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Introduction: Medical Science, Moral Controversy, and Legal Change

Craig M. Lawson

University of Nebraska College of Law, clawson1@unl.edu

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Introduction: Medical Science, Moral Controversy, and Legal Change

I. INTRODUCTION

Sometime late in 1982, Carlotta Locklear, a 27-year old resident of New Haven, Connecticut, gave birth to a son. It must surely be a sign of the times in medical jurisprudence that an event as humanly ordinary as childbirth is coming with increasing frequency to be attended with puzzling legal consequences. The doctors at Yale-New Haven Hospital first realized the difficulty of the legal problems that Ms. Locklear's case would occasion when they diagnosed her baby's serious illness as AIDS. The baby had almost certainly contracted AIDS *in utero*, and Mrs. Locklear was therefore presumably a carrier. She was also a prostitute and a heroin addict, placing her in two of the risk categories for AIDS.

Ordinarily, Ms. Locklear's doctors would have an ethical and legal obligation of confidentiality in respect of the information about her condition, but no conscientious doctor would ignore the enormous public health hazard involved. As an illicit intravenous drug user with a \$200-a-day habit, Ms. Locklear would expose other drug users to AIDS; as a young prostitute with no other means to support an expensive drug addiction and an ailing baby, she would expose her customers to it.¹ On the other hand, she was then free of symptoms and could only be presumed to be an AIDS carrier, rather than positively diagnosed as a victim of the disease. Should the public health authorities be alerted? Connecticut's relatively limited disease-reporting laws did not seem to apply to her case. Hospital confinement was not a legally available alternative either, for although she would later die of one of the opportunistic infections that typically kill AIDS sufferers, she was

* Associate Professor of Law, College of Law, University of Nebraska-Lincoln; Adjunct Associate Professor of Medical Jurisprudence and Humanities, College of Medicine, University of Nebraska Medical Center. A.B., Yale University, 1970; J.D., University of California, Hastings College of the Law, 1974. Admitted to practice: California, 1974.

1. This is probably what Ms. Locklear's doctors would have believed in 1982. However, the popular press has recently reported that AIDS may be far less transmissible through vaginal sexual intercourse between a female AIDS victim and a male. Its sexual transmission from men to women is apparently far more common. *AIDS: Myths and Reality*, NEWSWEEK, Sept. 23, 1985, at 20, 21.

not then a hospital patient, and no quarantine law applied. In any event, much of the doctors' power to protect Ms. Locklear's confidential medical information was destroyed by a series of magazine and newspaper articles, and finally a segment of CBS's weekly "60 Minutes" about Ms. Locklear.² The publicity in turn prompted the Connecticut Legislature to enact a quarantine law that would apply to future AIDS patients.³

In the course of the public controversy about her condition, Ms. Locklear offered to give her unfortunate son up for adoption. Here too the law and existing legal institutions were patently inadequate to resolve the problems presented. Even though for relatively long periods her young son was free from symptoms and not under any active medical treatment, no state institution — no school, no day-care facility, no custodial home — would admit him, no family could be found in which to place him, and the law provided no alternatives for his care.⁴ As a result, he lived the few years of his short life almost entirely within the walls of, and under the care of, Yale-New Haven Hospital. By late 1983 there had already been thirty-six known American cases of AIDS among children, most of them children of intravenous drug users,⁵ and the legal problems of these children, and of the health care professionals who treat them, can be expected to loom increasingly large as the number of diagnosed AIDS cases doubles every ten months.⁶

The bramblebush of hard issues in Carlotta Locklear's case is unusual primarily for the publicity that it attracted, as the progress of AIDS has everywhere thrown up a myriad of difficult legal issues. These range from issues of research confidentiality (a topic of discussion in this Symposium),⁷ to civil liability for transfusion-associated AIDS; from the rights and duties of staff health care professionals who wish to avoid contact with AIDS patients being treated at the institutions where they work, to the rights and duties of health care pro-

