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UNEXPECTED AGENCY: PARTICIPATION AS A BARGAINING CHIP FOR THE POOR

Clara Rubincam and Scott Naysmith

ABSTRACT

Populations in the developing world that are targeted for disease eradication programs are commonly seen as passive recipients of international aid. Poor people can, however, "participate" in these interventions in unexpected ways. In the absence of traditional sources of leverage, some marginalized people have used their one remaining form of influence — their noncompliance in public health initiatives — to articulate a higher priority need and to assert their basic human rights to food and primary health care. Vertical international health initiatives whose goals are to eradicate and control diseases may be forced to contend with this phenomenon. The success of these interventions will hinge upon ensuring that the basic human rights of the target populations are addressed.

INTRODUCTION

By the time the global smallpox eradication campaign concluded in 1978, it had eliminated the virus from human hosts. The success of this health intervention has been attributed largely to the containment and vaccination of infected individuals in previously endemic countries. Now recognized as one of the most effective global health programs in history, the vaccination campaign was, nevertheless, not without problems in ensuring participation. An entry in the field journal of Stanley Music, a senior WHO physician-epidemiologist from the Centers for Disease Control who was assigned to the Bangladesh Smallpox Eradication Strategy from 1973–1975, provides one example of the kind of problems encountered during the campaign. Describing his experience with a woman who resisted vaccination, Music wrote:

> [She was] an old woman who wore a dirty grey plain cotton sari over her gaunt and emaciated body. The [Sanitary Inspector] said that she wanted food and would not take vaccination unless someone gave her food. She was a beggar by "profession" but the times had been hard and she was frankly starving. I entered her house — a jute-stick and mud hut with thatch roof in poor repair — and asked her to take vaccination. She asked if I had brought her any food. I said no. She refused vaccination. I pleaded with her and took her outside to see the child two houses away only minutes from death [from smallpox]. I said that if she remained unprotected, she stood a good chance of getting smallpox. She [said she] had never been vaccinated in her life. She said that if I didn't care whether or not she died of starvation, why should I care if she got smallpox![1]

How do we interpret this story, in which an individual declines a health service that is free and potentially life-saving? The importance of facing the challenges suggested by such stories is particularly imperative

as researchers are challenged to confront the "interlocking orthodoxies that defraud poor people of the minimal requirements for a healthy life."[2]

Previous studies on noncompliance have focused predominantly on socio-economic conditions, cultural or cognitive traits, or patients' structural limitations. Florie Barnhoorn and Hans Adriaanse found that "three socioeconomic variables, i.e. the monthly [household] income per capita, the type of house in which a family lives, and the monthly family income" were the most significant factors distinguishing those who complied with anti-tuberculosis chemotherapy from those who did not.[3] S. De Villiers focused on cultural barriers to compliance with tuberculosis treatment, while Kim Streatfield and Masri Singarimbun highlighted the importance of village authority figures in encouraging village members to comply with vaccination initiatives in Indonesia.[4] Stressing the cognitive perceptions of patients, J. Dennis Mull and colleagues noted that noncompliers were much more likely to "deny having leprosy."[5] Paul Farmer argues that the above studies neglect the important role that structural factors play in determining compliance, emphasizing that "throughout the world, those least likely to comply are those least able to comply."[6]

Farmer's argument has refocused our attention on documenting the ways in which a patient is limited from accessing health services because of structural inequalities. Compelling factors support his claim; however, they do not readily explain the behavior of the Bangladeshi woman described in Music's field notes, who did not face immediate barriers of this kind. She did not need to take the vaccination with food or water, for example, nor did her participation in the vaccination program require costly transport to the local health facility. What factors, then, explain such behavior? In light of our imperative to study the structural limitations that hinder marginalized communities from accessing health care, how do we explain a poor woman's refusal of a free vaccine that is brought to her door?

As Farmer notes, "the destitute sick" lack the kinds of opportunities to exert agency that might change their circumstances.[7] The anecdote about the Bangladeshi woman, however, contradicts commonly held notions about powerlessness among the poor in developing countries. It instead highlights a manner in which individuals may use their "compliance" with public health interventions as a bargaining chip to prioritize their primary needs. In this case, the woman's gamble was only partially successful; the vaccinator was able to proceed without her formal consent but only after promising to bring food later. However, her actions clearly challenge preconceived notions regarding the power and participation of marginalized populations. This essay argues that some recipients of international health interventions have engaged in negotiations despite their relative "powerlessness" by using compliance as a form of leverage. In doing so, they prioritize their immediate needs over secondary threats.

A useful framework to explore the use of compliance to acquire leverage is found in the related concepts of "exit" and "voice" from management theory. Considerations of "exit" and "voice" help to illustrate how leverage and control are acquired by individuals to articulate their preferences and demonstrate their priorities.

"EXIT" AND "VOICE"

The concepts of "exit" and "voice" are mechanisms that both customers and citizens utilize to exert leverage against corporations and the government, respectively.[8] If the services provided by corporations or government are deemed unsatisfactory, the customer or citizen can either "exit" from the relationship entirely, by purchasing from a different company or by voting for a different political party, or they can "voice" their disapproval — for example, by writing a letter of complaint to the relevant CEO or political representative. This relationship of accountability works as long as choice exists in the private sector and accountable democratic institutions exist in the public sector. When monopolies or less-than-democratic political institutions dominate, however, this valuable form of leverage disappears.

