

“You need to do your research”: Vaccines, contestable science, and maternal epistemology

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Melissa L. Carrion

Georgia Southern University, USA

Abstract

Individuals who refuse vaccines are often painted as anti-science or ill-informed. However, drawing from interviews with 50 mothers who refused one or more vaccines ($n=50$), results from this study suggest that such depictions lack nuance and may detract from the ability of communication efforts to effectively address concerns. In particular, participants' explanations for vaccine refusal relied on paradoxical arguments about science and expertise. On one hand, participants defended the ideal of science but criticized existing research for failing to meet requisite standards. On the other hand, they suggested that maternal experience could supplant the ways of knowing that give rise to such claims. Collectively, these explanations reflected critical, postmodern, and feminist perspectives on science and knowledge production and can help explain the persistence of the controversy surrounding childhood vaccines in the United States.

Keywords

argument sphere theory, epistemology, interviews, mothers, vaccines

1. Introduction

Abby was a 39-year-old attorney and mother of five. We spoke for nearly 90 minutes one evening in August 2013. She was my 35th participant in a study exploring how and why mothers refused vaccines for their children. As with participants before her, she recalled her decision as a kind of epiphany, bound up not only with concerns about safety but also broader issues relating to confidence in the pharmaceutical industry, poor experiences with physicians, and her own journey of coming to trust her instincts as a woman and mother. She explained,

We as a society have kind of been taught to, you know, [doctors] are experts, just listen to what they are telling you, don't question it, they know best. They have all the training and you don't really know, you know? I'm not downplaying their training or anything like that, but I also think especially women—I think men have it to a certain degree too—but I think women have very good intuitive abilities, and we usually know when something is not right, especially when it comes to like us, or our children, or something else. And we kind of get that nagging voice that's like, “you shouldn't do this,” or “this isn't right,” or “there is

Corresponding author:

Melissa L. Carrion, Georgia Southern University, P.O. Box 8026, Statesboro, GA 30460, USA.
Email: mcarrion@georgiasouthern.edu

something wrong.” We know that, and a lot of times we’re kowtowed by doctors telling us, you know, “it’s all in your head,” or “blah blah,” when really we should just really stick up for that and say “no, that’s not right” or “I’m not comfortable with that,” or whatever. And we’re kind of taught, “oh that’s not polite,” and of course if you do stick up for yourself, I mean you do become the bitch [laughs] you know. So I guess, you know, it’s hard. But it’s easier once you know that the bitch no one wants to mess with [laughs].

Abby’s statement articulated in a clear manner the sentiments expressed by many of the previous 34 participants. That is, unlike media portrayals of vaccine refusal, the mothers who I interviewed were not anti-science, nor did they lack basic scientific literacy. On the contrary, they invested tremendous energy into researching about vaccines and respected the specialized training and knowledge that distinguished “experts” from lay citizens. Yet, like Abby, they also suggested that the social practice of science is fallible, that there are different kinds of expertise, and that there are times when a woman’s “intuitive abilities” can and should trump other kinds of “expert” guidance. This tension is at the heart of this analysis, which explores how participants’ arguments and explanations for vaccine refusal troubled the boundaries between personal and technical knowledge claims, and the notion of expertise itself.

Specifically, this article draws from argument sphere theory (Goodnight, 1982) to argue that the explanations for vaccine refusal provided by mothers in this study both challenged and maintained distinctions between the personal and technical spheres in a paradoxical and highly effective rhetorical balancing act. In one sense, participants’ arguments maintained the boundaries of the technical sphere and criticized the evidence included therein for falling short of prescribed standards. At the same time, however, participants’ arguments also challenged the boundaries of the technical sphere by critically interrogating the limits of scientific knowledge production and epistemology from the lay vantage point. Better understanding how mothers employed these paradoxical arguments can help explain the persistence of the controversy regarding vaccine safety, and also provide a context in which to theorize the broader implications of these arguments on the public understanding of science in the twenty-first century.

2. Literature review

Vaccine refusal

Despite overwhelming support for vaccines in the medical community, surveys suggest that over 11% of parents in the United States have refused at least one recommended vaccine (Freed et al., 2010). Likewise, rates of personal belief exemptions (PBEs) for kindergarten vaccinations (required for entry to public schools in the United States) have increased in the last decade (Omer et al., 2012), with some counties in California, for example, experiencing rates as high as 20% (California Department of Public Health, 2015). Unvaccinated children are themselves at greater risk of contracting vaccine preventable illnesses, and clusters of unvaccinated children have been implicated in recent outbreaks of measles and pertussis (Majumder et al., 2015).

