D. Dissertation in Philosophy, University of São Paulo (USP)

Monteiro Y (2003) Prophylaxis and exclusion: compulsory isolation of Hansen's disease patients in São Paulo. Rio de Janeiro, História, Ciências, Saúde - Manguinhos 10(1):95–121

Oliveira M, Mendes M, Tardin T, Cunha D, Arruda A (2003) Social representation of Hansen's disease thirty years after the term leprosy was replaced in Brazil. Rio de Janeiro, História, Ciências, Saúde - Manguinhos 10(1):41–48

Opromolla P, Laurenti R (2011) Hansen's disease control in the state of São Paulo: a historical analysis. Rev Saúde Pública 45(1):1–8

Penchaszadeh V (2012) Uso de la identificación genética en la reparación de la violación del derecho a la identidad durante la dictadura militar argentina. In: Penchaszadeh VB (ed) Genética y derechos humanos. Encuentros y desencuentros. Paidós, Buenos Aires, pp 263–298

Penchaszadeh V, Schuler-Faccini L (2014) Genetics and human rights. Two histories: restoring genetic identity after forced disappearance and identity suppression in Argentina and after compulsory isolation for leprosy in Brazil. Genet Mol Biol 37(1):299–304

Santos R, Maio M (2004) Race, genomics, identities and politics in contemporary Brazil. Crit Anthropol 24:347–378

Schuch P (2011) A vida social ativa da ética na antropologia. São Paulo. Revista Brasileira de Informação Bibliográfica em Ciências Sociais 71:5–24

Schuler-Faccini L, Osório C, Romariz F, Paneque M, Sequeiros J, Jardim L (2014) Genetic counseling and presymptomatic testing programs for Machado-Joseph disease: lessons from Brazil and Portugal. Genet Mol Biol 37:263–270

Víctora C (2004) Ética de pesquisa em equipe multidisciplinar. In: Víctora C et al (eds) Antropologia e ética: o debate atual no Brasil. Federal University of Fluminense (UFF), Niterói, pp 83–88

Weaver E (1944) Social service in the fight against leprosy in Brazil. Leprosy News and Notes. http://ila.ilsl.br/pdfs/v11a14.pdf. Acessed 01 November 2014

White C (2003) Carville and Curupaiti: experiences of confinement and community. Rio de Janeiro, História, Ciências, Saúde - Manguinhos 10(1):123–141