

The Status of the Family in Law and Bioethics

The Genetic Context

Roy Gilbar

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ASHGATE

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THE STATUS OF THE FAMILY IN LAW AND BIOETHICS

*To my parents
Ora and Gadi Gilbar*

Preface

The book concerns the legal and ethical obligations of doctors and patients in communicating diagnostic and predictive genetic information to the patient's family members. The focus is on two familial tensions. First is the tension between the patient's interest in keeping the information in confidence and the relatives' interest in being informed; second is the tension between the patient's interest in sharing the information and the relatives' interest in remaining ignorant. In these two familial tensions the doctor's professional obligations are investigated. On the one hand, doctors have to respect patient autonomy, confidentiality and privacy, but on the other hand, they may owe a moral and professional duty to help the relatives who may be affected by the information.

The examination of these conflicts is conducted within the liberal-communitarian debate. In this context, the two philosophies hold different perceptions of the individual, his or her autonomy, and the relationship he or she has with others. While, liberals support an individualistic perception of autonomy communitarians and proponents of ethics-of-care perceive this principle relationally.

Within this theoretical framework, this book examines the approach taken by English medical law and ethics to communication of genetic information to family members. Legally, the focus is on tort law (especially the duty of care), and the law of confidentiality. Ethically, it concentrates on the approach taken by the bioethical literature, and more specifically by codes of ethics and professional guidelines.

Subsequently, these legal and ethical approaches are compared to the leading medical model of doctor-patient relationship and the socio-medical empirical studies which examine the views of doctors and patients with regard to communication of medical information to family members. The conclusions arrived at this book is that there is a gap between law and medicine in this area and that this gap should be bridged.

A few people helped me arrive to this stage and it is my pleasant duty to thank them. There are the people in the Department of Law in Queen Mary College University of London. I wish to thank Dr. Paula Giliker, Mr. Jonathan Griffiths, and my friend, Dr. Jill Marshall. I would also like to thank Ms Penney Lewis, a lecturer in the School of Law in King's College London, and Dr. Michael Parker, a reader in medical ethics in Oxford University whose illuminating observations contributed to the completion of this book.

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The law is stated at 1 March 2005.

Roy Gilbar
Tel-Aviv, May 2005

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Chapter 1

The Liberal–Communitarian Debate in Medical Law and Ethics

1.1 Introduction

Robert Powell was 10 years old when he died from a condition called Addison's disease. Shortly after his death the doctors explained to the parents why their son had died, presenting them with the medical records. However, a few months later the parents discovered that the doctors had tampered with the medical records to cover up their negligent diagnosis. This caused the parents psychological harm.¹

Donna Safer was 10 when her father was diagnosed with colon cancer. It was known that that type of cancer had a genetic component, which meant that Donna might inherit it. The doctor did not inform Donna or her mother about the hereditary aspect of the disease and it was not known whether the doctor had informed the father. When Donna was 36 she was diagnosed with the same type of colon cancer as that of her father. When she received her father's medical records she realised that had she been informed in time the disease could have been prevented.²

The stories of Robert Powell and Donna Safer raise a significant issue in English medical law and medical ethics: the status of family members in health care. One can think of many situations where the patient's medical condition affects the lives of his or her relatives. For example, when the patient suffers from a serious disease, family members usually change their daily life to provide him or her with care and emotional support. In addition, the patient's condition may affect the relatives psychologically, causing them stress and anxiety when his or her health deteriorates. The above cases present another aspect of this issue, namely that medical information has implications not only for the patient but also for the family members.

Despite the close involvement of family members in a patient's medical care it seems that law and ethics do not pay sufficient attention to their interests. This circumstance can be observed from two perspectives. One is the *doctor–patient* relationship. In this context English courts and professional codes of ethics address the interests of family members in two respects: first, when patients are incapable

¹ *Powell v Boldaz* [1998] Lloyd's Rep. Med. 116 (hereafter: *Powell*).

