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Ian Harper, Tobias Kelly and Akshay Khanna

Excerpt

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## INTRODUCTION

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In the spring of 2013, the parents of Robbie Crane, a severely disabled 13 year old boy, won an out of court settlement of over £7 million from the English National Health Service. When Robbie was born he was seriously ill with a congenital heart defect. He underwent an operation when he was just a few days old, which seemed to be a success.<sup>1</sup> However, something went wrong during the ventilation afterwards. Robbie was left with cerebral palsy, limited speech, learning difficulties and behavioural problems. He will require round-the-clock care for the rest of his life. The settlement was designed to reflect compensation for any medical negligence, as well as to cover the cost of Robbie's future care. Such cases are far from rare. According to a report in 2012, the English NHS spent over £15 billion on medical negligence claims a year.<sup>2</sup> That is nearly one seventh of the entire NHS budget.

Ian Brady appeared before a mental health tribunal in Manchester in the summer of 2013. Brady is one of the most notorious serial killers in modern British history. In 1966, he was found guilty of the murder of three children and sentenced to life imprisonment. Nearly twenty years after first being sent to prison, Brady was diagnosed as a paranoid schizophrenic with a severe personality disorder, and sent to a high security psychiatric hospital. In 1999 he went on hunger strike, protesting against his incarceration. As Brady was being detained in a psychiatric hospital, doctors were permitted to continue his treatment and force-feed Brady against his will. Brady was therefore appearing before the tribunal to argue that he was no longer mentally ill and should be

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transferred to prison, so that he could have control over the time and manner of his own death.<sup>3</sup> His appeal was turned down.

In December 1998 Diane Blood gave birth to a baby boy. The boy's biological father had died more than four years previously.<sup>4</sup> Following a protracted legal battle, Ms Blood had won the right to artificial insemination with her husband's sperm. Ms Blood and her husband had been planning to have children when he was struck down with meningitis. She persuaded the doctors to remove her partner's sperm while he lay on life support. However, because the sperm was not removed with Mr Blood's consent, the hospital was not legally allowed to hand it over to Ms Blood. In February 1998, Ms Blood won the right to take the sperm abroad. The court ruled that although it was illegal to use sperm taken without consent in the UK, there was nothing in the law that prevented the insemination taking place outside the country. Ms Blood would eventually have two sons, Liam and Joel, after visiting a Belgian clinic. It was not until 2002, and a change in the law, that Mr Blood's name could be put on the birth certificate, as prior to this, fathers who were dead at the moment of conception could not be legally recognised as parents.

In 2001 Stephen Kelly was found guilty of recklessly causing injury to another by the High Court of Justiciary in Glasgow after infecting a woman to whom he had not declared his HIV status. Sentenced to five years in prison, this was the first successful case of the criminalisation of HIV transmission in Scotland (Chalmers 2002). Beyond the UK, in many parts of the world HIV transmission has been criminalised. Despite limited evidence that this has any public health benefit, a number of other countries have now added this measure as an aspect of the attempts to control the HIV epidemic.

Between 400 and 1200 patients died 'as a result of poor care' at Stafford Hospital between January 2005 and March 2009.<sup>5</sup> These deaths were revealed through statistical analysis, which enabled comparisons of death rates to be produced between hospitals, raising alarms should these lie outside of a deemed acceptable range. In a damning indictment of audit practices, Robert Francis, QC, the barrister chairing the public enquiry that followed, suggested that the 'NHS culture' was to blame, and that this focused 'on doing the system's business – not that of the patients'.<sup>6</sup> This stimulated an ongoing debate into the question of legal sanctions, and whether senior managers at the NHS could face criminal prosecution if they were deemed to be not open about mistakes that had been made, or whether already available provision of

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manslaughter law that can be levelled against doctors, or a corporate version of this, could force greater accountability.

