

Use of DNA Identification in Human Rights Work to Reunite Families in Latin America

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DNA (deoxyribonucleic acid) identification serves many purposes, including the preservation and defence of human rights. In Argentina, a military dictatorship disappeared 30 000 dissidents, including 500 babies born in captivity and, after their mothers' assassination, were appropriated by families associated with the repression. After return to democracy, search, localisation, DNA identification and family reunification were state policies and so far 120 individuals had their identity restituted and families reunited. When after a gruesome civil war in El Salvador caused 75 000 deaths and hundreds of missing children, a DNA database of families with disappeared children was developed and DNA testing of hundreds of people with unknown identity lead to identification and reunification of 265 youngsters with their families.

In Brazil, DNA identification of hundreds of individuals who were stranded from their relatives during compulsory isolation of patients with leprosy in Brazil, identified 158 pairs of individuals who did not have know they were siblings. In conclusion, the use of DNA identification as a tool to redress and repair human rights violations is a novel and valuable application of human genetics.

Introduction

DNA (deoxyribonucleic acid) identification requires the sequencing of specific segments (markers) of DNA of the person or remains to be identified and compare them with the DNA sequences at the same segments in putative relatives (establishment of family relationships) or with antemortem samples of known identity in the case of remains. If the compared DNA profiles do not match, the result is negative and the relationship is excluded. When the two compared DNA profiles match, the results are expressed as the

probability that the positive matching is not due to chance (probability of inclusion), which with current techniques it may reach 99.99% (Prinz *et al.*, 2007; ICRC, 2009).

Unprecedented recent advances in genetics have turned DNA identification of human beings an essential tool in paternity testing, criminalistics, investigation of mass catastrophes and investigation into human rights violations (see also: Kinship Testing; Genetic Profiling in Disaster Victim Identification).

In this article, I review three examples of the use of human genetic identification in human rights work: (1) redressing grave violations (disappearances and suppression of identity of the offspring of political dissidents) in Argentina and El Salvador and (2) identifying individuals separated from birth from their relatives with leprosy in Brazil, so they could learn their true identity, overcome stigma and recover family relationships.

During the 1970s and 1980s, many Latin American countries were subjected to oppression and dictatorship under repressive military regimes that paid no respect for political nor economic, social and cultural rights. Most military regimes came to power with the active political and military support of the United States as part of the cold war and in support of neoliberal economic policies which increased social injustice and wealth inequality to unprecedented levels. The United States continued to support these dictatorships for years in spite of the lack of rule of law and the egregious violations of human rights being committed, including crimes against humanity such as waging war against the civilian population, genocide, torture, forced disappearance and killing of dissidents, as well as appropriation and suppression of identity of their children. After years of incompetence of the military in all fronts, changing international political landscape with the end of the cold war, and popular resistance and struggle, the military were forced to leave power in most countries and allow the return to constitutional governments. The sequel of years of repression in these countries, with thousands of disappeared persons, included increased socioeconomic inequality, disruption of the social fabric and psychosocial distress.

Further, the appropriation of the offspring of dissidents practiced by the military led to thousands of children and young adults with suppressed identity and unaware of their true family relationships. With the advances in human genetic identification occurring since the 1980s, scientists soon realised that these techniques could and should be utilised to help these children and young adults recover their true identity. Indeed, in a number of countries, the return to democracy led to policies of the application of forensic genetics in investigations of the abduction of children and suppression of their identity by the military, honoring the right to identity as a fundamental human right and enabling the reunification of families in Latin America. The same techniques are being used all over the world for the genetic identification of human remains of disappeared persons (Doretto and Fondebrider, 2012; EAAF Argentine Forensic Anthropology Team, 2016).

The example discussed from Brazil, on the other hand, involves longstanding state public policies which called for the separation of the offspring of parents with leprosy to prevent contagion. These policies were based on social prejudice and stigmatisation of patients with leprosy and the erroneously presumed contagiousness of the condition. The results were hundreds of individuals through out the country separated from birth from their parents and ignoring their true identity. As we will see in the following, DNA identification in these cases also allowed many of these individuals reunite with their families.

