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Faith And Doubt At The Doctor’s: Class, Race, And The Role Of Community In Medical Decision Making

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Abstract
How do parents make medical decisions for themselves and their children? Why do some parents agree to interventions – such as vaccines, obstetrical treatment, and antibiotics – that others do not? And how do class and race shape those decisions? Past research has shown that white, middle class parents are the most likely to refuse medical interventions on philosophical grounds, including vaccines (Reich 2016a). Yet the existing research does not help us understand why others in similar circumstances don’t make the same choice, nor how we should understand working class patients with their own medical refusals.

The current study seeks to address these puzzles by taking a comparative view of medical decisions. Drawing on data from ninety interviews with middle- and working-class adults (overwhelmingly mothers) and over three years of ethnographic research, I show that community ties play a vital role in shaping participants’ medical decisions. These ties, mediated by social class and race, help participants interpret their interactions with the medical establishment, and orient patients towards either a skeptical or trusting relationship with providers. Ultimately, patients’ interpretations of those interactions, and if/how they draw on social support to make medical decisions going forward, determines their position in four distinct categories, which I label Entitled Skeptics, Constrained Skeptics, Believers, and Compliers.

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FAITH AND DOUBT AT THE DOCTOR’S:
CLASS, RACE, AND THE ROLE OF COMMUNITY IN
MEDICAL DECISION MAKING

Lindsay Wood Glassman

A DISSERTATION

in

Sociology

Presented to the Faculties of the University of Pennsylvania

in

Partial Fulfillment of the Requirements for the

Degree of Doctor of Philosophy

2019

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Thank you to the Louisville Institute, the University of Pennsylvania Office of the Provost, the Society for the Scientific Study of Religion, and the Religious Research Association for their generous support.
ABSTRACT

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CLASS, RACE, AND THE ROLE OF COMMUNITY IN
MEDICAL DECISION MAKING

Lindsay Wood Glassman
Melissa J. Wilde

How do parents make medical decisions for themselves and their children? Why do some parents agree to interventions—such as vaccines, obstetrical treatment, and antibiotics—that others do not? And how do class and race shape those decisions? Past research has shown that white, middle class parents are the most likely to refuse medical interventions on philosophical grounds, including vaccines (Reich 2016a). Yet the existing research does not help us understand why others in similar circumstances don’t make the same choice, nor how we should understand working class patients with their own medical refusals.

The current study seeks to address these puzzles by taking a comparative view of medical decisions. Drawing on data from ninety interviews with middle- and working-class adults (overwhelmingly mothers) and over three years of ethnographic research, I show that community ties play a vital role in shaping participants’ medical decisions. These ties, mediated by social class and race, help participants interpret their interactions with the medical establishment, and orient patients towards either a skeptical or trusting relationship with providers. Ultimately, patients’ interpretations of those interactions, and if/how they draw on social support to make medical decisions going forward, determines their position in four distinct categories, which I label Entitled Skeptics, Constrained Skeptics, Believers, and Compliers.
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Bridget’s Story

Bridget, a 29-year-old white woman, lives with her husband and two children in the working class, urban neighborhood where she grew up. A college graduate, Bridget was excited to become the editor of her community’s weekly newspaper, a full-time job that gives her ample flexibility to care for her young children. Bridget’s husband is in a laborer’s union, and recently started his own construction business with a friend.

On the day we talk, Bridget invites me in through a sliding side door while she breastfeeds her ten-month-old daughter on the couch. Hers is the rare rowhome that remains detached on one side, opening out into a small yard currently covered in an inch of late-winter snow. Inside, I see the crisp new floors that Bridget tells me her husband just installed. The room still smells faintly of fresh paint. Bridget is pretty and very wholesome looking, with shiny dark hair pulled into a low bun, and round, pink cheeks beneath lively eyes. She wears black calf-length leggings and a long green t-shirt. Despite the wintry day outside, she is barefoot.

Bridget leads me to the left through a cased opening and into the kitchen, which is older, with pale yellow tile and a worn wooden table pushed up against the wall. Brightly colored toys are strewn throughout both rooms, and Bridget’s two-year-old son runs happily back and forth along the long, narrow expanse of the home, front to back, back to front. She places her sleepy daughter into a reclining bouncer chair on the kitchen floor.
before sitting down with me at the table. Bridget told me on the phone that she uses conventional medicine. Her children see a pediatrician, and she is taking prerequisite classes to start a nursing program. Thus, I am surprised at how she begins:

“So my dad was very much not a big fan of doctors.” Bridget shrugs. “He was just kind of like, ‘this is what you have an immune system for.’” She says that instead of the doctor, when she was a child her father took a “wait and see” approach, prescribing things like soup, rest, and lots of fluids. Bridget had limited contact with her mother, an alcoholic, and her stepmother left Bridget’s medical decisions to her father. Thus, in Bridget’s words, “We probably didn’t go to the doctors maybe as much as we should have,” but she laughs as she says it, not genuinely concerned.

Bridget says that her approach to medical care for her own children has been similar, using a mixture of “wait and see” and conventional interventions like ibuprofen or cough syrup. Though Bridget can’t specify why her father wanted to avoid doctors, she is simultaneously more comfortable with doctors and exacting in her expectations of how their interactions will go:

We had a local pediatrician [for our son], and we didn’t realize that newborns have so many bowel movements. It was probably the weekend, and…I was frantic…Our pediatrician, it took him 48 hours to get back to us. We were just like, that’s not okay. Even if it’s a one-person practice, you’re on call
basically all the time; that’s what you signed up for. So we switched to
[another practice].

