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The practice of confidentiality in an Aboriginal medical service

What do GPs need to know?

Background

The medical ethic of confidentiality is usually taught from a western ethical perspective based on the Hippocratic oath. This study at an urban Aboriginal medical service aimed to explore how confidentiality is understood in a community controlled Aboriginal health service, with a view to informing the training of general practitioners.

Method

Twenty-three people, comprising staff, patients and general practice registrars, were interviewed about confidentiality between July 2007 and February 2008.

Results

Six themes were identified: overlapping contexts of confidentiality, key sensitivities, sharing of patient information, importance of consent, multiple roles, and consequences of maintaining or breaching confidentiality.

Discussion

Perspectives on confidentiality in this community included issues of social justice, the importance of public demonstrations of confidentiality, and the challenge of protecting all relationships when staff have multiple roles. Incorporation of community perspectives into the teaching of confidentiality may help doctors to understand the responsibilities of practising confidentiality in certain communities.

■ **Confidentiality is a greatly valued ethic in Aboriginal health.¹⁻⁴ Different cultures and communities bring different expectations to the concept of confidentiality.^{5,6} The patient-doctor relationship is enhanced for general practitioners if they understand how local community values influence these expectations.⁷**

General practitioners tend to construct their views about confidentiality from a Western ethical and legal perspective based on the Hippocratic oath.⁵ Working cross culturally in a community challenges GPs to also respect the ethical codes of people with whom they work.⁸

This project aimed to answer the research question: 'How is confidentiality understood and enacted by patients and staff of a single community controlled Aboriginal medical service?' and then to explore the implications of these findings for general practice registrars undertaking training placements in the service. Although Aboriginal communities have their own local cultural norms, and may differ from each other in their construction of confidentiality and their expectations of how the ethic is applied in practice, we hope that the findings of our study will have implications for GPs working and training in other communities.

Method

We chose a qualitative case study approach for our study,⁹ as a method that would permit in depth exploration of how confidentiality is constructed, understood, and produced at an organisational and community level. To ensure a broad interpretative perspective, the research team included both Aboriginal and non-Aboriginal members. The project was approved by the Aboriginal Medical Service Western Sydney (AMSWS) Board of Directors, results were presented to participants and the Board, and their feedback was incorporated into the final analysis of the data.

Aboriginal Medical Service Western Sydney is a multidisciplinary service that seeks to deliver holistic and culturally appropriate

health care to its patients. The clinical workers at AMSWS include Aboriginal health workers (AHWs), GPs and other health professionals; AMSWS is also a training post for general practice registrars. Cultural mentoring from the clinic coordinator and other AHWs is a central part of the training program.

We invited three groups of people to participate in this study: AMSWS staff, patients, and registrars who were doing, or who had previously completed, an advanced general practice term at AMSWS. We sent an initial email to all staff inviting them to participate. Four responded and were included. We then approached individual staff members personally, seeking a maximum variation sample with representation from the various teams within the service and from both genders. Patients and eligible registrars were personally approached with the same aim. The first author (JJ) conducted all 23 semistructured in depth interviews.

Patients whose primary GP was conducting the interviews and registrars who were under her supervision were excluded.

The second author (SC) assisted in the recruitment of Aboriginal participants and the construction of the topic list to ensure they were culturally safe. The AMSWS Board was also consulted about the questions for each participant group before the interviews began.

Interviews were recorded and transcribed with all identifying information removed. One author (JJ) undertook the initial analysis, using the constant comparative method¹⁰ to identify emergent themes and categories. This author then worked with the third author (TU) to further explore the meaning of the data, and with the second author for help with interpretation of issues of cultural import. Interviews and data analysis continued in parallel until interviews ceased to provide fresh insights, indicating that data saturation had been reached.

Ethics approval was received from the Aboriginal Health and Medical Research Council (AHMRC), Sydney West Area Health Service Ethics Committee, and Sydney University Ethics Committee.

Results

Twenty-three people were interviewed (*Table 1*). Six themes were identified as emerging from the data.

