

TEACHING AND LEARNING ETHICS

Is there an Aboriginal bioethic?

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It is well recognised that medicine manifests social and cultural values and that the institution of healthcare cannot be structurally disengaged from the sociopolitical processes that create such values. As with many other indigenous peoples, Aboriginal Australians have a lower health status than the rest of the community and frequently experience the effects of prejudice and racism in many aspects of their lives. In this paper the authors highlight values and ethical convictions that may be held by Aboriginal peoples in order to explore how health practitioners can engage Aboriginal patients in a manner that is more appropriate. In doing so the authors consider how the ethics, values, and beliefs of the dominant white Australian culture have framed the treatment and delivery of services that Aboriginal people receive, and whether sufficient effort has been made to understand or acknowledge the different ethical predispositions that form the traditions and identity of Aboriginal Australia(ns).

It has been repeatedly stated in the public arena that the health status of Aboriginal Australians is poorer than that of non-Aboriginal Australians.¹ Despite many reviews and inquiries at the commonwealth and state level, however, the health status of Aboriginal people continues to be significantly lower than the rest of the community. Also there has been little improvement in the socioeconomic status, infrastructure, and environmental health conditions of many Aboriginal communities.

Compared with non-Aboriginal people, Aboriginal Australians have a 19–20 year lower life expectancy, and twice the rate of perinatal mortality, as well as increased rates of premature birth.¹ Despite having considerably higher rates of hospitalisation for most diseases and conditions Aboriginal peoples continue to experience difficulties in optimising their access and utilisation of mainstream health services.^{2,3} This is evidenced by the fact that Aboriginal people frequently present to health services later and sicker than non-Aboriginal Australians.⁴ In addition, a recent review of data from the National Hospital Morbidity Database (NHMD) revealed disparities in procedure use which indicated that, “in Australian public hospitals there may be systematic differences in the treatment of patients identified as Indigenous”.⁵ It is well recognised that a number of biological, social, economic, and cultural factors contribute to these health inequalities.⁶ Structural inequality, poor social conditions, inadequate economic resources, communication difficulties, and the absence of culturally appropriate health services have been identified as key determinants of the health status of Aboriginal peoples.⁷ As the past chair of the National Aboriginal Community Controlled Health Organisation, has noted: “It is a well established fact that if health care services are not delivered appropriately, our people won’t use them”.⁴ In contrast to most other low socioeconomic groups the poor health of indigenous Australians results not only from the effects of prejudice and racism but also from the ongoing impact of colonial histories, dispossession, and marginalisation.⁸

Contemporary bioethics recognises that medicine manifests social and cultural values and that the institutions of health care cannot be structurally disengaged from the sociopolitical processes that create such values.⁹ Australian medicine and Australian society in general largely reflect modern, Western, Christian, and liberal values that have determined the way to behave, live, and work; the appropriate manner for communication; the construction and validation of interpersonal relationships, and the means for understanding the world. A medical system that is founded on such principles, beliefs, and values will have a negative impact on all those who do not share its common foundation. Difficulties can arise not only as a result of conflicting ethics, values, and principles but also as a result of how shared values and principles may be expressed differently.

The question of Aboriginal bioethics is a complex one. A part of this complexity arises as a result of the diversity of Aboriginal cultures. Therefore, a completely articulated Aboriginal bioethic will never exist, rather there will be a collection of bioethics that may or may not be linked by shared commonalities. Inevitably then, one may ask how “Aboriginal bioethics” may shape the illness/behaviour and healthcare decisions of Aboriginal patients.⁹ The very question of whether Aboriginal bioethics exists may, however, be culturally inadequate. The terms “ethics” and “bioethics” are not evident within Aboriginal cultures because the ethical convictions that form these cultures cannot be dissociated from them^{10,11} and values are woven through the very fabric of Aboriginal cultures. In general terms, Aboriginal societies do not differentiate bioethics or the process of healthcare decision making from the values, narratives, and contexts that define and structure all dimensions of living.

