

The information minefield: access to clinical information

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Abstract

A crucial element of any fiduciary relationship is the maintenance of confidentiality. While the obligation to keep detailed records remains, the South African Constitution and legislation have eroded the clinician's ability to absolutely safeguard their patients' privacy. Clinicians cannot guarantee absolute confidentiality and should always warn patients of the limits of privilege in their relationship (especially in forensic settings). A bewildering array of interested parties may now petition for access to clinical information, and it is not always clear under which circumstances legislation demands disclosure, and when ethical considerations prevent it. It is therefore incumbent on practitioners to understand when disclosure is sanctioned, and when the demands of legislation cannot be resisted.

Keywords: Access, Clinical information, Privacy, Confidentiality

"Whatever, in connection with my professional practise, or not in connection with it, I may see or hear in the lives of men which ought not to be spoken abroad, I will not divulge, as reckoning that all such should be kept secret." Hippocratic Oath

In 1966 Lord Moran, Sir Winston Churchill's physician, published a detailed medical memoir about his illustrious patient. His revelations were applauded by contemporary historians for providing much needed insights into the motivations and actions of an important historical figure. But the British Medical Association voted overwhelmingly to censure him, distraught that he had betrayed the trust and confidence of a patient, which they declared was "doubly owed to the dead".¹ The critical issue is that clinicians and patients enjoy a fiduciary relationship, which simply means that patients should always be able to trust their doctor to act in their best interests.²

Clinicians are taught and encouraged to keep accurate detailed records. These notes often contain not only intimate confidences trusted to the physician but also possibly sensitive collateral information from others, as well the doctor's own speculative musings. Although the clinician (or employing institution) is the owner of these records, they do not always have absolute control over their use. Before our new Constitution was implemented patients had no right of access to their own clinical records, and likewise a doctor had no right of access to another practitioner's or a hospital's clinical records, even with the patient's consent. It was considered a courtesy, but not an obligation to provide another involved practitioner with clinical information.

There is a general overriding obligation to preserve the privacy of patients. The Health Professions Council of SA (HPCSA) specifically states in its Ethical Rules that disciplinary action will be considered if professional confidentiality is breached by

"Divulging any information regarding a patient which ought not to be divulged, except with the express consent of the patient or, in the case of a minor under the age of 14 years, with the written consent of his or her parent or guardian, or in the case of a deceased patient, with the written consent of his or her next-of-kin or the executor of his or her estate." (Rule 20)

Disclosure, therefore, usually proceeds according to accepted exceptions to this rule. Even though the dedicated clinician may act zealously to protect their patient, they nowadays often have to with-

stand a cacophony of 'interested parties' clamouring for the sensitive information inside their folders.

Privilege and privacy

Privilege refers to an individual's right to control which information that was conveyed in confidence can be revealed in juridical proceedings, whereas privacy is the individual's right to confidentiality when (usually by necessity) one or more professionals have access to sensitive information.³

In South Africa clinicians cannot refuse to reveal sensitive information in court on the basis of privilege. Lawyers and journalists routinely do. The latter do so probably as a matter of expediency (to protect future sources), and the former cannot adequately represent a client without it. Mental health professionals have argued, unsuccessfully in many courts everywhere that without the right of absolute privilege their ability to act in their patients' best interests is impaired.

Threats to privacy are varied, and probably have become more common (and serious) as technological progress facilitates ever easier access to information. Not only are medical records now held in vast databases that can straddle continents, but amorphous entities (such as medical aids, insurers, government departments, multidisciplinary teams, hospital administrations etc) can claim valid interests in obtaining certain details. Many of these entities do not necessarily consider themselves bound by the same ethical standards that physicians impose on themselves.⁴ This may result in, for example, an insurer selling information about its clients to other commercial groups. Patients and clinicians often do not realise that when they fill out forms, or provide information on the telephone that these particulars are being logged and passed on. It is now quite common for contracts between health users and providers to contain clauses authorising access to sensitive information. Unfortunately many do not realise the implications of signing these agreements.

Clinicians are often careless in safe guarding their patients' privacy. How often has one overheard a colleague conducting a conversation with a patient on a cell phone? Can anyone recall an incident when a colleague has pointed out that the person he has just greeted in the restaurant happens to be a patient? Even discussions with colleagues about an 'interesting' or 'difficult' patient, whose anonymity may be easy to penetrate (my nameless patient is a well

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known rugby captain, etc) can be tantamount to betrayal of the fiduciary relationship.

