Public Health Research and Scheduled Tribes: An Ethical Lens

Katia S. Mohindra

PhD, Globalization/Health Equity Unit, School of Epidemiology, Public Health and Preventive Medicine, University of Ottawa 116 - 850 Peter Morand Cr. Ottawa, ON K1G 3Z7, Canada

Summary

In this commentary, it is argued that greater attention paid to ethical considerations related to doing Public Health Research with Scheduled Tribes (STs) should be prioritized. Given the high levels of health needs among STs as well as their high levels of deprivation, cultural oppression, and impingement on their rights, there is a need to revisit our research practices to contribute to better health and overall empowerment. Specific strategies that could be integrated into research practice are offered. The paper concludes with a call for the development of national guidelines for Public Health Research with STs.

Keywords: Ethics, National Guidelines, Public Health Research, Scheduled Tribes

Introduction

With India’s economic development comes a greater opportunity to improve the health of populations and increase health equity. Given the high level of health needs among Scheduled Tribes (STs) and inadequate understanding of how to improve their health,1,2 more research that specifically addresses ST health is warranted. However, the material deprivation, cultural oppression, and impingement on their rights raise the question of how to do research with STs that does not contribute to their exploitation or treatment as “no more than ‘objects’ of scientific study,”3 but rather contributes to better health and their overall empowerment. The objective of this commentary is to advocate for greater ethical considerations in Public Health Research undertaken with STs. First, key ethical guidelines used in Public Health Research internationally and in India are outlined. Second, it is argued that general ethical guidelines and current practices are often inadequate to ensure proper protection of ST health, rights, and well-being. Third, recommendations are made for additional ethical strategies that can be integrated into Public Health Research. Concluding remarks are made in the final section.

Ethical Guidelines in Public Health Research

Globally, there is increasing attention paid to ethics in biomedical and population health research.4,5 There are basic principles and guidelines for health research (e.g., informed consent, balance of risks, and benefits) outlined in the Declaration of Helsinki and the guidelines developed by the Council for International Organizations of Medical Sciences, as well as the Development of National Guidelines for Biomedical and Social Science Health Research in India.5-7 To

This is an open access article distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 3.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as the author is credited and the new creations are licensed under the identical terms.
ensure that research ethics are appropriately applied to each research program and project, the World Health Organization recommends the establishment of Institutional Review Boards and Research Ethics Committees.

The Need for Greater Ethical Strategies for Research with Scheduled Tribes

It has been argued that many of the available ethical guidelines are insufficient in protecting communities and individuals who are marginalized or vulnerable. Different issues can arise, such as collecting informed consent from populations who are impoverished, illiterate, and hold high levels of mistrust of individuals from outside their community; the appropriateness of collecting individual consent among communities who maintain a collective identity; or the extent to which participation can be truly voluntary if individuals or communities lack the capacity to refuse participation.

In addition, ethical concerns – including standard ethical practices and principles – can be sidelined or neglected in research with STs. One systematic review of the literature on population health interventions and STs found that many of the standard ethical procedures (e.g., obtaining informed consent) were not followed or adequately reported in the studies. Moreover, there was little consideration to any special ethical dimension that might be needed working with the ST communities. Scientific interest in the genetic makeup of STs due to dwindling numbers of certain tribal groups or interest in specific diseases that are over-represented among some tribal groups (e.g., sickle cell anemia) can lead to STs being viewed as objects as researchers engage in intrusive procedures (e.g., drawing blood) without proper consent, adequate understanding of the research, or benefits accrued to the participants. In addition to ensuring standard ethical principles are followed, there are further examples of unethical practices when working with STs, including implementing culturally insensitive research designs or methodologies, undertaking research that inadequately meets the felt health needs of STs, and failing to translate research into better public policies for STs and tangible benefits for ST participants and the wider ST community.

Recommendations for Increasing Ethical Strategies with Scheduled Tribes

While undertaking research with STs is complex including accounting for the large internal diversity among different ST groups - there are strategies that can be adopted to enhance ethically sound research. Three potential strategies for strengthening ethical practices with STs are recommended here. First, to the greatest extent possible, research priorities should reflect the felt health needs of STs and their concerns, instead of being dominated by the interests of funders, policy-makers, research institutions, and researchers’ own interests. This includes assessing the degree of correspondence between the main epidemiological and health problems identified among STs and the actual research being undertaken. Consulting with ST communities themselves should also be used to identify priority issues.

Second, maximizing ST participation should be integrated into the research design and methods to the greatest extent possible. Participatory approaches have been advocated as one way to increase the control of marginalized communities over their own research and policy priorities. Participatory approaches are rooted in the philosophy that those most affected by health and development issues should be active participants in the research process and how this research is translated into action, rejecting traditional scientific (positivist) approaches. Although participatory research has been used in India for an array of public health issues, there are only a few studies that have adopted participatory approaches with ST communities as part of the research process, such as developing research questions, providing input on study design, or contributing to data analysis and policy recommendations. The benefits of participatory approaches can extend beyond the study itself, by developing ST capacities to address their own health needs and reducing imbalances of power within the community.

Third, when working closely with ST communities, researchers can implement a Research Code of Ethics between researchers and ST communities as an approach to ensure ST values and culture is promoted throughout the research. Ethical codes encompass guiding principles and practices to ensure that research partners (e.g., researchers,
ST communities, and local stakeholders) achieve the study’s objectives respectfully and ethically. One research team developed and implemented an ethical code with the Paniyas of South India (a previously enslaved tribal group that continues to face high levels of deprivation and marginalization) as part of a participatory study. The ethical code was built on thirteen guiding principles and detailed the obligations of each of the partners in the study. Developed in partnership with local Paniya leaders (Moopans), it involved an iterative process, beginning with the collection of community consent (among each of the participating Paniya colonies) in addition to individual consent of participants. Although the ethical code involved additional time and resources, as well as challenges in the field, ultimately the ethical code helped build trust between the researchers and the Paniya communities. Such ethical codes do not come with a blueprint, but rather are meant to be tailored to the specific context, nature of the research project, and ST communities.

Conclusion

Adopting an ethically sound approach should not be viewed as a barrier to doing research with STs, but rather as an integral component of the research process. In addition to more population health research on STs, we also need to ensure how we are doing the research is culturally and ethically appropriate. This should involve a critical analysis of why and how we are undertaking our research initiatives, as well as the development of best practices and ideally, the development of national guidelines on doing research with STs. These practices will require greater attention and consideration by funders to provide the necessary resources and time to ensure that research is being done to the highest ethical standards. Given the high level of “voicelessness” among STs, ensuring greater voice and the promotion of ST participation in the research process should be a cornerstone in building better research initiatives.

Financial support and sponsorship
Nil.

Conflicts of interest
There are no conflicts of interest.

References