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2. The story first broke in *The New Journal*, a magazine edited by Yale students, though Ms. Locklear was there referred to pseudonymously as "Lana." Sides, *Lana: A Story of Scarlet Letters and Public Risks*, *THE NEW JOURNAL*, Dec. 9, 1983, at 16. Shortly thereafter, the New Haven papers picked up the story, see Barbuto, *AIDS Risk: Prostitute Suspected as Carrier*, *New Haven Register*, Jan. 23, 1984, at 1, col. 1, and ran a series of stories about her until her death. See, e.g., Hladky, *Carlotta Locklear dies; autopsy due*, *The New Haven Journal-Courier*, Jan. 15, 1985, at 1, col. 1. CBS aired her story in February, 1984. *Id.* at 3, col. 2.
 3. P.A. 84-336, § 1, 1984 Conn. Acts — (Reg. Sess.) (amending CONN. GEN. STAT. 19a-221: An Act Concerning Quarantine Measures).
 4. Hladky, *Carlotta Locklear dies; autopsy due*, *The New Haven Journal-Courier*, Jan. 15, 1985, at 1, col. 1 & 3, col. 1.
 5. Barbuto, *Researchers confer on AIDS, drug abusers at health center*, *The New Haven Journal-Courier*, Dec. 15, 1983 at 1, col. 4.
 6. Wallis, *AIDS: A Spreading Scourge*, *TME*, Aug. 5, 1985, at 50.
 7. Gray & Melton, *The Law and Ethics of Psychosocial Research on AIDS*, 64 *NEB. L. REV.* 637 (1985).

professionals who wish to treat AIDS patients over the objections of landlords, professional associates, and others. Just as the disease has spread, so too the literature about these difficult legal problems has overflowed the professional journals,⁸ and is beginning to seep into the popular press.⁹ And inevitably, as *Newsweek* has put it, AIDS has spread to the courts.¹⁰ The courts have once more become the primary forum for the resolution of a set of perplexing medicolegal issues, and in that forum public controversy is once more generating pressures for legal change.

Apparent legal inadequacy in the face of medical change, and the resulting pressures for legal reform—the field of medical jurisprudence has certainly experienced its fair share of this in other instances already, although it is perhaps unusual for pressures for legal change to result more from the progress of a disease than the progress of medical science. Legal change in medical jurisprudence is a major theme of this Symposium, which begins with Sir Zelman Cowen's Roscoe Pound Lectures, *In the Rear and Limping a Little: Some Reflections on Medicine, Biotechnology and the Law*.¹¹ Sir Zelman presents a sensitive exploration of complex problems raised when the law, which must inevitably settle itself with some degree of stability on a ground of accepted principles, encounters dramatic scientific and technological advances in medicine. Joni Gray and Gary Melton's Article, *The Law and Ethics of Psychosocial Research on AIDS*,¹² draws together several recent doctrinal developments in bioethics that have changed the face of the law. They show how these doctrines, protecting in principle against unnecessarily offensive invasions of privacy and damaging breaches of confidentiality in human-subject research, apply with special force to the case of psychosocial research on AIDS patients. In fact, in several respects further protective legal reforms are needed, and the two authors explore and advocate them. A particular doctrinal line of legal change is the subject of the article by Diane Janulis and Alan Hornstein, *Damned if You Do, Damned if You*

8. See, e.g., Bayer, Levine & Murray, *Guidelines for Confidentiality in Research On AIDS*, IRB: A REVIEW OF HUMAN SUBJECTS RESEARCH, Nov.-Dec. 1984, at 1; Curran, *AIDS, Research and "The Window of Opportunity,"* 312 NEW ENG. J. MED. 903 (1985); Miller, O'Connell, Leipold & Wenzel, *Potential Liability for Transfusion-Associated AIDS*, 253 J. A.M.A. 3419 (1985); Novick, *Quarantine and AIDS*, 49 CONN. MED. 81 (1985); Novick, *At Risk for AIDS: Confidentiality in Research Surveillance*, IRB, A REVIEW OF HUMAN SUBJECTS RESEARCH, Nov.-Dec. 1984, at 10.

