Stop Making Excuses: Understanding Hepatitis B and the Global Failure to Act

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Hepatitis B virus (HBV) is one hundred times more contagious than HIV/AIDS and is one of the leading causes of primary liver cancer. Merck created the first hepatitis B vaccine in 1982, but the distribution of it remains a global problem as does sustained HBV research, monitoring, and surveillance. As the seventh vaccine incorporated into the World Health Organization (WHO) Expanded Program on Immunization, what factors contribute to the under-delivery of HBV vaccine? Why has so little action been taken to lessen global HBV prevalence rates and what steps should be taken to remedy this global problem? Using a public goods framework, this article attempts to understand the global lack of attention given to the hepatitis B virus. In doing so, it highlights issues related to: public-private partnerships for health, public goods contingency, and perception of virus transmission and virus carriers. Further, WHO's role in HBV prevention and treatment activities is examined.

INTRODUCTION

"It's absolutely disgraceful that a disease that could have been eradicated from the planet has not been and actually is not looking like being in the foreseeable future unless we do something to shake people up." – Charles Gore, President, World Hepatitis Alliance¹

"It's money, it's politics, it's culture." – Cathy Hyett, President, Togo Run²

Cancer awareness and anti-cancer movements are at an all-time high. In the United States (US), for example, it is easy to locate broad-based cancer coalitions, such as the American Cancer Society, in addition to cancer-specific awareness groups, such as the National Breast Cancer Foundation. As a result of sustained research, development, and advocacy, our understanding of the causes of various types of cancer and our ability to prevent and treat these maladies continue to progress. Part of the reason for these persistent efforts is the growing public awareness that cancer kills, but that it can often be prevented or at the very least treated. It is surprising, therefore, that the world possesses the hepatitis B vaccine - the first anti-cancer vaccine - but this vaccine continues to be underdelivered. The hepatitis B vaccine was developed more than twenty-five years ago, but access to it remains a global problem. As a result, countless numbers of people in the developed and developing world continue to suffer the painful effects of liver disease.

Hepatitis B virus (HBV) is the leading cause of cirrhosis, liver disease, and primary liver cancer.³ The Hepatitis B Foundation estimates that approximately 400 million people are chronically infected with HBV and that 10-30 million

people become infected every year.⁴ One million people die from HBV induced liver disease each year, which equates to about two HBV-related deaths per minute.5 The World Health Organization (WHO) notes that hepatitis B is the fifth leading cause of death from infectious disease worldwide, surpassed only by lower respiratory tract infections, diarrheal diseases, HIV/AIDS, and tuberculosis. 6 In 2000, the Western Pacific WHO region accounted for ~ 52% of global deaths from HBV, followed by the South East Asian region (23%), the African region (11%), Europe (8%), the Eastern Mediterranean (3%), and the Americas (2%).7 As of 2007, 88% of WHO member states reported having introduced the hepatitis B vaccine; however, only 27% had incorporated a birthdose, which is perhaps the most critical. Further, only 65% of WHO member states reported the delivery of the recommended three doses.⁸ While the number of member states that have incorporated three doses of the HBV vaccine has increased significantly over the past twenty years (from less than 10% in 1989 to 65% as of 2007), more than 30% of member states have yet to meet the recommended WHO guidelines. Put differently, as of 2007, nearly 44 million infants globally were not immunized with the recommended three doses of hepatitis B vaccine. Seventy five percent of these unvaccinated children primarily come from ten countries: India (24.1 million), Nigeria (3.1 million), China (1.36 million), Indonesia (1.11 million), Japan (1.07 million), Ethiopia (0.79 million), UK/Northern Ireland (0.72 million), Pakistan (0.70 million), Niger (0.62 million), and France (0.54 million).9

It is possible to prevent hepatitis B virus transmission; however, the global health community's failure to tackle HBV vaccine distribution issues more effectively has resulted in the death of one million people annually, particularly in the developing world. 10 At the international level, incremental steps have been taken to remedy the global HBV problem but these efforts are not sufficient. In 1992, the World Health Assembly passed Resolution 45.17, which called on member states "to integrate cost-effective new vaccines, such as hepatitis B vaccine, into national immunization programmes in countries where it is feasible."11 In 1998, the WHO-cosponsored "Conference Regarding Disease Elimination and Eradication as Public Health Strategies" concluded that hepatitis B was "a primary candidate for elimination or eradication." Despite this "primary candidate" characterization, no global control or elimination effort has been initiated. In fact, the Western Pacific Regional Office of the WHO is the only region in the world to have established control targets for hepatitis B.¹³ In May 2010, the sixty-third World Health Assembly adopted a viral hepatitis resolution, but it remains to be seen how this will affect support, funding, advocacy, surveillance, and research for viral hepatitis, particularly hepatitis B. Until HBV is elevated to a higher priority within health decision-making bodies at all levels of governance, we can continue to expect millions to die from preventable liver disease.

