LETTER TO EDITOR

Can You Grow Grain in Jumla?

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Dear Editor,

I was attending a review and dissemination session for ethical review committees/institutional review boards in the Himalayan country of Nepal organized by the Nepal Health Research Council (NHRC) in the nation's capital, Kathmandu. A respected clinician researcher and member of the ethical review committee of the NHRC were highlighting the informed consent process. He was informing us how in developing countries like Nepal health researchers often were not fully cognizant of the rights of the general population (participants) while recruiting study participants and obtaining informed consent. In many Asian countries the educated elite may have a negative and slightly condescending attitude towards the general population (who may be from a lower socioeconomic and/or caste/ethnic group). This attitude may be evident when researchers recruit participants, obtain informed consent and deal with the general community. This may also be partly responsible for ethical problems noted with clinical and community based research in Nepal and the South Asia region.

The presenter was describing obtaining informed consent from a poor farmer in Jumla, an impoverished, remote and mountainous district of Nepal. Poor rural people from Nepal's remote districts may be looked down upon by the educated elite who conduct research studies. In Nepal like in other South Asian countries, manual labor is regarded as inferior to mental and intellectual pursuits. But the presenter provided a different perspective. As educated urban persons, he enquired, will it be possible for us to farm the steep hillsides, grow grain and survive in Jumla? Most probably we cannot. So why do we have a condescending attitude towards people living and thriving in that environment? All skills are important and while doing research, recruiting participants and obtaining consent we should consider the skills of the community and have respect for the perspective and views of the farmer from Jumla.

A recent article had examined essential elements of informed consent and the author mentions that during the first step the research team must provide full and transparent information about the research and participant's rights in an easily understandable manner.[1] During the second step, the participant must clearly understand what is expected of him or her. To ensure this the information must be presented in a simple, easy to understand manner. Preferably the consent should be obtained in writing. Participatory action research is gaining increased attention in community and public health research. However a number of ethical concerns can arise during the course of such research.[2] Community based participatory research (CBPR) must consider the rights and well being of communities. A recent systematic review concluded that the reviewed articles mentioned few measurable objectives or uniform guidelines to ensure that high ethical standards have been met.[3] Authors of the published papers reviewed seem to agree that ethics in CBPR are emergent and are situation specific.

Community based medical education is

becomingly increasingly important in the undergraduate medical curriculum.[4, 5] In Nepal, medical students are posted in rural or semi-rural areas at different periods during their undergraduate medical course. They stay in the community, interact with the population, obtain health related and other information (which may at times be sensitive), present the findings of their study to the community and arrive at a possible plan of action with community involvement. Appreciating and respecting the skills and knowledge of the rural community may lead to a healthier attitude towards and respect for them and the student may be more likely to consider the community perspective while addressing problems and suggesting solutions. I tell medical students the example of the farmer from Jumla to make them consider the rural perspective and develop respect for rural communities.

I also used to conduct a clinical research module for Pharm D students of Kathmandu University where I discuss the organization and conduct of clinical trials in detail.[6] Obtaining a proper informed consent is a major issue while coordinating a clinical trial. Respect for the study participants and their autonomy is important. I tell PharmD students the scenario of the farmer from Jumla to highlight the importance of the community perspective.

Since the last two years, I have been a faculty at a medical school in Aruba in the Dutch Caribbean. We conduct a module on research and critical appraisal of scientific literature for basic science students.[7] Informed consent is an important issue to be considered while analyzing a scientific paper and a clinical trial. With some clarification and explanation, I use the case of the farmer from Jumla to underline the importance of understanding the patient/participant and community perspective while conducting research.

I am impressed by the simplicity and possible profound impact of this scenario and its wide applicability in a variety of settings!

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