The Capability Approach in Genetic Research: Mediating Individualism and Solidarity*

Andrea Boggio
Unité de recherche et d'enseignement en bioéthique, University of Geneva
Geneva, Switzerland

Abstract

Genetic research raises important ethical challenges. Traditionally, those ethical challenges have been addressed by focusing on the widely-accepted Kant's categorical imperative that human beings are ends and not means. Consequently, bioethicists have focused on research participants and on protecting their autonomy. Other scholars have proposed an alternative ethical framework based on the principles of solidarity and equity. In this paper, I critically analyze the two ethical frameworks, concluding that both approaches present weaknesses and strengths. I then turn to the capability approach, as put forward by Amartya Sen and Martha Nussbaum as ethical approach that balances the tension between individualistic instances and community-oriented instances that genetic research raises.

1. Introduction

In this paper, I offer a critical examination of the significance of the capability approach, as put forward by Amartya Sen (1985a, 1985b, 1987, 1992 and 1999) and Martha Nussbaum (1999, 2000), to genetic research. To deal with the important ethical challenges that genetic research raises, scholars have put forward two ethical frameworks. One is more individualistic based on the autonomy of research participants (autonomy-based framework); the other more communitarian is based on solidarity and equity. In this paper, I critically assess these two ethical frameworks, and show to what extent both models are inadequate to cope with the ethical dimension of genetic research. I then turn to the capability approach as potential model for overcoming the limits of the proposed frameworks. The paper is intended to be a preliminary research into the subject

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rather than the conclusion of a well-thought research process. I hope to collect suggestions and ideas for improvement.

2. The Challenges of Genomic Biobanking

We are living in the genomics era. Genomics describes the study of all the genes in a person, as well as interactions of those genes with each other and with that person's environment. Since the Gregor Mendel's discovery of the laws of heredity, and its rediscovery in the twentieth century, the genetic aspects of biological researcher have significantly developed. The Human Genome Project represents one of the more recent accomplishments of such revolutionary path in biological research. The sequencing of the human genome provides a unique opportunity to improve our knowledge of the role of genetic as well as environmental factors in shaping our health. However, "the challenge of establishing robust paths from genetic information to improved human health remains immense." (Collins et al. 2003)

Large genetic databases containing human, biological samples and genetic data are key biomedical resources to take full advantage of the genomics revolutions. However, these human genetic research databases (HGRDs) raise important ethical issues. In its summary of the most pressing issues raised by advances in genetic research, the 2002 Report of WHO's Advisory Committee on Health Research (ACHR) on Genomics and World Health states: "The planned development of large-scale genetic . . . databases offers a series of hazards and ethical issues which have not been encountered before." (Advisory Committee on Health Research 2002)

The ethical issues become even more acute when genetic data are combined with information on individuals' health, lifestyle or genealogy. On one hand, the immense benefits that HGRDs and more generally genomics offer are pushing genetic research further in its path and new collections of biological materials are arising every day. On the other hand, the potential limitations to privacy and the risks of discrimination based on an individual's genetic patrimony are becoming increasingly discussed in society. Moreover, the genomics revolution cuts even deeper, challenging the identity of human beings and their perception of the society. "Due to the rapid pace at which practices in human population genetics are changing and data on population differences are accumulating, and given the problematic nature of foundational concepts such as population, race, and ethnicity, there is an acute need for critical philosophical inquiry at this time." (Gannett 2004).

The traditional approach to ethical issues of HGRDs is to apply the well-establish core principles of bioethics. Thus, great emphasis is given to the autonomy of research participants and the central role that the informed consent that is required to conduct genetic research on humans plays. In the last few years, some scholars have pointed out the limitations and inadequacies of the individualistic approach, and have proposed an alternative ethical framework based on solidarity (participation in research for the benefit of others) and equity (sharing the benefits of research). However, this alternative, more communitarian approach has been criticized. In this paper, I investigate whether the capability approach offers an alternative, valuable ethical framework to re-think the relationship between society and genetic research. The following sections follow my analysis first by outlining the ethical challenges that HGRDs raise. After briefly

presenting the factual background in which the ethical challenges arise (Section 3), I briefly analyze the autonomy-based ethical framework (Section 4) and the solidarity-based approach (Section 5). I then turn to the advantages of the capabilities approach as alternative ethical framework (Section 6). Finally, I present my conclusions (Section 7).