These stark assessments are not meant to undermine the efforts of hepatitis B advocacy and research groups, because without them global prevalence rates would be much higher. Further, it is possible to identify country successes, namely in East Asia and Southeast Asia. Taiwan, for example, has made significant steps towards eliminating HBV transmission. Hepatitis B was

"hyperendemic" in Taiwan.¹⁴ Beginning in 1984, the country initiated a national program of neonatal HBV vaccination.¹⁵ Two years later, the program was expanded to include all newborns, regardless of the mothers' carrier status, as well as older children. In 1986 newborn vaccination rates were 15% and by 1994 had increased to 84%.¹⁶ Targeting newborns coupled with a rigorous public awareness campaign and close monitoring of the healthcare system has positively served Taiwanese citizens, and the country is a model in this regard.¹⁷ At the end of the day, despite these successes, hepatitis B continues to pose a huge disease burden globally. Charles Gore, president of the World Hepatitis Alliance claims, "It's one of those circular problems. Awareness is low, so it's not on the priority list. Funds are not put into it, there is very little advocacy and nobody is doing anything to raise awareness."¹৪

As the seventh vaccine incorporated into the WHO Expanded Program on Immunization (EPI), what factors contribute to the under-delivery of HBV vaccine? Why has so little action been taken to lessen HBV prevalence rates and what steps should be taken to remedy this global problem? The world health community has capably drawn attention to the Big Three – tuberculosis, HIV/AIDS, and malaria. HBV, by contrast, is one hundred times more contagious than HIV and yet the attention given to it in international health decision-making circles has been pitiable. This article attempts to catalyze a more sustained conversation regarding the HBV epidemic and understand why HBV continues to be relegated to the back burner in health decision-making circles.

The potential eradication of hepatitis B represents a pure public good for health. Even if eradication is not possible at present, studies indicate that sustained efforts to more fully distribute HBV vaccine would significantly reduce health spending on acute and chronic carriers as well as positively contribute to a country's economic growth given the age at which hepatitis B attacks the liver in chronic carriers.²⁰ Eradication is global and its benefits are fully non-rival and fully non-excludable; non-rivalry and non-excludability are the two defining features of a public good.²¹ Non-rivalry implies that one person's consumption of the positive spillover effects of living in an HBV-free world detracts nothing whatsoever from others' ability to equally consume these benefits. Additionally, non-excludability means that no one can be barred from consuming the positive spillover effects of living in an HBV-free world because the disease would no longer exist anywhere. The classic free rider and collective action dilemmas come into play when referencing global disease eradication as well as elimination and control efforts. 22 In short, it is in everyone's interest to free ride on the advantageous actions of others while not bearing their relative share of the costs. As a final product, HBV eradication is a pure public good for heath. But, the intermediate inputs required to generate this final good are mixed. Some are impure, which means that the non-rivalry or non-excludability properties have been violated, while other inputs such as financing or research may be altogether private. The HBV story, therefore, highlights the multiple types of goods – pure, impure, private, and club - that are required to generate final public goods for the global health community. In noting these mixed inputs, the hurdles and obstacles faced when attempting to overcome barriers to collective action are also emphasized.

Whereas vaccine cost was once a key factor preventing its widespread distribution, over the past thirty years HBV vaccine prices have significantly decreased; thus, financial arguments against more fully distributing it should be When Merck marketed the first HBV vaccine, Heptavax cost approximately \$30 per dose and three doses were required to convey full immunity. Because the vaccine was prohibitively expensive, initial efforts to curb the spread of HBV were geared at high-risk communities: healthcare workers. men who have sex with men, and injection drug users. Recognizing these barriers to distribution, scientists from the Centers for Disease Control and Prevention (CDC), New York Blood Center, and the Program for Appropriate Technology in Health formed the International Task Force on Hepatitis B Immunization, which was instrumental in helping to reduce the cost of the HBV vaccine. The Task Force catalyzed vaccine pricing wars between big pharma companies such as Merck and other vaccine manufacturers such as Korean Green Cross Corporation. By 1990, HBV vaccine cost less than one dollar per dose.²³ The cost of the HBV vaccine today varies by country, but for developing countries that have little capacity to pay and need the vaccine most, the vaccine costs less than thirty cents per dose.²⁴ Moreover, the Global Alliance for Vaccines and Immunisation (GAVI) has been instrumental in providing low-income countries with affordable access to HBV vaccine. In countries where diphtheria-pertussistetanus (DPT) coverage rates are between 50-80%, GAVI provides support for vaccine purchase for five years and a "one off payment" of \$100,000 to assist in the introduction of HBV vaccine. Further, GAVI helps countries develop long term plans for the maintenance of hepatitis B immunization programs.²⁵ In short, it pays to vaccinate. Research has demonstrated time and time again that vaccinating infants against hepatitis B is cost-effective, particularly when compared to the cost of treating sick persons. As one recent WHO study concludes, "In the Gambia, vaccinating infants against hepatitis B is highly costeffective. Compared with offering no intervention, the vaccination programme would cost US\$28 per DALY [disability-adjusted life year] averted from the societal perspective or US\$47 per DALY averted from the payer's perspective."26

