Heralding the Pariahs: What the Narratives of Vaccine Hesitant Parents Can Teach Us about the Backfire Effect and Physician-Patient Relationships

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Abstract

Recent research has shown that pro-vaccine education can create a backfire effect, times in which vaccine hesitant parents report to believe in the presented scientific facts but are now less inclined to vaccinate their children. Most recommendations for mitigating the backfire effect involve avoiding or taming the parents’ worldview. This paper will take a different course. The purpose of this paper is to deeply explore the worldview of vaccine hesitant parents in order to better understand this backfire effect. 181 online narratives posted by vaccine hesitant parents describing their thoughts and feelings when their doctor attempted to convince them to vaccinate their children were collected and analyzed. 410 open codes and 14 axial codes were developed. The themes that emerged within this analysis showed that many parents felt demeaned and slandered when their doctor was trying to persuade them to utilize vaccines. Overall, the parents reported that they did not trust the character or motives of their doctor. This analysis shows that a potential hidden, though critical, mechanism driving the backfire effect might be the parents’ mistrust—not necessarily of just the science but of the doctors themselves.

Keywords

Vaccine hesitancy, Qualitative methods, Narrative ethics, Health communication, Physician-patient relationships

Introduction

In the past few years, vaccine refusal has burst again into public debate. There has been fervor, and outcry, and even anger directed toward vaccine hesitant parents with calls to shame them, or force them, or otherwise compel them to immunize their children. However, vaccine hesitancy, the delay in accepting or the refusal of available and accessible vaccines and services [1] is an entrenched problem in the modern medical landscape and is unlikely to be uprooted by mere communal pressure. For instance, up to 74% of pediatricians report confronting at least one parent per year who refused or delayed immunizations for his or her child [2]. In addition, while the refusal rate for all vaccines remains low (around 1-1.50%) [3,4] many are concerned that the US will not be able to maintain this rate. For example, by some estimates, 60% of parents of children 24-35 months old either delay or refuse some or all vaccines [5]. Vaccine refusal and hesitancy is not just a U.S. problem. According to the World Health Organization’s SAGE Working Group on Vaccine Hesitancy, globally one in five children do not receive vaccinations, which is due to issues of parental hesitancy not just poor access. In its report, the Working Group warns that vaccine hesitancy is “a behavioral phenomenon that is vaccine and context specific” [1]. Therefore, gaining a better understanding of vaccine hesitant parents’ context for refusal is a valuable endeavor.

Some have called for vaccine hesitant parents to be better educated on the safety and efficacy of vaccines. Such education efforts are common strategies for trying to increase vaccine compliance; however, they have been
shown to produce only modest attitude changes and very limited behavioral changes [6-8]. For example, a study compared the effectiveness of four common pro-vaccine messages and found that all four messages failed to persuade vaccine hesitant parents to inoculate their children [9,10]. Recent research has found similar results [11]. In light of this, more systematic research is needed [12].

Vaccine refusal is seen by many as a trying problem, one made all the more vexing by the doggedness of its proponents. One phenomenon, dubbed the backfire effect, shows how frustrating vaccine health education can be. The backfire effect occurs when vaccine hesitant parents are presented scientific information about the safety and efficacy of vaccines, report to believe it, but in light of that belief are now even less inclined to vaccinate their children [13].

Many scholars have developed recommendations for avoiding or diminishing the backfire effect in vaccine education. Some authors propose that health educators or physicians ought to directly and forcefully refute parental misunderstandings regarding vaccine safety and efficacy, others recommend that health educators use non-confrontational dialogue with vaccine hesitant parents to assure them of the benefits of vaccines, while a few advocate for denying service to children of non-compliant parents [14-16]. Many of these recommendations seem to hold little esteem for the world views of vaccine hesitant parents, and instead encourage health educators and physicians to tame or avoid parental view points. This paper will take a different tack. For the past five years we have sought to deeply explore and analyze vaccine hesitant parents’ worldviews. This work has brought new perspectives and insights into the backfire effect. The purpose of this paper is to detail the analysis of online narratives of vaccine hesitant parents, defined for this paper as a publicly told story of an interaction the parent had with a physician, and to propose an underlying mechanism that may be contributing to the backfire effect.