When I ask what she and her husband were looking for when they switched pediatricians,
she answers right away:

Definitely a more responsive [practice]. Just being in tune with what I was
looking for with treatments and everything, more holistic and natural type things.
I [want] a natural approach with everything, like, if we can avoid steroids or
antibiotics or anything I’d prefer to build up their immune system and have them
work it out. We’ll take them to the doctor if they’re sick, but [we’ll see] what can
we do to maybe do this at home. Like with the croup, the doctors are like, ‘Oh,
just go into the bathroom with hot showers going on to loosen them up. Use a
humidifier.’ Or they’re like, ‘Mom, do you want to nurse [your daughter] while
we’re giving the needles? That might help.’ They’re just very in tune with the
parents.

Bridget sips coffee from a stainless steel travel mug, pausing to think. She sits up
straighter in her chair as she clarifies why she likes her children’s current pediatrician:

They don’t talk down to you. I feel like a lot of times, some doctors, they just talk
down to you, or they’ll try to use their words or phrases so that you don’t know
what you’re getting into. But our pediatrician [uses] just basic, every day talk so
that you understand it. That’s important to me. I want to know what’s going on. They’re very much like, “Here are the [health] records [to see].” Growing up, the doctor would take the records and that would be it. He’d walk off with the records and then you wouldn’t see them again. They’re very much like, “Oh, this is where her weight is now. This is what percentile she’s in.” I like that sort of open dialogue back and forth.

At several points in her son’s life, Bridget tells me, she has questioned whether or not to get a specific intervention for him. For example, she agonized over whether to get him ear tubes after he suffered more than five ear infections in his first year. She felt that he was too young to go under anesthesia and was anxious at the thought of not being with him in the operating room. Bridget’s husband, however, was strongly in favor of the procedure, and Bridget explains her eventual agreement in terms of what other interventions it would help her son avoid:

[My son] had gotten a nebulizer\(^1\) at some point, and I didn’t want to do the nebulizer anymore. We had never really loaded him up with Motrin or anything, and I didn’t want to take that route, [but] he was waking up in pain and crying. I felt like [the tubes] would probably be the easiest way to fix that without having any other interventions. At that point, we were just like, tubes are probably the best way to go so we don’t have to do anything else.

---

\(^1\) A nebulizer is a machine that allows patients to inhale medication in the form of vapor. It is often used for asthma, cystic fibrosis, and other respiratory illnesses.
Vaccines were another intervention that raised concerns for Bridget, though she was eventually able to put those concerns to rest. Positive and respectful interactions with her children’s pediatrician, as well as pursuing her own medical education were key factors in her decision to follow the recommended vaccine schedule:

I talked about maybe doing the alternative vaccine schedule, and [my husband] and I talked about it, and he was like, “If you want to do that, that’s fine. As long as they’re getting their vaccines.” The pediatrician is okay with it, too. She’s totally on board with that. That was really important for me that the pediatrician wasn’t sort of dictating what needed to be done. She was like, “Oh, if this is what you’re comfortable with it’s fine, as long as it’s falling under the general guidelines of children’s healthcare.” That was a big deal for me.

I ask Bridget how she learned about vaccines, and what made her interested in pursuing a delayed schedule. Her response is instructive:

One of my good friends, we had both our children around the same time, and she did the delayed schedule, so I talked to her about it. I read up about it a little bit. I guess it was sort of peace of mind [because] it just seems like so much at one time. [My daughter] just got her first vaccines and they gave her four needles. Two in each leg and then the oral…It just seems like so much going into one little body.
Though Bridget delayed a few vaccines for her son, she ultimately chose the recommended schedule for her daughter after learning more about how vaccines work. I ask her to share more about how she sought out information on vaccines:

I think the big thing I read, there’s the MMR vaccine and there’s all that literature out there about links to autism and stuff, so that was one of the main things I was reading about. But I also just took prerequisites for a nursing program, because I’m going back to school for nursing. I took all the prerequisites and we learned a lot about vaccines, so that was sort of helpful in actually learning what the vaccines were and how it wasn’t a live virus necessarily. It’s just fragments [of viruses], so that really helped out and sort of put my mind at ease.

Bridget explains that though she has opted to use conventional medicine for her children, she still values meeting other mothers interested in what she terms “natural stuff.” A local business that hosted a new-mothers support group was particularly helpful, she said, as her friends were all unmarried and childless when she had her son. She smiles warmly as she tells me that she can put me in touch with a friend from that group who is “even more into natural healing than me.”
How Do We Make Medical Decisions?

How do parents make medical decisions for themselves and their children? Why do some parents agree to interventions – such as vaccines, obstetrical treatment, and antibiotics – that others do not? And how do class and class shape those decisions?

In the internet age, information about health and medicine is more readily available than ever before. Yet the supposed democratization of information presents its own challenge, as patients are faced with a dizzying array of websites, books, and videos about all manner of health conditions. Determining which sources to trust can be difficult. And in the face of so much information, it is easy to view a doctor’s recommendation as simply one among many. Thus, conventional medical providers face new and growing challenges to their authority.

