Volunteering Overseas — Lessons from Surgical Brigades

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Dr. Mark Migliori's approach to international surgical care is minimalist. With another surgeon, two anesthesiologists, and two or three nurses, he travels to a rural hospital in Guatemala. The group evaluates dozens of children from the surrounding villages whom local health care workers have identified as potential candidates for surgery — primarily the repair of cleft lips and palates. Each surgeon operates on as many as 15 children each day with the use of local hospital equipment augmented with supplies brought from home. When they leave, local health care workers provide follow-up care, consulting with Migliori by e-mail as necessary. Migliori has made such trips twice a year since 1993, leaving his Minneapolis practice to serve patients who normally face insurmountable financial or geographic barriers to surgical care. The budget for such a visit is less than $10,000.

Dr. Randy Sherman's trip to Brazil in 2004 as a volunteer for Operation Smile, an international organization that also repairs facial clefts, was vastly different. By the time Sherman arrived in the northeastern city of Fortaléza at the helm of a 33-person team, a group had been there for a week evaluating potential patients and readying the anesthesia and surgical equipment that the organization had shipped. During the following week, the group performed 125 cleft repairs and conducted an intensive educational program for local doctors and nurses. When Sherman and his colleagues departed, postoperative care was provided by an Operation Smile team that remained behind for several more days. The cost of such a mission can run as high as $1 million.

Every year, thousands of physicians like Migliori and Sherman travel to developing countries, with stays ranging from several days to several months, to volunteer their skills and knowledge. Some travel in loosely organized groups; others volunteer for organizations such as Operation Smile, Orbis, and Médecins sans Frontières that have an ongoing presence in many countries. Volunteers may focus on direct patient care, medical education, public health promotion, or improvement of the health care infrastructure. Some groups are secular, whereas others are coordinated by religious organizations, and their work may include an element of proselytizing. But whatever their affiliations, volunteers wrestle with a core set of challenges that distinguish overseas medical work from their usual clinical routine.

First, there is a preoccupation with avoiding complications that may arise from working with unfamiliar colleagues in a foreign setting and caring for patients who speak a different language and may never have seen a doctor before. Most volunteer surgeons simply steer clear of cases that carry a high risk of complications or a protracted recovery. Complications that do occur are often attributable to insufficient screening of patients or inadequate follow-up, so large organizations send an advance screening team and leave a group behind to provide follow-up care. Even so, a study of anesthesia care provided by Operation Smile volunteers found that although the complication rate associated with facial-cleft surgery in the field was similar to rates in developed countries, the brevity of missions may contribute to avoidable illness and death.[1] For smaller groups that cannot provide extended care, the challenge is to develop strong ties with local physicians who can offer postoperative continuity.

Migliori learned how perilous volunteer surgery can be when a Guatemalan boy who was referred for hernia repair had cardiopulmonary decompensation on induction of anesthesia. The boy, who had undergone a preoperative workup by Migliori's team, could not be intubated and developed flash pulmonary edema. The surgery was canceled, and the team struggled through the night to support the boy in a makeshift intensive care unit. In the morning, they transferred him to a university medical center in Guatemala City, where he died. "We don't know exactly what happened," Migliori recalled, "but we clearly tipped him over the edge."

Complications may be inevitable, but when they affect a poor patient in a developing country who is being treated by a volunteer physician, the situation can be politically as well as emotionally charged. Operation Smile volunteers have been accused by local surgeons of "dumping" their complications when their mission is over, though the organization refutes this charge.

Some countries have regula-

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tions designed to encourage continuity of care when visiting providers go home. El Salvador, for example, requires that visiting physicians be hosted by a local institution that can provide follow-up care. But many countries do not have the necessary infrastructure for monitoring volunteers or even for enforcing their own regulations.

Volunteer organizations also frequently struggle to balance direct patient care with medical education. "Initially, we went out and did surgery," said Dr. Robert Rubin, chief medical officer of Operation Smile. "But after a while, it became obvious that going to a country and doing 100 or 200 cases each year wasn't going to solve the problem." The organization's investment in education includes the planned involvement of local physicians in operations, depending on their interest and skills, as well as the involvement of local nurses in preoperative and postoperative care. The group also brings 60 physicians each year from developing countries to its headquarters in Norfolk, Virginia, for surgical training.

Orbis, an international eye-health group, is a volunteer organization that makes education central to its mission. Orbis launched its first program in 1982, in the form of a DC-8 airplane outfitted with an operating room. The plane traveled to developing countries, where ophthalmologists trained their local counterparts in various surgical procedures. Since then, Orbis has established ongoing programs in five countries and conducts short-term training missions elsewhere.

Not every underserved region presents an educational opportunity, however, as Migliori has discovered. "I love to teach surgeons in the area what we do," he said. "But in some areas, there is no one there to learn. You have to recognize that every area is different."

