THE RIGHTS OF PATIENTS AND THE LAW

The Sidaway Speech

Cumberland College Symposium

27 -28 June 1985

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The Case of the Surrogate Mum

The tale which I am going to tell you is of the interaction between the medical profession and the law. 1985 has been a vintage year for cases on the rights of patients and on the questions of medical law. When the year began, I happened to be in England, on one of my rare visits. This coincided with the case that came before Mr. Justice Laky in the High Court of Justice in London, concerning the woman who had "sold her body" for the purpose of producing a surrogate child. You may remember she was a down-and-out English woman who decided to carry the child for a rich American couple who could not have a child. The question became whether the child could be allowed to leave the United Kingdom. All sorts of xenophobic attitudes were raised. But, ultimately, Mr. Justice Laky pronounced that the principle to be applied was the best interests of the child. He let the child go. The woman had been paid a substantial sum for her story by certain United Kingdom newspapers. A substantial sum was also paid by the American donor of the sperm. And that fact complicated matters. People in England did not know whether they were more upset by this passing of money, or the passing of a born subject of the Queen out of the jurisdiction to live in a foreign republic.

The Case of the Down and Out Sage

Then in the middle of January, there came before the United Kingdom community a case of even more controversy and complexity, which is at the heart of the matter that I wish to address. The case concerned a man named Derek Sage. He did not have the attractiveness of the woman who had produced the surrogate child. He was a 42 year old gentleman who had suffered kidney damage a couple of years earlier. The kidney damage resulted in complications. He also had a brain tumour. In 1982 he had to go onto dialysis, he was maintained in that way. However, his condition continued to deteriorate. He began to be troublesome to hospital staff. For example, he would masturbate in their presence, would not take his tablets, and generally he became a thorough nuisance. The question arose in December 1984 as to whether his dialysis treatment should be continued. The nurses took the initiative of suggesting to the doctors that the continuation of treatment in respect of Mr. Sage was not really in that patient's best interests. He should, so it was said, be allowed to pass peacefully out of this life. The doctor confirmed the decision, but they could not really obtain the consent of Mr. Sage, who allegedly now had the mental age of a person of three. He was an incontinent, dirty, unloved, unbefriended man on dialysis who was a trouble to himself and to the medical staff. And the consideration was put that the hospital should use the dialysis equipment for some other person who could clearly benefit from it. Three thousand people a year die in the United Kingdom, so it was claimed, for want of dialysis. Therefore, the decision made in Mr. Sage's case, though rather unfortunate for Mr. Sage, would mean that the dialysis used for him would be available for some other, perhaps more "worthy" citizen.

Now, all would have been well in this hospital and in the Home for Homeless Men in Oxford where Mr. Sage spent his days alternating between dialysis and his lonely room. But the decision of the hospital, which would inevitably mean his death in a matter of days, came to the attention of a small group of his associates. They brought it to the notice of the President of the British Kidney Patients' Association. He was concerned about certain aspects of the Sage case. And he saw it as a vehicle to bring certain statistics to public notice. The statistics were that for every million citizens in the U.S.A., there are 97 people on dialysis. In Belgium there are 67, in Australia there are 65, in the Federal Republic of Germany there are 55, in France there are 44, and in Britain there are 33. Accordingly, the case of Mr. Sage was used by the President of the Kidney Patients' Association of Britain to draw attention to a cost/benefit decision that was being made by the National Health Service to grant fewer people life-saving dialysis in that country than would have been the case for similar patients in Belgium or in the United States and Australia.

It was suggested that private assistance be given to the Mr. Sage. As far as I know he is still undergoing his dialysis. The issue presented by his case is still with us, and it is an important one.

It is, of course not unique to dialysis. It is raised also in other areas of sophisticated medical treatment, such as the CAT scan. Who should have access to this expensive diagnostic equipment? I am told that, initially, in Sydney it depended very much upon which hospital you went to, which specialists were treating you, and whether they had access to the public hospital CAT scanners. Decisions have to be made. Life is thereby rationed so that only some will be given diagnostic aids and others will be denied them.

In vitro fertilisation (IVF) is relevant to this issue, because funds spent on this treatment and infertility diminish other public health expenditures, such as AIDS research. Frankly, I think that this may be the greatest, and most unsung issue of IVF. We do not see very much about it in the public media. There is much discussion about the morality of flushing ova down the sink. But not very much about the morality of spending public money on in vitro fertilisation and diverting money thereby from kidney dialysis and the Mr. Sages of this world, on the grounds that they are not really suitable for the continuance of treatment. The English Times newspaper, suggested that the criterion by which the decision to offer dialysis was made in the United Kingdom, depended on such a chance factor as chronological age. If you are over 45, you effectively become ineligible. Having, with reasonable recentness turned forty five, I immediately became anxious about such a rule. I decided that such a rule did not have, shall we say, an automatic persuasiveness about it. There might well be other and more rational criteria.

Presuming that we can afford to purchase some of the new diagnostic technology such as the nuclear magnetic resonance scanners at ten million dollars each, where do we locate such a service in Australia? At the macro level, the importation of such equipment is expensive. At the human or micro level, decisions have to be made which literally affect life and death and the quality of human life. The criteria by which these decisions are made are very much in the province of the medical profession. They are not matters which our legal system has tended to flush out in courts of law, or in the community, by public discussion.

