

Ethics of health research priority setting

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Pecha Kucha presentation

Conducting high priority research in over-researched communities in Pakistan: the ethical burden

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Brief description of case study context

The case study, based on factual events, describes a series of health research projects, centered on malnutrition, conducted in three peri-urban fishing communities* in Sindh province of Pakistan over the past two decades. These communities have similar features including high rates of poverty, low literacy levels and poor health indicators. They are located near to the largest city in the country, Karachi, an urban mega center boasting a wide range of different tertiary care and specialized hospitals, both in the public and private sector. The proximity to Karachi makes these communities attractive locations for local researchers (both students and professionals) to conduct their research projects.

Malnutrition is a major health problem in Pakistan, contributing significantly to child morbidity and mortality.¹ The province of Sindh is severely affected; 48 percent of children under the age of five are stunted whereas 35 percent of them are severely stunted.²

Majority of the researches are funded by international funding agencies but with local collaborators. These collaborators in particular include one private sector university in Karachi.[†] Studies include, but are not limited to, clinical trials that seek to assess the efficacy of multivitamins and other nutritional supplements to boost maternal health with the objective to improve infant health outcomes.

Ethical issues

Criteria and goals

It can be argued that malnutrition poses a major health problem in Pakistan and is therefore an important health priority. However, there are increasing concerns that despite several years of research being conducted in similar locations, limited health improvements have occurred.^{3 4} Rates of malnutrition continue to remain high but studies continue to be funded, with grants being allocated consistently to the same researchers and institutions who have worked in the field for decades. Therefore, this raises the ethical issue of balancing benefits or outcomes of research with general health inequities. Arguments can be made whether more research should be focused on improving the health systems as opposed to funding clinical trials which will generate similar data, study after study, but without any discernible improvement in lives of these communities.

* Names not mentioned for purposes of anonymity.

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While provincial governments and respective health departments are primarily held responsible for improving health outcomes, researchers working in the field for decades and benefitting tremendously cannot abstain from their own obligations towards the people they work with. The issue is also compounded when researchers operate in a vacuum and do not engage with pertinent stakeholders include those at the governmental level. The reasons for those are multifactorial including governmental apathy as well as lack of activism.

Global and local

Another ethical issue that arises is the problem of over-researched communities who have received limited benefit from research inputs conducted on them for more than two decades. Despite malnutrition being such a rampant problem in other districts of Sindh province, research projects continue to be carried out in these communities due to ease of access. It is laughingly remarked that “English speaking researchers in the private university can make a day trip to these communities and be back in time for dinner in their air conditioned dining halls” thereby representing a post-colonial legacy that underpins many research efforts at the global level. This also represents the issue of domestic injustice—the voices of communities may not be given priority even when research is carried out by local partners. Without any substantial improvement in their health outcomes, these communities appear to being used merely as a means to an end by local researchers and global funders.

Governance

It is often the same individuals or institutions that win the grants on the similar research agendas possibly reflecting a biased allocation of resources. While the institutes and their researchers have made immense strides in delivering quality healthcare, and are funded on merit, the issue remains. The prime goal of health equity remains unaccounted for. This issue raises a broader question: Should international funding agencies stress upon the importance of implementation research as well as health systems research that address governance structures? In this area, it is also important that local researchers have the required training in not only technical skills of research but also professional skills that include competencies in communication, teamwork and mentoring, leadership, mediation/negotiation and policy engagement. The latter are often left to international researchers.

Another flaw in governance structures particularly in LMICs is the weak regulatory system both at the institutional level as well as the national level. These include Ethical Review Committees (ERCs) that approve researches being conducted in over-researched communities thereby leading to a cycle of exploitation of vulnerable marginalized communities. Research committee reviewers at the national level also have the broader responsibility to ensure that the research translates not only into policies but implementation at the grass-root level. This may require them to inquiry about plans for stakeholder engagement (including communities and government) in ethics application forms.

Conclusions and recommendations

What this case study describes is a form of post-colonial mindset that local collaborators have imbibed over the years with only lip service being given to the voices that actually matter—those of mothers who are generally research participants in these studies, and the community in general, whose lives are affected tremendously.

On a broader scale, while malnutrition poses a major public health and socioeconomic problem, the ways to address this problem have been flawed. Local researchers should negotiate with international funding agencies to address social determinants of health by conducting health systems research and

implementation research. At the regulatory level, reviewers of research proposals should, as a bare minimum, ask for strong justifications for conducting studies at a specific study site, and raise relevant flags if research is being conducted in same communities repeatedly.

In addition, since many private companies make huge amounts of profit through drugs tested through clinical trials in such populations, community and research leaders should negotiate better healthcare interventions including post trials access which often times are not provided, or if available in the market, remain beyond the financial reach of these populations.

References

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