Application Of Ethical Principles With Cultural Sensitivity
Case Study Of Research Among Tribal Population

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This paper aims to bring out the need to incorporate cultural sensitivity to ensure the principle of essentiality in research processes while undertaking research among tribal populations. The authors establish the difference in the outcome of obtaining consent between tribal and other populations by examining the consent given for a standardised national survey in a follow-up study of women in the reproductive ages. They postulate that the difference could be a result of the application of a uniform approach to obtaining consent among heterogeneous groups and make a case for a culturally sensitive application of the requirement of consent.

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There is considerable heterogeneity within populations in terms of their cultural beliefs and practices. While undertaking research among different populations, this difference plays a role in shaping the nature of the process of informed consent in terms of the effort involved and time taken. Tribal populations in India mirror these differences and there are varied customs, beliefs and practices prevailing among them. This heterogeneity among tribal groups therefore calls for the use of different approaches to research, particularly with respect to the process of consent taking. ICMR guidelines [ICMR, 2000] stated that there is no alternative to obtaining informed consent in epidemiological studies and it would be necessary to have the consent of the community**,** which can be done through the village leaders, the panchayat head, the tribal leaders etc. Their understanding of the rationale for and the process of taking consent may not be uniform then there is a risk that they would be vulnerable to exploitation. The ICMR guidelines also mentioned that it is essential to prevent any disturbance to cultural sensitivities because of the investigation.

It is an ethical obligation to respect the individual autonomy of human subjects regardless of their class or caste [NCESSRH, 2000]. It is also important to not to cause them any harm either physical or mental. Causing them to go against the norms of the community could result in harm especially from the community reprisal when the norms are against signing consent forms or taking individualistic decisions. This will be felt very severely in societies where kinship structures and mutual dependence are a way of life. Therefore an assiduous application of the principle of autonomy of the individual and community are called for, but in order to not to violate this principle, it becomes necessary to also, simultaneously ensure that the principle of essentiality [ICMR 2000] of the research among this group is considered. Because by ensuring the principle of essentiality the investigator make sure, "the research entailing the use of human subjects is considered to be absolutely essential after a due consideration of all alternatives in the light of the existing knowledge in the proposed area of research and after the proposed research has been duly vetted and considered by an appropriate and responsible body of persons who

are external to the particular research and who, after careful consideration, come to the conclusion that the said research is necessary for the advancement of knowledge and for the benefit of all members of the human species and for the ecological and environmental well being of the planet" [ICMR 2000].

Objectives

This present paper aims to bring out the need to incorporate cultural sensitivity to ensure the principle of essentiality in research processes while undertaking research among tribal populations. We propose to do this by establishing that tribal populations are not uniform in their socio-economic characteristics or in their cultural practices. A comparative analysis of the social and economic situation of major tribes in Kerala will be presented as indicative of these differences.

The difference in the outcome of obtaining consent between tribal and other populations will be established by examining the consent given for a standardised national survey to collect socio-economic and health indicators, blood samples and participation in a follow-up study from women in the reproductive ages.

We postulate that the difference could be a result of the application of a uniform approach to obtaining consent among heterogeneous groups and that a culturally sensitive application of the requirement of consent would mean the use of different approaches to obtaining consent.

To establish the difference in the socio-economic characteristics of the tribes in Kerala, data from the Census of India, 1991 and the Socio-Economic Survey of Primitive Tribes-1996-97, Directorate of Scheduled tribes Development, Govt. of Kerala, 2002 and observations made during the data collection process for the author's doctoral thesis work have been used. To establish the differences in the outcome of the consent process by caste groups in India, data from the National Family Health Surveys, 1998-99 has been used [IIPS and ORC Macro 2000].

Heterogeneity Among Tribal Populations

Socio-economic and demographic characteristics:

Tribal populations in Kerala state are mostly concentrated in the forests of Wayanad, Idukki, Palakkadu, and in Kasaragod. The scheduled castes and scheduled tribes Orders (Amendment) 1976 (G O No. 108 of 1976) is taken as the base for 1991 census enumeration in Kerala, and this census reported a total of 35 tribal groups in the state [Census of India 1991]. The characteristics of first 12 groups in the order of declining proportion to total tribal population are described below as a demonstration of the differences in the levels of socio-economic status among them. The variables used are literacy level, percentage of population in forestry and related works, sex ratio and child woman ratio.

