MEDICAL LAW AND ETHICS

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# The Legal, Medical and Cultural Regulation of the Body

## Transformation and Transgression



Edited by

STEPHEN W. SMITH AND RONAN DEAZLEY

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# THE LEGAL, MEDICAL AND CULTURAL REGULATION OF THE BODY

# Medical Law and Ethics

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# Preface

The origins of this collection lie in a conversation in June 2007 about tattoos, body art and body modification, and in particular about the legal rights and claims (if any) that might subsist in relation to the same – not the body as property, but body adornment as intellectual property. As the conversation progressed, its focus shifted from intellectual property concerns to the various other ways in which the body, and the use of the body, is prescribed and regulated – not just in law, but medically and culturally also. From that conversation grew the idea for a one-day conference in September 2008, coordinated by the University of Birmingham's *Institute of Medical Law*, which conference in turn gave rise to this edited collection.

As the editors of this collection, we would like to take this opportunity to thank a number of people without whom this work would not have been brought to press. In the first place, we would like to thank the various speakers who contributed to the conference in 2008. When we began planning for that event we drew up a short list of academics and professionals – drawn from a range of disciplines – that we were interested in hearing give papers at the same. Remarkably, everyone we approached agreed to participate, and willing so. We are truly grateful for their time and effort in contributing to what was a thoroughly enjoyable conference and what we hope will prove to be a thoroughly engaging collection. Thanks are also due to the University of Birmingham's Collaborative Research Network fund for supporting the conference financially, to Emer McKernan and June Firth for their help and support in organizing that event and to Paul Mora who provided invaluable editorial assistance in preparing this collection for publication.

Particular thanks are due to Professor Margot Brazier. From the start we were certain that we wanted to end the conference with a keynote address, and from the start we were certain that we wanted Margot to deliver the same. As with the other contributors, Margot has been more than generous with her time and support. Moreover, on the day of the conference, as we sat listening to Margot deliver her concluding address, drawing together the various themes from each of the papers with such skill, and intelligence, and wit, we realized how redundant it would be to try to replicate that feat in writing our own introduction to this collection. And so, Margot's concluding address morphed into an Introductory Essay. Although unplanned, we thought that particular transformation particularly clever.

Stephen W. Smith
Ronan Deazley

# Contents

**PART III: TRANSFORMING THE BODY**



**PART IV: SELF-HARM AND SELF-DETERMINATION**

# Introduction
# Being Human: Of Liberty and Privilege

Margaret Brazier

## Introduction

This paper began as an ending and is transformed into a beginning.[1] The editors of this fascinating collection invited me to sum up at the conclusion of the day on which all the papers that follow were originally presented and debated, debated I should say with vigour. The task of summing up at the end of such a conference always sounds easier than it proves to be. My euphoria at not having to write a whole paper of my own for September soon evaporated. The papers began to arrive on my desk, and on 8 September 2008, I listened to the presentations through the day. Each was, and is, so packed full of thought and insight that I cannot in what is now an introductory essay respond to all of the speakers, or to any of them, in the depth that their work merits. Moreover, each section of the book has gained its own focused Introduction. So if I say little about some of the papers that follow, I trust that the authors will forgive me. I do no more than offer a 'taster' for some of what is to follow.

In the metamorphosis that this paper has undergone in its positioning in the collection, one may espy a rich metaphor connecting the publication to its subject matter of the body. For the nature of animal life, human and non-human, is that we struggle to draw boundaries asking when does life begin, when does it end. Yet life is a continuum. Gametes are living organisms even when ova are hidden deep in the body of a female fetus. Our organs may live on in others long after we are no more. The more science has to teach us about the biological organisms that house our identity, the more exciting and troubling the possibilities of bodies become.

## Why do Bodies Matter?

Scientific advances in transplant medicine, fertility treatment and, most recently, stem cell therapies have added a new dimension to ethical, social and legal[2] debates

1 For a more complete explanation of how this concluding essay became an introductory essay, please see the Preface to this volume.

