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Humanitarian ventures or 'fistula tourism?': the ethical perils of pelvic surgery in the developing world

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Abstract The vesico-vaginal fistula from prolonged obstructed labor has become a rarity in the industrialized West but still continues to afflict millions of women in impoverished Third World countries. As awareness of this problem has grown more widespread, increasing numbers of American and European surgeons are volunteering to go on short-term medical mission trips to perform fistula repair operations in African and Asian countries. Although motivated by genuine humanitarian concerns, such projects may serve to promote 'fistula tourism' rather than significant improvements in the medical infrastructure of the countries where these problems exist. This article raises practical and ethical questions that ought to be asked about 'fistula trips' of this kind, and suggests strategies to help insure that unintended harm does not result from such projects. The importance of accurate data collection, thoughtful study design, critical ethical oversight, logistical and financial support systems, and the importance of nurturing local capacity are stressed. The most critical elements in the development of successful programs for treating obstetric vesico-vaginal fistulas are a commitment to developing holistic approaches that meet the multifaceted needs of the fistula victim and identifying and supporting a 'fistula champion' who can provide passionate advocacy for these women at the local level to sustain the momentum necessary to make long-term success a reality for such programs.
Brief Summary: To avoid becoming ‘fistula tourists,’ short-term expatriate surgical volunteers need special training and should work only in environments that facilitate long-term institutional development.

Vesico-vaginal fistulas from prolonged obstructed labor no longer occur in the industrialized countries of Western Europe and English-speaking North America, but they are sad realities of daily life for millions of women in the impoverished countries of sub-Saharan Africa, South Asia, and Oceania [1]. The late Dr. Reginald Hamlin who, along with his wife Catherine, founded the world-renowned Addis Ababa Fistula Hospital in Ethiopia, coined the term ‘fistula tourism’ to refer to the phenomenon of doctors from medically advanced countries taking a ‘busman’s holiday’ in the developing world to try their hands at fistula repair, thereafter returning home well stocked with clinical tales with which to amaze their colleagues, but leaving a medical legacy of dubious value behind them in the places where their surgical sightseeing took place. The number of ‘humanitarian ventures’ organized by well-meaning gynecologists and urologists who set off for impoverished parts of Africa to “repair fistulas” is increasing. On the surface, this appears to be an unqualified good; but there is also a darker side to these sorts of activity which are rarely remarked upon in either the popular press or in medical journals.

Surgeons who wish to do fistula surgery in impoverished countries must first recognize what an obstetric fistula is, and what it is not. The post-hysterectomy vesico-vaginal fistula encountered in Europe or North America is completely different from an obstetric fistula due to prolonged obstructed labor. The former originates in a discrete injury to otherwise healthy tissue, but the fistula from prolonged obstructed labor is a different matter altogether. In these cases, broad swaths of vaginal tissue are crushed between the bony plates formed by the fetal head and the pelvic bones for prolonged periods of time. After 3 or 4 days of unrelieved labor of this kind, the extent of pressure necrosis that occurs is often breathtaking. The fistula that develops in such cases is often extensive, complex, and situated in a mass of rock-hard scar tissue, and the affected woman may have other extensive co-morbidities as well. [2].

Western surgeons are ill-prepared to deal with fistulas of this kind, particularly in settings where resources are scarce and surgical supplies are unpredictable. Attaining a skill in obstetric vesico-vaginal fistula repair requires long exposure under the guiding hand of a seasoned surgical veteran, perseverance, ingenuity, and both the common sense to know when operating is not in the best interests of the patient and the moral integrity to act on this knowledge. The first rule of medical practice since the days of Hippocrates has been primum non nocere—first of all, do no harm. It is easy for neophyte surgeons who have traveled to exotic settings and are confronted with unfamiliar pathology without the normal surgical support systems to which they are accustomed to make bad, sometimes tragic, clinical decisions. The tendency to put one’s surgical ego first and the best interests of the patient second must be resisted at all costs. With this in mind, we would emphasize the following points for those who wish to travel to Africa or other impoverished parts of the world to do fistula surgery.

You are not useful until you have been trained. Although you may be an “expert” surgeon in your home country, nevertheless, you need to get practical, supervised experience in the special problems presented by obstetric fistulas before undertaking volunteer work of this kind. There is no place for untrained fistula surgeons who set out on their own to learn repair techniques by
trial and error.

