Ethical, legal and social issues in restoring genetic identity after forced disappearance and suppression of identity in Argentina

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Received: 30 October 2014 / Accepted: 2 February 2015 / Published online: 18 February 2015
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Abstract Human genetic identification has been increasingly associated with the preservation, defence and reparation of human rights, in particular the right to genetic identity. The Argentinian military dictatorship of 1976–1983 engaged in a savage repression and egregious violations of human rights, including forced disappearance, torture, assassination and appropriation of children of the disappeared with suppression of their identity. The ethical, legal and social nuances in the use of forensic genetics to support the right to identity in Argentina included issues such as the best interest of children being raised by criminals, the right to learn the truth of one's origin and identity, rights of their biological families, the issue of voluntary versus compulsory testing of victims, as well as the duty of the state to investigate crimes against humanity, punish perpetrators and provide justice and reparation to the victims. In the 30 years following the return to democracy in 1984, the search, localization and DNA testing of disappeared children and young adults has led, so far, to the genetic identification of 116 persons who had been abducted as babies. The high value placed on DNA testing to identify victims of identity suppression did not conflict with the social consensus that personal identity is a complex and dynamic concept, attained by the interaction of genetics with historical, social, emotional, educational, cultural and other important environmental factors. The use of genetic identification as a tool to redress and repair human rights violations is a novel application of human genetics within a developing set of ethical and political circumstances.

Keywords Forensic genetics · Human rights · Identity suppression · Genetic identification · Genetics and ethics · Ethical, legal and social issues

Background

Developments in human genetics over the past half-century have been unprecedented, to the point that the twenty-first century has been dubbed “the century of the genome”. Nevertheless, discoveries and applications of genetic technology, with their potential for health and wellbeing, cannot conceal the fact that flawed genetic concepts were used in the past to justify gross violations of human rights, such as eugenics, negation of reproductive rights, racism, discrimination, stigmatization of differences and even genocide (Müller-Hill 1988; Kevles 1995). Recently, progress in forensic genetics has enabled human genetic identification for different purposes, including restoration of genetic identity to persons in whom it had been suppressed in the context of political repression, and to human remains of victims of human rights violations (ICRC 2009; Penchaszadeh 1997; EAAF 2012). Additionally, as the Convention on the Rights of the Child was being discussed at the United Nations in the late 1980s, the Abuelas de Plaza de Mayo (see below) lobbied intensely to make sure that it would specifically mention the right to identity as a fundamental human right. Eventually, a convention was approved by the General Assembly of the United Nations, in November 1989, explicitly stating in its article 8 that “States Parties undertake to respect the right of the child to preserve his or her identity, including nationality, name and family relations as recognized by law without unlawful interference” (United Nations 1989). Furthermore, in 2007

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

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the United Nations designated forced disappearance as a crime against humanity (United Nations 2007). A number of historical circumstances have connected these developments, as genetic identification became increasingly associated with preservation and defence of human rights, in particular as a tool to repair the consequences of violations of the right to identity and to bring those responsible to justice (United Nations 2009; Penchaszadeh 2011).

In the 1960s and 1970s, progressive and revolutionary movements aiming at social justice, which developed in Latin America, were forcefully repressed by military dictatorships. In Argentina, the military dictatorship of 1976–1983 was particularly gruesome and genocidal, resulting in the disappearance of approximately 30,000 persons (OAS 1978; CONADEP 1984; Andersen 1993). Abducted adults disappeared into secret detention centres run by the military, where they were savagely tortured and (with few exceptions) murdered, and their bodies hidden by various means: incineration, throwing them from airplanes into the sea, secret burials and other. Victims included pregnant women, babies and small children abducted with their parents. Pregnant women delivered their babies in humiliating circumstances in military barracks, only to be murdered shortly afterwards. It is estimated that approximately 500 babies were born in captivity to disappeared women and were handed over as “war booty” to someone within or linked to the security forces. Birth certificates were forged, and children were falsely registered as the biological offspring of their abductors (CONADEP 1984; Van Boven 1988; Penchaszadeh 1997, 2011). The appropriation of babies of murdered dissidents was part of a deliberate genocidal policy, based on the military’s conviction that “subversives breed subversives” and they had the duty of “freeing” these children from the “subversive” education of their parents, as admitted by one of the top generals (Camps 1985). This systematic plan followed the teachings of Vallejo Nájera, a fascist psychiatrist under the Franco regime in Spain, who directed the abduction of thousands of children of Republican women prisoners and their handing over to “good” families. His arguments were that “Marxism affects the biotype” and that only “immersion in morality (*sic*) would avoid deterioration of the Spanish race” (Vallejo Nájera 1937).

