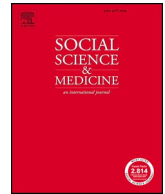




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“We are fierce, independent thinkers and intelligent”: Social capital and stigma management among mothers who refuse vaccines

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ABSTRACT

Despite measurable benefits of childhood vaccines, mothers with high levels of social privilege are increasingly refusing some or all vaccines for their children. These mothers are often clustered geographically or networked socially, providing information, emotional support, and validation for each other. Mothers who reject vaccines may face disapproval from others, criticism in popular culture, negative interactions with healthcare providers, and conflicts with people they know, which serve to stigmatize them. This article uses qualitative data from in-depth interviews with parents who reject vaccines, ethnographic observations, and analyses of online discussions to examine the role of social capital in networks of vaccine-refusing mothers. Specifically, this article explores how mothers provide each other information critical of vaccines, encourage a sense of one's self as empowered to question social expectations around vaccination, provide strategies for managing stigma that results from refusing vaccines, and define a sense of obligation to extend social capital to other mothers. In examining these strategies and tensions, we see how social capital can powerfully support subcultural norms that contradict broader social norms and provide sources of social support. Even as these forces are experienced as positive, they work in ways that actively undermine community health, particularly for those who are the most socially vulnerable to negative health outcomes from infection.

1. Introduction

The phenomenon of parents refusing some or all vaccines for their children has increasingly received public attention in the U.S. This is driven by the reality that many vaccine-preventable diseases are recurring in higher numbers and are linked to the rise in the number of children who are intentionally unvaccinated (Constable et al., 2014; Phadke et al., 2016). Vaccine refusal emerges from diffuse fear of unknown long-term health risks that seemingly require consumer vigilance and represent distrust of experts and regulatory bodies (Faasse et al., 2016; Hobson-West, 2007; MacKendrick, 2018). In examining which parents reject some or all vaccines for their children, particular patterns are visible. First, women are disproportionately responsible for children's healthcare decisions and are most engaged in discourse challenging vaccines (Ranji and Salganicoff, 2014; N. Smith and Graham, 2017). Second, mothers who deliberately refuse or delay vaccines are most likely to be white, college educated, and wealthier (P. J. Smith, Chu and Barker, 2004; Yang et al., 2016). Third, they tend to be networked with other mothers who also distrust of vaccination (Brunson, 2013; Onnela et al., 2016). These mothers have time and resources with which to gather information, customize healthcare and nutrition choices, and buck public health law without fear of formal

sanctions (Reich, 2014). With higher levels of income, fewer time obligations, and more economic and informational resources with which to seek and provide care, they are best situated to manage illness, lengthy quarantines, or missed work opportunities that might result from exposure to vaccine-preventable diseases than are families with fewer resources.

Maternal willingness to delay or reject some or all immunizations for their children, which I reference collectively as vaccine refusal, also clusters geographically and socially. Within those networks, children are as much as twice as likely to be missing key vaccines than are other children (Lieu et al., 2015), though it is unclear causally whether vaccine refusal results from networks or parents with these views seek out these networks (Chung et al., 2017). Belonging to a network with others who have higher levels of education may influence the sources and range of health information members seek (Song and Chang, 2012) and an increased willingness to seek out certain ways of conceptualizing children's health and sickness (Liu et al., 2010).

Social capital, the “resources embedded in a social structure,” can be “accessed and/or mobilized in purposive actions” for individual benefit (Lin, 2002, p. 29). Its utility is contextual, where actors may find social capital powerful in some situations and useless in others (Coleman, 1988). From an actor-based perspective, individuals or

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communities may invest and accrue resources through participation in networks (Lin, 2000, 2002), which can be particularly valuable for facilitating opposition or expressions of dissent (Coleman, 1988). They can operate, as they do for vaccine refusing mothers, at times through formal organizational membership or more informally through communication in person, or online (Ellison et al., 2007; Ostertag and Ortiz, 2017). Online communities, particularly those used by mothers, provide a virtual place in which “users interact, often daily, to help and check up on one another” and “are promoted as a place to find support and information” (Drentea and Moren-Cross, 2005, p. 924). They include other mothers who possess similar levels of social status and access to resources.

Resources that shape individual well-being—both material and emotional—flow from social networks (Carpiano, 2006; Kawachi et al., 1997), with members’ social connections, social ties, and influence providing social capital to other network members (Lin, 2002; Song and Chang, 2012). Networks often provide social support, including emotional support, which may offer empathy, sympathy, and shared sense of understanding; it may also offer appraisal support, which provides feedback relevant to self-evaluation, self-improvement, or affirmation for the appropriateness of acts. More instrumentally, social networks may offer informational support, including “advice and information leading to a solution to problems” or actions (Drentea and Moren-Cross, 2005; Ferlander, 2007, p. 116). Networks that support vaccine refusal—in-person or online—are often self-reinforcing as members share information to facilitate action (Coleman, 1988), like encouraging others to question vaccine safety and necessity (Kata, 2012; Sobo et al., 2016) or challenge legal or social requirements to vaccinate (Reich, 2018; Tangherlini et al., 2016). Vaccine refusal in many ways represents an “opting in” to a social group (Attwell et al., 2018; Sobo, 2016). As Sobo (2016, p. 345) explains, vaccine refusal “often serves as a declaration of identification with the social setting of import to the individual.” Accessing this network and building mutual trust with its members also provides access to social capital. In contrast, social distance among network insiders and outsiders can lead to greater stigmatization, including support for punitive policies for parents who reject vaccines (Carpiano and Fitz, 2017). Social capital within networks may mediate challenges and improve health (Perry et al., 2017), but can also lead to participation in behaviors that increase risk, even as members may not see the promoted behaviors as problematic (Lochner et al., 2003; Lovell, 2002), which is arguably the case with networks of mothers who refuse vaccines.