Poor people in the developing world rarely possess sufficient amounts of relevant currency — social, economic, or political — to make their preferences felt. They do not command the same authority as the wealthy to influence the priorities of the private or public sectors. This structural imbalance leaves poorer populations largely excluded from the traditional relationships of leverage and control. However, as highlighted above, there are limited, yet notable, exceptions when the poor possess a valued source of currency.

The story of the Bangladeshi woman who refused smallpox vaccination illustrates how individuals who lack viable channels to exercise "voice" can utilize their one remaining form of leverage: exit. This leverage exists because poor people's compliance is something that international health organizations strongly desire. The vast resources poured into health programs provide evidence of this to the lay public.[9] Disease eradication programs, such as the Global Polio Eradication Initiative (discussed further below), cannot succeed unless high proportions of community members are vaccinated. Disease control programs, such as the current effort to prevent new HIV infections, will struggle to contain the spread of disease without high levels of adherence to behavior-change directives, to the use of condoms, and to anti-retroviral medication regimens.

Using one's compliance as a bargaining chip when free and safe medicines are offered is, at first glance, a technique completely at odds with an individual's best interests. Surely, to refuse smallpox vaccination is only to put oneself or one's children at risk of blindness, disfigurement, or death. Despite the seeming irrationality driving such a decision, the case of the Bangladeshi woman is not an anomaly. Over 30 years later, similar "negotiations" are taking place on a different continent and with a different disease: polio.

THE GLOBAL POLIO ERADICATION INITIATIVE

The Global Polio Eradication Initiative (GPEI), which was launched in 1988 to eliminate polio worldwide, has largely succeeded: absolute known numbers of polio cases decreased from 350,000 cases annually in 1988 to 1652 cases in 2008.[10] The initiative is currently struggling to eliminate the remaining pockets of polio cases. Four endemic countries remain: Nigeria, India, Pakistan, and Afghanistan. Coverage in these countries has been hampered by war, instability, poor infrastructure, and inadequate health services. However, even when health workers have arrived in communities fully equipped with materials and medicine, they have faced an additional barrier: that of community members resisting, sometimes violently, participation in the GPEI.

In 2003, several communities in northern Nigeria boycotted the administration of polio vaccines by the GPEI. In several districts, rumors spread that the polio vaccine was "spiked" with HIV and/or sterilization drugs, leading political and religious leaders to urge parents to protect their children and refuse to have them vaccinated.[11] Resistance to vaccinators was strong, and by 2004 Nigeria was labelled the number-one reservoir of polio and the highest polio-transmitting country in the world. In subsequent years, 18 formerly polio-free countries had outbreaks that were traced to Nigeria.[12] These incidents led Kim Mulholland, an infectious disease expert at the London School of Hygiene and Tropical Medicine, to call the polio vaccine boycott "one of the single worst events in modern public health history."[13] Despite a resumption of the campaign in the boycott states in 2004, community resistance continues to the present day.

In July 2008, six Muslim clerics and a crowd of their supporters in Niger State (previously Niger Province) in Northern Nigeria halted polio immunization activities at a local school, in turn demanding social amenities in their communities.[14] These incidents of noncompliance with polio vaccination raise the same question that arose during the earlier smallpox eradication campaign: Why would poor people resist a vaccine for their children that is designed to prevent a debilitating disease that may result in paralysis or even death? As in the smallpox campaign, it would seem to be in the best interests of parents in Nigeria to accept free vaccination for any childhood disease whenever it becomes available. Explanations for this behavior are explored below.

POLIO VACCINE RESISTANCE: A HEALTH AND HUMAN RIGHTS PERSPECTIVE

During the 2003 polio vaccine boycott in Nigeria, several socio-cultural motivating factors were documented, including political and religious tension between northern communities and the federal government, as well as negative past experiences with pharmaceutical companies and foreign governments.[15] A further political motivation for the protest was the apparent incongruity between the impoverished state of the primary health care system and the well-funded polio eradication campaign.[16] One informant from Nigeria, for example, noted during the 2003 boycott: "Given that WHO and UNICEF have worked hand-in-hand with Nigerians for many years, many people do not understand why they were adamant to push the polio eradication campaign through a system that clearly

lacked the capacity to manage it."[17] Mallam Aliyu Yakub, one of the clerics in the Niger state protest in 2008, placed community priorities in sharp contrast to the polio eradication campaign, stating:

> Since 1960 when we had our independence, there are five things that government always talk about — water, light, housing, food and health — but up till today, we are still in the same problem. . . . It is not as if we don't want government to help us but the area we expect them to help us they are not doing it.[18]

Maryam Yahya documents a similar theme that had been highlighted during the 2003 polio boycott when suspicions arose due to the dissonance between polio's comparatively insignificant burden in society and the huge expenditures for the eradication initiative.[19] A local butcher commented:

> Some people have never even seen polio but yet they keep giving us medicine for it. 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 medicine 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![20]