The atrocities committed by the Argentine military were confronted with courage and determination by human rights organizations and associations of relatives of victims, such as Madres de Plaza de Mayo (Mothers of Plaza de Mayo) and Abuelas de Plaza de Mayo (Grandmothers of Plaza de Mayo) (OAS 1978; Kurtz 2010; Arditti 1999; Abuelas de Plaza de Mayo 2014). After years of failed social, political, economic and military policies, the regime was eventually forced to grant elections, which led to a democratic government in December 1983, albeit leaving behind a devastated society, with tens of thousands of talented citizens in exile.

Bioethics and genetics in Argentina after the return of democracy

Most of the few geneticists existing in Argentina in the 1970s fled the dictatorship and continued their careers abroad.¹ When democracy was reinstituted in December 1983, some of these geneticists returned to Argentina, while others continued their work abroad while reconnecting with the country as consultants and visiting faculty. That period, in turn, marked the birth of bioethics in Latin America, where it followed an approach based in human rights and social justice, contrasting with the individualistic approach of Anglo-Saxon bioethics (Garrafa et al. 2005; Tealdi 2008; Casado and Luna 2012). A fruitful interplay among socially committed geneticists and bioethicists concerned with the common good of society, influenced an ethical application of genetics in the field of human identification.

The Argentine democratically elected government took office on December 10, 1983, and a few days later, responding to demands of human rights organizations, it appointed a National Commission on Disappeared Persons (CONADEP 1984) to investigate the fate of the disappeared. Pressed by the discovery of hundreds of human remains in mass graves and the numerous reports of grandparents searching for abducted grandchildren, and given the lack of expertise in forensic anthropology and genetic identification, the government requested the collaboration of the American Association for the Advancement of Science, which sent an expert mission in January 1984. The group included forensic anthropologist Clyde Snow and geneticist Mary-Claire King, who assisted, respectively, in the identification of remains and the genetic identification of children suspected of being offspring of disappeared persons. Mary-Claire King’s work in Argentina was the key to future developments in the genetic identification and restitution of abducted children who were in the hands of appropriators. Indeed, a few months earlier, she had led a task group that developed an adaptation of the paternity index to be utilized in the genetic identification of abducted children taking into account the fact that their parents were disappeared and unable to be tested. This statistical formulation, named *grandparentage index*, calculated the probability of inclusion of presumed grandparents as the true grandparents of a child, based on the comparison of results from genetic markers. In that visit, the first identification of an abducted child, Paula

¹ The author of this article was one of the geneticists forced to leave his native Argentina in 1976. He continued his career, first, in Venezuela and, later (for 25 years), in the USA. He mixed the science of genetics with human rights activism and became an advocate of the use of genetics in support of human rights. He supported the work of the Abuelas de Plaza de Mayo from its very beginning, contributing to the formulation of the grandparentage inclusion-probability index and being an active speaker on behalf of the right of victims of identity suppression to recover their genetic identity and of the duty of the state to prosecute and punish the perpetrators.

Logares, was accomplished applying this calculation to results of blood group and HLA antigen tests in the child and her presumed grandparents (di Lonardo et al. 1984).

Ethics and the law regarding genetic identification while abducted children were still minors

The success in the identification of Paula gave a strong booster to relatives who were searching for their missing children and opened the way to strengthen their search and for the state to organize the technical, legal and ethical aspects of genetic identification in that context (Penchaszadeh 1997, 2011; Harvey-Blankenship and Shigekane 2010). The Ministry of Health centralized all genetic testing for identification of disappeared children in an immunogenetics laboratory in the Durand City Hospital. The Ministry of Justice instructed the courts to open a file on every request from people searching for disappeared relatives and to direct them to that lab (the only genetic identification available then in Argentina) and store the information for eventual future use. The Abuelas de Plaza de Mayo acted as legal representatives of relatives of victims and presented claims in the courts whenever circumstantial evidences provided a strong suspicion that a particular child could be the offspring of a disappeared person (such as forged birth certificates signed by physicians known to have had links with the repression, alleged home deliveries, reports by survivors from detention centres, and anonymous reports). When the judge in charge of a case considered that the circumstantial evidence was valid, court-appointed psychologists and child psychologists from the Abuelas met with the judge in charge to draw up an action plan that prioritized the best interests of the child. An investigation was started which included approaching the adults raising the child and determining whether or not they were the child's biological parents. If the investigation proved that the child was not a biological son or daughter, the judge ordered that his/her genetic markers be compared with those of potential relatives. Genetic identification was considered positive when the inclusion probability of grandparentage was higher than 99.9 %.

