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ORIGINAL ARTICLE

Ethical problems in health research with indigenous or originary peoples in Peru

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Abstract The varied, abrupt and amazing geography of the land of Peru is home of one of the major concentrations of indigenous peoples in the world. The asymmetry of power, however, in their relationship with the rest of society and the State is still very evident in their social exclusion, their gap in social and economic development, barriers in their access to health services as well as their marginalization and exploitation as subjects of health research. In this paper, we analyse two cases of research on indigenous populations in Peru, discuss them from the point of view of bioethics and reflect on important issues for researchers, research participants and the society, such as the need to respect different cultures, the need that the research being done is relevant to the needs of the population in which it is conducted and the necessity to empower indigenous communities in participatory research, to strengthen the institutions and to protect human rights, namely through ethics committees for research and the free, informed and meaningful informed consent. This approach should foster quality research, while at the same time fully respecting human rights and bioethics. We cannot forget that advancements in genetics, throughout the world, are very much in debt to indigenous populations.

Keywords Indigenous peoples · Vulnerable populations · Genetics piracy · Biocolonialism · Health research · Informed consent

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Introduction

Undoubtedly, the chief aim of scientific research should be the progress of society. Nevertheless, its implications and consequences for humankind as a whole, including future generations, must be taken into account.

In this respect, and particularly in Latin America, indigenous peoples deserve special consideration for several reasons, not least the fact that throughout the world they have been subjugated and exploited for many centuries. In this paper, we describe and discuss ethical problems that have been prevalent in biomedical research on indigenous peoples in Peru and are similar to what has happened throughout Latin America over many decades. We use indistinctively the terms *indigenous* or *originary* peoples, defined as people who are descendants from populations that inhabited the region before the time of conquest and colonization, and who, independently of their legal status, have preserved all or part of their social, economic, cultural and political institutions, and that, at the same time, self-recognize themselves as such (Law No. 29785 2012).

While in the last several years there has been more recognition of the rights of indigenous people, the problematic asymmetric relationship of these peoples with the State is still very much prevalent, particularly in the field of research, which has traditionally been viewed as an endeavour done on but not *with* originary people. Thus, it has been common practice for researchers to arrive to a community, collect data and depart without much consideration of what they leave behind nor what is the impact of their behaviour in the communities they studied (Fajreldin 2010; Campbell 2014).

There have been numerous experiences in the world and in Peru of health research on indigenous populations that have violated basic ethical principles and many that surely continue to occur (Arbour and Cook 2006; Brant Castellano 2004;

Harry et al. 2000; Justo 2012; Mello and Wolf 2010). The objective of this paper is thus to present some recent research on originary people in Peru, with the aim of discussing key points to consider to ensure ethical and quality research in these populations.

Indigenous or originary peoples in Peru

The Peruvian people has a 20,000-year history, during the last 5000 years of which it was host to numerous civilization processes (the most ancient in America), in its varied and uneven geography.

The State recognized the territory where indigenous populations have traditionally established, developed and organized, through the Ley 22175/1978 de Comunidades Nativas y Desarrollo Agrario de la Selva y Ceja de Selva (Native Communities and Agrarian Development in the Forest) and the Ley 24656/1987 de Comunidades Campesinas (Farmer Communities). Both laws were made part of the National Constitution in 1993. Moreover, Agreement 169 with the International Labour Organization, which deals specifically with the rights of indigenous and tribal peoples (www.ilo.org/indigenous/Conventions/no169/lang–en/index.htm), was ratified by the National Congress in 1994 and took effect in 1995.

In 2010, the Ministry of Culture was created, with a Vice-Ministry of Intercultural Affairs, which identified 54 indigenous or originary peoples in the Peruvian territory (Ministerio de Cultura 2015). The country does not count yet, however, with detailed information about many of these nations, which in itself denotes the historical debt our State has to these populations.

Some background on research projects in Peru

Peru as a country does not have a database with the number and type of health-related research projects conducted on indigenous peoples in its territory or of those currently being conducted. Many so-called research projects do not even count with the approval from a research ethics committee. During the period 2002–2013, the National Institute of Health (www.ins.gob.pe), the Peruvian agency of the Ministry of Health that funds or directs most health-related research, has registered 11 research projects on indigenous peoples, conducted by its own staff or by other institutions that voluntarily registered their projects, i.e. an average of 1 project every year (Table 1).

The following cases, analysed from a bioethics point of view, illustrate how research on indigenous peoples is proposed and conducted in Peru.