² *Safer v Pack* (1996) 677 A.2d 1188 (NJ Super Ct A D) (hereafter: *Safer*).

of giving consent to medical treatment;³ and second, when the patient's condition endangers the health of his or her family. Yet even in these two categories the interests of family members are not fully recognised. In the former, family members cannot make decisions for incompetent patients; usually the patient's doctors act as a quasi-proxy in accordance with what they believe to be the patient's best interests.⁴ In the latter category, when the patient poses a risk to family members, their interests are discussed in three instances: when a mentally-ill patient threatens seriously to harm them; when the patient suffers from an infectious disease; and when the patient suffers from a genetic disorder which may be passed on to other blood relatives. In these circumstances the ultimate authority is given to doctors. They are required to decide, especially when the patient is reluctant to inform the relatives, whether disclosure can save them from serious physical harm.⁵

The limited recognition in the interests of family members can be also seen from the perspective of the *patient-relatives* relationship. Courts hardly interfere with the relationships within families in the medical context. Since the opponents in legal procedures are usually the doctor and the patient or the doctor and the relative, the courts do not come upon circumstances where they are required to discuss the relationship between patients and relatives. By the same token, some professional codes of ethics are focused on the rights of patients vis-à-vis doctors to make informed decisions and not on the implications any decision would have for the relatives.⁶

Yet in the context of the patient-relatives relationship law and medical ethics seem not to speak in one voice. First, there are professional codes of ethics that address the relationship between patients and relatives.⁷ Second, there are ethicists who discuss the relevance and significance of the familial relationship when patients are involved in medical decision-making.⁸ A gap is apparent between law and ethics: while English law is focused primarily on the doctor-patient relationship, medical ethics addresses, even if not comprehensively, the patient-relatives relationship.

³ Examples are when an adult patient is incompetent to give consent to treatment, or when the patient is a child too young to understand the implications of the medical decision.

⁴ Kennedy I., Grubb A., *Medical Law*, London, Butterworths (3rd edn., 2000), 831 (Hereafter: Kennedy and Grubb). This position will be changed when the *Mental Capacity Act* 2005 comes into force, probably in 2007.

⁵ The General Medical Council, *Confidentiality: Protecting and Providing Information*, London, General Medical Council (2000), para. 14, 18, 36.

⁶ General Medical Council, *Good Medical Practice*, London, General Medical Council (3rd edn., May 2001); This prevails also in the GMC's guidance on Confidentiality. See Chapter 4 for analysis.

⁷ British Medical Association, *Human Genetics: Choice and Responsibility*, Oxford, Oxford University Press (1998), pp. 21–24.

⁸ Lindemann-Nelson H., Lindemann-Nelson J., *The Patient in the Family*, New York, Routledge (1995) (hereafter: the Lindemann-Nelsons).

The first assumption in this book is that law and medical ethics largely ignore the interests of family members. This assumption will be examined in a specific context, that of communication of genetic information from doctors and patients to family members. It is well established that not only does genetic information affect the individual patient, it has considerable implications for family members. Susceptibility to genetic diseases is transmitted from parents to their offspring in conception, so when a patient is diagnosed as a carrier or as a sufferer of a genetic disorder this implies that his or her family members may suffer from the same condition.

In these circumstances the question whether the interests of family members are fully recognised arises. When genetic information is communicated to the patient but has implications for family members, familial tensions may emerge. There are two possible tensions in this context. First, the patient may perceive the information as personal, and wishes to keep it in confidence, while the relatives may view the information as familial, and demand to be informed. A second tension may arise when the patient who receives the information from the doctor wishes to share it with his or her relatives but they wish to remain ignorant.⁹ In a broader sense these familial tensions regarding the access to genetic information concerns the involvement of family members in medical decision-making, namely whether their interests are taken into account in this process. In this chapter the emphasis will be on the first tension.

