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Human Genetic Research: Emerging Trends in Ethics

Genetic research has moved from Mendelian genetics to sequence maps to the study of natural human genetic variation at the level of the genome. This past decade of discovery has been accompanied by a shift in emphasis towards the ethical principles of reciprocity, mutuality, solidarity, citizenry and universality.

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In 1994, we were a long way off from the resources that we take for granted today, such as the human genome sequence or an almost complete HapMap. Autonomy, privacy, justice, quality and equity were the norms that framed human genetic research internationally (1). Although they are still prominent today, we now posit that the understanding of the complexity of genetic factors in common diseases and of the familial and socio-economic impact of genetic information and genetic tests, together with the concomitant expansion of public participation in policy making, have given rise to new trends in ethics.

For example, the increase in interest in population-based genetic research has led to calls for rethinking the paramount position of the individual in ethics. The WHO's (World Health Organization) report on genetic databases states: "The justification for a database is more likely to be grounded in communal value, and less on individual gain … it leads to the question whether the individual can remain of paramount importance in this context (2)."

We identify the new trends in ethics as reciprocity, mutuality, solidarity, citizenry and universality. Although they do not represent totally new ways of thinking in ethics, as they can be traced back to long-standing traditions of thought, they symbolize not only a move away from autonomy as the ultimate arbiter, at least in the bioethics of the developed world, but also an appreciation of the need for a participatory approach. Genetic research is forcing a public and therefore a political examination of personal and social values, and of the site of their expression.

The ways in which the ethical debate developed in the last decade of the twentieth century was, we suggest, twofold. First, there was a shift in the prominence of particular issues, although most of the issues continue to be debated. At the beginning of the 1990s, the ethical discussion largely focused on the impact of the *Human Genome Diversity Project* on clinical genetics; for example, genetic counselling (3–5), genetic testing and screening (6, 7), genetic discrimination (8) and the prospects for gene therapy (9–11). Second, as time wore on, the focus widened to include genetic enhancement, genetic essentialism and associated ethical issues—and with the birth of Dolly, the revival of cloning (12, 13). By the time the pending completion of the first draft of the human genome was announced in June 2000, the hot topics were preimplantation genetic diagnosis, commercialization (14, 15), patenting (16), DNA banking (including that of whole populations (17, 18)) and pharmacogenetics (19, 20).

There have also been changes in the way that "ethics" is understood. On the one hand, public anxieties—associated particularly with genetically modified (GM) food (21)—have led to growing demands for the recognition of public ethical concerns and to concerns that human genetic research might suffer from the apparent loss of trust in science. On the other hand, predictions of new models in health care (22), in the form of a shift to predictive medicine and targeted therapies—made possible by pharmacogenetic profiling and genetically informed prescribing (23, 24)—have led to queries about the applicability of existing ethical guidelines (25). Increasingly, ethics has moved to centre stage in public policy as concerns such as those mentioned above have been acknowledged. These wider contextual factors help to explain the shifts that we identify here. We aim to show how these shifts are framing the current discussion of issues without totally replacing the ethical norms of

the 1990s (Ref. 1). Indeed, those norms have remained important and continue to be subject to interpretation and reinterpretation.

Before we proceed, we consider one caveat. Debates about ethics and human genetics are a global phenomenon and take place in the context of different world views. In addition to the trends that we identify here, there is work on dignity (26), on virtue ethics (27) and feminist ethics (28), to give just a few examples, which we do not discuss specifically, but which we do not believe are at odds with the thesis concerning the shifts that we identify.

RECIPROCITY

Although the physician–patient relationship has greatly profited from the implementation of an expanded notion of informed consent that is based on respect for individuals (autonomy), the more recent trend towards informed choice has found its fullest expression in human genetic research (29–31). It is here that the notion of exchange, of reciprocity—that is, recognition of the participation and contribution of the research participant—has been further refined.

In the absence of legislation on access, the clinical researcher now offers increased security of data and the option for research participants to take part in a specific project, to bank DNA, to be coded or anonymized, to allow cell lines to be made, to allow access to others and to participate in future research (32). This trend towards reciprocity not only recognizes autonomy but also respects the personal and cultural values of the individual participant. It goes without saying that multi-site and international genetic studies tend to either limit and standardize these choices or simply to notify prospective participants of the options already chosen in a given protocol (33, 34). But if the information provided is clear as to the objectives, procedures and future uses, including the possibility of commercialization, the high level of communication and transparency required by the principle of reciprocity can be respected.