2 For an excellent analysis of law's neglect of 'embodiment', see Fletcher, R., Fox, M. and McCandless, J. (2008), Legal Embodiment: Analysing the Body of Healthcare Law,

about the body. Today our own bodies hold the potential to offer therapies to us and to others.[3] Science has joined faith and culture in claiming a stake in living and dead bodies at all stages in life's continuum. It has even blurred the boundary between human and non-human animal life. However rather than start with such 'grand' questions, reading the draft papers for this collection over the summer prompted me to reflect on the myriad ways we consider our bodies (and the bodies of others) in everyday life. So as will be apparent, I do not follow the order of the book with its nice journey from the start of life, but rather I begin with what may seem to be more mundane questions about what bodies mean to their inhabitants.

In her essay on cosmetic surgery, Victoria Pitts-Taylor notes how '[B]ody practices are increasingly positioned in various ways as expressing, reflecting or revealing various aspects of the self.'[4] She writes, not of the use of bodies for transplant or 'medicine', but of the importance of the exterior to many people, of the body as a 'project'. Had I been asked 12 months ago, 'do you spend much time thinking about your own body, Margot?' my answer would (I think) have been 'no, not much unless it isn't working properly.' Dysfunction reminds us of the body. However, had I answered 'no, not much' I would unconsciously have lied, for, of course, I think a lot about my body. And I do so in a range of contexts every day. I give just a few examples. It is my primary *vehicle*, getting me up each day, conveying me downstairs for breakfast when I begin to fill it with fuel for the day. It is a crucial *instrument* for my day – an instrument that switches on the toaster and bends to pet and feed my puppy. It is part of my *clothing* (*or adornment*) as I style my hair and (when I can be bothered) put on make-up.

And above all for me, as for all of the authors of these essays, it is my means of *financial support*. Reader, do not panic! I am not about to reveal a tawdry past in glamour modelling or worse, in selling my body in the tabloid sense. I sell my *brain* (such as it is). That organ of my body is crucial to my ability to persuade the University of Manchester to pay for my services. Yet it can only function as part of the whole. Dysfunction of the lowly bowels can impair the function of the lofty brain. When commodification of body parts is discussed, all too often we leave out the living brain *in situ*. Those who like me are concerned about the sale of kidneys or commercial surrogacy have to find an answer to why it acceptable for us to hire out our brains, but not for a woman to rent her womb.[5]

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*Medical Law Review* 16, 321–345; and see other papers in that Special Issue (Volume 16:3) of the *Medical Law Review*.

3 See Brazier, M. (2006), Human(s) (as) Medicine(s), in MacLean, S. (ed.), *First Do No Harm*, (Ashgate), at pp. 187–202.

4 See Pitts-Taylor, V., Medicine, Governmentality and Biopower in Cosmetic Surgery, below at pp. 159–170.

5 For a nuanced discussion of bodies and their uses see Dickenson, D. (1997), *Property, Women and Politics*, (Cambridge Polity Press), at pp. 160–165; and see Dickenson, D. (2007), *Property in the Body: Feminist Perspectives*, (Cambridge University Press).

I want to suggest that is the range of functions and symbolisms inherent in bodies, living or dead, human or non-human, that make the body such a vexing ethical, legal and social question. Staying just for a moment longer with the adult, living, human body, consider how varied individual perceptions (and prejudices) are about the functions of the body. Take the body as *clothing* (*or adornment*). Place a value of 1 (virtually nil) to 10 (most important thing in your life) on that function. Be honest. Now think about those who would give clothing/adornment a value of 9/10. Would you think them vain, or even a little odd?[6] Would you judge men differently from women, or the pensioner of 82 differently from the youth of 21?

## Altering Bodies

How we look can be an integral part of who we are, even if we score a low value to clothing/adornment. How we look will often be the first way in which others begin to define us. Asked to describe Stephen Smith for someone due to meet him for the first time, I will begin with a physical description, not an account of his considerable intellect. Unless his new acquaintance is blind, how Stephen looks is how he will initially be defined. Appearance is individual, yet because we live as a community – and are to an extent pack animals – throughout history attempts have been made to prescribe appearance. So long hair for men at the court of Charles I was the norm. Long hair for men in the 1950s was curtailed, often coercively. No junior lawyer or doctor could be seen with hair on his shoulders.