GLOBAL PUBLIC GOODS AND THE UNDERPROVISION OF HEPATITIS B VACCINE

Despite calls by the United Nations and the World Health Organization to increase the number and presence of public-private partnerships (PPPs) in the realm of health,²⁷ the HBV community remains disunited and lacking a global voice. Schafferhof, Campe, and Kaan²⁸ note that global PPPs "constitute a hybrid type of governance, in which non-state actors co-govern along with state actors for the provision of collective goods, and adopt governance functions that have formerly been the sole authority of sovereign nation-states." Within the hepatitis community, it is possible to locate hundreds of domestic advocacy groups, many regional organizations, and a newly formed global patient advocacy group – the World Hepatitis Alliance (WHA). The WHA, however, is not exclusively focused on hepatitis B. Rather, it speaks on behalf of the viral hepatitis community at large, with a specific emphasis placed on hepatitides B and C. Formed in 2007,

the World Hepatitis Alliance is a collaboration of two hundred hepatitis-activist groups operating globally in more than fifty countries. In this sense, the initiative is largely patient-operated and driven by the understanding that there is a large "disconnect between awareness and the size of the problem."²⁹ The Alliance "provides global leadership and supports action that will halt the death toll and improve the lives of people living with chronic viral hepatitis B and C."30 Although it is endorsed by a plethora of respected health actors, including the European Association for the Study of the Liver and GAVI, it has no formal connections to the CDC, the WHO, or the United Nations Children's Fund (UNICEF).³¹ Each of these actors has played a pivotal role in other successful PPPs for health such as the Global Polio Eradication Initiative and the Measles Initiative. At the end of the day, the World Hepatitis Alliance is the only global voice for viral hepatitis, and it has comparative advantages in leadership, advocacy, and awareness. Any global effort to assuage the HBV crisis, however, needs the help of other health agencies that can provide technical support, research, laboratory and scientific expertise, disease monitoring and surveillance, as well as country-specific knowledge.

It is unclear why a more centralized voice has not emerged within the hepatitis B community. Charles Gore, president of the WHA, notes the resistance within the WHO when it comes to bolstering hepatitis B control activities.³² Thus, one must question the extent to which this resistance affects support by other important health agencies and donors. We must also question the extent to which the lack of a hepatitis B-specific World Health Assembly Resolution hampers the attention that hepatitis B receives in health decision-making bodies.

In May 2010, the World Health Assembly adopted a viral hepatitis resolution and this is a huge accomplishment for the viral hepatitis community. The resolution will hopefully re-energize a lethargic international health community and bring renewed emphasis to the dangers of uncontrolled viral hepatitis (types A, B, C, D, and E). Even so, until recently the WHO has devoted insufficient attention to viral hepatitis and this inattention needs to be better understood. In other words, we should not let recent WHO actions cloud our examination of its prior track record. Dr. Alison Evans, of the Department of Epidemiology and Biostatistics at Drexel University School of Public Health and of the Hepatitis B Foundation, suggests that one reason the WHO has been absent is because it is more concerned with acute diseases than chronic ones.33 As a result of its organizational mandate, the WHO must limit its role and be selective about the diseases it chooses to focus on. Charles Gore takes a somewhat different approach and notes that the WHO is a bureaucracy and like all bureaucracies that possess standard operating procedures, rules, and regulations, change is difficult to achieve.³⁴ Because the WHO possesses finite resources, the creation of a new department dedicated to viral hepatitis would mean reallocating funds and personnel that are already scarce. And yet, as Gore notes, so many of the departments present in the WHO overlap with viral hepatitis Departments such as Family and Community Health; HIV, TB, Malaria, and Neglected Tropical Diseases; and Health, Security, and Environment each touch on research that is connected with viral hepatitis, either directly or indirectly. Even with these spill-overs, however, in early 2009 Gore claimed, "I do not have the support of the WHO."³⁶ In fact, one of the only reasons that there is any support given to viral hepatitis within the WHO is because the CDC has funded the single WHO viral hepatitis position since 1987.³⁷

Increased support from the WHO should have positive spill-over effects in other critical decision-making circles such as the United Nations Children's Fund and the United Nations Development Fund for Women. One must still question, though, if a hepatitis B-specific resolution would more fully benefit the hepatitis B community, given that different types of hepatitis possess diverse modes of transmission and disparate prospects regarding elimination and eradication potential.