In this paper, therefore, we (a Kamilaroi woman and Aboriginal health and education academic, an Aboriginal health liaison officer of the Wiradjuri people and a legal academic, and two clinical ethicists of Anglo European descent) address ourselves to the values and ethical convictions that may be held by Aboriginal peoples in order to

explore how Aboriginal patients could be engaged in a manner that is more ethically appropriate. In doing so we will consider how the ethics, values, and beliefs of the dominant white Australian culture have framed the treatment and delivery of services that Aboriginal people receive, and whether sufficient effort has been made to understand or acknowledge the different ethical predispositions that form the traditions and identity of Aboriginal Australia(ns). In this paper we have deliberately refrained from attempting to include a discussion of Torres Strait Islander people since our experience with this group of people in the healthcare context is limited and it would be inappropriate to include them within this discussion.

SUSAN'S STORY

I came home Wednesday afternoon from work with bad pains in the stomach. I decided to just come home and eat something 'cos I thought it might have been that. About two hours later the pain was getting worse—a crampy pain in the right hand side, it was down near me ovaries, sort of appendix sort of part. So then I thought bugger it, I'll go to the hospital.

The nurse who took me in asked me: "Haven't I seen you before?" and I said: "Maybe" and she said: "It was yesterday wasn't it?" and I says: "I was up with my brother, he was in hospital". "Oh, yeah that's why I thought I seen you already in here." She had a smart look on her face—you know—like she didn't think I should be there, like I wasn't sick. So she's put me into a gown, sat me on the bed, by this time I was screaming in pain. So I said to them: "I'm in pain, can I have something for the pain?" Then the doctor came, gave me painkiller for the pain. Didn't say what it was.

The doctor pressed on me stomach. "Oh, maybe it's kidney stones, you've been here before with kidney stones." I said: "It's the same sort of pain but it's severe, a lot worse than it was before." So he's given me some penicillin I think, or something in a needle. Anyhow it calmed it, settled it down a little bit but not that good. It kept on—every time the needle wore off it just kept on flaring back up. So the nurse wasn't interested because, I think she thought I was in for more needles for more drugs, 'cos she'd seen me in there through the day with me brother and 'cos he needed some painkillers for lung problems.

I asked her can I have some more painkiller and I'm holding me right side down, between me back and me stomach and she said: "Oh, I thought the pain was on the other side?" and I said: "No, what are you trying to suggest?" She come back later-on—about 15–20 minutes later—with some more painkiller.

Different doctors all this time, different nurses all the time.

The doctor ended up coming back late that night and saying I'll have to stay in because the pain hasn't gone away, they're not sure what it is. They couldn't rule out anything because there's a number of things that they were telling me it could have been. I said to them a fortnight ago that I had passed blood through my bowel, my back passage. I mentioned that I had been in with polyps before and I have to come every three years to the doctors to get the polyps checked. I also had a bit of vomiting and fever over the last couple of weeks with the pains in my side. I told the surgeon that I went to the toilet and vomited and that time I vomited up blood. I didn't end up going to the doctors because nothing happened and I thought, well I'll get better.

When I was in casualty I couldn't understand what the doctor or the nurse, I think, was going on about. It wasn't up until the time that I got into the ward that I understood what I was there for and what they were going to do. I asked the nurses in the ward what's going on, you know what's happening, and they said what the doctor was going to do

and the doctor ended up coming around on the Friday night, I'm not sure what time.

The surgical doctor came in, my brother was sitting on my bed at the time and he said he'd like to speak to me on my own and I said: "No my brother's gonna stay with me", and he said—"Well I'm not sure how to tell youse this, I been wondering how to tell you" and I just got a terrible look on me face, and he said: "Well, we found a mass in your back, in your bowel, a large mass in your bowel". He said he's 99% sure that it's cancer. He told me that there was all different cancers, that sort of thing, I just got that upset because he just said it was cancer—it could be cancer. My brother was that distraught that he just walked out and he had to go and ring the family. The doctor had said to me: "Would you like to ring your husband" and I said: "No, you ring him, I'm not telling him". So the doctor had rung my husband, to tell him what he thought was wrong with me. My husband had come up, my sister had come up and my family had been notified. By the time my husband got in, I was that upset, I didn't ask him what the doctor said.

