Speaking for Myself

Challenges in the conduct of community-based research

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ABSTRACT

Community-based research is an excellent opportunity for medical students to learn outside the boundaries of a medical college, where health-related conditions and factors can be studied in a larger social context. It also brings a variety of other educational and social learning with it. The research question is usually a community-driven issue. There are multiple ways to arrive at a research question. Sampling poses a unique challenge, especially in terms of availability of a sampling frame. However, accessing electoral rolls, census data and approaching community leaders of voluntary agencies working in a particular area can be a suitable way. The interview schedule should be culturally and socially appropriate and locally validated if possible. Prior preparation of a timetable of activities is much needed, including slack time and contingency plans to fall back on as some social situations might make the area inaccessible. An important team member in these situations is a chaperone from the community who can facilitate these social interactions, including negotiations for the time of the participant. There may be sociocultural problems, which plague the research as much as they affect the community, which the researcher has to be sensitized to. Extra effort is needed to achieve a high response rate in community-based studies. Refusals by selected participants and their non-availability despite 2–3 household visits need to be addressed with patience and perseverance. Several ethical issues arise during the research, and careful thought has to be given to avoid exploitation of the communities.

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INTRODUCTION

Health research is an important part of the medical education curriculum. For postgraduate students, it serves as an entry point into the world of scientific research. As a large part of medical training is institution-based, the exposure to research is also clinic-based or institution-based. Community-based research is often not undertaken due to various challenges. There are several variations of community-based research—participatory research, participatory action research and empowerment research to name a few—which involve active participation of the community members in the research process.[1] The hypothesis is often formed on the needs of communities, for which researchers need to work alongside community members as well as institutions or organizations.[2]

Unlike in institutions, community-based research is usually done on individuals who do not perceive themselves as ill. The conditions under which research is done in the community are not under the control of the researcher. However, this helps to study a factor in the larger social and community context.[3] The purpose of research is to provide something useful to society, and community-based research helps to link knowledge with social enquiry.

When done right, community-based research provides an opportunity for the researcher to learn outside the boundaries of classrooms. It produces a variety of positive attitudinal, interpersonal and academic learning outcomes, specifically, collective action, advocacy, critical analysis and collaboration.[4] It is known that students learn better when learning is not bound by textbooks and classrooms. Community-based research exercises combine theory with practice.[5]

COMPONENTS OF COMMUNITY-BASED RESEARCH

The most common examples of community-based research in a medical college are prevalence studies or studies that assess awareness of a given health condition in the population. As part of their training in research methodology, undergraduate medical students are required to undertake a community-based research study under the guidance of faculty members. Usually, this is a simple prevalence or knowledge, attitude, practice (KAP) study on a health condition. Like any academic research, community-based research starts with the formulation of a research question, followed by selection of the study population, methodology and outcome variables. In case of analytical study designs, or community and field trials, we also need a community for comparison and a clearly defined intervention. The research question in case of community-based research is a community-driven issue, for which researchers need to communicate with members of the community.

One way to identify a research question is to conduct focus group discussions. These help to sensitize researchers to the community, its language and its views, and may also help them to get ideas about how to best reach prospective participants and gain their trust.[1] However, community members may want to study a health condition which is more resource-intensive than what the researchers planned for, or the one which the researchers are not interested in.

After formulation of the research question, the study is planned, which includes the study population, study area, selection of a sample of study participants and study design. The challenges

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faced in the conduct of community-based research at various stages are discussed below. Solutions to address these issues are also offered.

Selection of the study population needs to be carefully considered. Young adults and school-age children are seldom found in or near the vicinity of their homes during the day. Hence, children aged 5–18 years, and adult males might be available for interview only during early morning and evening after working hours. It also makes working on weekends and public holidays important to meet such participants. During large studies, which take a long time, this may put some pressure on the study investigators.

