Go Big and Go Fast — Vaccine Refusal and Disease Eradication

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Disease eradication is an attractive public health goal. In addition to eliminating illnesses and deaths, eradication can lead to substantial cost savings. Eradication has been attempted for many human and animal diseases, such as smallpox, malaria, hookworm disease, polio, rinderpest, yaws, dracunculiasis (guinea worm disease), and yellow fever, and many tools have been employed in these efforts. But in the two diseases that were successfully eradicated, smallpox and rinderpest, the main tool was a vaccine. Eradication strategies for polio (a major current focus of global eradication efforts) and measles (whose eradication is being considered) rely on high vaccination coverage through routine and supplementary immunization.

Eradication efforts for vaccine-preventable diseases face many challenges, including vaccine refusal. Such refusal in communities in northern Nigeria and Pakistan, for example, has caused major setbacks to global polio eradication, contributing to continued endemic transmission of poliovirus in these countries and to the reintroduction of wild-type poliovirus into countries where transmission had been interrupted. Although wild-type polioviruses are no longer endemic in India, refusal played some role in delaying elimination. The resurgence of measles in Europe, partially attributed to vaccine refusal, threatens its regional elimination and eventual global eradication. It is therefore important to understand the determinants and dynamics of vaccine refusal affecting disease-eradication initiatives.

Many factors contribute to the development of clusters of people who refuse vaccines, including changes over time in attitudes toward vaccines. If aggressive control efforts have substantially reduced a disease's incidence, few people in a given community may have direct (or indirect) experience with that disease. Therefore, successive age cohorts have only a vague collective memory of the disease's dangers, whereas people may frequently hear about real and perceived adverse effects of vaccination. Parental perception of risks and benefits associated with vaccines is thus altered, and vaccine refusals often increase.[1] North American and European countries, for example, have seen substantial reductions in the rates of vaccine-preventable diseases. Since vaccines against measles, mumps, rubella, and diphtheria were introduced in the United States, their incidence has been reduced by more than 99%, and the incidence of tetanus has fallen by 94% since routine tetanus vaccination began.[2,3] These decreases have coincided with increases in vaccine refusal in the United States and Europe.

The notion that vaccine acceptance is influenced by rates of vaccine-preventable diseases is supported by theories from behavioral sciences. For example, a useful framework for understanding vaccine acceptance is the health-belief model, according to which the uptake of a health intervention is associated with perceived susceptibility to and severity of the relevant disease and the intervention's safety and efficacy.

Empirical studies have validated this model as a predictor of vaccine refusal. In the context of eradication, reduction in disease incidence reduces the perceptions of susceptibility to disease and its complications, diminishing an important motivation for accepting a vaccine.

It is often assumed that this phenomenon does not apply to low-income countries where there is increasing opposition to vaccines, despite the high burden of infectious diseases. This perspective misses an important point: perceptions regarding vaccines are often vaccine-specific and disease-specific. For example, in high-income countries, although many parents have generalized concerns regarding immunization, perceptions of specific vaccines vary considerably. Similarly, the more prominent instances of vaccine refusal in low-income countries have been specific to vaccines for diseases with actual or perceived low incidence. Refusal of the polio vaccine in northern Nigeria and parts of northern India, for instance, was vaccine-specific: communities that refused polio vaccine were still demanding measles vaccines. In fact, the low polio rates, achieved through intensive immunization efforts in previous years, were a reason why many did not consider polio eradication a priority: "Some people have never even seen polio, but yet they keep giving us medicine for it," one Nigerian told a researcher. "If you look around it is hard to find 2 or 3 people with polio, but it is easy to go to the hospital and find 50 people sick with no money to buy the medi-

cine they need to be treated with. Help them instead, but No! You find a small baby who is well and drop medicine in his mouth, for free!"[4]

Although change in the epidemiology of a vaccine-preventable disease is important in determining support for the vaccine, it is not the only important factor involved. Local sociopolitical, demographic, and health-system–related issues and competing health problems (e.g., HIV infection and malnutrition) affect both the response of parents and the community and the effectiveness of control programs. For example, in Nigeria, local politics, distrust of the central government and the West, and the history of unethical practices of Western pharmaceutical companies all contributed to polio-vaccination resistance.[4] Similarly, in northern India, the resistance to polio vaccination was centered in the Muslim minority communities that have historically felt marginalized. But local factors operate in a milieu of decreased appreciation of vaccines — an argument supported by the specificity of opposition to polio vaccine.

Other major challenges to disease eradication include suboptimal vaccine effectiveness in certain populations, emergence of vaccine-derived pathogenic strains, difficulties in reaching migrant populations, chronic underfunding, international conflict, and violence against health workers. The relative importance of various challenges, including vaccine refusal, varies among and within countries.

Resistance to vaccination can be overcome with carefully planned and executed social mobilization initiatives and bundling of eradication-related vaccination with other services that have higher

acceptance among the target population. For example, polio-eradication efforts in India led to the successful elimination of polio transmission in January 2011. But addressing vaccine refusal may require substantial human and financial resources. In northern India, it took sustained multiyear efforts and involvement of nontraditional stakeholders (such as Muslim religious leaders) to overcome resistance to vaccination. Implementing high-intensity communication and social mobilization programs is more challenging when factors such as lack of security are at play, as is the case for polio elimination in Afghanistan and Pakistan.

