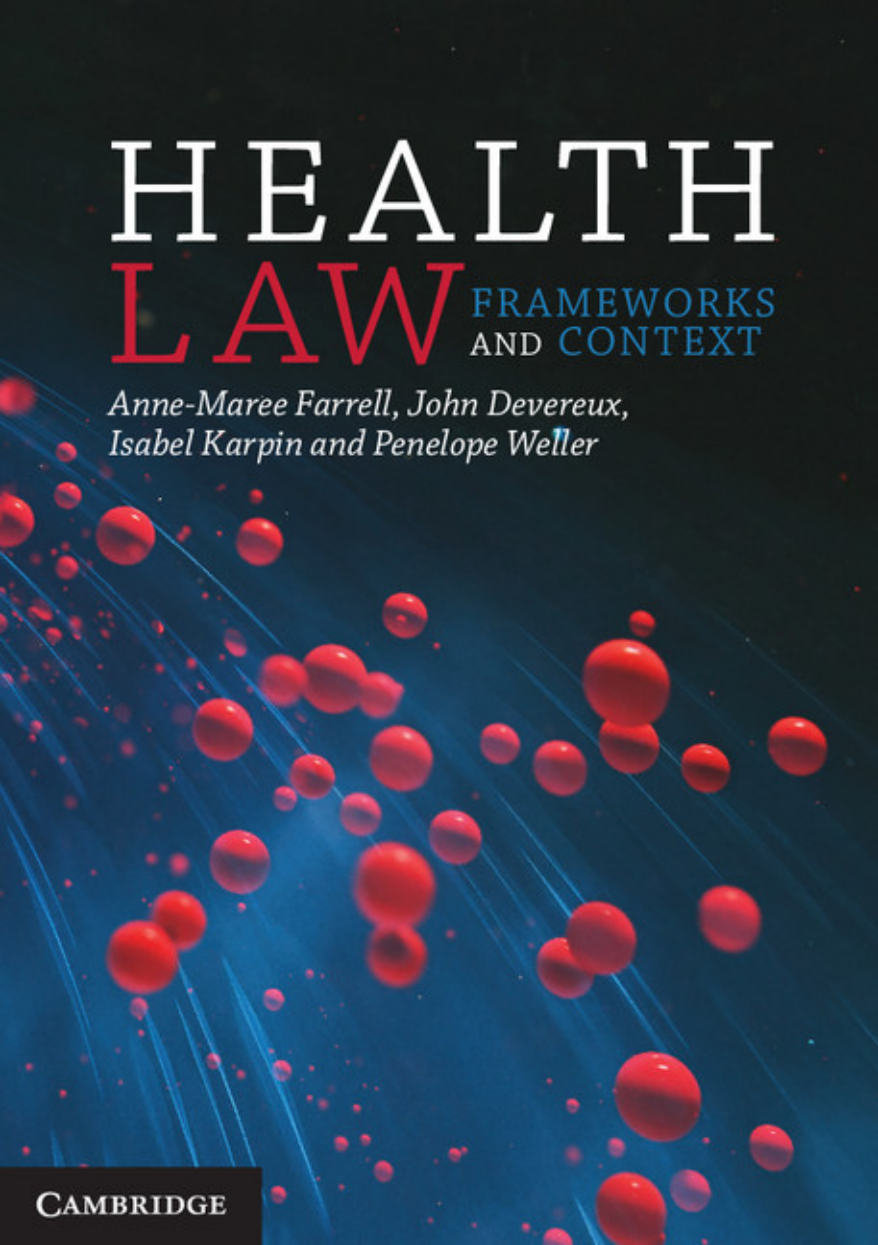
HEALTH LAW FRAMEWORKS AND CONTEXT

Anne-Maree Farrell, John Devereux, Isabel Karpin and Penelope Weller



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HEALTH LAW

FRAMEWORKS AND CONTEXT

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For Josephine Upton Farrell

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PREFACE

This book explores health in its socio-legal context in Australia and beyond. It critically examines key frameworks and contexts which underpin the relationship between law and health. This is done with a view to better conceptualising this relationship in what is a burgeoning area of national and international academic study and policy interest. As such, it offers a new way forward within legal scholarship in the field, which will be of interest to a range of audiences, including academics, policy-makers, health professionals and students. As we developed this approach, we have been greatly assisted by the insightful feedback we have received on each of the chapters from independent peer reviewers. We would like to thank them for their time and contribution. The policy and law described in this book is current as at 1 January 2017.

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INTRODUCTION

1

HEALTH LAW: FRAMEWORKS AND CONTEXT

Anne-Maree Farrell

In this book, we critically examine and reflect upon the relationship between law and health. Our approach is informed by a socio-legal perspective or 'law in context' approach. We start from the premise that health includes both good and ill-health at individual and population levels and should be viewed as a social and cultural construct that is influenced by science, medicine and technology, as well as by the law itself. We take a broad view of what constitutes law and we are particularly interested in how it is used as a method of social, political and behavioural control. We emphasise the importance of a contextual approach to understanding law's role in influencing the dynamics of patient-doctor relations and the provision of healthcare, the definition of health and ill-health, and the refashioning of human bodies, identity, normalcy and relationships through biomedical practices and technological innovation. In doing so, we explore how we should understand the ethical, social, institutional and equity issues that influence and constitute law's role at an individual, and population, level. In this introductory chapter, we briefly explore the evolution of health law. We then set out the particular approach we use in this book, before concluding with an outline of the organisation of the book.

Health law

From the late 1970s onwards, there was growing interest in the relationship between law and medicine in a range of common law jurisdictions, including Australia. The origins of such interest lay in the perceived growth in medical malpractice claims by patients who had been harmed during the course of medical treatment.[1] This was combined with a greater appreciation that law's coercive aspects could be used to facilitate an ethically principled approach in clinical practice.[2] This contributed to the development of a new legal sub-discipline, known as medical law. Drawing predominantly on the law of tort and contract, as well as the criminal law, it focused on a range of core areas covering the legal obligations involved in the doctor-patient relationship, including consent, confidentiality and privacy, and negligence. Indeed, law's role in such a relationship, underpinned by (philosophical) bioethical critique, remains a core aspect of study and scholarship in the field.[3]

More recently, the influence of human rights discourse and jurisprudence in the field has been the subject of considerable academic debate. Some commentators have argued that medical law should be seen as a 'subset of human rights law'.[4] While this was a claim that could be made in other common law jurisdictions, such as England and Canada,[5] the influence of human rights law in the Australian context has been limited by the fact that there is

1 Tamara Hervey and Jean McHale, *Health Law and the European Union* (Cambridge University Press [CUP], 2004) 11.

2 Jonathan Montgomery, 'Time for a Paradigm Shift: Medical Law in Transition' (2000) 53(1) *Current Legal Problems* 363.

3 Anne-Maree Farrell et al., 'Pioneering Healthcare Law' in Catherine Stanton et al. (eds), *Pioneering Healthcare Law: Essays in Honour of Margaret Brazier* (Routledge, 2016) 2. In the Australian context, see, for example, Loane Skene, *Law and Medical Practice: Rights, Duties, Claims and Defences*, 3rd edn (LexisNexis Butterworths, 2008); Bernadette Richards and Jennie Louise, *Medical Law and Ethics: A Problem-Based Approach* (LexisNexis Butterworths, 2013).

4 Ian Kennedy and Andrew Grubb, *Medical Law: Text With Materials*, 3rd edn (Butterworths, 2000) 3. For a more critical conceptualisation, see Thérèse Murphy, *Health and Human Rights* (Hart, 2013).

5 *Human Rights Act 1998* (UK) c. 42; Canadian Charter of Rights and Freedoms, Part 1, *Constitution Act 1982*.

no national legally binding human rights instrument, save for those of limited remit in the ACT and Victoria.[6] Having said that, human rights discourse is now much more influential, as a result of the incorporation of international human rights instruments into Australian law in health-related areas.[7]

Over time, the growth in health services, institutions and administration, combined with more emphasis being placed on a multi-disciplinary team-based approach to treating patients, has led some academic commentators to argue that the narrow focus on the doctor-patient relationship in medical law was no longer appropriate. Instead, it was suggested that the term 'healthcare law' better captured this change, as it encompassed a range of health professions, the administration of health services and the law's role in maintaining public health.[8] Incorporating insights from family law and public law, this shifted the focus to structural and systemic aspects of the health system, and recognised the importance of social care and welfare provision. Notwithstanding this more expansive approach, the provision of healthcare to patients remained a core aspect of analysis.[9]

The increased use of the term 'health law' marks a further conceptual shift. It recognises that the primary focus is on analysis of the relationship between law and health. *Health* is defined to include good and ill-health at both individual and population levels,[10] in circumstances where health is viewed as a socio-cultural construct which is influenced by science, medicine, technology and law. This has led to insights from a range of other disciplinary areas, including feminist studies, sociology, regulatory studies and the behavioural sciences, being incorporated into the field of health law[11]

In this book, *law* is broadly defined to include common law, legislation, courts/tribunals, norms, guidance, procedures and regulation.[12] It is understood as context driven and contingent on social understandings and political dynamics. The term 'regulation' is defined as a method of social control, incorporating both 'soft' and 'hard' legal mechanisms which are designed to promote standard-setting, information, and behaviour modification.[13] Adopting

6 See *Human Rights Act 2004* (ACT); *Charter of Human Rights and Responsibilities Act 2006* (Vic).

7 See Belinda Bennett, 'Human Rights and Health Law' in Ben White, Fiona McDonald and Lindy Willmott (eds), *Health Law in Australia*, 2nd edn (LawBook Co, 2014) 103–24; see also Chapter 5 in this book.