9. See, e.g., Findlay, *USA's 11,871 AIDS Victims Wait, Worry*, U.S.A. Today, July 25, 1985, at A1, cols. 3 & 4 & A2 cols. 1 & 2; *AIDS Spreads to the Courts*, NEWSWEEK, July 1, 1985, at 61.

10. *AIDS Spreads to the Courts*, NEWSWEEK, July 1, 1985, at 61.

11. 64 NEB. L. REV. 548 (1985).

12. 64 NEB. L. REV. 637 (1985).

Don't: Hospitals' Liability for Physicians' Malpractice,¹³ a critical survey of the recent steady expansion of theories of hospital liability for medical misadventures suffered by patients undergoing hospital treatment.

Taken together, the remaining pieces in this symposium all focus explicitly on aspects of physician authority and patient autonomy. But all importantly involve legal change as well — not only in centering on the concept of patient autonomy, itself the recent offspring of a course of legal change in medical jurisprudence — but also in arguing for further legal change, or in arguing for correspondingly changed medical practices in the spirit of the developing law of patient autonomy. Elizabeth Patterson's, *The Therapeutic Justification for Withholding Medical Information: What You Don't Know Can't Hurt You, or Can It?*,¹⁴ argues forcefully for a drastic narrowing — perhaps even for the essential elimination — of the therapeutic privilege, which under special circumstances exempts doctors from their ordinary duty to disclose the risks and alternatives of treatment. William Winslade and Judith Wilson Ross explore the related and difficult concepts of privacy and confidentiality in their Article, *Privacy, Confidentiality and Autonomy in Psychotherapy and Psychoanalysis*.¹⁵ They argue that respect for the patient's autonomy requires recognition of the exclusive authority of the patient to determine when confidences shall be disclosed to persons outside the therapeutic relationship. The concluding casenote, *The Scope of the Physician-Patient Privilege in Criminal Actions: A New Balancing Test*,¹⁶ argues that related policies standing behind the attorney-client privilege in the law of evidence ought to protect the physician in charge of an abortion clinic against the compulsory disclosure of patients' names to a grand jury investigating unspecified crimes by unspecified persons.

II.

Sir Zelman Cowen's Pound Lectures reflect upon certain insistent forces for legal reform in medical jurisprudence, arising under the pressure of striking changes in medicine and biotechnology. These changes have dramatically enhanced our power over the physiological processes of birth and death, and appear to have altered the balance of power between man and nature, bringing fundamental aspects of these natural processes under conscious human control. Inevitably these developments are broadly unsettling, altering as they do the giv-

13. 64 NEB. L. REV. 689 (1985).

14. 64 NEB. L. REV. 721 (1985).

15. 64 NEB. L. REV. 578 (1985).

16. 64 NEB. L. REV. 772 (1985).

ens, the factual setting, of our moral consensus regarding what is and what is not for man to manipulate.

As Sir Zelman's chosen title implies, his lectures are reflections. They are indeed deeply and humanely reflective. They show their author to be sympathetic to the inner imperatives of scientific discovery, and always willing to consider practical benefits to health, yet at some point willing to draw the line in the name of what we must preserve of the human condition as we know it, to safeguard what we believe humanity essentially to be. If the lectures are reflective rather than closely argued, a complex thesis emerges from them nonetheless: that the law can and should adapt itself rapidly if possible, but not intemperately, to these biotechnical developments. Further, if it is to do so satisfactorily, it can only do so after lawmakers, first, have consulted the experts and have mastered the relevant biotechnological data, and, second, have ascertained the general sense of the community on the broader moral, social, religious, and economic ideals at stake. This latter requirement of course presupposes the existence of an ascertainable consensus, and often makes extraordinary lawmaking processes, such as public consideration by blue-ribbon commissions, especially appropriate.

Lecture One concerns new technologies relating to human tissue transplantation; Lecture Two, new reproductive technologies. These are awesome technologies, and they create morally awesome potentialities. There is the human body cerebrally dead, but metabolically sustained to be farmed for its transplantable parts. There is the human child who may fairly claim to have five "parents": a sperm donor; an egg donor; a surrogate mother into whose womb the fertile embryo is implanted so that she may carry it to term; and the mother and father who raise the child as its legal custodians, and who indeed may lovingly have sought its conception, thereby initiating the entire process.

