

Understanding those who do not understand: a brief review of the anti-vaccine movement

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Abstract

Vaccines and the ability to prevent morbidity and mortality due to infectious diseases have been one of the greatest public health success stories. On a global level, it is one of the few cost-effective medical measures that result in universal benefit. Despite this, there is evidence of a growing anti-vaccine movement. In turn, this has, in some cases, resulted in major disruptions in vaccine programs, with resultant needless morbidity and mortality. Of interest are the factors that seem to contribute to the current trend of anti-vaccine sentiment. This paper will examine the current anti-vaccine movement and provide current examples. Finally, a review of suggestions for dealing with the anti-vaccine movement will be presented. © 2001 Elsevier Science Ltd. All rights reserved.

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“What has been will be again, what has been done will be done again, there is nothing new under the sun. Is there anything of which one can say, Look! Is this something new? It was here already, long ago; it was here before our time.” Ecclesiastes 1:10

1. Introduction

Vaccines and the ability to prevent morbidity and mortality due to infectious diseases have been one of the greatest public health success stories [1]. On a global level, it is one of the few cost-effective medical measures that result in population-level broad benefit across the age spectrum. Despite this, there is evidence in Western Europe, the US, Japan, Australia, and other countries of a growing anti-vaccine movement. This movement has resulted in major disruptions and even

cessation of vaccine programs, with resultant increased morbidity and mortality. Of interest is an examination of the factors that seem to contribute to the current trend of anti-vaccine sentiment. In this paper we will examine the current anti-vaccine movement and provide case studies involving pertussis and hepatitis B vaccines. We will then discuss the implications for public health vaccine policy. Finally, we will propose a framework for understanding how individuals make decisions about receipt of vaccines. This will be discussed in order to stimulate discussion and debate about how best to design public health policies aimed at improving immunization coverage rates.

2. Background

Infectious diseases have plagued mankind since the beginning of time. In fact, infectious diseases have been suggested as a major factor shaping the history of man [2]. It is therefore a considerable scientific and public health triumph to realize that mortality due to vaccine-preventable diseases is at an all time low [3]. In addition, once deadly or debilitating diseases such as

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smallpox, polio, and *Haemophilus influenzae* type b have either been eradicated or significantly reduced in most developed countries through the universal use of safe and effective vaccines. In the case of smallpox as one example, this occurred despite tremendous opposition at the onset of smallpox vaccination programs [4,5]. As infectious disease epidemics have waned and fear of death or disability due to infection has lessened, increasing concerns over possible vaccine side effects and safety have arisen. While history suggests that this sequence of events is predictable, the skilled use of the media and the internet in today's global communication network have allowed immense influence of the 'anti-vaccine' groups, further fueling public and media concerns over vaccine safety. In addition, this has led to concerns and objections over federal mandates to receive vaccines as a condition for school and military entry. In measurable ways the anti-vaccine movement has impacted state and national public health policy, and jeopardized individual and societal health. The issue then, is that even as we eradicate disease, we are now faced with anti-vaccine movements and widespread cultural concerns that may make eradication of disease impossible. For this reason, vaccine providers and advocates will increasingly be faced with being able to articulate the value of vaccines to anti-vaccine groups, persons with legitimate questions and concerns, and other groups such as hospital boards, legislative bodies, schools, and others.

3. Current cultural context and concerns

Many would argue that we have become a culture characterized by intolerance of any risk (particularly of co-mission as opposed to omission), such that when harm does occur someone is to blame. We have also become an information society where information, accurate or inaccurate, is widely available, utilized, and promulgated across the world via the internet. Influenced by these trends, many of the anti-vaccine groups also demonstrate an anti-authority stance (with implications for state or federal mandates for vaccines). This plays into widespread feelings on the part of many Americans who now view their government with varying levels of mistrust (some legitimate, some not) further fueling concerns over 'governmental' recommendations regarding vaccine use, and governmental reassurances regarding vaccine safety.

In addition, our society is poorly educated on risk and probability thinking such that we fail to grasp the undeniable notion that harm cannot be completely prevented and some risks remain irreducible or uncertain, and yet to do nothing offers greater harm to the public good. As an example, during the 1980s in the US, lawsuits over alleged serious and fatal side effects

of the whole cell pertussis vaccine caused manufacturers to substantially increase the cost of pertussis vaccine in response to increased financial liability. Due to this situation, several manufacturers simply stopped producing pertussis vaccine, resulting in a crisis that culminated in the federal government developing a vaccine injury compensation program to protect manufacturers and prevent the loss of the nations' ability to manufacture and distribute pertussis vaccine [6–8].