As the above five examples attest, law and medicine can be caught in a tight embrace. Although these examples are all taken from the UK, similar processes are at work around the world, from the USA to India, from the Czech Republic to South Africa, from France to Germany, Guatemala, Brazil and beyond. Clinicians may try to heal pain and suffering, but what counts as necessary or unnecessary suffering, suffering that should be prevented or allowed to continue, can be decided by the law. Furthermore, when medicine is unable to heal, the law can be called upon to provide redress. Litigation is often seen as the answer to medical needs and public health claims when doctors and public health physicians come up against their limits. Medical negligence cases, such as that of Robbie Crane's, involve lawyers deciding what clinicians can and should have done when confronted by a sick patient, as well as providing financial remedy for clinically inflicted distress. In the Brady mental health tribunal, it was the judges who had to decide which clinical diagnosis was most appropriate, and therefore implicitly whether the suffering caused by force-feeding was worse than the suffering caused by lack of treatment and potential suicide. It was not doctors who would decide how Brady would end his life, but a judge. In 2001 it was a judge who made the decision that Stephen Kelly was guilty of recklessly injuring his girlfriend when he failed to tell her he had HIV and subsequently infected her. Following the Mid Staffordshire Hospital deaths, it was suggested that criminal negligence charges might also be levelled at senior managers in the NHS. As such, and at multiple levels, medicine can be said to operate in the shadow of the law, as clinical, public health and institutional decisions are shaped by their potential legal outcomes.

Yet the movement is not all one way. Legal processes, for example, can rely on clinical evidence in order to make decisions. It is clinicians who tell the court what particular symptoms might mean and what forms of treatment are possible. The mental health tribunal relied on psychiatric evidence to decide whether Brady was clinically sane or not. The Robbie Crane litigation similarly needed clinical evidence in order to determine whether the staff at the hospital where he was born had exercised the required level of care. Law also has to respond to medical advances and new forms of diagnosis. Paranoid schizophrenia has been a diagnosis with shifting parameters and definitions reflected in the evolving Diagnostic and Statistical Manual (DSM) revisions, but the law is dependent on these shifting terrains of knowledge at

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particular moments in time. It was not proposed as a distinct clinical diagnosis when Ian Brady was originally sent to prison in the late 1960s, yet subsequent diagnoses were dependent on new categorisations of the condition. The development of IVF as a therapeutic treatment has also created new and challenging legal problems. Issues of parenthood, such as in the Diane Blood case, would simply not be legal problems if it was not for clinical developments. In another register, it has been the development of the capacity to collate and analyse complex statistical data sets that has allowed the emergence of thinking of larger institutional complexes as legal entities in relation to health outcomes.

The ways in which we acknowledge, and attach importance to pain and suffering, can be understood as a constitutive feature of modern political and social life (Brown 1995). Pain and suffering are deeply implicated in what it means to be human in contemporary societies. Alongside, or even instead of, a concern with equality, exploitation and fairness, claims about the nature, distribution and adequacy of the response to pain and suffering play an important part in the formation of collective identities and the distribution of resources. Pain and suffering, however, are never self-evident. Neither are the responses to pain and suffering. What counts as necessary and unnecessary, preventable and unpreventable distress, and what counts as adequate and suitable responses are profoundly political and cultural processes. Law and medicine are key to this wider politics of harm, deciding on what counts as injury, and what are the most suitable forms of redress. But both law and medicine also claim to lay out spaces for redemption, for cure, for healing and redress.

As law and medicine respond to harm and suffering, they become entwined. Let's take the concept of injury, for example, to illustrate the close relationship. Injury is a legal term *par excellence*. It derives from the Latin words 'in' and 'jus', meaning 'against justice' (Jain 2006: 4). Legally speaking, injury involves a violation of rights. Yet although injury can imply financial loss or damage to reputation, the archetypically modern image of injury is a body (or mind) in pain. Injury is therefore widely seen as a problem that can be addressed through medical intervention. However, the very fact that we refer to physical or mental damage by a term that implies justice or its absence, despite us not being necessarily conscious of this metaphorical inheritance, speaks to the powerful place of law in our imaginations of harm.