I come from a large family and because the doctor had said that I had cancer and told my husband—my husband had rang everybody. I've had all my family down from Armidale and Taree, where they don't worry about time limits and how many people are in there. One nurse didn't understand why there were so many people there and said there was too many people at a time—there's too many coming in and my brother had come in on the Friday night and the nurse that was on that night wasn't keen and asked him, would he go out. The thing is with Aboriginal families and my family, that in this situation we all stay together, if one is in hospital they're all there until we get better, but the nurses in there just didn't understand that you've gotta be with your family and your families have gotta be there or it's just no good—you don't get better.

It wasn't until the Saturday morning or Saturday lunchtime that another doctor came in. Still getting the pains in the sides, still had the pains in the side on the right hand side and every time the painkiller would wear off I would need more because it just wasn't doing what it should be. He says: "Well there's nothing to tell the children as far as I'm concerned". He couldn't see anything in the scans and he says the other doctor shouldn't have told me that it could have been cancer, he shouldn't have gave me results like that until he had looked at everything. No one had looked at what was going on, only what was on the scans and the x rays. He says as far as he's concerned, I'm a young 34 year old and that there shouldn't be any worry about cancer, I'm too young for it.

The surgeon came back Monday. He said have I still got the pains, I said yes, I've still got the pains. He said well, we're still gonna do tests on you to look for a cyst on my ovary, check for appendix, check for gallstones again, kidney. That afternoon the surgeon's back and says to me they couldn't find anything else that was wrong with me even though I've still got pain in the side and they said that I might as well go home.

It was very hard to communicate between doctors and patients in there. The way of wording things is just too big. You need to know normally, the normal way, without doctors saying everything in jargon. And as I was upset I had asked a nurse if there was any chance of getting an Aboriginal nurse into the hospital. He said no, it's very hard to get an Aboriginal nurse or doctor, there's hardly any.

DR JONES'S STORY

A 34 year old Aboriginal woman presented with atypical abdominal pain. Her past history included renal calculi and rectal bleeding due to colonic polyps. The pain appeared

maximal in the right iliac fossa but the patient was unable to clearly characterise the nature of the pain. She was at times aggressive and histrionic and had high narcotic requirements during her time in the emergency department.

Full blood count (FBC) and biochemistry was unremarkable and abdominal x ray film was normal. Abdominal ultrasound was initially reported as suggestive of an abdominal mass, however, subsequent review of the ultrasound by Dr X and the radiologist led them to believe that a mass was unlikely and that the findings were more consistent with faeces or artefact. The patient was initially informed that there was a possibility that colonic malignancy might account for her abdominal pain, although the probability of this diagnosis was reduced after review of the medical imaging. Following admission to the ward the patient required further parenteral analgesia for continuing abdominal pain. Efforts were made to keep her large and attendant extended family informed regarding her management.

At the time of discharge her pain had settled but the diagnosis was still unclear and colonoscopy and follow up was organised through the surgical outpatients' clinic.

GENERALISATIONS ABOUT ABORIGINAL PEOPLE

Differences in cultural and ethical value systems are well known as important factors that impede communication and service delivery in healthcare and other settings.^{4 12-14} Developing an understanding of the character of these differences and ways to broach them is more challenging. In approaching issues of cultural difference, however, it is vitally important to appreciate that values and ethical considerations may or may not be shared by all Aboriginal peoples. Indeed if one examines Susan's story, there are considerable differences between her response to her own experience and the values or moral attributes that we suggest may characterise Aboriginal traditions in general.

Aboriginal cultures are complex and diverse and health professionals should avoid applying a "standard" or monocultural approach to all Aboriginal people, and should not expect all interactions to "fit" a particular model. Susan's story and Dr Jones's story highlight some important values and ethical convictions that may be utilised to develop a deeper understanding of how to appreciate Aboriginal values or "ethics" in the Australian healthcare setting.

Medical and philosophical literature frequently invokes standard distinctions between Aboriginal and non-Aboriginal traditions and between the reductionist views of Western health and the holistic views of Aboriginal health. The reality is much more complex as there is considerable commonality and overlap between these views and traditions. Western definitions of health increasingly claim to be holistic, and Western moral or religious systems may be held by many Aboriginal people and coexist with traditional beliefs. Also the basic needs for security, love, and care will be held by both Aboriginal and non-Aboriginal people. Despite this commonality, however, and despite the fact that it is inappropriate and perhaps even imperialistic to construct a simplistic Aboriginal/non-Aboriginal dichotomy, we believe that it is important to attempt to articulate points of similarity and difference between Aboriginal and non-Aboriginal traditions.

