

Qualitative research in public health

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There has been an explosion of qualitative research in public health over the 1980s and '90s. It has delved into a wide range of issues, from the most public to the most private, often relating to some of the most socially and culturally sensitive of subjects. It has wide and deep ramifications for approaches to health service development and for changing social perspectives. Yet there has been little discussion of its ethical dimensions. Many of the issues dealt with are socially contentious and therefore there is a need to develop mechanisms for resolving them in accordance with ethical principles [non-maleficence, beneficence, autonomy, confidentiality and justice as enunciated, for example, in the draft code of conduct for ethics in social sciences and health research (1)]. Avoiding addressing them at this stage may harm the cause of qualitative research in public health as well as the cause of public health itself. This note attempts to raise some of the general issues that have emerged from specific instances of conflict related to qualitative public health research. It should be read as a form of loud-thinking and an invitation to brainstorming.

While some basic rules of ethical conduct of medical research can be extended to social science research in public health, some specificities of the latter raise additional ethical issues. Biological safety is the first prerequisite of medical research. For example, the clinical trial of a drug must ensure that there is only a low acceptable level of risk of side-effects to the persons to whom it is administered. Shouldn't the same principle of non-maleficence be applied to the likely negative social impact?

Secondly, the well accepted ethical guidelines for medical research are based on a notion of rights of the individual, for instance 'ensuring confidentiality' of persons undergoing

a screening test such as that for HIV infection, or 'taking informed consent' for any experimental medical procedure from the individual undergoing it. This is logical because the individual patient is the unit for intervention in clinical medicine. But for public health where the 'total population' and its subgroups are the units for action and analysis, should the ethical principles not be applied at that level?

New rules of ethical conduct?

If we accept both these propositions it would mean that rules for ethical conduct of qualitative research should include the following:

- Data with socially negative connotations should be presented in a way that they do not stigmatise a specific community or group,
- Mechanisms should be evolved for obtaining informed consent from the group (and not only from individuals within it) after providing it with information about the objectives of the research and its possible negative consequences, and
- The likely negative impact of the research, and its findings, on social processes affecting the study population and its sub-groups should be considered.

The obvious question to be addressed for all these is, how do we assess the impact of the research on social processes?

An understanding of the context in which research is being undertaken is crucial to assess its probable impact. There are primarily two kinds of social science studies in health. There are those that are purely addressed to social science agendas and attempt to analyse social processes through health issues. The second kind, relating to public health programmes and policies (2,3), are addressed in this article. The agendas for such research are commonly linked to public health programmes in order to know how the particular population or community will respond to the pre-decided programme strategy, and how best to

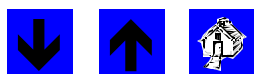
operationalise it.

Therefore, this qualitative health research has primarily focussed on (i) people's health-related behaviours (childcare and dietary practices, sanitation and hygiene, sexual behaviours, treatment seeking for illness, etc.), (ii) health-related perceptions (about the body and its functioning, illness and disease, preventive and curative measures, and the available treatment-providers and health care services), and (iii) health services research (structure and processes of institutional functioning, interaction between different categories of personnel, interaction of care-providers with lay people, etc.). Thus, public health programmes and policy agendas greatly influence the qualitative research, which can sometimes feed back and influence them in turn.

Qualitative research findings can be used for action within formal organised structures (as advocacy tools for policy and programme formulation, and for improving management of programmes and services). The health sector reforms of the 1990s illustrate this use of qualitative health research. They can also be used for socio-cultural intervention involving action in the 'community' for bringing about changes in knowledge, attitude and behaviour, through health education, community mobilisation for health issues or/and empowerment of socially weaker sections. This often implies questioning and changing existing social perspectives and values within the community and the health system. The action against gender disparities in recent years is an excellent illustration of this. The subject 'sexuality' is another such example but with less clarity and greater contention about the desirable directions of change. The worth and role of folk knowledge is also, similarly, a contended subject involving value positions on relationships between human beings and between them and nature.

The influence on social values and perspectives raises a set of ethical

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dilemmas because of the divergent views and interests that they represent at several levels. On the one hand is the notion of health as a product of people's social and economic context. (4, 5,6). On the other is the formal public health structure primarily shaped in the present by the biomedical paradigm of health and the technocratic approach to public health problems. This second perspective promotes the application of 'universal' strategies through centrally controlled, technology-based programmes which play down the significance of the social context of ill-health and health interventions (7). This involves a non-responsiveness to local context and priorities, and an inordinate power of the 'expert' and the international bureaucrat over 'lay people'. The failure of public health in the past has highlighted the negative consequences of such an approach (8).