Disclosure

Generally the clinician will maintain confidentiality unless the patient provides permission for him to disclose information. Even so, one cannot obtain a blanket consent to reveal any information (none of the "trust me, I'm a doctor"). One should discuss with the patient precisely what will be revealed. Circumstances in which permission from the patient may not be necessary (although one should try obtaining it) are:⁵

- If in the patient's best interests. This usually will arise when the patient is cognitively impaired, and it is crucial to share relevant information. An obvious example is the patient who is a victim of abuse and is afraid to provide permission
- Where a court orders disclosure. If the information is particularly sensitive or potentially harmful the clinician should attempt to persuade the court to maintain the confidentiality. There are rare cases when despite a court order one may continue to refuse (as a matter of conscience), which may result in a contempt of court conviction for the clinician. A tough choice.
- In the interests of others, especially where failure to disclose may expose others to the risk of death or serious harm.
- Where an Act of Parliament defines disclosure as a duty. Examples include the obligation to report notifiable diseases, reporting of serious accidents, terrorism etc.
- If the patient was forewarned that the information may be disclosed. This ought to be the rule whenever practitioners perform forensic assessments, or it is very likely that disclosure may be unavoidable.

The patient requests access to information about himself / herself

In the past despite their curiosity patients would hardly ever have thought to ask their attending doctor for even a peek at his notes. But section 32 of the final Constitution of RSA states that "everyone has the right of access to

- any information held by the State;
- any information held another person that is required for the exercise or protection of any rights."

As required by the Constitution the Promotion of Access to Information Act (Act No 2 of 2000) was enacted. Although the Act does differentiate between public and private bodies there is an obligation on both to provide a mechanism whereby patients can access information held about them. Public bodies have to appoint an information officer, whereas the heads of private bodies have to deal with requests for information.

Contrary to a prevailing expectation one does not have to provide a copy of the entire contents of the patient folder. Access can be strictly controlled and supervised. The clinician should be present when the file is perused, and should allow access only to information that is relevant to the stated reasons (that allows for the exercise or protection of a particular right).

If the information officer or head of private body is of the opinion that information may cause serious mental/physical harm to the requestor then it is advisable to consult with a health practitioner that has been nominated by the requester. If the nominated practitioner agrees that the information may be harmful arrangements for counselling of the requester can be made. And the designated counsellor should then be given access to the records. If the record contains information about a third party the latter must be consulted too.

A request for access to information should be refused in the following circumstances:

- if disclosure contravenes legislation (for example, revealing that a person is a secret agent for the country)
- if the information compromises a police investigation or ongoing court case

- if the privacy or safety of a third party will be significantly compromised
- if the request is vexatious, frivolous or may result in unreasonable diversion of resources.

The Act does not provide for penalties for refusal to reveal information, if this was performed in good faith. Therefore one is ultimately being asked to use good judgement, in which the interests of all involved parties are considered and weighed up.

Interested Third Parties

An almost bewildering array of other third parties can inundate clinicians for information. Consider these scenarios: A colleague requests information about a patient. An opposing divorce lawyer demands copies of all of the attending psychiatrist's notes. A company requests a psychiatric report on one of its employees that has been admitted for a psychotic illness. A court issues a subpoena, and during the proceedings orders the attending psychiatrist to surrender his notes for scrutiny by the other side's expert. Medical aids commonly demand that the psychiatrist provide DSM-IV multi-axial diagnoses (with supporting symptom lists) before authorizing treatment.

Not uncommonly some requests are coupled with threats, which may be conveyed via an order with 'High Court' displayed on the frontispiece, and signed by the court's registrar. Failure to comply, the recipient is informed, will result in a fine or jail sentence.

Again, the disclosure can be made if the patient provides permission. Often the request attempts to bypass the patient (obviously in the knowledge that the patient will refuse). Many permutations can occur. For example, the patient may be deceased (and the heirs are contesting the will), or the demand may be for a file that was used interchangeably for many family members.⁶ In all such cases the third party does not generally have an interest in all the information contained in a file, but now needs specific details in order to pursue a particular (usually juridical) course of action.

As a sweeping statement one could insist that any disclosure without the index patient's permission to an interested third party is unethical. Exceptions would include situations when cognitive impairment or obvious poor judgement prevents the patient from making an informed decision, which is contrary to his/her own best interests. You have to judge what 'best interests' means.