Bridget’s story has a lot to tell us about how and why parents make the medical decisions they do. As a young mother, Bridget takes seriously her role in making decisions for her children’s health, and has spent significant time weighing recommendations from doctors, information from outside sources like books and the internet, and the input of her family and friends. As Bridget told me, “At the end of the day, it’s more or less, ‘What’s going to be the best option for [our children]? What’s going to make them healthy?’” This statement is perfectly understandable, and one with which all parents would likely agree. Yet it also alludes to the deeper principles that guide parents’ medical decisions in the 21st century. These principles – that parents have medical options, that it is up to them to determine the best course of action, and that the goal is the optimal wellness of their individual child rather than the broader public’s
health – form the basis of growing skepticism of conventional medicine as the sole authority on health.

Drawing on data from ninety interviews with middle- and working-class adults (overwhelmingly mothers)\(^2\) and over three years of ethnographic research, I show that social and community ties play a vital role in shaping participants’ medical decisions. These communities, mediated by social class and race, help participants interpret their interactions with the medical establishment, and orient patients towards either a skeptical or trusting relationship with providers. How participants interpret those interactions, and if/how they draw on social support to make medical decisions going forward, ultimately determines their position in four distinct categories. I term these categories: Entitled Skeptics, Constrained Skeptics, Believers, and Compliers. Each term reflects participants’ orientation to conventional medicine, and how their social class position influences that orientation. Table 1 summarizes each group’s position:

**Table 1. Participant Groups**

<table>
<thead>
<tr>
<th>Views on Conventional Medicine</th>
<th>Skeptical</th>
<th>Trusting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Middle Class</td>
<td>Entitled Skeptics</td>
<td>Believers</td>
</tr>
<tr>
<td>Working Class</td>
<td>Constrained Skeptics</td>
<td>Compliers</td>
</tr>
</tbody>
</table>

\(^2\) I conceived of this study as primarily about parents with young children because I found in early interviews that parenthood brought on a host of new questions and concerns around medicine. Furthermore, like others (Hallstrom & Elander 2004) I found that mothers, rather than fathers, were the primary decision-makers around family health. However, in order to represent the broadest possible range of experiences, I ultimately included a handful of fathers, and a handful of single women. Their input in no way altered the patterns I was seeing, and actually confirmed that the perspectives I was learning about health were not exclusive to mothers.
Entitled Skeptics are middle class participants who refuse some or all conventional medicine in favor of CAM. They are deeply skeptical of medical authority, and approach clinicians with the expectation that they will be treated as educated medical consumers who can and should have input on their treatment. Entitled Skeptics are embedded in broad communities of CAM users who help craft meaning around health decisions and offer practical and emotional support for health decisions.

Constrained Skeptics are working class participants who refuse some or all conventional medicine in favor of CAM. Though they are skeptical of medical authority, their working class position hinders their ability to make alternative medical choices with the freedom of their middle class counterparts. They participate in much smaller CAM networks, and often feel like they are unsupported in their medical choices. Constrained Skeptics are also acutely aware of institutions like Child Protective Services, and some, particularly participants of color, worry that their medical choices could leave them vulnerable to state intervention.

Believers are middle class participants who use only conventional medicine for their medical needs. I call them Believers because, beyond simply using conventional medicine, this group believes strongly in the efficacy and importance of the medical establishment. They were the only participants to talk repeatedly about the importance of public health, the necessity of medical expertise, and to decry those who refuse conventional medicine. Notably, though, Believers don’t accept clinicians’ recommendations without question. To the contrary, they get second opinions, ask questions, and seek out information about health issues independently. Many are able to
draw on the knowledge of doctors in their own social circles. They differ from Entitled Skeptics in that their questions are not about the nature of medicine itself, but about the quality of their physician.

*Compliers* are working class participants who use only conventional medicine for their medical needs. Like Believers, they follow doctors’ recommendations and are not interested in alternative medicine. Unlike Believers, however, Compliers approach clinicians without entitlement, and express no expectation that they will collaborate in decisions. Compliers do not typically push back against medical professionals, even to switch doctors in the face of poor care. Despite their alignment with conventional medical authority, Compliers’ working class position mean that they accrue fewer benefits than Believers, and face more barriers to quality care.

Ultimately, I define participants as “skeptical” (either “Entitled Skeptics” or “Constrained Skeptics”) if they refuse one or more standard conventional interventions in favor of an alternative treatment. For the purpose of this study, a person must have refused one or more of the following for themselves or their children:

---

3 In most cases, respondents who refused a conventional intervention selected a clear alternative intervention, such as an herbal remedy or chiropractic manipulation. In a few cases, skeptics believed that they had been incorrectly diagnosed, leading them to refuse treatment without a specific alternative treatment in mind, because they fundamentally disagreed that they were ill. However, in these cases the respondents still typically chose to “strengthen the immune system” by making dietary changes, removing substances like alcohol, and taking specific supplements.
• Some or all vaccinations

• Obstetrical/hospital birth (in favor of giving birth at a birth center or at home)

• Antibiotics or other prescribed medications

• Treatments for conditions considered life-threatening, such as chemotherapy treatment for cancer

In many cases, participants refused more than one qualifying treatment, while in others, participants were concerned about only one intervention. Indeed, as the reader will appreciate in the pages that follow, labels like “Entitled Skeptic” and “Complier” are imperfect at best. Respondents reported beliefs and behaviors around health that placed them along a spectrum, from total use of conventional medicine to total use of alternatives. The sample was somewhat skewed towards conventional medicine, with only 10 percent of the sample using alternative medicine exclusively, while about a third of my ninety respondents used only conventional medicine. Table 2a shows the proportion of participants in each group who refused one, two, or three or more interventions, while Table 2b illustrates the range of conventional interventions that participants refused. Note that the categories of interventions refused are not mutually exclusive. For example, most participants who refused “School Mandated Vaccines” also refused a prescribed medication and opted for childbirth in a birth center or at home.