Methods

In order to explore and analyze the worldview of these vaccine hesitant parents, we chose to employ a grounded theory qualitative method. For the analysis, we exclusively collected online narratives from blog postings, website articles and comment sections posted on anti vaccination and other websites. This online format allows parents the space to publish detailed stories of their interactions with their physicians and to also respond to critics and allies of their positions. In addition, research has shown that anti-vaccination communities are idiosyncratic [4], therefore data from national websites, with contributions from parents across the country, provided more generalizable results compared to interviews or focus groups within an immediate geographic region.

The online sources initially considered for this study were those affiliated with known anti-vaccine websites such as Age of Autism, Generation Rescue, and the Australian Vaccine Network; however, this convenience-based selection strategy was too broad for the specific purpose of our study. Therefore, a more specified purposive sampling was used in the final selection of the online narratives. As such, the final inclusion criteria for this study were the following: First, the post was written by a parent who was refusing to vaccinate their child; second, the post itself must be a narrative, a story about an actual clinical interaction, not just a collection of thoughts regarding the topic of vaccine refusal or a rebuttal to an other comment; third, only one post per parent would be analyzed; and fourth, the clinical interaction must have

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<thead>
<tr>
<th>Axial code name (# of open codes associated with the code)</th>
<th>Axial codes</th>
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<tbody>
<tr>
<td>Doctor demeans (69)</td>
<td>Parental research (53)</td>
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<tr>
<td>Doctor uses rote persuasive strategies (65)</td>
<td>Doctor dismisses family from practice (38)</td>
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<td>Parental research (53)</td>
<td>Autism etiology and fears (30)</td>
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<td>Autism etiology and fears (30)</td>
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<td>Doctor misleads or ‘lies’ (17)</td>
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<td>Parents seek more accepting doctor (17)</td>
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<td>Doctor does not respect parent’s autonomy (12)</td>
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<td>Parents seek more accepting doctor (17)</td>
<td>Parents lying (5)</td>
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<td>Doctor does not respect parent’s autonomy (12)</td>
<td>Doctors and money (3)</td>
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*Every narrative collected in this article was posted anonymously on public websites with the expressed intention of fostering discussions about vaccine hesitancy.*
been with a physician seeking to convince the parent to vaccinate their child. These tailored inclusion criteria allowed for a more expansive website search, and included, in addition to the previously mentioned websites, sites like: The New York Times, USA Today, The L.A. Times, Science, Nature, Reuters, The Healthy Home Economist, Ideal Medical Care, The Verge, Salon, The Blaze, The Science Blogs, Forbes, as well as numerous personal blogs and websites. Narratives were gathered from 2013-2016; all of the narratives were in English and represented parents from North America, the UK, and Australia. In total, 181 online narratives met the inclusion criteria.

From these narratives we developed open codes and axial codes. We used a random sample of 50 narratives to create the initial codes. After forming these initial axial codes, we analyzed the remaining 131 parental stories and refined the axial codes accordingly. In total, 410 open codes were created and sorted into the 14 axial codes (see Table 1).

Results

The axial codes with the lowest frequencies were “Doctors and Money” (3 open codes, 0.7%); “Parents Lying” (5 open codes, 1.2%); and “Doctor Does Not Respect Parent’s Autonomy” (12 open codes, 2.9%). Open codes in these axial codes typically read as follows:

He [the doctor] then abruptly ended the appointment, and again told me that he was serious about me not taking him anywhere in public. It was unbelievable, and only reinforced my belief that the medical community cares more about their pocket books, and the money that they gain from these vaccinations, than they care about the health and well-being of our children.

And:

He [the doctor] then told us very bluntly that if we decided not to vaccinate our boys that he would drop our boys as patients and we would have to take them elsewhere. Since then, we have simply skirted the issue by lying.

And:

Of the code of ethics that doctors are suppose [sic] to adhere to, one is respected [sic] the decision of a patient.

A more common axial code was “Parents Seek More Accepting Doctor” (17 open codes, 4.1%). The phrase “Accepting Doctor” in this axial codes used in two senses: first, are physicians sympathetic or even in agreement with these parents’ view of the dangers of vaccines; and second, are physicians who disagree with the parents, but nevertheless seldom or never broach the subject of vaccinations with the parents. Parents often told of the different practices they visited before settling on a specific physician who seemed to be accepting. For example:

She [the doctor] then closed my case, and we have been fighting to find a reasonable pediatrician ever since.