Otherwise, use the declamation "See you in Court", knowing that you may ultimately have to reveal the information under duress.

Some Concluding Guidelines

A crucial component of any fiduciary relationship is honesty. Clinicians should always warn patients that information may have to be revealed, particularly if the assessment is expressly for a third party, such as the courts or insurance companies. Patients cannot be expected (or trusted!) to divine the actual limits of a specific professional interaction.

Try to anticipate future threats, such as pending divorces and litigation. And finally, consult with other senior colleagues when in doubt. At the least you will be able to act within the prevailing ethos, which can be a relatively good defence.

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Modern psychiatry – a change in ethics?

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Ethics in psychiatry is a complex, controversial and often confusing topic. Psychiatrists in different areas bring their own values to their work, but they must also deal with the values of their colleagues and patients. This intermixing of such values sometimes leads to conflict, which may arise about issues such as confidentiality, informed consent, involuntary hospitalization, the right to treatment, the right to refuse treatment, duties to third parties, and regulation of psychiatric research. Laws may change, as they have in regard to involuntary hospitalisation and treatment, or may be ambiguous, as they are in regard to the limits of patient confidentiality, further complicating the situation.

The papers by Radden, McLean and Kaliski address separate areas of ethical concern in contemporary psychiatry. Yet, they have a common thread in the application of ethical standards to a changing face of modern psychiatric practice. Historically mental health has been neglected and resource allocation inadequate. Conditions in psychiatric facilities remain generally poor, increasing stigma with both the mentally ill and intellectually disabled discriminated against. Diagnosis in psychiatry includes a whole range of conditions and severities requiring the various therapeutic situations to be carefully considered as to the ethical issues applicable. The need to provide culture appropriate care requires that ethical issues are addressed in particular contexts. Monitoring of the quality of standards of care and the implementation of mental health legislation is essential. Although there are common themes to general medicine, some of the dilemmas are quite different but care must be taken to avoid overgeneralisation. General principles may be utilised but there are no universal solutions. Each situation has to be analysed and solutions sought as to the best interests of the patient. In psychiatry this occasionally involves others in the community as well. The risk of exploitation due to the vulnerable nature of the psychiatric patient extends the ethical issues particularly in long-term psychiatric management.

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Professional codes

Since ethics involves a set of principles guiding individuals in deciding what is right or wrong, good or bad, doctors are often seeking answers to the problems they encounter in professional codes of ethics. Such approaches do not necessarily solve problems. Mental health professionals are not required to take any further declaration or oath on qualifying or registering. The Madrid Declaration on Ethical Standards for Psychiatric Practice issued by the World Psychiatric Association (WPA) is a comprehensive document displaying significant advances for setting ethical standards for psychiatrists.¹ There are also further statutory obligations in various codes of conduct. These become important guidelines in psychiatric practice and have been endorsed by all member countries of the WPA. Codes clearly reflect the consensus about the general standards of appropriate professional conduct. They include references to the use of new treatments, scientific techniques and medications. Self-regulation of misconduct within the profession, and respect for the rights and needs of patients, families, colleagues and society form part of the codes. Such codes are reinforced by the standard ethical principles, such as beneficence, autonomy, respect for the persons and justice.

A criticism of professional ethics codes, in psychiatry and in other professions, is that they may have limited effect on education, on advanced training, or on routine professional practice. The efficacy of a mechanism of enforcement for the codes is absent because of the lack of suitable actions against those psychiatrists who have acted unethically. Codes of ethics as with the legal statutes are also subject to change and are frequently reviewed. Ethical principles can support the goals of psychiatric practice and research and an awareness of the relevance of these principles can help clarify treatment options and justify particular decisions in treatment and management.

The ethical issues peculiar to the mentally ill person should be recognized in general medicine and not result in further discrimination. The World Medical Association's statement on ethical issues concerning patients with mental illness reflects the situation, focusing on the patients.² This document reflects the progress in psychiatric therapy which allows for better care of patients with mental illness. Recognition that more efficient drugs and other treatments are ca-

pable of curing mild cases and bringing about long remissions for patients whose conditions are more serious is addressed. The document further states that patients with mental illness are to be viewed, treated and have the same access to care as any other patient.