This trend has significant implications for public health and, accordingly, research has focused on identifying the factors influencing vaccine refusal. Demographically, children with PBEs are more likely to live in predominantly White communities and in households with an annual income over US\$75,000 (Smith et al., 2004). Research has also suggested that parents who refuse vaccines express low levels of susceptibility and severity with regard to vaccine preventable disease (e.g. Luthy et al., 2012) and low response efficacy for vaccines (e.g. Kennedy et al., 2005). However, while understanding these factors is important in developing effective strategies to counter vaccine refusal, the development of effective communication strategies also requires better understanding the ideas and rhetorical strategies that underscore vaccine refusal arguments.

Argument sphere theory

Argument sphere theory provides one useful lens for such theorizing and posits that all deliberative discourse can be categorized into one of three different spheres—the public, personal, or technical. Goodnight (1982) explained that “differences among the three spheres are plausibly illustrated if we consider the differences between the standards for arguments among friends versus those for judgments of academic arguments versus those for judging political disputes” (p. 216). In other words, these spheres are differentiated primarily by the types of claims and evidence necessary for successful participation.

Within this framework, the public sphere functions as the space for questions regarding broader policy, values, and controversy. The standards for arguments in the public sphere do not require formal evidence or special expertise, but rather an attention to the needs and concerns of a broad audience (Goodnight, 1982: 220). Likewise, the personal sphere requires only brief and improvised arguments with little need for formal evidence, privileging individual emotions and experience. In both the public and personal spheres of argument, all voices are necessarily welcome; it is the content of argument rather than the ethos of the speaker that determines acceptability. The technical sphere, by contrast, focuses exclusively on questions of fact and requires formal and reliable data. Because the norms for presenting acceptable data are dictated by the discursive practices of the discipline(s) involved, the discourse also functions to facilitate the demarcation of expertise (Goodnight, 1987). That is, in practice, the technical sphere of argument limits both what counts as evidence *and* who is qualified to present it.

Goodnight (1982, 1997) acknowledged that the boundaries of the spheres are amorphous and subject to revision, representing “contexts of contestable and contested choices ... alterable over time” (Goodnight, 1997: 272), and communication scholars have explored this contestable terrain. For example, Olson and Goodnight (1994) used the term “social controversy” to discuss discourses in which the public and private spheres overlap (p. 249). Similarly, Boyd (2002) analyzed discourse about Food and Drug Administration (FDA) approval of the fat substitute Olestra and used the term “regulatory controversy” to describe the overlap of the public and technical spheres (p. 91). Stewart (2009) coined the term “socio-scientific controversy” to denote debates in which all three spheres overlapped (p. 124).

To date, however, scholarship has yet to fully examine the inter-relationship between the personal and technical spheres of argument, a relationship that is especially germane to understanding discourses about health decisions. Discourse about vaccine refusal provides a context for theorizing the overlap of these spheres, and examining how mothers negotiate the boundaries between scientific and personal arguments can help us to better understand both the ongoing controversy surrounding vaccines, and how other challenges to science and medicine are discursively constructed and maintained.

3. Methods

Recruitment

Following protocol approved by the Institutional Review Board at the researcher’s university, participants were recruited from online forums dedicated to non-vaccination. Recruitment was limited to mothers who had given birth or adopted within the last 2 years and who had refused one or more recommended vaccines. This focus was motivated by research suggesting that mothers report bearing primary responsibility for decisions regarding their children’s health (e.g. Kaiser Family Foundation, 2005), including in the specific context of vaccination (Petts and Niemeyer, 2004), and by scholarship suggesting that attitudes and beliefs related to motherhood constitute a unique

and salient context for shaping health decisions (e.g. Apple, 2006; Kukla, 2008). The specific website and forums for recruitment were chosen based on high user traffic, the presence of an active and dedicated forum for vaccine-critical commentary and/or non-vaccinating mothers, and discussion forums which were open for public viewing. The participant recruitment message included a description of the study and asked that interested participants contact the researcher; those who did were sent the informed consent and a list of the interview questions. Participants were asked to read the materials and, if interested in participating, return the signed informed consent to the researcher, at which time an interview was scheduled. Participants were compensated with a US\$20 retail gift certificate.

Participants

In total, 96 mothers sent emails expressing interest, and 50 returned the signed informed consent and scheduled interviews. Emails were responded to in the order in which they were received, and no willing participants were excluded. The decision to end recruitment once these 50 interviews were completed was made with consideration to a sample which approached maximum variation based on age, education level, income, and geographic location, and with regard to funds available to compensate participants. Participants ranged in age from 21 to 41 years ($M=29.84$, standard deviation (SD)=4.95), and 44 of the participants described themselves as White or Caucasian, five as Hispanic, and one as Pacific Islander. Less than half of the participants were employed outside of the home, and annual household income ranged from less than ten thousand dollars to more than three hundred thousand.