The availability of a sampling frame also becomes an issue. The health management information system and census may be used. However, accuracy of the sampling frame, if available, may be low due to migrations, births and deaths.[6] The sampling frame of a particular area may be prepared using electoral rolls, after which simple random sampling can be done.[7] To conduct a study among inhabitants of slum clusters or at construction sites, the chief or leader may be contacted; he would usually have a list of people and contacting that person might be useful. The researcher can approach non-governmental or voluntary agencies that are already working in the area. Sometimes, complete rapid enumeration of the area may be warranted to enlist the population. Systematic random sampling may be done if there is a dearth of data and resources.

A longitudinal study design is generally cost-intensive, while cross-sectional studies do not have a temporal dimension for causality. For community-based intervention trials to be done smoothly, institutional, local and political support is required. These can be facilitated by community–institution partnerships. The outcome must be a change in practice that is measurable.

Developing a questionnaire or interview schedule for community-based research is a huge task on its own, and should not be taken lightly. Questions should be articulated clearly, and in measurable terms. There may be different connotations of different terms, and translation may not always be accurate. A Delphi survey or focus group discussions might help to phrase questions better in the local context.[8] If a standard tool is available, it must be validated in the vernacular before use. The researcher may also choose to modify and translate the questions for local use.

Recruitment of study investigators and training them for data collection is of paramount importance. This step goes a long way in ensuring collection of good quality data. Going house-to-house, explaining the study, collecting data with optimal use of time, can be an exhausting process. Further, over a period of time, data collection becomes monotonous, and quality of data collection may be compromised. Some breaks may have to be built in during data collection in such studies. If measuring instruments are being used, agreement studies may be done at intervals to ensure that mental fatigue does not lead to suboptimal quality of data. Every evening, forms filled during the day must be checked by supervisors to ensure completeness and consistency. If required, respondents can be visited the next day to collect missing information.

During data collection in the community, multiple unforeseen problems may be encountered. Preparing a schedule for field activity, including slack time, is a must to minimize wastage of time. Researchers may need chaperones well-versed with local customs and language to facilitate this process. There is difficulty in meeting participants who go out for work as they can only be contacted outside of their working hours. Their availability at home has to be adjusted for. This becomes more challenging for female researchers owing to their safety issues during evening hours.

Often, study investigators find themselves responding to emotional issues of the participants, especially if a good rapport has been established.[9] Study investigators may find themselves in a moral dilemma in day-to-day situations regarding the extent to which help should be provided, informing higher officials and authorities on sensitive issues, etc.

The problems that plague the community also affect data collection. Anti-social activities, drunkenness, crime and violence are more in urban slums.[10] However, what constitutes ‘risk’ to an outsider may be a part of everyday experience for individuals within a community. Teasing and making fun of the study investigator by unsavoury persons in the community may happen, and special training sessions on avoiding and managing conflict must be a part of the research teams’ preparation strategies.[11]

Cultural humility means different things to different people. However, here, it means a list of traits of people in the community that are different from those of the interviewers, and respecting those traits. Participants, especially from poor communities, are often not vocal as they feel less privileged. They might also wrongly assume that there is a knowledge gap between the study investigator and themselves, and tend to be less expressive. Other reasons also include social issues: suppression and gender issues in family, fear or maybe just a lack of time for not being able to answer properly with honesty.[12]

Coverage

Coverage or response-rate of a community-based study needs to be high to ensure validity of the results. Various factors influence coverage. First is the inability of the research team to contact the participant, perhaps due to haphazard arrangement of households in slums, use of common names, less community interaction of people in general and busy schedule.[13] In such situations, engagement of community leaders in the research activity shall be useful. Second, refusal of the contacted participants, which may be higher in urban studies, contributes to low coverage.[14]

Reasons for refusal

Gender issues. Male interviewers may not be permitted to talk to females, elderly or children without the presence of another male member in the household. This sometimes becomes an issue, as a convenient time has to be negotiated. Often, an outright refusal might also take place, as male members (husband, son and father-in-law) of the family may not permit females talking to a male interviewer. Females are engaged in various household chores in a joint family, which might leave them with no time for researchers. Working females have the dual role of doing both the household chores and working outside, which makes them even more likely to refuse.[15] Engaging female interviewers addresses some of these issues. The participants’ availability and convenient time needs to be given priority.