While recent developments in human genetics have been awesome, current applications of genetic technology for the benefit of people should not allow us to forget that flawed genetic concepts were used in the past to justify troubling violations of human rights, such

as eugenics, racism, discrimination, stigmatisation of the ‘different’ and even genocide (Müller-Hill, 1988; Kevles, 1995). Recently, however, and as exemplified below, human genetic identification is increasingly being used for the preservation and defence of human rights, specifically the right to identity, which is a fundamental human right (United Nations, 1989), enabling investigation and reparation of its violations, recovery of suppressed identities, reunification of families and bringing perpetrators to justice (United Nations, 2009; Ministerio de Relaciones Exteriores, ICRC, 2015).

Argentina: Stealing Babies as a Tool of Repression; Restoring Their Genetic Identity as an Instrument of Human Rights and Justice

During the dictatorship that ruled Argentina between 1976 and 1983, the military engaged in savage repression and egregious violations of human rights, including the forced disappearance of 30 000 political dissidents (CONADEP, 1986). Abducted adults were taken to one of many secret detention centres run by the military, where they were savagely tortured and, with few exceptions, murdered in the most abject ways, including throwing them from airplanes to the sea, alive and sedated. The disappeared included pregnant women, as well as babies and small children abducted with their parents. Pregnant women delivered their babies in humiliating circumstances in military barracks or hospitals, only to be murdered shortly after delivery. It is estimated that no less than 500 babies were born in captivity to disappeared women (Van Boven, 1988; Andersen, 1993) and were kept as ‘war booty’ by someone within, or linked to the security forces.

Birth certificates were forged, and the children were registered as biological offspring of their appropriators (OAS Organization of American States, 1978; Penchaszadeh, 1997) and raised with suppression of their true identity. The appropriation of babies of dissidents was part of a deliberate military policy based on the perverse conviction that those in power had the duty of ‘freeing these children from the subversive education’ (sic) of their parents (Penchaszadeh, 2015).

After the return of democracy in 1984, a search for the *disappeared* children began, led by the *Abuelas* (grandmothers) of Plaza de Mayo, a nongovernmental human rights organisation with the specific mission of finding the children of their disappeared sons and daughters. The constitutional government appointed a National Commission on the Disappeared (CONADEP, 1986), and many suspected appropriated children started to be localised through various means (anonymous reports, reports from survivors of detention camps, investigation of forged birth certificates, suspicious adoptions and others) and legal procedures for their identification started. While the first stages of this work occurred in the pre-DNA testing era, by comparing gene products (blood groups and human leukocyte antigens) between children suspected of having been appropriated and their putative grandparents (Di Lonardo *et al.*, 1984), soon DNA technology was incorporated (Penchaszadeh, 1997, 2015). Requests for genetic testing were mandated by the courts, after proper legal, ethical and psychological handling of each suspected case.

The National Bank of Genetic Data (BNDG, by its initials in Spanish) was created by law in 1987 and developed a database of genetic information from samples voluntarily donated by grandparents and other relatives of disappeared children, with the purpose of matching the genetic profiles of the database with those of children suspected of being offspring of the disappeared.

Currently, the database contains profiles of 15 nuclear DNA microsatellite or short tandem repeats markers, from 311 families (Penchaszadeh, 2015), complemented when needed

with mitochondrial DNA sequences, and following guidelines from recognised international forensic genetic bodies (Bär *et al.*, 1997; Carracedo *et al.*, 2000; Prinz *et al.*, 2007; ICRC, 2009). Genetic identification was deemed positive when the inclusion probability that an individual with unknown identity could be a grandchild of a specific set of putative grandparents was 99% or higher.