Data collection

In-depth interviews were used to collect data, which preserved participants "rhetorical construction of their experience" (Lindlof and Taylor, 2002: 173). A semi-structured format maintained a level of structural similarity while providing flexibility to alter questions and incorporate new ideas according to the unique nature of each participant's experiences (Corbin and Strauss, 2008). The interview protocol contained seven demographic questions, and 17 open-ended questions focused on participants' experiences and opinions regarding vaccines, motherhood, experiences with health care, and general beliefs about health. Participants were also asked what advice they would give to another mother struggling with the decision to vaccinate. Interviews were conducted via phone, ranged in length from 23 to 96 minutes (average 46 minutes), and were audio recorded and transcribed by the researcher. In total, there were 2159 minutes of interviews and 1386 double-spaced pages of transcripts.

Analysis

All transcripts were uploaded to NVivo 10 for analysis. Analytical strategies were ongoing throughout all phases of the project and guided by constant-comparative techniques (Corbin and Strauss, 2008). In particular, the analysis aimed to trace the discursive patterns that shaped participants' understanding about vaccines. This was in line with Keränen's (2014) call to "[shift] attention from official biomedical texts to the roles publics play in shaping biomedical and health discourses and practices," thereby enabling scholars to "better map existing patterns of influence and identify places and strategies for rhetorical intervention in matters of public health and wellbeing" (p. 105).

Initial rounds of coding sought to capture and categorize the different arguments participants presented in explaining their decision to refuse vaccines. These included arguments relating to low perceived susceptibility and severity with regard to vaccine preventable diseases, the ethical and

political dimensions of vaccination, as well as concerns with vaccine safety and efficacy. Subsequent rounds of coding drew from Toulmin's (1958) model of argument to identify the specific evidence and warrants that participants called upon in explaining and supporting these arguments. Given the framework of argument sphere theory, I was particularly attentive to how participants used arguments situated in the scientific and personal spheres to explain and justify their decisions.

4. Results

Policing the boundaries

Many of participants' arguments implicitly reinforced the boundary between the technical and personal spheres. Participants acknowledged that they did not have the skills or credentials to themselves engage in the technical sphere. Felicia, a 31-year-old mother of one, reflected this contention when she conceded, "there's no way to prove [vaccine risks] because most of us aren't scientists." Participants further acknowledged the inferiority of anecdotal evidence, and they stressed the importance of backing up their own arguments with credible research. These admissions testified to the overall acceptance of science as an arbiter of truth.

Existing conclusions as unsubstantiated or flawed. Despite this tacit acceptance, however, participants also argued that much of the technical sphere discourse surrounding vaccines was itself neither credible nor in line with rigorous standards. In this sense, participants suggested that the very standards which excluded their own ability to be legitimate voices in the technical sphere also excluded the evidence produced by so-called experts. This argument was related to the warrant that truly "conclusive" research was lacking. For example, Felicia, discussed her perception of the risks of vaccination, noting, "From what I've seen out there, it's kind of difficult to say what the risks are because there's just not enough research done on it." Positioning herself outside the technical sphere, Felicia's intention was not to produce counter-claims but to challenge the sufficiency of existing evidence.

For many participants, this perception of unsubstantiated research claims was exacerbated by frequent changes in vaccine formulation the recommended schedule. For example, Samantha, a 29-year-old mother of one, explained, "I think that [vaccines are] changed too frequently, and I think that people say, 'Oh, this small amount of changes in the ingredients won't change or affect anything'. But the truth is that we really don't know." Samantha's statement suggested that, at one time, recommended vaccines and timing were perhaps safe. However, she argued that alterations to both the vaccine schedule and vaccines themselves had not been adequately tested. More broadly, her argument contrasted what passes for evidence among medical scientists in this case with what she believed actually constitutes evidence. Samantha's argument again points to the idea that "experts" are not living up to the standards of the technical sphere.

Additionally, mothers in the sample criticized research for failing to isolate specific potential causal mechanisms, or for generalizations made to populations not explicitly included in studies. Barb, a 32-year-old mother of two, argued,

They say [vaccines are] safe but when you read the inserts, they say this has not been tested, for example, on pregnant women or whatever they're pushing. So that for me just doesn't seem good for that side of the argument.