The choice to refuse vaccination, a cornerstone of U.S. public health, can be a stigmatizing one. I use stigma here to denote the result of interactions in which mothers who refuse vaccinations are labeled negatively individually and as a group, are treated as separate from the mainstream, and face relative status loss and discrimination (Goffman, 1986) by those supportive of vaccines. Stigma lies within relationships and emerges in interactions with others who lack the discredited characteristic who Goffman (1986) references as normals. Mothers who refuse vaccines experience stigma situationally in mixed encounters with healthcare providers, schools, and even extended family. They are also portrayed in the popular press as ignorant, selfish, and as presenting unnecessary risk to other children (Gottlieb, 2016). The experience of stigma may inspire those with the discredited trait to more strongly identify with others who share that trait—who also reject vaccines—and gain emotional support from them (Crabtree et al., 2010). Mothers who refuse vaccines for their children often enter mixed encounters with high levels of privilege, including race, class, and education. As such, they have more social capital available with which to manage stigma that they bring into these networks in support of others. The findings examine how mothers who opt out of vaccines provide social capital to each other through these networks.

In the following sections, I use qualitative data to examine the processes by which mothers who reject vaccines mobilize social capital to bolster their decision to reject vaccines for their children and manage

resulting stigma. Rather than focusing on health outcomes, I use qualitative data to elucidate the processes by which mothers who refuse some or all vaccines access social capital as they gain informational, emotional, and appraisal support from networks for their position and in opposition to those who disapprove. Notably, these women who are racially, educationally, or socioeconomically privileged in some contexts are diminished in others. I first show how mothers create, promote, and share information to define themselves as experts on their children and on vaccines. These claims of expertise serve to validate their choices and increase their claims to social capital in their networks. Second, I demonstrate how they rely on networks of similar mothers for resources to combat stigma. Third, I show how networks provide resources with which to manage stigma in interactions with outsiders. As they craft their shared understandings of disease and vaccines and challenge opponents, they articulate an obligation to support other vaccine-refusing mothers, and in so doing, grow their network. I conclude by considering the challenges networks that distribute social capital in opposition to vaccines present to public health efforts.

2. Methods

I collected qualitative data during in-depth interviews with mothers who refuse some or all vaccines; through ethnographic observations at community events and national conferences of organizations (detailed below); and from analysis of online parenting forums and sites where discussions of vaccines were common. These data came from a larger study for which data were collected from 2007 to 2014 (Reich, 2016). I interviewed 28 mothers who live in Colorado who either opt out completely or provide consent to some vaccines on a schedule of their own devising. Colorado has among the lowest rates of vaccination in the U.S. with among the highest rates of parents opting out of vaccines (CDPHE, 2015; Draper, 2015). None of these mothers were members of the online communities observed and only one of the 28 attended national meetings that I also observed.

Maternal rejection of vaccines is quite fluid. Mothers, with shifting perceptions of need and risk, often reassess vaccine strategies. Many described ways they consider each child in the family differently, at different ages, and select different vaccines for each child. Thus, I include those who opted out entirely (more than half have at least one child who has received no vaccines) and mothers who consented to vaccines on a schedule other than that recommended by federal advisory bodies, state law, and physician organizations.

Among mothers interviewed, all but one was white. All but one identified as heterosexual; 24 were married; and four were divorced or separated from their child’s other parent. Nine mothers had bachelor degrees, eight had graduate degrees, seven had some college and four were high school educated. Nine mothers stayed home full-time; seven worked full-time for wages; twelve worked part-time, often with limited work hours and great autonomy. At the time of the interviews, ten mothers had one child, nine had two children, four had three, four had four, and one had eight. Mothers were between 26 and 54 years old. All but one had at least one minor child at home. Interviews captured mothers’ narratives of their vaccine choices retrospectively, not necessarily as they were making vaccine decision.

Interview participants were recruited using convenience sampling; they were referred by others familiar with the study who were not themselves participants, including colleagues, friends, and acquaintances or through listservs including those for parents who choose to homeschool or enroll in schools with low immunization rates. Invitations communicated interest in the views of parents who were making “independent decisions about healthcare, particularly around vaccination.” Notably, no participant referred any other participant—so there was no snowball sampling—and I did not discover evidence of any shared social networks. Participants were geographically dispersed across the state. Semi-structured interviews lasted between one and

four hours and were recorded and transcribed verbatim. All were conducted in-person and each mother was interviewed only once, though some emailed or stayed in touch after without solicitation about their children's health. All interview participants volunteered, provided written and verbal consent, and received no compensation.

