

Editing and Publishing Humanitarian Medical Research for Doctors Without Borders/ Médecins Sans Frontières

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Introduction: Research in Medical Humanitarian Emergencies

In December 2008, the World Health Organization declared a cholera outbreak emergency in Zimbabwe, a country in political and economic turmoil whose health-care system has all but collapsed. As of June 2009, more than 4,000 people had died and close to 100,000 cases had been reported. In response to the crisis, the international medical humanitarian organization Doctors Without Borders/Médecins Sans Frontières (MSF) (www.doctorswithoutborders.org) provided treatment to those affected. Roughly two-thirds of the cholera cases in this outbreak were treated by MSF.

This emergency is one of many that MSF has responded to in recent years. Others include a meningitis outbreak in Nigeria this year, civilian trauma in the civil war in Sri Lanka, sexual violence in the Democratic Republic of Congo, and severe malnutrition in Niger. Founded in 1971, MSF operates in more than 70 countries to provide emergency life-saving care to those endangered by violence, disaster, or neglect. MSF is based on the humanitarian principles of medical ethics, impartiality, and independence; it assists people who are adversely affected by armed conflict, epidemics, malnutrition, natural disasters, or exclusion from health care, and it often speaks out publicly to bring attention to vulnerable populations and neglected health crises.

MSF's health-care programs span the globe, providing medical support where others are not working. The programs

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Patients in the Oromiya region of Ethiopia, August 2008, where Doctors Without Borders/Médecins Sans Frontières carried out an emergency intervention to treat malnutrition. © ALICE DAVIES/MSF

generate medical data on patient populations typically neglected by the health-care community. Some of these unique data are analyzed, organized, and published in the scientific literature, and MSF strives to increase dissemination of its medical-program results to researchers, policy makers, and the general public.

Because of the contexts in which MSF works, it is inherently difficult to collect high-quality data for peer-reviewed publication, and strategies to solve this problem have included increasing capacity for scientific editing and writing. The position of medical editor was created in the US section of MSF, and I became the first medical editor for MSF-USA in 2007. I will describe here the important role of medical research in MSF and how MSF shares its data, experiences, and knowledge to support and improve medical care in resource-limited settings.

Both Sides of Journal Publishing

I joined MSF in April 2007. My background is in science; I studied microbiology and neuroscience in college at the University of California, Los Angeles, and genetics in graduate school at Columbia University. After receiving a master's degree in 1997, I answered a classified ad in *Science* magazine and obtained an entry-level editing position at a medical-communications company in Hackensack, NJ, where I worked on scientific articles, abstracts, posters, slide kits, and other technical literature for the pharmaceutical and biotechnology industries. I remember being handed my first-ever sheet of proofreading marks and was instantly smitten by all the symbols, squiggles, and curlicues. It was like learning a secret code, albeit one used by editors the world over.

After 5+ years of editing biomedical manuscripts at that company and a similar firm in New York, I moved to Washington, DC, to head the communications office

of the multidisciplinary scientific journal *Proceedings of the National Academy of Sciences of the United States of America* (PNAS). At PNAS, I learned the ins and outs of scientific, technical, and medical (STM) publishing and gained an appreciation of the rigors, difficulties, and joys (yes, there are some) of peer review and journal publishing. I selected articles for media promotion and highlighting in the journal and commissioned and edited feature articles.

After 2.5 years at PNAS, I moved back to New York to join MSF. My primary goal at MSF has been to increase the dissemination of field research to medical and other specialized audiences, particularly in the United States, through peer-reviewed journal publications, conferences, and special events. However, the duties are flexible and continually adjusted on the basis of MSF's needs and strategies.

Medical Priorities, Operational Research

The concept of "humanitarian medicine", a somewhat redundant (or perhaps even meaningless) term, drives much of MSF's actions in the field. MSF field programs include general health care for refugees and internally displaced persons; treatment and prevention of HIV/AIDS, tuberculosis (TB), and malaria (including coinfections of these "big three" diseases); control of infectious-disease outbreaks, such as those of cholera, measles, and meningitis; diagnosis and treatment of neglected diseases, including visceral leishmaniasis (kala azar), human African trypanosomiasis (sleeping sickness), and Chagas disease; malnutrition interventions; vaccination campaigns; mental-health care; treatment and counseling for victims of sexual violence; surgical procedures, including advanced orthopedic trauma operations; and natural-disaster relief.

Data from the medical programs vary greatly in type, quality, and value. The myriad types of programmatic data include patient demographics; patient outcomes, such as cure rates, mortality, and loss to follow-up; immunologic and virologic out-

comes of therapies; specificity and sensitivity of rapid diagnostic tests; drug-related adverse events; lengths of hospital stays; mental-health assessments; direct and indirect costs—the list goes on.