8 Jonathan Montgomery, *Health Care Law*, 2nd edn (Oxford University Press [OUP], 2002) 4.

9 See Margaret Brazier and Nicola Glover, 'Does Medical Law Have a Future?' in David Hayton (ed.), *Law's Futures* (Hart, 2000) 371–88.

10 John Coggon, *What Makes Health Public? A Critical Evaluation of Moral, Legal, and Political Claims in Public Health* (CUP, 2012); Lawrence Gostin, *Global Public Health Law* (Harvard University Press, 2014); Roger Magnusson and Paul Griffiths (eds), 'Mini-Symposium; Who's Afraid of the Nanny State? Freedom, Regulation and Public Health' (2015) 129(8) *Public Health* 1015–34; see also Chapters 24 and 25 in this book.

11 See, for example, Ruth Fletcher, Marie Fox and Julie McCandless, 'Legal Embodiment: Analysing the Body of Healthcare Law' (2008) 16 *Medical Law Review* 321; Muireann Quigley, 'Nudging for Health: On Public Policy and Designing Choice Architecture' (2013) 21 *Medical Law Review* 588. On the use of qualitative research methodologies in health law, see, for example, Isabel Karpin et al., 'Analysing IVF Participant Understanding of, Involvement in, and Control over Embryo Storage and Destruction in Australia' (2013) 20(4) *Journal of Law and Medicine* 811.

12 Norms may or may not be overt, particularly in case law in the field: see Jonathan Montgomery, Caroline Jones and Hazel Biggs, 'Hidden Law-Making in the Province of Medical Jurisprudence' (2014) 77(3) *Modern Law Review* 343.

13 Julia Black, 'What is Regulatory Innovation?' in Julia Black, Martin Lodge and Mark Thatcher (eds), *Regulatory Innovation: A Comparative Analysis* (Edward Elgar, 2005) 11.

this interpretation allows for a more flexible approach to understanding the diverse ways in which regulation intersects with health provision, systems, services and technologies in multi-level governance environments.[14]

Our approach

Health law: terminology and remit

It is for the reasons noted above that we use the term 'health law' in this book. We view the relationship between law and health as being one which is conceptually and analytically broader than that between law and medicine, although we recognise that the latter is an important aspect of study in the field. We note that there has been some academic debate over time about whether it should be recognised as a distinct field of legal study, and if so, what its remit should be.[15] However, the exponential growth in academic study in the field, its expansive engagement with a range of other disciplines, and its critical engagement in law reform, shows that such debate has now concluded in favour of its recognition as a thriving and exciting area of academic scholarship in the 21st century.

Frameworks and context

This book examines key frameworks which we argue influence law's relationship with health, both in terms of principles and in practice. Part I identifies and explores such frameworks. The first section is headed 'Theories, Perspectives and Ethics in Health' and contains chapters which explore the relationship between philosophical bioethics and health law; socio-legal perspectives on patient-doctor relations; the social determinants of health and the law; and human rights and health law. The second section is headed 'Institutions and Regulation' and covers overarching institutional and regulatory arrangements impacting the health system, including the regulation of health professionals and patient safety and redress.

Our choice of key frameworks underscores the importance we attach to examining health law in context. In adopting this approach, we draw inspiration from the socio-legal studies literature. There are differing opinions as to what is distinctive about this approach. One view is that socio-legal inquiry is about the study of law in its social context, in circumstances where law is viewed as one among a range of social phenomena. Another view is that it is concerned with the study of law and legal institutions from other disciplinary (social science) perspectives. As one commentator has observed, consensus on a definition is likely to prove elusive. In the circumstances, it is perhaps best to view socio-legal inquiry as a 'broad church', offering the opportunity and the space to engage in a critical examination of the role of law, legal institutions and practices from different disciplinary lenses, or in the context of other disciplines.[16]

14 Anne-Maree Farrell et al., 'Regulatory "Desirables" for New Health Technologies' (2013) 21(1) *Medical Law Review* 1–171 (journal special issue).

15 See, for example, Derek Morgan, *Issues in Medical Law and Ethics* (Cavendish, 2001) Ch 1; Kenneth Veitch, *The Jurisdiction of Medical Law* (Ashgate, 2007); Ben White, Fiona McDonald and Lindy Willmott, 'Health Law: Scope, Sources and Forces' in Ben White, Fiona McDonald and Lindy Willmott (eds), *Health Law in Australia*, 2nd edn (LawBook Co, 2014) 7–11.

16 Kerry Petersen, 'Socio-Legality and La Trobe University: Introducing and Celebrating a Broad Church of Ideas' (2013) 29(2) *Law in Context* 1.

While an in-depth examination of these debates is not possible here,[17] we argue that what is valuable about such an approach is the type of critique it offers regarding assumptions of law's neutrality and benign power in the field of health. In adopting a socio-legal analysis of health, we are able to explore the way in which law constitutes, and is constituted by, health discourses and practices. This may lead us to ask about the extent to which law is constitutive of the relationship between doctors and patients. Or conversely, the extent to which the particular area of health under examination determines law's role and response. While the starting point may be law, the end point of socio-legal inquiry may show that a range of non-legal factors – social, cultural, economic, institutional – influence the ways in which we answer such questions, and those ways are ones that may be omitted or not deemed relevant by those engaged in doctrinal study of the law.[18]

Socio-legal inquiry also highlights the importance of an interdisciplinary approach which seeks to understand and critique the way in which legal issues, practices and institutions are constituted by their social context and vice versa. While there is a long tradition of interdisciplinary engagement at the intersection between bioethics and the law,[19] we argue that socio-legal inquiry requires a more expansive approach in both theoretical and methodological terms, incorporating insights from a broader range of disciplinary perspectives, including sociology, economics, politics and anthropology.[20] Adopting such an approach offers a richer, more nuanced analysis of the health law topics covered in the book.

Organisation of the book

The book is organised into two Parts. As noted previously, Part I examines key ethical, social, equity and human rights frameworks that we argue must be taken into account in any examination or analysis of discrete topics in health law (Chapters 2–5). Thereafter, an examination is provided of overarching institutional and regulatory arrangements impacting the health system in Australia (Chapter 6), health professionals (Chapter 7) and patients (Chapter 8). Part II is divided into a number of areas which cover select issues in health law. The first section is entitled 'Patients, Doctors and Healthcare' and covers core legal topics relevant to the relationship between patients and doctors. The first topic is consent to medical treatment, which explores how the law deals with a failure to obtain consent through actions in

17 There is a voluminous literature examining the nature, scope of and rationale for socio-legal studies. For example, see Donald Harris, 'The Development of Socio-Legal Studies in the United Kingdom' (1983) 3 *Legal Studies* 315; Phillip Thomas (ed.), *Socio-Legal Studies* (Dartmouth, 1997); Brian Tamanaha, *A General Jurisprudence of Law and Society* (OUP, 2001); Paddy Hillyard, 'Invoking Indignation: Reflections on Future Directions of Socio-Legal Studies' (2002) 29(4) *Journal of Law and Society* 645; Austin Sarat (ed.), *The Blackwell Companion to Law and Society* (Blackwell Publishing, 2004); Roger Cotterell, *Law, Culture and Society: Legal Ideas in the Mirror of Social Theory* (Ashgate, 2006); David Nelken, *Beyond Law in Context: Developing a Sociological Understanding of Law* (Ashgate, 2009); Dermot Feenan (ed.), *Exploring the 'Socio' of Socio-Legal Studies* (Palgrave Macmillan, 2013); Kerry Petersen (ed.), 'Socio-Legality: An Odyssey of Ideas and Context' (2013) 29(2) *Law in Context* (special issue); David Cowan and Daniel Wincott (eds), *Exploring the 'Legal' in Socio-Legal Studies* (Palgrave Macmillan, 2015).

18 Sally Wheeler and Phillip Thomas, 'Socio-Legal Studies' in David Hayton (ed.), *Law's Future(s)* (Hart, 2000) 267–79, 273.

19 Ian Freckleton, 'The Emergence and Evolution of Health Law' (2013) 29(2) *Law in Context* 74.

20 See Annelise Riles, 'Representing In-Between: Law, Anthropology, and the Rhetoric of Interdisciplinarity' (1994) *University of Illinois Law Review* 597, 601.

contract and battery, and includes a section on consent and capacity in relation to children (Chapter 9). This is followed by a chapter on substituted decision-making which examines a range of legal and other processes and mechanisms for people who lack capacity and are unable to make decisions for themselves in respect of specific medical treatment or their healthcare more generally (Chapter 10). The next chapter examines how the law addresses harm caused to patients as a result of medical treatment (Chapter 11). The final chapter in this section examines ethical and legal issues that arise in the area of confidentiality and privacy in the patient-doctor relationship, as well as the circumstances in which patients are able to access their medical records (Chapter 12).

The second section is headed 'Law at the Beginning and the End of Life'. Topics covered include the regulation of reproduction, which covers assisted reproductive technologies (ART) and aspects of pregnancy, including prenatal screening, abortion and surrogacy (Chapter 13). This is followed by an examination of a number of emerging reproductive technologies and the socio-legal implications likely to accompany such innovations (Chapter 14). The next two chapters examine ethical, social and legal issues in relation to end-of-life decision-making and care. The first examines the withdrawal and withholding of medical treatment near the end of life, including the management of post-coma unresponsive or minimally responsive patients (Chapter 15). Case law and law reform debates concerning euthanasia and assisted suicide are examined in the following chapter, which includes an overview of recent prosecutions and other legal challenges in the area in a range of jurisdictions (Chapter 16).