Lack of community interaction. Compared to rural areas, urban families are smaller, and there is less interaction in the neighbourhood. This social structure leads to a perception of reduced security, and people doubt the intentions of anyone who knocks on their doors. It leads to outright refusal, without listening to the participant information sheet and consent form.[15,16] Local volunteers need to accompany the research team. Their presence tends to alleviate the suspicions of participants. Some honorarium for them should be included in the budget. If any examination is being conducted at a designated site, the presence of a community leader will be a great motivator.

Fear of strangers. People may refuse to participate when researchers are strangers to the community. There is a lack of trust, especially for female participants and elderly persons. They are likely to refuse if they are alone at home, because of perceived security issues. As indicated above, presence of local volunteers can be useful. The team members should prominently display identify cards from their institutions.

Poor informed consent procedures. Sometimes, participation is refused when researchers fail to explain clearly the purpose of their research. While enrolling participants, researchers must convey to them in simple language the purpose of the study, the nature of the intervention/s, the study methodology, their rights and responsibilities as participants, potential risks and benefits, and methods of maintaining confidentiality. Despite the effort put in by the researcher in obtaining and documenting informed consent, the comprehension of study information varies among participants.[12,17]

Nature of the study. A study that requires collection of biological samples, commonly, blood samples, is likely to have a suboptimal response rate. Similar is the case of a study where some information is collected at the household level, but clinical examination with the help of equipment or specialist is conducted at a central site within the community. In such studies, there would be participants who would provide information, but may refuse to provide biological samples, or come to the examination site. Participants in the neighbourhood who have provided full cooperation, may be able to persuade such participants.

Not knowing/following customs and traditions of the community. One of the reasons people refuse to participate in studies is when they are not informed in advance about the study. This can be dealt by planning for a more active community engagement in research, which would also dispel rumours and misconceptions that circulate in their communities. A better practice is to first seek consent from community leaders, sensitize the community through group meetings where the residents would be briefed about the study, or through distribution of pamphlets and information brochures.

Lack of perceived benefits for the participants. What people expect to hear is how the research would be conducted and how the study will benefit them. If they are convinced that the study will be beneficial for them, they would be more likely to cooperate in the study. Participants need to be informed that appropriate management shall be provided for any clinical condition diagnosed. They would be provided the clinical reports for future reference. These should be ensured for ethical reasons.

Lack of cultural sensitivity. Researchers and field workers must try to understand cultural practices while approaching and talking to people. They should be trained in how to approach people, and should not be overbearing or aggressive. Gender-sensitive issues should be taken up with adequate care.

Poor timing. Most often during the daytime, people are busy and cannot spare time to respond to researchers' questions. It is important to know the time when people are free, and this may require special visits on holidays or evenings.

Previous bad experience. Frequently researched communities may have participants who were part of previous health research. They are likely to refuse if they experienced bad behaviour or research-related adverse health effects in the past. This is a difficult issue to address. The reputation of the institution of the current research team may be used to persuade participants to agree. If the previous unpleasant experience was in the recent past, efforts can be made to mitigate the damage done.

Time versus priority. Some groups, such as daily-wage earners, have long working hours. For them, giving time to research may mean loss of wages for a few hours. The other commitments include looking after the family and children, daily household chores or travel plans (especially among home-makers and elderly). The convenience and availability of participants is of paramount importance. This needs to be addressed in scheduling of data collection activities.