Table 1. Sociodemographic characteristics of participants

Gender	Female	17
	Male	6
Category	Staff	13 (including two GPs)
	Patients	7
	General practice registrars	3
Indigenous status	Aboriginal	17
	Non-Aboriginal	6
Age	Less than 50 years	16
	50 years or over	7

Overlapping contexts of confidentiality

Interviewees were first asked to reflect on what confidentiality meant to them. The registrars linked confidentiality to the patient-doctor relationship.

‘As doctors we are there to protect our patients’ rights – information the patient has given to us, we do not reveal them without the patient’s permission’. Registrar

In contrast, some staff members identified other domains from within which confidentiality operates.

‘There is a cultural, spiritual confidentiality within the Aboriginal organisation that must be upheld – confidentiality that’s first regarding to the organisation, also confidentiality is between myself and clients, and also confidentiality is between my team that I’m working with’. Staff member

Some staff linked confidentiality with organisational loyalty and the political vulnerability of Aboriginal organisations.

‘We’ve got to protect our own confidentiality in regards to our own organisation ...Government organisations will start asking questions’. Staff member

One patient regarded confidentiality as conditional on the patient’s moral behaviour.

‘[Confidentiality] wouldn’t worry me cause I don’t go doing nothing wrong – I never robbed a bank or been with other women’. Patient

The importance of publicly demonstrating respect for confidentiality was emphasised.

‘It’s quite tricky if you’re sitting on the front desk and a client will say, “I want to see the doctor I seen last time.” Now to do that you have to look at the notes – if I’m asked to I do it in view of the client, sort of open the last page and say, “I think it’s doctor so and so”’. Staff member

Staff members linked respect for confidentiality with upholding the rights of those who are socially disadvantaged.

‘...probation and parole – they’re slowly getting the message – they deal with confidentiality so they basically know they’ve got to get a consent form from the person before they ask, and that’s what we remind them of’. Staff member

Key sensitivities

Interviewees identified three issues as particularly sensitive: sexual health, medical records and pregnancy related issues. The registrars worried about how to resolve situations involving issues of sexual health and confidentiality. One registrar, when imagining a hypothetical scenario, wondered how she would manage the situation were she to ever face such a dilemma.

‘...this patient’s HIV positive, not going to report to the partner, how should I deal with the problem?’ Registrar

Patients mentioned it was important for GPs to turn off their computer screens outside consultations.

‘Wipe the screen off when you’re dealing with someone – take a person who’s on AVOs [apprehended violence orders] and the bloke comes in and sees his wife up there’. Patient

Sharing of patient information

One patient felt that his very presence at the Aboriginal medical service constituted confidential health information.

'X was there last night' and I just say to them, "Well you have a right to tell them that you're there, but you can't tell them that I am there". Patient

Common knowledge is information about a patient known throughout the community. Some staff members considered common knowledge to be confidential nevertheless.

'Often they'll say, "Oh has that one had her baby yet?" And I always say to them, "You will have to find out I can't tell you other people's business," the community shares that information amongst themselves but I'm not at liberty to be giving out information'. Staff member

Some health workers said they just wanted to be informed what treatment the GP would like done, and that was enough information. This was linked to increasing the patient's sense of privacy.

'I'm happy if the GP just tells me what to do, I don't have to know what they've got. If you've got something like AIDS, you're more comfortable if less people know'. Staff member

Importance of consent

Patients expressed a great sense of ownership over their personal health information and that no assumptions should be made about consent on behalf of the patient.

'If people want to use my things they should ask me – we have a right to voice our opinion about what happens to our files'. Patient

One registrar was not always comfortable about the use of implicit consent in a multidisciplinary team.

'We share information with health workers without checking first which bits are OK, should I be getting consent for every bit of information I talk to other staff about?' Registrar

However, the impracticalities of always seeking explicit consent for sharing of health information were recognised.

'It's impossible for a patient to know, when you're giving consent to allow information to be shared, every single situation where that may happen'. Staff member

Multiple roles

Aboriginal staff members can be a health professional, community member, friend, family member and patient all at the same time.