KEY ISSUES TO CONSIDER WHEN INTERACTING WITH ABORIGINAL PATIENTS

Spirituality and holistic views of health

In contrast to many Western Anglo American cultures, Aboriginal cultures can be described as "premodern" in the sense that there is generally no separation between the self, community, and universe, or between mind, body, and

spirit.^{12 14 15} Not only does lack of separation form the basis of very different views of the world and of the land, it also forms the basis of different models of health, disease, and therapy. Indeed for many Aboriginal people true "healing" is not possible without some acknowledgment of spirituality or the relationships of individuals to their family and community.

Aboriginal people tend to have a holistic view of health, encompassing the physical, spiritual, emotional, and cultural wellbeing of individuals and communities.¹⁶ Aboriginal cultural values or belief systems also tend to emphasise pluralism, self determination, community, family, relationships, and achieving balance within all the domains of human life. In the health sphere these values translate into a decision making process that turns not only on Western notions of individual autonomy but also on involvement of families and communities. Aboriginal values may also be evident in some individuals' commitment to maintenance of quality of life rather than the exclusive pursuit of cure, and the desire to have healthcare that acknowledges culture, community, and spirituality and is delivered by Aboriginal people.

Recognition of trauma and loss

Colonisation and dispossession has had a dramatic impact on the physical, emotional, and spiritual wellbeing of Aboriginal peoples. This experience and history is unique to Aboriginal peoples within the Australian context. Some aspects of this history may not be immediately obvious, but the impact extends beyond the loss of land, to continuing domination, racism, exploitation, and economic disadvantage and is the basis of the tremendous sense of outrage, loss, and grief felt by the Aboriginal community.¹⁷⁻¹⁹ Within the health sphere recognition of the sense of loss felt by Aboriginal Australians is critical to the success of individual and public health strategies.

Diversity and pluralism

Medicine and healthcare providers often seek abstract principles or generalisations that can aid them in understanding the world, concepts or people. As Brough²³ notes, for example, in epidemiological descriptions of Aboriginal and Torres Strait Islander health problems: "Historical notions such as social Darwinism, assimilation, and dangerous other are all seen to be woven into the epidemiological text". When confronted with an Aboriginal culture very different from their own, non-Aboriginal Australians have frequently developed stereotypes about a homogeneous Aboriginal culture and generalisations about Aboriginal values, spiritual beliefs, "ethical" frameworks, and decision making processes.^{2 4} The reality is quite different. Aboriginal cultures, communities, and values are extraordinarily diverse. Across Australia there is a wide spectrum of Aboriginal kinship and family groups, languages, and spiritual beliefs. Appreciation of this diversity is important for two reasons. Firstly, understanding the shared values but also respecting the inherent diversity of Aboriginal cultures will remind health professionals of the need to explore each Aboriginal person's own values, beliefs, and cultural norms. Secondly, recognising the diversity of communities and cultures that are central to an Aboriginal person's identity and life will be critical to providing appropriate and successful inpatient and community care.

Narrative and the construction of identity

In recent years it has been increasingly recognised that narrative plays a pivotal role in the creation and maintenance of individual and community identity. Narrative can be understood as a dynamic, evolving, language dependent account of a series of events.²⁰ Indeed it is through discourse

and the construction of narrative that we identify both the community to which we belong and the community from which we differ.²¹

Aboriginal narratives, like their communities, are extraordinarily diverse, and are not reducible to a single story. While Aboriginal narratives are diverse, however, it may still be possible to identify commonality. The narratives of Aboriginal peoples are often strongly local and firmly grounded by reference both to a common ancestry and to family and tribal communities. Aboriginal dreaming and lore explain the world and social structures through the relationship between spirituality/supernatural beings and the corporeal world, and are told as exempla.*

The construction, style, and content of Aboriginal narratives are incomprehensible to many non-Aboriginal Australians, appearing to lack structure and point, whereas they actually have both. Indeed the differing nature of Aboriginal and non-Aboriginal narratives may lie at the heart of differing sociopolitical and moral differences between individuals and between these cultures.²² While such differences make true understanding extremely difficult, there is an undeniable need to achieve effective intercultural and intersubjective dialogue.

