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Obtaining consent from Aboriginal patients: a culturally sensitive approach

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Introduction

This paper describes the process of obtaining consent from two Aboriginal families in order to present their clinical cases in a medical journal. Our approach was guided by cultural protocols and was quite different to the 'standard' process expected by the target journal. Here we describe the methods used, proposing that they enabled proper respect for cultural differences in the consent process. Clinicians and researchers can perceive working with Aboriginal peoples as too difficult when they fail to understand cultural protocols which differ from their own. To 'close the gap' in health status experienced by Aboriginal compared to non-Aboriginal Australians, we need to critically question our clinical and administrative practices and adapt them where necessary to privilege a culturally-sensitive approach.

Background

Thalassaemia trait was recently identified in two young Aboriginal patients in a regional NSW hospital, surprising some clinicians. The condition has been characteristically clustered in Mediterranean, African and South Asian populations. However, as evidenced by our two cases, thalassaemia does occur in Aboriginal people and doctors should look for it when investigating mild anaemia.

Thalassaemia is an inherited blood condition caused by dysfunctional haemoglobin that leads to anaemia. Patients may experience the typical symptoms of anaemia—fatigue, lethargy, weakness, shortness of breath, pallor; however, thalassaemia trait is generally asymptomatic. Failing to diagnose thalassaemia can have ramifications. For example, inappropriately prescribing iron, in the belief that a patient has iron deficiency rather than thalassaemia, may lead to iron overload and its cardiac and endocrine complications.¹ Additionally, misdiagnosis may prevent people from making informed decisions about their health and that of their children.

Thalassaemia trait has been reported in Aboriginal people decades ago, yet it has been seemingly forgotten.^{2,3} This prompted us to consider writing a case report to propose that clinicians may be too readily narrowing their differential diagnosis of anaemia to exclude thalassaemia.

'Informed consent' is a term that was coined in 1957⁴ and further explored by the legal community in the 1970s.⁵ However, this ethical approach to medical decision-making dates to the 18th Century.⁶

Informed consent is a legal and ethical duty of healthcare providers, ensuring clinicians provide information about the investigation, treatment or research before the patient decides. By maintaining transparency, our patients' dignity and autonomy are protected.

There are multiple requirements for valid consent: that the individual consenting has capacity, that adequate information has been provided, that reasonable opportunity has been given to allow the patient to decide and that the patient consents freely, without undue pressure or coercion.⁷

The aim of this paper is to describe the cultural protocols we followed to obtain informed consent to prepare a case report on two Aboriginal patients for a medical journal.

Methods

On reading the recommended patient consent forms supplied by the journal, we considered how these might be perceived by the patient group of young Aboriginal people and their families. We were concerned that the language and structure of the consent form was formal and legalistic in nature, and that this may result in alienation of the patient group. We realised that using the 'standard' approach risked not obtaining permission and hence the opportunity for us to advocate for better treatment for Aboriginal people with thalassaemia.

Our process was a collaboration of many players. Informed by discussion with the NSW Aboriginal Health and Medical Research Council and using the journal-prescribed form as a template, we drafted a plain language version and included an information sheet appropriate for the patients' families to keep. Knowing that each Aboriginal community is different we approached the Aboriginal Liaison Officers (ALOs) who resided in the towns where the families lived. We explained thalassaemia and why we thought it was important to better educate doctors to identify thalassaemia in Aboriginal people. We sought the advice of the ALOs to determine whether this issue might be important for the Aboriginal community and whether writing a case report to share our findings with other doctors should be a priority. The ALOs in each site endorsed the significance of the issue and voluntarily contacted the paediatric patients' parents to explain what would be involved in a case report, its implications and why their consent was required to proceed. This process was lengthy, with one ALO visiting the family in person on multiple occasions and allowing time for the family to consult with appropriate community Elders before considering consent. Both families separately agreed to have their contact details passed on to two members of the team who made phone or face-to-face contact (or both, as preferred by each family). The team again described what was involved in a case report and answered questions from the families before written consent was obtained.

Once written, the case report was shared with the ALOs for their feedback. While the article was prepared for a medical audience, we kept our philosophy of plain language so that it was also accessible to the patients' families. The families had the opportunity to read and give approval of the written case report before our submission to the journal. The families and ALOs wanted to check that they had been appropriately anonymised and written about respectfully in the manuscript.

Discussion

If honest, there were times when we considered giving up for lack of certitude about how to go about obtaining consent, thinking we would not succeed by following the 'standard' approach. Once we had decided to follow cultural protocols, while time-consuming, the process yielded consent from both families. Moreover, it strengthened relationships and built trust between health services and community members.

Following cultural protocols facilitated the 'right' people to be part of the decision-making, including community Elders in the case of one family, respecting a cultural dimension of capacity to give consent. Adequate information in plain language was supplied, delivered with the assistance of an ALO who also acted as a patient advocate. Building trust by working with the ALOs, allowing time and following cultural protocols, meant our patients felt they could decline to participate without fear of reprisal.⁸

Maintaining patient autonomy and dignity is the primary objective of informed consent. Overlooking cultural protocols impinges on both of these patient rights, and therefore, we feel the variance from the 'standard' approach is justified.

Failure to attain valid consent from Aboriginal families for treatment or research has ongoing implications for the health of Aboriginal Australians. Management plans seemingly agreed to but not followed by patients, or research with sub-optimal participation and non-specific findings, perpetuates a medical community who does not really understand how to work with Aboriginal people to improve health. In this case, it would have represented a missed opportunity to advocate for improved diagnosis and treatment of Aboriginal people with anaemia. Furthermore, obtaining consent via the 'standard' approach may have placed stress on the therapeutic relationship, resulting in these patients further disengaging themselves from the healthcare system in the future.

The continuing effects of colonisation contribute to ongoing mistrust of institutions such as government organisations and universities for Aboriginal communities. Non-Aboriginal clinicians and researchers must factor in time to learn, and patience to follow, cultural protocols for the Aboriginal communities they serve.

Conclusion

Following cultural protocols resulted in the granting of consent to publish a case report about these Aboriginal patients. This process was both worthwhile and rewarding for the research team and patients alike.

Cultural protocols are context-specific and dynamic, so local Aboriginal community members and staff are best placed to advise clinicians on how to proceed. In this way, diversity between and within Aboriginal people of different Nations is respected. Cultural protocols should shape the process of obtaining consent and clinicians should expect to adjust their approach on each occasion, recognising the importance of developing mutual respect and trust.

As non-Aboriginal clinicians and researchers become more confident applying cultural protocols, the more meaningful research with Aboriginal people will become. It is only then that we can truly work together to 'close the gap'.

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Presenter

Elise (Lise) Kempler is a recent graduate from the University of Sydney and from the beginning of 2019 will be a Junior Medical Officer at Sydney's Royal Prince Alfred Hospital. Lise spent her final year of medical school at the School of Rural Health in Dubbo, during which she developed a deeper understanding of what it means to be a clinician in the country. Having seen the inequalities in healthcare access that exist between city-based and rural-based Australians, she is passionate about doing her part to improve them. During her year in Dubbo, Lise also came to appreciate the need for culturally appropriate care for Aboriginal patients. Her presentation shares an example of how an approach to care can be modified to ensure cultural safety for patients who are the focus of a case report.