Barb was not pregnant at the time of the interview nor was she facing the decision to be vaccinated herself. However, formal recommendations for pregnant women to be vaccinated despite explicit testing led her to question whether other vaccine protocol was substantiated by evidence.

The focus on inadequate study design and methodology was also reflected in other participants' arguments. Jenni, a 36-year-old mother of one, explained,

My big thing is when, you know, they don't do a double-blind research on it. So it's not like they take a test group and give them this vaccine, and take another test group and not give them a vaccine because, from what I've read, they feel that would be unethical to deprive a child from the vaccine. So what they do is, they test it against some different form of vaccine that's not even the same vaccine.

For the medical research community, the gold standard for studies includes the use of double-blind, randomized, placebo-based trials (Kaptchuk, 2001). In their absence, and despite acknowledging the practical and ethical difficulties associated with such designs, Jenni dismissed the validity of existing conclusions. Jenni's criticism appropriated scientific language inasmuch as she called out what she understood to be a sub-standard study design. However, her repeated use of "they" signified her recognition that she did not include herself among those who could potentially contribute better evidence.

In line with these criticisms, participants also questioned the lack of long-term safety data. For example, Jenni continued,

And then, like, if you read the news, you see these studies like, "Oh, twenty year study on vitamins and supplements" and they really don't do anything. So you see all this research and studies come out on other things, but you never see long term research studies come out on vaccines.

Jenni used multivitamins as an example of how even conclusions drawn from methodologically sound studies may lack the longitudinal depth to reflect a true understanding of a particular product's safety or efficacy. Thus, just as multivitamins appeared effective in promoting health until longitudinal data suggested otherwise, so too might new vaccines, formulations, and schedules appear safe in the absence of long-term data.

Both of Jenni's arguments maintained the integrity of the technical sphere but used its own exclusive standards against existing support for vaccines. These arguments from participants were not based in a contention that participants had the right to be included in the technical sphere but rather suggested that the standards of the technical sphere had become too lax. This distinction is important because it challenges the commonplace assumption that vaccine refusers believe in pseudo-science as definitive. Instead, participants in this study lacked confidence in the quality of much published research on this topic in light of traditional scientific standards.

Even cases of otherwise "credible" research were discounted by participants due to a perceived "conflict of interest," particularly regarding studies funded by pharmaceutical companies. Nancy, a 39-year-old mother of one, explained how she had debated with another mother on a vaccination discussion board. When the mother challenged her research, claiming they were reviews of studies and/or carried out by dubious sources, she challenged her to bring her own:

So, when she came with this list, I went to each one and I said, "yeah, you've got the same thing. You've got a bunch of reviews, and the ones that are double-blind studies were the ones done by pharmaceutical companies. They're paid for by marketing so they don't mean anything to me," I said. So we're just going to continue to be this way—we don't see eye to eye on this because you trust something that I don't, I trust something that you don't.

Nancy challenged the reliability of existing studies in what was a common rhetorical strategy among participants. She did not claim her evidence as superior but rather pointed to the similarities that rendered both "sides" as questionable.

Other arguments suggested that it was not simply the results of research that failed to meet standards but the knowledge and skills of the experts themselves. Participants suggested that, although scientific expertise exists, education and titles did not necessarily confer it. Frances, a 33-year-old mother of two and a high school math teacher, explained,

Before, I had blind faith in doctors—that all doctors were good doctors. And then, you know, as I became a teacher and you realize not all teachers are good teachers, it's like, “hey, wait a minute, not everybody is good at what they do.”

Participants cited doctors who made factually inaccurate statements, missed key diagnoses, or were unable or unwilling to answer particular questions. Again, these arguments maintained the ideal of expert knowledge but challenged particular claims to expertise. As Naomi, a 38-year-old mother of one, explained, “don't just blindly do what the doctors tell you to do. They don't even know half the time what they're doing.” For participants in this study, the perception that a doctor lacked either skills or ethics played a significant role in perpetuating doubt about vaccines, and this in turn cast doubt not on the technical sphere itself but rather on the credibility of those communicating within it.

Doubt about the expert status of health care providers was also related to concerns about their motives. Karen, a 33-year-old pregnant mother of three, warned against just “blindly” following the recommendations of doctors with regard to vaccination, explaining that, “the doctor ... has done no direct research into vaccination. They just do what they're told by the pharmaceutical companies.” Participants also drew connections with doctors' motives with regard to other health scenarios, especially those related to obstetric care. For example, Felicia discussed increasing rates of labor induction, and how many expectant mothers comply because they assume their physician is basing the recommendation on medical need:

When you look into it and you find out why they are pushing those things you're like, really? Really, my health is not of the utmost importance to you. Really, it's your time schedule. It's that you are not going fast enough, and “I want to be home and have dinner” [laughs, you know what I mean?