In Western society, are we more liberal now? Or have we just shifted the boundaries a little? So in 2009 in Britain, whether we are male or female, long or short hair (or no hair) is fine. A middle-aged woman can access Botox to smooth out her wrinkles without charges of excessive vanity. But are there still limits? Does chopping off a limb to complete the individual's body image remain beyond the pale, even though, as Robert Smith has shown in his formidable essay,[7] the impact on the individual for a person with Body Integrity Identity Disorder of constraining his or her bodily choices is much greater than any decision by an ageing female law professor about whether to go for Botox or not. Or do I trivialize the Botox dilemma? Does society still play a commanding role in how some of us should look? The ageing woman becomes invisible. Her younger sister is instructed by her employers to wear discreet make-up. Victoria Pitts-Taylor notes that cosmetic medicine and surgery inscribe 'hierarchies of race and gender onto the body'.[8] I would add a hierarchy of age to her list. The challenge for liberals is does it matter or should we simply rejoice at transformations that make the individual happier? Should we join Pitts-Taylor in rejecting simplistic assumptions that the individual

6 I confess I would think them both vain and misguided.

7 Smith, R.C., Less is More: Body Integrity Identity Disorder, below at pp. 147–157.

8 Pitts-Taylor, *op. cit.* at p. 166.

seeking to alter his or her appearance is somehow a 'victim' of the cosmetic (surgery) industry rather than simply exhibiting a care of self?[9] Remember the broad definition of health offered by the WHO: 'a state of complete physical, mental and social well being and not merely the absence of infirmity'. For the older woman, or man, preserving the exterior illusion of youth may enhance the internal conviction that age is a state of mind, not being. I might regret that appearance should matter so much to my 'sisters' and see them as vulnerable to the influence of the media and the cosmetic industry but am I equally influenced by the blue stocking environment in which I grew up and lead my life? As John Harris[10] has so cogently argued, there is no such thing as a fully autonomous choice and when we scrutinize the choices of others to assess whether they are maximally autonomous we are ourselves heavily influenced by outcomes.[11]

At what point might we move from transformation to transgression? The voluntary amputee sets us a test.[12] Amputation of a limb and excision of a healthy eye are perceived as so far outside the norm that at best the individual must be seen as *ill*, and if complying with his wishes is lawful at all, it is as treatment. Medicalizing Body Integrity Identity Disorder is a prerequisite of rendering the choice valid. But paradoxically, once we medicalize the condition we start to doubt the choice. Is this ill person competent to give consent?[13]

Where boundaries are drawn is troubling. Robert Smith noted that surgery for gender identity disorder is seen as 'currently justified'[14] yet removal of womb and breasts constitutes riskier and more major surgery than amputation below the knee. There are those who tattoo their whole body surface and pierce every orifice. They can do so (if adults) without troubling the medical or legal professions.

What we allow people to do to themselves, what we allow others to do to them, what we allow surgeons to do, is an age-old dilemma. And just as adornment of the body has fashions so, as Robert Arnott has shown,[15] does medicine. Consider bleeding, once the physician's remedy of choice, though carried out by less elevated

9 See also Latham, M. (2008), The Shape of Things to Come: Feminism, Regulation and Cosmetic Surgery, *Medical Law Review* 16, 437–457.

10 See for example, Harris, J. (1985), *The Value of Life*, (Routledge and Kegan Paul), at pp. 195–203.

11 Some argue that the Court of Appeal took this outcome-based approach in *Re T (Adult: Refusal of Treatment)* [1992] 4 All ER 649. Ian Kennedy and Andrew Grubb commented that the court may well have 'adopted the undue influence approach out of its desire that the patient should not die'; Kennedy, I. and Grubb, A. (2000), *Medical Law*, 3rd Edition (Butterworths), at p. 757.

12 Elegantly explored in MacKenzie, R. (2008), Somatechnics of Medico-Legal Taxonomies: Elective Amputation and Transableism, *Medical Law Review* 16, 390–412.