In an environment in which basic medicines are too expensive for the average person, some have expressed resentment that a free vaccine can stand in sharp contrast to an individual's need. One security guard expressed his annoyance, commenting:

> If I go to the hospital, even simple panadol [paracetamol] for a headache, I cannot buy and these people are following us in to our houses forcing us to bring our children for free medicine for polio. What kind of humiliation is this?[21]

A taxi driver echoed a similar frustration:

> There are problems concerning healthcare, housing, hunger, unemployment that bother people. With all these problems, they now say that they want to help us with polio. My people will never be able to understand this.[22]

Further hindering the vaccination campaign is the fact that individuals who are disabled as a result of polio are successfully integrated into society. They are generally viewed as healthy and active members of the community who are able to manage their daily chores despite being somewhat limited by their physical capabilities. Communities opposed to vaccination campaigns may express far more concern for those who are unwell and in need of treatment and medicine.[23]

Such dissonance between perceived and actual need was harshly illustrated in the regions of Northern Nigeria that experienced an outbreak of measles in February–May 2001. With approximately 100,000 cases reported, hundreds of children died. Volunteers from the GPEI, ready to administer polio vaccinations, were "met with even more ridicule as [they] went from house to house to administer polio vaccines as parents mourned the deaths of their children from measles."[24]

In this context, one motivation for the boycott of the polio vaccination campaign can be interpreted as a political refusal to participate in vertical health programs while primary health care remains neglected. An assessment of the polio vaccination campaign in Nigeria suggested that:

> [P]olio "fatigue" has set in across much of the country, with widespread resentment at the quantity of human and financial resources being thrown at a single disease that, both in public health terms and in popular perception, is relatively unimportant in Nigeria. National Immunization Days (NIDs) take health staff away from their regular work. . . . Thus NIDs contribute to the continuing dysfunction of the primary health care system.[25]

The clerics and their supporters in 2008 made it clear that "the greatest priority of the community was social amenities and not immunization."[26] In a report on routine immunization, researchers reiterated that polio, "in both public health terms and in popular perception, is relatively unimportant in Nigeria."[27] The individuals who resisted polio vaccination there-

fore used their noncompliance in a public health initiative as a way of making their preferences felt.[28] As such, they exercised their one remaining form of leverage by "exiting" from the campaign. In doing so, they threatened the success of a costly and high profile global health goal.

DISCUSSION

The elimination of polio, like the elimination of smallpox, is an extremely expensive but worthwhile global health initiative, the success of which hinges on the participation of individuals in endemic areas. If one case of polio remains active, the goals of the initiative have not been achieved, and the money that has been hitherto spent on its eradication may have been spent in vain. Thus, in these final years of the eradication campaign, it is understandable that vast amounts of funding and energy are being directed toward stamping out the disease in these final four endemic countries. The difficulty is that, too often, these priorities have not translated coherently at the community level. In the face of such inadequate primary health care, housing, water, electricity, and food, it appears suspicious at best, and malevolent at worst, that the government and the international community would continue to direct their energies toward a seemingly minor concern. Lacking the influence with either government or donors to make their preferences felt for fundamental human rights, communities have manifested their discontent by refusing to participate in a global disease eradication program.

Theorists and practitioners who subscribe to a health and human rights approach must view such dissent for what it is: marginalized people insisting upon the fulfillment of their basic human rights for food, shelter, and primary health care. Their bargaining stems from marginalization and is spurred by necessity. As analysts crowd to explain why people at risk of polio would refuse vaccination, let these examples serve to widen our analysis and inform our responses and priorities.

By examining this phenomenon through the lens of "exit" and "voice," one sees the ways in which many of the destitute poor, far from being passive recipients of international health aid, have used their participation as a point of leverage and a source of power. The "power" demonstrated in these examples, however, should ultimately be recognized for its limitations as much as its strengths: individuals who refuse to participate in global health programs may influence the priorities of the international community, but they may also become disabled or die. That these are the choices available to the destitute poor is cause for renewed urgency to ensure that they have access to basic needs.

In these communities, an education-focused strategy to encourage compliance may not be the only appropriate response. Lack of knowledge about the disease and its consequences is not the main problem in some contexts. It is our hope that efforts to recognize and lobby for a balance between eradicating diseases and addressing basic human rights for food, shelter, and primary health care will help alleviate communities' concerns and prevent their "exit." Without this balance, these expressions of unexpected and potent agency have the potential to disrupt well-funded health programs, threatening the achievement of their laudable goals.

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28. This case raises questions about protests initiated by individuals with more relative power in a community (clerics) in relation to the most impoverished, marginalized citizens: Whose power is exercised by these protests, and who stands to benefit? If this were purely an example of an issue that affected the poor being co-opted for political gain by elites, referencing this example would not serve to widen our understanding of noncompliance as a bargaining chip for the poor. However, due to the widespread support that these clerics received for their protests (echoed in the quotations above) and the fact that a village cleric in northern Nigeria still lacks significant political power in relation to federal politicians or international agencies, their actions can still be viewed as an exercise in the leveraging power that individuals who are marginalized by society can wield.