Another trend of concern is the failure of public health officials to educate both the public and providers on the benefits of vaccines, and the failure of health systems to develop safety monitoring systems to answer patient concerns with convincing data. In addition, in an era of increasing numbers of vaccines, we may, on occasion, fail to intelligently deploy vaccines — using a 'one size fits all' approach — mostly due to an inability to deliver vaccine to the highest risk groups (often for political or other reasons). Finally, our own observation has been a surprising number of health care workers at all levels, who themselves do not understand vaccine safety and efficacy, and are not champions of vaccines.

4. Genesis of concerns

We must first acknowledge that vaccines can and do cause harm and may even theoretically carry unknown risks. Vaccines are immunobiologics, and all immunobiologics have been associated with adverse effects, from the frequent occurrence of brief and mild local inflammation following tetanus toxoid injection to the rare occurrence of paralytic polio following vaccination with the oral polio vaccine (OPV). Inescapable, however, is that it is impossible to fully know all the possible risks of a given vaccine *until* it is widely used in the population.

The genesis of many of the concerns commonly expressed by anti-vaccine groups include the idea that immunobiologics are 'foreign' material injected into the body of otherwise healthy persons, in order to lower the probability of future harm. In parallel with this concern is that an increasing number of antigens and injections, by virtue solely of the number of vaccines, are thought to somehow carry additional risks not true of the individual vaccines by themselves, such as vague concerns over an increased risk of cancer or of auto-immune illnesses. The Center for Disease Control and Prevention has developed a booklet examining the most common objections that anti-vaccine advocates express regarding vaccines [9]. These include the idea that the disease had already begun to disappear prior to the use of vaccines; concerns that the majority of people who get a vaccine-preventable disease were previously immunized, that there are 'hot' lots of vaccines particu-

larly associated with a greater frequency and/or severity of adverse events and deaths than other lots; that vaccines cause illnesses and deaths; that vaccine-preventable diseases have been eliminated already; that multiple vaccines 'overload' the immune system; that vaccines are not 'natural' with a preference for disease-induced immunity, and finally any variety of political/economic conspiracy theories regarding manufacturer profits, minority issues, and even genocide issues.

The concerns expressed above are widely, in one form or another, promulgated on anti-vaccine internet web sites. Anti-vaccine groups have taken advantage not only of the internet to increase their presence in the debate, but also exaggerate, publicize and dramatize cases of vaccine reactions to the media and the public. At the current time we were able to identify well over 300 anti-vaccine internet sites from a single simple search. An inadequate scientific knowledge base within the media, and an irresponsible tendency toward the sensational contributes and plays into public fears and concerns as the media and the anti-vaccine groups engage one another without regard to scientific knowledge, facts, or credentials, leading to the coining of the term 'scientific terrorism'. In addition, anti-vaccine groups have been successful in finding outspoken and articulate spokespersons for the cause. Members of the public, in turn, develop concerns about vaccines and vaccine programs when an authority (i.e. the government) mandates them, and where the loss of philosophical or religious exemptions is threatened. Finally, in the face of such concerns, the decreased advocacy by some health care workers for vaccines contributes to an increase in societal concerns relative to vaccine risks and benefits and vaccine coverage rates.

An example of the effects described above is illustrated by a recent nationally representative telephone survey of 1600 US parents of children < 6 years old [10]. The results of those interviews revealed that 25% of parents believed that a child's immune system was 'weakened' by too many vaccines. Twenty-three percent believed that children got more immunizations than was good for their health, and 15% did not want their next child to get at least one of the currently recommended vaccines. Further evidence of this phenomenon is that the number of reports to the Vaccine Adverse Event Reporting System (VAERS) is now about 11 000 per year, exceeding the reported incidence of most childhood vaccine-preventable diseases combined [11]. Of course, as individual concerns rise, the number of reports rises, without regard to differentiating adverse events caused by a vaccine, versus those associated coincidentally with the timing of vaccine administration.