Getting appropriate training is not easy. Centers that do large volumes of fistula surgery have a prima facie ethical obligation to use their resources to train local surgeons who feel a passion for the plight of the fistula patient and who will continue to work in areas where the need for fistula surgery is greatest. Thereafter, such centers need to train volunteers from overseas who are making long-term commitments to serve in medically deprived parts of the world. Giving somebody “experience” in fistula surgery for their own personal edification or to “round out their fellowship” is not why such centers exist. When the first go out, volunteers should be prepared to work as assistants for a local surgeon until they “learn the ropes.” No one would be granted hospital operating privileges for new procedures at home until they had done this. Do African women deserve less?

Remember that women with obstetric fistulas are human beings and that they must be respected as such. Most Western volunteers who travel abroad to do fistula surgery will be interacting with poor women of a different race who are largely illiterate, who speak a completely foreign non-European language, who have been traumatized psychologically by the ordeal of prolonged obstructed labor, and who often come from remote rural settings. The cultural and educational gap between these women and visiting Western surgeons (who may never have been to these parts of the world before) is enormous. It is easy to fall into the trap of thinking that the normal rules do not apply here. They do. As a doctor, you are obligated to respect the integrity and worthiness of each individual who comes under your care. These women are more than “surgical work objects.” Patients must always be treated as ends in themselves, not means to another end (such as racking up a big number of fistula repairs for the gratification of your own ego or “doing a really great case”).

You have a moral obligation as a surgeon to insure that your patients receive appropriate postoperative care. It is unethical to leave the country right after you have done surgery if you have not made sure that all of your patients will receive adequate post-operative nursing care. It is unethical to perform complicated reconstructive operations only to have them fall apart because patients do not receive appropriate ongoing attention after you have gone. You must provide continuity of care and this includes developing a viable surgical back-up plan in case late complications develop. These are very serious ethical issues for would-be “fistula tourists” and they are especially troubling in cases in which patients have been subjected to complex procedures with known long-term complications, such as urinary diversion.

Bear in mind that fistula patients represent a particularly vulnerable population. For the most part (but certainly not exclusively) [3], they are young women (typically under the age of 20, sometimes as young as 12 or 13) who have suffered catastrophic obstetric complications through no fault of their own. Blameless themselves, they have nonetheless often have been rejected by their families, divorced by their husbands, mistreated by their communities, and stigmatized in almost incomprehensible ways [4–7]. They need compassion, but they also need money. These patients are usually destitute. They cannot afford to buy supplies or pay hospital charges and surgeon’s fees. Volunteer surgeons should be prepared to cover all of the costs of care for the women whom they operate on, particularly when they first go out as “learners.” More to the point, in the absence of reliable sources of funding to support fistula repair programs on a long-term basis, it can be questioned if short-term volunteer programs really make any meaningful impact. Perhaps, the money expended on such trips could be better spent on other projects, such
as building up the local infrastructure to the level needed to sustain an ongoing effort at fistula eradication. The development of durable institutional structures is a more pressing priority than pleasing visiting surgeons.

Short-term visitors to settings where fistulas are problematic also need to curb their appetite for surgical innovation. Operations appropriate for the industrialized world might not be suited to an impoverished tropical country. This is especially true when radical solutions such as permanent urinary diversion are proposed for complex fistulas. It is absolutely imperative that innovative surgical approaches to the special problems posed by fistula patients are scrutinized carefully before they are put into effect. This requires two things.

First, because good surgical ethics ultimately rests on good clinical science, any "new" ideas that are to be tried out on fistula patients must be evaluated according to universally valid principles of clinical study design. Endpoints should be specified in advance, data should be collected prospectively, studies should be properly powered to actually show the differences in treatment outcomes that are expected, and the data should be analyzed carefully to insure that the proposed innovation really is beneficial to fistula patients.

Second, innovations should not be introduced without appropriate ethical review. Surgeons who travel from abroad with a 'new idea' to try out should be prepared to submit their ideas to formal scrutiny by an ethical review board both at the local hospital where they intend to operate as well as in their home countries. If the proposal does not meet basic ethical standards, it should not be carried out. Thoughtful local oversight of schemes proposed by visiting surgical teams is imperative to prevent possible abuses of patients. Unfortunately, the administrative infrastructure to do this is often rudimentary in Third World settings. Medical journals that accept articles describing new operations from impoverished tropical countries should require proof that an ethical approval for the introduction of such innovations has been obtained in advance of beginning the study. In all cases, it is imperative that patients undergoing innovative operations give their informed consent prior to surgery. This requires the intimate involvement of knowledgeable persons who can speak local languages fluently and who are culturally competent to address issues that may never have occurred to visiting outsiders. For example, in parts of the world where ostomy supplies are virtually non-existent, a urinary diversion merely relocates a fistula to a different part of the body, and the body image that results from such operations may be even more devastating to the affected woman than the original injury [8]. If the operation is completely new and unproven, has it been tried in an animal model first? If not, why not?