There are numerous reasons that a hepatitis B public-private partnership would further the goals of the hepatitis community. First, a partnership would eliminate some of the competition between domestic, regional, and global hepatitis B groups, particularly in terms of research, development, advocacy, and funding. With so many unconnected actors, overcrowding can make it difficult for decision-makers, nationally and internationally, to know who to listen to, who to take advice from, and who to fund. Second, with so many unconnected actors there is no clear understanding of what has been done and what needs to be done. Instead, groups operate in isolation from one another even though they may possess the same end goals. Third, the more unified the hepatitis B community becomes, the easier it will be to disseminate information to the public that remains uninformed and to petition governments and private organizations for funding and support. Additionally, PPPs bring together actors with very different specializations. Any global health initiative requires the skills and expertise of players who can provide technical support, research and development, bargaining skills for vaccine procurement, funding, advocacy, and country-specific knowledge of disease epidemiology. No single actor alone can provide all of these necessities and thus it becomes necessary to distribute tasks and capitalize on actors' comparative advantages. Whereas a more unified front from advocacy groups and the WHO could help to assuage issues related to technical support and public awareness, funding as well as research and development remain critical issues that neither the WHO nor advocacy groups alone can provide.

Regarding funding, increasing the amount of resources allocated to the hepatitis B community will certainly allow for the increased distribution and availability of HBV vaccine. However, Dr. Harold Margolis, former Director of the CDC Division of Viral Hepatitis, notes that increased financial resources are also needed to conduct sustained surveillance and monitoring.³⁸ Without an established system to globally monitor vaccine distribution, prevalence rates, morbidity and mortality, as well as high-risk (and low-risk) regions, the health community remains under-informed.³⁹ In other words, we do not know what programs and strategies are working and which ones are not. Last, Dr. Chham Samnang, Program Team Leader for Immunization at the Program for Appropriate Technology in Health, reminds us that in the developing world increased funding is also needed for healthcare workers themselves.⁴⁰ Improved incentives for healthcare workers will amplify their desire to be informed about hepatitis B immunization and provide vaccination services in home, where many

births occur. If healthcare workers have an incentive to remain local, this can potentially lessen the brain drain from the global South to the global North.

Along these lines, many centrally funded research and development agencies remain resource-deprived. For example, the CDC Division of Viral Hepatitis is currently working with a budget of roughly eighteen million dollars.⁴¹ This budget must support staff working at the CDC headquarters in Atlanta, staff in all fifty states, and the single WHO viral hepatitis position. Jeffrey Caballero, Executive Director of the Association of Asian Pacific Community Health Organizations (AAPCHO), claims:

[Viral hepatitis] is so grossly underfunded that they [the CDC] can provide a staffing support to a state but that's all they can do is provide that person with a salary. They don't have enough money to give them tools or resources to actually do the work and the reporting to CDC that can contribute to national surveillance. 42

In 2008-2009, members of the Association of Asian Pacific Community Health Organizations and other US-based hepatitis groups lobbied the US government to increase viral hepatitis funding in the CDC by fifty million dollars. However, the 2009 fiscal budget increased such funding by only one million dollars. Caballero suggests that this limited increase results from competition with other federal priorities and health advocacy groups. For example, the HIV/AIDS lobby in the US remains extremely powerful and some speculate that it has worked against the hepatitis B cause, albeit not intentionally.⁴³ What is odd is that each organization overlaps with the other given that HIV/hepatitis B coinfections are quite common. Because of its limited stock of personnel, money, and support, the hepatitis B community arguably has more to gain from a HIV/hepatitis B joint collaboration, but a combined effort could benefit both communities, given the similarities in disease epidemiology between HIV and hepatitis B.

Finally, a hepatitis B public-private partnership may help to re-energize a cause that continues to fall short of attention. At the very least, support from organizations like the WHO, UNICEF, and CDC makes a statement. It demonstrates that the main actors in the global health community take the disease seriously and are dedicated to decreasing morbidity and mortality rates associated with it. PPPs bring together the masses and speak on behalf of a united front. In the realm of hepatitis B, future progress is likely dependent on the development of a hepatitis B-specific PPP. The seeds of such a partnership have already been planted in the form of the World Hepatitis Alliance, but the Alliance needs support from public health agencies in addition to private donors and other nongovernmental groups. Many people engaged in the hepatitis fight acknowledge the value in developing a hepatitis B public-private partnership.⁴⁴ Without one, the hepatitis B landscape will remain decentralized, isolated, and "desert-like."⁴⁵

For quite some time, public goods scholars have noted how a more interconnected and globalized world can produce negative externalities in the form of disease transmission and movement that states alone cannot handle.⁴⁶ The proposed hepatitis B public-private partnership has the potential to unite

developing and developed countries with international and regional health agencies, nongovernmental organizations, as well as private firms and investors - all of which can positively contribute to remedying the global HBV crisis.