III.

William Winslade and Judith Wilson Ross explore incidents of the treatment relationship relating to the patient's moral and legal autonomy in their Article, *Privacy, Confidentiality, and Autonomy in Psychotherapy and Psychoanalysis*. The Article focuses upon the special context of psychotherapeutic treatment. The authors' thesis, however, applies generally to physician-patient relationships. The authors initially explore the distinct but related concepts of privacy and confidentiality. They argue that although confidentiality is a relational concept respecting information shared between persons in a relationship of trust, privacy is a personal concept respecting the exclusive control that individuals must be accorded over certain self-referring information. Nevertheless, they maintain that confidentiality is a de-

rivative value depending essentially upon privacy. Confidential information is private information *confided* to another, that is, disclosed to another in a relation of trust on the understanding that it is not further to be divulged — not, at any rate, without the confider's consent. In professional relationships, the client's expectation of controlling further disclosure shows that the client, by confiding her secret to the professional, has only agreed to a limited relinquishment of her autonomy.

The law, the authors continue, seems to recognize the client or patient, not the professional, as the holder of all rights to the continued privacy of confidential information. Unfortunately, the various codes of conduct of the psychotherapeutic professions, and their actual practices relating to secrecy or disclosure, seem to adopt the paternalistic attitude that decisions about the protection of patient confidences, even when made in the patient's apparent therapeutic interest, are for the therapist to make: it is the therapist who controls the further privacy of the information. This fails to make sense either of the patient's autonomy, or of her equal dignity as a person, and it violates the patient's expectation that she will be in control of the continued privacy of her medical information beyond the confines of the therapeutic relationship. The authors reinforce their argument, explaining how their conception of personal privacy as a form of control over information that must continue, even after confidential information has once been disclosed in the professional relationship, is therapeutically beneficial and need not conflict significantly with the therapist's assessment of what course of treatment will most clearly further the patient's cure.

All rights of privacy and confidentiality belong to patients, not to therapists. Once this is recognized, the authors conclude, a decent respect for the patient's autonomy and dignity, even perhaps for his prospects for a cure, demands first, that the patient be given sufficient notice of any disclosures that the therapist is by law required to make, and second, that the patient have the exclusive power to permit or to forbid any other disclosures that the therapist might wish to make, even in the patient's own interest.

IV.

As Joni Gray and Gary Melton point out toward the opening of their Article, *The Law and Ethics of Psychosocial Research on AIDS*, the varying interests of human subject, researcher, and society frequently come into conflict in medical and behavioral research on human subjects. In all such research there are at least these potentially divergent interests at stake: the social interest in advancing the general welfare by deepening and broadening our understanding of the human condition; the researcher's separate proprietary interest in

advancing a career through maximizing her chances that the results will be favorably received in the research community; and the subject's personal interests, which are typically some combination of altruism, curiosity, a desire for any available monetary or other compensating reward, and the hope that the research may lead to the more effective treatment of his own condition.

In the case of psychosocial research on AIDS these conflicts are almost unbearably acute. First of all, in striking primarily gay men and intravenous drug abusers, AIDS has victimized members of groups already socially stigmatized. Second, the apparent transmission of AIDS through illicit drug use or sexual intimacy requires research into areas ordinarily accorded the highest degree of personal privacy. Third, the continuing rapid spread and apparently fatal prognosis of AIDS require our utmost efforts to understand and eradicate it. And fourth, some combination of these factors has caused, or at least has substantially contributed to, the creation of an overheated climate of opinion, verging on public hysteria, about the disease. The magnitude of the medical risk from the AIDS epidemic is great, and the need for research and knowledge is correspondingly high. Against this must be weighed the individual needs of AIDS research subjects; given the stigma attached to mere participation in such research, their needs for confidentiality and for privacy are also substantial. Psychosocial research on AIDS is therefore painfully sensitive.