Questions were open-ended and explored a wide range of topics, including parental history, education, employment, healthcare experiences, relationship and family formation, family planning and pregnancy, birth, parenting practices, interactions with healthcare providers and schools, sources of information, care for children's health, process of coming to question vaccines, and views of vaccination in general. Transcripts were initially coded and analyzed thematically, and then as patterns were identified, I built theoretical analysis drawn from those patterns (Charmaz, 2006).

Data also came from ethnographic observations of spaces where vaccines are discussed. These included three annual meetings of two national organizations that oppose vaccine mandates or support natural living (which may include avoiding vaccination). I attended sessions, had lunch with parents, observed casual conversations, and spoke with organizers, presenters, and attendees. Over several years, I also observed community educational presentations in different Colorado cities held by pediatricians or naturopaths for parents about vaccines, educational events for physicians, and a meeting of the Institute of Medicine (IOM) where experts discussed vaccine safety. With the exception of the IOM meeting where I wore a badge indicating I was a guest observer, I attended these events as an interested parent. At times in conversation with attendees my research interest in the topic was disclosed and at other times not, depending on circumstance and which was least invasive. At each observation, I took fieldnotes without identifying information, which were coded thematically alongside interview data.

I also analyzed discussions on social media, blog posts, and listservs open to parents around the country. I did not participate in online discussions but remained a passive observer, sometimes searching archives for past discussions specifically about vaccination. Some were on social media sites like Facebook that do not require membership and others were in targeted forums. In each, users could post comments or questions and receive feedback and advice. Based on comments or limited available profile information, these forums appeared to be used predominantly by women, which is consistent with research that suggests mothers are more likely to use social media to engage networks for parenting advice, information sharing, or social support than are fathers (Duggan et al., 2015) and that websites in opposition to vaccines are “highly feminized” (N. Smith and Graham, 2017). Admittedly, I can say little about participants' offline lives. Information about mothers in online communities suggests they are elite. Generally, mothers who write blogs or participate in parenting forum discussions are more likely to have a college education, be white, and have a higher annual income than mothers who don't (Laird, 2012; Morris, 2014). This reflects larger trends in online usage, which show a persistent digital divide in internet usage by income, education, and race (Anderson, 2017; Dutton and Reisdorf, 2017). Excerpts from online posts are reproduced without correction. Throughout, data may not represent what mothers actually do, but their values and priorities as they present themselves.

3. Findings

Mothers who reject vaccines mobilize social capital to gain validation for their decision to reject vaccines and to manage stigma they may experience as a result. In the following sections, I examine how these women create and exchange information that serves to reify their sense of themselves as experts on their children and on vaccines, how their networks of mothers who have made similar choices provide resources with which they can combat stigma, and how these women use their shared understandings of disease and vaccines to not just challenge those who disapprove of them, but also to support other vaccine-

refusing mothers in an effort to grow their network and increase their access to social capital.

4. Using social capital to support alternative ways of knowing

Mothers, not specific to questions of vaccines, frequently rely on communities of other mothers to access information and advice, receive validation for parenting choices, and give and receive support. These communities are often online (Haslam et al., 2017; Petersen, 2015) and offer mothers opportunities to communicate with other mothers about a range of topics, including healthcare decisions (Drentea and Moren-Cross, 2005). These social networks offer support for particular “ways of knowing” that may decenter scientific fact in favor of intuition, prioritize more inclusive forms of communication, and communicate reverence for motherhood as producing particular kinds of knowledge (Belenky, 1986; Ruddick, 1989). In turn, networks become powerful places for women to draw on social capital in support of their parenting practices.

Many of the mothers in this study referenced the importance of building a network of other mothers who share their experiences or views. As one mother explained during an interview, “Having a community of other mothers. It's essential. It's so essential.” As she considered the negative responses to her parenting decisions she has received from childless friends, she noted how other mothers have been sources of solace and support. She recalled,

I actually had an aversion to some of our friends who didn't have children in the beginning, did not want them around, had a couple instances where I was deeply, deeply offended by their opinion because how could they know when they don't have the right to say that? That's gone away. I like my friends again, but I only wanted mommies and when I was out for a walk, if I saw other mommies, I needed to have contact with them and I've really—I've taken part in—in building a mommy community.

Another mother described in an interview how she prioritized networking with mothers who share her views to compensate for the disapproval she otherwise faced: “I feel like in certain circles, I'm kind of an oddball. I try to surround myself with people that are like-minded because then you feel—it makes you feel more relaxed or like you fit in a little bit more.”

As mothers who invest heavily in parenting, they comprise a network that provides appraisal support and affirmation for the importance of their work as mothers, which many pursue instead of wages. As they share information and emotional support, they confirm that their ways of knowing are grounded in experience and are more trustworthy than those of their friends without children. Like this mother, many devote energies to building community and tightening networks with other mothers, which can provide social capital to her and the other members. Like other studies that demonstrate how networks may increase behaviors that are risky, these mothers provide social capital that affirms and encourages their challenges to public health (Carpiano, 2007).