Collectively, these arguments suggested that doctors are not only often ill-informed about issues such as vaccine safety but also that they are motivated by priorities that place convenience and financial incentives above evidence-based best practices. This perception relates directly to another common argument that simultaneously upheld the boundaries of the technical sphere yet criticized the policing of those boundaries.

Research as political. In addition to arguments suggesting that vaccine recommendations are based on insufficient evidence, many participants likewise suggested that the social practice of science—despite claims of objectivity—reflects a political or economic agenda. This notion of the technical sphere as subject to a political agenda was reflected in the way that participants talked about the pharmaceutical industry as what Jill, a 25-year-old mother of two, called “a huge money-making machine.” Perhaps most significantly, however, participants' doubts about the conflicting interests infiltrating the technical sphere were manifest in their concerns regarding the legal status of vaccines. In fact, vaccinations are unique in terms of consumer products in their criminal and civil liability (Kraemer and Gostin, 2011). Jessica, a 41-year-old mother of two, cited this fact in explaining her doubt regarding a proper system of checks on vaccine safety: “I think that the vaccine industry is still [so] well protected from lawsuits and from, you know, answering the real questions, that we can't be sure what all is really in [vaccines].”

Several mothers interpreted this legal aberration as evidence that the government acknowledged vaccines' potential harms, a contention further strengthened by the ambiguous status of rulings from the National Vaccine Injury Compensation Program (NVICP), a no-fault litigation process for victims of adverse reactions caused by vaccines. Individuals suffering from certain, pre-determined injuries temporally following administration of a vaccine benefit from a "presumption of causation" that is compensated with either the cost of lifetime medical care or a lump sum in the case of death. From its inception in 1989 to June of 2014, over US\$2.7 billion was awarded to more than 3600 individuals (United States Department of Health and Human Services, Health Resources and Services Administration, 2015).

For mothers in this study, the rulings of the court served to validate concerns about the potential dangers of vaccination. As Jacqueline explained, "There's even a government reporting system for vaccine reactions, as well as a fund set up to compensate vaccine injured people, so there are definitely risks to vaccinating." In this case, the safeguards put into place to protect consumers were presented as clear evidence that the government was aware of vaccine safety risks. Diane, a 37-year-old pregnant mother of two, forwarded this argument when she noted,

You look at things like the vaccine injury court system. You know, they obviously take great scrutiny when they review those cases, so when you have those cases coming through and being found that the vaccines are negligent, or are related to the disease—you know, the effects that people have had—are hard to argue with.

That such settlements paid to families were largely unacknowledged in the public debate about vaccines was repeatedly upheld as further evidence that the ideal technical sphere had been corrupted.

Challenging the boundaries

The arguments discussed up to this point maintained the boundaries of the technical sphere inasmuch as they upheld and appealed to high scientific standards, and regulated the types of voices and evidence that should be included. Paradoxically, however, mothers' arguments also suggested that traditional scientific approaches (including those that underscore the idea of a technical sphere itself) were not actually sufficient to ascertain truth. This idea was supported by several contentions.

Science as relative. First, participants suggested that truth itself is a relative entity. This idea is in line with critical approaches that have argued for scientific truth as a social construction (e.g. Latour and Woolgar, 1979). In particular, participants argued that it was not the conclusions of research that matter but, rather, the process of discovery. This distinction reflected the importance of doing one's own research, which was overwhelmingly included in participants' advice to other mothers. This advice communicates the importance of being informed and educated, but also reflected a contention that scientific research—and the conclusion it yields—is personal. In particular, the use of the possessive noun in advice regarding research was almost ubiquitous and, I argue, crucial to the meaning that mothers ascribed to the phrase. That is, the advice to other mothers was not to "do research" but to "do *your* own research" or "she needs to do *her* research." The possessive pronoun both indicated and constituted a broader worldview in which research and science can yield multiple and contestable truths. Holly, a 31-year-old mother of one, further illustrated this idea in her advice to mothers:

I would never tell her what to do because, just because I decided not to vaccinate does not make me right or wrong, but it doesn't make her right or wrong either to vaccinate. And like I always tell people, for example, if I were to feed my child a pop tart for breakfast, and you were to give your child oatmeal for breakfast, doesn't make me right or me wrong or you right or wrong. It's just two different styles of parenting.