3. New Ethical Challenges?

Although all human beings are 99.9 percent identical in genetic makeup, each individual presents differences in the remaining 0.1 percent that makes her genetic patrimony unique. Such *genetic diversity shapes the possibilities of individuals to expand their capabilities in a unique way*. In fact, genes affect basic genotyping traits such height, skin color, ability to read and hear, to name a few. Moreover, genes play a role in developing monogenetic diseases (i.e. caused by single genes),[1] and complex diseases (i.e. caused by a combination of genetic factors and environmental factors.)[2] Indeed, genes may show an inherited tendency to develop a certain illness. Having a genetic risk does not mean that the carrier will develop a particular condition, but rather that she has a higher chance of developing it than if she did not have the risk.

Genetic information have peculiar traits: they are predictive of health conditions and diseases, are not specific to time, and are shared between blood relatives. Moreover, because of the rapid scientific and technological developments of genetic research, predicting how genetic information will be used in the ext future is highly speculative.

[1] Huntington's chorea and cystic fibrosis are two well-known examples of monogenetic diseases.
[2] Cardiovascular diseases, hypertension, diabetes, cancer, mental illness are examples of complex diseases.

Furthermore, although individuals are genetically unique, genes are inherited and transmitted across generations, albeit with variations. A common say is that we share our genes with our family. In fact, each family's history reflects the combination of shared genes, environment, behavior, and culture. Traits like curly hair, dimples, leanness and athletic ability are partly inherited. So are risks for health conditions like asthma, high blood pressure, diabetes, and heart disease. It follows that individuals share genetic traits that may affect their health, with their families. Thus, participants approach genetic research in a twofold way: on one hand, they donate a biological that contains a unique genotype; on the other hand, blood relatives, and to a lower degree, members of the same ethnic group, share some of the genetic information that the sample contains. Studying the genes of the members of a given population or group or "community" has an impact that community as a whole. Research results could ultimately point to treatment or prevention strategies that benefit many people in that community. Conversely, the results of genetic research may also cause stigmatization and discrimination for the same community.

Therefore, the participation in genetic research challenges the traditional *relationship between individuals and communities.* On one hand, HGDBs divide people in different "genetic" communities. Genetic research that draws on genetic databases often studies individual donors of biological samples as member of groups of people having different characteristics in common, i.e. family relationships, population membership, ethnic background, geographical presence, sexual traits, diagnosis of rare diseases, to name a few. DNA donors are thus potential members of different "genetic" communities depending on the characteristics to be researched. On the other hand, HGDBs need

communities to exist. Without participation of a substantial number of donors, HGDBs provide limited information to genetic researchers. Furthermore, participants will benefit from genetic research, either directly (through genetic counseling and pharmacogenomics) or indirectly (other family members or future generations may benefit).

The two-fold dimension of genetic, individual and collective, requires revisit concepts such as "informed consent" and "participants' right of withdrawal" of their consent. Moreover, new questions of privacy arise. Privacy may be defined as "the state where others do not have access to you and to information about you (Moore 2000: To what extent should HGRD be made secure enough to guarantee participants' privacy? Does society have a responsibility to avoid discriminatory effects (with regard to health insurance, employment etc.) and to what extent? Moreover, should access to repositories/databases be universal for all researchers or should some researchers have privileged access?

Furthermore, the notion of *benefits* of genetic research is related to the relationship between individual participants in the research and society. Nowadays, direct benefits to research participants in terms of health improvement remain largely hypothetical. The participation in today's genetic research projects, however, is likely to produce benefits to people other than the donors, more likely for future generations. HGRDs thus raise the issue of whether participants should be informed about the results of the genetic tests performed on their data and under which conditions should such a feedback take place. Furthermore, the same question extent to family members and other blood relatives who might share a great number of genes with the research participant. Therefore, should

family members be informed of related participants' test results that indicate risks for diseases?