The authors quite effectively demonstrate those reasons for which psychosocial research on AIDS is more than ordinarily susceptible to invading the subject's privacy, diminishing his autonomy, or betraying his confidences. They then explore certain specific problems of informed consent, intrusiveness, and confidentiality arising in the design and conduct of research studies, the recruiting of subjects for them, and the reporting of research results. In the interest of minimizing risk to the research subject, of assuring that his choice to participate is free and informed, of preserving his right to withdraw, and of protecting his confidential information, Ms. Gray and Mr. Melton make a number of practical suggestions that must be regarded as more in the nature of research imperatives, in view of the gravity and sensitivity of AIDS research. Finally, they demonstrate that the law now quite inadequately protects certain vital interests of AIDS research subjects. In response, they advocate necessary legal reforms, and suggest how researchers in the meantime might go about protecting their subjects' interests as fully as possible under the current law. Their Article closes with an Appendix, "Proposed Guidelines for Informed Consent to Psychosocial Research on AIDS," an extremely thoughtful treatment of elements and procedures in obtaining the informed and free consent of subjects in an AIDS study. Anyone generally interested in bioethical developments in medical jurisprudence, and in the larger

theme of legal change in response to morally controversial developments in medicine and health, or in the legal and ethical implications of research on human subjects, should read this Article.

V.

In *Damned if You Do, Damned if You Don't: Hospitals' Liability for Physicians' Malpractice*, Diane Janulis and Alan Hornstein examine the current doctrines of hospital liability to patients harmed by medical misadventure caused by a physician during hospital care. Each major theory of relief — respondeat superior, ostensible or apparent agency, estoppel to deny agency, and corporate negligence — is reviewed. Against this background of developing legal theories of hospital liability for harms caused by independent physicians with staff privileges, Ms. Janulis and Mr. Hornstein explore not only some of the pressures favoring continued expansion of hospital tort liability for physician malpractice, but also some of the countervailing obstacles to effective hospital monitoring of the quality of care provided by staff physicians.

The authors' primary thesis is that, because of the inconsistent, sometimes conflicting, and constantly changing, social pressures to which hospitals are subject, it is still unclear whether hospitals will be able to meet their expanding obligations in ways that are to the ultimate social good. Before this will ever become clear, we must clarify the hospital's role in the provision of care; only then can we determine the hospital's soundest mandate in the assurance of the quality of medical care. Ms. Janulis and Mr. Hornstein argue their point vigorously. Even the reader who disagrees will find a fuller airing of the issues than most courts have yet given them, as well as a good summary of observable trends in this branch of the law.

VI.

The law places the physician under important duties, one of which is disclosing to the patient the risks of treatment, so as to assure that the patient's consent to treatment be fully informed. Many courts have carved out an exception to those duties, allowing nondisclosure of risk when the mere knowledge or discussion of the risk would represent an independent threat to the patient's health, or as the doctors might put it, when risk disclosure is medically contraindicated. In such a case, concealment of risks furthers a therapeutic purpose, and so this exception to the usual duty of disclosure has come to be called the therapeutic privilege. Elizabeth Patterson mounts a sustained attack on the privilege in her Article, *The Therapeutic Justification for Withholding Medical Information: What You Don't Know Can't Hurt You, or Can It?*

Ms. Patterson is surely correct to argue that the therapeutic privilege has been, at best, only imperfectly understood; in fact it appears more frequently in dictum than in decision. In principle only a narrow version of the privilege is defensible, allowing physicians to withhold risk information only when the information carries a *serious* risk of causing anxiety-related health problems: "Because of the importance of autonomy, the justification for nondisclosure must require at a minimum a significant likelihood of a substantial negative effect."¹⁷ So conceived, the principle finds only relatively feeble support from the current state of the medical arts. We do know that certain stressors can cause anxiety-related health disorders, some of them quite grave, but this is virtually all that we know. We are as yet medically quite unsophisticated in predicting what type of disclosure of what type of risk will, by acting as a psychological stressor, cause a disease or anxiety disorder in what type of person. And since studies suggest that a major source of the patient's anxiety is what the patient does not know, nondisclosure of risk may be a major stressor itself, doing harm more often than avoiding it.