A more recent extension of reciprocity expands the concept from exchange with the individual or his/her family to the community or population. Where genetic research extends to homogeneous (35) or isolated populations, to sub-populations for the study of candidate genes, or even to whole countries with heterogeneous populations for the study of genetic variation, prior consultation and communication with these specific communities and populations are emerging as ethical prerequisites (36–39). Biobanking studies of genetic variation (genotyping) often use only anonymized or double-coded samples if phenotype–genotype longitudinal analysis is done. These studies offer no immediate personal benefits (40). Much groundwork is required to explain to the public the goals of this genotyping research that is focused on genetic or genomic variation, research that is distinct from traditional "gene hunting" in identified, at-risk populations (phenotyping).

MUTUALITY

The classical quandary in genetic research and testing has been the case of non-paternity. Increasingly, however, attention is turning to the issue of sharing genetic information with other family members. First proposed in 1982 by the US President's Commission (41), the idea of an ethical (distinct from a legal) duty to warn at-risk family members is emerging (42). This potential breach of medical secrecy is circumscribed by the following factors: the family member must be identifiable and at high risk for a serious condition that is preventable or treatable (43).

Similarly, there is the approach that views the family as a distinct social unit. It implies that DNA and the information it contains is family property. This position is often found in guidelines that provide for access to be granted to family members to the DNA or genetic information of another family member for their own needs, even after the death of the person (44). It is justified by the familial nature of genetic information and therefore by the need for mutuality or sharing within families, rather than discretionary physician control over access.

Interestingly, the concept of mutuality has long been a cornerstone of the insurance industry. Regarded as a form of pooling and of spreading all known risks, it is being challenged by the arrival of predictive genetic tests. Although the industry does not require such tests to confer insurability, it has been prevented from accessing such tests through prohibitive statutory approaches specific to insurance, voluntary moratoria with governments or anti-discrimination legislation, or by a therapeutic approach whereby no genetic testing is allowed unless for health purposes (45). Accepted underwriting principles are being challenged during the wait for more scientifically sound, and therefore actuarially fair practices. It remains to be seen whether insurance applicants will wish to avail themselves of genetic data that acts in their favour.

SOLIDARITY

The increasing prominence of solidarity in the ethical debate might be seen as one aspect of a

"communitarian turn" in ethics (46), moving away from the paramount position of individualism and autonomy. It is important to recognize, however, that the "individual choice model did not always prevail in ethical genetics but might itself be seen as a reaction against the eugenic rhetoric and practices of the early parts of the twentieth century. Arguably, the fear of eugenics still influences debates in the present day (47). However, today the challenge to the primacy of the choice model tends to be framed not in the language of eugenics, but in terms of responsibility and solidarity.

Solidarity has entered the discussion about ethics in numerous debates that surround the right to know or not to know, insurance and human genetic databases. In the case of the right to know or not to know debate, the issue is whether individuals have a responsibility to know their genetic make-up to then make responsible decisions (for example, whether to have a predictive test, or for making reproductive decisions (48,49)). Some bioethicists believe that this is the case and that the basis of this is a kind of solidarity (50) that can be expressed as a willingness to share information for the benefit of others, rather than an autonomy-based argument for a right to know in order to promote one's own interests. Pertinent questions are: who are the relevant others? Are they only blood relatives or also partners? What about future generations?

These questions alert us to different meanings of solidarity. A distinction has been made between communal solidarity and constitutive solidarity (51). Communal solidarity is that practised by a group of people having a common interest, whereas constitutive solidarity is that practised by a group of people having an interest in common. For example, all people have a common interest in having clean drinking water. This arises from facts about human nature. Other examples of common interest might arise from the nature of particular kinds of activity. For example, members of a professional group that carry out a specific activity might have a common interest arising out of the nature of that activity and in things that relate to it. However, members of certain groups that cannot be defined by any common interest arising from the nature of the human condition or sphere of activity might nevertheless happen to have interests in common, which lead them to decide to form groups to protect such interests. In the former, the common interest can be defined by the perception of a bond between individuals that forms the grounding of a moral responsibility to each other; for example the perception of shared vulnerabilities, as in humanist solidarity. In the case of constitutive solidarity, individuals that have an interest in common realize the mutual advantage of getting together to create a group towards which individuals can be expected to show solidarity, and this will depend on which sense of solidarity is at stake.