The next section is headed 'Law and the Human Body'. The four chapters in this section deal with different aspects of the law relating to human tissue and genetic information and data. The first of these chapters deals with organ and tissue donation and transplantation, covering living and deceased donation, consent models, markets and trade, the diagnosis of death and transplantation allocation criteria (Chapter 17). The law covering ownership and control of human bodies, parts and tissue is explored in the next chapter, as well as the merits or otherwise of a property-based approach in the area (Chapter 18). This is followed by an examination of biobanks, which store human tissue and related genetic information, issues of consent, privacy and confidentiality, property rights, and commercialisation (Chapter 19). The final chapter in this section provides an overview of the law as it applies to genetic technologies and their therapeutic uses. It engages with disparate legal areas including therapeutic goods regulation, discrimination, privacy, Indigenous rights and ownership. Developments in the area of epigenetics are also identified and their relationships with understandings of the social determinants of health are discussed (Chapter 20).

The final section in Part II is entitled 'Law and Populations'. The first three chapters in this section engage with specific populations that have been constituted as vulnerable, marginal or otherwise stigmatised in terms of the relationship between law and health. The first of these chapters explores the deeply troubling relationship between Indigenous people, health and the law in Australia, showing how a complex interplay of historical, social, political and systemic factors have adversely impacted Indigenous health and compromised law's role in the provision of healthcare in this population (Chapter 21). The next chapter explores the way in which the idea of disability is constructed through medical, social and legal discourses, as well as interrogating whether, and if so how, we should conceptualise the relationship between health law and disability. It also considers how disability has been defined and interpreted, as well as reviewing contemporary scholarship on models of disability (Chapter 22). The

following chapter draws on and develops some of the key issues raised in the previous chapter in order to explore the relationship between law and mental health. It identifies how mental illness has been defined and interpreted, before going on to examine how law deals with mental illness in the health system, with a specific focus on laws that permit detention and involuntary treatment (Chapter 23).

The final two chapters in this section deal with the relationship between law and health at the general population level. In the first of these chapters, the relationship between public health and the law is examined, by reference to definitions, sources, principles and institutional arrangements. By way of example, public health challenges in Australia are also identified (Chapter 24). The next and final chapter in the book explores the (potential) role of law in global health. It begins with an overview of the emergence of the global health agenda and the role of key institutions in developing such an agenda. The way in which the law intersects with global health is examined and its impact in Australia is considered, drawing on examples from health security, non-communicable diseases and trade agreements (Chapter 25).

There is potentially a wide range of topics that we could have included in Part II, given that health law is a rapidly expanding area of academic legal study. Choices had to be made as to what would be included. This was done on the basis of topical interest, as well as the fact that particular topics were within the authors' research expertise. A contextual approach was taken to the examination of these topics, with a view to linking them into one or more of the key frameworks identified in Part I. Although the chapters are primarily Australia-focused in terms of their examination of legal issues, comparative and international perspectives have been incorporated, where relevant and appropriate.

PART

FRAMEWORKS

THEORIES, PERSPECTIVES AND ETHICS IN HEALTH

2

PHILOSOPHICAL BIOETHICS AND HEALTH LAW

Justin Oakley

Introduction

Discussions of ethical issues in healthcare and reproduction often move quickly from judgments about the morality of a certain practice to judgments about how that practice ought to be regulated. However, it is important to distinguish between these two levels of analysis. Someone might believe, for example, that abortion is morally wrong in certain circumstances. However, they might not believe that abortion should be prohibited by law in those circumstances. One may hold that there is a variety of reasonable views about the morality of abortion, but that the law should not be enforcing one such view. So, being justified in judging a certain practice as immoral or unethical might not provide sufficient reason to hold that such a practice should be deemed unlawful.

Ethical theories and concepts can therefore be used to evaluate individual health decisions and laws, and also to justify changes to healthcare practices and law reforms in this area. Two distinct levels of ethical frameworks are commonly appealed to in philosophical bioethics. They can serve as a basis for judgments about regulating a practice, as well as for judgments about the morality of the practice itself. There are broad-based ethical theories and approaches, such as Kantian ethics, Utilitarianism, Virtue ethics, and Feminist ethics, and there are also more practical ethical frameworks specifically addressing healthcare practice, such as the well-known 'principlist' framework developed by Beauchamp and Childress. The key elements of this framework are the concepts of autonomy, beneficence (including non-maleficence, or doing no harm), and justice.[1] This chapter outlines both these broader and more specific ethical frameworks, and briefly explains the constituent concepts involved in each of them.

Rights-based approaches

While a range of rights-based ethical theories have been applied to healthcare practices, the most influential contemporary rights-based theories have been developed from an approach devised by the 18th-century German philosopher, Immanuel Kant. Kant argued that it is through using reason to govern actions that human beings become truly self-determining and therefore free. On this approach, only reason can reveal to us how we ought to act, and any human being with a capacity for rationality can recognise what is right and wrong, and can perform morally right actions. As a key figure in the Enlightenment, Kant aimed to develop a morality in which any person, insofar as they are rational, has the opportunity to live a moral life, to act in ways which are morally good, and is owed a certain basic respect. Because Kant saw reason as a means through which anyone can seek ethical guidance, he sought to underwrite an ethic of respect for persons which was independent of the contingencies of fortuitous birth or social circumstances.

Kant's basic approach to the evaluation of actions revolves around what he calls the 'Categorical Imperative', which provides a criterion for assessing actions whereby the principles or 'maxims' upon which a person is acting are examined. Kant initially formulates

1 Tom Beauchamp and James Childress, *Principles of Biomedical Ethics*, 7th edn (Oxford University Press [OUP], 2012).

the Categorical Imperative in a rather abstract way (which his subsequent formulations flesh out):

> Act only according to that maxim by which you can at the same time will that it should become a universal law.[2]

One example Kant uses to illustrate this criterion involves a person asking to borrow money from another, and falsely promising to repay it. Kant argues that borrowing money on the basis of a false promise contravenes the Categorical Imperative, because acting on such a maxim could not feasibly exist as a universal practice. Under a universal practice of false promising, a promisee would 'only laugh at any such assertion [of a promise] as vain pretense'.[3] Thus, deception is morally impermissible because it cannot consistently be universally willed without self-contradiction. Kant uses this kind of approach to derive a range of duties, such as the general duty that we must not make false promises, and the duty to provide much-needed help to others when we can.

By using the reasoning employed in the Categorical Imperative, Kantians provide a theory of basic moral rights. These rights include a right not to be deceived, and a right not to be coerced or manipulated by others. Acts are then evaluated according to what would or would not infringe those basic rights. So, if we observe the duties which correlate with those rights, we will not act wrongly. This will be so even if we thereby fail to bring about the greatest welfare or happiness for the parties involved in the situation.

The key idea, which later Kantians have appealed to in applying Kant's theory to practical issues, is that we should act with a due regard for the autonomy of other moral agents. In doing so, subsequent theorists have been guided by Kant's second formulation of the Categorical Imperative:

> Act so that you treat humanity, whether in your own person or in that of another, always as an end and never as a means only.[4]

In other words, we should act so that we treat others as autonomous, self-legislating, moral agents. Thus, for Kantians, autonomy – the capacity for rational, universalisable self-legislation – is intrinsically valuable, because it is in deciding and acting autonomously that we express our true humanity as free, rational beings. This approach provides a clear ethical rationale for practices such as obtaining informed consent from patients for medical treatment, and maintaining patient confidentiality, as such practices serve as important ways of respecting the personal autonomy of the patients involved. When applied to health policy and regulation, Kantians typically argue that the state has a responsibility to uphold basic respect for persons, through, for example, enacting laws which discourage people from demeaning or degrading themselves or others. Some Kantians argue that commercial surrogacy arrangements and selling one's organs are necessarily demeaning or degrading to some or all of the parties involved.[5]

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2 Immanuel Kant, *Foundations of the Metaphysics of Morals* (trans. LW Beck, Bobbs-Merrill, 1959) Ak 421.

3 Ibid Ak 423.

4 Ibid Ak 429.

5 For a detailed critical analysis of ethical and legal issues that arise in the context of (cross-border) commercial surrogacy and organ donation, see Chapters 13 and 17 respectively.

Kantian ethics illustrates well how rights-based approaches do not regard considerations of welfare as paramount in determining what we ought to do. While some rights-based theories see the impact of an action on the overall welfare of the affected parties as morally relevant, such theories do not regard such factors as settling the matter. Even if a certain action or practice would maximise the welfare of the parties involved – such as complying with relatives' requests to withhold a diagnosis of terminal illness from a patient with full decision-making capacity – it may still be thought wrong, for it may violate an individual's moral rights. The directive to respect others' rights is thus taken as a constraint on what can be justifiably done to benefit others.

Utilitarianism

Where Kantian ethics focuses on personal autonomy and respecting people's rights, Utilitarian approaches to ethics in health consider the impact of a decision or practice on the welfare of the parties involved. That is, Utilitarianism judges a particular decision, action, or policy according to the total effect it can reasonably be expected to have on people generally, and specifically, according to whether overall welfare is increased or decreased – where 'welfare' is understood as pleasure, happiness, or preference satisfaction.

Advocates of Utilitarianism present this theory as providing a more scientific and humane approach to dealing with questions about what we ought to do than appeals to human rights. For instance, one of the founding fathers of Utilitarianism, Jeremy Bentham, argued that the justifiability of various forms of punishment for convicted criminals is to be determined by looking at whether a certain system of punishment makes the relevant parties better off overall (by reforming the criminal and by deterring future crimes), rather than by whether any individual or communal rights to retribution have been fulfilled.[6] The early 19th century view of certain British settlements in Australia as social laboratories made them quite receptive to the reformist emphasis of Utilitarianism, which was being developed by Bentham at the same time that Australia was being colonised by Great Britain. Indeed, early examples of the influence of Utilitarianism in Australia are Bentham's panopticon-style prisons at the penal settlements of Port Arthur, Fremantle and Norfolk Island, in which guards at the hub could efficiently monitor prisoners in the cells which radiated out from the centre like spokes on a wheel.[7]

The general doctrine of Utilitarianism holds that:

> A practice is right if, and only if, it can reasonably be expected to produce the most utility, compared to its alternatives.