The next vaccine-preventable disease being considered for global eradication is measles. A global technical consultation commissioned by the World Health Organization (WHO) to assess the feasibility of global measles eradication concluded that "measles can and should be eradicated."[5] This conclusion has been endorsed by the WHO Strategic Advisory Group of Experts on Immunization, and regional elimination goals have been established by all WHO regions except the Southeast Asian region. However, there has been no target date set for global eradication. Initiatives for eradicating diseases with a high herd-immunity threshold (such as measles, which has a threshold of approximately 94%) are more vulnerable to the effects of pockets of vaccine refusal than are attempts to eradicate disease with lower herd-immunity thresholds, such as smallpox (which had a threshold of approximately 80 to 85%).

One lesson from past eradication efforts is that the last mile is the longest. Aggressive early efforts often cause dramatic re-

ductions in disease rates, which paradoxically increase the risk of vaccine refusal. It is difficult to quantify the precise rate of decline in favorable perceptions of a vaccine, so it's challenging to predict the exact timing and location of emergence of clusters of vaccine refusers. Yet it's reasonable to assume that the longer it takes to move from aggressive control or regional elimination to global eradication, the more likely it is that vaccine refusal will emerge.

Eradication should therefore not be a halfhearted effort. Aggressive disease control is in itself a worthy public health goal, but it shouldn't be assumed to be an automatic stepping-stone to eradication. If a disease such as measles is considered a priority by the global public health community, human and financial resources should be committed up front to a full-scale eradication initiative, conducted with a sense of urgency. If we don't "go big and go fast," we may have to spend a prolonged period on eradication efforts with a diminished likelihood of success.

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From Illness as Culture to Caregiving as Moral Experience

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In the early 2000s, my wife developed early-onset Alzheimer's disease, and I got taken up in the everyday reality of being her primary caregiver. The experience was transformative on a professional as well as a personal level: although it validated my decades-long insistence on the primacy of patients' lived experience of illness, it deepened my questioning of the distinction, which I had popularized, between illness (as patients experience it) and disease (as physicians diagnose, treat, and understand it). The usefulness of this conceptual divide began to seem inadequate to me, just as I was becoming dismayed by the way it was being applied in medical education and practice. Meant to enrich the living art of medical care, the distinction and the philosophy it reflected had instead been co-opted and compartmentalized as a discrete element of a rote medical science.

Back in the early 1970s, at a time of rapid growth of high technology, reductionism, and bureaucracy in medicine, there had been rising anxiety that clinicians weren't treating patients as individuals whose lives and disorders had a richly human background and social context. I began writing articles and books, drawing on my work as a consultation–liaison psychiatrist and cross-cultural researcher, on how physicians' narrow focus on diagnosis and treatment led them to miss or intentionally exclude the centrality of the patient's experience. I argued that the patient and fam-

ily's anxious and burdensome experience of illness and the clinician's intense quest in diagnosing and treating disease were two substantially different kinds of things.[1] The former was a struggle to bear, interpret, and respond to symptoms; the latter, the application of a particular medical system's classification of disease entities and enactment of prototypical treatment interventions. Calling for renewed attention to patients' lived experience of symptoms, I emphasized the illness–disease distinction and proposed that by eliciting lay explanatory models through eight questions, clinicians could understand illness experiences and so provide care as well as cure.[2]

Those questions — beginning with "What do you call your problem?," "What do you think is its cause?," "How does it affect your body?," and "What do you most fear about it and the treatment?" — were meant to open conversations by bringing patients' illness narratives into the patient–doctor relationship, converting a rather one-sided interaction into a richer, more egalitarian one. Patients' and physicians' distinctive explanatory models reflected cultural orientations of the society, the profession, and the institution that authorized a certain kind of clinical reality, which would shape the patient's treatment and the evaluation of outcomes.

This clinical method became widely taught, especially as a model for delivering effective, culturally informed care to ethnic

and immigrant minority groups.[3] But by the 1990s, it became clear that the illness–disease distinction was being used in a way that undermined exactly the sort of understanding it was meant to foster. Eliciting the explanatory model had become a conversation stopper, a mechanical task that assumed that dynamic meanings could be fixed as a single, unchanging, material thing in the patient's record. On clinical rounds, trainees presenting cases treated the patient's explanatory model as one more concrete parameter, like the CBC or electrolytes. What was meant to humanize care by providing room for lay voices and practices appeared instead to be reducing complex lives to limiting, biased stereotypes. I hadn't reckoned with people's capacity to routinize and objectify others' suffering and fears in the quest to render their tasks manageable.

To make matters worse, certain aficionados fetishized illness narratives per se as symbols and stories, divorcing meaning from the economic, emotional, and relational context of the lived experience of suffering, rather than using storytelling to make experience available for reflection and communication. Moreover, the method seemed to assume that culture was relevant only to laypersons, not professionals, and it got caught up in a cultural-competence movement that reified esoteric cultural beliefs and ethnic stereotypes.[3] That had not been my point. The way illness was being separated from disease also