The next most common axial code was “Doctor Misleads or ‘Lies’” (17 open codes, 4.1%). The most common of the doctors’ ‘lies’ cited in these narratives was that vaccines were required for school admissions:

I was going against my instincts in every way, allowing them to inject my baby, but I allowed it because they [the doctors] told me it was the LAW, that I HAD to vax my child…I found [out that] SURPRISE SURPRISE [vaccines] were not mandated by law.

Another less common topic, but still one that these parents identified as a lie told to them by physicians, concerns the safety of vaccines. These safety issues include vaccine ingredients, possible side effects, and efficacy:

He told me that there were NO side effects to the vaccines but if she caught one of the diseases she could be crippled or even die. I tried to counteract his comments but he always seemed to come back at me with something to contradict what I was saying….The doctor gave HIS version but NEVER offered another stance on the issue.

The next axial code was “Doctor Predicts Ominous Outcomes” (21 open codes, 5.1%). The ominous outcomes, in this case, refer to instances in which a doctor warns parents of some possible deleterious outcomes for their children if they remain unvaccinated. For example:

I have had a doctor tell me my child was a sitting duck for anything he is not vaccinated against…[my child] is now 7-month-old and has never had a single health problem.

Another axial code was “Parent’s Avoid ‘Mainstream’ Medicine” (25 open codes, 6.1%). Open codes in this themes range from an a version toward allopathic medical doctors but still utilizing their services for certain medical requirements (such as acute illness) to exclusive using alternative medicine practitioners for all health related needs:

Our chiropractor is now our expert on health and wellness…our doctor, so to speak. But we now have a different idea of what health care should be. Doctors deal with sickness, not health.

Another common axial code was “Parents View Unvaccinated Children As More Healthy” (26 open codes, 6.3%). Open codes in this theme expressed the view that

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children who have been vaccinated are less healthy and that the unvaccinated fare better or when these parents’ children have experienced an adverse reaction—be it real or imagined—after immunization:

[The doctor] badgered me until I finally gave in. Shame on me! I took my poor innocent little baby home and listened to him scream for hours. I called the Dr. twice and was told to give him Tylenol...His little body kept jumping while he was sleeping and I called the Dr. again. He hung up on me. Little did I know back then that my infant was having seizures.

He was never the same after that night and it would take a full book to tell all his problems.

The next axial code was “Doctor Insinuates ‘Bad Parents’” (29 open codes, 7.1%). The open codes in this axial code were times in which the doctor either stated or implied that the parents were substandard:

He [the doctor] then proceeded to tell me that I was “bordering on child negligence” for not vaccinating my child.

The next most common theme was “Autism Etiology and Fears” (30 open codes, 7.3%). The open codes associated with this axial code were not mere mentions of autism or vaccine causation; rather these open codes were the emotions parents felt when they expressed their beliefs about vaccines and autism in the clinic. For example, one parent, who told her doctor about her concerns that her son would contract autism from vaccines, reported the following:

I just didn’t want him [her son] to get any more vaccines and if he [the doctor] could check his [the son’s] titer instead. Oh my!!!!!! He [the doctor] started ranting and raving ...he said that is over, they proved there is no relation between vaccines and autism!...I didn’t want to and really felt forced...why couldn’t I fight back with him [the doctor]?! I feel so stupid letting him talk me into it...I still can’t believe I couldn’t stick to my instincts and be strong.

The next axial code, “Doctor Dismisses Family From Practice” (38 open codes, 11.4%), also relates these parents’ thoughts about the inappropriateness of being dismissed from a doctor’s practice for refusing to vaccinate. Parents generally felt that doctors were dismissing them in order to either strong-arm them into vaccinating their children, or as a means the doctor uses to protect herself:

A...weapon. Pediaticians use to cajole parents to vaccinate is the threat that they will be dropped as patients if they don’t comply.

And:

After a verbal bashing from him [the doctor], he ended by saying, “well, I can’t continue to see your children if you’re not going to vaccinate because they’re a liability”.