Earlier Utilitarians used the notion of utility to refer to pleasure or happiness, but many modern Utilitarians understand utility in terms of preference satisfaction, which they regard as more feasibly measured than pleasure or happiness. Utilitarianism can be applied to the evaluation of individual acts, or to the evaluation of general practices, rules, or policies; and maximisation of utility is the yardstick used to judge the rightness and wrongness of acts and

6 Jeremy Bentham, *An Introduction to the Principles of Morals and Legislation* (Hafner, 1961).
7 For discussion of Bentham's panopticon and its use in Port Arthur, see Julia Driver, *Ethics: The Fundamentals* (Blackwell, 2007) 42–3.

practices – thus, if an act fails to maximise utility, then it is wrong. This is meant to factor in the intensity with which those preferences are held, in that satisfying a strong preference counts for more than satisfying a weak preference. For example, RM Hare explains how Utilitarianism would decide which of two people ought to have access to a parking spot which they are both vying for:

> Suppose you are trying to park your car in a place where I have left my bicycle, and you have a *strong* preference to park your car in this spot, while I have a *mild* preference to leave my bicycle where it is. Suppose these are the only preferences which will be affected by your action. Then I ought to let you park your car in this spot. The fact that it is *my* bicycle, or that I got there first, is morally irrelevant. All that counts are our preferences and their strength.[8]

Thus, in the context of evaluating healthcare practices, such as upholding confidentiality in patient care, Utilitarians evaluate whether or not confidentiality can ever be justifiably breached by considering whether breaching confidentiality in certain circumstances – say, to protect a third party from a mentally ill patient who has confided in a clinician a threat to harm such party – would likely produce more benefit to the various parties involved than would maintaining absolute confidentiality.

When applied to public policy, Utilitarianism asks whether legalising a practice – such as commercial surrogacy – would maximise overall utility, even if the actions of the parties in a particular commercial surrogacy would not thereby maximise utility, considered on their own.[9]

Legal prohibitions of various activities often have all sorts of negative consequences. For example, a foreseeable consequence of a legal prohibition against abortion is that some women will be injured through turning to illegal 'backyard' abortionists in order to terminate a pregnancy. Whatever one's view of the morality of abortion, many think that the undesirable consequences of anti-abortion laws are sufficient to make such laws unjustifiable. Utilitarians argue that the justifiability of creating a law against a certain practice is entirely dependent on what we could expect the consequences of outlawing that activity to be. Thus, while there might be sound utilitarian reasons why a certain practice is wrong, there may nevertheless be sound utilitarian reasons against making such a practice unlawful, as legal prohibition may do more harm than good.

Of course, questions about whether to *prohibit* a certain practice by law are not the only legislative decisions faced by the state. Governments must also often decide whether or not to enact legislation which *decriminalises* certain practices in particular circumstances. For example, governments must decide whether or not to permit voluntary euthanasia and, if so, under what conditions. Utilitarian justifications of legislation decriminalising activities often point out how such legislation allows the state to exercise some kind of control over them, so that they are conducted properly. This is done to minimise harms which can result when the criminal law leads to such activities being practised covertly. However, critics of

8 Richard Mervyn Hare, *Moral Thinking: Its Levels, Methods and Point* (Clarendon Press, 1981) 111. See also John JC Smart, 'An Outline of a System of Utilitarian Ethics', in John JC Smart and Bernard Williams, *Utilitarianism: For and Against* (CUP, 1973).

9 See Richard Mervyn Hare, 'Public Policy in a Pluralist Society', in Peter Singer et al. (eds), *Embryo Experimentation* (CUP, 1990).

utilitarian approaches to law-making argue that while the consequences of enacting laws are important considerations, they do not settle the issue of what the law should be. For some critics, important moral rights and serious breaches of moral principles are the proper business of the law, whether or not creating laws protecting such rights and principles might have harmful consequences overall.

Virtue ethics

Instead of asking whether an action is in accordance with a particular duty or is likely to maximise the good, Virtue ethics asks a different sort of question: what sort of person would do a thing like that? For example, we can ask whether an action was generous or mean-spirited, courageous or cowardly, friendly or unfriendly. We can also ask whether this is the sort of thing which a kind person, a just person, or a self-respecting person, would do in the circumstances.

A Virtue ethics criterion of what makes an action right can thus be stated initially in broad terms as follows:[10]

> An action is right if, and only if, it is what an agent with a virtuous character would do in the circumstances.

On this approach, a right action is one that is in accordance with what a virtuous person would do in the circumstances, and what *makes* the action right is that it is what someone with a virtuous character would do. For example, it is right to help a stranger in distress because this is what someone with the virtue of benevolence would do. A person with the virtue of benevolence would do this because benevolence is directed at the good of others, and having this virtue involves being disposed to help others in circumstances where assistance is likely to be beneficial to them.[11]

Several forms of Virtue ethics have been developed recently, but the most influential is that based on Aristotle's ethics. Aristotle argued that there are certain sorts of things or activities which it is in our nature as humans to have and to do. For example, we are naturally social animals who have friendships and loving relationships. We naturally seek understanding of the world around us, we use reason to guide our lives, and we care about or are moved by what we value. These are the things which a good human being aims at having and achieving.[12]

Thus, two distinctive features of Virtue ethics are its emphasis on the connections between right action and the agent's motives, and its pluralist view of the good. Acting rightly, in many situations, requires acting from a particular sort of motivation, since this is an important aspect of doing what a virtuous person would do in the circumstances.[13] In

10 Rosalind Hursthouse, *On Virtue Ethics* (OUP, 1999) 28–31.

11 Philippa Foot, 'Euthanasia' (1977) *Philosophy and Public Affairs* 6(2).

12 See Aristotle, *The Nicomachean Ethics* (trans. WD Ross) (OUP, 1980).

13 An exception to this is the 'target-centred' pluralistic form of Virtue ethics developed by Christine Swanton, *Virtue Ethics, A Pluralistic View* (OUP, 2003) 294, 245–6, who argues that one can hit the target of a particular virtue from no relevant inner state at all. As such, Swanton appears to reject the idea that hitting the target of the contextually relevant virtue always requires acting from a particular virtuous motive or disposition.

contrast, most versions of Utilitarianism and Kantian ethics generally hold that one can act rightly whatever motivation one acts from. As long as one maximises expected utility, or acts in accordance with duty, one has done the right thing, whether or not one's motives were praiseworthy. Another important distinguishing feature between Virtue ethics and most versions of Utilitarianism is that contemporary Virtue ethicists commonly regard virtues as intrinsic goods whose value is not reducible to a single underlying value, such as utility. For instance, the value of personal integrity goes beyond its utility (eg. its pleasure) to oneself or others.[14]

In recent years, Virtue ethicists have applied the above criterion of right action in the context of various roles, such as medical practice, parenting, and personal relationships. Accounts have been developed of role virtues that demonstrably serve the proper goals of the profession or practice in question, mirroring Aristotle's goal-directed or 'teleological' account of how broad-based virtues enable us to live humanly flourishing lives. A key feature of these Virtue ethics evaluations of actions within roles is the central place given to the proper goals of the profession or practice in question, and to showing how a commitment to these goals should regulate or govern a practitioner's conduct in the context of that role. For example, in the healthcare context, Virtue ethics advises doctors to provide truthful diagnoses to their patients, not because patients have a right to know this information, or because truth-telling maximises utility, but because this is what is involved in a doctor having the virtue of truthfulness. A disposition to tell patients the truth serves the doctor's goal of achieving good health for the patient without breaching the patient's autonomy.

Other key virtues for doctors are medical beneficence, medical courage, and trustworthiness. Medical beneficence counts as a virtue because it focuses doctors on their patients' interests and blocks inclinations towards unnecessary interventions characterised by defensive medicine. Medical courage helps doctors work towards healing patients by helping doctors to face risks of serious infection when necessary, without rashly disregarding proper precautions against becoming infected themselves. Trustworthiness assists with effective diagnosis and treatment by helping patients feel comfortable about disclosing intimate information.[15]

One way of applying Virtue ethics to evaluating health regulation focuses on whether or not permitting a certain practice threatens to jeopardise doctors' medical virtues by undermining therapeutic relationships with patients. For example, the therapeutic orientation of doctor-patient relationships can be distorted by doctors' links with the pharmaceutical industry, and by direct-to-consumer advertising of pharmaceuticals. When the state supports (or fails to support) doctors developing and maintaining therapeutic relationships with their patients, it is supporting (or failing to support) doctors having and acting on the medical virtues they committed to having when they joined the profession. Therefore, the state needs to consider whether to allow practices which may threaten such professional relationships and virtues.

14 See Justin Oakley 'Varieties of Virtue Ethics' (1996) 9(2) *Ratio* 139–40.
15 Justin Oakley and Dean Cocking, *Virtue Ethics and Professional Roles* (CUP, 2001) 93.

