7 Ethical Considerations for a Genetic Future in Diagnosis and Drug Development

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7.1 INTRODUCTION

With the availability of the full human genome sequence, the genome sequences of other species, and rapid progress in the development of technologies with which to analyze and apply genetic insights and discoveries, a dominant future for genetic intervention and individual gene profiling in medicine is certain. This book has examined some exciting scientific developments and insights that will contribute to the gene profiling of patients, and the application of genetic knowledge to new drug designs. However, while such scientific progress provides potential solutions to health problems (i.e., more accurate diagnosis of disease and drugs of enhanced efficacy), there are also potential new problems created because of the accuracy and power of gene-based technologies, such as those described in this volume. These additional challenges apply outside of the cellular, molecular, and biochemical details of the genetic revolution, to the impact of this science on individuals and on their societies. Therefore, while accepting the scientific benefits of a given scientific discovery and its subsequent application to human health, it is essential that bioethical perspectives also be captured as part of the incorporation of genetic technologies into the standard practice of health and medicine. Decisions must be made on the application of new genetic technologies, and bioethics provides an intellectual platform from which to make these decisions.

Bioethics is a relatively recent phenomenon in health, arising from the much older disciplines of philosophy and medical ethics. Its aim is to come to a greater understanding about complex issues and to address profound philosophical questions such as what it means to be human [1]. This chapter provides an overview of some of these important considerations, with specific reference to gene profiling and associated drug design. The chapter does not purport to be a definitive analysis of bioethics relative to advances in gene technology and science. Rather, it is more a flavor of the topic to stimulate thought and to provide guidance to scientists beginning their ethical inquiry into the implications of their work in genetics and gene technology.

7.2 BECAUSE WE CAN, WE SHOULD...?

Any scientific breakthrough or technological advance brings with it the capacity to perform tasks that were not previously possible without the new technology, or with an earlier superseded version of the technology. The instinct to benefit by taking advantage of such advances is understandable, but should always be prefaced by the "because we can, we should...?" consideration. This question forces the broader contemplation of what is now possible to achieve technically in terms of the wider impact on individuals or society and an assessment of whether or not the technical possibilities should indeed be acted upon, and to what end. With the advance of science and subsequent technologies that emanate from basic discoveries, we now have the burden of boundless choice concerning treatment and diagnoses, and the need to make challenging decisions about how to implement the technologies. This burden, and the exciting possibilities new technologies open up, is an example of a classic philosophical analysis along the lines of identifying and justifying the means and the end [2].

With such ever-expanding choice comes growing complexity, and with this complexity comes the need for a framework to think through, in a careful and considered way, what might be the implications of the technology, not only for the individual concerned but for society as a whole. For example, who is best placed to make the decisions and what weight should be given to individual decision makers? Also, who decides which decisions are valid, and using what criteria? Should the decisions of the individual concerned be paramount, or are those of the family to take precedence? On the other hand, is it best to defer to "experts," such as medical and legal professionals and/or bioethical experts? To what extent should legislation be developed and

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enforced to facilitate (desired) behaviors that allegedly benefit the wider society? At heart, these are all ethical issues, and bioethics provides a framework with which to approach the increasing complexity resulting from technological and scientific advances. In this sense, bioethics is a great deal more than the submission of a form for clearance by a research ethics committee, notwithstanding the importance of obtaining that kind of approval prior to a research project or clinical trial.

7.3 APPLIED ETHICS

The use of bioethical approaches as a means of making decisions in the face of complexity and uncertainty, especially in health care, has come to be called applied ethics. As its name suggests, applied ethics attempts to apply philosophical interpretations about ethics to practical professional problems and issues [3–5].

For a professional, the aim of applied ethics is to decide on appropriate moral actions in given situations via the application of ethical principles and theories. This process is also known as normative or action-guiding ethics [5]. The decision-making processes take into account the legitimate moral claims of all those involved in the particular circumstance/s as well as providing justifications for the decisions themselves in order to demonstrate that the decisions extend beyond mere self-interest or preference. Individuals can make these kinds of ethical decisions on their own behalf and act on them alone, for instance, the actions of a scientist in his or her normal day-to-day work. Alternatively, decisions can be made by groups and acted upon by the individuals in the groups, for instance, the actions of a research team in a clinical trial. The decisions made can directly affect individuals in single circumstances, or they may be generalized to larger groups, and to society as a whole.