The registrars expressed high awareness of the multiple roles of the AHW. Their focus regarding confidentiality was on how that might affect the patient-doctor relationship.

'A lot of people would be related to other people and know a lot of staff members here – it's important to check with the patient before you talk to another health staff'. Registrar

Multiple roles placed staff in a position where they had to keep certain information about a patient acquired outside the health

setting quarantined from the reservoir of information they obtained from being involved in that patient's clinical care.

'I'm not just working nine to five, it's 24/11. I'm facing my clients, and there's so much information that I have on clients that's on a personal level outside, and on a work level I've got to balance which information I then use and cannot use'.

Staff member

Health workers felt a duty of confidentiality owed as a consequence of a personal bond with community members, but also felt their duty as a health worker was to ensure health information got to the GP.

'They tell me everything before they tell you everything. Am I being unfaithful to them when I go, "Don't forget to tell that bloody doctor about blah, blah," and they go, "I won't," and then I'll make sure a doctor sees them'. Staff member

Health workers in nonclinical roles felt stressed when patients told them about personal issues that were affecting their health. They then felt under an obligation of professional confidentiality, without being in a position to act.

'You just pick up the phone and people are blurting out things – you feel you're not in a position to be able to stop them talking and that can be stressful'. Staff member

Some staff felt a responsibility to encourage patients to discuss what is troubling them, in preparation for seeing a GP. They might share some of their own health history with the patient, using the personal bond as a guarantor of confidentiality.

'They get it from me too, I'll say, "You're not the only one, I have a bit of blah, blah, blah, keep that to yourself," and they tend to have that trust in you, where you give away a little bit of your life, they're going to open up a bit about what's the matter with them and their lives'. Staff member

Consequences of maintaining and breaching confidentiality

Some patients feared that if confidentiality were to be broken their health would be adversely affected.

'Anonymity is a big thing you know – [if confidentiality is broken] it can ruin a person's recovery'. Patient

Keeping confidentiality can offend people when sharing information is expected from a friendship, but the health professional role forbids such information to be shared.

'I've lost a lot of friends over [being careful to maintain] confidentiality – so in the end I just had to say, "...if you don't need to know for your job then I can't tell you"'. Staff member

Mandatory notifications are an occasional necessary part of health care practice and involve a legally justifiable confidentiality breach. When recalling a mandatory breach discussed with other staff, one AHW talked from a personal perspective.

'I gotta clear my own head – I feel like I'm dobbing them in'. Staff member

This contrasted with a GP, who justified mandatory breaches using a professional ethic.

‘One of the reasons that you can break confidentiality is where we’ve got legal mandatory reporting requirements’. Staff member The registrars felt stress where potential mandatory breaches were possibly required.

‘I find it most difficult – knowing when I should breach confidentiality or when I need to report an incident’. Registrar

Discussion

Patients’ and registrars’ focus on confidentiality was centred on the patient-doctor professional relationship. This is also the central confidentiality concern of the Hippocratic oath.¹¹ Many staff at AMSWS talked of confidentiality in a wider context, so that certain information could be shared within a particular group of people, but not beyond. For example, cultural issues such as women’s and men’s business, were mentioned as imposing special degrees of confidentiality, as in other Aboriginal settings.³ Also prominent was caring for confidentiality when discussing the organisation, and this was seen to be the responsibility of the staff (including GPs). Within this domain, keeping confidentiality was linked to the trait of loyalty. The multidisciplinary nature of AMSWS created another domain of confidentiality whereby information is discussed within teams. The registrars worried about the challenges involved in sharing information within a team. They felt unsure about the application of implicit, as opposed to explicit, consent.

Many staff linked respect for confidentiality to upholding the rights of the socially disenfranchised, while some patients felt full confidentiality rights should not necessarily be universal and may have a component that is conditional upon the patient’s moral behaviour.