Feminist approaches to bioethics

Feminist philosophers highlight the shortcomings of traditional bioethical theories, which, they argue, pay inadequate attention to gender inequities, as well as disparities in health, that result from differences in class, race, ethnicity and susceptibility to genetic disease. While there has been significant feminist analysis of key bioethical concepts such as autonomy (see below), separate consideration of the contribution of feminist bioethical critique as a distinct field is warranted. It is important to keep in mind, however, that there are a range of feminist approaches to bioethics, and that these resist encapsulation into a single criterion of right action.[16]

One prominent approach which originated from the work of feminist psychologist Carol Gilligan is an ethics of care. She claimed that there were female patterns of moral reasoning that emphasised relationships, as well as responsibilities within those relationships.[17] Unlike Virtue ethics, which focuses on the value of certain character traits and their role in a humanly flourishing life, care ethics focuses on the value of relationships, such as those between parents and children, spouses, partners, and friends. Care ethicists commonly emphasise how one's family typically plays a crucial role in the development of one's moral agency. They argue that the picture of moral agents in traditional ethical theories as self-sufficient and independent, rather than as relationally embedded and vulnerable, is misleading and unrealistic. Rather than viewing issues in terms of any rights individual agents may have, care ethics sees moral problems in terms of our responsibilities to others, and it encourages the development and maintenance of relationships which are both caring and equitable.[18]

As Shildrick notes, however, more recent feminist critique of the ethics of care challenges the central idea that biomedicine has, as its primary aim, either cure or care. Instead, she argues that 'health care is as much about control, containment and normalization as it is about treatment'.[19] Feminist scholars, such as Tong and Lanoix, have called for a reconsideration of the ethics of familial, as opposed to societal, responsibilities in the area of health.[20] Yet others, such as Fineman, have argued that the focus should instead be on inevitable dependency, rather than individual autonomy;[21] and Rogers has called for greater recognition of the importance of a feminist critique of public health.[22]

16 For a good summary, see Stanford Encyclopedia of Philosophy, '*Feminist Bioethics*' <http://plato.stanford.edu/entries/feminist-bioethics>.

17 Carol Gilligan, *In a Different Voice: Psychological Theory and Women's Development* (Harvard University Press, 1982).

18 Virginia Held, *The Ethics of Care: Personal, Political, and Global* (OUP, 2006).

19 Margrit Shildrick and Roxanne Mykitiuk (eds), *Ethics of the Body: Postconventional Challenges* (MIT Press, 2005) 17.

20 Rosemarie Tong, 'Long-term Care for the Elderly Worldwide: Whose Responsibility Is It?' (2009) 2(2) *International Journal of Feminist Approaches to Bioethics* 5; Monique Lanoix, 'Caring for Money: Communicative and Strategic Action in Ancillary Care' (2013) 6(2) *International Journal of Feminist Approaches to Bioethics* 94.

21 Martha A Fineman, 'Masking Dependency: The Political Role of Family Rhetoric' (1995) 81 *Virginia Law Review* 2181.

22 Wendy A Rogers, 'Feminism and Public Health Ethics' (2006) 32 *Journal of Medical Ethics* 351.

It is also worth noting one further area in which feminist bioethics has had a significant impact on bioethical critique, and that is the field known as feminism of the body.[23] Scholars working in this field argue that mainstream bioethics tends to use universalising ethical principles that work only for decontextualised and disembodied individuals, who bear little resemblance to material persons who exist in the world. These scholars argue that such approaches, where they do relate to the embodied and embedded person, tend to favour those whose bodies are most accommodated or normalised: that is, white, middle-class, able-bodied men. Instead, it is argued that mainstream bioethics should take account of non-normative, marginalised bodies – not in order to find ways to normalise them, but rather to embrace difference and to build theoretical models that recognise diversity.[24] One of the key contributions of feminist bioethicists in this regard has been to argue that biomedical discourse is an incredibly powerful force in the construction of normalcy, and this makes it incumbent on mainstream bioethics to take account of such critique in ethical analysis of healthcare practices.

Autonomy

In the 1980s, the value of personal autonomy was at the forefront of the critique of medical paternalism, which inaugurated the field of bioethics. It remains a central concept in the justification of various aspects of decision-making in healthcare practice. The ethical demand to respect the autonomous decisions and actions of patients is a crucial requirement upon health professionals. To be autonomous is to be self-determining in one's decisions and actions. To act or decide autonomously is to do so in accordance with one's values. We saw above that Kantian ethics places respect for autonomy at the centre of ethical decision-making; however, many philosophers who emphasise the importance of patient autonomy adopt conceptions of autonomy which are less demanding than Kantian accounts, and which allow a person's desires and emotions to play a greater role in constituting and expressing autonomous decisions.

Various philosophical theories have been put forward regarding what constitutes autonomy. Mainstream bioethics asserts that the capacity for autonomy involves two broad components: a *cognitive* component, which requires that one decides on the basis of one's understanding of relevant information about what one proposes to do; and a *volitional* component, which requires that one makes a voluntary decision, not prompted by inner compulsions, and without being coerced by others' threats or manipulated by others who deliberately target one's weaknesses.[25] Thus, when people talk about autonomy in clinical care, they often talk in terms of informed and voluntary decision-making by patients. For example, the recent emergence of advance care planning, where individuals are encouraged to develop and express better informed views about possible clinical interventions

23 This work must be read alongside the growing body of ethical critique in disability studies; for a detailed discussion of such work, see Chapter 22.

24 Shildrick and Mykitiuk, above n 19, 16.

25 For an overview of how the ethical position on autonomy maps onto the law of consent in the context of both capacity and incapacity, see Chapters 9 and 10.

towards the end of their lives, is based squarely on the idea that personal autonomy must be respected by health professionals.[26]

Feminist philosophers have also been critical of this mainstream approach to conceptualising autonomy, suggesting that it can operate only in circumstances that do not exist for most (if any) people. Instead, they have argued for recognition of the concept of 'relational autonomy', which views individual capacity to act as existing only or largely in the context of social relationships, and as being shaped by a complex interplay of social determinants, such as race, class, gender and ethnicity.[27] Yet other feminist scholars have rejected mainstream bioethical conceptions of autonomy altogether, arguing that our inevitable dependency on each other and our universal vulnerability ought to be the ordering principles for a system of ethical exchange.[28]

Beneficence

To act beneficently towards a patient is to act so as to benefit them, or at least to protect them from harm. Given that serving patient health is clearly a central goal of clinical practice, the ethical requirement to act beneficently towards patients is arguably of paramount value. Indeed, whatever else the idea of professional integrity in clinical practice might involve, it clearly includes a commitment to act in the best interests of one's patients. However, there are debates among health professionals about how the concept of 'best interests' is to be understood – consider here, for example, controversies about the meaning of 'medical futility' – and these debates often reflect philosophical disagreements about the nature of human wellbeing or welfare.[29]

A key issue here is how the quantity of life likely to be gained by a certain intervention is to be compared with the quality of life the patient is likely to subsequently experience. Some accounts of best interests hold that the quality of a patient's life is ultimately determined by their own subjective values or preferences; whereas other accounts understand quality of life in more objective terms. As an example of the latter, the 'capabilities approach' to wellbeing was devised as an alternative to preference-utilitarian approaches to measuring quality of life. As one of its originators, Martha Nussbaum, puts it: 'we want to know not only how people feel about what is happening to them … we also want to know what they are actually able to do and be'.[30] In any case, it is widely held that we can have a general duty of beneficence to help a stranger in considerable distress. In patient care, there are specific duties of beneficence deriving from institutional roles and the commitments to patients which such roles involve.

26 For an overview of advance care planning, end-of-life issues and the role of law, see Chapter 15.

27 Catriona Mackenzie and Natalie Stoljar (eds), *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self* (OUP, 2000) 4. See Chapter 4 for a detailed discussion of how such social determinants impact health, as well as law's role in shaping such impact.

28 Fineman, above n 21; Catriona Mackenzie, Wendy Rogers and Susan Dodds (eds), *Vulnerability: New Essays in Ethics and Feminist Philosophy* (OUP, 2014).

29 See Lawrence J Schneiderman, Nancy S Jecker and Albert R Jonsen, 'Medical Futility: Its Meaning and Ethical Implications' (1990) 112 *Annals of Internal Medicine* 949; James Griffin, *Well-Being: Its Meaning, Measurement and Moral Importance* (OUP, 1986).

30 Martha Nussbaum, *Frontiers of Justice* (Harvard University Press, 2006) 73.

Justice

Beneficence and autonomy are not the only broad ethical principles needed for justifying decision-making in healthcare. For example, even if we have a duty of beneficence to put a particular patient on a kidney dialysis machine, it may not be right to do so because this might be unjust. This is because such devices may well be a scarce resource and another patient might have a stronger justice-based claim to the device. So healthcare decision-making and practice should also be governed by an overarching principle of justice. The values of autonomy and beneficence focus on how it is proper to treat individual patients, whereas the principle of justice looks at how a patient is to be properly treated within the broader context of whether a treatment they may have autonomously consented to ought to be provided to them, or to another patient who might have a stronger justice-based claim to it.

An important principle of justice in healthcare practice, stated abstractly, is that scarce health resources ought to be distributed according to morally relevant features of individuals, rather than according to morally irrelevant features (such as a patient's social status). A range of different specific allocative principles has been advocated by bioethicists. For instance, some argue that justice requires that such resources be distributed according to the urgency of a patient's needs; others argue that resources should be distributed according to the relative benefit that the patient stands to gain from the resource, compared with other potential recipients of this resource. Yet others argue that resources should be allocated in accordance with policies which promote consumers' freedom of choice among health programs.[31]

How might these three ethical principles work together?

One way of understanding how the values of autonomy, beneficence and justice might function effectively together in an overall ethics for healthcare is that respect for patient autonomy should be regarded as a side constraint rather than a goal of healthcare practice. Each profession has its own distinctive goal(s), which a health professional's role should be geared towards serving. For example, good health is a central goal of medicine, and effective caring is an important goal of nursing. Patient autonomy becomes morally significant in this context because whatever a health professional does to help restore or promote the health of a patient, it must be done in a way that does not violate their autonomy. Respect for the autonomy of patients is an important side constraint on the ethical pursuit of any proper professional goal, but this demand assumes particular importance for the health professions. This is because illness makes us especially vulnerable to various internal and external influences, which can undermine our capacity for autonomous decision-making. As a result, this places health professionals in a particularly powerful position when compared to other professionals.