COMMUNITY-BASED RESEARCH BY UNDERGRADUATE MEDICAL STUDENTS

As part of their training, undergraduate medical students undertake a simple community-based research study under the guidance of faculty members. This is usually a prevalence or KAP study. The primary purpose of this study is to teach students the steps in conducting research. While planning such a study, students learn to formulate objectives, undertake a review of scientific literature and develop an interview schedule to collect information. During fieldwork, they develop communication skills. After data collection, students undertake statistical analysis and present their results to the departmental faculty. The students are sensitized to ethical issues in research. The research studies conducted by medical students are also vulnerable to the various challenges described above. In addition, they have to undertake the study in the limited time available to them during their posting. Often, it is not possible for them to complete data collection from all selected participants, as per sample size estimation. The response rate may also be low, as they are unable to undertake multiple visits to the non-available participants. This is acceptable, as long as the students understand the importance and process of estimation of sample size, sample selection and adequate response rate. Inter-observer variation is an issue in such studies, as students undertake these studies in groups or batches. Adequate emphasis needs to be laid on training in the administration of interview schedule and taking measurements, as per the study protocol. Agreement studies may be undertaken. Quality assurance in data collection and data entry need to be highlighted.

CHALLENGES IN CREATING A PARTNERSHIP WITH A COMMUNITY

It takes years of service provision for a community to accept an institution and its members as its partner.[18] A health institution is particularly susceptible to defamation on occurrence of any untoward event; hence, continued maintenance of this partnership is as much of a challenge. Health problems and their determinants in the community are complex, and hence not well suited for outsider-driven research and interventions.[2] Community–institute synergy is required to undertake good quality community-based research. This partnership includes a relationship with the community leaders and the people of the community, and is necessary to identify and create alliances with other organizations and groups working in that area (voluntary agencies and faith-based groups). They can act as a bridge to people, help researchers to utilize community resources and engage with policy-makers. To enter into a partnership, researchers need to share views, agree about the goals and strategies, and have mutual trust and respect. Any imbalances of power should be addressed at the earliest, which would need good communication skills, empathy and flexibility. Identifying and starting a joint activity can be facilitated by frequent communication with the groups and organizations to build a partnership.[19]

To build a community partnership, it is necessary to include all stakeholders in the decision-making process and involve key community persons as co-investigators. However, sometimes, institutional guidelines allow only persons with a certain academic qualification to hold decision-making posts in research. The institutional policies should be revised towards a more democratic and participative approach.

ETHICAL ISSUES IN COMMUNITY RESEARCH

The ethics of community-based research are no different from those of institution-based research. There are 4 main principles in research ethics:[20]

1. Autonomy: respect for person/participant and their decisions
2. Beneficence: must benefit the participant
3. Non-maleficence: do no harm
4. Justice.

Community-based research, which involves engaging with people in their own homes on personal matters, has the potential to raise questions of intrusion and confidentiality. The voluntary nature of informed consent and questions about personal matters make it challenging for the researcher to get at the truth. A bond is also established between the researcher and the participants, which creates a moral dilemma while releasing sensitive information, for example, survival strategies in slums and streets.[9]

Once a good partnership has been built between an institution and the community, it is easy to use community-based research for individuals and institutes as a means for their own ends. Communities may be coerced, misled, over-searched and over-researched by the institutes.[21] A full ethical review becomes necessary to weed out such unethical practices. Sometimes, the results of a research may be subject to bias, and differences in interpretation. The results may have sensitive findings. In such cases, releasing the results might further stigmatize and marginalize the communities.[18]

CONCLUSION

Community-based research comes with its own set of challenges. The barriers and challenges arise at all stages, but scientific rigor is seldom compromised for feasibility if properly planned and undertaken. It serves as an entry point for young medical researchers to factor in social determinants, and learn few other soft skills in this process. Research may not be done in a controlled setting, with many external factors in play. However, it helps to integrate current knowledge in the local social context and is a fruitful way to pre-pilot public health programmes.

Conflicts of interest. None declared

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