Death too, to give another example, is simultaneously a medical and a legal category rather than the self-evident end of life. As Margaret

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Lock has famously shown, the category of brain death requires both clinical and legal interventions (Lock 2002). Developments in medical technology have forced a re-evaluation of the very distinction between life and death. In order for organs to be harvested for donation, bodies have to be legally dead – or a clinician could be charged with homicide – but clinically alive, as otherwise the organs would be medically useless. Anglo-American law has decided that this event takes place in the brain, rather than the heart. Medicine had to respond by providing ways in which the exact time of brain death could be identified.

The relationship between law and medicine can, equally, be symbiotic or collaborative. In a sense, both law and medicine may be understood as practices in the management of uncertainty. In the context of law, this is not just in relation to ‘subjective’ elements such as ‘intention’ and *mens rea*,<sup>7</sup> but in the very processes through which ‘facts’ are assessed, produced and appreciated in a court of law. This is most obvious in adversarial systems of law, where litigating parties are typically engaged in making objects and chronologies intelligible. The production of ‘facts’ is thus contingent upon such things as the resources available to contesting parties, the diversity of principles in laws relating to procedure and evidence, the political milieu and most significantly, the very ability of the court to sense, recognise and name objects. The legal process is in this sense the identification of ‘true’ facts in the face of ambiguity. Also, as several chapters in this volume suggest, the practice of medicine is about the production of facts in the face of disparate possibilities. The process of diagnosis, for instance, is an inherently intersubjective process where physicians and patients are entangled in a negotiation of their realities, and the languages and metaphors through which bodily or psychological experiences gain intelligibility. The diagnosis of a syndrome such as AIDS, i.e. the enumeration and identification of ‘symptoms’ and the recognition of patterns is an obvious case in point. Here again we see the socially, economically, politically, procedurally and epistemologically contingent process of producing certainty in the face of ambiguity. What is interesting is the ways in which, often, both law and medicine project the responsibility of this management of uncertainty onto each other, thus mutually reaffirming their positivist claims, their authority in speaking objective truths.

Yet the relationship between law and medicine can also be deeply uneasy. The ways in which lawyers and clinicians try to understand the world, as well as the responses they put in place, can be very different. Lawyers may understand harm through legal languages and

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definitions of injury, victim and perpetrator. Medical practitioners might think about harm in terms of categories of disease and pathology translated from the subjective illnesses of patients. The law courts allocate compensation and redress. Medical practitioners try to alter the course of disease processes, and thus heal and alleviate suffering, albeit within narrow medically defined parameters. As two high status forms of expert knowledge, it is not always clear which, or how, either should predominate in particular contexts. The law can marshal far greater resources, it can decide what can and should be done, and can invoke legal sovereignty to do so. However, it is this political dominance of the law that medicine counters through access to levels of intimate knowledge that is simply unavailable to the law. A legal decision might provide formal redress – which in certain circumstances might assist with healing as broadly socially defined – but clinicians can, and frequently do, improve the subjective feelings of being unwell through their clinical interventions.

#### ANTHROPOLOGY, THE LAW AND MEDICINE

Historically, legal and medical anthropology have often talked past each other. We publish in different journals and go to different conference panels. Yet over the past ten years at least there has been an increasing convergence of analytical and ethnographic interests. Issues such as biological citizenship and its wider family of terms (Petryna 2003; Rose 2007; Nguyen 2010) have brought the importance of rights and the sovereign power of the state over bodies, life and death to the heart of medical anthropology (Das and Poole 2004; Inda 2005). Similarly, a concern with the provision of pharmaceuticals and their place within particular economies of ownership and need, has meant that legal property regimes have been a key object of analysis (Petryna et al. 2006; Hayden 2007; Petryna 2009). Many medical anthropologists have become interested in exploring the implications of institutional and expert responses to suffering, turning to issues historically more associated with legal anthropology, such as human rights, citizenship and bureaucracy (Farmer 2001, 2004; Fassin and Rechtman 2009; Biehl and Petryna 2013; Redfield 2013).