Genetic variability, genetic analysis in neurologic and mental disorders and microbial ecology in indigenous communities

In 2010, the National Institute of Research of Peru received information that a Peruvian researcher started, in 2007, a research project on genetic variability in native populations of different areas in Peru; its purpose was to use data collected to understand factors that caused the genetic diversity within and among the populations studied, such as historical events and environmental factors. This project was approved by a Peruvian committee of research ethics but underwent for nearly 6 years without authorization of other instance, since there is no regulation on the matter. It called for the collection of saliva samples for DNA analysis in four departments of Peru and was funded in part by the Wenner-Gren Foundation and the University of Oklahoma.

Another researcher conducted studies on anaemia and malnutrition in the Department of Huancavelica, which has the highest poverty index of the country (INEI 2010) and which allegedly had been approved by a research ethics committee. As a clear example of genetic *extractivism*, samples collected were “donated” to the University of Oklahoma. Researchers from this university then conducted studies on genetic variability in Peruvian populations, in collaboration with the Universidad Nacional del Altiplano (in the Department of Puno), without approval by a local ethics committee.

An inquiry by the National Institute of Health of Peru revealed that the University of Oklahoma was the receptor of samples of saliva, faeces and buccal smears from people of six departments of Peru, most likely obtained without informed consent and without the knowledge, authorization or control of the Ministry of Health. These samples were being processed for the following investigations: (1) genetic variability in native Peruvian populations, to demonstrate genetic similarities and differences within and between peoples from different regions of Peru; (2) genetic analysis to detect genes associated with neurologic and mental disorders in a sample of Peruvian indigenous peoples; and (3) ecology of human intestinal microbial flora in indigenous communities.

What is particularly troublesome is that this research was being conducted on indigenous people, without proper ethical revision nor the knowledge or authorization of national authorities and the natives in the communities themselves. The participation of a foreign university that did not follow established international ethical standards and misappropriation of biological samples and potential information, without the consent or even the knowledge of the research subjects, are a clear violation of human rights, sometimes known as genetics piracy.

Population health has environmental and social determinants with direct implication on the health of individuals, in addition to the possible contribution of genetic factors. While

Table 1 Research on indigenous people in Peru 2002–2013

No.	Title of research project	Year approved
1	Sustainable program for health promotion in Amazon communities	2002
2	Amazon Project: Promotion of sustainable human development Peru-Ecuador-Unicef	2002
3	Intercultural strategy against hepatitis B and yellow fever	2003
4	Ethnic emergencies, cultural strategy against hepatitis B and yellow fever in Amazon communities	2003
5	Nutritional status and cultural factors influencing alimentary habits. Study in the Ashaninka y Aguaruna populations	2004
6	Prevalence of enteral parasites in children under 3 years of age and women of reproductive age in Ashaninka y Aguaruna populations	2004
7	Prevalence and phylogenesis of HTLV-1 in different population groups of Peru	2004
8	Nutritional and parasitic status, cultural factors and alimentary habits. Study in Shipibo-Conibo and Chayahuita populations	2005
9	HIV and syphilis associated behaviour in the indigenous people of Chayahuita in the province of Alto Amazonas, Loreto, 2005	2005
10	Promotion of traditional food to improve nutrition and health of Aguarunas of Bajo Cenepa	2006
11	Perceptions of health personnel and the community on culturally appropriate maternoperinatal services in rural Andean and Amazon areas in the Huanuco Department	2006
12	Identification of the prevalence of hepatitis B, their risk and determinant factors among the peoples Kandozi and Chapra in the Daten del Marañon	2010
13	Analysis of genetic variability among indigenous and mestizo population of Peru as a platform for the development of genomic medicine	2011

Fuente: Instituto Nacional de Salud (www.ins.gob.pe/). The database of clinical trials was not analysed

genetic studies have a role in health research, the context of generalized poverty, cultural distinctiveness and social exclusion in which most indigenous people live makes them highly vulnerable to research exploitation (this is understood as the use of vulnerable subjects or populations for the benefit of researchers, without any benefits or capacity building for the community or contribution for the reduction of the disadvantages from which the subjects suffer). Therefore, health research should prioritize approaches and issues that are relevant to the actual needs of the population, respecting and protecting their human rights and autonomy, namely through real individual and community informed consent. As repeatedly stated in numerous international ethics norms (UNESCO 2005; WMA 2013), it is essential that research *participants* are given proper and balanced information and feel free to give consent without coercion or improper incentives.