Society's ethical expectations of particular professional groups may be developed by that profession, and in that case are typically explicated in professional codes of ethics and of conduct [6]. Alternatively, they may be developed and published by governments, for example, the Australian National Health and Medical Research Council's *Australian Code for the Responsible Conduct of Research* [7].

7.3.1 Morals and Ethics

Broad consideration of the meaning and background to the philosophical constructs of ethics and morals is pertinent at this point. The two words have their lexical origins in ancient Greek and Latin, respectively, and most philosophers do not distinguish between them [5]. In popular parlance, however, they are sometimes distinguished as ethics being the ideals we aspire to and morals as being the minimum standards of professional behavior and attitude [6]. To put it even more simply, morals can be seen as the actions and ethics as the theory that informs the actions. In this chapter the two words are used interchangeably.

7.3.2 Bioethical Principles and Applied Ethics

In the Western philosophical tradition, there are many different approaches to bioethics and applied ethics, including feminist epistemology and philosophy [3–5, 8]. Perhaps the most influential of them, however, are the bioethical principles articulated by the authors Beauchamp and Childress in their seminal text, first published in 1979, *Principles of Biomedical Ethics* [9]. The principles include autonomy, beneficence, nonmaleficence, and justice, and they have been enthusiastically embraced and applied by all kinds of professional groups in health care and beyond [5], although the approach is not without its critics [10–12].

The application of these principles is meant to encourage and facilitate critical and careful thinking in order to reach reasoned and justifiable conclusions about actions that can be defended while, at the same time, being practical in their outcomes. The defense is usually in the form of rational arguments and often includes evidence-based science, either in the actual decision-making process or in the justification itself. Since all health care is directed to benefits rather than harms, a justification for an ethical action is always required, although the actual form and content of that justification may vary. Robust justifications are required so that the community can be confident that ethical decisions will be more likely than not to promote best interests rather than simply serve an individual whim, preference, or prejudice.

7.3.3 Autonomy, Beneficence, and Nonmaleficence

Autonomy, beneficence, and nonmaleficence are perhaps the most significant of the principles, since they are at the heart of important concepts in the Western world, namely, the notion of reciprocal rights and duties. Rights are generally thought of as applying to an individual, and where they apply, others have a duty to act to respect and facilitate those rights. Rights may also be accorded to collectives or groups, e.g., as in consumer rights, and once again others have duties to fulfill to honor and respect those rights [9]. When rights clash with duties, as they so often do in a health-care system delivered in a society characterized by ethical pluralism [10], then a classical ethical dilemma arises. It may even be the case that what is to constitute a right, and whether or not a duty is then owed, constitutes the nature of the dilemma itself, e.g., as may occur in randomized controlled trials [13]. There is a vast literature on these kinds of topics in health care, and chapters 1 and 2 of the Beauchamp and Childress text [9] and chapters 3 and 4 of the Preston text [5] are recommended as beginning references for the articulation of moral norms and principles, ideal virtues and moral excellence, and the application of ethical theories in responsible decision making in the context of professional life.

We turn now to a brief description of the salient features of the three principles.

7.3.3.1 Autonomy

Autonomy concerns the right of a person to make, and to then act on, decisions they make about themselves and their bodies. Its essential feature is self-determination and the exercise of free will, not in a capricious sense, but in a sense where one's values, expressed as choices, show a degree of consistency over time [3, 4, 9]. So, for example, a person may make a decision to accept or decline certain treatment, based on what that individual judges to be in his or her best interests. An example is when a person makes decisions about treatments in order to follow the dictates of his or her religious faith [5, 10]. Ideally, autonomous decisions are freely made, are based on adequate information provided in a form that can be readily understood by the

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When others act on these kinds of considered and autonomous decisions, then they are said to be acting out of respect for autonomy [9]. In so doing, they are fulfilling a duty to protect the rights of individuals to decide what will or will not happen to them, physically and psychologically. That right is protected in law through the legal principle of informed consent [14, 15], although autonomy and informed consent, in the context of genetic testing, has its own set of problems, for example, confidentiality [16].