Individuals, communities, and decision making

As with other Anglo American societies, the shape of Australian medicine, law, and ethics have been substantially determined by specific cultural conditions and so reflect the primacy given to liberalism, autonomy, and rationalism in Western society.^{14 23–25} many Aboriginal people, however, operate in a very different cultural milieu. For many Aboriginal patients it may be the family or community, rather than solely the individual that is owed information and respect as the “autonomous” decision making “unit”. This “unit” may be present simply to support the Aboriginal patient or to reaffirm his or her wishes and beliefs. The patient, in turn, may also consider the interests of the family and community, may defer to the wisdom of an elder or may elect to use a family member as a proxy decision maker in the consent process. This “alternative” view of autonomy is one that can take account of Aboriginal values of community, ancestry, and respect. This need not suggest that autonomy is, or should be, devalued but should rather suggest that “autonomy” may be manifested in alternative behavioural frameworks and discourses.

Recent Australian High Court decisions such as *Rogers v Whitaker* (1992) 175 CLR 479 and *Rosenberg v Percival* [2001] HCA 18 have emphasised that when making decisions about what information to provide to patients note must be made of the *circumstances* of the individual patient. These circumstances will include issues of Aboriginality and the views that people may have about the way in which decisions are made. As long as there are no issues of coercion it is entirely valid for an Aboriginal person to choose to use a process of decision making that is suited to their particular cultural values.

Healthcare providers must be able to recognise the different models of decision making that may be used by Aboriginal peoples. Equally important is an understanding of the different notions of “family” and their roles in decision making. Having an understanding of the services available and appropriately utilising such services—for example, interpreters and Aboriginal liaison officers—may assist the

*“Exempla” is the plural of “exemplum”, which is a brief story used to make a point in an argument or to illustrate a moral truth to educate the young and preserve tribal traditions. The life stories of individuals and the narratives of Aboriginal communities also contain a common “metanarrative” which is the experience of colonisation, dispossession, and discrimination. Susan’s story is reflective of one such Aboriginal narrative.

Aboriginal patient and their family as well as the healthcare professional in the decision making process. This communicates respect not only for the patient, but also for elders and others with high status, and for the culture itself.

Even within Western medical frameworks difficulties frequently arise regarding the provision of information concerning diagnoses, management, and prognoses. Interactions with indigenous patients are often considerably more fraught because of inadequate understanding of the manner in which Aboriginal patients may make and communicate decisions in the healthcare setting, and because of racial stereotyping by healthcare staff. Susan’s story clearly illustrates difficulties in two realms. It is not clear from her story who was involved in the decision making process. Clearly, she and her husband had a role, as did her extended family. The nature of those roles went unexplored and many communication difficulties ensued. In addition, while Susan requested support from an Aboriginal healthcare worker, one was not provided for her and nor was she informed about the existence of an Aboriginal liaison officer within the health service. Clearly, further investigation was required and the presence of an Aboriginal health professional might well have benefited Susan and her family.

Healthcare professionals would also benefit from ongoing professional development in regards to the legal issues surrounding decision making and their applicability to Aboriginal people. This may help to alleviate concerns about alternative decision making processes available to all patients in the healthcare system. This may also facilitate the development of more appropriate policies and procedures. Implications for the right of patients to access their own medical records—such as provided by the Privacy Act 1988 (Cth)—also need to be explored in this context. The stark contrast between Susan’s story and the notes of Dr Jones included in the medical record could be confronting for some Aboriginal patients.

Aboriginal patients and the importance of family

The healthcare decisions of Aboriginal people are often highly situational and uniquely dependent upon the values and beliefs of the individual within the context of his or her family and community. Indeed, these relationships are central to Aboriginal identities and lives, encompassing reciprocal affection, healing, sharing, and responsibilities. As a consequence, Aboriginal people frequently respond to the crisis of an individual’s illness as a group or community, and the large numbers of people visiting and supporting an Aboriginal patient may be both puzzling and intimidating to non-Aboriginal Australians. The presence of family or community may be viewed as having a therapeutic function as well as expressing community values in what may be an unfamiliar environment. This was illustrated in Susan’s story.