This case is just one example of foreign institutions that fund research on indigenous populations throughout the world, and obtain and take possession of biological samples without regard of the imperative of competent and lawful ethical evaluation, both at theirs and the local country, as well as free informed consent. These vulnerable populations usually have no knowledge of the research objectives and may fall victims of unconsidered potential harms, such as group and ethnic stigmatization, inadequate acknowledgement of their unfamiliarity with *western* norms and no proper recognition of their own cultural values and traditions.

HIV and syphilis among the Chayahuitas

The Census of Indigenous Communities in the Amazon in 2007 (INEI, UNFPA 2010) showed 105,900 native persons, from 29 ethnic groups, distributed by 41 districts of the Department of Loreto of the Peruvian Amazon. The ethnic group self-identified as Shawi o Chayahuita is composed of 20,540 persons in 7 districts of Loreto. Those older than 14 years of age account for 10,561 persons, with an illiteracy index of 33 %, an estimated infant mortality rate of 64 per 1000 and a global fertility rate of 7.7 children per woman (compared to a national rate of 2.6).

A research study on “Endemic Infectious Diseases of the Peruvian Amazon”, approved by the Committee of Research Ethics of the Ministry of Health and performed by Peruvian researchers with funds from the NIH/Fogarty International Center, Training Grant D43 TW007120, was conducted in a Chayahuita community of 162 individuals (Zavaleta et al. 2007). The results of the study included the following: (a) among the Chayahuitas, condoms are not used to prevent sexually transmitted diseases because “it is not part of their culture”; (b) a high frequency of homosexual behaviour; (c) a cultural tradition of early initiation of sexual activity and polygamy; and (d) a higher prevalence of syphilis than in the general population of the city, which could be a risk factor for HIV. The study concluded that, considering the prevalence of HIV/AIDS in the region, homosexuality among the Chayahuitas could be a significant threat to this and other similar ethnic groups.

This study and its published conclusions reveal a number of biases that are common among westerners conducting research on indigenous peoples with different cultural traditions. (1) According to the publication, from a modern west-centred point of vision, absence of use of condoms, homosexual behaviour, early initiation of sexual relations and polygamy are interpreted as the "cause" of AIDS, disrespecting the culture of the Chayahuita nation and stigmatizing this ethnic group (inside and outside Peru). (2) The publication contains no information about which educational actions were taken in the community to promote health and prevent, detect and treat sexually transmitted diseases that were the object of the study. (3) This publication includes information that may be of academic or scientific interest but is of little usefulness or benefit for the studied communities. It is an accepted ethical practice that in this type of studies, the communities involved should accept if, where and how results are presented and how to prevent stigmatization and discrimination; also, this publication does not mention if results were disclosed to participants and, if so, how this process was conducted and what benefits, if any, were derived for the community itself.

Both the scientific and ethical appropriateness of conducting a study on only 0.78 % of the Chayahuita population and making general conclusions, not only to this ethnic group but also to all indigenous peoples of the region, are highly questionable. Particularly troublesome is the generalized assertion that homosexuality and polygamy are "cultural traditions" of indigenous peoples, given the alarm and stigmatization this can generate, in the face of significant prevalence of HIV and syphilis in this particular population.

Relevant considerations on the ethics of research with indigenous peoples

Indigenous peoples have been promoting research by developing their own proposals, taking into account participatory and/or emancipatory approaches. It allows them to conduct their own research and make them less vulnerable (Justo 2004). For instance, it is worth to mention the following policy developed by the Kuna, Maori peoples and the new Nations of Canada:

The Ethnic Kaupapa Maori from New Zealand have been developing research inspired by the traditional Maori philosophy and participatory action research theories in accordance with Freire (1973). Based on his words: "The methodology we are defending requires that, in the research course, both investigator and research subject become subjects of research itself", and in addition, he explained that "research…has also this fundamental dimension to its meaning and safeguard: the critical presence of representatives of the people, from its beginning to its final phase, which implies that the thematic analysis continue in the organization of the program content of educational action to become a liberating cultural action" (Freire 1973). The vision of Kaupapa Maori focuses on strong educational actions at the university level, including the training of technicians. Then, the Maori have under their control all stages of the research in the field of science and technology. As a result, their participation involves the determination of research priorities, the methodology design to be used, applicable ethical standards, criteria for peer review and publication, evaluation of the results in relation to the research objectives and the translation of these results into integrating evidence-based research with policy and practice. As a consequence, the Kaupapa Maori ethnic group has been developing "internal" mechanisms and methodologies, which comprise the criticism of "traditional" methods in research by implementing a research for Maori, with Maori and by Maori (Tuhiwai Smith 1999).