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4 This excludes participants who refused the flu shot for themselves or their children. I found widespread opposition to the flu shot, including among a number of respondents who were otherwise fully committed to conventional medicine. Among the population of medical believers who refused the flu shot, their reason was typically either that they had received the flu shot in the past and then still gotten the flu, or that they knew multiple people who became ill after getting the shot. I decided to discount refusal of the flu shot as a qualifying event because participants’ reasoning in combination with their other medical choices did not indicate true skepticism of modern medicine.
Table 2a. Number of Interventions Refused (% of Sample)

<table>
<thead>
<tr>
<th>Interventions Refused (% of Sample)</th>
<th>No Interventions</th>
<th>One Intervention</th>
<th>Two Interventions</th>
<th>Three or More Interventions</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Entitled Skeptics</td>
<td>0</td>
<td>23</td>
<td>23</td>
<td>54</td>
<td>100</td>
</tr>
<tr>
<td>Constrained Skeptics</td>
<td>0</td>
<td>10</td>
<td>40</td>
<td>50</td>
<td>100</td>
</tr>
<tr>
<td>Believers</td>
<td>89</td>
<td>11</td>
<td>0</td>
<td>0</td>
<td>100</td>
</tr>
<tr>
<td>Compliers</td>
<td>65</td>
<td>35</td>
<td>0</td>
<td>0</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 2b. Interventions Accepted and Refused (% of Sample)

<table>
<thead>
<tr>
<th>Flu Vaccine</th>
<th>Prescribed Medication</th>
<th>School Mandated Vaccines</th>
<th>Hospital Birth</th>
<th>Advanced Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Refuse</td>
<td>Accept</td>
<td>Refuse</td>
<td>Accept</td>
</tr>
<tr>
<td>Entitled Skeptics</td>
<td>65</td>
<td>35</td>
<td>65</td>
<td>35</td>
</tr>
<tr>
<td>Constrained Skeptics</td>
<td>90</td>
<td>10</td>
<td>30</td>
<td>70</td>
</tr>
<tr>
<td>Believers</td>
<td>11</td>
<td>89</td>
<td>0</td>
<td>100</td>
</tr>
<tr>
<td>Compliers</td>
<td>35</td>
<td>65</td>
<td>0</td>
<td>100</td>
</tr>
</tbody>
</table>

What factors dictate one’s position on the spectrum? I argue that it’s the intensity of one’s negative medical experiences coupled with a supportive community. Parents are more likely to become skeptical if, after having a negative experience at the doctor’s office, they have ample examples of friends and family who have had positive experiences.

Note that the category “Constrained Skeptics” in this table excludes members of Full Truth Calvary Church. I exclude Full Truth members here because their total refusal of conventional medicine makes them highly unusual (a topic I explore further in chapter 5), and gives a false impression of the overall patterns I observed in looking at how social class impacts medical decision making. Including Full Truth members would make it appear that working class families are more likely than middle class families to refuse conventional medicine, which is inaccurate based on both my study and past research. As I discuss in chapter 5, Full Truth members share distinctive beliefs and an unusually high degree of social support, which allows them to make choices that would be extremely difficult for other working class families.

As noted, above, the category “Constrained Skeptics” in this table excludes members of Full Truth Calvary Church. See footnote 5 for a fuller explanation.
experiences with CAM practitioners. Conversely, even after a negative medical experience, parents are less likely to become skeptical if they have close social ties, such as a partner or family member, who disagree with their interest in CAM treatments. Doctors make a difference only when they engage with patients respectfully, acknowledging them as informed medical consumers (regardless of what and where they gained their health knowledge). Those who push hard on specific recommendations, and who lecture or argue, seem to make very little headway on reversing skepticism; these parents simply stop making appointments or seek out another doctor.

Community Ties: The Mechanism of Medical Decision-Making

Having outlined the four key participant groups, let me step back a moment to discuss how and why these groups come to be so different. What determined participants’ position? Certainly, the nature of the doctor/patient relationship was important to participants’ decision-making, particularly the degree to which participants perceived that relationship as one in which the doctor respected their status as an educated health consumer. Respondents who felt that their doctors disrespected their opinions or knowledge were more likely to refuse conventional medical care and seek out alternatives than those who reported positive interactions with their doctors. This was true even when those interactions included patients who were questioning a doctor’s recommendation, such as Bridget’s story of raising questions about vaccines. Note that the tone of

7 Note that the term “doctor” is somewhat unspecific in this context. Most respondents discussed interactions with doctors as the most impactful on their health decisions. Several, however, noted positive or negative experiences with nurses, physicians’ assistants, or other medical professionals. Unless stated otherwise, the term “doctor” is used interchangeably with the broader range of clinicians.
Bridget’s interactions with her children’s pediatrician was a key factor in her satisfaction with – and trust in – the pediatrician’s care. Bridget felt that the doctor was not trying to “talk down” to her, and that she recognized Bridget’s desire to be closely involved in her children’s care. The doctor’s willingness to engage with and respect Bridget’s concerns about vaccines reduced her anxiety, and contributed to her decision to vaccinate on the recommended schedule. Despite the questions she brought to her medical encounters, I classify Bridget as a Believer because she fundamentally trusted her doctor as a medical authority. Indeed, I will show that parents who feel that clinicians respect them as educated medical consumers are more likely to trust medical expertise, while those who feel disrespected in that role are prone to look to alternatives for treatment and validation.