The ethical and legal principles followed by the courts were the following: (a) the children taken from their captive mothers and raised by appropriators were victims of forced disappearance and suppression of identity, which are crimes against humanity; (b) international human rights law establishes the state's obligation to investigate crimes against humanity, find the truth, prosecute and punish the perpetrators and provide reparation to victims; (c) the right to identity and to learn the truth about oneself and about the fate of disappeared parents are fundamental human rights, which should be preserved even in the minority of cases in which these children were adopted in good faith; (d) the biological family, who battled against all odds and risked their lives during the

dictatorship to search and find the offspring of their disappeared loved ones, had a legitimate right to recover the appropriated children and (e) the best interests of the child, as determined by the courts, with the advice of child psychologists, always guided the decisions.

The emotional shock experienced by the children when learning that the adults who were raising them had been, at a minimum, accomplices in the disappearance and murder of their parents, was of great magnitude in all cases. Initial disbelief and feelings of despair led some older children and adolescents initially to resist the action of justice. However, psychological support, the gentleness of the judges, the loving embrace of the biological family and the patience of all involved helped the children to cope with the stress and supported a healing process. Given the victims were minors, the judiciary represented the legal authority of the state and, as such, was responsible for all decisions from testing to custody. Law and ethics coincided in that victims had the right to their identity, to learn the truth about who their parents were and what had happen to them and to have their identity restored. In the minority of cases in which children had been adopted in good faith, accommodation was usually achieved between adoptive parents and biological relatives (Abuelas of Plaza de Mayo 2014). In most cases, however, where children were in the hands of persons linked to security forces, often in perverse relationships tainted with subtle or overt violence, restoration of their true identity and the transfer of custody to the biological family had a healing effect in the children. For those who already knew they were not biological children of those who were raising them, learning that their parents had not abandoned them, and their family searched tirelessly for them, was a key factor in the healing process (Argento 2008).

It was soon realized that this process required the development of a genetic database to compare the genetic profiles of relatives with those of located children. Thus, in 1987, a law of the Congress created the Banco Nacional de Datos Genéticos (BNDG), which started to store genetic profiles from samples donated by searching relatives and conducted forensic genetic testing in all cases referred by the courts. The specific aim of the BNDG has always been the genetic identification of individuals born during the military dictatorship and suspected of being victims of forced disappearance and suppression of identity (Penchaszadeh 2012). The database became DNA-based and automatized, in the early 1990s, and in 2009, Congress put the BNDG under the responsibility of the Ministry of Science and Technology, raising its scientific and ethical standards (MINCYT 2014). Over the past 30 years, the BNDG applied standard forensic genetics techniques (Prinz et al. 2007; ICRC 2009) and has identified 116 individuals appropriated at birth or as small children by the military, enabling the restoration of their true genetic identity. This was deemed

positive when the inclusion probability of an individual with unknown identity of being a grandchild of putative grandparents was 99.9 % or higher.

Ethical and legal issues of restoring genetic identity of adults

Over time, as appropriated children became adults, ethical nuances became more complex. Abuelas de Plaza de Mayo kept very active over the years as a social and human rights movement, conducting awareness campaigns about the crimes of forced disappearance, child abduction and suppression of identity during the dictatorship. Intense publicity informed the public about how to find out if someone, who doubted her/his identity, was in fact a child of the disappeared. A special government agency, the National Commission for the Right to Identity (CONADI), was created in 1992, under the Ministry of Justice and Human Rights, where anyone could seek information confidentially and have their DNA checked against the BNDG's database if their doubts were deemed to have merit. Over the past 10 years, approximately 10,000 young adults voluntarily had their DNA compared to profiles of 311 families in the BNDG, resulting in the genetic identification of approximately 50 young adults proven to be children of the disappeared and who thus recovered their true genetic identity.