According to Argentina's law, genetic testing of a minor suspected of being the victim of forced disappearance and suppression of identity was mandatory through the courts, with heavy involvement of psychology professionals, who cared for Grandmothers of Plaza de Mayo demonstrating in the streets of Buenos Aires in 1984 to demand the restitution of their appropriated grandchildren. The text of the banner says: "Where are the hundreds of babies born in captivity?" the best interests of the child. When the true genetic identity of a disappeared child was determined, he/she was informed of the results and put in contact with the biological relatives, and the true identity of the individual was legally restored. As appropriated children became adults, those who suspected that they could be offspring of disappeared parents had the right to request genetic testing using the BNDG database, through a special state agency, the National Council for the Right to Identity (CONADI by its initials in Spanish) or through the courts.

Furthermore, and in accordance with the proactive stance of the Argentine state policy of human rights, the Supreme Court ruled in 2008 that when required to solve crimes against humanity such as forced disappearance and suppression of identity, the state had the obligation of obtaining DNA for testing, and if the possible victim declined, DNA could be obtained by non invasive means (i.e. extracted from personal belongings, such as tooth brushes and underwear). Between July 1984 and June 2016, 120 individuals appropriated as children and with their identity suppressed, were genetically identified and recovered their true genetic identity (Penchaszadeh, 2015).

It is impossible to describe in depth the horrifying experiences of these 120 individuals who, at varying ages, were informed that they were not the children of those, who until then, they had considered their parents, that their true parents had been murdered by the dictatorship, that the appropriators who had raised them were in many instances directly or indirectly responsible for the disappearance and murder of their parents, that they were misinformed consistently about their origin and ancestry and that they had biological relatives who had been searching for them for decades. While the experiences of these children and young adults were shocking and terrible, most of them expressed feelings of liberation and healing when informed of their true identity (Argento, 2008).

Identified children and young adults reacted to the revelation of their true genetic identity in different ways, depending on the age of the child at the time of disclosure, the nature of the relationship between the victim and her/his appropriators and whether there existed loving and suitable biological relatives (usually grandparents) to take on the custody and rear the child after the restoration of identity. In general, younger children adjusted well to the passage from a usually perverse rearing environment in the hands of appropriators, to a loving and healing relationship with close relatives, accepting their true identity with relief and with no evidence of psychological trauma from the process. On the other hand, young adults had diverse reactions, depending on whether testing had been decided voluntarily to solve their own identity doubts or instead initiated in the courts by biological relatives. Although most victims experienced psychological shock initially, knowledge of the truth, painful as it was, was emotionally liberating from the perversity, lies, concealment and violence that had surrounded their rearing (Argento, 2008).

In fact, many of the ‘recovered’ young men and women are pursuing the same ideals of their disappeared parents, becoming activists for human rights and social justice. The following is a quote from a young woman in the suit she filed against her appropriators: *Can someone who stole a newborn, who concealed from her that she had been stolen, who might have disappeared or tortured her parents, who kept her away from them and her family, who always lied to her regarding her origin, who frequently mistreated, humiliated and deceived her, really feel parental love? My answer is no, that this type of relationship is marked by cruelty and perversion and not by love* (Vales, 2008).

While the power of genetic testing for human identification had the potential of heightening notions of genetic determinism and DNA infallibility in society at large, most of those involved in this tragedy (victims, biological relatives, geneticists, psychologists and judges) acknowledged the fundamental role of emotional, educational, social, cultural and political factors, interacting with genetics, in the conformation of personal identity.

In Argentina, the search, localisation, identification and restoration of the true genetic identity of children of the disappeared was based on the notion that forced disappearance and suppression of identity are crimes against humanity (United Nations, 2007) and that the state has a legal responsibility to investigate, prosecute perpetrators and provide reparations to victims. The most important guiding ethical principle in this saga has been that of the value of the truth. The Argentine experience and the proactive state policy on human rights were key factors in the promulgation of a resolution UN Council of Human Rights recommending the use of forensic genetics in cases of serious violations of human rights (United Nations, 2009). Furthermore, the Argentine government teamed up with the International Committee of the Red Cross to produce a good practice guide for the use of forensic genetics applied to human rights and international humanitarian law investigations that has been praised by forensic geneticists across the world (Tidball-Binz *et al.*, 2013; Ministerio de Relaciones Exteriores, ICRC, 2015).