The assumption that law and ethics do not take the interests of family members seriously at least in the area of genetic information leads to a series of questions which will be examined in this book. First, if it is accepted that law and medical ethics do not fully recognise the interests of family members, the immediate question is why not. A possible hypothesis is that in their underlying philosophy both law and ethics rest on liberal-individualism, which calls on doctors to respect the autonomy of patients to make informed decisions without controlling influences. If this is accepted, the next question is whether this philosophy accords with current medical practices and public views about the involvement of family members. It is assumed that there is a gap between the two because numerous studies indicate that doctors and patients consider the interests of family members during the course of treatment. Lastly, if this assumption is accepted, the final question is whether a different philosophical approach exists that may represent more adequately the practical involvement of family members generally and in the context of genetics particularly. The argument put forward in this book is that values such as solidarity, moral responsibility, care and commitment should be taken into account with liberal conceptions of autonomy and justice when the interests of patients and those of their relatives are considered.

⁹ A third tension, which will be discussed briefly in this book, is between the interest of the patient in not receiving information from the doctor about his or her condition and the relatives' interest in receiving it.

To sum up, the three hypotheses examined in this work are: (1) English law and medical ethics reflect a liberal-individualistic approach which constricts the interests of family members in knowing and not knowing genetic information. (2) This liberal individualistic approach is not compatible with current views of doctors and patients. Therefore (3) English law and medical ethics should adopt a different approach, which combines communitarian as well as ethics-of-care conceptions with liberal principles.

These three assumptions dictate the structure of this work, whose theoretical framework is laid down in this chapter. The discussion will concentrate on the liberal and communitarian perceptions of the individual and its relationship with others. This will be followed in Chapter 2 by a brief account of genetics, how genetic disorders are manifested and how they affect patients and their relatives. This leads to a fundamental question in this book of what constitutes a family in genetics: is a family in genetics defined by its blood relations or are social bonds important as well? In Chapters 3 and 4 the first two assumptions will be examined, namely whether or not English law and ethics recognise the interests of family members in knowing and not knowing genetic information, and whether this position is based on a liberal discourse. In Chapter 5 the last assumption will be investigated, namely how doctors and patients perceive the role of family members in health care and whether there is a gap between their views and the legal position. This will lead to the final chapter, where some suggestions for a change in the legal position are made.

Focusing on these three assumptions requires beginning with a brief account of the main themes of liberalism, communitarianism, and ethics-of-care. This is the main purpose of this chapter. It will discuss the philosophical debate on the perception of the individual and its relationship with others. In this debate, there is the liberal belief that the individual can choose his or her ends and the communitarian view that the individual is defined by its ends.

Consequently, the first part of this chapter will provide a brief account of liberalism. The second part will examine whether liberal principles are adopted in medical ethics and the law. It will be shown that principles of autonomy and utility underlie the leading ethical position but are less influential in medical law. The analysis of the liberal perception of the individual will lead to the question, discussed in the fourth part, of whether liberal conceptions alone provide a satisfactory solution to familial tension over medical genetic information. Since the answer to this question will be that a liberal approach is not comprehensive enough to deal with this particular subject, a brief account of communitarianism and ethics-of-care will be provided. In the fifth and final part of this chapter some models that apply communitarian conceptions in the specific context of genetics will be examined. The discussion about these models will reflect not only the gap between law and ethics in this area but also the limitations of the legal position with regard to the status of family members.

The discussion in this chapter is brief, as it aims only to set out the complex issues this book raises. The hypotheses put forward in this chapter will be

examined in more detail in the subsequent chapters. In addition, the analysis of medical law and medical ethics in this chapter is not comprehensive: it simply aims to illustrate the general attitude to family members.

1.2 Liberalism: The Individual as Autonomous Person

It is difficult to provide a brief account of liberalism, as this branch in political philosophy has many variations.¹⁰ Classical liberals, such as John Locke and Adam Smith, promote the ideas of restricted governmental control, preservation of the rule of law, avoidance of arbitrary power, primacy of private property, freedom to contract, and individuals' responsibility for their own lives.¹¹ In contrast, modern liberalism limits the scope of freedom of contract and of property rights. Rawls, for example, accepts that personal property is an essential element to individual self-expression.¹² He believes in liberty and justice but he also maintains that inequalities are justified to the extent that they improve the position of the least advantaged. This is not accepted by classical liberals.¹³

There are three different justifications for liberal principles.¹⁴ There are utilitarians, such as Bentham and Mill, who believe that the morally right act is the one which produces the greatest happiness for all members of society. There are libertarians, such as Nozick, who believe that the individual owns his or her rights as a form of private property; and there are those, such as Kant and Rawls, who believe in justice based on a social contract. However, despite the differences between them, the literature perceives these justifications as strands of the liberal approach.¹⁵

Three conceptions are common to all strands of liberalism: *individualism*, *universalism*, and *egalitarianism*.¹⁶ In this book the focus will be on *individualism*, as it relates to the perception of the individual and his or her relationships with others.