The most important factor in parents’ medical decisions was the role of community ties. I found that respondents’ medical experiences were mediated and given meaning by their communities. In other words, while medical experiences themselves were important, how respondents interpreted those experiences was even more important for their future medical decisions. These interpretations were heavily influenced by the medical values and norms of their communities, or social groups. All participants valued respect from their medical providers (conventional or alternative), and expected to be recognized as educated and competent individuals. But they differed in their relationship to medical authority and if/how they believed that medical authority related to their own expertise. Specifically, Entitled Skeptics and Constrained Skeptics had typically had negative experiences in which they felt that conventional clinicians disregarded their own knowledge. In the face of declining trust in experts, these participants believed they must rely instead on themselves, resulting in a language of “doing my own research” coupled
with “self-trust,” “intuition,” and “gut feelings.” Conversely, though Believers and Compliers had also sometimes had negative conventional medical experiences, they were less likely to interpret those experiences as a direct affront to their own authority. Instead, they tended to frame the problem as emanating from a bad practitioner rather than a bad system. Bridget’s story illustrates both points of view, as she reported initially questioning vaccines after a close friend decided to use a delayed schedule for her own children. Ultimately, however, after looking up information on vaccines and eventually attending pre-nursing-school classes, Bridget felt comfortable aligning her views with those of her wider community (and, it might be added, with the views of her husband).

Increasingly, the culture of intensive parenting frames medical decisions as part of that commitment. Parents today face growing pressure to make informed and effective medical decisions as part of what it means to raise a child responsibly. Choices about medical care thus take on a moral element that marks the healthy child as sign of good parenting. Even parents who ultimately use all conventional medicine speak the language of having “researched” and “considered” medical information as a signal that they are responsible, educated consumers of the health industry.

Importantly, however, parents’ ability to draw on support from their communities differed by class. Working class participants – both Constrained Skeptics and Compliers – reported fewer close social ties to whom they could turn for medical advice than did middle class participants. This isn’t to say that working class parents had smaller communities overall – I didn’t collect detailed social network data, and many working class participants did indeed note close relationships with family or friends. The
difference was that working class participants of either medical orientation noted fewer contacts to whom they could turn specifically for advice on questions of health. This more limited social support around medical choices was particularly impactful for Constrained Skeptics, as these working class participants faced the double challenge of bucking medical norms and doing so without much community help. Compliers, on the other hand, were less impacted by their limited ties, but received little encouragement to advocate for themselves in medical settings, even in the face of poor care.

The Role of Class, Race, and Religion

All the parents I spoke with, regardless of their perspectives on medicine, shared a commitment to raising their children the best way they know how. However, they faced different privileges and constraints in their ability to align their actions with their beliefs. I show that the key factors in medical decision-making – the quality of clinician/patient relationships, and medical beliefs in one’s community – were heavily mediated by class, race, and religion.

Following Lareau (2011), I combined markers of education and occupation to determine participants’ class designation. I defined participants as middle class if they had earned a bachelor’s degree or above, and if they were currently employed in white collar professions. Middle class participants worked in a variety of settings, including law, medicine, education, social work, and marketing. Twelve middle class participants were stay-at-home mothers. I defined participants as working class if they had less than a
college degree, and/or if they worked in a traditionally blue collar professions, such as administrative work, childcare, or retail. Table 3 summarizes my respondent numbers by medical orientation and social class:

Table 3. Medical Orientation and Social Class (n)

<table>
<thead>
<tr>
<th>Views on Conventional Medicine</th>
<th>Skeptical</th>
<th>Trusting</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Middle Class</td>
<td>26 (Entitled Skeptics)</td>
<td>27 (Believers)</td>
<td>53</td>
</tr>
<tr>
<td>Working Class</td>
<td>20 (Constrained Skeptics)</td>
<td>17 (Compliers)</td>
<td>37</td>
</tr>
<tr>
<td>Total</td>
<td>46</td>
<td>44</td>
<td>90 Respondents</td>
</tr>
</tbody>
</table>

Middle class parents approached medicine from a privileged position. Those that I spoke with were quick to discuss their educational backgrounds and how those impacted their ability to assess available information, frequently referencing their claims as “evidence based” or from “a study.” Though their medical education ranged widely, Entitled Skeptics and Believers felt uniformly comfortable expressing their bona fides as informed medical consumers. In turn, they expected their doctors to take seriously what they had to say, and were offended when they felt that their input was disregarded. When they perceived their doctors as disrespectful, middle class parents felt entitled to push back in a number of ways, including changing providers, disregarding recommendations, and seeking out alternative treatments. Notably, race did not appear to alter medical decisions among middle class parents, but black mothers – both skeptics and believers – reported more reservations about trusting the medical establishment overall, citing past abuses like the Tuskegee experiment. In other words, mothers of color – including black, Latina, and Asian mothers – did not report facing barriers to making medical choices that
differed from those of white women, such as concerns that their doctors would report them to Child Protective Services for refusing an intervention like vaccines. Still, women of color, particularly black participants, were more likely to mention past medical abuses and to note the role of those abuses in their current thoughts about conventional medicine.