PUBLIC GOODS CONTINGENCY

Health causes often find themselves in competition with one another when it comes to funding, political attention, and research and development. Consider, for example, the Global Polio Eradication Initiative and Measles Initiative. The former is dedicated to the eradication of polio and the latter to global measles control. In endemic polio/measles countries, most notably India, measles control activities are frequently hindered because of the push to finalize polio eradication. While both initiatives are quite supportive of each other, there is no denying that the Measles Initiative, at times, falls short due to polio eradication activities. Hepatitis B also suffers because other global health needs remain unmet. As the seventh vaccine incorporated into the WHO Expanded Programme on Immunization, hepatitis B is frequently treated as the EPI outsider. For quite some time, the WHO was reluctant to incorporate hepatitis B into the Expanded Programme on Immunization because the EPI was already struggling with the distribution of measles, polio, BCG, tetanus, pertussis, and diphtheria vaccines.⁴⁷ Until the HBV Task Force demonstrated the feasibility of incorporating hepatitis B vaccine into national immunization schedules, the inclusion of HBV into routine immunization programs, particularly in poor countries, remained unlikely. Muraskin's interview with Terrel Hill, former EPI advisor for UNICEF, lends support to the claim that increased efforts for hepatitis B are contingent upon other successes:

[W]e have a measles goal: control by 1995. There will be a doubling of our investment on measles. Also, there is a neo-natal tetanus goal; [that] will [require] double the investment. The bottom line is we don't have the resources...We have other goals [too] – education, jobs, etc. All require more funds. If we fundraise where do we put the emphasis. [If UNICEF started to raise funds aggressively for hepatitis B, then] that money will not be available for AIDS, diarrheal disease...or education...[It is a case of] competition with scare resources.⁴⁸

In short, the hepatitis B community finds itself constrained on a number of fronts. Health targets stemming from the World Health Assembly and WHO regions, such as polio eradication, measles control, and diarrheal disease reduction, continue to complicate efforts to do more for the global HBV crisis. Because we have limited resources to combat global health ills, selective decisions have to be made and hepatitis B frequently stands on the losing end of these decisions. As I will discuss, one reason for the continued resistance to hepatitis B reduction activities may be related to perceptions of HBV transmission. The distorted and misguided perceptions of HBV transmission, combined with a limited global voice, create a perfect storm whereby hepatitis B continues to be overlooked, pushed aside, and neglected.

As we move the public goods agenda forward, it is clear that there is a deep interconnection between public goods cohorts of the health variety. Hepatitis B is related to HIV/AIDS, polio, measles, malaria, and tuberculosis in more ways than one. It is therefore necessary to understand better how these communities interact, engage, and compete with one another. Doing so may help us create health policy that is more all-encompassing and wide-ranging.

PERCEPTION AND HEPATITIS B TRANSMISSION

One of the hallmarks of public goods analyses has been a reliance on formal modeling and quantitative methodology to assess the costs and benefits associated with public goods provision. Indeed, the use of sophisticated quantitative techniques has earned public goods theory the reputation for being robust and generalizable. Economic analyses of health interventions frequently guide policymakers in executing health decisions. When the benefits of intervention outweigh the costs, intervention becomes a viable policy option. In contrast, when the costs of intervention outweigh the benefits, intervention is much less likely. Of course, even economic models can contain subjective biases, and as Dr. Harold Margolis reminds us, early attempts to model the costs and benefits of HBV reduction activities made it appear that it was cheaper to let people die from hepatitis B than to seriously engage in national immunization, improved surveillance measures, and similar activities.⁴⁹ For example, in 1997/98, the Pennsylvania Health Care Cost Containment Council concluded, "while we recognize that prevention—through immunization—is an effective method in combating this chronic disease, we did not find evidence to recommend acceleration of the hepatitis B immunization program as currently outlined in this bill."50

Eventually, a more accurate understanding of HBV-associated costs and benefits emerged, and it is now widely believed that the benefits of universal infant vaccination, measured in life years lost due to premature death (disability adjusted life years) and the costs of treating patients with liver disease, significantly outweigh the costs of providing the vaccine.⁵¹ In short, it pays to vaccinate, but HBV vaccine is still under-delivered.