El Salvador: War, Stolen Children and International Collaboration for the Application of Genetics to Reunite Families

In the period 1980–1992, El Salvador was torn by a cruel civil war, with roots in an explosive mix of longstanding harsh circumstances: decades of repressive governments, concentration of land and wealth in a small number of oligarchs and landowners (14 families owned 90% of the land), iterative massacres of peasants and death squads killing progressive politicians, intellectuals and priests. After decades of oppression, growing number of young activists confronted repression with a popular armed struggle that the government’s army could not quell in 12 years of warfare, in spite of overt political and military support from the United States.

The war ended by a peace accord brokered by the United Nations in 1992. Shortly afterwards, a UN Commission of Inquiry (United Nations, 1993) estimated that 75 000 people, mostly civilians, had been killed during the war and reported 22 000 violations of human rights (extrajudicial executions, forced disappearances and torture), 95% of which were perpetrated by the military; it also estimated that the conflict led to over one thousand disappeared children. Indeed, during the war, massacres and disappearances did occur daily, with children being killed or abducted by soldiers, who took them orphanages, from which they were irregularly adopted, mostly in the United States and Europe. After the peace accord of 1992, constitutional governments were elected periodically but, unfortunately, the enactment in 1993 of an amnesty law for those who had committed

crimes during the war (IACHR,1994) meant an obstacle impossible to overcome for the search of disappeared children, as identifying many of these children would have required sensitive information from the Salvadoran Army (who was responsible for their disappearance in the first place). This explains the absence of any proactive action in this respect by succeeding governments (WOLA, Washington Office for Latin America, 2013), in contrast with the proactive state policy of Argentina to investigate past human rights violations and prosecute perpetrators (Penchaszadeh, 2015). In 1994, the nongovernmental association Pro-Búsqueda ('búsqueda' means *search*) was founded in El Salvador by Jon Cortina, a Jesuit priest, with the participation of local families and communities, with the task to search for and identify missing children that were forcibly separated from their families and reunite them with surviving relatives (Asociación Pro-Búsqueda, 2013, 2016a). This task was conducted by a small number of volunteers who developed a database of missing children and relatives searching for them. A big hurdle was that, even though Pro-Búsqueda did count with a forensic geneticist, it did not have a laboratory of its own and the only public forensic genetics laboratory in El Salvador, belonging to the Supreme Court, did not have enough resources to conduct the anticipated hundreds of genetic identifications that the task would require. At this point, a network of committed forensic geneticists from the United States and Europe (Alliance of Forensic Scientists for Human Rights and Humanitarian Investigations), working in several private and public laboratories, began performing DNA tests for Pro-Búsqueda, at very reduced prices, including *pro bono*, training its personnel in forensic genetics and helping the Association to eventually develop a robust DNA database to reach adoptees living abroad (Orrego, 2013; Barten, 2013; Riordon, 2014). All DNA profiles of families searching for their disappeared children as well as young persons searching their own identity are stored in Pro-Búsqueda's database and analysed by the local geneticist, with assistance from the Alliance.

This assistance programme grew recently with funding from the US Government through the Human Rights Center of the University of California Berkeley and continues to date (Barten, 2013).

Two developments are to be noted in this regard. The first is that in 1999 a family sued the Salvadoran Government at the Inter-American Court of Human Rights for the disappearance of two small children who were sisters (Erlinda and Ernestina Serrano-Cruz), providing strong testimonies that they were abducted by a high ranking officer of the Salvadoran Army during an armed episode of the war. The IACHR (Inter-American Commission of Human Rights) found the Salvadoran government responsible for the sisters' disappearance, making the Serrano-Cruz case a seminal indictment of the responsibility of governments for violations of human rights committed by the state, even in the past (IACHR, 2005). As a result of several reparatory measures imposed by the IACHR to the government (including an obligation to pursue investigations on the fate of the disappeared sisters, prosecute perpetrators and provide free medical care and psychosocial support to the surviving family), in 2007, it promulgated the commemoration of March 29 as the 'Day of the Children and Youth Disappeared During the Conflict'. Although the Serrano-Cruz sisters continue disappeared, the symbolic strength and jurisprudence implications of the obligations imposed to the Salvadoran state, legitimised the work of Pro-Búsqueda and galvanised its search of children and youth disappeared during the war. The second note of interest is that 20 years after its promulgation,

there are indications that the amnesty law may be repealed as unconstitutional and contrary to international human rights legislation (WOLA, Washington Office for Latin America, 2013).