For working class parents, on the other hand, race was a key mediating factor in medical decisions. Specifically, black working class mothers faced more barriers to choosing CAM interventions, often due to concerns about potential state intervention or the ramifications of pushing back on the school system. Though working class parents shared many of the same worries about conventional medicine as middle class parents, they were more likely to use CAM as a complement to clinician-recommended care rather than an alternative. Furthermore, they were more likely to use CAM treatments that did not require the (costly) services of a practitioner, meaning that working class parents were more often interested in herbal remedies and dietary supplements than in acupuncture or a chiropractor.

One barrier that most working class parents faced, regardless of race, was finding a social circle that supported alternative medical choices. Those working class mothers who chose CAM for themselves or their children were much more likely to report that they were “flying solo” or “the lone soldier” in their choices, and that they faced

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8 This is notable because past research has shown that black families, particularly those from working class or poor backgrounds, are more likely to face government intervention than are white families in similar circumstances (Roberts 2009). However, while black women recounted general distrust in medical institutions, most reported that they felt comfortable pushing back against clinicians when making medical decisions without worrying that they would face state censure.
pushback from family and friends, ranging from gentle joking to outright criticism. The exception was mothers who were already embedded in communities that support alternative choices, such as homeschooling groups and/or conservative religious congregations. For these parents, resisting cultural norms – whether related to education, culture, or medicine – was already part of their identity, and more often than not something they relished.

Finally, it is important to note that just as decisions are made on a spectrum, so too the impact of class and race are fluid. Medical choices are influenced by the intersection of multiple factors, and may be affected by things like the class background of respondents’ parents and partner, time spent in college, or racial privilege. For example, Bridget’s experience reflects her position on a number of borderlines, including social class, social groups, and ultimately medical decisions. Consider that while she had a four-year degree and hoped to become a nurse, Bridget’s husband was a union laborer who had only recently started a small business. They lived in a working class neighborhood, and both came from working class families. As such, Bridget was just barely in the middle class. Nonetheless, Bridget did possess class and racial privilege that made her confident speaking with doctors. Though she noted that some doctors tried deliberately to obscure what they were saying – something my upper-middle class respondents never complained of – Bridget also felt entitled to seek out a doctor with a better style of communication, and who was willing to listen to her opinions.

Bridget’s story shows us that medical decisions are often experienced as an intensely personal process, shaped by subjective incidents, health histories, and strong
feelings. Ultimately, however, we see that though these decisions feel individual, they are actually a social process shaped by factors of class, race, and religion. Where parents land on the spectrum of medical decisions is the result of all these factors, and the complex ways that they influence our most important decisions.

The Study

I set out to answer two main questions: first, why do some people actively reject some or all conventional medicine in favor of alternative medicine while others do not? And second, how are medical decisions shaped by class, race, and religion? To answer those questions, I conducted interviews and ethnographic observations with parents who use all conventional medicine and parents who refuse some or all conventional medicine in favor of alternative treatment. I collected data between March 2014 and August 2018. Below, I briefly summarize my methodology. For a fuller description of my data collection, including details about my role in the field, please see the Appendix.

Ethnographic Observations

The study began with ethnographic observations at a fundamentalist Christian church whose members refuse all conventional medicine in favor of prayer. This group, which I call Full Truth Calvary Church, truly reject all modern medicine, including antibiotics, contraceptives, surgery, chemotherapy, eyeglasses, and even seatbelts. As a

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9 All names of organizations and individuals have been changed to protect participants’ confidentiality.
white, working class group with strict beliefs and practices around healthcare, I viewed the community as an extreme case of medical skepticism that could illuminate the factors at play in families with less exacting health guidelines. I ultimately spent over three years conducting observations in the Full Truth community. I attended an average of two of the congregation’s three weekly services, as well as participating in social events like picnics, bridal showers, dinners, mini-golf outings, and holiday parties.

I also conducted observations with two secular organizations devoted to supporting parents interested in choosing alternative medicine for themselves or their children. I call these groups Mothers for Sustainable and Alternative Parenting (MSAP) and the Women’s Health Consortium (WHC). These groups each met once a month, and typically featured a chosen speaker to present on topics from hypnotherapy to herbal remedies to packing organic school lunches. MSAP members were exclusively mothers, most of whom were white and middle class, though one black mother and one Asian mother attended on occasion. As the name suggests, WHC was also majority female, but despite the group’s name typically two to five men attended the meeting each month. I was open to finding groups with more men, but was not surprised to find that the limited number of groups to promote alternative medicine were geared towards women. The female-dominated nature of MSAP and WHC is in keeping with past research finding that women are more likely to use alternative medicine than men (Bair et al. 2008; Nichol, Thompson & Shaw 2011). Both MSAP and WHC gave me the opportunity to observe the way that community leaders frame health and medical decisions, and to hear from members about how they use incorporate these messages into their own lives.
Interviews

In addition to ethnographic observations, I conducted ninety formal interviews. Eighteen of these were with current or former members of Full Truth Calvary Church (specifically, ten current members and eight former members). The remaining seventy-two interviews were with families unrelated to Full Truth who make a range of medical choices. I recruited the majority of my respondents through a combination of neighborhood listservs, personal contacts, and social media. Approximately one third of the seventy-two participants were recruited through snowball sampling. In an effort to find more working class participants who refuse conventional medicine, I ultimately joined three Facebook groups devoted to rejecting medical interventions. I then recruited eligible participants from these groups, specifying that I was seeking mothers who had “chosen to work or parent after high school.” Though the vast majority of my interviews were conducted in person, sixteen interviews took place by phone or Skype, usually because the respondent lived too far away to meet in person.