Whether these facts make genetics information special has been debated at length in the literature. Those who argue that genetic information is special – the so called *genetic exceptionalism* argument – conclude that traditional medical ethics is inadequate to cope with the challenges that genetic research presents. HGRDs have also stirred a vigorous debate about whether the traditional bioethics approach is appropriate to cope with critical aspects such as the informed consent of research participants, the protection of their privacy, and benefit sharing.

4. The Traditional, Autonomy-Based Approach

The traditional ethical approach to genetic research is to apply the general principles of bioethics to the use of genetics in medical research and practice, thus emphasizing the individual and the patient-physician relationship. Thus, scholars' main focus is on participants in genetic research is influenced by the widely-accepted Kant's categorical imperative that human beings are ends and not means (Beauchamp 1996). In biomedical ethics, this categorical imperative acts as a ground rule to determine if human actions are good or bad, and shapes the classical principles of respect of autonomy, beneficence and justice (The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979). These principles provide the traditional ethical framework to deal with the issues raised by HGRDs.

Thus, to participate in genetic research is morally required that donors have information about the type of research that might be done on their samples and that the

fully-informed donors freely consent to the collection and storage of their tissue. (UNESCO 97) Moreover, donors are usually granted an absolute right to refuse consent, or to withdraw the same, once one has agreed to participate in research. Furthermore, confidentiality of the donors' identity and of any sensate information relating to them is morally required.

The collective or community aspects of genetic research come into place in dealing with public health dimension of HGRDs. A classical illustration is the discussion of whether HGRDs may favor health disparities among different demographic groups. Although partially addressed, the autonomy-based approach does not address many issues that involve the "collectivity." Thus informed consent is substantial, logical barrier to the use of biological samples gathered for one purpose for other purposes, such as epidemiologic research. Moreover, the public accessibility of genetic databases puts in substantial jeopardy the confidentiality of genetic information and its personal nature. (UNESCO 04, Art.13). Indeed, the UNESCO International Declaration on Human Genetic Data, Art.18, requires member states "to foster international medical and scientific cooperation and ensure fair access to this data" through mechanisms of cross-national circulation and international cooperation. Furthermore, "[t]he possibility of feedback . . . is clearly in tension with the preservation of anonymity, which is a safeguard against the potential harm arising from misuse of genetic information." (Chadwick and Berg 2001).

Theses few illustrations show how the autonomy-based approach fails to consider important aspects of genetic research. I now turn to an alternative framework as proposed by Chadwick and Berg.

5. An Alternative Approach: Solidarity and Equity

Ruth Chadwick and Kåre Berg have set forth an alternative ethical framework based on solidarity and equity (Chadwick & Berg 2001). While solidarity is intended as "participation in research for the benefit of others", equity stresses the importance of sharing the benefits of research fairly. The two scholars argue that "[i]t is not obvious . . . why a right to refuse to participate in genetic research, when it could be to the benefit of others, should be overriding." The logical conclusion is that "one has a *duty to facilitate* research progress and to provide knowledge that could be crucial to the health of others." (Chadwick & Berg 2001, emphasis added). Indeed, solidarity and equity better fit a factual reality in which benefits may substantiate only in future and more likely to the advantage of future generations.

Solidarity also affects the commercial exploitation of HGRDs and genetic research. In fact, because solidarity shapes the donors' participation in HGRDs, Chadwick & Berg argue that "the duty of those who are well off to share with the poor that is the central element in the moral duty of the pharmaceutical industry to share benefits — in the same way that responsible rich countries assist developing countries" (Chadwick & Berg 2001).

