

CASE STUDY RESPONSE

Purity of standards: at what price?

PIERRE LAPLANTE

Staff Nurse, King Faisal Specialist Hospital and Research Centre, MBC 56, Unit F-1, PO box 3354, Riyadh 11211, Saudi Arabia. e-mail: pierrepeter@justice.com

The dilemmas presented by Mr Rajan Patil, although not new, are difficult to resolve with straightforward answers.

The account reminded me of similar communities with whom I have interacted. For example, among some Aboriginal Canadians, traditionally hunter–gatherers, the chief was identified as the one most capable of assuring the tribe's survival—by his skills and his ability to discern and accommodate the spirits prevailing in a given situation or time. With the arrival of the Europeans and the consequent impact on resources, the chief became the person most capable of 'playing the game'. This could mean corruption of the principles guiding the choice of a chief.

How leaders are chosen, and who they represent is not clear in many societies even today. In such situations, would it be judicious to take the community leader's approval as representative of the community?

Mr Patil asks: Is it ethical to tamper with the value system of a tribal community? The question could be rephrased as: Is it permissible to allow anyone to engage in destructive behaviour just because they think that such behaviour is normal? Some cultures tolerate child and spousal abuse. Is this acceptable just because it is cultural? Care must be taken to guarantee the integrity of the research and to be sensitive to the dynamics of the local culture.

Using only the standard of individual consent poses risks for participating individuals. It would be interesting to know how the tribe responds to a member who goes against the leader's direction.

Researchers must be clear about the goals, values and standards that govern any group or effort. Violation of community norms, by seeking individual consent while sidelining the community leader, might subject individuals to retribution of a kind that researchers might not foresee. Unwillingness to bear such responsibilities

may pose problems with community-based research. Further, research without an intervention or follow-up plans gives the participants no opportunity to contact the researchers, should the need arise.

Research of this type will inevitably come across people needing health care. Is it ethical for researchers to design a project without tangible benefits, such as improved health care access, to research participants or the community? Aboriginal Canadians have frequently told me, 'We have been researched enough!'

Inducements may not be ideal and have their own pitfalls, but do they compromise the research? Should people be deprived of life-saving health care because giving it in the research context might be seen as an inducement? Clinical trials worth millions of dollars were stopped halfway when the trial drug performed well; it was unethical to deprive the control group of the more effective drug. People's lives are more important than additional knowledge that might be gained by continuing the trial. Therefore, health care provision must be built into the research budget, not added later.

Another issue is that of 'maintaining privacy' during interviews with research participants. The public manner in which the research team worked resonates with the traditional functioning of Canadian Aboriginals. The use of the 'talking circle' and the 'talking stick' is essential to tribal decisions and reflects their appreciation of public action with everyone having a say.

Finally, one should consider whether exceptions to research guidelines should be anticipated, discussed and decided upon before the work starts, or whether they can be decided on the spot. The case study does not indicate that preliminary discussions took place. The statement that community consent would mean 'phenomenal time saving' raises doubts about the researcher's understanding of principles of research ethics.