I divided my sample by social class because past research suggests that social class plays a role in the prevalence and type of CAM use, but frames the relationship as one primarily of correlation (Barnes, Bloom, and Nahin 2008; Poloma and Green 2010). Using a comparative model, my goal was to better understand if and how class actively operates in medical decision making. Finally, I recruited a racially diverse sample to explore how the intersection of race and class influences health decisions. My total sample included 29 participants of color, including black, Latina, and Asian women,
making them 32 percent of the total. Table 4 summarizes my participants by medical orientation, class, and race:

<table>
<thead>
<tr>
<th></th>
<th>White</th>
<th>Black</th>
<th>Other</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skeptical of</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conventional Medicine</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Middle Class</td>
<td>16</td>
<td>7</td>
<td>3</td>
<td>26</td>
</tr>
<tr>
<td>Working Class</td>
<td>16</td>
<td>3</td>
<td>1</td>
<td>20</td>
</tr>
<tr>
<td>Trusting of</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conventional Medicine</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Middle Class</td>
<td>21</td>
<td>4</td>
<td>2</td>
<td>27</td>
</tr>
<tr>
<td>Working Class</td>
<td>8</td>
<td>6</td>
<td>3</td>
<td>17</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>61</td>
<td>20</td>
<td>9</td>
<td><strong>90 Participants</strong></td>
</tr>
</tbody>
</table>

After receiving permission from the Institutional Review Board, I offered participants $20 cash in appreciation of their time.

**What This Study is Not**

A tremendous body of research explores patients’ refusal of specific interventions, like vaccines, medications for severe mental illness, and diabetes treatment (Barber et al. 2004; Larson et al. 2014; Wade 2017). I discuss this literature, in addition to related bodies of research, in chapter 1. Yet it is important to note that while this study certainly examines the specifics of refusals – when they happen and what is refused – my goal is both broader and narrower than most of the “non-adherence” literature. It is
broader because I examine wide range of refusals, including resistance to things like vaccines, antibiotics, obstetrical birth, and even critical treatments like chemotherapy. Yet it is also narrower because I focus specifically on non-adherence that results from skepticism of the medical establishment, not because of barriers to access. To be sure, the problem of access for things like childhood vaccinations is a serious problem, as parents are unable to fully vaccinate their children due to constraints on time, cost, and travel (Briesacher, Gurwitz & Soumerai 2007; Ronsaville & Hakim 2000). For this study, however, I am interested in those for whom refusal is a choice that hinges on beliefs about health, medicine, and the body. To that end, I explore the trend of medical skepticism that is exemplified by, but not limited to, anti-vaccination advocates. I argue that medical skepticism as a phenomenon is really a story about social connection, class privilege, and the fracturing of medical authority.

**Chapter Overview**

The dissertation is organized around within-class comparisons designed to show how and why participants beginning from a similar social position come to make very different choices about their health.

In chapter 1, I present the motivation for my study, summarizing past literature on medical decision making, patient non-adherence, CAM use, and group resistance to norms. I argue that my work contributes to the field by offering a causal explanation for divergent medical decisions. While others have offered valuable descriptive work on
related groups like “anti-vaxxers” (i.e. anti-vaccination advocates), these projects take a narrower view, exploring medical decisions from the perspective of only those who refuse specific interventions, and only those from the middle class. Specifically, studies like those of Jennifer Reich (2016a,b), which argue that anti-vaccination advocacy derives from intensive parenting, contribute valuable insights but stop short of explaining why those with similar parenting perspectives fail to make the same vaccination decisions. My study is unique in offering comparisons that illuminate how class, race, and even religion shape medical decisions, leading to divergent choices from seemingly similar people.

Chapter 2 explores medical decision making among Entitled Skeptics. I show that these participants draw on their class privilege to resist conventional medicine (and providers) that they view as not in keeping with their own experience or expertise. When Entitled Skeptics experience negative interactions with medical professionals, they interpret the encounter as indicative of a flawed system rather than an individual provider. Entitled Skeptics’ decisions are ultimately shaped by their broad and supportive communities, which bolster their interpretation of conventional medicine and legitimize alternative treatments.

In chapter 3 I turn to Believers, showing that they operate in much the same way as Entitled Skeptics, but in the context of communities that support using conventional medicine. This means that while Believers approach their medical encounters with questions, second opinions, and independent research, they fundamentally trust (and encourage one another to seek) medical expertise. Their middle class position means that
they can respect doctors’ authority while also expecting to be treated as collaborators in their own care.

Chapter 4 delves into the choices of Constrained Skeptics. I find that these working class participants become skeptical of conventional medicine in much the same way as Entitled Skeptics, but that their community ties, particularly those dedicated to alternative medicine, are much more limited. As a result, Constrained Skeptics often report feeling like “lone soldiers,” trying to resist conventional medicine without adequate social support. Their limited financial resources and their awareness of institutions like Child Protective Services also contribute to these participants’ perception of constraint in their medical choices.

In chapter 5, I show that though it is challenging for Constrained Skeptics to resist conventional medicine, it is not impossible. Using the case of Full Truth Calvary Church, I show that working class families can make alternative medical choices if they are embedded in an extremely strong community. Specifically, I demonstrate that Full Truth members are able to refuse all conventional medicine not only because their leaders offer a religious meaning for members’ health choices, but also because those choices are universally and strongly supported by this close-knit community.