7.3.3.2 Beneficence

Beneficence is essentially concerned with benefiting, i.e., with acting so that the actions of one person result in an overall balance of benefits to others while at the same time not resulting in undue harm to the individual. Beauchamp and Childress [9] have developed conditions that they regard as necessary to fulfill to determine when, and if, one person owes another an obligation to benefit [9, pp. 170–176]. Of course a health-care professional may experience a dilemma when he or she can foresee that respecting autonomy is likely to result in harm for that person. These dilemmas are generally discussed in terms of paternalism [3, 4, 9], and they can be extremely complex, especially in genetics [16].

7.3.3.3 Nonmaleficence

Nonmaleficence is a closely related principle, since it concerns benefiting (or doing good) through refraining from doing some harmful action. It is often expressed in the form of the maxim, "Above all, do no harm" [9]. When harm to another can reasonably be foreseen, and that harm can be prevented by someone not doing something, e.g., not giving a drug that would constitute an overdose, then there is an obligation to act to benefit, or to do good. The legal principle pertaining to both beneficence and nonmaleficence is negligence [14]. Once again, conflicts between acting to benefit rather than causing harm can create dilemmas, e.g., whether or not the professional should offer his or her specialist knowledge to enhance autonomous decision making, especially if the provision of that information is likely to make a difficult decision-making process even more onerous for the individual concerned.

7.3.3.4 Ethical Dilemmas

An ethical dilemma occurs when we are faced with making a decision where the options available do not clearly indicate that one action has more benefits than another. In other words, there are moral imperatives or duties to act, and in respecting one, we can't at the same time respect the other. On the other hand, if it is clear that one action has more benefits than another, then it is likely to be a clinical practice situation with complex ethical dimensions, rather than a dilemma. It needs to be remembered that refraining from taking an action can be the action; namely, not to act can have as much moral weight as acting (the nonmaleficence principle).

Essentially, then, a dilemma occurs when we know that whatever action we take, there will be both benefits and harms: a "damned if you do and damned if you don't" circumstance. For examples of dilemmas, refer to the *Dax Cowart* case in Widdershoven [11] and the variety of cases discussed in Beauchamp and Childress [9].

In health care, we are aiming for overall benefits, not harms, and where we can reasonably foresee harms arising, then we are obliged to fulfill a duty to strive to limit those harms and maximize the benefits. Where we cannot do both simultaneously, or where we anticipate that more harms are likely whatever the course of action we take, then we probably have an ethical dilemma. It is often the case too that a "gut reaction" about something being "bad" or "wrong" can indicate that an ethical dilemma has arisen, a situation where we need to think through, in a careful and considered fashion, what course of action is the ethical one, and what is the justification for that decision.

The application of ethical principles and the associated process of thinking through the options (the normative-ethics approach noted earlier) not only bring to prominence the essential nature of the situation, they also lead to more robust and defensible decision making. It is at this thinking-through stage that objective evidence may be called upon, for example, to clarify the clinical circumstances of the case. Professional codes of ethics and of conduct, as well as legal principles, may also be drawn upon as part of the decision-making process. When none of these avenues, clearly and unequivocally, indicates the direction to take, then there is an ethical dilemma. In that case, the application of ethical principles (and theories [5]) will bring the most clarity and provide the best guidance in what are frequently emotionally charged and troubling circumstances.

The above description of the decision-making processes involved in an ethical dilemma can sound overly tedious and unnecessary. Professional life is full of ethics, though, and we "do" ethics all the time, even when we are not consciously aware of it. Thinking through each situation in the manner described, either as an intellectual classroom exercise or in the real world of clinical practice, enables the practitioner to not only reach a decision, but to also build up a repertoire of ethical skills that can be drawn upon in subsequent and similar scenarios. In this respect, developing ethical expertise is not dissimilar to building up skills and expertise in a professional discipline. As the Canadian bioethicist and lawyer Margaret Somerville notes, "doing" ethics takes time [17], and it cannot be applied like a "cookie cutter" to any one situation [18]. That is not to say that we "waste" time deliberating while the patient suffers. It is rather that, once developed, then already-learned ethical skills and expertise can be drawn upon when a rapid and robust, yet fully defensible, ethical decision is required. A mentor is an invaluable asset in building up an ethical repertoire, and all readers are encouraged to find their own mentor to further develop this aspect of their professional lives.

7.4 BIOETHICAL PRINCIPLES AND THE NEW GENETICS

To illustrate these issues in the context of "gene profiling in drug design," the following future hypothetical dilemma is suggested, followed by questions that may be asked around this dilemma when applying the three ethical principles being discussed.