The different interpretations show up starkly in the continuing debates about the relevance of genetic information to the insurance industry (52).We have already demonstrated the relevance of mutuality in this context: an appeal to solidarity can also be made by both sides in the debate, in more than one sense. It is sometimes argued that the whole basis of the insurance industry is solidarity and that genetic information should therefore not be used to discriminate. In this argument, the type of solidarity that is appealed to is communal (moral) solidarity. In other words, because of shared human vulnerabilities, people have a common interest, giving rise to moral responsibilities to each other to contribute to a protection scheme through insurance. On the other hand, it is argued that it is a situation not of shared moral responsibility but the pursuit of advantage: individuals have an interest in common and get together to protect it through joining an insurance scheme (constitutive solidarity). From this perspective, however, the complementary principle of equity is taken to imply that the contribution of individuals should be in line with their known level of risk.

In the case of human genetic databases, it could also be argued that what is at stake is constitutive solidarity (53). In so far as it can be argued that the establishment of human genetic databases is a means towards the provision of more effective therapies, individuals might perceive that they have an interest in common, namely better health care, and they might collectively choose to get together to create a genetic database for the public good (54). Some have argued that the metaphor of the gift relationship (55) is applicable in the context of human genetic databases (56). However, the individualistic approach to databases persists, as can be seen in the continuing debate not only about informed consent, but also about access to feedback on findings that relate to individual samples (57–59).

CITIZENRY

We consider that the principle of citizenry has become prominent in the past decade, along with the voicing of public concerns mentioned above.

First, there were programmes to facilitate public understanding of science (60). They arose out of a perception that genetics was not only poorly understood but was also difficult to understand—the "deficit model" of public understanding. The

model was challenged from at least two directions: from research that demonstrated the extent of knowledge in this area among the general public (61), and from the realization that information might not be sufficient if it is not provided in context (62). What counts as "public understanding" itself became a topic of study (47, 63), leading to thinking in terms of public "consultation," "engagement" or "involvement." The aim of informing the public, or different "publics," has led to the recognition of the need to listen to the public and the search for methodologies of public consultation, including focus groups and citizens' juries (64), as well as large-scale public surveys such as *Eurobarometer* (65). Following the discussion about the Icelandic population database (66–69), the implementation of processes that respect the need for public consultation and debate has come to prominence, particularly in relation to population databases (70) such as the proposed *UK Biobank* (71) and the *Quebec CARTaGENE project* (36). It should be noted however, that the legislated presumed consent of Icelandic citizens under the Health Sector Database Act was declared unconstitutional by the Icelandic supreme court in November 2003.

These developments have been accompanied by two other phenomena. First, the influence of social sciences on ethics has become more evident, adding to the expertise of other disciplines such as philosophy, theology and law (72). Work of this kind has included research on attitudes to developments in the life sciences, including xenotransplantation and genetic modification. Second, there has been a reinterpretation of the concept of "expertise" in genetic ethics, arising out of the sense of disquiet about isolated scientific expertise. Advisory committees have not only grown in number, but have also changed in character towards greater and more explicit incorporation of ethics in their terms of reference; for example, the *National Bioethics Advisory Commission* during the Clinton administration and the *President's Council on Ethics* under President Bush in the United States, and the *Human Genetics Commission* in the United Kingdom.

Another aspect of the principle of citizenry concerns collective identity. The link between genetic heritage and collective identity is important from an ethical point of view. It might involve how particular population groups—for example, Icelanders—become characterized in relation to population genetics research. This has been a point of concern in connection with the *Human Genome Diversity Project* (73), and now with the *International HapMap Project* (74)—how specific disease groups think of themselves as sharing an identity; how disability-rights activists might construe a common identity (75) or at least a point of view (76, 77).

The issue of the definition of disability is controversial: one definition makes functional limitation an essential feature; another defines it in terms of social justice (78) (it is social arrangements that determine the extent to which people are disabled). It might be appropriate to acknowledge that disability involves a complex mixture of functional and social factors. Disability can be equated with disadvantage if either functional limitations or social structures are the main factors producing the disadvantage. The expressivist objection to genetic interventions maintains that such interventions "express" intolerance of disability, and therefore contribute to social factors; but opinions vary, and indeed some thinkers who write from a disability perspective support an individual-choice model.