Unfortunately, as a consequence of culturally incompatible practices and/or personal and institutional inflexibility, Aboriginal patients frequently feel isolated and intimidated by the experience of inpatient and outpatient care.² This can be addressed by the provision of culturally and ethically appropriate health services incorporating both institutional factors, such as acceptable waiting and patient care areas, and flexible visiting hours to enable easier access to family members or community, and “process” factors, including facilitation of family involvement in decision making, where that is desired. Most important, however, is the availability of Aboriginal liaison officers, Aboriginal nurses, and Aboriginal doctors in the hospital setting, as they may not only provide expert care but also assist in facilitation between Aboriginal patients, their families, and the health system.

Discourse and care

Aboriginal peoples may communicate in a manner that is unfamiliar to many non-Aboriginal Australians. They may not openly explain themselves—for example, but may communicate quietly, gradually, indirectly, physically, or obliquely, so that much is left to the recipient to observe, observe again, question respectfully, and then derive an answer.² This is clearly illustrated in Susan's story. Within Aboriginal communities enormous store is placed on talking and the pace and style of talking is markedly different from non-Aboriginal patterns of communication.¹¹ Important information may be communicated in a circular fashion or in the form of stories full of cultural nuance or metaphors of experience that may be given, not only by the individual but also by others in attendance.

Discourse with Aboriginal patients may also be different in many other ways. Some may prefer that "bad news", such as reference to cancer of terminal prognosis, not be communicated directly and prefer to have full disclosure offered rather than imposed.²⁶ Others may prefer to ignore some questions, or information, and instead accept uncertainty or "mystery" in disease diagnosis or prognosis in preference to chronological estimates of survival.¹¹ In each interaction it is also critically important to appreciate that there may be times when silence reflects disempowerment and "compliance" reflects isolation, fear or misplaced trust.²

The challenge for many healthcare professionals therefore is to avoid the expectation of direct responses to explicit questions and be open to listen, and to listen well, for understanding the message in discursive accounts of illness takes patience, sensitivity, and training. While this may be difficult, it is critically important as the "stories" of Aboriginal people are the cornerstones of interaction and they need to feel able to tell them. Healthcare professionals also need to be acutely aware of their responses to the patient's and the family's story. They need to be conscious not only of the content of their language—that is, the use of medical jargon, but also the way in which they deliver that information.

CONCLUSION

As the provision of healthcare is one of the chief means by which members of a society express their commitment to each other's wellbeing,²⁷ there is good reason to question the effectiveness and appropriateness of the healthcare that Aboriginal peoples receive. Aboriginal peoples make up just over two per cent of the total Australian population and constitute an even smaller proportion of the health and community services workforce.²⁴ Given their high rate of hospitalisation² it is likely therefore that Aboriginal people will receive their healthcare from non-Aboriginal carers. As the values and beliefs of the dominant culture are likely to frame the treatment and delivery of health services, both medicine and ethics must become more flexible and dynamic in order to acknowledge cultural, linguistic, and moral pluralism and develop models appropriate to the cultural context of the person.²⁸ This is not an impossible task as there are already established Western ethical systems, including feminism, communitarianism, virtue ethics, narrative ethics, discourse ethics, and the ethics of presence, which share some common ground with Aboriginal values and might provide the basis of better relationships between indigenous and Western systems.²⁹

It would not be difficult to make a commitment to communities by rewriting the "bills of rights" or "statement of values" held by many health services, with the involvement of local Aboriginal peoples and cultural groups. Such documents should not simply include a statement of core ethical values and principles (as is generally the case) but

should also accommodate differing expressions of these, for in many instances it is the expression of these ethical values and principles that result in apparently irreconcilable cultural conflicts. Reform is, however, required in many areas. Healthcare providers must also incorporate cultural competence training of non-Aboriginal staff and students, reform institutional policy and procedures, and commit themselves to increasing the number of Aboriginal healthcare professionals. Susan's story illustrates a number of ethical considerations that arise in cross cultural interactions which, we believe, clearly demonstrate the need for healthcare providers and individual healthcare professionals to alter their practice and ways of thinking when providing a service to Aboriginal patients.

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