5. Case study: pertussis and hepatitis B vaccines

During the 1970s, anti-vaccine groups increasingly voiced media-intense concerns about perceived ill effects due to the whole cell pertussis vaccines, while the disease itself caused millions of cases and hundreds of thousands of deaths, globally. The result of these concerns was widespread cessation of pertussis vaccine use in Sweden, Japan, UK, the Russian Federation, Italy, former West Germany, Ireland and Australia. A review of the association between the anti-vaccine movement in each country and the resulting decrease in pertussis immunization coverage rates, led to documented increases in pertussis infection 10–100 times higher than in neighboring countries without disruption of pertussis immunization [12]. Indeed, strong evidence, using standard epidemiologic criteria for causality, revealed a causal relation between anti-vaccine movements against pertussis vaccine and pertussis epidemics. These countries have now reinstated pertussis immunization programs — but only after considerable and avoidable morbidity and mortality. In comparison, countries such as USA, Hungary, former East Germany, and Poland with sustained use of pertussis vaccines, did not experience pertussis epidemics.

As another example, for some years questions about the possible association between vaccines and auto-immune disorders have been raised — in the absence of data suggesting merit in this hypothesis [13]. Since 1994, vocal anti-vaccine groups in France began advocating a countrywide shut-down of hepatitis B immunization programs among pre-adolescents, due to concerns that the vaccine was causing demyelination syndromes, particularly multiple sclerosis among this age group. As a result of increasing pressure from these groups, and their effective engagement of the public and the courts in these concerns, the government of France suspended all hepatitis B immunization programs among adolescents on October 1, 1998. This occurred despite expert advice from the WHO and others, as well as studies demonstrating that no evidence existed suggesting such an association in studies conducted in France, the UK and in the US [14]. When science began to prevail over anecdote, and it became clear that such concerns were unfounded [15–17] the program was later reinstated by the government. Nonetheless, acceptance of the hepatitis B vaccine in France has predictably fallen, despite evidence contrary to the hypothesis that there is a causal association between hepatitis B immunization and multiple sclerosis [17].

Finally, concerns over possible associations between measles vaccine and both autism and inflammatory bowel disease have arisen in UK, again in the absence of plausible evidence suggesting causation [18]. Unfortunately, measles vaccine uptake will predictably suffer with untold harm to many children.

6. Understanding societal and individual decision-making regarding immunization

As others have demonstrated, as the incidence of vaccine-preventable diseases decreases due to efficacious vaccines, vaccine adverse events become more noticeable and highly publicized [19]. As a result, loss of confidence in the vaccine may occur, with the result that outbreaks once again occur. Fortunately, this usually leads to resumption in confidence of the vaccine [11].

So how then, does loss of confidence occur — at least at the population or societal level? We have proposed that a ‘pyramid effect’ is operative in the way societal decisions are made about vaccine safety and acceptance in society [20]. The base of the pyramid can be imagined to resemble the benefit of a widespread public health policy such as the use of a vaccine to prevent a common disease that causes harm. It is broad in its effects. The vaccine benefits the vast majority of the public. The peak of the pyramid represents harm or risk. In all cases, it has an effect on very, very few individuals, however, its effects are perceived as severe, acute, and major in harm. The majority benefits from the vaccine but never or rarely is aware of the benefit (i.e. the gradual cessation of an epidemic). A few are actually harmed, or perceive harm, but perceive it intensely, acutely, and substantially. For this reason the societal (and media) voices are unbalanced. The vast majority who benefit from an immunization program are passive participants. The minority who experience or perceive harm may become passionate and vociferous opponents. In many cases, they may become the only individuals who voice their opinions, thus causing a societal sense that the vaccine leads to more harm than good.

Also, as we have discussed elsewhere [20], the perception of risk or probability of harm in this ‘pyramid model’ among the population arises from a ‘dilution of benefit’. As the widespread use of a vaccine diminishes or eliminates the risk of a disease, the public’s perception of the vaccines’ *value* paradoxically diminishes — because the public no longer observes the disease or its aftermath, and hence perceives little or no benefit. The very success of the vaccine causes its benefit to be diluted or less valued once the disease is no longer considered a high-level threat or risk. Paradoxically, the more effective a vaccine is the more powerful the dilution of benefit effect appears to be. Chen has proposed a model that attempts to define these stages of an immunization program starting with the introduction of a new vaccine, where such programs go from the pre-vaccine stage to the stage of increasing vaccine coverage, loss of confidence in the vaccine (due to real or perceived side effects), resumption of vaccine confidence, eradication of disease, and finally cessation of vaccine use [21].

