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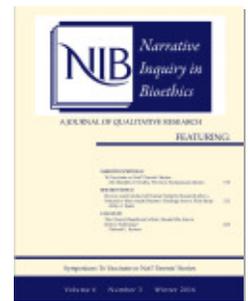
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To Vaccinate or Not? Parents' Stories

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Abstract. In recent years, the vaccine debate has become increasingly vitriolic and entrenched. The goal of this symposium is to aid in a more constructive conversation between pro-vaccination/ anti-vaccination groups. Twelve parents share their personal stories discussing why they chose to vaccinate—or not. In addition to these narratives, four experts in sociology, rhetoric, ethics, and medicine provide commentaries about the stories and add their own insights about the vaccine debate. The stories and commentaries illustrate the complexities and depth involved in vaccine decisions, and challenge the simplistic way in which the vaccine debate is typically depicted.

Key Words. anti-vaccination, bioethics, doctor-patient communication, pro-vaccination, public health, vaccination, vaccine controversy, vaccine debate, vaccine hesitance

Introduction

After decades during which vaccination enjoyed widespread legitimacy and public adherence to medical and public health recommendations, public attitudes towards vaccination have become nearly as controversial as they once were in the heyday of the anti-vaccination movement of a hundred years ago. Despite scientific evidence and widespread consensus among healthcare professionals of immunization's preventive public health benefits and the low risks that modern vaccines pose, once isolated pockets of public resistance to vaccination have spread and grown in number, undermining the authority of health professionals.

The fact that lay conceptions of the safety and efficacy of vaccinations have gained enough

adherents to rival the medical and scientific proponents of vaccines (at least in certain public discourses and communities) is a surprising development in itself. Unfortunately, the controversy is also threatening to become intractable as constructive dialogue between pro- and anti-vaccination camps has broken down and discourse has become polarized and vitriolic. Bolstered by recent American Academy of Pediatrics practice guidelines that assure pediatricians the practice is "an acceptable option," it is increasingly common to hear stories of doctors abandoning their patients for nonadherence to suggested vaccine schedules, as well as parents taking to social media to express frustrations and conspiracy theories (Edwards, Hackell, The Committee on Infectious Diseases, & The Committee on Practice and Ambulatory Medicine, 2016, p. e9).

One of the problems that others have pointed out about the vaccination debate is the apparent incommensurability of the discursive modes and narrative forms of the debate. Jerome Bruner (1986) and Donald Polkinghorne (1988), among others, have observed that there are two main narrative modes we all use to order our experience of the world: a “logico–scientific” mode that appeals to our need for structured, evidence–based reasoning, and a “story–crafting” mode that appeals to our need to make sense of the world through stories that resonate with our lived experience. These two narrative ways of knowing are examples of what Thomas Kuhn called “paradigms”—each with their own structures, syntax, grammar, and criteria for verification (Kuhn, 1996; Bruner, 1986; Polkinghorne, 1988). Although both narrative modes are legitimate ways of understanding the world and we all tend to use them both when communicating with and convincing others, this does not mean that they are easily translated or reducible to one another. Bruner (1986) characterizes the logico–scientific mode as “verif[y]ing by eventual appeal to procedures for establishing formal and empirical truth” while the story–crafting mode “establishes not truth but verisimilitude” with our experience and expectations (p.11). One reason for the apparent intractability of the vaccination debate is that arguments are advanced with narrative modes aimed at target audiences who are bound to find them unconvincing. These arguments often fail to “make sense” to the listener, and this “nonsense” prompts an answer in the other narrative mode which, in turn, continues the vicious cycle of confusion. Repeated encounters along these lines result in mutual frustration and a retreat to entrenched “echo chambers” of discourse, further polarizing the debate. But in the vaccine debate, where the public health stakes are high, mutual understanding is needed in order to break the impasse.