Informed consent

Informed consent questionably transfers responsibility from doctor to patient. Informed consent is the basis of autonomy theory. Adult patients are assumed to have the right to consent to or refuse treatment. To permit competent adults to make important personal choices about life-styles, careers, relationships, and other values is one way to demonstrate respect for persons. The disabling effects of illness, especially mental illness, influences this issue. When the capacity to choose is compromised by the symptoms for which the treatment is offered, can this person be expected to decide? A document of informed consent serves only as a record of the completion of a process. That process should include enough uncoerced time and information to make an informed choice about treatment. Even voluntary patients have a degree of coercion. The authority of psychiatrists is well documented. Patients often regress in response to mental and physical illness and may become especially vulnerable to influence and exploitation. Psychiatrists must guard against the tendency to dominate their patients' decision making in such circumstances.

Right to die

The right to die suggested in discussions on euthanasia is more appropriately referred to as "end of life decisions". The patient's right to refuse treatment is part of the rationale used to support seriously ill patients' right to forgo life-sustaining treatment. It has been recognised that patients who believe that their quality of life would be compromised by continued treatment have the right to demand that such treatment be withheld or with-drawn. Patients who expect to lose their capacity to make decisions may express their wishes on a prospective basis. This is usually through the use of an advanced directive or "living will". These directives have legal standing in some countries and can elsewhere be used as evidence of a patient's wishes. Living wills present problems because they are often too general, making it impossible to cover all the eventualities in the course of a serious illness within the knowledge of a layperson. The role of the psychiatrist is complex in these situations. Often the psychiatrist is only involved at the end stage of the process. Evaluation of competency by a psychiatrist has been suggested in the proposed legislation. Can the psychiatrist contribute more than the regular attending clinician? Closely related are the circumstances of the suicidal patient. Should all patients who attempt suicide be treated? Some patients who attempt suicide refuse treatment. These patients are invariably treated by referral to hospital. Many questions remain difficult to answer. Is this treatment justified? The assessment comes down to justify the sufficiency of competency and rationality to be allowed to die. The importance of competence cannot be over emphasised. Are they really deciding what is good for themselves or acting on their own conceptions of the situation? Can a person

competently desire to die? The concept of a refusal of treatment certificate (red ticket) is common in hospital clinical practice. Are "red tickets" acceptable in psychiatric patients? Which persons ought to be allowed to die in so called passive euthanasia? Is suicide different to a seriously ill dying patient. Danger to self is one of the indications used for involuntary hospitalisation. Does the psychiatrist have to decide what makes a person's choice rational? This must be made in the face of all relevant available information, consequent to all the various options to be chosen with intelligence that is rational and adequate.

Surrogate decision making

A surrogate is designated to make treatment decisions for patients who have lost decisional capabilities. The surrogate may be selected by various procedures or by the courts. The designated surrogate is usually a next of kin, although next of kin, may not always be the appropriate decision makers. Relatives may have psychological and other agendas that interfere with their ability to make just decisions. In the past, surrogates made decisions for patients on a "best-interests principle". The surrogate was supposed to decide which treatments could be reasonably expected to be in the patient's best interests. Present autonomy-based approaches require surrogates to decide on the basis of what the patient would have wished. The surrogate would need to be familiar with the patient's values and attitudes. These substituted judgments present problems because it may be difficult to determine whether the surrogate is really able to determine what the patient would have wished. Does the psychiatrist have a role in the assessment of the surrogate?

Involuntary psychiatric treatment

This arises from the refusal to consent to treatment or when involuntary treatment is considered justified as compulsory treatment. Preventative detention of a potentially dangerous patient who has not committed an offence remains problematic.

Treatment of those who actively resist treatment is different to other areas of medicine and is the focus of mental health legislation. Mentally ill persons incapable of giving consent are different to physical treatment patients. It must be emphasised that involuntary patients have the right to appropriate treatment despite having their freedom restricted. This is important in considering the problems of substandard facilities to which psychiatric patients are frequently admitted. This in itself presents further ethical issues. The principle of beneficence is invoked to justify treatment of some persons against their will. If a person has a mental disorder and is dangerous to self or others, the law permits involuntary treatment. The legal ground for treatment of persons dangerous to others is "to protect public safety." The legal basis for treatment of suicidal or gravely disabled persons is to protect their lives or safety. In both cases the ethical basis is to benefit the patient by treating the mental disorder. There are legal and ethical limits to involuntary hospitalisation. Involuntarily hospitalized patients must have the right to a judicial review of the grounds for their confinement and treatment.³ Because involuntary treatment restricts a person's freedom and per-

sonal choice, the mental health law requires that this be done. Hospitalization may no longer be indefinite. From an ethical perspective, involuntary treatment may be considered if it is time-limited. The law usually permits a longer duration of involuntary treatment for persons dangerous to others than it does for patients dangerous to themselves.