In addition to these voluntary requests, court proceedings occurred, either through prosecutions resulting from the proactive action of the state or through claims by presumed biological relatives. Thus, a small number of unsuspecting young adults turned into presumed victims of identity suppression and found themselves in court with their apparent genetic identity challenged. Most often, they accepted voluntary DNA testing, so there was no ethical or legal dilemma; however, in a few cases, a young adult would decline testing, alleging right to privacy. A Supreme Court ruling, in 2003, accepted the objection of a presumed victim of identity suppression to be tested, based on the right to privacy. This ruling created controversy, as the prevailing view among human rights advocates and bioethicists was that the right to privacy in such cases could not trump rights and obligations of a higher status, i.e. (a) the rights of families of the disappeared to learn the truth about their fate and the identity of their appropriated offspring; (b) the right of society to heal the social wounds of the horrors of state terrorism, by learning the truth and building a historical memory and (c) the obligation of the state, established by national and international human rights legislation, to investigate crimes against humanity, find and punish its perpetrators and repair damages to the victims. As DNA testing became a necessary tool to implement justice, it was a paradox that the objection of a presumed victim would be an obstacle for that quest. Based on these considerations, in 2008, the Supreme Court reversed its

previous ruling and (a) asserted that the interest of the state and of society in solving cases of crimes against humanity has the highest ethical status and, hence, the state had not only the right but the obligation to establish the truth in cases of presumed identity suppression and forced disappearance; following that reasoning, a suspected victim of such crimes could not decline DNA testing and (b) acknowledging that the right to privacy should be observed, the Court restricted its meaning to the physically invasive action of obtaining a biological sample, while asserting that obtaining DNA from indirect means (i.e. clothing and other personal objects) did not conflict with the right to privacy. This ruling, which is currently the law in Argentina, in fact enabled a number of genetic identifications. In any case, it should be noted that most young women and men that initially resisted being tested, eventually agreed to give a DNA sample voluntarily, suggesting that deep in their minds there was a coming-to-terms with reality, for which they needed the time and support from society. Interestingly, it was some of these persons who eventually developed the strongest antagonism towards their abductors, to the point of taking them to court for reparations (Elkin 2008; Forero 2010). A related legal issue of this process was that it inevitably uncovered the related crimes of abduction, forgery of birth certificates, and suppression of identity. These crimes were actively prosecuted by the state, resulting in prison terms to those found guilty.

The most well-known case of identification occurred in 2014 and has been that of the recovered grandson 114, a 37-years-old man named Ignacio Hurban, raised as a biological son of rural workers in the countryside of the province of Buenos Aires. Ignacio developed doubts about his identity because of lack physical resemblance and common interests with his presumed parents, and asked them whether he had been adopted. As soon as he was told that indeed he was adopted, he contacted voluntarily the Abuelas and, shortly thereafter, his DNA profile, processed at the BNDG, showed two positive hits: one with the DNA profile of a man disappeared in 1976, Wilmar Montoya, whose remains had been identified in 2009 by the Argentine Forensic Anthropology Team in an investigation of clandestine burials, as part of its Latin American Initiative for the Identification of the Disappeared (EAAF 2012) and the other with the DNAs of Estela Carlotto (president of the Abuelas) and her deceased husband, whose pregnant daughter Laura had disappeared and been murdered after delivery (no DNA was available from Laura herself). Interestingly, the fact that Laura was pregnant when she disappeared (in 1976) and that she had delivered a baby only became known to her family at autopsy, in 1978, when her remains were turned over to her parents. Equally unknown was the fact that Wilmar and Laura had been love companions (they were living underground, escaping the military). According to the law, the last names of Ignacio were changed to Montoya Carlotto. Further, honouring his mother,

who had named him Guido at birth (according to survivors who witnessed his birth), as well as his maternal grandparents, who for 37 years were searching for him as “Guido”, Ignacio decided he would become Ignacio Guido (del Carril 2014; Gilbert 2014; Reuters 2014). He publicly declared he had a happy childhood and an excellent relationship with the couple who he had always thought was his biological parents. As of this writing, the facts about how and who took him as a baby from the detention centre to the home where he grew, or about what those who raised him knew about his true identity, have not been made public, as they are part of a criminal investigation.

Discussion

The Argentine military usurped power and imposed terror upon society to quell any dissent over their regressive economic policies. It resorted to forced disappearances, torture and the assassination of thousands of dissenters, combined with the appropriation and suppression of the identity of hundreds of their offspring. During the ensuing 30 years after return of democracy, the ethical, legal and social-political issues surrounding the genetic identification of victims of abduction by the military turned out to be much more complex and nuanced than the technical issues. While forensic genetics became standardized, automated and quite straightforward (Prinz et al. 2007; ICRC 2009), the ethical and legal issues unveiled unprecedented social complexities which included (a) the influence on public opinion of a generally conservative mass media which favoured the status quo and only recently began to support the search for, and establishing the identities of, victims of appropriation; (b) the lack of independence of the judicial system, where many judges appointed by the military were still in function and (c) the life experiences of those who had their true identity restored.