4.1. Supporting vaccine refusal as maternal choice

For mothers who reject vaccines, networks of mothers with similar views are especially important. Members of networks critical of vaccines tend to bring cultural capital with them to these networks, as they are disproportionately college educated, white, and have higher average incomes. Celebrities who are critical of vaccines also bring cultural capital to these networks as they persuade parents to question vaccine safety and amplify parental concerns (Freed et al., 2011; Hoffman and Tan, 2015). Members of networks of vaccine-refusing parents are able to mobilize their collective social capital to keep their concerns in public discourse. Much of this is accomplished by maintaining an online presence. Webpages of groups critical of vaccines

typically frame opposition as a question of parental rights, as supportive of safe vaccines, or as defensive of individual choice, while also claiming that vaccines are toxic and harmful (Davies, 2002; Kata, 2012). These claims are widely disseminated through social media (N. Smith and Graham, 2017). These posts and reposts at times tighten their community norms and at other times support mothers' insistence that despite being a numerically small community, their perspective in the vaccine debate deserves equal consideration.

Offline, discussions among these privileged mothers underscore the importance of individual choice as synonymous with good mothering (Hobson-West, 2007; Reich, 2014). Illustrating this, one mother in an interview insisted each mother should question expert recommendations to develop her own strategy for vaccines: "... it irritates me that people don't ask why. Not so much that they've chosen what they've chosen (to vaccinate), but why they've chosen what they've chosen; because they haven't even considered another option. Back to that whole 'people just blindly trust,' you know? And I think that irritates me more."

By discussing vaccine choices within their networks, women receive appraisal support for refusing vaccines since vaccine refusal is normative. For example, one mother described in an interview her discussions with other mothers at her son's Waldorf School, a private school where about half of children are not fully vaccinated. "It's not like we ever have a conversation about [vaccines], it's just you know—things will come up in conversation where you're like, 'Oh, okay, that's similar to the decision I made,' or 'Wow, they're even more strong on that issue (of vaccine refusal) than I am.'" These conversation and insights provide support for mothers questioning or rejecting vaccines, but also signal a social norm expected for membership and access to capital. Reflecting on this support, this mother considered how access to these networks—and this private school—required cultural capital, including time, money, and education: "I do feel like I sort of selected it, where it's kind of a combination of more—not alternative, but there's more people who do alternative health than [at a traditional school]."

The views of children's health and definitions of good parenting that are normative within these networks—including vaccine hesitance or refusal, extended breastfeeding, attachment parenting, commitment to organic foods, and alternative views of medicine—are not necessarily valued outside these parenting networks (Reich, 2011; Sobo, 2016). Through these communities, mothers may find support for their decisions, and with the social capital their networks offer, emerge feeling validated. They also at times may feel pressure to adopt certain behaviors required of their network to maintain access to social capital (Moore et al., 2009; Portes, 1998). For example, one mother in an interview remembered seeking information from others as she considered how to promote her baby's health without vaccines:

I actually ended up living close to kind of a small mommy group, like walking group ... [One woman in it] didn't vaccinate her baby and he was 24 months when I first met her. And what she did was she had these, I guess it was like some kind of drops, like vitamin drops or whatever, and something else ... And then she also took him to the chiropractor once a month, which I think is crazy. Like taking a baby to a chiropractor? Like do they really need—like they have such flexible joints anyway but she's like, "No, it really helps and, you know, that affects everything in their body." So yeah, I definitely listened to what she had to say ...

Women often cited informational support they received from other mothers as important. Even in the above passage where she decided the advice offered did not seem useful to her, she recalled spending a great deal of time considering it and rethinking her own vaccine choices.

Information often comes from other women who recommend resources that they perceive as free from corporate influence or government oversight, and thus credible. This can be seen in one online exchange between two mothers. One mother online confidently asserted that she is a self-made expert on vaccines, equal to those with

professional credentials, and advised another mother about the risks of vaccines. She explained, "I have researched vaccines for more than a decade and information confirming the toxicity of many ingredients continues to trickle down to the public." She then offered a link to a story on the website, *Natural News*, which she described as "a very credible holistic-minded publication." The linked article, not part of mainstream medicine, offered, according to the woman recommending it, "irrefutable proof" that pregnant women who receive vaccines against influenza "are being routinely injected with toxic mercury by their own doctors under the excuse of 'public health.'" She advised, "If you're not a subscriber, I highly recommend it. I've been so impressed with its articles."

Another mother replied online to this information. "Thank You for sharing ... I know I feel bullied when it comes to vaccines ... I would love to learn more about my rights...):):) I am definitely going to tune in to a few of these." The discussion offered support for a view of vaccines as risky and those who recommend them as suspect, alongside endorsement of alternative sources deemed credible. This kind of informational support also translates to emotional support and serves to strengthen the network connections among women who share an experience of feeling disrespected or "bullied," while casting those outside their network as illogical, aggressive, or misinformed.

Women who laboriously seek out information about vaccination often define themselves as experts, and more knowledgeable than other parents—and even more informed than many healthcare providers. They often view their network members as also knowledgeable and trustworthy, identifying their declared commitment to protecting children's health as shared norms (Coleman, 1988). This lies in contrast to the perceived motives of healthcare providers, government agencies, or for-profit pharmaceutical companies who manufacture vaccines. One mother described in an interview her sense of herself as an expert on vaccines and her desire to help other parents by contributing regularly to an online community. Highlighting how pediatricians dismiss parents' concerns, she explained,

I'm part of a vaccine group online, and I'm on there every day, and it's interesting, because one of the things that's talked about is how so many moms will say, "What's going on with my child? We really only got vaccines and now she's lethargic." But they don't put two and two together that it was the vaccine. And part of that's because they called the doctor and the doctor says, "No, it's not the vaccine." Part of it is, there's this huge cover-up and they don't want to admit it.