It is also important to distinguish between justified and unjustified restrictions of a patient's autonomy. For example, assume that only one of two patients can be given an

31 See Norman Daniels, *Just Health: Meeting Health Needs Fairly* (CUP, 2008).

intensive care bed. Suppose a patient with advanced renal failure is denied admission to the intensive care unit in favour of a patient who stands to benefit far more from treatment in the unit. Here, the former patient's autonomy is certainly restricted by being refused admission to intensive care; but if justice requires that the bed be provided to the other patient instead, then the restriction of the first patient's autonomy in denying them an intensive care bed is ethically justifiable. A patient's autonomy counts as being violated when their autonomy is restricted unjustifiably. The requirement for health professionals to respect patients' autonomy demands that health professionals do not restrict their patients' autonomy unjustifiably. Such a requirement does not demand that health professionals meet whatever informed and voluntary requests patients make of them.[32]

Conclusion

Understanding key concepts in philosophical bioethics is important for clarifying the various contested issues that arise in health law and regulation. Lawyers and doctors need conceptual tools in order to critique such issues, and in order to find a principled way forward through these issues. In this chapter, we have seen how healthcare practice, law and regulation can be evaluated according to comprehensive, broad-based ethical theories and approaches, such as Kantian ethics, Utilitarianism, Virtue ethics, and feminist ethics. We can also draw on a more specific ethical framework in healthcare practice, whereby the concepts of autonomy, beneficence and justice (and the principles containing them) serve as crucial cornerstones. In outlining these ethical theories and concepts, this chapter has indicated their key differences, along with the motivations behind their development. This can help to clarify what is at stake in key ethical controversies which are relevant to healthcare practice, law and regulation. In addition, the need for such ethical frameworks as a basis for evaluating any proposed changes and law reform is likely to become increasingly important, given encroaching market and political pressures in the health sector more generally.

32 Oakley and Cocking, above n 15, 84–5.

3

SOCIO-LEGAL PERSPECTIVES ON PATIENT-DOCTOR RELATIONS

Anne-Maree Farrell

From the 1970s onwards, growing interest in the critical examination of the relationship between law and medicine led to the emergence of a new area of academic study known as medical law. While the initial catalyst for such interest was the exponential growth in medical negligence litigation in a number of common law jurisdictions, including Australia,[1] it was also influenced by an appreciation of law's potential role in promoting an ethically principled approach to the doctor-patient relationship.[2] Law's role in such a relationship, underpinned by (philosophical) bioethical critique, remains a core aspect of study and scholarship in the field of medical law, as well as within the expanding field of health law.[3]

While the relationship between bioethics and the law has become an established approach to understanding and critiquing the moral dilemmas and challenges that arise in the doctor-patient relationship,[4] what it lacks is a more nuanced and contextual account of other important social dynamics that influence such a relationship.[5] In turn, this may impact upon what law does and does not take into account in determining the acceptable parameters of such relationships. Law's role in this regard includes, for example, the regulation of the health system, the health professions and patient safety (Chapters 7–9); legislation which may either directly or indirectly impact upon such relations (Chapters 4 and 10), and redress mechanisms for harm caused to patients in healthcare settings (Chapters 8, 11 and 12).

Through a number of illustrative examples, the aim of this chapter is to highlight the importance of a contextual analysis of the patient in the study of health law, which is embedded in their day-to-day experiences with their treating doctors (as well as other health professionals). The objective in doing so is to facilitate a more critical reflection of the limits of the traditional twinning of ethical and legal analysis in seeking to understand how patients interact with their treating doctors, and to encourage a broader engagement in health law with both theoretical and empirical research in the social sciences.

The first part of the chapter presents a brief consideration of the social context in which patients access and receive healthcare, as well as law's role in that context. The social determinants impacting health are important in this context and they are considered in much more detail in Chapter 4. This part also includes a discussion of the primacy accorded to the principle of autonomy in mainstream bioethics and law and how it is (or should be) balanced against patient responsibilities. In the second part of the chapter, the power imbalance in patient-doctor relations is explored. This includes examining medicine's claim to expert knowledge; how such imbalance plays out in the framing of patients as good or difficult; and in the disclosure of risks in medical treatment. The final part of the chapter briefly considers law's role in shaping risk disclosure in this context.

1 Ian Freckleton, 'The Emergence and Evolution of Health Law' (2013) 29(2) *Law in Context* 74.

2 Jonathan Montgomery, 'Time for a Paradigm Shift: Medical Law in Transition' (2000) 53(1) *Current Legal Problems* 363.

3 See Chapter 1 for an overview of the development of medical and health law; see also chapters in Part II, A: Patients, Doctors and Healthcare.

4 Jose Miola, *Medical Ethics and Medical Law: A Symbiotic Relationship* (Hart, 2007); see, for example, J Kenyon Mason and Graeme T Laurie, *Law and Medical Ethics*, 9th edn (OUP, 2013); Ian Kerridge et al., *Ethics and Law for the Health Professions*, 4th edn (Federation Press, 2013).

5 See Ruth Fletcher, Marie Fox and Julie McCandless, 'Legal Embodiment: Analysing the Body of Healthcare Law' (2008) 16 *Med L Rev* 321, 322–3.

The patient in context

Within clinical settings, patients are individuals who are in ill-health or have a disease, and are receiving medical treatment. Patients may be young or old, poor or rich, have acute or chronic illness, and come from different racial, ethnic or identity backgrounds and geographical locations. Such diversity may be reflected in the extent to which they consider themselves to be sick or ill, whether or not they are considered to have (legal) capacity, and whether they feel marginalised, either as an individual or as part of a particular group. Depending on the type of treatment needed, patients may access the public or private healthcare sector or a mixture of both, which in turn may depend upon personal preferences, finances and location. Patients may present alone or be accompanied by family and friends. How they approach decision-making about their healthcare may also vary depending on their relations with family, friends and the broader community to which they belong.

Individuals who present as patients are in a relational, interconnected world, and are embedded in a range of social and cultural relations and practices. Within the social sciences literature, the concept of embodiment has been used to highlight the importance of taking account of the subjective experience of patients in dealing with ill-health and disease, as well as their experience in accessing and receiving healthcare. There is a recognition that patients (and their bodies) cannot be seen as solely biological objects, subject to control through medicine and technology.[6] Patients' 'being-in-the-world' – sensation, emotions and experience – comes with them, and affects the way in which they access and receive healthcare, as well as the way in which they navigate health professional and institutional practices.[7]

So where does bioethics position itself in conceptualisng the patient? As highlighted in Chapter 2, feminist approaches to bioethics, such as the ethics of care, recognise that patients are relationally embedded with family and friends and that moral problems need to be addressed in terms of our relations with others.[8] Others have argued that our vulnerability as human beings and the consequent dependency that brings to our relationships, should guide ethical decision-making and behaviour.[9] For those in favour of a relational autonomy approach, atomistic accounts of autonomous choice in healthcare decision-making by patients fail to take account of the context in which such decision-making takes place, which is informed by a range of social determinants, such as race, class, gender and ethnicity.[10]

Communitarianism acknowledges the importance of community and the social good. This requires that account be taken of meaning, implications and context in determining

6 See, for example, Nancy Scheper-Hughes and Margaret Lock, 'The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology' (1987) 1 *Medical Anthropology Quarterly* 6; Mike Featherstone et al., *The Body: Social Process and Cultural Theory* (Sage, 1991); Thomas J Cordas, 'Introduction: The Body as Representation and Being-in-the-World' in Thomas J Csordas (ed.), *Embodiment and Experience: The Existential Ground of Culture and Self* (CUP, 1994) 3–6; Fletcher et al., above n 5, 321–2.

7 Csordas, above n 6, 8.

8 See Virginia Held, *The Ethics of Care: Personal, Political, and Global* (OUP, 2006).

9 See Catriona Mackenzie, Wendy Rogers and Susan Dodds (eds), *Vulnerability: New Essays in Ethics and Feminist Philosophy* (OUP, 2014).

10 See Catriona Mackenzie and Natalie Stoljar (eds), *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self* (OUP, 2000); see also Chapter 4 for a detailed discussion of the social determinants of health.

what constitutes an ethically principled approach in healthcare, rather than relying solely on the autonomous choice of individuals.[11] In contrast, more mainstream bioethics, as exemplified in the principlist framework, is concerned primarily with the one-on-one relationship between patients and doctors.[12] The focus is on promoting the autonomous choices of individual patients and the use of ethical decision-making in clinical practice, rather than on the social and political issues impacting patients.[13]

Largely mirroring mainstream bioethics, the development of common law principles, and indeed legal precedent in general, has been predicated on the one-to-one relationship between patient and doctor. Law's role has been primarily to set out the scope of patients' rights and protections, as well as to determine what will be permitted (or not) in relation to patients' bodies. Mind/body dualism is largely perpetuated, with patients' bodies viewed as biological objects around which choice or rights have been infringed, and/or where harm has been done. More often than not, this is conceptualised in terms of the need to uphold or respect patient autonomy, which we consider in more detail in the next section.

Patient autonomy

Autonomy has become the pre-eminent ethical principle underpinning patient-doctor relations. Its importance has also been recognised by the courts,[14] with the most prominent affirmation to be found in the law of consent.[15] Although framed differently, it is also given effect in (international) human rights instruments and jurisprudence.[16] The importance of patient autonomy is also recognised in the patient-centred care approach in healthcare settings. The promotion of autonomous decision-making by patients is seen as important in enhancing patient satisfaction; in ensuring that treatment and medication regimes are adhered to; and in bringing about better health outcomes overall.[17]

What does it mean to uphold patient autonomy in clinical practice? First and foremost, respect for autonomy does not on its own mean that doctors must automatically respect and follow decisions by patients regarding their healthcare. Instead, to attract such respect patients must be considered to have made a decision (or choice) that is 'maximally

11 Daniel Callahan, 'Individual Good and Common Good: A Communitarian Approach to Bioethics' (2003) 46(4) *Perspectives in Biology and Medicine* 496–507.