In this volume we acknowledge these intellectual shifts and explore the intersections of, and relationship between, law and medicine. The book asks: How do those working in law and medicine seek to understand harm and suffering, and allocate remedies? What are the points of

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convergence and contradiction between law, medicine and their own sub-disciplines, as they seek to understand and respond to harm and suffering? Are new spaces for political and moral action created by the intersection of law and medicine? Crucially, we do not take the central role of law and medicine in responses to harm and suffering as self-evident. As law and medicine define and categorise, options are closed down, just as new ones are opened up. What happens, for example, to a sense of mutual obligation for the sick and unwell when they are framed in terms of legal rights? What issues arise when medical care is determined and overshadowed by the potential for criminal redress? Such questions allow us to explore the relationship between a politics of suffering, expert claims to privilege insight, and the potential for remedy and redress. Rather than reify law and medicine as two separate ways of interacting with the world abstracted from each other and their conditions of entanglement, we argue that responses to harm and suffering have to be understood in terms of their enactment and engagement within specific local contexts. Hence, the issues are ones that are fundamentally and necessarily open to ethnographic investigation.

The volume is organised into two sections. The first section deals with the different ways in which legal and medical processes understand, confront and conceptualise harm and suffering, in short, an epistemological exploration. The second section deals with the ways in which law and medicine understand and allocate remedies to harms, that is the more practical side of how interventions are managed. The distinction between understanding harm and providing remedy is of course not hard and fast. Remedy is only possible once harms have been identified, and harms are seldom categorised for abstract reasons, but often with the aim of providing some form of alleviation. While there may be a case for some of the chapters appearing in either section, we have made the division as a way of pulling out and emphasising important analytical themes and as a heuristic undertaking. Before addressing issues of pain and suffering, remedy and redress in more detail, it will be useful to examine what types of expert knowledge are represented by both law and medicine.

## EXPERT KNOWLEDGE

Law and medicine are both highly technical forms of expert knowledge. They seek to define, categorise and regulate. Indeed, they may be the archetypal form of modern expertise (Carr 2010). Law and medicine are



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both backed by powerful institutions and bureaucracies, such as hospitals and courts, not to mention universities. Law and medicine are high status, highly paid professions, represented by powerful lobbying bodies. They are also both learned at university, and contain languages and forms that are only available to the initiated (Sinclair 1997; Mertz 2007). Law and medicine both fundamentally involve a claim to superior positivist knowledge by those who speak in their name. Finally, in all their technical specialisms, law and medicine can also both be seen as highly pragmatic forms of knowledge, concerned with getting things done, rather than philosophical hair-splitting or political negotiation. Doctors want to make their patients better. Lawyers want to come to a final legal decision.

However, even though law and medicine may both be pragmatic disciplines, they can produce very different relationships between means and ends. Legal processes aim to seek finality, as they look to end the debate and come to a legal decision. In doing so, they frequently turn in on themselves, referring to little else than the law. As Bruno Latour has famously argued, writing about the French Conseil D'Etat, legal decision-making is a process of trying to move beyond questions of fact as fast as possible, in order to arrive at legal debates (Latour 2004). Legal processes then become concerned fundamentally with reaching a decision that is legally justifiable, rather than making a profound statement. The law is what matters, not the outside world (Riles 2006). Law, ideologically at least, claims a self-referentiality, that gestures to other laws, and other cases. While new objects and issues are constantly entering the legal realm, especially following developments in medicine and clinical practice, legal regimes always try to articulate these new arrivals within self-referential terms, as though they already always existed in the legal realm, and are merely finding articulation through new interpretation.<sup>8</sup> As far as legal actors are concerned, there is no need to look elsewhere, as in the end, it is the judge who decides what happens and the outcome of a legal case. As such, once a decision is reached, it is final. In the common law system it can be appealed, but only on matters of law, not on fact. The facts of the case are frozen in time when a judge comes to a decision. Law decides on both the means and the ends.