Another prominent axial code was “Parental Research” (53 open codes, 12.9%). Many parents thought that their doctor unfairly dismissed their research without much consideration. A number of parents also felt that their doctor did not know much about vaccine-related research. For example:

He yelled at me non-stop for about 15 minutes, during which he repeated himself several times, and finally concluded with, “I want you to go home and read that paper”. I quietly replied, “Thank you, I will.” And I did. Considering the amount of reading I had already done on the subject, I found his paper laughable, pathetic and insulting.

The second most prominent axial code was “Doctor Uses Rote Persuasive Strategies” (65 open codes, 15.9%). It may seem like simply using the same persuasive strategy with different patients would be fairly innocent; however, for these vaccine hesitant parents, doctors using the same arguments and statistics were a major issue:

I think what he [the doctor] must have heard me say (as opposed to what I ACTUALLY said) was “please convince me that vaccinations are safe”. He went into the standard spiel.

Many parents felt that the doctor used rote arguments and handouts inorder to avoid truly engaging with them:

She told me there is no longer thirmisol [sic] in vaccines and nothing to worry about. I told her that was not my only concern and tried to explain a few things to her. She wouldn’t even listen to me.

Also, by using the same strategy many parents felt that their doctors were mouthpieces for the government’s stance:

Then the pediatrician at the hospital harassed me for the next 2 days of recovery about [refusing] the...shot. She said my baby could get a brain hemorrhage and die. She even gave me this research paper out her AAP book of bullshit on the shot saying it doesn’t cause Leukemia and death etc [sic].

The most prominent axial code was “Doctor De-means” (69 open codes, 16.8%). As such, this axial code has a sizable range of behaviors linked to it, from standard medical undertakings (such as lecturing) to excessive acts—such as vaccinating a child against the expressed wishes of the parent:

She [the doctor] then knelt down looked at my daughter and said “I am just trying to protect you but your Mommy won’t [sic] let me”. I was in shock. I couldn’t say anything I was frozen, like my voice had run out on me.
And:

When my husband told the doctor his mother (me) didn’t want our son to have any additional vaccinations, the doctor said to my husband “now who knows best, his mother or the doctor”? and gave him the vaccinations anyway!

Discussion

Overall, these narratives demonstrate that many vaccine hesitant parents feel belittled and slandered during the clinical encounter. The most frequent theme within the analysis indicated that these parents felt that the doctor demeaned them in the clinic. These parents are disturbed and outraged by the demean or of some physicians, with one parent complaining that “I did not seek medical attention for my child for us to be demoralized, judged and lectured like I myself am the child”. These narratives also implied that the parents viewed their physicians as not just misinformed about vaccines but as willfully ignorant; they viewed the doctors as not merely unwilling to engage in a conversation about vaccine dangers but as without regard to the needs of parents or their children. In each of these cases, vaccine hesitant parents saw their doctors as failing to conduct themselves in accordance with the standards that ought to animate their practice of medicine or as a person truly interested in helping the parents or their families.

The analysis of the parents’ narratives indicates that how a doctor presents herself in the clinic might play a crucial, though hidden, part in the backfire effect. A strong mistrust of the science of vaccines is a default position for many vaccine hesitant parents; however, at the beginning, this mistrust does not necessarily extend to the physicians themselves. Research has shown that most patients, including vaccine hesitant parents, initially see physicians as trusted sources of information [17] and that most vaccine hesitant parents who later decided to immunize their children were initially skeptical of the health information being provided by their doctor. It was the continued assurances made by a trusted physician that eventually persuaded these parents to change their minds [18]. But when a doctor’s actions reflect poorly on her, it reifies the parents’ feeling that physicians, not just the science, should not be trusted. Of the 69 narratives that mentioned the doctor demeaning the parents, 65 (94.2%) also indicated that their physician’s attitude toward them lowered their trust in the doctor. In these narratives it was not merely discussing vaccines that lowered the parents’ trust, but the doctor’s poor demeanor. As one parent put it “[doctors’] apathetic distancing from the suffering of fellow human beings is profoundly chilling!”

