

NEGOTIATING HUMAN ETHICS COMMITTEES IN AUSTRALIA

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For the last two-and-a-half years, I have lived and worked in Australia. I am one of two non-occupational or diversional therapists in the School of Occupational Therapy and the only anthropologist. Much of my time is spent advising staff and students on research designs and methods, particularly those associated with qualitative research. Through my research activities and those of my colleagues and students, I have become quite familiar with human ethics committees in the Sydney metropolitan area and the state of New South Wales. So now I also spend a lot of time advising on ethics review applications.

First Encounters

Among my initial interesting, and frustrating, research experiences were my first encounters with Australian Human Ethics Committees. At first I thought my experiences were unique and the result of my being new to the system. But I quickly learned that my experiences were not unique nor due to cultural ignorance. In fact, with a few twists, they resemble those encountered by others involved in qualitative, culturally-oriented, and anthropological research, especially those working within medical and health science contexts. Because these experiences appear to be widespread and raise some important and interesting ethical concerns, they seem to warrant a continuing discourse.

Space does not permit a full description of the policies and procedures for negotiating human ethics committees in Australia, so I will focus on a key area of concern that has come out of my experiences. Do the policies, procedures, and expectations of contemporary ethics committees, with their orientation towards experimental and questionnaire survey designs and the values of primarily one group of people, encourage ethically and culturally responsible research? Are researchers, and in particular qualitative researchers, compromising their research designs and procedures to make it less difficult to negotiate the system and to do so in a timely fashion? And finally, what can we do to avoid compromises that border on the unethical?

The Application Procedure

The National Health and Medical Research Council (NH&MRC) provides the primary ethical guidelines for research involving humans in Australia. Its counterpart in the U.S. would be the National Institutes of Health. If the research involves people identified as Australian Aboriginal or Torres Strait Islander, there are additional ethical guidelines from governmental and community organizations. The NH&MRC produces a reasonably easy-to-obtain booklet outlining the broad, general guidelines. The guidelines are primarily directed towards clinical research and research using experimental or questionnaire survey designs. They are essentially the same as those outlined in the Helsinki Declaration. Getting detailed information or guidelines or expectations for other types of designs is a bit more difficult.

Every university and nearly every health care, human service, and educational organization has its own ethics committee, and each has its own application form, procedure, and submission dates. Human ethics committees are generally made up of academics and representatives from the community. In most cases, information on the membership

of the committee is considered confidential. Contact with the committee is generally through an administrative person or, in some cases, the chair of the committee.

Application forms are generally based on NH&MRC guidelines, so they focus on clinical research, especially those projects involving invasive physical procedures, toxic substances, and genetics. It is rare to

find a form of less than five pages, and some are as long as ten. Fortunately more and more are using check (tick) boxes for many of the standard questions, but most still require a two-to-five page synopsis of the project covering its aims, hypotheses, potential significance, and design, including an explanation of all methods or procedures to be used – not an easy task for a complex qualitative or multiple method project. Committees usually discourage attaching a copy of the full proposal.

Nearly every organization's committee requires a separate application. Thus, if a researcher needs access to people associated with different organizations, they must submit an application to each organization and, if necessary, comply with the modifications stipulated by each. This means that the researcher may have to prepare multiple applications and, for every requested or required change in de-

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sign, must return to each committee that has already granted approval to get permission for a modification.

Generally, the shortest possible time from application to granting of approval is about one month. More often, it takes at least two-and-a-half months and can take up to one year. These periods can be even longer if more than one institution is involved. Researchers are generally not required to submit for ethical approval prior to submitting a grant application for funding and in some cases are actually discouraged from doing so.

One way to deal with the issues is to make the effort to inform ethics committees about appropriate practices.

The applications that seem to evoke the most questions from committees are those that focus on qualitative methodologies. It is clear that most committees lack knowledge and experience with qualitative methods. Others have some knowledge, but this is generally limited to a narrow range of designs, most often Strauss' "grounded theory." Until recently, one of the most common requests was for copies of "the questionnaire" when in-depth or semi-structured interviews were proposed. This kind of request is becoming less common because of a variety of education efforts and because I have started to encourage people to state clearly that they are not using a questionnaire. As some committees have become familiar with grounded theory, they no longer ask for questionnaires but have begun to ask for details of the data-coding procedures. (A little knowledge can sometimes be more of a problem than none at all.)

One important problem area is associated with advised consent forms in qualitative research, especially when such research involves people from culturally diverse backgrounds. The issue is not advised consent but the use of one model for obtaining consent. There are questions about the cultural appropriateness of such forms with some groups of people and the impact that requiring the use of such forms can have on these people and on the research itself. Is it ethically appropriate to cause distress in a potential participant by asking them to sign a piece of paper – and then have it witnessed by a third party? We tell people they will remain anonymous, but then we ask them to sign their names on an official-looking document. In some societies, such actions suggest that we do not trust the person nor accept that their word is their bond. And what about those people who come from countries where putting one's name on a piece of paper can have disastrous results, such as putting them or a family member in physical, economic, or political jeopardy?