The acceptance and support of society of the quest of the Abuelas de Plaza de Mayo fluctuated through these 30 years, from an initial peak of support during the first few years, to a low level during the late 1980s and the 1990s, as two successive governments developed policies to accommodate with the military: first discontinuing the trials started in 1985 and then issuing pardons to those who had been convicted of human rights violations. Support resurged coinciding with the strong human rights policies enacted in 2003, under the influence of the late president Kirchner, when the laws that granted immunity to perpetrators of human rights violations were declared unconstitutional and the prosecution of hundreds of former members of the security forces was reinitiated. The past 10 years witnessed a revival of popularity of the genetic identification of individuals thought to be children of the disappeared. The BNDG has been performing about 1,000 genetic tests annually, for the past 10 years, and as of this

writing, 116 individuals have been identified and reunited with their families.

Although initially most victims experienced psychological shock when their true identity was revealed, knowledge of the truth, painful as it was, was emotionally liberating from the perversity, lies, concealment and violence that in many cases had surrounded their rearing (Argento 2008). Each case, however, is distinct from all the others, depending on differences in the circumstances of appropriation and rearing (i.e. whether good faith, concealment or crime played a role; personality of the appropriators), doubts of victims about their identity and their search for answers, age at identification, acceptance or resistance to the action of the law and characteristics of the living biological relatives. Interestingly, many of these young men and women have eventually identified with the ideals of their disappeared parents, becoming activists for human rights and social justice, many of them working as volunteers for the Abuelas. The identification of the grandson of Estela Carlotto and his positive attitude towards learning the fate of his parents and his biological family has given immense popularity to the issue, leading to hundreds of calls from young men and women with doubts about identity received at CONADI during the weeks following the news. Ignacio Guido Montoya Carlotto is one of the most popular celebrities today in Argentina.

Bioethical guidance based on respect for human rights, privacy and the truth, and the provision of justice, helped Argentine society navigate the nuances of each case, making this experience an example to follow in the interaction of science and ethics, in complex problem-solving of transitional justice after military dictatorships. At the same time, the science of genetics, now helping a just human rights cause, has been vindicated from the abuses it was associated with in the past and is now a very popular discipline in Argentina. There has been an intense cross-fertilization of genetics and bioethics, shaped in public debates about the nature of personal identity and the role played by genetic factors. These debates have a permanent presence in academic, political and societal life, fuelled by factors as diverse as press reports on still ongoing trials against military repressors and appropriators of children, identification of young adults who doubted their identity and turned to be children of the disappeared, meetings organized by different academic societies and student activists. Initially, the popularity of DNA testing to prove genetic identity gave impulse to a somewhat reductionist view that “genetics trumps environment” in the development of personal characteristics, such as talents, vocations, personality, etc. The extreme confrontation of the victims with the perverse objectives of the military to suppress any traces of genetic identity in the appropriated children explains some of their statements privileging genetics over environmental influences in personal identity, including political ideology. It is understandable that in the Argentine context, genetic identity

established via DNA testing took preeminence over other factors involved. Given that appropriation of children and suppression of identity is a crime against humanity, the country prioritized genetic identification to redress those egregious violations of human rights. This initial tendency towards a mystification of DNA as an all-powerful substance that determines the identity and fate of human beings is being replaced by a more balanced view that personal identity is a complex phenomenon, in which genetics is only one of the factors involved, interacting with culture, history, emotions, education and other environmental influences throughout life.

The application of genetic tools in an ethical way to help solve crimes against humanity is helping to heal the horrifying violations of human rights committed by the military in Argentina and has provided still another example of the power of science to be used either for good or bad causes. The important role of genetics in this endeavour has been emphasized by the United Nations Council on Human Rights, which recently passed a resolution declaring forensic genetics as a fundamental tool to investigate violations of human rights (United Nations 2009). Genetics should never again be used to justify abuses such as racism, stigmatization of different persons, discrimination and genocide and should promote actions that benefit humankind while avoiding the trap of genetic reductionism, acknowledging that genetic identity is only one dimension of personal identity.

Acknowledgments The actions leading to localization, genetic identification and restoration of true identity of 116 appropriated children and young adults could only have happened thanks to the courage, determination and resilience of Abuelas de Plaza de Mayo and the excellent work of the forensic geneticists of the Banco Nacional de Datos Genéticos.

Compliance with Ethical Guidelines

Conflict of Interest Victor Penchaszadeh declares that he has no conflicts of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by the author.

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