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How private is our privacy in health care?

People seeking medical care expect that health professionals will respect their dignity and that all aspects of their care will remain private. Yet the reality is that their privacy is frequently violated. The legal and ethical challenges related to preserving privacy in health care will be discussed in a two part series. Part one examines personal and informational privacy in health. Part two, next bulletin, will examine how privacy is secured.

The Victorian Public Hospital Patient Charter states that ‘health services will be provided in surroundings which allow privacy, including privacy to undress and only be seen by the doctor, nurse or other health care staff providing care’.¹ Breaches of privacy may be unintentional. It may not mean that the individual will litigate, but it will leave a legacy of insecurity and mistrust. In addition, other information about patients may be exposed to numerous individuals without their knowledge or consent. Again this may be unintentional yet have serious repercussions for that individual. But what is privacy and do we have a right to claim it.

Do we have a right to privacy?

There are varying opinions about the philosophical and ethical assumptions about a right to privacy. Placing privacy in the context of a moral principle aligned with respect for autonomy as argued by Beauchamp and Childress, ‘includes the right to decide in so far as possible what will happen to one’s person – to one’s body, to information about one’s life, to one’s secrets, etc.’² They extend this right to those who have never been autonomous in that they have rights not to be ‘needlessly viewed or touched by others’.³ However, if I go out in public I don’t have the right not to be seen. Anyone can look at me and I at them, in certain social situations. People have developed tolerance for this because humans are social beings, which implies some degree of interaction with others, though there are limits to this tolerance from a social, cultural, legal, ethical and individual point of view.

There appears to be no explicit right to privacy generally conferred by federal or state laws. We have legislation covering aspects of privacy but none that categorically gives an individual the right to be left alone. This was made apparent when the High Court found that a tort of Privacy was not recognised in Australian Law.⁴ However, a Queensland judge recently paved the way to allow individuals to recover civil damages for mental, psychological or emotional harm, where ‘a willed act of another intrudes on their privacy or seclusion in a manner which would be considered highly offensive to a reasonable person.’⁵

It’s suggested that Australia’s lack of a constitutional or statutory Bill of Rights means that any attempt to develop privacy laws as an aspect of human rights is thwarted. In addition, there have been few cases in court to test privacy laws.⁶ The Victoria Law Foundation defines privacy as the right to be left alone, and includes stopping or setting limits on intrusions into one’s body, place of residence, personal mail, telephone calls or other private communications and personal information.⁷ Whilst Australia lacks a Bill of Rights to enforce assumed privacy rights there is a

universally declared agreement in principle. Article 12 of The Universal Declaration of Human Rights states: 'No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks'.⁸

Legal protection of privacy

Some examples of Commonwealth and State Laws which protect aspects of privacy in Victoria include:

- Information Privacy Act 2000 (Vic)
- Health Records Act 2001 (Vic)
- Privacy Act 1988 (Cth)
- Surveillance Devices Act 1999 (Vic)
- Telecommunications Act (Cth) 1997
- The Crimes Act (as amended) 1914 (Cth)
- National Health Act 1953 (Cth)
- Health Services Act 1988 (Vic)

Information Privacy

Personal information is information about an individual whose identity is clear or can reasonably be worked out from that information, eg., name, address, age, financial status and eligibility for concessions or benefits, and family information. Privacy laws cover documents, photographs, electronic material and digital databases. Sensitive information refers to a person's racial or ethnic origin, philosophical or religious beliefs or affiliations, political opinions, membership of political associations, professional or trade association or union, sexual preferences or practices, or criminal record. The Commonwealth Privacy Act recognises health information as sensitive information but Victoria's Information Privacy Act doesn't, because health information is protected by the Health Records Act. A general exemption to privacy of personal information is allowed with employee records, which are not covered by the Privacy Act.⁹

Preserving privacy in health care is a challenge

Health care professionals have certain privileges in relation to privacy due to the nature of their work, but are not above the law if they abuse them to the detriment of their patients. Australian case law permits breaches of confidentiality only in situations where there is a clear risk of harm to an identifiable person, though there is not a duty to warn.¹⁰ The Privacy Act does allow for disclosure if it is in the public interest, eg. serious threats to life, health or safety. This concept can be interpreted in terms of community versus individual benefit where it is suggested that doctors not only seek to restore a patient's health but must do so in a manner that preserves and promotes the common good.¹¹ Examples of this may be informing authorities about a person's medical condition that may impair their ability to drive safely. Another is reporting suspected child abuse under mandatory reporting laws. In general the common good protects confidentiality: cases are rare when disclosure is required. When the common good requires disclosure in particular circumstances, public trust in medical confidentiality is not eroded.