One committee also tends to insist that potential participants, regardless of research design, be approached only

through a third party. While it is clear that their concern is associated with the idea of coercion (a noble concern), they fail to appreciate that the use of a third party can often be more coercive and more confusing than dealing directly with a member of the research team. They do not seem to recognize that third-party involvement has the potential to confound issues like anonymity and confidentiality. Nor do they appreciate the logistical, theoretical, and ethical problems of advised consent forms and third-party interventions in some types of research design.

How do we deal with such issues on ethics committee forms designed for clinical research where the questions are inappropriate or irrelevant and the spaces too small for the necessary detailed explanations and supporting evidence? How do we deal with the questions and the resulting delays when our research is assessed by people using a different research paradigm, perhaps even a different ethical paradigm?

Do we modify our designs to make them acceptable to ethics committees? And do we make modifications and compromises so that we can get the application through the committee before we have lost a precious opportunity or precious funding? Are we writing research proposals and ethics committee applications that are acceptable according to the standards and values of ethics committees rather than ones that are ethically responsible to all the participants in the research (including members of the research team)? Have ethics committees become barriers to responsible research rather than safeguarding the welfare of the people involved?

A Cautionary Tale

Anthropologists are good at telling stories from the field, so let me offer one as an example of some of these issues. About a year ago, I was approached by a health professional who wanted to do research (using her own funds) in a local hospital, using semi-structured and in-depth interviews to

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better understand the "inner" experiences of parents of seriously ill children. Because of her professional background and skills, she seemed particularly well qualified to engage in this research using this design.

When she approached me, she had been negotiating with the hospital's ethics committee for a year. She had become so frustrated that she was about to abandon the project. Every time the committee reviewed the applica-

tion, they requested additional changes. She had modified the design so many times that it no longer had any coherence, and she no longer knew what to do with it. As she reviewed what she had originally proposed and the modifications she had been requested to make, it became clear that the original design was quite sound and the committee was judging it with standards appropriate for a quantitative project. Through their requests, they had gradually tried to reformulate the project into a quantitative study by transforming her initial coding guide into a highly structured questionnaire.

With my encouragement, she went back to the original design and rewrote the application. We made no significant changes to the original design but used the proposal to educate the committee. One thing we did was to include a much larger number of references from methodological texts to reinforce that what she wanted to do was consistent with the practices of many engaged in such research. She also gave the committee my name so that they could approach me if they had further questions regarding qualitative research. I did not hear from the committee, but she did get approval. She has now completed the interviews and has shared some insightful preliminary findings with groups of practitioners who work with these parents.

Relationship Questions

This woman's story is not unusual. It is just one example I could offer to indicate the kinds of problems ethics committees can create. It suggests that one way to deal with the issues I have very briefly outlined is to make the effort to inform ethics committees about appropriate practices. I do this, not only through the material in my applications and my answers to their questions, but I also send relevant articles to the committee. I do not know if anyone reads them, but I know I can now more easily refer the committee to such information. I have also used my skills as an anthropologist to learn what I need to know to function in this context. Because the same issues kept coming up in the reviews of my applications and those of my students and colleagues, I now have a better idea about how to advise people preparing applications for local ethics committees.

One unfortunate result is that my colleagues and I have begun to see ethics committees as adversaries and barriers to research rather than as a kind of superego. Too often we find we have to stop and evaluate what we are doing. Are we making a modification because of our concerns for the rights and welfare of the people we work with, or are we making it because what we proposed, while ethical and sound, just won't get through the committee? Or at least it will not get through quickly and without hassle. And how many people are submitting a design they know will get through a committee, knowing full well that it is unreasonable and unworkable and they will not follow it? I think these are very serious concerns.

I am hopeful that as these committees, and health researchers in general, become more familiar with a variety of research methods (and we are taking steps in our school to encourage this), ethics committees can return their attention to the sensible review of research proposals. I am also hopeful that the procedures will be modified so the procedure itself will not continue to deter people from engaging in human research.



WHAT IS SFAA'S CONTRIBUTION?

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In the November, 1993, *Newsletter*, I expressed concerns about the decline in SfAA membership and about the real contribution of the Society. I have been gladdened to see several responses in subsequent issues of the *Newsletter* since they suggest that there is still a lot of life in our fiftysomething-year-old association. It was especially heartwarming to learn about how SfAA is helping graduate students participate in the annual meeting, but it is unclear what the Society is doing to help students cope with the realities of the present job market.

To get beyond rival opinions about SfAA's welfare, we need the executive committee to respond to a larger question: How does it measure the success of SfAA? This question presumes that the executive committee (and the membership committee) can identify exactly what SfAA is trying to contribute, what its current goals are, and how SfAA's goals and its budgeted activities are linked to those goals.

My concern is that during the last ten-or-so years, SfAA has become overly concerned with self-preservation, which has led to an overemphasis on membership numbers and annual meeting revenues. If we are attempting to make a contribution to scholarship, then what can we say about the intellectual value of our publications and the meetings? How has SfAA impacted anthropology and the broader domain of applied social science?