As Ms. Patterson further argues, the therapeutic privilege centrally undercuts the very purpose of informed consent rules, which serve to assure that treatment decisions are for patients to make freely and autonomously, provided, of course, that they are competent to do so. Patients must be free to reject any proffered course of therapy, however promising its expected benefits, and regardless what therapy health care providers would order were they empowered to issue binding treatment directives to their patients. All relevant medical information, especially information respecting risks of a particular treatment and alternatives to it, can bear on the patient's choice whether to undergo treatment. The physician who exercises an authority to withhold this information thereby deprives the patient of some part of the patients's own decision-making authority. Hence a decision not to disclose risks of treatment exerts an undefined but important governing influence over the patient's choice of treatment. When nondisclosure is premised on the patient's own health, as it is when it is therapeutically privileged, the nondisclosure decision is itself a treatment decision: a decision that a particular course of action — namely, nondisclosure — is in the patient's best medical interests.

The nondisclosure decision, however, is thrust upon the patient, whose autonomy is thereby proportionately diminished, for the patient is of course not asked to consent to nondisclosure. Why not? If there is a principled distinction between the therapy of nondisclosure in cases in which risk information may create separate stress-related threats to the patient's health, and other therapies that patients are

17. Patterson, *supra* note 14, at 738.

required to choose freely, it is perhaps that presenting the patient with the choice whether to receive anxiety-producing risk information is enough to do the harm that nondisclosure would avert. Such a choice might be presented in terms like these:

As your physician, ordinarily I would describe the risks of your treatment. But sometimes just knowing the risks causes intense worrying, and the worrying in turn may further damage your health. The choice is yours; but, knowing how worrisome the risks of your treatment might be, I thought that perhaps you'd rather forego that part of our discussion.

The existence of undisclosed risks, serious enough that information about them alone may cause stress-related harms to health, may well make the stress-prone patient brood over the danger, thereby harming his health. If this is so, there can be no effective choice by patients. Either the physician alone decides that risk disclosure is likely to be harmful, and makes no disclosure of any kind, thereby protecting only the interest of all patients who might have chosen therapeutic nondisclosure, and imposing nondisclosure upon the others. Or the physician presents the patient with the choice, thereby telegraphing something about risk, protecting only the interest of patients who might have chosen risk disclosure and imposing risk information upon the others. Ms. Patterson concludes her Article with a proposal for a form of advance consent, requested early in the treatment relationship, that would protect the autonomy of all patients, even those who would elect nondisclosure for therapeutic reasons, without unduly risking that the choice itself will be harmful to the patient's health.

VII.

The Symposium closes with a casenote. In *People v. Florendo*,¹⁸ the Illinois Supreme Court held that the names of patients visiting an abortion clinic were not privileged against disclosure in response to a grand jury subpoena served upon the physician in charge of the clinic. The court reasoned that the public interest in unfettered grand jury investigations outweighs any interest that the individual patients might have in the secrecy of their names. The author argues that the case was wrongly decided, since protecting this information furthers the basic interest behind the physician-patient privilege, the interest in encouraging confidential disclosures by the patient in aid of treatment. Shielding the names of these patients from discovery in this case would therefore square with legislative policy. Furthermore, statutory and constitutional rights of privacy should protect the secrecy of the patients' names in this case, absent any compelling state interest in disclosure. No such state interest is apparent; the bare

18. 95 Ill. 2d 155, 447 N.E. 2d 282 (1983).

claim to an interest in unfettered grand jury investigations, unsupported by any showing of need for this information, cannot suffice.

VIII. CONCLUSION

Thus the casenote concludes the Symposium with a plea for rejection of the rule in *People v. Florendo*, a limited call for legal change, leaving us with yet another reflection on the topic with which the Symposium began, legal flux in medical jurisprudence. How, when, and in what particulars should the laws change to accommodate medical advances when fundamental values are implicated? These remain vexing questions. Is the reader now any the wiser? Read the Symposium, and reflect.