Breaches of privacy would appear to attract equal consideration in law, but are more difficult to prove and defend. Privacy can be breached merely by unauthorised access

to client information. Unless this information is disclosed in some way, technically the rights of confidentiality may remain inviolate. The Crimes Act does cover offences relating to unauthorised access. Can one's privacy be breached if one does not know one's information has been accessed without consent? In reality, this practice may be pervasive but we don't know about it. Whilst much of this relates to written information, can similar questions be asked about personal and bodily privacy? People trust health professionals to treat their bodies with dignity and respect in life and death.

Ethical issues and privacy

It would be possible to be very respectful yet at the same time violate a patient's privacy. How much information is really relevant? How much looking and touching is unnecessary? How many people not involved in a patient's care, have access to their health information or invade their privacy by intruding during discussions or examinations. Perhaps someone inadvertently witnesses or overhears a patient's private examination or discussion with a health practitioner because they are being treated in the near vicinity. Has the practitioner been negligent in not protecting privacy? Has the patient suffered damage by another's inadvertent intrusion even if that person just happened to be passing by and looked. Should this be the expected standard and can it be condoned, even though, technically, someone's privacy has been breached.

Who has access to an individual's health record is not always accurately conveyed to that particular individual. Sharing of information between treating practitioners has also come under scrutiny following a survey which identified that implied consent for 'routine' uses of health information should not be assumed.¹² Privacy laws now allow an individual to access their own health information held by private and public health providers. How this information is regulated is currently being drafted in the form of a National Health Privacy Code. The draft code generally aims to safeguard the health privacy and dignity of all individuals in a consistent way nationally, taking account of technological change.¹³

Reality TV shows which give us a voyeur type view into aspects of life, including medical care, are considered entertainment. Viewers are exposed to real medical dramas with sick and injured people, not actors. Does having an audience, albeit a hidden one, then affect the therapeutic relationship for that person in some way? Do the health professionals change the way they practise for the camera? Does editing of the material give a biased perspective? The potential for these images to be used for litigious purposes has been considered in America, where filming an emergent medical situation may take place before consent can be obtained. If consent is then denied, the filming may technically be considered as an invasion of privacy.¹⁴

Threats to privacy

Over the years there has been an insidious march into territory that was once considered private. The country supports a welfare state, and in doing so, requires both givers and recipients to disclose personal information. Tax File Numbers are a form of national identity for financial purposes, yet Australia rejected the idea of an identity card many years ago. Some suggest that health data about individuals should be traceable throughout all jurisdictions nationally, and a system is being considered for a HealthCare card to carry data about us from birth till death¹⁵.

Everyday our privacy is intruded upon; video-camera surveillance as we enact our daily commercial chores, some whilst we engage in work activities. Picture enabled mobile phones are popular and issues regarding their potential to violate privacy have been discussed in the media.¹⁶ There are also calls to restrict solicitation over the phone by direct marketers.¹⁷ Personal frustration with such cold calls has prompted me to demand, 'Where did you get my number?' 'From a database,' is the usual reply. 'Where did you get the database?' 'We bought it!' Transaction details are used to create such databases.¹⁸ Some calls, representing Australian Companies, are from overseas phone numbers, eg. India.

Is a person's health data safe from commercial exploitation? Traditionally, health data has been used for research and auditing purposes. The various privacy laws have impacted on how data can be accessed and in what circumstances. For example, ethical research conduct mandates that human participants give a valid consent. Yet at present a person's consent is not required for use of their de-identified health data and it is irrelevant if they state that they do not wish their health data to be used for research purposes. In this respect a person has no rights to decline since their information becomes part of a large data and statistics pool – one that can be bought and sold for commercial and research purposes. Use of their data may confer a social good if used to further knowledge, but it does take away the right of that individual to choose.