This mother described her expertise as someone who listens to parents, shares information online, and identifies collusion between physicians who do not believe mothers and pharmaceutical companies that hide evidence of the risks vaccines present. This reportedly informs her efforts to challenge medical expertise. Logging on to websites, forums, and online community spaces regularly, as many mothers do, requires large amounts of time, technology, and flexibility. Those that contribute regularly often position themselves as leaders in the community.

For those searching for information about vaccines, these networks provide confident role models who seem knowledgeable and willing to provide informational support, alongside emotional support for their efforts to make what they see as the best choice for their children. Women who seek advice find themselves, at different times, consumers of these resources and experts offering advice to others. Some expressed surprise that their views were valued by others, particularly as they saw themselves as also searching for answers. As one mother explained in an interview of this new role, "For whatever reason, some of my mommy friends ask me for advice, which I think is ridiculous because I'm swimming in this new world, just like they are ... because we all do that with each other."

As women feel recognized as leaders who contribute to the community, their own influence in their network grows. It also increases

their sense of themselves as experts and learners engaged in reciprocity, which in turn tightens their connections within the network. As another mother explained in an interview of her search for information, “I get ideas from other parents. I’ll always take good advice. Like right now, I’ve got a girl who’s so into science, so right now I’m exploring things.” In these ways, mothers who are networked see themselves and others as part of a community of women searching for good answers for their families and bring social capital—confidence, information, support—to each other’s efforts to do so.

4.2. Decentering medical care

These networks extend social capital to members who aim to reconceptualize vaccine-preventable diseases in ways rejected by allopathic medicine. By providing information alongside affirmation, they reframe infection as a way of strengthening the body, rather than something to fear. For example, one mother explained in an interview, “Measles and mumps and chicken pox are necessary immune stimulants.” Insistence that infection can be beneficial, rendering vaccines and medical care unnecessary, can be seen in this online exchange in which one mother posted about her children’s illness, seemingly in search of support: “My two girls got diagnosed with [chicken] pox yesterday. Ugh.” She explained, “I am looking for tips to keep them comfortable while preventing their 10 year old sister from catching it.”

The first reply she received suggested she should see herself as fortunate. “I wish we lived closer and I could come over for a chicken pox party! I hope you can see that this is a good thing to have and that it will give your daughter lifelong immunity and strengthen her immune system.” She then recommended a book about raising an unvaccinated child, which, she suggested, would explain how to provide herbal and homeopathic care for each vaccine-preventable disease. The mother of the sick children seemed moved by this effort to reframe illness. “I am sure I will appreciate it more once we are over it. As of now I am giving them showers with grandpa pine tar soap, applying calamine lotion, and giving them a homeopathic medicine ... hoping we will get to comfortable stage soon.”

Informational support to reframe disease and manage symptoms serve to powerfully decenter medical care from doctors and place it with the mothers themselves. Many described their sense of control over their family’s health and recommended ways others could better manage their children’s health, whether through control of food and ingredients in their home or the use of complementary healthcare. One mother in an interview described her laborious efforts to manage household products as a way of promoting immunity without vaccines: “So the toxins that we can control, we control, even in our body products ... So we set our bodies up to win ... And we’re healthy.”

Self-described efforts to promote health without vaccines were often resource-intensive, requiring time, money, and information that are not equally accessible to all women. The claims that these practices, aimed at strengthening the immune system, can effectively replace vaccines are scientifically disputed. Few outside these mothers’ social networks agree these efforts are adequate to manage disease risk. Within their networks, these techniques are accepted as powerful tools to fight illness that place them in control. As mothers confidently described their processes and advised others, they reiterated the reasonableness of vaccine refusal and extended social capital to those making similar choices.

5. Social capital in the face of stigma

The decision to reject some or all vaccines is often met with criticism from those outside of the mothers’ sympathetic networks. Parents who reject recommended vaccines encounter negative feedback from peers, doctors, schools, or even their own family members. These mixed

contacts (Goffman, 1986) allow those in the mainstream to informally communicate, sometimes aggressively, that these mothers have violated important social rules by rejecting vaccines. The stakes are, for these mothers, significant. Stigmatization comes with significant emotional and social costs, from feeling excluded, surveilled, exhausted, and even bullied to spoiling contacts with friends, family, and mainstream healthcare providers. As a result of these high stakes, vaccine refusing mothers expend time and energy strategizing when and how to disclose their choices to others: school administration, pro-vaccine friends, family, neighbors, and health care professionals. For example, one mother explained in an interview, “I’m sort of cautious who I talk to about it.” Recalling a preschool parent meeting, she continued, “somebody brought up that not everybody’s fully vaccinated here, there’s a child in this school that’s not fully vaccinated ... So a couple parents were getting up and going off about it and how it was putting their children at risk and I thought they were talking about me so I went to the director and I was very upset about it.”