Other factors also may promote an anti-vaccine ethos in the culture. Mandatory federal programs with punitive consequences for failure to comply, as opposed to ‘promotive’ immunization programs, may increase vaccine non-acceptance [22]. Evidence for this is simply the large number of ‘anti-vaccine’ groups who frequently cite this issue. Additionally, federal attempts to institute childhood immunization registries in each county and each state add to concerns about the role of government in individual health matters, particularly the right of the government to ‘coerce individuals to have themselves or their children vaccinated [22]’. Streefland et al. comment that ‘the imminent expansion of vaccination schedules with more vaccines and vaccine combinations, ...will stress parents’ perception that, in vaccination practice, ‘experts’ are making fundamental decisions about their children’s health, without consultation or providing the option to exempt [22]’.

On an individual level, it is also instructive to examine how individuals make decisions regarding vaccines. Such decisions are often made on the basis of common ‘rules of thumb,’ or heuristics. The availability heuristic occurs when we assume that the ease with which we can recall something (such as dramatic media reports of a dreadful side effect to a theoretical vaccine) represents the probability with which such side effects really do, in fact, take place, or the representativeness heuristic (judging probabilities according to similarity of circumstances) [23]. For this reason, the public may be easily misled, lose confidence, and make faulty decisions, about a vaccine where there are unbalanced reports of vaccine adverse events.

Another theory, the extended parallel process model, states that people are unlikely to undertake a risk control measure unless they feel that they can effectively control the risk and that it is personally relevant and serious. Finally, other factors found to be involved in the individual decision as to whether to receive a vaccine includes such issues as omission bias [24] (a bad outcome is worse if it occurred due to an active choice to do something rather than as a consequence of not doing something, ...), free-loading (as long as everyone else gets the vaccine, there’s no reason for me to get it, ...), altruism (I should get vaccines to protect others too, ...), bandwagoning (I get vaccines because it seems like everyone else does, ...), risk perception (I get vaccines because the risk of not getting them is so much worse, ...), and adverse event avoidance (I don’t get vaccines because there might be a side effect, ...) [25]. Interestingly enough, social research suggests that the highest rates of vaccine coverage are achieved in a milieu of bandwagoning, where everyone else is apparently getting the vaccine and it seems to be the expectation that everyone does this good and right thing for themselves and their children. Others have named this phenomenon ‘passive acceptance’ and attribute high

vaccine coverage rates to this situation where ‘people have their children vaccinated because everybody does so and it seems the normal thing to do’ [22].

7. Conclusion

In recent years, concerns about vaccine safety have hampered efforts at increasing immunization rates among individuals and important subsets of the population. As we have demonstrated within this paper, the controversy and alarm caused by anti-vaccine groups has a demonstrable detrimental effect on population-level vaccine coverage rates. This, in turn, increases the burden of human suffering, increases health care costs, consumes resources otherwise useful for a productive economy, and finally, compounds the problem by putting other individuals and groups at risk.

Since we have much to gain, individually and as a society, by protecting ourselves against infectious diseases, we must be prepared to engage in the hard work of engaging the public and demonstrating the safety and benefits of vaccines. We must also do this in a manner that protects individual rights of autonomy and freedom of choice, including what we might see as the misguided choice of not receiving vaccines. Efforts at developing promotive, rather than prescriptive immunization programs are likely to achieve better long-term results in a free society where trust in government and public health recommendations must be maintained. For this reason, as we have promoted, our own view is that the role of the government is to inform, educate, recommend, and even provide incentives for immunization — but not to mandate without exclusion acceptance among the civilian population [20]. Informed refusal must remain an acceptable choice in a free democracy, and the culture of informed consent, with both religious and philosophical exemption must be maintained. We recognize the difficult balancing act in determining the right of the state to control an infectious disease, and the right of the individual to choose. This might be negotiated by considering (with informed refusal) universal immunization against those diseases that pose unacceptable risks to others in the community.

Finally, much more in the way of research must be funded and carried out in understanding vaccine safety, and in particular social research designed to understand how individuals make vaccine decisions [22,25]. As we move into the 21st century, new technologies such as the Human Genome Project and gene expression array systems, may offer the ability to easily individually screen individuals for gene-mediated risks of adverse reactions to vaccines, and predict who might suffer harm from a vaccine. Until then, health care providers must be informed advocates for vaccines and offer the

public and the media balanced scientific facts, credibility, and an understandable assessment of the risks and benefits of their immunization choices.

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