The end of privacy as we know it

We may wish to preserve our bodily privacy out of modesty, and our personal health information for fear of it being used to discriminate against us, yet it appears we are tolerant about the prospect of our physiology and/or behaviour being used in ever more innovative ways to prove we are who we purport to be - for security purposes to protect our notion of privacy. Since the September 11 terrorist attack, people in the Western World may be forgiven for having a heightened sense of vulnerability. It is surprising, therefore, that the USA Patriot Act of 2001¹⁹, rushed through soon after the attacks, is now causing some concern due to the inordinate and unregulated nature of surveillance and detection activity that it legitimises. Some suggest that aspects of the Act violates civil liberties²⁰. Strict privacy laws, not only in health care, but generally, have expanded the security market. Hence the boom in the Biometric industry, which is the topic of Part Two in this series about Privacy.

Endnotes

¹ Victorian Public Hospital Patient Charter, <http://patientcharter.health.vic.gov.au/patsfirst.htm> accessed 24/9/03.

² T Beauchamp and J Childress, *Principles of Biomedical Ethics*, 4th Edition, Oxford University Press, (New York, 1994) p. 410.

³ Beauchamp and Childress ...p. 411.

⁴ ABC vs Lenah Game Meats Pty Ltd as cited by Malcolm Crompton, 'Privacy, Technology and the Healthcare Sector', <http://www.privacy.gov.au/news/speeches/sp79notes.html#5> accessed 17/9/03.

⁵ Grosse v Purvis, 16/6/03, cited by Duncan Giles and Gayle Hill, 'New Australian Privacy Right', *Mondaq Business Briefing*, (2003) July 2.

⁶ G Greenleaf, *Enforcement of the Privacy Act: Problems and potential*, Privacy Law 2001 Conference, Sydney May 2001, <http://www2.austlii.edu/~graham/publications/2001/enforcement.html> accessed 17/9/03.

⁷ Victoria Law Foundation, *Private Lives*, <http://www.victorialaw.org.au/PrivateLives/index.htm>

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- ⁸ United Nations Universal Declaration of Human Rights, <http://www.un.org/Overview/rights.html> accessed 17/9/03.
- ⁹ Victoria Law Foundation ...
- ¹⁰ C Hirst, 'Law Report, Health Professionals Duty of Confidence and Disclosure in the Public Interest', *VHA Report*, October, 2001: 181.
- ¹¹ B Tobin, S Leeder, Ernest Somerville, 'Community versus Individual Benefit', *Medical Journal of Australia*, (18 March 2002) 176:279-280.
- ¹² M Paterson and E Mulligan, 'Disclosing Health Information Breaches of Confidence, Privacy and the Notion of the "Treating Team"', *Journal of Law and Medicine*, (2003) 10(4):460-469.
- ¹³ The Australian Health Ministers' Advisory Council National Health Privacy Working Group, *National Health Privacy Code (draft) Consultation Paper*, December 2002.
- ¹⁴ J Geiderman, G Larkin, 'Commercial Filming of Patient Care Activities in Hospitals', *JAMA*, (2002) 288(3):373-379; W Tannenbaum, 'Hospital reality show falls within 'news' definition', *The News Media & the Law*, (Summer 2003) 27(3):49 <http://www.rcfp.org/news/mag/27-3/con-hospital.html> accessed 15/10/03.
- ¹⁵ 'Federal Govt mulls health ID card', *The Age*, August 30, 2003, <http://www.theage.com.au/articles/2003/08/30/1062050693801.html> accessed 12/9/03.
- ¹⁶ K Nguyen, 'Pools ban mobiles over photo fears', *The Age*, 11/6/03.
- ¹⁷ L Johnson, 'Direct marketing faces new restrictions', *The Age*, 11/3/03.
- ¹⁸ I was able to access Australian web-sites which sell and rent databases or lists for direct marketing purposes, comprising of people or organisations who had purchased particular products.
- ¹⁹ Short for, 'Uniting and Strengthening America by Providing Appropriate Tools Required to Intercept and Obstruct Terrorism' Act, accessed at http://www.eff.org/Privacy/Surveillance/Terrorism/20011025_hr3162_usa_patriot_bill.html 22/10/03.
- ²⁰ S Herman, 'The USA Patriot Act and the US Department of Justice: Losing our balances'. *Jurist Legal Intelligence*, 3 December, 2001, <http://jurist.law.pitt.edu/forum/forumnew40.htm> accessed 22/10/03.

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