Interactions like this one make these mothers fear they will be evaluated negatively for their parenting choices. They also illustrate how mothers with social capital feel entitled to communicate their frustration to school directors and expect to be supported, as this mother did. Nonetheless, they may feel stigmatizing and how to manage them is a major topic in online discussion boards. Like the interviewed mother above, another mother wrote online of her own struggles deciding when and to whom to disclose her vaccine decisions:

I’m actually having a hard time too, especially with sharing our choice if anyone ever asks, most of my really close friends and family just respect it and leave it alone (maybe secretly think we are nuts, but i’ll take that) ... I’m tired of feeling nervous or anxious about this conversation coming up with play groups or new friends, parents who may be uncomfortable, or attack me because “their kid is in danger.”

Another noted similarly online, “Our son is 2.5 and we haven’t vaccinated, nor do we plan to, but am I the only one who feels bullied about having made this decision? Or even scared?”

In online discussions, women frequently posted about their experiences of receiving negative feedback for their vaccine choices or fear the choice will cost them access to other relationships or networks. These exchanges, they suggested, often follow high profile news stories, including those covering recent outbreaks of vaccine-preventable illnesses. The public comments posted in response to these stories insist that vaccine refusal creates risk to others, a hurtful proposition to mothers who reject vaccines but don’t see their individual choice as affecting others. Illustrating this, one mother described online her sense of shock that a friend posted on Facebook a news article about record-high rates of measles. Dismissing the concerns of this childless friend as not credible, she explained, “The friend who posted this does not have children, and the article posted is probably the only vaccine-related article they’ve read this year, and sometimes I feel that the entire pharma-medical industry keeps their pockets full by fear-mongering.” In contrast, she proudly claimed she and mothers like her can see through these tactics. In complaining about these stories to others in their sympathetic networks, mothers receive appraisal support for their views and actions. Nonetheless, these interactions carry costs. As one mother commented online, “We are definitely in the minority in our circle of friends and are okay with that, but wow, sometimes it is just exhausting.”

Social media often provide an outlet in which users can post opinions without directly interacting with those they criticize. On a platform like Facebook, comments may be posted by individuals a vaccine-refusing mother doesn’t know, but who is visibly linked in their broader social networks—with weaker ties—through common connections. Such comments successfully communicate disapproval for not

vaccinating and condemnation for violating social norms, which these mothers experience as bullying. One woman described her frustration in an online forum:

A FB friend ... posted this [measles story] today too. Along with some angry comment about “stupid people who dont vaccinate.” My children are not vaccinated and I won't be bullied into it.

Rates of vaccine-preventable diseases are increasing, which is linked to increasing rates of vaccine refusal (Constable et al., 2014; Phadke et al., 2016). Increased awareness of this relationship has fueled public rhetoric that blames these parents for increasing risk to others. For mothers who refuse vaccines, encountering these concerns among their friends, family, or even those with loose ties to them feels painful. As high status women, the material consequences of these interactions are likely minimal; they are nonetheless upsetting and socially alienating. As they retreat into their networks of likeminded mothers, they are able to reframe these discussions and reclaim expertise. They seek and receive validation for their views, agreement that others are foolish, and confirmation that they are right for making this unpopular decision. They may also become more entrenched in their views. In these ways, these networks provide social capital on which they can draw in these uncomfortable interactions.

6. Strategies for managing stigma

As mothers share their sense of stigma because of their vaccine choices, social support from their network provides strategies with which to challenge or manage it. In addition to providing sympathy and understanding, their networks provide opportunities for “stigma management rehearsal,” a “backstage” interaction (Goffman, 1986) in which members of a stigmatized identity group discuss possible strategies for responding “in ways normally curtailed by their everyday stigma management concerns” (O'Brien, 2011, p. 296).

In discussing how to best respond, mothers lend each other social support, but sometimes disagree about tactics. Throughout, mothers see their group as correct or wise (Goffman, 1986) in a social world where most everyone else is misinformed. One strategy often recommended in discussions among these women is to exercise caution when deciding with whom to share information about vaccine refusal. Others describe a responsibility to confront those who assign stigma. Both strategies aim to mobilize social capital, but identify different risks and benefits.

6.1. Non-confrontational strategies for managing stigma

When facing criticism for not vaccinating, many mothers advocate a strategy of non-confrontation. Instead, they suggest mothers should politely smile and ignore critics. In so doing, they can potentially maintain their relationships with those who are unsympathetic to their position without suffering further alienation. One mother suggested in an online forum:

I think it's to the point where we need to keep quiet about our health choices if we are not within a like-minded community. I used to feel like I was a rebel and was educating people when the subject came up (not lecture-y or anything, just sharing in a simple way to show that “normal” people are thinking about these things), but now I just nod and smile if I am with a group that might not accept my views.

Another mother agreed online, “Good input, especially about keeping our mouths shut and just smiling. Otherwise it's just a problem. I'm sure most of us deal with it within our own family circles too. I have a retired [physician] mother in law; imagine how she feels about our choices!”

These non-confrontational strategies allow mothers to maintain membership in networks with those who are critical of vaccine refusal while feeling free to exercise their own preferences. This may be significant in efforts to maintain relationships with extended family

members, for example, who do not respect their vaccine decisions. It also potentially allows them to continue to benefit from the social capital provided by these other networks, even as it underscores their lack of capital within them. These discussions provide emotional support for the frustration and appraisal support for the decision to keep quiet to avoid confrontation that could prove costly to their access to social capital outside these sympathetic networks. Yet for other mothers, this style betrays a larger sense of themselves as enlightened and empowered, which they suggest calls for more confrontational strategies.

