122

AUSTRALIAN HOSPITAL ASSOCIATION NATIONAL CONGRESS

CANBERRA, 27 OCTOBER 1979

PRIVACY AND HOSPITAL RECORDS

The Hon. Mr. Justice M.D. Kirby
Chairman of the Australian Law Reform Commission

October 1979

AUSTRALIAN HOSPITAL ASSOCIATION NATIONAL CONGRESS

CANBERRA, 27 OCTOBER 1979

PRIVACY AND HOSPITAL RECORDS

The Hon. Mr.Justice M.D. Kirby
Chairman of the Australian Law Reform Commission

INTRODUCTION

The Law Reform Commission is established by the Commonwealth Parliament to reform, modernise and simplify the laws of Australia. The Commission is established in Sydney and there are eleven Commissioners, four of whom are full-time. The Commissioners are assisted by a staff of twenty and by teams of consultants chosen, with the approval of the Attorney-General, to work on particular projects. The Commission engages public debate about the law, its purposes and its reform. It does this by the use of the media and by publishing papers setting out tentative ideas. As well, the Commission holds public hearings at which experts and ordinary citizens can have their say. Only when the processes of consultation are completed does the Commission report to the Attorney-General and the Parliament.

Two great forces are at work for change in our society. The first is the impact of a changing population and changing social and moral values. One could scarcely expect that a society that is better educated and better informed would conform to a legal system laid down in earlier times when the law was there to be obeyed and that was it.

Many of the problems facing hospital administrators today reflect, in part, this phenomenon. People nowadays ask why this or that law should be so and why what they perceive

as their rights are being denied. We will not turn the clock back. We will see more rather than less of this.

The second force for change is science and technology. Science affects the law as much as it affects the hospital, its government and its services. There are many illustrations of the impact of science and technology on the law. The task of the Law Reform Commission in connection with Human Tissue Transplants is but one example.

The Commission is now working upon a reference received from the Attorney-General concerning the protection of individual privacy in Australia. In connection with this reference we have been examining many attributes of privacy, in police records, employment records, educational records and, relevantly to you, hospital and other medical records.

I propose to say something about the privacy of hospital records and the way in which we are tackling the re-examination of some long established and entrenched views about the rights of patient access to hospital and medical files.

THE PRIVACY REFERENCE

During the 1975 election campaign, Mr. Fraser promised that if he were returned, the government would refer to the Law Reform Commission an inquiry into the laws protecting privacy in Australia. The reference was duly made. The Commission is well advanced in its research on the reference. One aspect of the task has been in part discharged. It relates to the publication of private facts in the media. That subject seemed appropriate to be dealt with in the context of the proposed uniform law of defamation. The balance of the reference remains. It has many problems and many facets. Some concern you specifically in hospitals.

In Australian medical, nursing and hospital practice it is tradition rather than law that has protected privacy and confidentiality up to now. A number of pressures have

lately diminished the security of medical and hospital information. The first is the growing perception of competing moral principles, not least at a time when medical care is passing from being almost exclusively a private responsibility to, substantially, a community responsibility. The development in this country and overseas of forms of national health insurance raise for consideration the rights of the insurance schemes to have information which, at the beginning of this century, would have been regarded as intimately private. For example, whether the schemes are government or privately funded, some form of auditing control may be necessary. This requires the divulging of details about the patient and his treatment.

Furthermore, since the War the focus of epidemiological research has been on chronic non-infectious diseases such as emphysema and cancer. But these require intensive medical surveillance of a substantial population over a long period of time. The moral issues are not limited to resolving the competition between an individual's right to the privacy of hospital information on him and outsiders' demands for information for society's greater good.