The solidity-based approach resonates in international guidance documents and declarations too. The UNESCO International Declaration on Human Genetic Data, Art.1, states the "equality, justice and solidarity" are guiding principles in conducting genetic research (UNESCO 03). Moreover, the WHO Report on Genetic Databases suggests that

> [I]t will be necessary to depart in certain cases from a strictly individualistic and atomistic approach, for it is an important feature of certain forms of genetic data that they also reveal information about the blood relatives of the person from whom the data were originally derived, as well as their ethnic communities. In this respect, an individualistic, autonomy-driven perspective does not assist in the resolution of the various claims or conflicts which might arise surrounding this information and its use. (WHO 2001)

Finally, the Human Genetics Commission sets forth a principle of genetic solidarity and altruism: "This sharing of our genetic constitution not only gives rise to opportunities to help others but it also highlights our common interest in the fruits of medically-based genetic research." (Human Genetics Commission 2002)

However, the solidarity-based approach presents critical aspects. First, it compresses the interests of individual participants in genetic research. The solidarity-approach creates a moral duty to participate in genetic research that is hard to combine with the notion that participants in genetic research are moral agents able to make moral judgments of their actions. Furthermore, the solidarity-approach substantially limits the ability of participants in genetic research to control the process in which they decide to take part (or have a duty to take part of, if with accept the premise that a moral duty to participate exists.) In fact, their right to refuse participation, and most importantly, to withdraw their consent along the process is curtailed. Furthermore, the idealistic albeit reasonable argument that the pharmaceutical industry has a moral duty to share its benefits based on the grounds that that those who are well off have a duty to share with the poor, is difficult to combine with the laws protecting intellectual property and, more generally, with the reality of capitalistic economies. Finally, the solidarity-based does not take in full account cultural diversity. People around the world have different sensibilities toward the use of human body for biomedical research.

6. The Capability Approach and Genetic Research

The autonomy-based framework and the solidarity-based approach have asymmetric strengths and weaknesses. Each approach is particularly well-suited to deal with the areas that the other approach fails to fully address. In the remains of the paper, I discuss whether the capability approach provides an ethical approach that balances the weaknesses and the strengths of the discussed ethical approaches.

I turn to the capability approach because it has already provided an important contribution to issues such as quality of life, gender inequality, welfare economics, well-being and human development. Sen includes health care as one of freedoms based on "social opportunities" that have an instrumental role in making positive freedom possible. Genetic research has the potential to develop individual health care treatments indeed. Thus, if we consider health and health care as "constituent component of development", genetic research is instrumental to human development (Sen 1999). In terms of policy goals, the capability approach construes "health policy as expansion of individuals' choices or opportunities for a healthy life, instead of judging health policy by health spending or defined benefits, important as these are." (Prah Ruger 2004). Thus, a person's capacity to function should be at the center of policy-making stage. Society is in fact morally obligated to attach importance to address and enhance physical capacity to function of its members by taking in consideration their physical attributes and predispositions.

Thus, the capability approach presents interesting concepts that are potentially valuable in perfecting the conceptual thinking of the ethical dimension of genetic research. Some of the features are the following elements:

- Health as "constituent component of development";
- The policy emphasis on *individuals*' choices or opportunities for a healthy life;
- Individuals are moral agents, and their freedom is essential in translating their capabilities into "functionings;"
- People's personal characteristics and physical characteristics are different, and so the capabilities that individuals may expand;
- The network of capabilities is inherently multidimensional, thus recognizing that health is the sum of multiples dimensions or metrics; and finally;
- Many "value judgments" are required and public debate is essential in shaping public policy.

This schematic catalogue of components of the capability approach points out that both the capability approach comprises both of individually-oriented components and more collective-oriented elements. On one hand, the capability approach recognizes human diversity, which is certainly intertwined with genetic diversity. Each individual's genetic patrimony *shapes the possibilities that that individual has to expand their capabilities in a unique way.* Furthermore, although individuals are genetically unique, genes are shared with the family and, to a lesser extent, with the community in which they live. Sen points out that "genetical propensities" influence health achievements. (Sen 2002) The capability approach thus provides a framework for balancing individual entitlements and

collective interests. On one hand, the capability approach recognizes individuals as moral agents who are unique in their capacity to perform different activities. Therefore, it leaves open the door to the autonomous decision whether to participate or not in genetic research. The capability approach also frames the benefits of genetic research as tailored on individual with different physical attributes. On the other hand, the capability approach shifts the focus of the moral action from the individual to society. Each community makes value judgments of the priorities in genetic research through its democratic deliberative process. It is also important to outline who Amartya Sen's writings show that the democratic process is not a uniquely Western trait, but that it democracy belongs to many political traditions around the world (Sen 03).