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A patient from a family with a history of Huntington's disease (HD) is genetically screened for the HD disease gene, located on chromosome 4. With HD causing neurological dysfunction in middle age, the genetic screening also includes specific genetic markers for other brain proteins associated with the HD phenotype. The results come back as negative for the HD allele, but a genetic defect was detected for another key brain protein that will possibly lead to disease within the next five years. While the patient will be told about the expected HD result, should the patient also be informed about the other mutation of likely health consequence?

This hypothetical scenario presents us with a situation where genetic technology has advanced to allow the detection of new gene mutations that were not previously tested, thus creating an ethical dilemma. Normally the patient would have been oblivious to the presence or consequence of this gene and its biological function. Importantly, having the mutated gene may not necessarily lead to a disease phenotype (whereas with a purely genetic disease like HD, an autosomal dominant disorder, an adverse health outcome, is definite). In other words, the new genetic results do not unequivocally indicate that the patient will inevitably progress to a certain disease outcome, as they will with HD. Therefore, we have the ethical dilemma of whether or not to inform the patient of these wider genetic findings as revealed by laboratory testing, i.e., the dilemma between the patient's right to know, or to not know [19], information that may have a significant bearing on the patient's ability to make autonomous decisions about his or her own body. This is a classic tussle between benefiting by providing information in order to facilitate autonomy (a right to know versus a duty to inform), or not providing information in order to prevent harm (a duty not to harm [nonmaleficence] versus a right to make a fully informed autonomous decision).

This dilemma is compounded by questions such as: Do we also have a duty to inform the patient's family, employer, and life insurance company of the findings? If the answer is "yes" for any of these choices, what are the moral reasons for that decision? A further ethically based question is, to what extent do we need to involve the patient in that decision-making process, and for what moral reasons?

Applying the ethical principles of autonomy, beneficence, and nonmaleficence to the above gene-profiling dilemma illustrates the positive role for bioethics in the challenges presented by advances in human genetics. Rather than launching into a comprehensive analysis of the complexities of this situation from the perspectives of all those involved, or providing a detailed exploration of the ethical (and other) ramifications of all the available options, we pose some key questions to address around each principle and suggest how each principle may assist in the necessary ethical deliberations. The readers are invited to reflect on the questions we pose, to add others they consider relevant, and to then reflect on what they would do in this hypothetical scenario, and for what moral reasons.

For the purposes of this exercise, we have assumed the following: that the patient is fully competent to make decisions in both a legal and a clinical sense; that the patient has made autonomous decisions in a noncoercive context, including the decision to have the test in the first place; that there are no reasonable barriers to giving the patient the information, legal or otherwise; and that the laboratory is fully competent in the testing procedures, supported by the appropriate quality control measures, so we can be confident of the veracity of the results.

As an aside, this hypothetical scenario also illustrates the multidisciplinary nature of bioethics, e.g., the roles of lawyers, medical scientists, cultural experts, and genetic counselors. If, in time, this hypothetical scenario became reality, then the expertise of genetic counselors would be called upon, for example, in a formal counseling session with the person (and the person's family). In any case, the ethical principles they would use and apply in assisting the careful thinking-through process will most likely be those we have identified.

We turn now to the considerations to be taken into account in the application of autonomy, beneficence, and nonmaleficence to the above hypothetical scenario. Identify the exact nature of this dilemma by asking the following kinds of questions.

1. *Who are the moral actors (or moral agents) in the case?*

   It is important to identify who they are because, as a moral actor or agent [5], each person has various moral rights to certain things, such as information, and each also has a reciprocal duty to fulfill to others, such as acting on information in order to benefit and not harm. Deciding what is to count as a benefit (beneficence) and what is to count as a harm is, of course, part of the thinking-through process. Objective evidence, such as that provided by randomized controlled trials, is frequently used to assist in making these kinds of decisions, i.e., the evidence will show if option *x* will benefit. Note that the evidence alone will not necessarily resolve the dilemma; it merely clarifies and so contributes to a robust and defensible decision.

   The moral actors include those who will need to make decisions about whether or not to tell, who will act on those decisions, and who is told or not told. Should the professional provide everyone with the same information and in exactly the same format? To what extent should each of the moral actors be involved in the decision-making processes, namely, to what extent are we obliged to respect autonomy? To what extent do cultural mores impinge on this dilemma? In some cultures, for instance, the family makes the autonomous decision, not the individual alone [7]. From the perspective of the health-care professionals, it is also not always the case that the person who makes the decision is also the one who acts. In this hypothetical scenario, for instance, a team may make a decision to tell (or not tell), but an individual professional may be the one who tells the patient and/or the family.