Recently, scholars such as Gaizer and Touffut⁵² and Kaul⁵³ have begun to address the socially constructed nature of public goods. In other words, what we accept as public and private largely result from deliberate decisions made by policymakers. This has ultimately led scholars to question the processes that lead a particular good to be classified as either public or private as well as the mechanisms that can be pursued to shift a good from public to private and vice versa. These types of analyses are much more "sticky" and hard to quantify. They present an added "fuzzy" dimension to an overly formal theoretical lens. If we accept that public goods are subjective entities, then we should also assume that decision-makers have the power to decide which goods receive attention and which do not. With this in mind, skewed perceptions of HBV transmission, and disagreements surrounding disease epidemiology, continue to obstruct attempts to elevate hepatitis B to a higher position on the global health agenda, despite the

known economic benefits that a more sustained global effort to reduce HBV prevalence could produce.

To expand, hepatitis B can be transmitted in a variety of ways: unprotected sex, mother-to-child, child-to-child, intravenous drug use, sharing personal items with someone infected, tattoos and piercing needles, and human bites.⁵⁴ In the developing world, particularly in Africa and Asia, mother-to-child and child-to-child are common modes of hepatitis B transmission. In developed countries, like the US, intravenous drug use and unprotected sex are more commonplace modes of transmission and contribute to higher rates of acute infections. In this sense, there are what we might call innocent and risky modes of HBV transmission. This is a very different situation from diseases such as polio, measles, or pertusiss, all of which are associated with innocent routes of transmission in infancy and childhood.

Anti-vaccine advocates have unfairly highlighted high-risk modes to the disadvantage of the global hepatitis B community. For example, Schlafly argues:

My new grandchildren were not at risk for hepatitis B, which is primarily an adult disease transmitted through bodily fluids. Those most at risk are the highly promiscuous (heterosexual or homosexual), needle-sharing drug addicts, health care and custodial workers exposed to blood and babies born to infected mothers.⁵⁵

As a result of this manipulation, developing countries are disadvantaged because of the perceptions of hepatitis B held by key decision makers in the developed world, even though the most common modes of transmission vary greatly from the global North to the global South. That perception of disease transmission works against the hepatitis B struggle is widely accepted in the hepatitis community. For example, Dr. Alison Evans notes, "among more educated people who do understand what hepatitis B is, there's a lot of stigma." ⁵⁶ Charles Gore (2009), adds:

Yes – there's a huge stigma. One of things that you have to remember is that communicable diseases per se carry a stigma...people do not like talking about communicable disease: this is sexually transmitted disease, this is blood borne viruses, this is anything regardless of how you get it. Because, you know, you are a risk to other people - it's that whole kind of you're a leper [thing].⁵⁷

Additionally, Kathy Hyett, President of Togo Run notes, "So I think it's almost like the perfect storm of all these conditions coming together and...it's just so big that lots of people keep trying to fix it but they're just...taking little chunks out of the problem."⁵⁸ Stigmatizing hepatitis B-positive persons has tangible consequences that run deep. In China, for example, discriminatory employment laws against hepatitis B carriers mean that some people actually lose their jobs, or fail to get hired, if they are known to be infected with the virus.

The consequences from this stigmatization and ostracism generate a negative cycle which is hard to interrupt. First, people are reluctant to get tested, which means that the virus will continue to circulate. Few people are willing to openly talk about their infection and thus some of the greatest potential advocates remain silenced. Third, because people remain silent, the problem gets

overlooked in decision-making circles and the issue is relegated to a less important status than it really deserves. Dr. Alison Evans notes that many chronic carriers in the US are legal migrants from Asia.⁵⁹ These individuals, particularly parents of adopted children, are reluctant to address the issue over fear that hepatitis B will be associated with immigration - a politically heated debate. As we've seen in the past, particularly in reference to the HIV/AIDS community, some of the most influential advocates who've fought for public recognition of the disease are carriers themselves.⁶⁰ That so few hepatitis B-positive persons are willing to come forward and publicly engage with the issue, particularly in countries that have the ability to make a difference, is therefore very troubling.⁶¹

In order to assuage the stigmatization of hepatitis B carriers, a concerted effort needs to be made to downplay high-risk modes of transmission – a goal that the proposed hepatitis B PPP could further. This is because in areas where carrier rates are highest, high-risk modes of transmission are less common. Thus, the global North has painted an unfair and inaccurate picture of hepatitis B transmission that has transnational effects. Instead, highlighting the multiple innocent routes of transmission would have the potential to increase public acceptance of the vaccine for infants. Particularly in cultures where homosexuality and promiscuous sexual encounters remain taboo subjects, finessing the way we talk about hepatitis B can help shift individual perception regarding hepatitis B transmission and infection. Additionally, it is more politically attractive to allocate funds to vaccines that protect the innocent as opposed to the "high risk." ⁶²

Perception of disease transmission is not the only social construction working against the hepatitis B community. So too is perception of the carrier. Hepatitis B vaccine is a childhood vaccine that prevents middle-aged liver disease. Whereas diseases like polio and measles most frequently infect and subsequently kill or paralyze children, few kids die from hepatitis B infection. Rather, the earlier children contract it, the greater their likelihood of becoming chronic carriers and thus battling liver disease later in life. This is a tension with which the hepatitis B community continues to struggle. Is hepatitis B a childhood or an adult problem? As Dr. Steven Wiersma of the WHO notes:

