Community-based participatory epidemiology in tribal areas in India

Deo et al., have presented the findings of an epidemiological investigation of hypertension and diabetes among the Katkari tribes of Raigad District of Maharashtra.[1] The study reports a prevalence of hypertension of 16.8% and diabetes of 7.3% despite a preponderance of low-fat vegetarian diet, high levels of vigorous physical activity and high prevalence of severe undernutrition. This prevalence though lower than the rates reported in systematic reviews of hypertension and diabetes prevalence among tribal communities in India indicate a steady transition of disease patterns from communicable to noncommunicable diseases among the indigenous populations.[2] The study has some important limitations including a volunteering bias (only people who volunteered to the study were included), healthy worker bias (only people who remained in the village after the majority left for work were surveyed), nonprobabilistic sampling of the participants, which could adversely impact the findings. Although these limitations preclude the definitive conclusions from the study, this study is an excellent example of community-based participatory epidemiology where members of the community participate in design and conduct of the epidemiological research. Research among tribal populations has unique ethical considerations. The marginalized tribal communities have poor access to resources. The access to health care is also restricted in these communities. They fall outside the safety net provided by the public health system. Therefore, research in these communities has to be nonexploitative and sensitive to the unique needs of the communities.[3] Community-based participatory research (CBPR) is a recent development in public health, which aims at involving communities in the research process. This study shows the use of community-based participatory epidemiology with the help of Adivasi children studying in Class X–XII toward understanding the health issues of the community.

Public Health Research among Tribal Communities

Public health research among tribal communities is scarce. However, there is a need to understand the health status and health problems of the tribal populations to tailor public health services to these communities. Embarking on research in tribal communities can be challenging for a researcher hailing from a nontribal area because of geographic access, cultural and linguistic barriers.[4] There are also issues of unfamiliarity among tribal populations about research, unrealistic expectations from the researchers and other logistic issues. Studies have also shown trust deficit of indigenous populations on researchers and scientists. Overcoming these barriers to research can be daunting. This is where community-based participatory approaches to research come handy.[5]  

Community-based Participatory Research

CBPR is a research paradigm which engages communities actively in the research process starting from framing the research question, collecting research data, analysis and interpretation of the research findings till using the research findings toward the improvement of health of the community.[6] By actively engaging communities in the research process, the research becomes relevant, responsive, and actionable for the community. CBPR helps reflect the social and environmental context and realities of the communities in the research. CBPR appreciates a social construction of knowledge and therefore places emphasis on social analysis and interpretation of the research findings.

Community-based Participatory Research as a Strategy to Overcome Barriers to Research among Tribal Communities

Community engagement in the research process significantly enhances the trust that communities have on research.[7] The research is perceived as originating from within the community, and hence the community develops ownership of the research. This helps repair the major trust deficit. When the CBPR employs the members of the own community for data collection and analysis, it further reduces logistic, cultural, and linguistic barriers. The concern of undue exploitation of the tribal communities by the researchers is also reduced. Participatory epidemiology is a type of CBPR in which members of the same community engage in the epidemiological research process. It has been widely used in veterinary epidemiology. It utilizes participatory rural appraisal methods such as semi-structured
Community-based Participatory Epidemiology in the Katkari Tribes

Deo et al., who are part of the Moving Academy of Medicine and Biomedicine, have collaborated with the Vanvashi Ashram Shala, a tribal residential school in the study area (Mangaon) to conduct this participatory epidemiological work. It was part of the “Discovering Adivasi Little Scientists” Program of the Government of India where school students are encouraged to develop a scientific attitude and bent of mind. A total of ten students performed the study between 2012 and 2014. All these students belonged to the Katkari tribe, and at least one member of each team that went to the hamlets to conduct the research belonged to the same hamlet. Engagement of the local residential school and students from the community in data collection significantly improved the compliance of the tribal community with the research protocol. The students who collected the data spoke the same language as the community and understood and followed similar cultural beliefs and practices. It is likely that the data errors are also lesser because of reduction of barriers in communication between the researchers and the community (personal communication with author of the paper).

Data collection for epidemiological investigations such as the investigation of outbreaks, assessment of the prevalence of noncommunicable diseases and their risk factors, behavioral epidemiology can be conducted by persons with minimal training. In sensitive areas like primitive tribal communities, engagement of such local “lay epidemiologists” may come in handy. Not only does this actively engage communities and foster trust in the research, but it also empowers the tribal communities by making the research responsive and relevant to their needs. Such models of participatory epidemiology should be encouraged and explored in various parts of the country. This will help in bridging in the wide health information disparity that is present between tribal and nontribal communities.

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