NEGLECTED DISEASES: WHY DO SOME MAJOR DISEASES RECEIVE LESS ATTENTION THAN OTHERS?

Dear MJM,

Infectious diseases pose serious threats to healthcare in developing countries. The list of these diseases is endless. They are all damaging and they are all serious. However, a few of them receive most of the public attention. The media is always after 'juicy' stuff. It likes to focus on murderers who kill in a 'stylish' way like HIV which attacks the patients' immune system leaving them vulnerable to other opportunistic infections or like Ebola and other hemorrhagic fevers that makes patients bleed from every body orifice they have (1). There are many movies about AIDS victims (2). Ebola has inspired a few best-selling novels and at least one Hollywood movie (Outbreak, Directed by Wolfgang Petersen) (3). But, as far as I know, there are no movies, except for documentaries, featuring malaria (300 million acute illnesses annually)(4), Bilharziasis (200 million people infected, 600 million at risk) (5), tuberculosis (one third of the world's population infected) (6) or Onchocercal river-blindness (17.7 million people infected) (7). In 2004 about 40 million people were living with HIV/AIDS and 3.1 millions died of it (8) however, the WHO stresses the fact that while tropical infectious diseases permanently disable millions of people each year, they cause comparatively few deaths and it is this low mortality that makes it harder to draw international attention to their grave toll (9).

This trend is dangerous because it steals public interest and consequently resources from legitimate efforts against many other killers (10). Probably malaria, tuberculosis and Bilharziasis are not as 'photogenic' or as slick as HIV or Ebola but they still claim millions of people every year (4-9). These are not diseases that can be overlooked. In the context of their chronicity the word 'lives' gains another sense; it stands for the miserable tens of years patients live after they catch any of these debilitating diseases multiplied by the millions of individuals affected. If we look at things this way we will realize the impact of such "unlucky" infections on those unfortunate patients.

Blaming the media is probably the more good-natured explanation; the other one carries the more selfish face of the drug industry in rich countries. Of the 1233 new drugs identified as reaching the market between 1975 and 1997, only 13 were approved for neglected tropical diseases (11,12). This has given rise to a global 'drug gap' (13), in which the drug companies invest almost exclusively in drugs for the developed world that will be marketable and profitable (14,15). Funds and resources mostly come from developed nations, which are primarily interested in targeting diseases that affect their citizens (like AIDS), the people who can pay for the drugs (14,15). Patients who contract the same infection in poor countries may indirectly share some of the benefits of such programs, such as the development of new antiretrovirals drugs just because they are 'lucky' enough to be infected with a disease that receives interest from the rich drug companies. In such cases the pharmaceutical industry sees a potential market in patients from developed countries infected with the same disease, for example a poor African patient might not be able to afford antiretroviral treatment but many patients from the US or Europe with HIV/AIDS will have medical insurance to pay for the drug thus making the whole deal profitable (14). Not all patients are that 'lucky'. Many have infections confined to developing, poor countries that present no market prospects for the pharmaceutical industry (14,15), thus making infections like sleeping sickness and Chaga's disease the world's 'most neglected diseases' (14).

It has been estimated that less than 10% of global spending on health research is devoted to diseases or conditions that account for 90% of the global disease burden (15,16), a disparity known as the 10/90 gap (16).

What we need now are initiatives to provide equal opportunities for patients with different diseases; that is, some sort of "affirmative action" to reverse the ill-effects of a long lasting discrimination between diseases. Médecins sans Frontière believes that the best hope of controlling the world's most neglected diseases is for the public to accept responsibility for drug development (14). Highlighting neglected diseases in the media would be a very effective tool to move the public. Medical students can play a vital part in that. They should learn about diseases not common in their locality, especially major global infections that do not receive due attention from the media or medical school curricula, and transmit their knowledge to other healthcare workers and to the public. We should strive to bring the suffering of millions of patients with these diseases into focus. The increasing awareness will hopefully help to direct more resources and funds into interventions and research projects to alleviate suffering.

Sincerely,

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PRIMUM NON LUCRIFACERE:
THE INTRODUCTION OF NO FREE LUNCH AT MCGILL

Dear MJM,

In this era of exponential advances in medicine and biomedical technology public resources to fund this explosion of research are becoming increasingly strained. It is a result of this that researchers are forced to rely or seek private funding in basic science and clinical research, with as many as 66% of therapeutic trials receiving some form of pharmaceutical industry funding.