These differences — in the medical needs of populations, the skills of local health care providers, and the level of interest in international collaboration — present a challenge to volunteer organizations, particularly if they send volunteers for short periods. "There is a need for people who can volunteer for a few weeks, especially if you can coordinate with others," said Dr. Gilbert Burnham, who directs the Center for Refugee and Disaster Response at the Johns Hopkins School of Hygiene and Public Health and worked for 15 years as an internist in mission hospitals in Africa. "But the real impact is made by people who are able to stay in a place for years on end. In my own experience, it took a year to really understand what was going on in a cultural and social context."

Surgery at a Rural Hospital in Guatemala.

Mark Migliori performs a cleft-lip repair, with help from surgical assistant Jeanne Prin-Wyatt.

Burnham's concern is echoed by other critics of medical volunteerism, who charge international volunteers with providing substandard care and squandering millions of dollars that could be put to better use by local authorities. "I have seen professors from fancy American universities teaching endoscopy skills in Laos to internists who don't have access to an endoscope," said Dr. Christian Dupuis, a Belgian plastic surgeon who has volunteered in Southeast Asia for two months each year since the 1970s.[2]

Hundreds of organizations provide medical and public health services around the world; they include religious organizations, relief groups, United Nations affiliates, and military health brigades. One of the most visible U.S. physicians, Senate Majority Leader Bill Frist (R-Tenn.), travels to Africa annually to participate in medical volunteer work. But although many groups collaborate with one another and with host governments, there is no formal system for coordinat-

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ing or evaluating the work of so many volunteers.

Some organizations conduct internal evaluations, and they tend to agree with experienced volunteers on some guidelines for effective overseas missions. It is best, they say, to send an advance team so that requirements such as lodging, an adequate electrical supply, clinic space, and surgical facilities can be anticipated. Many stress the importance of developing strong relationships with local physicians on the basis of respect for their skills, knowledge, and traditions and, whenever possible, using locally available medications. Surgeons recommend a conservative approach to choosing patients and operations to perform. Finally, says Migliori, "don't operate the day before you leave."

An interview with Dr. Mark Migliori can be heard at www.nejm.org.

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FOCUS ON RESEARCH

Adopting Orphan Drugs — Two Dozen Years of Treating Rare Diseases

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In 1982, when the Orphan Drug Act was passed as an amendment to the Federal Food, Drug, and Cosmetic Act,[1] few suspected the extent to which this law would alleviate the plight of patients with rare diseases. The law defines an orphan drug as one with efficacy against a disease affecting fewer than 200,000 people in the United States or one that scientists and economists at the Food and Drug Administration (FDA) determine will not be profitable for seven years after FDA approval.[2] In the 24 years since this law was passed, 282 such drugs and biologic products, providing treatment for more than 14 million patients in the United States, have come to market under its aegis. In the 8 to 10 years before 1982, by contrast, only 10 treatments for rare diseases had been approved by the FDA and brought to market.

Much has been learned about rare diseases in the United States since the passage of the law. Of the orphan drugs that have been approved, 56 percent are for chronic diseases. Examples include ovine digoxin immune Fab (Digibind) for the treatment of life-threatening digitalis intoxication; ceramide trihexosidase–α-galactosidase A (Fabrazyme) for the treatment of Fabry's disease, a lipid-storage disorder; and nitisinone (Orfadin) for the treatment of type 1 tyrosinemia, a metabolic disorder caused by the lack of the enzyme fumarylacetoacetate hydrolyase, which, if left untreated, results in hepatic carcinoma, often before four years of age.

Many rare diseases have a genetic component, and the patients who have them require treatment throughout their lives. Many cancers are also quite rare, and a number of drugs for cancer have been developed under the Orphan Drug Act (see graph) — for example, imatinib (Gleevec) for chronic myelogenous leukemia and gastrointestinal stromal tumors, tretinoin (Vesanoid) for acute promyelocytic leukemia, and ifosfamide (Ifex) for testicular cancer. A substantial proportion of the drugs in development are for use in children; for example, somatrem for injection (Protropin) has been developed to treat congenital growth hormone deficiency. Although most rare diseases are chronic, a number — such as infant botulism, discussed by Arnon et al. in this issue of the *Journal* (pages 462–471) — are acute.

Whether a disease is rare or common, however, the discovery, development, and clinical testing of a drug that can treat it represent a long, arduous, and expensive process. Drug companies are therefore loath to invest in a product for a disease that affects relatively few people unless they can be assured of a return on their investment. The Orphan Drug Act created government incentives to encourage academic researchers to participate in research on drugs for the treatment of rare diseases and to encourage the pharmaceutical industry to invest in the development and marketing of such drugs. Under this law, a

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