For Holly, there is no such thing as a "right" choice for everyone; what is right or wrong is determined for and by each individual. This rhetoric of individual choice is commonplace in US culture (e.g. McCarver, 2011; McMullen, 2012). However, this rhetoric, and the ideas it represents, pose a particular challenge to public health initiatives; from a public health perspective, vaccinations *are* right, just as oatmeal *is* a better choice than pop tarts.

This broader argument also contrasted with participants' discussion of the (shortcomings of) scientific evidence regarding vaccines. Specifically, arguments discussed earlier respected the boundaries of the technical sphere by suggesting that definitive evidence of safety was possible but not yet achieved. However, these same participants contradicted that suggestion by arguing that no one course of action is itself better than another. For example, Jenni discussed her doubts about vaccine safety by citing a lack of double-blind, randomized, placebo studies and longitudinal data, but went on to say, "I think as long as you research, and you are making an informed decision, then whatever decision you're making is the right one whether you vaccinate or not." Jenni's statement suggests that the decision is "right" not because of a particular outcome but by virtue of the process used to produce it.

The focus on the individual and the idea that there are multiple and equally valid truths were also illustrated by Lauren, a 26-year-old mother of two, who made a similar point in the advice she provided:

I would tell her to do her own research, to educate herself, and to really know that it is her baby and it's her choice. It is not her doctor's choice, it is not her mom's choice, it's not her neighbor's choice, and it is not her school's choice.

The presumption of the technical sphere is that policy decisions—including those related to public health—should perhaps be informed by public concerns but ultimately determined by experts. Lauren's advice, however, suggested that mothers' decisions about vaccination should instead be guided by individual and subjective, albeit well-researched, reasoning. Lauren continued,

Really my biggest piece of advice would just be to let her know that there are two sides to the story, and moms are really only subjected to one side of the story. Often that's how it is until it is a little too late, and so just educate yourself and know that there are two sides to it.

For Lauren, the very presence of "two sides" seemed to indicate that there were multiple truths at play. The technical sphere, in this case, was implicitly situated as itself a space of contested claims. While critics have argued that science reflects not truth but consensus (e.g. Keränen, 2005; Kuhn, 1962), mothers in this study seemed to suggest that individual deliberation, rather than consensus, should be the final arbiter, and that dissensus is allowable.

This inability of any one side to yield certain truth was also related to the argument that the human body is beyond scientific understanding. For example, mothers consistently anthropomorphized the body and immune system; as Natalie, a 31-year-old mother of one explained, "we kind of let the body do what it needs to do." Within this context, the body is attributed a way of being that is above or outside of scientific epistemology. That is, in the absence of understanding about

the body, the best a mother can aim for is to protect the body from the threat of taint or artificial and inevitably damaging intervention. As Nancy, a 39-year-old mother of one, explained, “I think that when you, like, artificially stimulate the immune system, you’re messing with something that’s already, you know, working fairly properly.” Similarly, as Lauren, a 26-year-old mother of two noted, “any time you introduce any foreign material into the immune system, especially that of a newborn child, you are just throwing the body completely off track.” These comments suggested that—even meeting objective standards—scientific findings are nevertheless inadequate to understand or intervene in the practices of a healthy human body.

Maternal instinct as superior

Given the inadequacies of scientific epistemology, then, mothers’ personal experiences and perspectives were endowed with greater significance and credibility. Lauren, who held a Bachelor of Science in Nursing, explained how she contrasted traditional scientific information and discourse with her own personal experience with vaccine injury:

When I was in nursing school we, you know, meta-analysis, we had a research system for every article we found on pub med and I was so into, okay, you need a large study sample, you need this, you need that to be credible. But for one, you know those studies with unvaccinated children don’t exist so there is nothing for me to compare to there and, again, you know, when you find real stories, real families, real faces, and one of them is your daughter, you know, that is my biggest source of information—listening to other parents.

Lauren acknowledged the types of evidence required to ensure that scientific findings are reliable, implicitly endorsing the boundaries of the technical sphere. Nevertheless, she suggested that—in the face of her own personal experience—such evidence would be secondary, even if it were available.

This paradox of rigid adherence to scientific standards mixed with a lack of faith in their ultimate potential is also evident in the way participants talked about anecdotal evidence. On the surface, many mothers criticized anecdotal evidence for being unreliable. At the same time, however, participants suggested that anecdotal evidence was nevertheless necessary in raising points for consideration. Paige explained,

The personal stories mean something to me. When I hear people talking about it, and [who] lived through it, and I just know the CDC isn’t honest with how many people have been vaccine injured [and] are not acknowledging it.