Why does MSF conduct research at all? Simply put, research is done to support and advance our medical field work. The immediate goals of performing research, analyzing data, and publishing peer-reviewed findings include rigorous evaluation of our medical programs to assess effectiveness and ensure acceptable quality of care for our patients, generation of credible data to bolster our advocacy, and sharing of results to support policy change and inform the work of others, including local and national health authorities. Regarding advocacy and policy, conducting and publishing research also provide reliable data for supporting the objectives of MSF's Campaign for Access to Essential Medicines (www.accessmed-msf.org) and the Drugs for Neglected Diseases initiative (www.dndi.org).

Research thus has high priority in MSF, as evidenced by the creation of Epicentre in 1987. Epicentre, the epidemiology and research arm of MSF, was founded to bolster our field practices through operational research (research conducted specifically in, or on, our medical programs) and dedicated data-analysis support. When they are feasible and in line with field priorities, operational research trials may be set up in MSF programs after ethical review and approval. Epicentre marked its 20th anniversary with a commentary published last year in *PLoS Medicine*, reviewing its experience in conducting research in complex humanitarian emergencies.¹

Examples of recently published MSF operational research include a randomized controlled trial in Uganda on fractional dosing (using smaller than the licensed dose) of a meningitis vaccine in cases of massive shortages during epidemics,² a study comparing the TB-diagnostic technique of sputum microscopy after bleach sedimentation with conventional direct smear microscopy in a setting of high HIV prevalence in Kenya,³ and a random-

ized trial assessing the effect of preventive supplementation with ready-to-use therapeutic foods in young children in Niger, where access to sufficient nutritious food is a chronic problem.⁴

MSF's medical priorities for the near future are nutrition and vaccination, without, of course, taking away from MSF's continuing medical programs and emergency responses. MSF programs will include increased integration of nutrition and vaccination components into the care provided, and this will probably result in further opportunities for operational research and generation of medical data for peer review.

MSF in the Scientific Literature

MSF published more than 50 peer-reviewed research articles in 2008 and more than 175 in 2006–2008. The largest proportion of the articles were on HIV/AIDS, followed by malaria. Other MSF research-publication topics include TB, visceral leishmaniasis, sleeping sickness, meningitis, measles, hemorrhagic fevers, mental health, and malnutrition. With respect to TB, drug-resistant TB and HIV-TB coinfection were topics of research articles over the last few years, and these disease conditions continue to be of concern in the field. Technical topics included diagnostics, vaccines, and surveys (for example, on mortality, nutrition, and epidemics). The wide breadth of research topics gives a good overview of the different medical areas in which MSF works.

MSF scientific articles have been published in various STM journals, from such well-known general medical publications as the *Journal of the American Medical Association*,⁴ *BMJ*,⁵ and the *Lancet*⁶ to such specialized journals as *Conflict and Health*,⁷ *Emerging Infectious Diseases*,⁸ and the *Journal of Tropical Pediatrics*.⁹ Most articles are available at the MSF Field Research Web site (fieldresearch.msf.org/msf), launched in May 2008. The Field Research site acts as a clearinghouse of sorts, providing free public access to the full text of all MSF research and commentary articles.

Editing and Publishing continued

MSF publications in STM journals, especially high-profile ones, are few and far between compared with the output of Western academe. Although MSF faces challenges similar to those of other academic researchers in publishing findings, we and other aid organizations have an arguably more difficult path to publication owing to the emergency and resource-constrained contexts in which we work. Data from our programs tend to be descriptive, observational, and retrospective in nature since we rarely have the luxury of setting up tightly controlled prospective trials with blinding or randomization. In the conflict, disaster, and resource-poor settings where we work, setting up controlled, comparative studies is often impossible, especially when more basic concerns take precedence, such as security, shelter, sanitation, food, medical supplies, trained staff, and ethical issues.

In addition to journal articles, MSF often presents medical findings from its field programs at scientific conferences. This avenue of data dissemination is another important means for sharing our programmatic results with the medical community at large. In the last year, MSF has had oral presentations and scientific posters at the International AIDS Conference, the Conference on Retroviruses and Opportunistic Infections, the Union World Conference on Lung Health, and the American Society for Tropical Medicine and Hygiene annual meeting.

Medical Research as *Témoignage*

One of the basic tenets of MSF's philosophy is *témoignage*, a French word roughly trans-

lating into "bearing witness". MSF often bears witness to the inequalities, abuse, or neglect suffered by various populations and speaks out publicly to draw attention to these crises. This act of speaking out is what has traditionally separated MSF from other neutral-party aid organizations, such as the Red Cross or United Nations agencies.

Disseminating data and research findings from our medical programs may also be considered a form of *témoignage*, where we bear witness to the suffering of specific patient populations, whether a person coinfecting with TB and HIV, a mother with cholera, or a severely malnourished child. Presenting and discussing their medical ailments and treatment outcomes in a peer-reviewed format can help us to speak out credibly on their predicaments and suggest solutions to ease suffering and save lives. Peer-reviewed data can be used to both frame and bolster such *témoignage*. Through medical research from complex humanitarian emergencies and resource-limited settings, we and others may more readily help those who are not able to help themselves. 🕯

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