13 See Elliott, T. (2009), Body Dysmorphic Disorder: Radical Surgery and the Limits of Consent, *Medical Law Review* 17 (forthcoming).

14 Smith, *op. cit.* at p. 152.

15 Robert Arnott provided a talk on the day of the conference entitled Transforming the Body: Rights and Power about Cranial Trepanation which has not been included in this edited

barber-surgeons.[16] Cranial trepanation has antiquity, but a mixed pedigree. Arnott suggests that today there are limited therapeutic uses for trepanation in proper hands, but notes that shamanistic trepanation continues across the world, and that, as with body integrity identity disorders, some people actively seek relief that they believe will come from having a hole drilled in their skull.

Assume I join their ranks. I seek trepanation to enhance my brainpower, to release the 'inner me'. No reputable surgeon in the UK is likely to see my request as therapeutically indicated. Yet amateur neurosurgery risks my life and were a layfriend to help me out, she would be likely to face prosecution for causing grievous bodily harm, regardless of my consent. Bizarre choices need medical validation. 'Reasonable surgery' transforms assault into a lawful act.[17] So at what point should all the non-medics rise up to condemn the paternalism of state and the surgeons? Our bodies – our choices, we cry. Liberty should endorse any choice of a competent adult.

## Transgression and the Criminal Law

Bob Sullivan addresses this thorny question in his rich and complex essay. I am fascinated by the line drawn between gladiatorial combat and *R v Brown*.[18] He exposes the fallacy of the easy way out, that is to claim that the individual seeking amputation of a limb or deliberately seeking to contract an STD lacks mental capacity. Regret does not negate choice. Bizarre, even morally repugnant, choices do not conclusively indicate lack of capacity.[19] Sullivan argues for robust liberalism, at least in the context of sexual conduct, and rules out legal moralism as a means of overruling choices that are *prima facie* self-harming and others abhor. But, bravely, he puts the case for limited paternalism. He contends that there may be a case for state intervention 'where an agent proposes to do something to herself or have something done to her which threatens to end a life potentially worth living or an immediate, serious and permanent setback to the core interest of her physical health or soundness with no offsetting gain remotely commensurable with the loss'.[20] Even in such cases, Sullivan would eschew the criminal law[21] and

collection. For a further discussion on cranial trepanation, see Arnott, R., Finger S. and Smith, C. (eds) (2003), *Trepanation: History, Discovery, Theory*, (Swets and Zeitlinger).

16 See Brazier, M. (2008), The Age of Deference: A Historical Anomaly? in Freeman, M. (ed.), *Law and Bioethics: Current Legal Issues*, Volume II (Oxford University Press), at pp. 464–475.

17 See Elliott, *op cit.*

18 [1994] 1 AC 212.

19 *St George's Healthcare NHS Trust v S* [1998] 3 All ER 673, at 692.

20 Sullivan, G.R. Liberalism and Constraining Choice: The Cases of Death and Serious Bodily Harm, below at pp. 205–233, 232.

21 As does Elliott, *op. cit.*

suggests some form of civil commitment to prevent self-harm. We must be sure that the 'intervention will advance the long-term interests of the agent' and that the process has 'robust review and release procedures'.[22]

Sullivan offers a neat solution to the question posed by Smith.[23] Would the argument that he (Smith) advances for performing single below the knee amputations hold good for the man who seeks to be a double amputee or to have his eyes put out? The answer no could be justified by Sullivan's formula that by so disabling yourself, you threaten your core health and soundness. He may offer us an escape from medicalization. It does not seem that Sullivan insists that only a qualified and licensed doctor could comply with a request for bodily mutilation, if it fell short of the threshold he sets that there be no impact on the person's core interests, although opting to have an unqualified person 'operate' on you may both increase the risk to your core health and the likelihood that your mental capacity may be questioned. There still remain two issues. (1) Civil commitment still deprives me of my liberty and so, should Sullivan's proposal ever be implemented, the devil would be in the detail determining exactly when I forfeit the liberty to decide my own interests. (2) Must I ever consider weighing my interests against others? As I have noted elsewhere, autonomy has in popular debate become 'I want therefore must have'.[24]