Further, the local social disparities exist in the context of global politics and neo-imperialism. Within the study population or group that is often defined by geographic and administrative boundaries, there is diversity, for example, of caste, class and gender. Dominant sections within the community (upper caste and class, male) will favour perspectives that help maintain their superior status, and oppose social interventions that threaten their position. The 'universal' international strategies, with their liberal democratic perspective giving equal rights to each individual irrespective of gender, caste, class or race, are then more attractive than the communitarian approach (9). And the current dominant international development discourse promotes the liberal perspective, thereby gaining support of one section of progressive forces at the local level.

On the other hand is the context of international politics and the hegemony of the 'northern' perspectives on the policies of the 'southern', which creates the dilemma in accepting the international discourse as the desirable social perspective and value framework to which all communities and peoples must be channelised. In the current situation, significant determinants are the economic structural adjustment

policies (SAP) which bring with them ramifications in other spheres. According to one view, SAP create an environment that allows the dominating biomedical and technocratic paradigm of public health to make even greater inroads into southern countries (10). Others add to this analysis the understanding that SAP and technocratic programmes bring with them an aggressive cultural promotion of consumerism and individualism that are essential for establishing market mechanisms and breaking down local collectivities and social support structures. This results in economic, social and cultural degeneration of societies of 'the south'

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which breaks their self-confidence and weakens their ability to regenerate themselves, thereby further legitimising the dominance of 'the north'.

The negative social consequences of these processes are suffered most by the previously marginalised at both the international and local community levels. The international intervention and the neo-liberal perspective from which it draws its legitimacy is thereby a negative influence even for the marginalised. This is reflected in the sphere of public health as well (11, 12). Ironically, it is not within the individual rights framework that a fight is put up against this international hegemony. Collectives with a nationalist or community identity usually drive such agitations.

If we accept that this analysis of the current international impact is even partially valid, then we face a dilemma because there is no one perspective or value framework that we can consider 'the best' and use as a reference point for evaluating the impact of qualitative research on processes of social change.

Is it then ethically justifiable to

impose research from a certain perspective on a study group or community with a predominantly divergent perspective? But certainly this question cannot mean that researchers should not question community value positions. How do we resolve this?

We can turn to anthropology that has long dealt with the issue of diverse value frameworks for some methodological ways of dealing with this ethical problem. One is the whole debate of the emic (the 'insider' view) vs. the etic (the 'outsider' view). The emergent understanding (13) was:

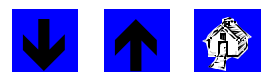
1) That the researcher cannot become an 'insider' but can attempt to understand the study group's worldview.

2) To do this the researcher must contextualise in great detail the collective process and the specific case studies and then interpret them in relation to the group's worldview, and

3) The researcher must not stand in judgement about the study group but only attempt to explain their behaviour and perceptions by understanding their logic.

A conceptual study design which allows contextualising of findings on a specific subject is important here. For instance, studies showing greater recourse to the private sector and services for payment even by the poor could be interpreted to justify user fees and promotion of the private sector because the treatment seeking was not placed in the context of the condition of the public sector or the degree of indebtedness of these groups due to spending for treatment. Similarly, analysing the sexual behaviour of those with multiple partners within the context of the norm of the whole group provides a very different perspective to the problem of AIDS from the high risk group approach espoused by the AIDS control programme. Analysing the factors leading to the norms can also provide directions for a more effective AIDS control strategy (14).

However, this alone has not been found to be adequate in safeguarding the study group's interests. Given the ramifications (of conflicting social values and perspectives as well as conflicting material and power



interests) related to the qualitative research in public health, three ethical issues arise —

1. How does the research represent the needs and views of the marginalised within the study group as against the dominant groups?

2. How does the research represent the needs and views of laypeople (which may include the community's dominant view but not the minority view within the community) as against the technocratic view?

3. How does the researcher mediate between the possible positive and negative consequences of the liberal technocratic perspective and of the study groups' perspective?

The basic issue would be the right of the community — and within it of the marginalised — to decide if they want to participate in such research, to be given information up front, and to be fed back the findings. This also requires ensuring an environment in which the study group feels free to call upon and articulate its own value positions.

In addition to the methodological solutions provided by the anthropological debate given above, some possible checks could be:

1. A self-critical assessment to see if the researcher's agenda and reference point is the local context or the international dominant discourse.

2. A mechanism for dialogue between the researchers and the community about objectives of the research, its findings and their interpretation of it.

This dialogue is the ingredient for finding the common ground of researcher perceptions and study group perceptions. It also allows the researcher and the study group to maintain their own value positions even while they examine them critically and may be even modify them. However, for this to occur there must be a respect for the others' value frame so that the exchange can occur on an equal footing. This may require a self-reflective exercise by the researcher.

The best way to really put all the above ethical requirements into practice may be by the researcher being in constant interaction with the group

over a long time in diverse situations. Acquire friends with whom to share laughter and tears, with whom to fight, and from whom to learn. Respect the collective wisdom of the community and yet debate with it. Such ethical research in public health would certainly be a demanding exercise but also a rewarding one.

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