Table 1: Socio-Economic and Demographic Characteristics of Tribal Population, Kerala, 1991

Tribe	Literacy	Percentage in Forestry and related work	Sex ratio	Child-Woman ratio
Kerala (all tribes)	57.22	11.14	996	374
Paniyan	40.65	14.87	1042	394
Kurichiar	71.94	7.27	966	442
Marati	67.78	11.81	977	381
MalaiArayans	93.18	5.92	995	256
Kurumans	69.73	16.69	976	348
Irular	35.03	1.53	988	361
Muthuvar	30.47	11.60	983	576
Kanikkaran	72.50	2.18	1072	345
Ulladan	76.20	7.08	1000	282
Kattunayakan	29.41	35.60	938	456
Uraly	65.78	14.26	944	375
Adiyan	43.25	6.97	1022	412

Source: *Census of India, 1991*

Table 1 shows that there are differences in education, occupation, sex ratio, and child woman ratio between the selected tribal groups. The literacy of Malai Arayan (93.18per cent) Ulladan (76.20 per cent), Kanikkaran (72.50 per cent) and Kurichiar(71.94 per cent) were comparatively higher. But Kattunaykan (29.41 per cent) Muthuvar (30.47 per cent) and Irular (35.03 per cent) had relatively lower levels of literacy. Occupation-wise, Kattunayakan is the group having the highest proportion population in forestry and related works. Groups like Kanikkaran, and Malai Arayan were less dependent in forest for their livelihood.

Sex ratio (number of females per 1000 males) is an indicator showing the overall development and status of women in the society. In a state where sex ratio is favourable to women, sex ratio of tribal groups seems to be unfavourable to women. Chauhan (1990) pointed out that the status of tribal women in India has gone from bad to worse due to the impact of changing social structure. The sex ratio of Kattunaykan tribal group is only 938 females per 1000 males. On the other hand Kanikkaran (1072) and Paniyan (1042) had sex ratios similar to that of the state as a whole (1058) [Census of India 2001].

Child-woman ratio (the number of children in the age group 0-4 to 1000 women in the age group 15-49) is an indicator of recent fertility (here, in the last five years preceding the census) net of child mortality. The child woman ratio of women in Kerala was 330 in 1991 Census. But for the tribal women it is 374. In the analysis of the 12 major tribes it was found that the child –woman ratio ranges from 576 (Muthuvar) to 256 (Malai Arayan).

Clearly on the basis of their socio-economic and demographic characteristics, there exist wide variations between the different tribal groups in Kerala.

Cultural and Behavioural Characteristics:
To examine the cultural and behavioural heterogeneity between the tribal populations, two tribal groups that were most similar to the state and most distant from the state in terms of the above mentioned four variables were selected, viz. Kanikarran (similar to that of Kerala state) and Kattunayakan (most distant level of indicators from those of the Kerala state).

Table 2: Characteristics of Kani and Kattunayaka Society in Kerala, 2002-2003

	Kanikkaran	Kattunaykan
Major nature of work	Agriculture	Collection of forest produces
Treatment seeking	Generally -Modern	Normally -Traditional At the time of emergency –modern (but conditional)
Decision making	At household level	At settlement level
Important decisions	By household head	Chieftain or age old Person
Contact with non-tribes	Usual	Not usual
Tribal system	Generally Slackened	Generally rigid

Source: For information on major source of work Census of India, 1991
For all other variables Data collected as part of the Doctoral Thesis Programme of the ICSSR, Govt. of India and *Socio-economic Survey of Primitive Tribes-1996-1997*, Directorate of SCH. Tribes Development, Govt. of Kerala, 2002

An examination of the two tribal groups situated at the two extremes of the integration process, ie. Kanikkaran and Kattunayakan, indicates the differences in their behaviour and practices. The variables used for this comparison are the major nature of work, treatment-seeking behaviour, unit of decision-making and rigidity of tribal system. While Kanikkaran generally uses modern medicines, the other group uses traditional medicines for common ailments. They use modern medicine at the time of emergency but only after seeking consent from 'God' through the chieftain or priest (generally both roles are taken by the same person) through a well-defined set of traditional 'poojas'. Among the Kanikkaran the household decisions are normally by the household head except for things like marriages, but generally decisions are at settlement level by the chieftain or elderly person in Kattunayakan group. Even, issues relating to acceptance of immunisation programmes are decided at settlement level in some Kattunayakan settlements. Yet, the degree of autonomy for women regarding the selection of a life partner among Kattunayakan groups is high.

