Book

Bridging the theory–practice gap in global health research

Transnational health research in low-income countries (LICs) has transformed not only our knowledge of the causes and effects of ill health, but also health itself. Malaria mortality, for example, has more than halved since 2000. Research showing the benefits of insecticide-treated bednets, indoor residual spraying, and artemisinin-based combination therapy was fundamental to the progress made. HIV infections in children have fallen by about 60% since 2009. Research into the prevention of mother-to-child transmission of HIV showed how such improvements could be achieved. Infant mortality has halved since 1990, in large part thanks to research done in LICs that showed the benefits of oral rehydration therapy, breastfeeding, multiple micronutrient supplementation, vaccination programmes, and other medical and public health measures.

LICs have benefited from these advances, but the rewards for those individuals whose participation was crucial to the success of research studies have not always been obvious. While researchers earn promotions on the back of successful studies, research participants continue to live in poverty long after projects have finished. Those whose lives have been prolonged by free health care provided as an incentive for involvement in a trial are left high and dry once studies are complete. Local researchers may help impoverished study participants out of their own pockets, while some of their more well educated, less well-off, and less healthy than the people who design the studies. Members of transnational research teams differ widely in their knowledge, expectations, and reasons for involvement. The local and national government officials whose approval is needed for a project to proceed are often motivated by private rather than public concerns. The gap between international guidelines and on the ground realities can be vast.

A plethora of regulations and research guidelines have been designed to address the broad ethical dilemmas inherent in transnational medical and public health research. Individual studies, moreover, can go ahead only after they have been reviewed by research institutions’ and sometimes governments’ ethics advisory boards. But research on the ground is a less predictable affair than international guidelines reflect, the process of interacting with individual people messier and more complex. No overarching framework could possibly cover the multitude of ethical questions and dilemmas faced by research teams and those who sponsor them—not even, as Gemma Aellah, Tracey Chantler, and P Wenzel Geissler highlight in Global Health Research in an Unequal World: Ethics Case Studies from Africa, advisory boards with extensive on the ground experience. In LICs the process can be even more complex. Research participants are often less well educated, less well-off, and less healthy than the people who design the studies. Members of transnational research teams differ widely in their knowledge, expectations, and reasons for involvement. The local and national government officials whose approval is needed for a project to proceed are often motivated by private rather than public concerns. The gap between international guidelines and on the ground realities can be vast.

Aellah and her co-authors’ book is an attempt to bridge this gap. The authors are anthropologists, who have spent a decade observing the minutiae of health research studies in homes and health facilities in the villages, towns, and cities of Africa. They use 42 fictionalised case studies, based on real experiences, of ethical dilemmas they have witnessed to encourage those involved in transnational research to reflect more deeply on the ethical questions their work throws up. They look not only at the relationships between researchers and study participants, but also at the involvement of communities, families, and public sector institutions, and at interactions between research staff.

The case studies, each of which is accompanied by a list of questions for discussion, cover an impressive array of topics, from informed consent in contexts of high illiteracy, to public officials asking for family members to be given jobs by research centres, to the question of incentives for participation. No issue is shirked: westerners’ higher pay and more luxurious living conditions; African participants lying to remain in a study; and the responsibility of researchers for the health of the wider community. The question of whether research is more important than participants’ health—or in some cases their lives—underlies several cases.

The book is designed as a training tool for those involved in transnational medical and health research. It raises so many difficult questions that the reader can easily become frustrated at the complexity of it all. In one instance, a research team had to decide whether to provide treatment to a participant they realised had epilepsy (a stigmatised condition in some parts of Africa) and the authors report that after hours of discussion the team could not find a satisfactory solution. It is difficult to dispel a sense of futility as you make your way through the case studies, and the inclusion of a few suggested solutions might have helped allay such pessimism. But the difficulties of conducting research in an ethical way should not deter researchers from engaging with it, and this challenging, uncomfortable book is a must-read for all of us who work in global health.

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