Experienced surgeons can learn the basics of fistula repair fairly quickly, if they are given appropriate instruction and supervision [9], but the acquisition of real skill in such matters takes time. The most important prognostic factors for successful surgical outcome appear to be (1) the degree of scar tissue present in the operative field and the accessibility of the fistula, (2) whether or not the continence mechanisms of the bladder neck and urethra have been involved in the fistula, and (3) the size of the fistula and the amount of viable bladder tissue that remains for surgical reconstruction at the time of fistula closure. Neophyte fistula surgeons should confine themselves to cases appropriate to their level of skill until they have accumulated significant experience in fistula repair. This means that most volunteers need to limit themselves to the repair of accessible fistulas occurring in minimally scarred operative fields so that the prognosis for success is favorable. Catastrophic fistulas in which the vagina has been obliterated, in which the bladder has largely been destroyed, in which the urethra is gone, or that require complex

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reconstructive operations requiring urinary diversion, multiple complicated flaps and grafts, etc., should only be undertaken by skilled surgeons at dedicated fistula centers that have extensive experience in the management of such patients.

How can these problems be overcome? We believe that the answer lies not in promoting “cowboy” trips abroad by inexperienced surgeons who want to ‘do a few fistulas,’ but rather in developing long-term partnerships between European and North American surgeons who want to help and their African and Asian counterparts who need external support to function. We would make the following suggestions as to how such programs can be strengthened.

Western surgeons who travel to Third World countries with an interest in fistulas should be encouraged to pay for the costs of those patients in whose care they will be involved and to help sponsor further training for indigenous surgeons who want to improve their abilities to take care of women afflicted by obstetric fistulas. Well-established fistula hospitals usually take Third World surgeons for intensive training sessions of a month or more, as long as they can be assured that these individuals will return to areas in which fistulas are a problem and that they will make a continuing commitment to work in this field. These are the people who most need the training and who are likely to make the biggest impact once they have it. Our experience in multiple settings across Africa tells us that the single most important prerequisite for developing a successful fistula program is finding and nurturing a ‘fistula champion’ at the local level, a surgeon who understands the needs of fistula patients and who is filled with passion to help them. Such individuals are rare, but without them no program will succeed over a long term. The role of a ‘fistula champion’ cannot be filled by an expatriate visitor who drops in occasionally to do a few fistula cases, but expatriate visitors can do much to support and sustain such individuals when they find them.

Western medical institutions, particularly university teaching hospitals, should be encouraged to form partnerships with sister institutions in Africa and Asia to promote research, faculty enhancement, and residency training, with the view of integrating fistula projects into such programs. Ongoing institutional links of this kind are far more likely to result in sustainable progress with a long-term impact than scattered, intermittent ‘goodwill trips’ by well-meaning overseas visitors. The successful development of an indigenous residency training program in Ghana, for example, has both transformed obstetrics and gynecology in that country and has also set the standards to which all other residency training programs in the West African sub-region aspire [10–12]. Similar models should be developed in other needy parts of the world. The fistula problem will ultimately be solved only by preventing the occurrence of prolonged obstructed labor, but this requires the development of a robust infrastructure for the provision of competent routine maternity services as well as universal access to emergency obstetric care when such need arises [13]. The professional development of obstetricians and gynecologists in these countries is critical for such efforts to succeed.

Finally, we wish to restate our strong conviction that any program developed for the care of women with vesico-vaginal fistulas from prolonged obstructed labor must be based on a holistic philosophy that emphasizes care for the entire person, not just ‘fixing the hole in her bladder.’ These women often have multisystem injuries and have been subjected to a level and intensity of rejection, abuse, and social stigmatization that is difficult for outsiders to understand. They need compassion, empathy, literacy classes, and vocational and psychosocial rehabilitation as well as expert surgical care. Provision of such multidimensional services requires a commitment to long-
term institution building, not just short-term ‘fistula trips’ by overseas surgical visitors. It is only by nurturing the development of enduring institutional structures that these goals can be realized.

References