¹⁰ Ryan A., "Liberalism" in Goodin R., Pettit P. (eds.), *A Companion to Contemporary Political Philosophy*, Oxford, Blackwell (1993), pp. 291–312.

¹¹ Ibid., at p. 293; For a more detailed account of classical liberalism see Gray J., *Liberalism*, Milton Keynes, Open University Press (1986), Chapters 2 & 3.

¹² Rawls J., *A Theory of Justice*, Oxford, Oxford University Press (1971), 272–274.

¹³ See Ryan, *supra* n. 10, at p. 297.

¹⁴ See Gray, *supra* n. 11, chapter 6, pp. 45–61; see also Kymlicka W., *Contemporary Political Philosophy: An introduction*, Oxford, Oxford University Press (2nd edn., 2002), at p. x where he defines these three approaches as 'three influential defences of liberal democracy'.

¹⁵ See Gray, *supra* n. 11, at p. ix.

¹⁶ Ibid., at p. x; For a comprehensive analysis of liberalism see Kymlicka W., *Contemporary Political Philosophy: An Introduction*, Oxford, Oxford University Press (2nd edn., 2002), 2–4

Liberals value individual rights and freedom, equality, the conviction that all people are potentially¹⁷ rational, and most importantly the understanding that the individual is first and foremost distinct from others and potentially in conflict with society.¹⁸ When analysing the nature of the individual, liberals argue that people are not only rational but also possess the capacity to choose and to enter into agreements. One of the core perceptions of the liberal tradition is that the individual is pre-social, namely that individuals have a fundamental essence before they enter into society. Thus, what makes one an individual does not depend upon a specific social situation.

The argument that the individual is pre-social prevails in the seminal work of John Rawls, *Theory of Justice*, where he emphasises that justice is the most fundamental principle.¹⁹ Rawls describes a hypothetical situation, 'the original position', where all the participating parties do not know their inherent characteristics, such as race, class, ethnicity, and the like. Thus, the parties to the original position are under what Rawls calls a 'veil of ignorance'. In this position, when they do not know what their social status will be, the primary good the parties are likely to wish for is justice because it will secure their basic needs.²⁰ In addition, according to Rawls, the parties to the original position are mutually disinterested, and in promoting their goals they do not owe moral duties to each other.²¹

It is apparent from Rawls's theory that the process whereby the parties to the original position reach justice is based on agreement and social contract.²² Thus, agreement is a fundamental principle in this theory because it leads to justice. Agreements and contracts are perceived as the result of acts of will, whose morality consists in their voluntariness. The act of will leads to the concept of autonomy, namely the notion that the individual determines and chooses his or her way of life. Therefore, from the perspective of autonomy, the individual's obligations to others are to those he or she voluntarily assumes.²³ In other words,

¹⁷ There is a dispute whether individuals must exercise their autonomy *rationally* or whether they can act foolishly so long as they do not harm others. This debate exists in the context of the patient's right *not* to know genetic information. For an argument that supports rational choice see: Rhodes R., "Genetic links, family ties, and social bonds: Rights and responsibilities in the face of genetic knowledge" (1998) 23 *Journal of Medicine & Philosophy* 10; for the opposite view see: Takala T., "The right to genetic ignorance confirmed" (1999) 13 *Bioethics* 288.

¹⁸ Frazer E., Lacey N., *The Politics of Community*, Hemel Hempstead, Harvester (1993), 41–53.

¹⁹ Rawls J., *A Theory of Justice*, Oxford, Oxford University Press (1971), 3; still, Rawls justifies an unjust act only if it can improve the least advantaged.