Confidentiality and privacy

Large computer databases store information which is more freely accessed. Advanced technology has brought issues of privacy and confidentiality to the fore. The problem is further exacerbated in that the databases that store information can be accessed, for example, by managed health care companies with different motivations. Problems arise relating to the extent of access to the relevant information. Reasons for complying with the obligation of privacy and confidentiality may be advanced but these must be cautiously considered. Privacy and confidentiality are often confused but are distinct concepts and the differences must be appreciated. Some information about individuals is in the public domain and is in reality not private. The privacy of information lies in the detail, for example, of the patient's condition etc. A dichotomy has developed in practice as to what is sensitive and nonsensitive with a spectrum in between. Again guidelines may be derived from the principle of respect for autonomy. Privacy for psychiatric practice remains an absolute condition for the relationship necessary in therapy. Infringement of confidentiality only occurs when the individual to whom the information has been granted, in confidence, fails to take care in disclosure especially when another statutory circumstances present.

Forensic settings

For those working in forensic settings ethical issues are becoming of even greater concern than previously. Forced medication has been discussed and considered in making an individual competent to stand trial, as well as in incompetent psychotics in involuntary settings and for the violent patient. The least intrusive procedure should always be utilised. Psychiatrically ill persons in prison pose another ethical dilemma when considering patient rights. The right to refuse treatment, as well as the right treatment must be considered in these settings.

In forensic psychiatry, the role of the professional is aimed at documenting, obtaining, preserving and interpreting evidence in evaluations for the courts and other bodies. This is designed to assist in gathering evidence for decision-making bodies. The evaluator must retain a duty to respect the human rights of the persons being assessed and to adhere to strictest ethical standards of the profession, including the duty to inform the person about the nature and objective of examination. Disclosure of fact that examination is not confidential with respect of findings must be specifically addressed. The conflict between the role as forensic evaluator and as health professional results in a dual loyalty. The psychiatrist cannot accept that a terminology change to that of the evaluation role frees him or her from ethical duties to the patient being evaluated. The dilemma can be partially resolved by performing the assessment consistent with the rights of an individual in-

dependent from influence of others. If the patients are incompetent then disclosure must be made to the person authorised to act on behalf of the patient. An obligation to treat in an emergency and refer for treatment to another facility when the condition assessed so requires remains.

Justice

Justice is an ethical principle that is especially relevant to mental health policy. It should be understood, in this context, as the fair distribution and application of psychiatric services. New advances require new resources which are ever increasing. With deinstitutionalisation, discharge of patients into the community without the ability to cope or with the occurrence of risk behaviour places even more strain on limited resources and requirements for a comprehensive service. This is perhaps a political concern and not an ethical issue. Cross-cultural issues are important in all areas and their influence on illness contributes to ethical debate. The ethical issues arise in public health policy. In the debate about the right to health care, opinions remain divided between the professionals and the providers, both public and private. Some believe that health care is a right to which all persons are equally entitled. Others think that health care is a privilege that must be privately purchased. Still others believe that some amount of health care should be provided for all those with significant health care needs who are unable to obtain them with their own resources. The argument states that if not as a matter of right, as an act of benevolence. Various proposals for a national health insurance are being considered and this will extend the dilemma. Private insurance appears to be continually moving toward a reduction of psychiatric coverage. Many persons' psychiatric needs are inadequately provided for or not at all by their medical aid companies. As result of policy, many indigent persons and even people with moderate financial resources who have serious and chronic psychiatric needs go inadequately treated.

Modern psychiatry requires ethical issues to be considered even more carefully and illustrates the dynamic nature of appropriate ethical consideration in specific instances.

" It is the duty of all psychiatrists responsible for taking major decisions with a patient's function to constantly backup the opinions through dialogue and transparency concerning the approach adopted vis-a-vis their peers, they patients and the community at large." - Council of Europe Committee on Bioethics.⁴

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