THE GENERAL RIGHT TO ACCESS TO ONE'S OWN FILE

This debate extends to demands by an individual for access to his own hospital file. In the United States, the last decade has seen radical changes in this area. Until then, and still in this country, general medical and hospital practice was to deny the patient access to his own records. During the last ten years, the United States has seen a revolution in the provision of access to information. At a governmental level, the principle is found in the legislation known as the Freedom of Information Act. At a personal level, it is found in a wide range of legislation, the most famous of which is the Privacy Act 1974. It may seem curious to include rights of access to information in so-called privacy legislation. A moment's reflection will explain why it is thus. Nowadays, the threats to privacy arise not so much from the old-fashioned physical intruder (the trespasser who enters

the home or the listener at the door). The threat arises from the perception of a person through the growing mass of information accumulated on him. It is the desire to control such perceptions and to make sure they are accurate which has given rise to the United States legislation. Central to that legislation is the maintenance of security of personal information kept on people, the logging of access to ensure that security and the provision, with exceptions, of access by the individual to it so that he can check its accuracy and secure its correction, if wrong or unfair.

Certain federally aided hospitals have already come under the obligations of the access provisions in the U.S. Many objections were raised to them, some of cost and some of principle. However, in nine States of the United States legislation currently grants a patient a right to inspect and in some instances obtain copies of his hospital record. Colorado applies its statute not only to hospital records but records held by private physicians, psychologists and psychiatrists. Some States exclude psychiatric records. Some cover only hospital records. In some cases the hospital authorities determine how much of a medical record the patients may see. Certainly, the experience of federal hospitals under the current Privacy Act in the United States would appear to allay fears about the number of requests for patient access and the cost of administering it. At a federal level, with a total estimated patient population of 5 millions, requests for records by patients from the Bureau of Medical Services has so far numbered about 3,000 in three years.

INCREASE IN THE BULK OF PERSONAL HEALTH RECORDS

One factor which causes calls for changes in the laws is the enormous increase in the bulk of personal medical information held in society. Until the last War most confidential health information was secured by a local family physician in sole practice. In these circumstances the typical medical record was nothing more than a small card with entries showing the dates of visits, medications prescribed and charges. Security, confidentiality and privacy were protected by this system. The physician was usually able to

elaborate the intimate private details of the patient's medical or emotional condition from the "safe crevices of his mind". A recent United States Commission puts the modern problems this way:

> "In contrast, a modern hospital medical record may easily run to 100 pages. The record of a family physician may still hold information on ailments and modes of treatment, but also now note the patient's personal habits, social relationships and the physician's evaluation of the patient's attitudes and preferences, often in extensive detail".

That abuse can occur is clearly demonstrated in the same United States report. It points out that,

> "Hospital records are routinely available to hospital employees on request. Most of these people are medical professionals who need such access in order to do their jobs, but not all of them are. Besides the physicians, psychologists, nurses, social workers, therapists and other licensed or certified medical practitioners and para-professionals, there are nearly always medical students and other people in training programmes conducted either by the medical-care institution itself or affiliated with the institution. These people, too, have access to medical records for training or job-related purposes, as do non-professional employees and voluntary workers".

Attention is drawn to one case in 1976 where a firm was established in Denver precisely to provide a variety of investigative services by the surreptitious acquisition of medical record information from hospitals and physicians. It was then sold to investigators and lawyers for a variety of purposes. One of the sources of information was a hospital employee. A Grand Jury condemned the "laxity of hospital security measures". The question we have to ask is whether this kind of abuse could happen or has happened here in Australia. The Hospital and Allied Services Advisory Council was concerned that it could.

GROWING INTRUSIONS

There are other problems in addition to the burgeoning growth of medical hospital records now abetted increasingly by computerisation. The obligation to answer subpoenas, the increasing inquiries by insurers and researchers all procure information which would formerly have been thought private and confidential. The list of notifiable diseases and conduct expands. The reasons for securing this information increase is our interdependent society. Again, it is useful to look at the United States report :

> "There are few statistics indicating the number of requests for medical-record information that are not directly related to the delivery of medical care, but testimony before the Commission suggests that the number is high. For example, the Director of the medical record department of a 600-bed university teaching hospital testified that he receives an estimated 2,700 requests for medical record information each month, some 34% of them from third party payers, 37% from other physicians, 8% in the form of subpoenas and 21% from other hospitals, attorneys and miscellaneous sources. The attorney for the [Mayo Clinic] testified that the clinic receives an estimated 300,000 requests for medical record information a year, some 88% of them patient-initiated requests relating to claims for reimbursement by health insurers".