The Case of the Little Old Lady with a Bad Back

I now take you to a later case in 1985. Amy Sidaway brought a case for damages to the House of Lords. This case has just been reported in the law reports. She was the original little old lady, 71 years of age and with long term back trouble. She had gone to an excellent neurosurgeon named Mr. Murray Falconer who had performed a partially successful operation upon her. In due course she returned to the surgeon. He indicated that a laminectomy would improve things for her. Now, the case is somewhat complicated by the fact that Mr. Falconer died in 1977. Accordingly, his evidence was never available in the litigation. So we only had Amy Sidaway's side of the story. She claimed that, after the operation, she had this terrible tingling down one side. It was extremely uncomfortable. She considered her condition worse than before. She wished that she had never had the operation. Other specialists asked whether Mr. Falconer had warned her of possible risks in such intricate surgery, which might touch a blood vessel releasing blood into the spinal cord thereby impinging upon nerves giving rise to the tingling sensation. In one to three percent of laminectomies performed, this is apparently an unfortunate byproduct of the operative procedure. Mrs. Sidaway claimed that she had not been forewarned. She brought her case to the High Court of Justice contending that she should have been told. She said she made no complaint about the diagnosis, and no complaint about the treatment or surgeon's skill. Her complaint was that she had not been given the opportunity to stay in control of her own person. She said she would not have accepted such a risk, if she had known.

The case went to trial. Partly for the problems of the evidence and partly for the application of the principle of law which obtains in England, Mrs. Sidaway lost. That principle of law, is known as the Bolam Test, after an earlier case in 1957. That case lays down the criterion of what the "reasonably careful man" (sic) would have done in the position of the doctor in the performance of the operation. It is a rule of law which suggests that the way in which we ought to approach the rights of a patient and any complaint by the patient is by reference to a criterion of what the reasonably careful <u>doctor</u> would have done in that situation. Well, Mrs. Sidaway's lawyers were not happy with that test. In part, this was because of an interesting development which had occurred in the Supreme Court of Canada. There had been a decision in Canada in which the Chief

Justice of Canada propounded a different test, following Justice Cardozo's ruling many years before in the United States, - a ruling which had also been adopted by about a third of the States there. In essence this alternative test was a principle that looked at the problem of patients' rights from the point of view of the patient instead of the point of view of the reasonably careful doctor. It asserted that there should be full knowing consent by the patient. That is, the question to be asked should be what the reasonably prudent patient would have done in the circumstances. Mrs. Sidaway might still have found it difficult to make a decision about her operation. But plainly, if the test is what a prudent patient would do it becomes terribly important that the patient be fully informed, so that he or she can make the decision as a reasonably prudent person would.

The Sidaway case meandered through the courts of England. It went to the English Court of Appeal and there was dismissed unanimously. It went to the House of Lords, and Mrs. Sidaway lost, Lord Scarman dissented on an important point. The Lords rejected the suggested variance from the Bolam test. They accepted that test and consequently rejected the American "informed consent" approach. Only Lord Scarman would have embraced the principle which the American and Canadian courts had adopted. The majority judges in the House of Lords, decided that, if we were to introduce informed consent from across the Atlantic, it really could not work because a patient can never know all of the diverse problems of an operation. How could a doctor ever explain fully to patients all of the issues that are involved? How, in a short consultation, could one ever comprehend all of the complexities of medical practice which a lifetime's devoted service accumulates in the wisdom of the medical profession? Lord Diplock, in upholding the Bolam rule, said that the American approach would lead to defensive medicine and excessively cautious doctors. It would frighten patients by telling them too much. For those and like reasons, the majority said that they would stick with the Bolam test. Mind you if a patients asks, you must tell them fully and firmly. But if they do not ask then you are under no obligation to exercise all the best of your skills as a professional person doing your best according to those standards. Lord Diplock referred to the fact that every judge who has been a lawyer knew of the necessity to look to your own experience and your own integrity to solve professional problems. Lord Scarman, although he also favoured dismissing the appeal for want of evidence, laid down a different legal principle. Essentially, he said: Every adult person is entitled to control their own body. Different principles may apply in the case of children, and in the case of the mentally ill. But in the case of a fully adult, mature individual such vital decisions should be left to them. And if there is a risk, then a reasonably prudent patient should have been told, so that an informed decision could be made.

The Case for Accountability

I link the case of Mr. Sage and Mrs. Sidaway in this way. In the latest part of the centenary issue of the Law Quarterly Review, there is an extremely interesting article. In his criticism of the Law Lords and of the decision in the Sidaway case, the commentator says, in essence, what could you have expected? What could you have expected from an elitist and secretive society which has not embraced the principle of accountability? What could you have expected of the legal profession looking at complaints against another profession? What could you have expected of judges, and authority figures, looking to this patient's insistence on the right to know, and the right to have information? This academic, from the North of England, said that in Sweden they have had a Freedom of Information Act since 1766, and in the United States such an Act was enacted in 1976. In Canada and Australia such statutes have been passed only in the last three years. Essentially the commentator is making a political point. Arising out of the more robust political circumstances of Scandinavia, and finding a happy planting ground in the United States with its Jacksonian democratic tradition, the notion of people in authority being accountable has borne fruit. But in the British tradition, which has so profoundly affected our society in Australia, that notion is not as congenial. It does not take root quite so easily. The thesis of this author is that, at the heart of the problem presented by the Sidaway case, and I would suggest also by the Sage case, is the right of the community to have the secrets of the profession flushed out. So that decisions on community medicine can be made by informed individuals in an informed community.

In the Sage case this would require exposure of the rules governing decisions affecting life and death. And in the Sidaway case it would require information about the risks of the operation.

I hope this is relevant to the theme of the Congress. We can learn from the crisis of Mr. Sage and the crisis of Mrs. Sidaway.

References

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