²⁰ *Ibid.*, at p. 12.

²¹ *Ibid.*, at p. 13–14.

²² Sandel M., *Liberalism and the Limits of Justice*, Cambridge, Cambridge University Press (1982), 105

²³ *Ibid.*, at p. 107.

the individual and the contract are the primary conceptions in Rawls's theory. The individual is prior to his or her ends because he or she chooses them, and the contract is prior to the principle of justice because the parties to the original position agree to it and do not merely find it.

Rawls relies on the work of Immanuel Kant.²⁴ Kant argues that the individual is always an end in itself and should never be perceived as a means to other people.²⁵ This Kantian approach (also called deontological) suggests that the individual possesses a will he or she can exercise freely. Thus, Kant argues, the individual is capable of acting autonomously. The most important characteristic of the individual is not the ends he or she chooses but his or her ability to choose them.²⁶

The importance of autonomy is evident in the work of Isaiah Berlin. Berlin argues that there are two concepts of liberty. A positive concept of liberty is the individual's freedom to lead his or her ordered form of life²⁷ which derives from the individual's wish to be his or her own master.²⁸ A negative concept is absence of interference by others. In his discussion Berlin refers to Mill, who stresses that society should not interfere with the decisions of individuals so long as they do not interfere with the freedom of others.²⁹

Yet arguing that liberals perceive the individual as socially unencumbered is not accurate. Following considerable criticism³⁰ liberals modified their perception of the individual. Rawls, for example, denies that his conception of the individual is individualistic. In his later work he emphasises that he intends his theory of justice to be a political conception, not a general moral approach. Rawls argues that in formulating his conception of justice he has tried to avoid dependence on philosophical claims regarding the essence of the identity of the individual.³¹ Focusing on the original position, Rawls explicitly recognises the dominance of the social aspect of life, and observes that the original position generates a social perspective.³²

²⁴ Rawls's work derived from his dissatisfaction of utilitarianism. See Rawls, *supra* n.19, at pp. 26–27, 33

²⁵ See Gray, *supra* n. 11, at p. 50–51, Frazer and Lacey, *supra* n. 18, at p. 43–45.

²⁶ Mulhall S., Swift A., *Liberals and Communitarians*, Oxford, Blackwell (2nd edn., 1996), pp. 43–44; Rawls explicitly relies on Kant in developing his contractual theory. See Rawls, *supra* n. 19, at p. 11.

²⁷ Berlin I., *Four Essays on Liberty*, Oxford, Oxford University Press (1969), 131.

²⁸ Ibid.

²⁹ Mill J.S., *On Liberty and Other Essays* (London, 1859), Oxford, Oxford University Press (1991), pp. 83–104.

³⁰ See the discussion about communitarianism in this chapter.

³¹ Rawls J., "Justice as fairness: Political not metaphysical" (1985) 14 (3) *Philosophy and Public Affairs* 223, 224–225.

³² Rawls J., "Kantian constructivism in moral theory" (1980) 77 *Journal of Philosophy* 515, 552, 570.

Rawls was not the only one to clarify his perception of the individual. Other liberals did so as well. They stress the individual's ability to critically evaluate his or her ends.³³ Daniel Bell explains this change in focus, commenting that liberals may accept the social context of the individual, but they also argue that he or she can engage in an autonomous examination and reflection of the relationships he or she has.³⁴

These clarifications or modifications made in the liberal discourse did not satisfy the critics. Focusing on the 'original position', Frazer and Lacey argue that it seems inherently unable to generate the social perspective that Rawls now explains it aspires for. Instead, the two critics argue, the parties to the original position must have a particular social standpoint to begin with, and this obviously contradicts the requirement of the veil of ignorance.³⁵ In addition, as we shall see, communitarians still maintain that individuals cannot distance themselves from close social attachments as they constitute part of their identity and help them exercise their autonomy.