6.2. Confronting critics

In contrast to those who suggest smiling and keeping quiet, others insist mothers who reject vaccines need to speak out about their choices to educate others. One mother of children who received some vaccines before she began questioning vaccine safety, explained online the importance of bridging to other parents: “How I wish that someone cared enough to enlighten me. If someone would have just shared, I would not have made all the mistakes I made. The only people that were opening their mouths and giving me their advice & telling me what to do were the wrong type of people.”

In thinking through how to respond when confronted about her vaccine choices, one mother described online her plan to dismiss her critics by accusing them of following recommendations blindly. “I've decided that if anyone should outright attack me, I am going to ‘baaaa’ them. I'm going to just not bother w/justifying myself and just tag them for what they are: ‘Oh, sheeepy, sheeepy, sheeepole, so sad that you're a sheeepy. Baaaaa, baaaaa.’”

Mothers who refuse vaccines see themselves as uniquely aware of the risks vaccines present in contrast to parents who ignorantly follow expert recommendations like sheep. Yet, unlike sheep, critics are characterized as abusive or bullying as they unquestioningly enforce social norms. As they co-construct their own network members as superior, they centralize social capital. Illustrating this, one mother argued that to resist expert recommendations requires a strength others lack. She explained online, “... We are fierce, independent thinkers and intelligent. Tough skin comes with the territory, without that you cave.”

7. Mobilizing social capital for other parents

As mothers feel empowered to challenge experts for their own children's benefit, they aim to inspire naïve parents to do the same, which they view as a greater good. By explaining to other parents the problems they see with vaccination, they imagine themselves as helping others, which could extend their network's social capital to those they see as weak, ill-informed, or unsupported. Some referenced feeling indebted to others who brought them into their networks and helped them to understand the problems with vaccines, and felt responsible to do the same for others. For example, one mother online remembered how inspired she was by another woman who encouraged her to question vaccines. This woman, described as high status as a chiropractor who she initially sought out for care, extended social support to her by bringing her into the network of non-vaccinating parents:

I never knew or met anyone who didn't vaccinate their child, until I met a chiropractor who kept those books around her office. She had monthly “Vaccine Talks” that were decidedly more on the “think again side”. She asked us to put as much research into both sides as we would into buying a new car or house ... She put the seed into my head. What would I have done if she kept her mouth shut?

Mothers often referenced significant moments in which they became empowered to question vaccine doctrine. These stories served as turning points in mothers' identities. Goffman explains that in reviewing one's “own moral career, the stigmatized individual may single out and retrospectively elaborate experiences which serve for him to account for his coming to the beliefs and practices that he now has

regarding his own kind and normals” (Goffman, 1986, p. 38). As members of a community, mothers voiced confidence in their vaccine decisions, referenced the process of coming to feel enlightened as significant, and recast their members as the ones with resources and insights—the true normal. They then communicated an obligation to use the social capital from their network to empower others, just as they received support from mothers before them. This social responsibility, defined within their networks, overshadowed personal discomfort or disapproval that might result. Illustrating this, one mother explained online, “I think we have it as our duty to keep our mouths wide open. If people don't like what we say ‘Forget them! You did your part.’”

In thinking through how to best encourage other mothers to question vaccines, women identified and deployed several strategies. At one meeting I observed, several women recommended what they termed “the Walmart Strategy.” They suggested concerned women should linger in the diaper section of stores and stop young mothers there to advise them of the dangers of vaccines. They could offer pamphlets or other information, extending informational support to them. Others suggested social media provide an important vehicle with which to speak out. One woman in an online discussion suggested strategies for doing so effectively:

FB is the easiest place to be completely frank about these things. I never hesitate to stir up trouble on web boards *when new moms ask* or seem to be searching. To not be completely obnoxious, and not cause too much trouble, I rarely say anything unless someone specifically asks a general question at mom's groups about vaccination and even then, often I don't say anything unless I'm asked directly.

In each of these narratives, mothers understood themselves as independent, thoughtful, and deliberate, in contrast to those who mindlessly accept expert advice. These perceptions were not crafted alone, but were developed and reinforced through interactions with other mothers who offered them advice or deferred to their expertise. Even when faced with criticism, those negative interactions did not inspire mothers who refuse vaccines to reconsider. Rather, these critical interactions served to reaffirm their positions and commitment to questioning experts. As relatively high status network members, they centralize social capital and aim to extend it to mothers who can be brought into the fold.

8. Discussion

Mothers who refuse some or all childhood vaccinations challenge public health systems. They reject expert knowledge and instead substitute their own understandings of health, risk, disease, and prevention for their children and encourage others to do the same. As a result, vaccine-refusing mothers face disapproval for breaking social norms and rejecting consensus that supports community standards for disease prevention. Women who are disproportionately white, college educated, and wealthy, bring cultural capital into their networks of like-minded mothers. Yet, they face stigma in their social interactions outside of those networks, with those who insist vaccines are a public good, illustrating the limits of their access to social capital in these mixed interactions.