Overall patients used the notion of confidentiality interchangeably with respect and competence, suggesting it might not be viewed as a separate ethic, but within a group of traits that are seen to constitute a trustworthy health professional.¹² Doctors viewed confidentiality dilemmas in areas of key sensitivities from a professional perspective. In contrast, indigenous staff felt that they must fulfill their responsibilities to the ethic of confidentiality according to all the obligations of their multiple roles. This placed great demands on staff. They viewed challenges from both professional and personal perspectives in order to outline their duty of care, placing a high value on the protection of relationships. This creates a potential gap of understanding between non-Indigenous doctors and AHWs, which culturally informed teaching can address.

Staff and patients spoke of the importance of public demonstrations of confidentiality, emphasising the need to not only do the right thing, but be seen to be doing the right thing. This may stem from a belief that historical breaches make it more difficult to gain the community’s trust in health professionals and thereby create the necessary conditions for openness in sharing of information in consultations. Other research indicates that patients in health care settings where disclosure is potentially damaging will value confidentiality more highly.^{6,7} It is possible that areas

of key sensitivities in this community, such as sexual health, are linked to historical incidences of confidentiality breaches by medical professionals in other Aboriginal communities. Some past breaches have had links with human rights abuses.¹³

Our study showed the importance of Australian historical influences on ethical viewpoints for the respondents and the clear link between human rights and confidentiality. This link is not new. Enshrined in human rights declarations, such as the World Medical Association’s Declaration of Helsinki,¹⁴ are clear statements about the importance of confidentiality and its link with protection against discrimination based on illness.

Breaches of confidentiality were regarded badly by participants in the study, as they are in other health settings.^{6,7,15,16} Our study showed both strong deontological and consequentialist reasoning for this: breaches were regarded as fundamentally wrong acts, and they were also seen to harm many more people than just those immediately involved, because breaking confidentiality may cause the community to lose trust in their health service and therefore

Table 2. Implications for GP training in Aboriginal medical services

AHWs strive to protect all existing professional and personal relationships, and an understanding of the demands of the multiple role dynamic will help GPs work more effectively with their Aboriginal colleagues
Aboriginal cultural trainers should be involved in teaching nonindigenous registrars about their community’s views on confidentiality in health care
GPs need to know that what is regarded as confidential health information depends not only on its content, but also its context. The physical/social space in which information is shared and the role of the person to whom the information is told will affect the patient’s expectations of confidentiality. ‘Common knowledge’ in the community may take on the status of personal health information once it is spoken about in the physical/social space of the Aboriginal medical service
Confidentiality operates in the domains of: the patient-doctor professional relationship; the cultural realm (eg. women’s business information that can only be shared by people of one gender); individual teams within the multidisciplinary framework; and the Aboriginal medical service itself. Different issues of confidentiality arise in each domain
GPs need to not only do the right thing with regards to confidentiality, but be aware of the importance of being seen to do the right thing. Public demonstrations of confidentiality care apply, particularly to the handling of medical files
Respect for confidentiality has social justice implications. Doctors should be mindful of this when seeking consent from patients to release information to outside organisations, particularly when the patient is socially disempowered
GPs need to reinforce to their patients that confidentiality is regarded as exceptionally important, not only within the patient-doctor relationship, but within the Aboriginal medical service itself. Doctors should inform patients of Aboriginal medical service confidentiality policies

cease to seek health care. This finding from our study has powerful contemporary resonance given the recent successful attempt by the Australian Crime Commission to seize medical files from Aboriginal health services in the Northern Territory.¹⁷

Our study is by definition a case study,⁹ and consistent with statements of ethics in Aboriginal health research,¹⁸ our findings cannot be used to infer conclusions about views on confidentiality in other Aboriginal communities. This was emphasised by the AMSWS Board, which also pointed out that the research focused on issues of GP training, and the findings should not be taken to be representative of Aboriginal views outside of the research framework. As in any social research, the makeup of the research team will have influenced the design, findings and interpretation; the nonindigenous status and medical role of the first author will have influenced the way in which participants responded. Nevertheless, the study has identified issues that GPs working in Aboriginal health services should consider. *Table 2* lists what we believe are the implications of our study for GP training in such settings.

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