The other thing that's made this vaccine...less interesting...is it's not a child survival vaccine. Think about all the EPI vaccines...common, universally used vaccines [that] in some way impact child mortality and this one absolutely doesn't and I think it just got missed by a lot of people.⁶³

We are much more willing to accept death at forty or fifty years than we are at age one or two. If we view HBV through an economic lens, the productive life years lost due to premature death at a young age significantly outweigh the productive life years lost from death at forty or fifty. In this sense, perceptions of *who* are the rightful referents of health and health goods are a vital part of the hepatitis B story. There are direct policy implications that emerge from this assessment. Namely, in order to increase vaccine distribution, raise public

awareness, and heighten political will, hepatitis B needs to be portrayed as a childhood issue.

Moreover, if this assessment is indeed true – that the global health community and health policymakers are more inclined to address acute and childhood diseases - then one must question how this might affect the support and attention devoted to other chronic diseases and non-childhood illnesses. For example, a recent breakthrough in the obstetrics/gynecology community has been the discovery of the HPV (human papillomavirus) vaccine, which can prevent cervical cancer in women. HPV is a sexually transmitted disease and most severely affects sexually active women between the ages of 15-24. In the US, there is still resistance to full financial coverage of the HPV vaccine for sexually active women among healthcare providers, many of whom will not fully cover the cost of the vaccine or will not do so after a certain age. As the CDC notes, "while some insurance companies may cover the vaccine, others may not." Just as with hepatitis B, it is likely that resistance to funding this beneficial anti-cancer vaccine is related to perception of disease transmission and carriers.

A final note about perception is in order. One of the reasons that HBV vaccine pricing dropped significantly in the early 1990s was due to an increase in non-Western vaccine manufacturers, like the Korean Green Cross Corporation. ⁶⁵ As Dr. Alison Evans claims, "Now, countries like China, Taiwan, and Korea make their own vaccine and... at least in China...it's made in government factories and...they're not trying to make a profit from it. They're trying to distribute it as widely as possible." The increase in HBV vaccine manufacturers means that supply is increasing while price is decreasing. Thus, no single corporation can claim a monopoly on vaccine distribution and demand unreasonable prices for it.

However, not everyone agrees that increasing the number of developing country vaccine manufacturers is the most appropriate way to decrease costs on the international vaccine market. In other words, some see this phenomenon as troublesome because they fear developing countries will manufacture vaccines that are of subpar quality and may actually inflict more harm than good. Advocates of developing country vaccine manufacture respond that the reason some pharmaceuticals do not meet internationally established vaccine standards is because public health agencies are unfairly persuaded by big pharmaceutical companies who demand vaccine standards that are unachievable to all but big pharma. For example, with regards to hepatitis B vaccine standards, Muraskin argues:

When the Task Force was organized, the existing WHO standards for vaccines were exceptionally rigorous – many people considered them unreasonably so – and the suspicion existed that the inability of most vaccine manufacturers to meet those standards was not coincidental...one of the key aspects of the requirements involved a level of purity for the vaccine that was only achievable by using the process Merck employed.⁶⁷

Erecting barriers that work against the creation of developing country vaccine manufacturers is not only wrong on ethical grounds, as such companies have the potential to significantly increase the availability of medicines needed to combat health ills largely confined to the global South, but it also interferes with

the free market and the free exchange of goods and services. As Jadhav claims, more and more developing country vaccine manufacturers are demonstrating that they can develop quality vaccines and at a reduced price. Furthermore, they are more likely to focus on vaccines that big pharmaceutical companies neglect.⁶⁸

Assuming that developing country vaccine manufacturers continue to produce quality vaccines, it is in the interest of the global health community to facilitate large-scale investment in public health agencies as well as aiding the transfer of medical technology. Doing so will put downward pressure on vaccine prices and it can also catalyze increased research on neglected tropical diseases. Of course, this policy suggestion will not be accepted by all decision-makers alike, particularly those with ties to big pharma, but it is one way to aid developing countries in their attempts to improve basic national healthcare services. An increase in developing country vaccine manufacturers may also help to meet a number of the Millennium Development Goals that target children's health and wellness, poverty, and maternal mortality.

CONCLUSION

Using a public goods framework to better understand the failure to more effectively tackle the global HBV crisis suggests that a hepatitis B specific public-private partnership could help to overcome issues related to vaccine distribution, global surveillance and monitoring, as well as aiding individual states who are either unable, or unwilling, to elevate the fight against HBV to a higher status in health decision-making circles. The public goods framework also reveals areas of tension between the hepatitis B community and other disease cohorts that continue to battle for international recognition and attention. As we move the public goods agenda forward, scholars must make a more concerted effort to question how different types of health communities can engage one another and what this type of engagement might look like. Where the public goods framework remains weak, however, lies with its rational choice leanings which make it difficult to incorporate issues related to perception and misperception of disease transmission and the carrier.