12 Tom L Beauchamp and James F Childress, *Principles of Biomedical Ethics*, 7th edn (OUP, 2013).

13 Fletcher et al., above n 5, 322–3. As to whether the principlist framework actually informs day-to-day clinical practice, see Katie Page, 'The Four Principles: Can They Be Measured and Do They Predict Ethical Decision Making?' (2012) 13 *BMC Medical Ethics* 10.

14 See, for example, *Secretary, Department of Health and Community Services v JWB and SMB* (Marion's Case) (1992) 175 CLR 218; *Rogers v Whitaker* (1992) 175 CLR 479; *Re T (adult: refusal of medical treatment)* [1993] Fam 95, 102 (CA); *Chester v Afshar* [2005] 1 AC 134; *Montgomery v Lanarkshire Health Board* [2015] UKSC 11.

15 There is a voluminous academic literature in the area. For recent examples, see Alisdair MacLean, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (CUP, 2009); Sheila McLean, *Autonomy, Consent and the Law* (Routledge, 2010); Mary Donnelly, *Healthcare Decision-Making and the Law* (CUP, 2014); see also Chapter 9 for a detailed examination of the law of consent in the context of medical treatment in Australia.

16 For a critical overview, see Thérèse Murphy, *Health and Human Rights* (Hart, 2013); see also Chapter 5.

17 Nicola Mead and Peter Bower, 'Patient-Centredness: A Conceptual Framework and Review of the Empirical Literature' (2000) 51 *Social Science & Medicine* 1087.

autonomous – an informed and free decision made by someone with the capacity to make such a choice'.[18] In certain circumstances, the law has imposed limits on the autonomy of some individuals and their bodies, as exemplified in the English line of cases involving women being forced to undergo caesarean sections against their wishes.[19] Law's neutrality in such cases is subject to challenge, particularly given the long history of marginalisation of women's bodies in social and legal terms.[20] This is in addition to difficulties experienced by both the courts and legislatures in conceptualising the maternal-fetal relationship, notwithstanding the lack of legal recognition of the fetus.[21]

The pre-eminence of respect for autonomy as the dominant ethical principle in clinical practice raises the question as to whether, and if so what sort of, legal limits might be imposed on the expression of such a principle. Clearly, legal limits have been imposed due to incapacity,[22] but what of the competent patient? The law has upheld the right of an adult competent patient to refuse medical treatment, regardless of the outcome.[23] However, it has not followed that a competent patient will be entitled to demand medical treatment if their treating doctor is of the view that it is not clinically indicated or appropriate.[24] Treating doctors are not required to continue with treatment they consider to be futile[25]

Whether there should be ethical and legal limits imposed on the principle of autonomy has been the subject of academic debate, particularly with regard to where the balance should lie between patient autonomy and responsibility, particularly in the context of publicly funded health systems.[26] In ethical terms, it has been argued that patients have moral responsibilities in their relationship with doctors, as well as to the health system more generally. For commentators such as Sorell and Draper, the focus in ethical analysis on doctors' responsibilities in treating patients has been too one-sided. Traditionally, the ethical positon has been to place a 'big and largely unconditional responsibility on doctors to treat patients "no questions asked"'.[27] This has resulted in doctors becoming 'captive helpers', even in

18 Margaret Brazier and Emma Cave, *Medicine, Patients and the Law*, 5th edn (Penguin, 2011) para 3.3.

19 For an overview of the English line of cases, see Sara Fovargue and Jose Miola, 'Are We Still "Policing Pregnancy"?' in Catherine Stanton et al. (eds), *Pioneering Healthcare Law: Essays in Honour of Margaret Brazier* (Routledge, 2016) 243–54.

20 Margaret Brazier, 'The Body in Time' (2015) 7(2) *Law Innovation and Technology* 161, 179–84.

21 Fovargue and Miola, above n 19. See also public debate over fetal legal personhood which arose in the context of an ultimately unsuccessful legislative proposal in NSW which sought to criminalise harm caused to late-term fetuses due to injuries inflicted on their mother: see Hannah Robert, 'Why Losing My Daughter Means I Don't Support Zoe's Law', *The Conversation* (8 November 2013) <http://theconversation.com/why-losing-my-daughter-means-i-dont-support-zoes-law-19985>.

22 See Chapters 10, 15 and 24.

23 See, for example, *Brightwater Care Group v Rossiter* (2009) 40 WAR 84; *Medical Treatment Act 1988* (Vic).

24 *R (Burke) v General Medical Council* [2005] EWCA Civ 1003. Note that in the case of an incompetent adult patient, a best interests test would apply: see, for example, *Messiha v South East Health* [2004] NSWSC 1061.

25 See Chapter 15 for an overview of ethical and legal issues impacting the withholding and withdrawal of medical treatment.

26 See Margaret Brazier, 'Do No Harm – Do Patients Have Responsibilities Too?' (2006) 65(2) *Cambridge Law Journal* 397.

27 Heather Draper and Tom Sorell, 'Patients' Responsibilities and Medical Ethics' (2002) 16(4) *Bioethics* 335, 337.

circumstances where their patients are not acting in accordance with the medical advice provided.[28] While Sorell and Draper accept that patients may be vulnerable in seeking healthcare, this does not mean that patients can do no wrong.[29] They suggest that patients should be seen as moral agents with responsibilities for their own health: this requires them to follow the advice given to them by their treating doctors, and in doing so to limit their claims on the finite resources of publicly funded health systems.[30] Of course such reasoning assumes that doctors are best placed to mediate such claims.

Brazier also argues that patients have moral responsibilities, which exist in an environment in which the actions of patients, health professionals and institutions, as well as the community, are all engaged.[31] She acknowledges that one of the advantages of identifying patients' moral responsibilities may be to identify the limits of doctors' obligations to patients,[32] suggesting that it is this reciprocity which may determine the acceptability of moral (and perhaps even legal) responsibility.[33] While remaining wary of law's engagement in this area, she argues that there is a need for more critical reflection as to when and how such responsibilities should be balanced against the empowerment of patients brought about by the law's promotion of autonomy. She concludes that to do otherwise would be to potentially put at risk the advances which have been made as a result of the recognition of patients' rights.[34]

While there is a need to engage with academic debates about what should constitute the moral and legal boundaries of patient autonomy, there is also a need to recognise that such debates bring a range of other social and political factors into play. In making arguments about the importance of patients' moral responsibilities, there is a risk that this transforms into a political demand that individuals accept personal responsibility with respect to their own health,[35] without taking account of the broader social determinants of health which may adversely impact upon individuals' health, and over which they may have little control.[36] This may be used to create financial, institutional or indeed legal obstacles to accessing and receiving healthcare, often for those who need it the most. It may also result in a lack of political commitment to engaging in preventive health policy and regulation on a population basis.[37]

28 Ibid 346.
29 Ibid 339.
30 Ibid 347, 350–2.
31 Brazier, above n 26, 401.
32 Ibid 413. Note that Brazier excludes from her examination questions of self-responsibility (eg. where excess alcohol consumption may preclude eligibility for a liver transplant).
33 Ibid. Indeed, it may even raise the (albeit rare) prospect of contributory negligence being recognised as a defence in medical negligence claims. For example, see Jennifer Yule, 'Defences in Medical Negligence: To What Extent Has Tort Law Reform in Australia Limited the Liability of Health Professionals?' (2011) 4(1–2) *JALTA* 53, 54–6.
34 Brazier, above n 26, 422.
35 Gerald Dworkin, 'Voluntary Health Risks and Public Policy' (1981) 11(5) *Hastings Center Report* 26; Daniel Wikler, 'Who Should Be Blamed for Being Sick?' (1987) 14(1) *Health Education Quarterly* 11.
36 See Chapter 4 for a more detailed discussion of the social determinants of health and the role of law.
37 See Chapter 24, which examines how the political context has adversely affected preventive public health initiatives in Australia in recent years.

A question of power

The rise in patient autonomy is said to have been accompanied by patient empowerment, and represents a move away from the dark days of medical paternalism, where patients were passive and deferential towards their treating doctors, as well as uncritically accepting of the medical advice they received.[38] It is asserted that patients have been empowered through a more patient-centred approach to healthcare, which emphasises shared decision-making between patients and doctors.[39] Yet empirical evidence shows that such assertions may be aspirational at best in the face of the power imbalances which exist in patient-doctor interactions. From the perspective of patients, there are a number of factors contributing to such imbalance, which include knowledge about the illness or disease, treatment options and personal preferences; perceptions about what constitutes the 'good patient'; interpersonal characteristics and communication skills of treating doctors; and institutional practices which shape interactions between patients and doctors.[40]

In general terms, one of the ways in which power may be asserted is through claims to having expertise in a particular area. Those who make such claims often engage in boundary work to establish their expertise,[41] which includes distinguishing between expert and lay forms of knowledge.[42] Michel Foucault used the term the 'clinical gaze' to describe how claims to expert knowledge in the medical sphere were used to underpin doctors' social prestige, influence and power.[43] With this in mind, he conceptualised the relationship between knowledge and power in the following terms:

> We should admit … that power produces knowledge (and not simply by encouraging it because it serves power or by applying it because it is useful); that power and knowledge directly imply one another; that there is no power relation without the correlative constitution of a field of knowledge, nor any knowledge that does not presuppose and constitute at the same time power relations.[44]

In the face of what has been described by Lupton as the 'competence gap'[45] brought about by the knowledge/power nexus, patients may respond by presenting themselves in particular ways in their interactions with doctors, as a form of protection in the face of their vulnerability.