As mothers build networks with other sympathetic mothers, they gain information, alternative ways of understanding illness and health, and support for vaccine refusal. As both audience and expert, they share strategies for navigating mixed interactions. These networks may be local or they may be virtual, spanning huge distances, and may result from daily interaction, or contact that is more sporadic. Yet, they embrace norms of reciprocity that support their sense of themselves as enlightened and empowered consumers. Social capital in this context can powerfully create and maintain subcultural norms that contradict broader social norms and provide sources of individual support for doing so (Coleman, 1988).

Because of this, public health organizations and agencies are struggling with how to respond to evidence of an association between membership in a network of vaccine refusers and increased likelihood of refusing vaccines. Vaccine advocates are increasingly trying to identify how to best emulate or use social networks, particularly those online, to create norms that promote, rather than undermine trust in vaccination (Rubin and Landsman, 2016; Shoup et al., 2015). They have not been particularly successful or sustainable. Architects of these efforts are challenged by their limited ability to create an individualized experience for each user, respond quickly to questions, and engage parents on their own terms. Reflecting on their effort to use online forums to improve vaccine coverage during a polio outbreak, Rubin and Landsman (2016) note, “The immediate nature of social networks means that any question left unanswered by a professional will soon be answered by someone else.”

Yet, these programs likely fail not just in their limited ability to reply quickly, but also because they fail to account for the social capital members bring to and take away from these networks. Mothers engaged in networks with other mothers share a sense of common experience, values, and community. They respond quickly to each other and through a norm of reciprocity, communicate obligation and appreciation for the investment they provide. With cultural capital on and off-line, these socially advantaged mothers have more time than do most mothers to commit to supporting each other and quickly meeting each other's needs. In the case of vaccine refusal, social capital generated from both in-person and online social networks powerfully supports mothers' efforts to refuse expert vaccine recommendations and manage social stigma that results. They provide not just information, but emotional and appraisal support that help mothers manage stigma and feel validated. These kinds of social capital cannot be easily replicated by those seeking to promote evidence-based health outcomes. My findings also highlight how these relationships and resulting access to social capital do not require geographic proximity to access.

Mothers insist that refusing some or all vaccines is a personal choice that everyone should have. They often criticize mothers who follow public health recommendations, insisting that individualized choice is a sign of good mothering. This expectation then becomes woven through the network and may become a condition for access to social capital. Throughout, there is little acknowledgement that not all mothers have access to the same resources with which to make these choices and deal with the consequences. Mothers who refuse vaccines identify, for example, a range of resources they can deploy should their children become ill. They share information about managing infectious disease, have time resources with which they can care for sick children, and likely have income or insurance that would allow them to seek medical care if necessary.

In fact, the costs of vaccine-preventable diseases are significant. One study found that high rates of vaccination in a single birth cohort creates net savings of \$13.5 billion in direct costs and \$68.8 billion in total societal costs (Zhou et al., 2014). In Colorado, with its low vaccine rates, estimates are that hospital and emergency department charges to treat children with vaccine-preventable infectious diseases totaled more than \$35 million in 2015 (CCIC, 2017). For families with fewer resources and less access to social capital—those with inflexible employment, limited access to healthcare, fewer informational resources, or network members with low levels of social influence—the financial and social costs of infectious disease may be deleterious. As mothers with access to social capital aim to persuade other women to opt out of vaccines, they often overlook how others might face greater consequences in terms of lost wages, medical expenses, or even state sanctions, which can include reduction in public assistance benefits or child welfare investigation (GAO, 2000). As mothers who refuse vaccines communicate support for each other's efforts, their elevated levels of social status—and privacy that buys them—remain unacknowledged. This may prove costly to other families with less social capital.

At times, social capital results in negative health outcomes, as is arguably the case in vaccine refusal. Vaccine-refusing mothers communicate their disapproval of mothers who fail to question medical authority and strongly encourage other mothers to adopt a host of resource-intensive behaviors—including extended breastfeeding, regular chiropractic adjustments for their children, or nutritional supplements—as an expectation of network membership. The aforementioned medical costs of vaccine-preventable illnesses also means some children get very sick. In these ways, as other have argued, “Not all social capital is good capital” (Moore et al., 2009).

Questions about the costs to children as they grow and age and how their status as lacking key childhood vaccines may matter remain. As these children enter adulthood, they may encounter stigma. They may be excluded from opportunities for military service, higher education, or certain professions—all of which require immunization and may not allow exemptions available in childhood. Some may face other losses that carry stigma including sterility, miscarriage, birth defects in offspring, or disability from infectious diseases that are often much worse when encountered in adulthood. They may face illnesses that exacerbate chronic illnesses, or increased risk of vaccination complication, which may go up with age (CDC, 2018; Galazka et al., 1999; Hambidge et al., 2014). Exploring the long-term outcomes to unvaccinated children would increase our understanding of how mothers' efforts to increase their social capital within networks may present an intergenerational loss of social capital to their children not often seen in research on social capital, which more often identifies how capital accrues in families. This study elucidates how women concentrate social capital in support of each other and their efforts to refuse some or all vaccines. Using multiple kinds of qualitative data allows us to examine women's access to social capital as they discuss and reflect on it. Yet, this study cannot answer more fine-grained questions about network structure, hierarchies within networks, or how individuals come and go from networks. Future studies that can measure how members with varying levels of social capital enter these networks and how network structure shapes access to social capital, particularly around significant health issues like vaccination, could continue to help our collective understandings of social capital and health.

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