In the 22 years of existence of Pro-Búsqueda, the organisation has established itself as *the* voice of families with disappeared children and youth. Given that a common fate after disappearance were orphanages and adoptions abroad, it is not surprising that many young people requesting identification are adoptees. In October 1981, more than 500 persons were murdered by the army of El Salvador during the Massacre of “La Quesera”, with many children abducted from their families. Nicolás was one of them. His mother, Milagros, lost three more children in the massacre. In 2016, Pro-Búsqueda’s forensic genetics team found a “cold hit” between the DNA profile from an adopted young adult searching for his genetic identity and that of Milagros, which was in the database. The picture shows the family reunion on January 16, 2016, with the embrace of Milagros and her son Nicolás, living abroad who come to El Salvador to find their roots and reunite with surviving family members. With virtually no help from succeeding governments, Pro-Búsqueda has compiled data on 960 missing children and has localised and identified 265 persons alive with subsequent family reunions; an additional 70 were found dead and another 90 have been localised and their identification is pending; 535 cases are pending of localisation (Asociación Pro-Búsqueda, 2016b). Every identification has been a very emotional event, particularly when young adoptees from the United States or Europe who requested identification, found their relatives in El Salvador two decades later (Asociación Pro-Búsqueda, 2013).

Brazil: Genetic Identification and Family Reunification of Persons Separated at Birth from Their Parents Because of Leprosy

In the late 1800s, the isolation of leprosy patients became public health policy in the United States, mainly due to the discovery of the bacillus that causes leprosy, *Mycobacterium leprae*, by GA Hansen in 1873. In Brazil, hospitals designed for leprosy patients were first established in the 1700s (White, 2003) and continued in the early twentieth century, as patient segregation was considered the only way to protect the healthy. The Inspectorship for the Prevention of Leprosy and Venereal Diseases enforced the policy of isolation in leprosaria (Cunha, 2010) and the model adopted in Brazil during the twentieth century was based on the Trinity of leper asylum, dispensary and prevention centre. Each of these institutions had its own distinct, albeit complementary, roles. The asylum was the most important for the isolation of the sick. The dispensary’s role was to locate new patients and refer them for isolation. The role of the prevention centre was to provide shelter for the healthy children of patients and all of the children born in the leper colonies (Monteiro, 2003). If the children or spouse were infected, they all would be isolated together. However, their healthy children would be given to healthy relatives or be isolated in the prevention centres. The prejudice and fear from relatives of being infected or segregated because of these children, increased the number of children referred to prevention centres. Similarly, children born inside leper colonies were immediately handed to relatives, given for informal adoption or isolated in the prevention centres. The children, identified as relatives of leprosy patients, were subjected to further discrimination by society in general, who avoided contact with them. Ultimately, the children were not allowed to leave the prevention centre. Many children were put to work at a very early age (Monteiro, 2003). In

1960, there were 31 prevention centres formally established in Brazil (Ministério da Saúde, 1960).

The isolation of leprosy patients was maintained as a mandatory public health policy until 1962, even after the development in the 1940s, of effective treatment (sulfones). Mandatory isolation of patients ended 1962 through a federal decree, although in São Paulo, patients were admitted until 1967 (Opromolla and Laurenti, 2011). As a result of decades of a split family policy, many people currently do not know their parents or siblings or have no formal proof of their genetic identity.

At the beginning of the 1980s, the Movement for the Reintegration of People Affected by Hansen's Disease, a nongovernmental organisation (MORHAN, 2013), started a campaign to search and identify people who had been separated from their kin. Until 2013, MORHAN had registered 9000 individuals who were separated as children from their parents due to compulsory isolation. In 2011, the INAGEMP (the National Institute of Science and Technology in Medical Population Genetics) collaborated with MORHAN to conduct DNA testing and establish family links in identified individuals. The project was called "REENCONTRO", which means reunion.