**Refining in Autonomy**

Before considering wants and demands, and essaying the murky waters of reining in autonomy, we should be clear, as Sir James Munby[25] is in his paper, that doctors do owe a duty to treat those whom they accept as their patients, and that a key question in modern health care law has become whose views take precedence if the patient's judgement of his own best interests conflict with that of his doctors. Such a conflict arose in the tragic case of Leslie Burke. Claire McIvor[26] mounts a vigorous defence of the Court of Appeal.[27] Their Lordships were clear that patients had no right to demand treatment – and now we are considering orthodox medical treatment, not holes drilled in the skull. In defending the Court of Appeal, McIvor notes a number of problems with any notion of autonomy as driving demand. To me, one the hardest tasks is to reflect on how one might view Burke in a Utopian world where financial resources were not a problem. Would we still be constrained

22 Sullivan, *op. cit.* at p. 232.

23 Smith, *op. cit.*

24 Brazier, M. (2006), Do No Harm – Do Patients Have Responsibilities Too?, *Cambridge Law Journal* 65, 397.

25 Munby, J., A Duty to Treat? – A Legal Analysis, below at pp. 179–182.

26 See McIvor, C., Bursting the Autonomy Bubble: A Defence of the Court of Appeal Decision in *R (On the Application of Leslie Burke) v GMC*, below at pp. 183–203.

27 *R (On the Application of Leslie Burke) v GMC* [2005] 3 WLR 1132.

by professional integrity[28] and some kind of broader responsibility to others? Consider a demand for IVF and multiple embryo transfer made by a woman who already has six children under 10 – an example not a million miles away from the case in the USA of the woman who gave birth to octuplets in January 2009.[29] She knew, and her doctors knew, that she herself might die and that a multiple pregnancy might result in disability to her babies – did she act wrongly? I suggest that she did for she ignored her obligations to her existing offspring, as well as to the possible future children. McIvor presents a compelling case that no doctor has any obligation to comply with her demands. But has the law the legitimate claim to stop her if she can find a compliant doctor and pay for all her treatment? After all, I have an unfettered right to refuse treatment. The possible paradox in endorsing a right to say no, yet refusing a claim to insist on implementing every yes, requires that we follow the lead of Nicky Priaulx[30] and John Coggon[31] in recent papers where they dissect what the judges mean when they speak of autonomy. Does the core legal value remain bodily integrity?

## Embryonic Bodies

So far I have focused on the adult human body and the papers that address such bodies. Three papers consider our bodies in their earliest stages. Why do we bother at all about the human embryo, a microscopic bundle of cells invisible to the human eye? That we do is proven by the millions of words written about, and the substantial jurisprudential attention devoted to, the embryo. Even those who espouse the view that embryos are nought but a cluster of cells care deeply about them.[32] The current debate about human admixed embryos addressed by Robert Song[33] and Marie Fox[34] delves into the heart of the main question surfacing in all our papers within this collection, why do bodies (and in particular human bodies) matter at all?

Song quotes Baroness O'Cathain speaking in the debate on the Human Fertilisation and Embryology Bill in the House of Lords in 2007. She affirmed that 'God created man in his own image', and so 'a clear definition between the

28 See Draper, H. and Sorrell, T. (2002), Patients' Responsibilities in Medical Ethics, *Bioethics* 16, 335.

29 See Mother had 'multiple IVF' although she already had six children, *The Times*, 31 January 2009.

30 Priaulx, N. (2008), Rethinking Progenitive Conflict: Why Reproductive Autonomy Matters, *Medical Law Review* 16, 169–200.

31 Coggon, J. (2007), Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism, *Health Care Analysis* 15, 235–255.

32 Consider the proportion of John Harris's published work devoted to the embryo, an entity he declares lacks moral value.

33 Song, R., Human-Monsters, Monstrous Humans? Humanity, Divinity and Interspecies Embryos, below at pp. 127–141.

34 Fox, M., Legislating Interspecies Embryos, below at pp. 95–125.