We elicited the stories people use to make sense of the practice of vaccination to help both sides of the controversy better understand the presumptions, beliefs and forms of reason used by others. We gathered here the stories of a dozen people throughout the pro–vaccination/anti–vaccination spectrum, and asked a panel of thoughtful experts to explore the various narrative structures, tropes

and themes that appear, with the hope that such insights can aid a more constructive conversation between these groups to emerge.

The Call for Stories

The call for stories was posted to a variety of webpages, including the *Narrative in Bioethics* website *NIBjournal.org*, as well as the NIB Facebook page and newsletter. In addition, we also contacted parents and parent groups directly. The first groups we contacted were large national and regional pro– and anti–vaccination organizations. These organizations hold sway within the vaccine debate and have a large reach, especially online. However, organizations on both sides of the vaccine debate refused to post our call for stories on their respective websites. The heads of several anti–vaccination websites expressed a strong distrust of our project and questioned our motives, since we did not share their convictions about the dangers and ineffectiveness of vaccines. This mistrust lingered even after we discussed the purpose of the symposium. Some website editors accused us of being disingenuous and assumed that we were actually set on misrepresenting their views. We can only imagine what prior experiences might have prompted these responses. Similarly, pro–vaccine organizations and blogs also refused to post the call for stories. The webmasters for some of these pro–vaccination organizations objected to the inclusion of vaccine–hesitant voices and stances in a medical/bioethical journal. For example, one editor wrote, “having stories [of anti–vaccination parents] heard with equal weight [of pro–vaccine parents] is actually something we work against.”

These refusals by the most visible proponents on both sides of the debate were not only frustrating because they delayed the process of organizing this issue, they were also disconcerting—especially after we started contacting parents and smaller groups via social media.¹ Almost without exception, the

¹ *The difference in the response between the national organizations and the parents is telling, and raises many troubling questions. However, a full consideration of these questions is beyond the purpose of this introduction. For now, it is*

parents and leaders of these social media pages promoted and “liked” the call for stories. Almost a dozen parents, on both sides of the vaccine debate, contacted us directly to express their excitement for the project and their gratitude for being able to tell their stories. In total, the call for stories was posted to almost 80 different social media pages (despite the reluctance of the highest profile sites to post the call), with many more shares and likes. The call for stories continues to receive daily likes and shares, months after the submission deadline.

The call for stories explained that we were interested in factual narratives, written by the parents themselves, which detailed the personal reasons they chose to vaccinate—or not. To aid with these stories, we asked the parents to consider the following questions:

- What decisions have you needed to make about vaccinating your children, and what did you decide?
- Why do you hold your current views about vaccination?
- Have you felt pressured to change your mind about having your children vaccinated? If so how? What was your response?
- What do you wish those who disagree with your decisions knew about your views on vaccines?
- Is there anything that you think might help to resolve the controversy surrounding vaccinations?

We encouraged parents to focus on the issues they felt were most important to share with others.

The Narratives

The stories gathered for this symposium represent a spectrum of viewpoints about vaccines. Of the 12 parental narratives in this issue, six tend toward support of vaccines, five stories are critical of vaccines, with one story discussing both sides of the debate. In these stories, parents cite the many factors that contributed to their stance on vaccinations, including: losing children, dealing with disabilities,

working with doctors, and conducting personal research. Interestingly, regardless of the parent’s stance on vaccines, these stories detailed times of tragedy, fears of the unknown, frustration with health professionals, and a resolve to learn. The stories within this symposium illustrate a common thread that binds all the parents in the vaccine debate; namely, a desire to balance an onslaught of sometimes–conflicting information with the realities of life.