Universality

The claim that the moral point of view is, by definition, universal in scope has a long history, but it has taken a new twist in the context of genomics. Current ethical rhetoric emphasizes universality on the basis of the characterization of the genome itself (rather than, for example, shared human vulnerabilities) as a shared resource. Even in the absence of the current debate surrounding the globalization of markets, the human genome is said to be, in the collective sense, shared by all. This understanding of the human genome at the level of the species has led to the specific emergence of the principle of universality in relation to the genome. Often expressed as the common heritage of humanity (79) and justifying obligations to future generations, it highlights and reinforces the approach of benefit-sharing (80, 81) (also grounded in equity) and of genomic knowledge as beneficial to the public (82).

An example of the application of benefit-sharing is the idea of recognizing the contribution of participating communities, disease groups and populations through technology transfer, the sharing of profits from patents or the provision of humanitarian aid. Another example of universality is the idea of global public goods, demonstrated by the creation of international, publicly accessible genomic databases (81).

Universality also underpins the current work of UNESCO (United Nations Educational, Scientific and Cultural Organization) on a universal instrument on bioethics. Its international bioethics committee has been given responsibility for the elaboration of this non-binding instrument. It will focus on the fundamental principles of bioethics,"in ac-

cordance with international human-rights law and taking into account cultural diversity" (83). Paradoxically, this respect for cultural diversity might hamper the achievement of such a goal, so the Director General of UNESCO, although recognizing that such an instrument could only be declaratory in nature, has stated that "Practices and experiences point to the need for people of all nationalities and their governments to look beyond their borders in understanding the bioethical issues that are being generated and in providing solutions that are fair to all and compatible with the plurality of values and interests of the international community (84)."

CONCLUSION

We have attempted to demonstrate the most prominent emerging trends in ethics — reciprocity, mutuality, solidarity, citizenry and universality. Ethics does not consist of a static set of theories or principles that can unproblematically be "applied" to new situations. Indeed, there have been calls for a new pragmatism in bioethics (85). However, we do not take the view that pragmatism is at odds with principles. On the contrary, what we have identified is the tendency for ethical norms to change, and for different principles to be the focus at different times. The ones that we have identified here have not replaced those of a decade ago (1), which have themselves been subject to reinterpretation in the past decade.

For example, during the 1990s, autonomy was (arguably) increasingly used to denote self-definition rather than self-determination (86). Self-definition might mean choosing not to be defined in terms of one's genes—a factor that has been particularly prominent in disability-rights perspectives (87). In general, however, self-definition represents a resistance to scientific and professional reductionism, which might be an aspect of the phenomenon known as "geneticization" (88). This point also relates to the discussion of citizenry, in the context of collective identity.

In 1994, equity was discussed in terms of equity of access. Access to genetic services that are currently in place remains a live issue. Today, however, the relationship between equity and commercialization issues is perhaps even more controversial, and one that has been discussed by the HUGO Ethics Committee in its statement on benefit sharing (81). Issues of equity, however, are also relevant to the debate about the principle of citizenry. Although the importance of engaging the public is now widely accepted, as described above, there are problems in involving those groups who have experienced health inequalities, and who might feel alienated from expressing an opinion if it seems unlikely that they will share in the benefits of the genetic "revolution." This is a matter that needs to be addressed in programmes of public engagement.

Quality, privacy and justice continue to be invoked— quality control of genetic tests has become more complicated with the advent of long-term storage of genetic information, direct-to-consumer advertising on the internet and the prospects of new forms of health care such as pharmacogenetics. An incorrect result in genetic or pharmacogenetic profiling might affect an individual's health care in the long term.

The application of justice is particularly complex. Although distributive justice has been concerned with the criteria for distribution of goods, it could be argued that the "new genetics" has brought to prominence questions about how theories of justice dictate who is included in the distribution; for example, the question of who is disabled (44).

Issues of privacy have become entangled with bioinformatics as, increasingly, we rely on technology rather than on human beings to resolve our privacy issues. Will individuals be better protected by greater privacy rights or by moves towards greater solidarity (89)?

Ethical thinking will inevitably continue to evolve as the science does. The principles that we have outlined provide a framework for addressing ethical issues, and also provide the basis for a comparative approach in analysing both cultural differences and the prospects for harmonization in the context of globalization. There might not, and cannot, be universal norms in bioethics, as emerging ethical norms are as "epigenetic" as the science they circumscribe.

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