38 Brazier, above n 26, 401.

39 Cathy Charles, Amiram Gafni and Tim Whelan, 'Decision-making in the Physician-Patient Encounter: Revisiting the Shared Treatment Decision-Making Model' (1999) 49 *Social Science & Medicine* 651.

40 Natalie Joseph-Williams, Glyn Elwyn and Adrian Edwards, 'Knowledge is Not Power for Patients: A Systematic Review and Thematic Synthesis of Patient-Reported Barriers and Facilitators to Shared Decision Making' (2014) 94(3) *Patient Education and Counselling* 291.

41 Thomas F Gieryn, 'Boundary-Work and the Demarcation of Science from Non-science: Strains and Interests in Professional Ideologies of Scientists' (1983) 48 *American Sociological Review* 781.

42 Brian Wynne, 'May the Sheep Safely Graze? A Reflexive View of the Expert–Lay Knowledge Divide', in Scott Lash, Bronislaw Szerszynski and Brian Wynne (eds), *Risk, Environment and Modernity: Towards a New Ecology* (Sage, 1996) 44–83.

43 Michel Foucault, *The Birth of the Clinic: An Archaeology of Medical Perception* (Routledge, 1973); see also Bryan S Turner, *Medical Power and Social Knowledge*, 2nd edn (Sage, 1995).

44 Michel Foucault, *Discipline and Punish: The Birth of the Prison* (Vintage Books, 1977) 27.

45 Deborah Lupton, *Medicine as Culture: Illness, Disease and the Body in Western Society* (Sage, 2003) 113.

Good v difficult patients

In order to foster better relations with their treating doctors, research has shown that patients can internalise the need to be seen as a 'good patient', a position characterised by passivity and compliance.[46] Where an individual is receiving ongoing treatment for a chronic condition, how to be seen as a good patient becomes more complex. Although such an individual may acquire more knowledge about their condition over time, as well as becoming more confident about self-management, there is also a need to maintain good ongoing relationships with treating doctors and other health professionals. This may involve being suitably deferential and compliant in order to facilitate access to medication or health services they would like to receive, as well as ensuring the quality and safety of the treatment they receive.[47] This may be made more difficult by the fact that they need to navigate institutional practices in which power asymmetries and paternalistic behaviour towards patients may be entrenched, particularly in publicly funded health systems where resources are finite.[48]

What of the situation where patients encounter doctors with whom they experience difficulties in communicating about their health and medical treatment? Empirical research has shown that patients place a high value on being able to communicate in a meaningful way with their treating doctors. This allows them to express their fears and concerns, as well as to obtain information and feedback about their treatment and its likely outcomes.[49] A range of difficulties may arise if either doctors have poor communication skills or patients are unable (for a range of reasons) to communicate in a full and frank way with their treating doctors.[50]

In such circumstances, patients run the risk of being branded as 'difficult' by their treating doctors. Although it has been suggested that there is a tendency on the part of the medical profession to view this as a one-sided affair, with blame lying solely with patients,[51] the findings from empirical research have shown that it may in fact involve both 'difficult patients' and 'difficult doctors'. In the case of doctors, this may be attributable to particular personality characteristics, accompanied by poor communication skills. Where this combination occurs, it may result in worse short-term health outcomes for patients.[52] Such findings only reinforce the need for doctors to be more consciously aware of the power they hold and are able to exert in their relations with patients, as well as what ethical – and indeed legal – obligations may arise as a result of failures in communication with their patients.[53]

46 Joseph-Williams et al., above n 40.

47 Su-Yin Hor et al., 'Finding the Patient in Patient Safety' (2013) 17(6) *Health: An Interdisciplinary Journal for the Social Study of Health Illness and Medicine* 567–8.

48 Alison Pilnick and Robert Dingwall, 'On the Remarkable Persistence of Asymmetry in Doctor/Patient Interaction' (2011) 72 *Social Science & Medicine* 1374, 1381.

49 Hor et al., above n 47, 576; Anne-Maree Farrell and Sarah Devaney, 'When Things Go Wrong: Patient Harm, Responsibility and (Dis)empowerment' in Catherine Stanton et al. (eds), *Pioneering Healthcare Law: Essays in Honour of Margaret Brazier* (Routledge, 2016) 103–15.

50 Such reasons may include anxiety/depressive disorders, lack of trust and recent episodes of stress. See Sheri A Hinchey and Jeffrey L Jackson, 'A Cohort Study Assessing Difficult Patient Encounters in a Walk-In Primary Care Clinic, Predictors and Outcomes' (2011) 26(6) *Journal of General Internal Medicine* 588.

51 Jean Abbott, 'Difficult Patients, Difficult Doctors: Can Consultants Interrupt the "Blame Game"?' (2012) 12(5) *American Journal of Bioethics* 18.

52 Hinchey and Jackson, above n 50.

53 Michael Jefford and John R Zalcberg, 'Broken Doctor-Patient Relationships; Why Won't They Listen?' (2014) 201(6) *Medical Journal of Australia* 347; Loane Skene, 'Legal Issues When a Doctor's Relationship with a "Difficult" Patient Breaks Down' (2014) 201(6) *Medical Journal of Australia* 350.

Information disclosure and the role of law

As highlighted in the Introduction, there are a range of legal mechanisms in place to regulate interactions between patients and doctors in Australia, and any adverse consequences of those interactions. Clearly, the law has sought to promote the principle of autonomy in order to uphold patients' rights and protections in such relationships. The question is whether the law has been able to fully take account of the broader social and political contexts which may affect how patients access and receive healthcare and interact with their treating doctors.

In the seminal case of *Rogers v Whitaker*,[54] the High Court considered what sort of 'material risks' should be disclosed to patients by doctors in relation to their medical treatment. Acknowledging the need to take account of the particular circumstances in a given case, the Court stated that the types of risks that should be disclosed were those which 'a reasonable person in the patient's position, if warned of the risk, would be likely to attach significance to' or where the doctor 'is or should reasonably be aware that the particular patient, if warned of the risk, would be likely to attach significance to it'.[55] In this instance, the knowledge of the patient about the sorts of risks they might be prepared to undertake was given preference over what their treating doctors might consider to be clinically indicated or relevant.

Despite concerns on the part of the medical profession that the case would open the litigation floodgates, this has not eventuated. Indeed, empirical research has subsequently shown that many doctors remained ill-informed about their legal obligations regarding the disclosure of risks to patients, and 'routinely underestimate the importance of a small set of risks that vex patients'.[56] In addition, the High Court has since adopted a fairly strict interpretation of causation in subsequent information disclosure cases, which has operated as a control mechanism to mitigate any prospect of the floodgates opening.[57] This approach has been reinforced by the adoption of politically contentious restrictive tort law change in Australia in the early 2000s, at a time when there were increasing concerns about a personal injury litigation and insurance crisis.[58] These concerns led to the adoption of state/territory legislation in which patients' views on what they would have done if they had been warned of a material risk in relation to their medical treatment are not to be taken into account.[59]

Following yet another restrictive interpretation of causation by the High Court in a recent unsuccessful information disclosure case brought by a patient in *Wallace v Kam*,[60] one commentator felt compelled to observe that the Court was clearly showing 'undue deference to a

54 (1992) 175 CLR 479 [16] per Mason CJ, Brennan, Dawson, Toohey and McHugh JJ.

55 The test of material risk was held by the majority of the High Court to be subject to therapeutic privilege. For further details of this exception, see Chapter 11.

56 Marie Bismark et al., 'Legal Disputes Over Duties to Disclose Treatment Risks to Patients: A Review of Negligence Claims and Complaints in Australia' (2012) 9 *PLoS Medicine* e1001283.

57 See, for example, High Court judgments in *Chappel v Hart* (1998) 195 CLR 232; *Rosenberg v Percival* (2001) 205 CLR 434; *Wallace v Kam* (2013) 250 CLR 375.

58 See Review of the Law of Negligence: Final Report (the Ipp Report) (Commonwealth of Australia, 2002).

59 This is subject to the exception where statements given by patients would be against their own interests, see *Civil Liability Act 2002* (NSW) s 5D(3)(b); *Civil Liability Act 2003* (Qld) s 11(3(b); *Civil Liability Act 2002* (WA) s 5C(3)(b); *Civil Liability Act 2002* (Tas) s 13(3)(b). For a more detailed discussion, see Chapter 11.

60 (2013) 250 CLR 37.

fundamentally unjust stream of legislative change' which had been driven by powerful political and economic interests, rather than by any sound evidence of a litigation or insurance crisis.[61] Twenty-five years on from *Rogers v Whitaker*, Australian case law on information disclosure regarding the risks of medical treatment to patients provides an example of how the law has been influenced by the broader political context, shifting towards a restrictive judicial and legislative approach which limits rather than enhances patient autonomy. It also now stands in stark contrast to the more expansive approach taken in other jurisdictions, such as England. [62]

Conclusion

This chapter has offered a socio-legal perspective on patient-doctor relations. It has presented an analysis of how issues such as autonomy, responsibility, power and risk impact upon such relations, with an empirically grounded focus on the patient perspective. Using a contextual analysis of the patient into the study of health law should be encouraged, as it contributes to a more developed account of the dynamics of patient interactions with doctors and other health professionals. It also has the potential to offer insights into how law constitutes, and is constituted by, the broader social and political contexts which shape such interactions.

61 Thomas Faunce, 'Disclosure of Material Risk as Systems-Error Tragedy: *Wallace v Kam* (2013) 87 ALJR 648; [2013] HCA 19' (2013) 21 *Journal of Law and Medicine* 53, 64.

62 See Anne-Maree Farrell and Margaret Brazier, 'Not So New Directions in the Law of Consent? Examining *Montgomery v Lanarkshire Health Board*' (2016) 42(2) *Journal of Medical Ethics* 85.