2. *Who should be told the test results?*

   The key consideration here is to what end that information is being passed on, and the reason for doing so (the "because we can, we should" notion). If autonomy is considered paramount, as it so often is in the Western world, then we tell only the patient. All other decisions about who is told and what they will be told are made by the patient, probably in consultation with the professionals, and perhaps a genetic counselor. It may be the case that the patient decides to involve the family, perhaps for cultural reasons, but essentially, if we are benefiting by respecting autonomy, then we tell only the patient in the first instance. In that case, it has been decided that the patient has a right to know the results of the tests so that they may make subsequent informed and freely chosen decisions, for instance, about whether or not to take steps to ameliorate the effects of the impending brain disease.

If the decision is made not to pass on the information, e.g., on the grounds that the information is unnecessarily burdensome for the patient (the nonmaleficence principle), then subsequent questions arise, including rights to know or not to know [19] versus duties to not harm (by withholding information) and issues around paternalism.

3. *Who is best placed to pass on information and how should it be done?*

   Since it is likely to be a sensitive and emotionally charged situation, the team member with the most experience in these matters is generally chosen as the one who does the telling. The assumption here is that someone with more experience will be able to maximize benefits (the beneficence principle) and reduce any harms that may arise from well-meaning yet inexperienced professionals providing information (the nonmaleficence principle). With the patient's permission (the autonomy principle), the more junior professional may sit in on the interview in order to expand his or her own experience. In that circumstance, this is an example of developing ethical expertise with a mentor as he or she "does" ethics. It is also an example of beneficence in action, since the more junior professional benefits by learning, and ultimately all patients will benefit from that expanded expertise.

   There will also need to be a decision made as to whether or not the patient will be told alone or in the company of family members. Will the patient, who is the principal moral actor, be given the opportunity to make that decision him- or herself (autonomy and beneficence in action), or will there be no need to consult because we already know what the patient wants, i.e., we already know that the patient's autonomous choice is to be told the test information, irrespective of the results?

4. *How and in what form will the information be passed on?*

   This is private and sensitive information, so a quiet room where conversations cannot be overheard would be the best choice. It may be appropriate to offer the patient follow-up counseling. Consider how much information the patient can realistically absorb in this one situation. Would it be useful to invite the patient to have another person of his or her choosing to be present? Do we also need to give the patient some kind of printed information with the option for a follow-up appointment for further discussion? Answers to these questions see the beneficence and nonmaleficence principles in action: respectively, acting to benefit by giving real choices that we then honor with follow-up appointments and refraining from intentionally harming (by considering the room, the persons present, the format of the information), proactively offering further care, and so on.

5. *To what extent can this experience be generalized to other situations?*
   The answers to this question illustrate the more universal nature of applied ethics. The actions that have been taken in this case will affect not only the patient, but the professionals involved as well as future patients and their loved ones. So, for instance, this experience will act as a guide for professionals, say for making policy recommendations about what kinds of genetic information can be (or should be) passed on to patients, by whom, in what circumstances, and for what purpose. Who else will and can benefit from these kinds of experiences? Do we, for example, have a duty to enlist the media and other health-care professionals to mount a preventive public health-awareness campaign around the new genetic test results associated with HD testing? Making these kinds of decisions about providing, or not providing, information [2, 19] to current and future patients brings all three principles into action.

7.5 CONCLUSION

This chapter has provided a short introduction to the practical possibilities of the application of bioethical principles to the exciting, yet complicated, future world of genetics in human health. It is certainly the case that as science and technology produce ever more undreamt of possibilities for the treatment and prevention of genetic and other health disorders, the companion to this future universe and future generations will be challenging decisions about how to ensure that those advances benefit rather than harm. We also need to think about how much science will challenge the age-old ethical questions such as what it means to be human. These are questions that have long bedeviled philosophy, and now they are becoming increasingly important for science.

We have suggested that bioethics and applied ethics provide the intellectual and philosophical platforms with which to confront these challenges. Applied ethics cannot be "done" in isolation, and we urge all readers to develop their ethical expertise so that it can be brought to bear on the fascinating and complex ethical problems they will undoubtedly face in the future.

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