Barb likewise spoke to the power of anecdotal evidence, especially when it is derived from a mother’s embodied experience:

You know, a lot of the sources that I do rely on more mostly would be doctors, obviously, but also mothers. You know, mothers that have been there. There are many mothers that have actually written books, there’s a lot of blogs by moms that have lost children from reactions like that, and there are horrifying pictures. I mean, I don’t—you can’t ignore that kind of evidence.

Barb acknowledged doctors in the technical sphere among the sources she trusts, however, her statement that “you can’t ignore that kind of evidence” speaks to the weight also granted to personal experience. For the scientific community, “that kind of evidence” is dismissed as anecdotal. But for participants in this study, when so-called anecdotal evidence couples with a mother’s “gut” feeling, it takes on decisive significance.

Indeed, in light of the perceived failures of science, the “mommy gut,” or maternal intuition, emerged as a significant sense- and decision-making tool. As Claire, a 33-year-old mother of one, explained—this intuition functioned as an evaluative tool that rivals other technical forms of expertise:

Honestly, you can read all the things you want to read, you can, you know, sort of like I was saying before, find both sides out there I mean, and it’s really gonna come down to your gut. You know what you know about your child, and weighing the risks and benefits in your own mind, you know, it comes down to you. You’re responsible for this child, what’s best for him or her, and you’re the only person who knows what you know.

Claire suggested that a mother’s intuition situates her uniquely to truly “see” what is happening with regard to vaccines and related experiences. In this sense, participants’ explanations suggested an alternative form of knowledge production that could supplement and/or trump existing knowledge claims.

5. Discussion

This analysis sought to understand how mothers’ explanations for vaccine refusal negotiated personal experience and scientific evidence. Ultimately, participants’ explanations for vaccine refusal both challenged and supported the distinction between technical and personal spheres of argument in complex and, at times, contradictory ways. Although participants maintained a clear demarcation of the technical sphere to criticize shortcomings in the research and evidence used to promote vaccines, they simultaneously suggested that mothers’ unique perspectives and embodied experience challenged both specific knowledge claims about vaccines and the particular ways of knowing that give rise to such claims. This line of argument challenged the boundaries between the personal and technical spheres by proposing an alternative model of knowledge production, just as it suggested that personal arguments can constitute an unconventional but perhaps superior model of expertise. These findings have both theoretical and pragmatic implications.

First, arguments about science as failing to meet rigorous standards serve an important strategic function. Vaccine critics are often framed in public discourse as being simply anti-science or lacking in scientific literacy. Invoking arguments based in a criticism of scientific methodology thus enabled participants to demonstrate their scientific literacy. Additionally, the use of such arguments meant that participants were not required to present compelling arguments regarding how and why vaccines are dangerous. Rather, they focused on casting reasonable doubt on the proof that vaccines are uniformly safe.

Additionally, by invoking arguments based on the socio-political nature of science, and especially the economic interests tied up in public health, participants called upon an increasingly widespread lack of trust in industry, as well as arguments that are legitimated in many other academic and activist communities. For example, the argument that scientific studies are inconclusive, poorly designed, or biased by economic or political agendas are rhetorically similar to those waged within the widely disparaged community of climate change denialists, but also the generally accepted communities of genetically modified food activists and other consumer safety movements. In this way, such arguments are tolerated in public discourse when they support public health goals or popular sentiment but are demonized when they challenge them. This contradiction only serves to strengthen the appeal and credibility of vaccine critics and arguments, and lends further credence to the argument that scientific policy and consensus are subjective entities.

Collectively, these critiques of the social and political practice of science also reflect dominant critical and postmodern perspectives and illuminate the potential of such models to challenge public

health initiatives. That is, participants were doing exactly what they have been told to do: seek out information, question safety and “expert” directions, and understand that all perspectives are relative and partial. This highlights the paradox of patient advocacy, which is celebrated in many contexts (e.g. preventing hospital error) but marginalized in other cases (e.g. questioning vaccines). Examining how this advice culminates in the context of vaccine refusal points to the need for researchers to continue grappling with the impact of such ideas in the context of public health.

Finally, envisioning mothers’ arguments about vaccine refusal as a space in which the personal and technical spheres overlap contributes to existing scholarship regarding argument sphere theory and its relationship to knowledge production. Such boundary-spanning serves to “realign the spheres to achieve particular ends and thereby alter the grounds of legitimate scientific practice” (Keränen, 2005: 112). That is, we can understand these arguments as rhetorical, but also epistemological, and the paradox exists at both levels. In this way, participants’ rhetoric reflects what Moscovici (2008) called cognitive polyphasia, or the “dynamic co-existence—interference or specialization—of the distinct modalities of knowledge” (p. 190). Indeed, other studies of health sense-making (e.g. De Graft-Aikins, 2012; Provenchar, 2011) have drawn from this framework to suggest that individuals “draw on different types of knowledge to make sense of the world around them” (Provenchar, 2011: 377), often in seemingly conflicting ways.