In the same way, in the First Nations in Canada, the development of research benefits included ownership, control, access and possession (OCAP), as well as their related areas, such as dissemination and publication of research findings (Schnarch 2004). Ownership refers to the relationship between the First Nations and their knowledge, data and cultural information. Control covers the whole research process by the First Nations and involves the management of the resources, review, the conceptual frameworks formulation and data handling, among other aspects. Access implies that they have the right to access all related information which concerns them, regardless of the place where it is stored. And, possession refers to the availability of data and information, which must be in the hands of the First Nations.

Probably the most expressive change in the connection of *research* and *indigenous people* over the recent past is the use of the preposition *with*, as opposed to *on* indigenous people. Also, participants should replace the term subjects. Among the several issues that should be mentioned as epitomizing ethical health and genetics research with indigenous peoples are the following:

Respect for other cultures Among the historical problems that research with indigenous peoples have been confronting is the colonial legacy that imposed a monocultural hierarchy that has devaluated traditional knowledge and wisdom. To overcome these limitations, a serious, respectful and symmetrical interaction among diverse cultures is needed, avoiding the trap of a hegemonic monocultural view and leading to empowerment of the leadership and membership of indigenous peoples in a legitimate defence of their rights (Brant Castellano 2004; Arbour and Cook 2006), and local capacity building.

Ensuring that research is relevant Evaluation of research as being ethically acceptable must also include an assessment of the relevance of the project in relation to the needs of the population with whom research is to be performed. That is, research must be geared to answer specific knowledge gaps needed to improve health and produce tangible benefits to the community. The work of ethics research committees is crucial in this regard, provided they are able to tackle these difficult issues.

Institutional empowerment It is crucial that State institutions are formed or strengthened and are committed to the needs of indigenous peoples, that a proper legal framework is advanced and that ethical principles guide and the law enforces respect and protection of the rights of indigenous peoples.

Creation, expansion and strengthening of committees of research ethics The number of ethics research committees under the aegis of the National Institute of Health should be increased, with special assignment to underserved regions of the country, where the control of ethics of research projects is most needed. There should be a network of such committees, with proper training of its members, and the inclusion of representatives of vulnerable populations, including indigenous peoples.

Meaningful informed consent Research with indigenous peoples requires a historical knowledge of their development, economics, politics, national customs, cultural expressions, traditions, habits and world vision. The framework of reference should be centred in a meaningful informed consent as an instrument for respect of dignity and autonomy. Its application in originary populations requires conditions of competency, information according to their reality, comprehension, language and absence of coercion over the will of the individual in the community, which are of difficult fulfilment (Quijano 2010). Furthermore, the social structures of indigenous peoples require, in addition, a community consent process. In this respect, it is important to realize that indigenous peoples should not adapt to the western notion of informed consent, but, on the contrary, it is the format of the informed consent that must be adapted to the culture and idiosyncrasies of each indigenous people. Whose consent are we looking for: the individual subjects'? the collective community's? or that of both? Is it written in the language spoken by those whose consent is being looked for? Given that informed consent is a *process*, it does not end with a signature of the document, but it is a guide for the performance of all steps of the study. Furthermore, research should not take place when the persons that form the community do not have the capacity of understanding the implications of participating in a research project, even if a translator or interpreter is available (Justo 2012).

Participatory research Many of the ethical problems encountered in research with indigenous populations and that have been documented in numerous publications would not have occurred if, from the beginning, they would have counted with the participation of community leaders or representatives. We contend that this participation should include the formulation of the scientific questions the research intends to answer, the design of the research protocol, the conduct of research and the publications of results (Justo 2004, 2012).

Equitable health system It is known that indigenous people usually depend on inequitable health systems, with many problems of access to services, which for the most part do not take into account their world vision and traditional health practices, leading in turn to markedly poor health indices, as compared with the non-indigenous population of the same country (Montenegro and Stephens 2006). In order to revert this situation, indigenous populations must have fair and equal access to health services, which may clear the way for research geared towards answering real health needs of these populations.

Conclusion

It is imperative that health research in indigenous populations (1) respects their dignity, traditional culture, world vision and autonomy; (2) is conducted in a participatory manner with research participants; and (3) is geared primarily to produce knowledge needed to improve their wellbeing and health, as well as their own research capacity.

Conflict of interest The authors declare that they have no competing interests.

Compliance with ethical standards This paper does not include research involving human participants and/or animals.

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