In a first phase (Penchaszadeh and Schuler-Faccini, 2014), INAGEMP tested only pairs or triplets of potential relatives, who were selected by their personal histories. All of the testing was completely voluntary and initiated either by a formerly isolated individual who was looking for his/her relatives or by the relatives looking for someone who was isolated or separated from them in the past. Tests were performed only in living persons and only if all members of a possible family group agreed to give samples for testing and to provide written informed consent.

A thorough and comprehensive explanation about the test and potential limitations and risks was given in large meetings in the communities, organised by MORHAN, and in individual talks. Subjects were assured that the sample obtained would be used only to establish family links and that the result would be confidential. A detailed questionnaire included information on place of birth, colony-hospital, prevention centre, circumstances of the separation, names of known relatives and adoptive family.

The probability that a specific individual with unknown identity was part of a particular sibship (probability of inclusion) was determined by the use of 15 microsatellites or short tandem repeat DNA markers, and the identification was deemed positive when that probability was 98.0% or higher. Of 196 individuals from 8 Brazilian states and who presumed but had no proof that they had a sibling or a second-degree relative, a sibship relationship was proved in 158 individuals.

The confinement of leprosy patients and the segregation of healthy individuals from sick relatives during the twentieth century was not restricted to Brazil, as it was a policy practiced throughout the world, including the United States (White, 2003), Europe (Cruz, 2009) and Asia (Robertson, 2009) and other countries in Latin America where leprosy was endemic (Levinson, 2003; White, 2003; Leandro, 2013). MORHAN has data on 9000 individuals registered as having been separated from their families because of leprosy, of which only a small proportion were tested in the Project 'REENCONTRO'.

While the majority of registered individuals did not need DNA testing because they had legal proof of their filiation, the project REENCONTRO undoubtedly contributed to reunite families in those cases in which DNA testing was confirmatory of kinship. Together, these individuals form a strong and empowered group trying to regain a dignity that was taken

away by the stigmatisation of people affected by leprosy, which unfortunately extended to their families (Fonseca *et al.*, 2015).

Conclusions

The three experiences reported here have differences and commonalities. In Argentina, the military committed egregious crimes against humanity including not only disappearing dissenters but also appropriating and suppressing the identity of their offspring. In El Salvador, the horrors of war included children lost in battlegrounds, overt appropriation by the military, life in orphanages and illegal adoptions abroad. In Brazil, the suppression of identity of the children of patients with leprosy was a tolerated human rights casualty from an ill-conceived and undemocratic health policy of the state, based on ignorance, prejudice, stigmatisation and unwarranted fear of contagion.

However, the three examples have in common the relevance given to forensic genetics as a tool for the defence of human rights, in particular the right to identity. Indeed, forensic genetics has been at the forefront of actions to repair egregious violations of human rights throughout the world, to support the right of identity, to bring perpetrators to justice and to heal the pain and suffering resulting from those violations (Penchaszadeh, 2015; Ministerio de Relaciones Exteriores, ICRC, 2015). This article would be incomplete without mentioning the extraordinary work of the Argentine Team of Forensic Anthropology which since 1984 has been identifying human remains of disappeared persons throughout the world, contributing to human dignity and justice (Joyce and Stover, 1991; Doretto and Fondebrider, 2012; EAAF Argentine Forensic Anthropology Team, 2016).

The experiences reported here prove that science is not neutral and that it can be used either for good or bad causes. Geneticists should strive to prevent the abuses that were associated with genetics in the past (racism, stigmatisation of the different, discrimination and genocide) and make sure that DNA technology is a tool to benefit humankind. At the same time, one should avoid the trap of genetic reductionism and acknowledge that genetic identity is only one dimension of personal identity, which is a complex phenomenon resulting from many factors, including those that are genetic, social, emotional, educational and political in nature.

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