Given this heterogeneity in the cultural beliefs and practices, would it be possible to use the same approach to undertake research among these two groups? The issues associated with participation, the process of obtaining informed consent, etc cannot be the same for the Kanikkaran and Kattunayakan groups. It is in this context that the application of ethical principles without cultural sensitivity could be problematic. In fact, clearly many of the decisions in the Kanikkaran group may be taken at the family or individual level

whereas the group leader may make the decisions among the Kattunayakan group. Therefore, the gate-keepers in these communities are at different levels – among the Kanikkaran it would be at the household level and in the Kattunayakan it would be at the settlement level.

The consent-taking process amongst these two groups may also be different because the people of Kanikkaran are more exposed to non-tribal populations and therefore may comprehend the explanations quickly. On the other hand the Kattunayakan group is less exposed to non-tribal ways of life and therefore the nature of explanations, time taken for clarifications may vary. Therefore, cultural sensitivity would be an integral part of the application of ethics in the research process and the adoption of a universal approach while undertaking research among different tribal groups could jeopardise the very research process.

Consequences of these Differences to the Research Process

Differences in research outcomes:
Table 3 illustrates the difference in the values of an indicator (the Infant Mortality Rate-IMR) using different approaches to data collection.

The absence of 'respect for culture' would not only affect the application of ethical principles but it is also an essential for ensuring the quality of the collected data, especially socio-demographic data in tribal areas. As can be seen, even after making allowances for the differences in size of sample and the errors in estimation due to that, it is clear that the second approach shown in table 3 did not provide any information.

Table 3: Infant Mortality Rate and Child-Woman Ratio for Kattunaykans Using Two Different Approaches

	Study I*	Study II**
IMR	79 per 1000 live births, 1998-2002	No infant death reported, 1995-1996
Sample Used	608, 20per cent sample of total households	3162, total Kattunayakan households in Kerala
Approach used	Before seeking the permission of the respondents, the concerned Tribal Extension Officer of the settlements, Panchayat President or member and chieftain of the group were informed about the study and the word used to inform the purpose of research is "to study"	It was a government programme and total enumeration, no informed consent process from chieftain and panchayat member.

* ICSSR Doctoral Fellowship Programme, data collected in 2002-2003
** *Socio-Economic Survey of Primitive Tribes-1996-97* (Government of Kerala, 2002)

The tribal group studied had a strong belief that death before old age is the harmful effect of evil spirits. These evil spirits are actually the souls of those who experienced deaths before old age and reporting such deaths would mean calling upon such evil spirits and they could cause harm again. This belief may come in the way of reporting infant and child deaths as the causation may be attributed to the same evil spirits (*bootham and prethem*) and result in under-reporting. Under-reporting could be reduced if the

population is taken into confidence and the purpose of the research explained to them at length. Before taking informed consent or explaining the risks and benefits from individuals the head-man's consent would also reduce under reporting and ensure the participant's co-operation among this population.

Differences in Consent Process

Such heterogeneity within populations would result in differences in the extent to which people would be willing to consent to participate in research. To illustrate this, we have used data from the National Family Health Surveys 1998-99 [IIPS and ORC Macro, 2000] where 90,303 women were interviewed as to their socio-economic, demographic and health parameters. The study was undertaken after obtaining informed consent from the women and they included the data on the willingness of women to sign the consent forms and such women who gave consent to being visited subsequently. The proportion of women who signed the consent form, the number of women who consented to have their blood tested and the proportion of women who agreed to also be interviewed at a later date are given in table 4 for Scheduled Caste (SC), Scheduled Tribes (ST), Other Backward Communities (OBC) and Others separately. This information has been analysed for rural – urban differentials as well.

Table 4: Proportions Consenting for Participation, Participation in Future Study and Testing Blood, by ethnicity, NFHS II-1998-99

Ethnicity	Signed the consent form			Agreed for subsequent interview			Agreed for blood test		
	Rural	Urban	Total	Rural	Urban	Total	Rural	Urban	Total
Scheduled castes	92.27	93.34	92.56	7.65	28.78	13.08	90.14	93.34	90.42
Scheduled tribes	93.59	91.23	93.20	2.79	7.57	4.38	91.96	90.85	91.78
Other backward castes	92.54	94.34	93.03	11.94	32.01	18.20	90.41	92.63	91.01
Others	90.71	90.69	90.70	4.95	21.21	12.40	88.18	87.38	87.86

Source: IIPS, Mumbai and ORC Macro, 2000. National Family Health Surveys, 1998-99, IIPS, Mumbai.