Medical decisions, in contrast, are often provisional and open to being revised in the light of clinical advances or as a patient's health fails or improves. As Foucault has argued, modern medicine is marked



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by a concern with observation and the clinical gaze (Foucault 2003). Clinical categories may shape what is seen, and the clinician may cultivate a sense of detachment from the body being observed, but the clinician always returns to that same body. Medicine has no luxury of near total self-referentiality. It must always look beyond itself to the sick patient, whose responses it can never totally control. Although medicine too is a field with a strong sense of its own traditions, canons and principles, however diverse, any attempt to transform the world into its own terms can reach its limits when it confronts a mind or body in pain which seems to resist medical intervention. A diagnosis is only useful and clinically correct if it helps the patient's condition improve. There is relatively less space to switch off the outside world, to say 'clinically speaking the decision was right'. Biographical narrative, individual history and life intervene (Bowker and Starr 1999). It is no coincidence that many general practitioners and community health workers rapidly come up against the limits of the purer forms of disease abstraction in the everydayness of their patients' lives, and turn to other modalities of intervention to help them in their struggles with being subjectively unwell. Medical means and ends, when compared to the law at least, are relatively more open and contingent.

A contrast between a 'distanced' law and an 'engaged' medicine can be overplayed of course. Lawyers are not always unconcerned with the outside world. Doctors too can also be relatively satisfied with a clinical outcome, irrespective of how the patient feels about it. An asthma sufferer, for example, may have a decrease in the constriction of their bronchioles – the medical outcome of an intervention – but still not feel that well in themselves. A surgical intervention might be a technical success, even in the absence of subjective improvement in well-being. Furthermore, to talk about law and medicine, the clinic and the court, doctors and lawyers, as unified entities, and coherent bodies of knowledge is untenable. While both law and medicine may have relative coherence as professional identities, both also have a tendency to fracture and contradict, breaking down into sub-fields. Criminal law, civil law and administrative law can have very different assumptions and goals, as can surgery, psychiatry, public health and palliative care, to give but a few examples. In such situations, law and medicine have been known to submit to one another, the ability to resolve internal contradictions. The recent case where the Supreme Court of India reinstated Section 377, the colonial anti-sodomy law, provides us with an

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instance of this. Parties on both sides of the litigation introduced medical evidence to support their cases – those that sought to get rid of the antiquated law filed evidence that homosexuality was no longer considered a ‘disease’, that the protection of human rights of same-sex desiring people was a central tenet of public health policy, and that the continuation of the law in force had mental health implications for gay, lesbian, bisexual and transgender citizens. The parties in support of the law similarly introduced medical opinion to the contrary, claiming that homosexuality was indeed a curable affliction, one responsible for the spread of the HIV epidemic and which must thus remain criminalised. The court, in this case, was called upon to act as an arbiter of what constituted ‘good’ science, and to resolve the apparent conflict within the realm of medicine. Conversely, in the making of HIV/AIDS policy, the government’s National AIDS Control Organisation was essentially tasked with the responsibility of identifying ‘good’ law, having to decide between the fact that homosexuality was, in effect, criminalised under Indian law, and the constitutionally guaranteed Right to Life, which included the Right to Health. What we see here is a circularity, where the practices of law and medicine draw upon each other for the resolution of their own internal conflicts, and always in the context of pragmatic questions. As inherently pragmatic disciplines and sub-disciplines, law and medicine are always context specific, trying to answer very particular questions at very particular moments, and for particular ends.

There is an obvious danger in presenting law and medicine as self-enclosed, all-powerful forms of knowledge, despite the sovereign forms of power invested in them. It is also important to recognise their limits, hesitations and inconsistencies. Neither law, nor medicine, even in their own eyes, is all knowing and all seeing. There are limits to their expertise. People will die for reasons that are beyond medical knowledge; indeed, death itself brings medicine abruptly up against the limits of its domain (even if defining the moment of its coming can be complicated). The law can become confused. Clinical categories can contradict one another – as different bundles of signs and symptoms from the reading of the contours of the body are placed in different diagnostic categories – as can the law. Judges are as fallible as doctors. It is in these spaces of uncertainty that innovation can take place. It is here that the space for ethnographic investigation is most needed. Law and medicine, in all their various and contradictory forms, interact and contradict, producing new potentials and closing down old.