Research has shown that the majority of these parents are informed of the scientific evidence for the safety of vaccines and have read the literature that question the link between vaccines and autism [19-21]. But many education programs meant to persuade hesitant parents to vaccinate tend to put the proverbial cart before the horse. Parents do not trust the source of the information, even if they concede to the facts as they are presented. Some of the most prominent themes within these narratives were times in which the parents voiced frustration with having their research unceremoniously dismissed while simultaneously having doctors repeat the same statistics and arguments. The parents in these narratives felt a kinship with the anti-vaccination information they found and many of them felt alienated by their doctor’s dismissive attitude. Studies have shown that many vaccine hesitant parents desire an authentic conversation with their doctor regarding why they have decided to forgo immunizations [3]. But the education these parent’s received in the clinic was not a free flow of ideas and viewpoints but a monolithic pre-set agenda. Also, many parents felt that the doctor used things like handouts or regurgitated governmental stances about vaccines in order to avoid truly engaging with them.

Importantly, the parents in these narratives did not trust physicians in a specific manner: They did not trust the doctor’s character. In essence, bad experiences in the clinic solidify these parents feelings that their physician did not adequately care for them or their family. This belief is independent of any scientific claim. Parents in these narratives, and in other studies [19], expressed a feeling of guilt about possibly harming their children by using vaccines, e.g. “I feel so stupid letting [the doctor] talk me into [vaccinating]…I still can’t believe I couldn’t stick to my instincts and be strong”. These are intimate, strong feelings that need a portion of compassion and care that is, sadly, missing in many clinical encounters. Therefore, winning a vaccine hesitant parent’s mind is only a small part of the persuasion equation—doctors must also capture the parent’s heart.

Parental mistrust provides the missing link between educational programs and the backfire effect: Parents continue to not trust the messenger, even if they come to believe the message. Many of the parents’ narratives, 157 of the 181 (86.7%), noted that the manner in which a doctor had presented herself in the clinic strengthened their mistrust. Parents often made statements similar to the following in their narratives:

After years of scare tactics by the doctors I had “TRIED” to trust. I was STEAMING, I was hurt, I felt betrayed, but most of all...I felt like I let my children down. I was supposed to protect them, and I didn’t [sic] do it.

Trust has also played a major component in findings.
from other research studies investigating the characteristics of vaccine hesitant parents and vaccine refusal [17,18,22]. In addition, when the physician attempted to educate these parents regarding vaccine safety and efficacy, many parents reported that their physicians hastily rejected their concerns regarding the safety of vaccinations while also underestimating the overwhelming impact disorders like autism had on their families. As a result, parents in other research studies have described their doctor’s approach as inflexible and prone to undue inducement or even coercion [19]. Thus, trust (or mistrust) in the physician is a recurrent theme within many research studies investigating the influence of persuasion techniques on vaccine hesitant parents.

**Conclusion**

When faced with the backfire effect many authors propose that health educators and physicians should be more forceful in refuting misconceptions or in extolling the virtues of vaccines [14-16]. Even authors who are more sensitive and attuned with the importance of the worldview of these parents still recommend that doctors try and avoid dwelling on the parent’s worldview [23]. Such recommendations seem to either assume the backfire effect is, in reality, residual parental doubts regarding the validity of the information [24] or a psychological bias stemming from the over use of misinformation in the educational strategies [25]. Therefore, the parents’ biased worldview can be overcome by simple avoidance and self-affirmation techniques [23]. Regardless of its attributed genesis, these authors are squarely blaming the parents for the backfire. Worse, the proposed methods for countering or eluding the backfire effect have already been disproven in the literature. Aggressive arguments regarding the scientific validity of vaccine safety and efficacy has not only been shown to be an ineffective strategy [10] it also contradicts the central premise of the backfire effect since the parents have reported a belief in the presented information.

What if, on the other hand, we were to take the backfire effect on its face? In other words, what if we took seriously the parents’ reported belief that they understood and believed the presented scientific facts? What other variables might account for the backfire effect? One contributing factor to the backfire effect might be the parents’ mistrust of their physicians’ motives and character. In such an instance, remedies for the backfire effect would not focus on avoiding or ameliorating the parents’ worldview but would, instead, encourage physicians to critically and honestly consider how they convey trust and how they present their character in the clinic.

In Aristotle’s famous treatise, *On Rhetoric*, he states that the speaker’s *ethos* (how she presents her character to the audience) is the most important aspect of persuasion. The analysis of narratives from vaccine hesitant parents emphasizes this notion and points to the need for character education. Current education efforts may have helped some vaccine hesitant parents have more trust in the *science*, but physicians still need to put in the effort to help these parents trust *them*.

**References**