The differences in the consent process of the scheduled castes and tribes and others do not seem to be very different while considering the consent given for the interview or the consent given for blood testing. However, a lesser proportion of tribal women seem to have consented for future interviews when compared to women from other groups in both rural and urban areas. While the reasons for this could be the unstable nature of tribal residence patterns, it could also have its roots in the adoption of a uniform process of obtaining consent.

The disparity between the proportions currently consenting to be interviewed and provide a blood sample and those which agreed to future interviews across all groups is a cause for concern. Just about a third of the women among the SC and OBCs consent but this proportion is even lower among the STs and others. One possible reason for current consent could be 'courtesy bias' where the respondents were not able to say 'no' to people who were conducting a government sponsored study (which the NFHS was). So,

rather than declining to participate, the participants may express their disagreement by refusing to be a part of any future surveys. There could also be other unknown explanations for these differences.

However, given these differences in the proportion of women who have consented for future interviews among the four categories of population, the drop out rates for each of them would be different. Therefore comparisons between specific rates and ratios estimated using any data subsequently collected through future surveys may be biased given the differentials in drop out rates across populations. It is possible that their inability to deal with universal explanations result in their consenting for studies that they do not want to participate in. the proportions of women consenting for future interviews among tribal populations is very low. Therefore any research initiative among these groups has to be carefully planned and executed in order to be ethical as the explanations that are used amongst other populations are not useful. The use of uniform norms for undertaking studies among such heterogeneous populations may vitiate the application of ethical principles and the validity of the data collected.

Conclusions

The possible constraints in the application of selected ethical principles outlined in the ICMR guidelines and the implications for application of this principle with cultural sensitivity has been outlined in Table 5.

Table 5. Ethical Principles, Constraints and Cultural Sensitivity

Ethical Principles	Constraints	Application with Cultural Sensitivity
Principle of Essentiality	If essential for satisfying the quest of researcher but not necessary for the benefit or well being of tribal populations, interference in cultural norms may cause problems to the participants and to the researcher.	Already living in vulnerable conditions. Therefore the risk-benefit ratios should be considered carefully. Only if the study is essential for the tribal populations, should it be undertaken.
Principles of voluntariness & Informed Consent	Tribal populations may not be literate or used to the written way of expression or have faced problems in the past because of affixing thumb impressions and loosing valuable resources.	Indigenous people are not incapable or incompetent to give consent but consider the option of oral consent depending on the attitude of the community. Before individual consent the headman's consent (not as a substitute for individual consent) may be necessary, depending upon the culture.
Principle of non-exploitation	Even though compensation is in-built in the research including treatment during and after the research, reporting may be low. Past exploitative practices may result in suspicion of the researchers.	Should make aware of the possible risks and compensation packages during and after the research process. All potential participants can be provided information in more culturally homogenous groups (such as young men/women or families, mothers, etc) instead of individual basis. This may reduce fears and also serve to increase the awareness.
Principle of Privacy and confidentiality	Low means and measures for ensuring privacy and confidentiality in tribal settlements	Select suitable methods of data collection to ensure maximum possible privacy and confidentiality to the subjects.

A guideline may emphasize 'respect for local cultures,' but how or whether this is achieved is subject to interpretation by the researcher and by the community as well [Firehock 2003]. While dealing with minority groups such as tribal populations, it is important to ensure that their rights are not violated, particularly with respect to autonomy. Therefore, researchers would have to carefully plan for obtaining consent amongst such groups and the approach used would not be the same at that used among mainstream groups. Respect for culture may not mean a lesser value attached to the rights of individuals within them or privileging the rights of the leadership amongst them. However, given the fact that such populations are more vulnerable to courtesy bias and also may find it difficult to decline participation once the leaders acquiesce, there is a need to ensure that any research among them is directly beneficial to them. This means, that the research would have to be essential to the population in question. It is in these contexts when the study populations would be otherwise vulnerable (even if adult and capable of autonomous decisions) that we suggest that the principle of essentiality has priority over all others.

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