However, liberals sometimes struggle with situations of conflict, especially when the interest of one individual clashes with that of another. For example, in the context of this study the patient's interest in keeping genetic information in confidence may clash with the relatives' interest in receiving this information. In addition, an individual's right may clash with public interest. For example, a policy that enforces screening all newborns for cystic fibrosis may, on the one hand, compromise the autonomy of parents to take decisions regarding their child, but on the other hand it may improve public health in general by controlling the spread of a fatal disease. Does the interest of the patient outweigh the interest of family members in the first conflict? Can the individual's right to autonomy outweigh public interest in the second conflict? Some liberals, such as Ronald Dworkin, acknowledge the force of this argument and make a concession by relying on a utilitarian philosophy.³⁶ Mill, in "Utilitarianism", argues that the promotion of social utility may lead to the sacrifice of the individual's interests.³⁷ Hence, the conflict may be resolved by arriving at a decision that causes the least harm to the parties involved. Dworkin agrees that if an individual's right seriously endangers the welfare of the public at large, the

³³ Kymlicka W., *Liberalism, Community and Culture*, Oxford, Clarendon Press (1989), 52; see also Dworkin R., "Liberal Community" (1989) 77 *California Law Review* 489.

³⁴ Bell D., *Communitarianism and Its Critics*, Oxford, Clarendon Press (1993), 9.

³⁵ See Frazer and Lacey, *supra* n. 18, at pp. 58–59.

³⁶ Mason JK., McCall-Smith RA., Laurie GT., *Law and Medical Ethics*, London, Butterworths (6th edn., 2002), 7 provide a brief account on utilitarian approaches.

³⁷ Mill J.S., *On Liberty and Other Essays* (London, 1859), Oxford, Oxford University Press (1991), pp. 131–201.

public interest should prevail.³⁸ Therefore, in the above conflicts the patient's right to confidentiality can be breached if this may prevent greater harm to family members; and the parents' right not to screen their child for CF may be compromised if population screening indeed reduces morbidity and mortality. However, the circumstances where individual autonomy can be compromised should be, according to this approach, extremely rare.³⁹

1.3 The Application of the Liberal Approach to Medical Law and Medical Ethics

So far, I have argued that law and ethics failed to recognise the involvement of family members. I assumed that that position derived from reliance on a liberal philosophy, which includes deontological and utilitarian conceptions. Hence, these conceptions were briefly described. Consequently, the next stage is to examine whether these conceptions prevail in medical ethics and law generally. Examining this will provide the basis for the discussion in Chapters 3 and 4, where the legal and ethical attitudes to family members in the context of genetics will be specifically investigated.

1.3.1 Medical Ethics

The most prominent principle in medical ethics today is respect for autonomy.⁴⁰ Two components are essential when individuals exercise their autonomy: (1) *Choice*,⁴¹ which includes respect for one's choices and the ability to act without interference by others;⁴² and (2) *Agency*, or the capacity to act intentionally.⁴³ Agency is not under discussion in this work; it is assumed that the patient is competent. By contrast, choice is a central theme in this study and it is viewed as an element of one's identity.⁴⁴ Autonomous people are 'choosers', who act intentionally with a substantial degree of understanding and without controlling influences.⁴⁵ Beauchamp and Childress recognise that several professional

³⁸ Dworkin, R., *Taking Rights Seriously*, Cambridge, Harvard University Press (1977), pp. 190–192.

³⁹ Rawls argues that utilitarians fail to take seriously the distinction between people. See *supra* n. 19.

⁴⁰ Mason, McCall–Smith and Laurie, *supra* n. 36, at p. 8.

⁴¹ Raz J., *The Morality of Freedom*, Oxford, Clarendon Press (1986), 370–373.

⁴² Dworkin G., *The Theory and Practice of Autonomy*, Cambridge, Cambridge University Press (1988), 18–19.

⁴³ Beauchamp T., Childress J., *Principles of Biomedical Ethics*, New York, Oxford University Press (5th edn., 2001), 58.

⁴⁴ This notion is borrowed from Bergsma J., Thomasma D., *Autonomy and Clinical Medicine*, Boston, Kluwer Academics (2000).

⁴⁵ See Beauchamp and Childress, *supra* n. 43, at p. 59.