The Commentaries

An illustrious panel of experts joined us for this Narrative Symposium. Jacob Heller, Ph.D., a sociologist at SUNY Old Westbury, is the author of “The Vaccine Narrative,” a book that reconceptualizes the vaccine debate as much more than mere disagreement about facts or a clashing of ideologies (Heller, 2008). In his commentary for this issue, Dr. Heller issues a common refrain among our commentators that vaccines are more than biological tools to confer heightened immunity to disease. Vaccines have become “things” with complex social meanings and different connotations in different contexts, as Bernice Hausman, Ph.D., Director of Virginia Tech’s Vaccine Research Group also contends. In her commentary, Dr. Hausman shows how vaccine narratives often belie complicated judgments of the social commitments of individuals to society, and how these judgments become contested even when unspoken. Heidi Lawrence, M.A., Ph.D., of George Mason University, brings her experience studying the narratives of vaccine–hesitant parents to bear on her reading of the stories in this issue. In doing so she finds that her most recent experience—that of new parent—helps her to bear witness to the role of emotion in vaccine decisions by parents as well as the importance of empathic listening. Similarly, Ken Haller, M.D., a pediatrician at Saint Louis University as well as a respected thespian, shows how a respectful and empathic dialogical practice can provide the stage for a more positive outcome between both sides of the vaccine debate. Through a story of his own, Dr. Haller prescribes charitable listening and humbly opening ourselves to our interlocutors to cultivate mutual respect and understanding between patient families and care givers.

sufficient to say that this experience has highlighted the potential conflict of interest between a proxy organization’s duties for serving a community of parents while also wanting to promote a certain ideology.

Conclusion

We wish to thank all of those who have written for this Symposium issue. Venturing an opinion or critique is not without risk in such a volatile debate, and we applaud the moral courage that many in this issue display. We hope that this small collection of stories and the expert commentary on them will edge the debate over vaccination toward more productive pastures of understanding and mutual respect. In a time when social discourse is becoming more polarized, it is comforting to witness a more constructive dialogue taking place.

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Personal Narratives

How Vaccines Changed Our Lives Forever

Tonya Ankeney

Thirteen years ago our daughter had a severe adverse reaction to vaccination. Audra was ten months old in June 2003 when she received the second round of Hepatitis B (Hep B) and Diphtheria–Tetanus–Pertussis (DTaP) vaccines. Audra received her vaccines on a Wednesday and was totally paralyzed, with severe breathing difficulties, and on life support by Sunday.

In the process of trying to figure out what had happened, my husband, I, and the medical team dissected the prior month of her life. It was then that one of the neurologists asked, “Has she received any vaccinations within the last 30 days?” We both answered, “Yes, this past Wednesday.” That’s when we first realized that vaccines could even cause serious injuries. We already knew that live-virus vaccines could shed because our older children had gotten and then transmitted varicella (chickenpox) to Audra two months earlier.

The doctors spent some time arguing over what exactly was wrong with our baby and finally agreed she needed an MRI. The MRI showed them the extent of the damage done by the vaccines. Her immune system had been attacked, and the myelin (insulation) around her spinal cord was destroyed. The scans also revealed that Audra had pre-existing damage, which was attributed to a probable reaction to her first round of DTaP and Hep B vaccines.

Audra was diagnosed with transverse myelitis and acute demyelinating encephalomyelitis secondary to the Hep B and DTaP vaccine reactions. The CDC was notified, and on her first 4th of July, she was in surgery getting a tracheostomy. We spent four months in ICU and inpatient rehabilitation. Then we spent two more months in almost home Pediatric Intensive Care Unit (PICU).

Audra had a tracheostomy and was ventilator-dependent for three years. Then she was strong enough to be weaned off the ventilator and eventually had the tracheostomy closed. We were not so lucky with the paralysis. To this day she remains paralyzed and confined to a wheelchair. Audra was left with neurogenic bladder that requires her to be catheterized three to four times a day. She has problems with her bowels, requiring her to take Miralax and at times be “helped” to have a bowel movement.

In the years since her first prolonged hospitalization, we have been in and out of the hospital. In 2012 the spinal surgeries began. Due to the paralysis, she developed dextroconvex scoliosis that puts pressure on her left lung and heart. She had to have VEPTR rods (titanium rods) placed in