The existence of interdependence in society has led to the call for breaching the wall of confidentiality in the name of a higher value even than privacy, viz. "the public interest". It is on this basis that the law has traditionally upheld the subpoena, the obligation to answer questions, statutory duties to provide information of communicable diseases, births and deaths, gunshot cases, drugs and so on. The latest addition, in the name of a higher public interest, is the obligation to report cases of suspected baby bashings. The

point to be made here is that so many have become the exceptions, that the rule itself is rendered fragile. That is the conclusion of the recent American report. It is a conclusion which should concern hospital administrators anxious to uphold at least sufficient privacy so as not to damage the trusting relationship that is vital for the proper health care of the community. The U.S. report recommended many new laws to protect privacy in U.S. medical and hospital health care. These laws arise from the Commission's conclusions as follows :

> "The medical-care relationship in America today is becoming dangerously fragile as the basis for an expectation of confidentiality with respect to records generated in that relationship is undermined more and more. A legitimate, enforceable expectation of confidentiality that will hold up under the revolutionary changes now taking place in medical care and medical record-keeping needs to be created".

The Law Reform Commission is now consulting informed reaction of medical and hospital authorities throughout Australia to proposals for Australian laws. We do not start this exercise with a blank page. We have the benefit of the earlier Australian inquiries, the work of the New South Wales Privacy Committee and the conclusions of the United States Commission. We will secure the assistance of consultants including those who have already been appointed to acquaint us with the special problems in the health services area. The short review that I have given today indicates that there is a problem here which will not simply go away. To do nothing is to allow the gradual erosion of an important and efficacious privilege of privacy which has existed until now. The time has come for the law, stating today's standards, to face up to these issues.

WHAT IS BEING DONE

The Commission's Research Paper. In April 1979 the Commission issued a research paper seeking to analyse the approach that should be taken in Australia to the protection of the privacy of hospital records.

This is not the time to detail at length the proposals contained in the research paper. A number, however, stand out as important :

1. So far as the collection of personal information is concerned, it is proposed that a person should not be required to disclose personal information which is not immediately relevant and necessary for proper health care.
2. Where standard forms are normal, they should be cleared to ensure that only minimum personal information is extracted by them.
3. A patient should normally be entitled to direct access to any personal records maintained about him or her unless it falls within a limited number of exempted records.
4. The records exempted are those which contain information concerning the mental health of a patient, the health of a patient under 15 years of age or medical information that might be prejudicial to the physical or mental health of the patient.
5. In the event of direct access being refused, provision should be made for health care records to be accessed indirectly by a medical practitioner, next of kin or legal guardian nominated by the patient.
6. Where disclosure follows legal process, as for example a subpoena directed at a hospital, the subject of the record should be notified as soon as possible so that he can, if he wishes, contest its scope or relevance.
7. Record-keepers in health care centres including hospitals should appoint an information manager with whom the subject can deal in relation to his personal record.
8. Logs should generally be kept by information managers in respect of access to personal information.

as in all tasks before the Law Reform Commission, we seek out expert and lay opinion before delivering our final report to Parliament. The protection of privacy is important because the development of computing and other information sciences will put the individual in our society at risk. It is vital that whilst we take advantage of the new technology, we should preserve proper protections for the individual. It is important that he should never become a mere object, a file number or a record peered at and pried into by others, with no right to know how they are perceiving him and no assurance of the confidentiality of personal medical information in hospital records.

FURTHER CONSULTATION

The whole purpose of the Law Reform Commission's procedures of consultation is to elicit public and expert comment and criticism. We are well aware of the strongly felt views in some hospital and medical quarters contrary to the notion of patient access. We are equally aware of the direction in which privacy protection legislation is going in many countries, including in the field of medical files. It will be important to have the views of the Australian hospital and medical profession. I hope that all those with views and opinions will put them forward to the Commission so that its report can be informed and balanced when it is ultimately presented to Parliament.

Address for submissions : Mr. G.E.P. Brouwer, Secretary & Directo of Research, G.P.O. Box 3708, SYDNEY, N.S.W., 2001 (02-231-1733).

Note on Research Paper : The Law Reform Commission, Privacy Research Paper #7, Medical Records & Privacy (Mr. Bryan Keon-Cohe April 1979.