This leads toward a situation which lends itself to an ethical dilemma, and a conflict-of-interest: a pharmaceutical company's primary obligation is toward its shareholders, a clinician-researcher is expected to be both a scientist and a physician - they must hold themselves to the standards of the scientific process, and above all, to the care of the patient.

The breach of the social obligation of the pharmaceutical company and the researcher toward the ethical and evidence-based care of the patient, and the introduction of systematic bias into clinical research, has been widely documented (1). Research articles with findings non-favourable to industry goals are often delayed or suppressed, principal investigators with principled objections are removed from publication or threatened, and in one study it was demonstrated that eleven percent of articles were "ghostwritten", and nearly twenty percent of articles named authors who did not sufficiently contribute to their writing (2).

Research is certainly not the only area of medical practice into which the influence of the pharmaceutical industry has crept. Pharmaceutical representatives are omnipresent in primary-care practices, at CME or all kinds, including hospital rounds and medical conferences, and in private offices or private events. Exposure to pharmaceutical representatives and pharmaceutical advertising has been adequately studied and repeatedly demonstrated to adversely influence appropriate prescribing and educational practices, and cost of prescriptions (3). The benefits of extricating medical education and medical practice from the influence of the drug industry are well known; up to 75% of Canadian family medicine residency programs thus far have implemented some form of guidelines regulating the interactions between their residents and the pharmaceutical industry, however less than a quarter of residents in family practice have actually read the national guidelines, and 60% to 90% (4,5) of residents polled agree that more teaching about industry-physician interactions is warranted. Pharmaceutical advertising is effective, though few physicians have the
insight admit that they themselves are affected by it. In a telling survey of resident attitudes toward pharmaceutical advertising, 61% of residents felt their clinical decision-making to be unaffected by pharmaceutical advertising, whereas only 16% felt their peers to be similarly uninfluenced (6).

Even those not in direct and frequent contact with pharmaceutical detailing or advertising are at risk of being misled: Choudhry and colleagues surveyed 192 authors of clinical practice guidelines (CPGs) for common adult diseases; they found that nearly 60% of the respondents noted a prior financial relationship with a pharmaceutical company whose drug was being considered in the CPG (7).

The lists of offenses against ethical medical practice continue: the distribution of false and even downright dangerous advertising material in the name of profit(3); disseminating false or inappropriate information in educational settings (3); engaging in advertising practices targeting the general public shown to create strain in the patient-physician relationship (8).

Perhaps the most frightening evidence of the unsuspecting nature of the physician toward this covert, and overt, manipulation of their policies and practices is the surgical precision with which the pharmaceutical industry has analyzed the cost-benefit ratio of advertising. They know down to the dollar how much advertising is required to bend the doctors far enough to maximize their profits. A recent publication in the Journal of Marketing has even come to the statistical conclusion that doctors are under-saturated with pharmaceutical representative visits and colourful journal advertisements (9). The same author published another recent article on how to best manipulate the public to persuade their physician to prescribe a particular company's medication (10).

For those readers who still do not believe the dangers of the intimacy between pharmaceutical companies and medicine at all of its levels have simply to answer one question - why else would the pharmaceutical companies, who are profit-driven, spend well over $11 billion per year in advertising to physicians in the United States alone (3)? To quote an economic analysis by the non-profit health policy NGO, FamiliesUSA.org: "U.S. drug companies that market the 50 most often prescribed drugs to seniors spent almost two-and-one-half times as much on marketing, advertising, and administration as they spent on research and development (R&D) in 2001".

The solution rests in the hands of the medical profession. The pharmaceutical companies are not to blame: they do what they are meant to do, which is to appease their share holders, and they do it very well. The solution must begin on an individual level - it is up to each physician to improve their standards of ethical behaviour. There have been several guidelines written by national organizations to this effect (11), but the bottom line is self-awareness. It is for this reason that a group of medical students at McGill University have decided take an active stance on this critical issue, and to create a local chapter of No Free Lunch at McGill.

Sincerely,

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