In this case, the knowledge that participants drew from their own maternal experience aligns with what Borkman (1976) called “experiential knowledge,” or “truth learned from personal experience with a phenomenon rather than truth acquired by discursive reasoning, observation, or reflection on information provided by others” (p. 446). Likewise, other scholars have explored the role of such “lay expertise” (Epstein, 1995), “patient knowledge” (Pols, 2014), and “lay epidemiology” (Davison et al., 1991) in shaping understanding about health, especially as it conflicts with traditional biomedical expertise. However, whereas most previous scholarship in this vein has focused on illness experiences, the alternative form of knowledge production suggested by participants in this study derives from the social experience of motherhood, and constitutes what I suggest we can understand as a kind of standpoint—and specifically, maternal—epistemology.

Standpoint epistemology suggests that certain social positions—especially those which have historically been marginalized—may in fact offer a valuable and otherwise invisible perspective. Such perspectives are not relative but partial (Harding, 2004), and are largely celebrated by critical scholars. Sara Ruddick (2004) positioned “maternal thinking” as one such epistemology, writing,

I speak about a mother’s thought ... A mother engages in a discipline. That is, she asks certain questions rather than others; establishes criteria for the truth adequacy, and relevance of proposed answers; and cares about the findings she makes and can act upon. (p. 347)

In line with this conception, participants presented maternal instinct as superior to other forms of knowledge- and sense-making because it is so intimately tied to mothers’ lived experiences. Although the arguments derived from this epistemology are similar in many ways to those used to contest scientific consensus more generally, the specific deference to maternal epistemology is unique in its rhetorical effectiveness. That is, such arguments leave little space for counterclaims; the underlying logic attacks not just competing knowledge claims but also broader ways of knowing.

This final assertion relates to the pragmatic implications of results from this study, and particularly how public health efforts can be effectively mounted in response to such arguments. Certainly, this is a communication problem. Results suggest a benefit to targeted and tailored vaccine messages for vaccine hesitant mothers, and ones that account for both lived experience as well as traditional scientific evidence. This may include a need for increased information and

detail provided via both written documents and interpersonal communication from healthcare providers. This is not to suggest an information deficit; on the contrary, because of the high need for cognition demonstrated among participants, as well as the ability to consider conflicting information, participants like those in this study require the kinds of detailed arguments (including hedging) that are often anathema to public communication about scientific controversy. For example, healthcare providers should be ready and able to respond to concerns about study design by explaining the serious ethical roadblocks that exist with regard to double-blind trials with vaccines, or the inclusion of children and pregnant women in clinical research. More generally, specific training should be provided to healthcare professionals to ensure that they are comfortable and confident in their ability to explain vaccine policies and formulations, and respond to patient concerns.

In addition to communication issues, however, results from this study point to broader problems in the healthcare system. That is, participants in this study levied legitimate concerns about the credibility of expert science and the factors influencing science and health policy. This line of argument suggests that there are concrete steps—for example, attending to the inconsistencies raised by the NVICP, reforming the clinical trial system, or re-structuring the economic development of vaccines to remove potential financial conflicts of interest—that might assuage some concerns. Although such steps may not be immediately effective, they may help create a space for both sides to agree upon the criteria for a valid knowledge claim. This step is, in and of itself, a crucial one.

However, in the case that participant arguments against vaccines (based in the technical sphere) were successfully refuted and/or rectified, contrary arguments from participants suggest that the changes would nevertheless be challenged by a maternal epistemology to which traditional public health campaigns are not equipped to respond. These challenges may also mirror those that emerge from other scientific controversies (e.g. climate change) which provoke similar rhetorical patterns among critics. Despite a lack of easy answers, however, accounting for these patterns is vital to understanding and responding to the challenges of vaccine refusal specifically and contemporary scientific controversies more generally.

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Author biography

Melissa L. Carrion (PhD, Purdue University, 2014) is an Assistant Professor of technical and professional communication in the Department of Writing and Linguistics at Georgia Southern University. Her research explores rhetoric and health communication, especially in the context of science-based controversies. She is grateful to Susan Morgan, Robin Clair, and Gerald Hyner for their support during the development of this project and is especially thankful to Robin Jensen for her guidance and invaluable feedback on earlier versions of this manuscript.