There are many lessons and recommendations that emerge from this assessment of the hepatitis B crisis and efforts (failed and successful) to curb the spread of hepatitis B globally. Below is a plan of action which will ideally move these suggestions forward.

A Proposed Plan of Action to Eliminate Hepatitis B:

- The proposed hepatitis B public-private partnership needs collaborators that will combine their expertise in the following areas: technical assistance, research and development, bargaining skills for vaccine procurement, funding, laboratory expertise, monitoring and surveillance, advocacy and awareness, and country-specific knowledge of disease epidemiology.
- Some players that will likely be critical in the proposed hepatitis B partnership are: World Health Organization, Centers for Disease Control

- and Prevention, United Nations Children's Fund, GAVI, World Hepatitis Alliance, and Hepatitis B Foundation.
- WHO, UNICEF, and CDC should aid in providing the following necessities to the proposed partnership: technical assistance, laboratory expertise, research and development, country-specific knowledge, monitoring and surveillance, and vaccine procurement.
- The World Hepatitis Alliance and Hepatitis B Foundation stand in the best position to spearhead the proposed public-private partnership given their comparative advantage in promoting hepatitis B awareness and advocacy. The World Hepatitis Alliance is a global partnership that brings together hepatitis B (and C) patient and advocacy groups. The Hepatitis B Foundation is the only US non-profit organization solely dedicated to the global problem of hepatitis B.
- GAVI already provides support to developing countries for the incorporation of hepatitis B vaccine into routine immunization schedules. GAVI expertise and experience should be drawn on, particularly as GAVI is operative in developing countries with poor routine healthcare services.
- For the past twenty-three years, the CDC has funded the sole WHO position for viral hepatitis. As one of the most respected international authorities in the realm of health, the WHO needs to increase the resources it devotes to hepatitis B and hire more staff for research and development. Some of this staff should solely confine their activities to hepatitis B and not viral hepatitis broadly speaking (which includes hepatitides A, B, C, D & E).
- Increased funding from private foundations/donors is necessary to increase the delivery and supply of HBV vaccine, treatment for infected persons, advocacy and awareness campaigns, as well as permanent staff for the proposed partnership. Private donors such as the Bill and Melinda Gates Foundation and the UN Foundation continue to donate enormous sums of money to various global health projects; however, it is absolutely necessary to tap into new sources of funding. Due to donor fatigue and donor schizophrenia, diversification of funding sources is critical.
- Once formed, and pending future decisions in the World Health Assembly, the proposed partnership will need to enact structural decisions. Namely, will the partnership be structured as top-down or bottom-up? If the partnership favors the former, then looking to the experiences of the Global Polio Eradication Initiative (WHO, CDC, Rotary International, and UNICEF as core partners) is recommended. If the partnership chooses to remain decentralized and operate from the ground up, it is recommended that it explore the history of the Measles Initiative (WHO, CDC, UNICEF, UN Foundation, and Red Cross as core partners).
- The proposed partnership needs a simplistic but straightforward mission and plan of action. This will address questions regarding the overall program goals, relationship of partners to one another, target regions/countries, frequency of partner interaction, and modes of communication.

- In addition to increasing the delivery of hepatitis B vaccine and treatment for sick persons, the partnership must make a concerted effort to portray hepatitis B as a childhood vaccine and childhood necessity regardless of the fact that the worst effects of chronic hepatitis B infection do not set into until middle age. This will require sustained public advocacy and awareness.
- The partnership should attempt, when possible, to disassociate hepatitis B infection from issues related to immigration. This will ideally increase the partnerships support base as potential advocates and proponents will be more willing to speak up and become active.
- Given the success of Taiwan in significantly reducing acute and chronic cases of hepatitis B transmission, the partnership should use the Taiwan program as a model to emulate. Other Western Pacific countries have since adopted similar approaches to HBV prevention universal infant vaccination, close monitoring of vaccination status, and sustained public awareness campaigns. This approach to HBV elimination should be applied elsewhere.

Charles Gore claims, "I wouldn't be doing this if I didn't feel so strongly that this is just a totally unacceptable situation that I, like you, cannot understand. I cannot understand why these people are dying...its ridiculous." ⁶⁹ We, the global health community, possess the first anti-cancer vaccine. It is technically feasible to eradicate hepatitis B, and yet every year millions of people suffer and die unnecessarily from hepatitis B-induced liver disease. While the international community may be late in responding to the HBV crisis, as the sage says, better late than never.

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