Indeed, the public debate that shapes public policy enables research participants to participate in the "value judgments" that might affect her or her "community." The capability approach fits particularly well genetic research in developing countries where each community has different "needs" with regard to the expansion of the capabilities of its members. Individuals will participate directly or indirectly in the process of choosing the possible material benefits that their participation in a specific genetic project entails for their communities.

7. Conclusion

In this paper I analyzed the ethical framework to address the issues raised by genetic research and HGRDs. My preliminary conclusion is that the capability approach offers a viable framework to address the critical issues left open by the autonomy-based approach and the solidarity-based approach. Its focus on freedom, capabilities and diversity, the

shift of the policy focus from individuals to society, and the crucial role of the deliberative process in assessing the policy priorities are concepts that can help us rethink the basic ethical premises of genetic research. The challenge ahead is to refine the theoretical thinking and to find practical ways to operationalize the capability approach in genetic research.

References:

The Advisory Committee on Health Research (ACHR) (2002) *Genomics and World Health*. World Health Organization: Geneva

Beauchamp, T.J. (1996). Moral foundations. In. S. S. Coughlin, & T. L. Beauchamp (Eds.), *Ethics and epidemiology*. New York: Oxford University Press

Chadwick, Ruth and Berg, Kåre (2001) "Solidarity and equity: new ethical frameworks for genetic databases", in *Nature Reviews Genetics*, Vol.2: 318-21

Collins, Francis S., Eric D. Green, Alan E. Guttmacher & Mark S. Guyer (2003). "A Vision for the Future of Genomics Research", in *Nature*, Vol.422: 835-47

Gannett, Lisa (2004) "The Biological Reification of Race" in *British Journal Philosophy Science*, Vol.55: 323-45

Human Genetics Commission (2002) *Inside Information: balancing interests in the use of personal genetic data*, available at http://www.hgc.gov.uk/insideinformation/

Moore, Adam D. (2000) "Owning Genetic Information and Gene Enhancement Techniques: Why Privacy and Property Rights May Undermine Social Control of the Human Genome" in *Bioethics*, Vol.14: 97

The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (1979) *The Belmont report: Ethical and guidelines for the protection of human subjects of research.* Washington DC: Department of Health, Education and Welfare.

Nussbaum, M. (2000) *Women and Human Development.* Cambridge: Cambridge University Press

—— (1999) *Sex and Social Justice*. Oxford: Oxford University Press

Prah Ruger, Jennifer (2004) "Combating HIV/AIDS in developing countries", in *British Medical Journal*, Vol.329: 121-22

Sen, Amartya K. (2003), "Why democratization is not the same as westernization?" in *New Republic Online*, at http://www.tnr.com/doc.mhtml?i=20031006&s=sen100603

—— (2002), "Why health equity?" in *Health Economics*, Vol.11: 659-66

—— (1999) *Development as Freedom*. Oxford: Oxford University Press

—— (1995) "Maximization and the Act of Choice" *in* Sen, Amartya K. *Rationality and Freedom*. Cambridge: Harvard University Press

—— (1992) *Inequality Re-examined.* Cambridge: Harvard University Press

—— (1985a) *Commodities and Capabilities.* Amsterdam: New Holland

—— (1985b) "Well-Being, Agency and Freedom: the Dewey Lectures, 1984", in *Journal of Philosophy,* Vol.82 (4): 169-221

UNESCO (1997) *Universal Declaration on the Human Genome and Human Rights available at* http://www.unesco.org/shs/human_rights/hrbc.htm

UNESCO (2003) *International Declaration on Human Genetic Data, available at* http://portal.unesco.org/en/ev.php-URL_ID=17720&URL_DO=DO_TOPIC&URL_SECTION=201.html

World Health Organization Regional Office for Europe (2001) *Genetic Databases: Assessing the benefits and the impact on human & patient rights. Report for Consultation*. World Health Organization: Geneva