Chapter 6 explores the choices of Compliers, working class participants who choose all conventional medicine. Though this group does not resist medical interventions, they do not demonstrate the entitlement that I find in Believers, nor the tendency to research their options or switch doctors at will. Instead, Compliers appear to
make few demands of the medical system, following doctors’ recommendations with little pushback.

Finally, chapter 7 looks at the role of race in medical decision-making. I focus on the link between race, medical orientation, and institutions, as I find that the impact of race is most evident in interactions – or the perceived potential for interactions – with outside authorities like Child Protective Services and the public school system. Specifically, middle class participants of color – both Enabled Skeptics and Believers – report no concerns about institutional interventions, but do note making decisions with an eye to past medical abuses of black Americans. For working class participants, however, medical orientation mediates the role of race in medical decision making. While both white and black Constrained Skeptics report concerns about institutional intervention, white Constrained Skeptics ultimately overcome these concerns with a degree of privilege, advocating for their freedom to make alternative medical choices. Black Constrained Skeptics, on the other hand, were more reluctant to actually refuse conventional interventions in the face of institutional threats, and were more likely to use alternative medicine while continuing to see the doctor. Their concerns around potential institutional intervention were not unfounded, as past work shows that the state is more likely to intervene in families of color (Roberts 2009). That means that ultimately, black Constrained Skeptics faced barriers to medical choice not only because of more limited social support for their alternative decisions, but because of additional anxiety vis-à-vis state intervention.
Finally, I conclude with an overview of my contributions to the broader sociological literature, as well consideration of what my work could add to best practices in patient education. Having elucidated the role of community ties and trust in medicine as key factors that determine patients’ decision-making, I believe my work has much to offer health professionals interested in improving their relationship with skeptical clients.
CHAPTER 1: BACKGROUND AND MOTIVATION

Introduction

For most patients, medical choices feel personal. Indeed, in many ways, they are: Patients must consider their lifestyle, their family history, their insurance (or lack thereof), among a host of other factors when making a decision about their health. Yet past research shows that interactions with the medical establishment – and ultimately, medical choices – are also shaped by social factors like class, race, and gender. Even if a patient does not follow the doctor’s recommendation, that seemingly individual choice is layered with social influences, including systemic issues of access, the unequal impact of side effects, and cultural beliefs about health.

So what do we know right now about how patients make the medical decisions they make? In this chapter, I draw on existing research to show that changing models of clinical decision making have fractured medical authority, paving the way for growing patient skepticism and the increasing popularity of alternative health etiologies. Yet even in the new landscape of medical care, inequalities persist: women, people of color, and working class or poor patients still face unique challenges when seeking treatment.

What we don’t know is why seemingly similar patients make different decisions, particularly regarding the choice to use or refuse clinician-recommended care. If, for example, most anti-vaxxers are middle class white parents, why aren’t all middle class white parents anti-vaxxers? And how do we explain working class anti-vaxxers? My work contributes to this knowledge gap by comparing a class-stratified sample of patients
who use only conventional medicine with those who refuse some or all conventional care. I show that these comparisons illuminate the role of communities in crafting meaning and support for different medical choices, leading ultimately to different outcomes in similar circumstances. Below, I explore past research that helps motivate my own study, including research on models of medical decision making; the role of class, race, and gender in clinical care; medical non-adherence; and alternative understandings of health.

**Individualized Care and the Fracturing of Medical Authority**

For much of the 20th century, decisions about medical interventions for a patient were primarily the purview of physicians, with little input from patients themselves (Brody 1980; Kaplan and Frosch 2005). Physician driven decision-making privileged biomedical understandings of the body (Kaplan and Frosch 2005), and positioned doctors as the dominant authority on health and wellness (despite findings that physicians often disagree with other physicians [Eddy 1994; Welch 2004] or even themselves [Zir et al. 1976] regarding a diagnosis).

In recent years, patients have increasingly challenged physicians’ authority, pushing for greater autonomy in decisions about their medical care (Kaplan and Frosch 2005). This trend has a number of origins, notably greater general access to medical information (Haug 1976), changes in medical malpractice laws (Light and Levine 1988), and growing distrust of managed care networks (Anders 1996). Decreasing confidence in medical authorities has contributed to a rise in contested disorders such as fibromyalgia
(Barker 2009), Lyme disease (Aronowitz 2015), and Morgellons (Fair 2010), in which patient advocacy has significantly shifted the medical discourse from dismissiveness to growing recognition of patients’ claims. Patient advocacy is important because it both front-stages patient experience while also situating those experiences within a medical framework that posits official diagnosis as a kind of moral judgment. Consider that many of these contested illnesses were previously described as psychosomatic, and often attributed to women in a way reminiscent of earlier claims of female hysteria. By advocating for recognition, patients both fought back against the medical establishment’s assessment of their experience while also seeking clinicians’ approval to classify what they are experiencing as medically “real” (Aronowitz 2015).

In recognition of patients’ self-advocacy – and, importantly, as part of a profit-driven shift towards treating patients as consumers (Beisecker 1988; Lupton 1997) – most hospitals now support a “patient-centered” approach that strives for a model of shared decision making (Frosch and Kaplan 1999; Woolf 1997; Charles, Gafni and Whelan 1997; Hamilton et al. 2016). As a challenge to the old paradigm of physician-determined care, shared decision making presents benefits and drawbacks to the treatment process: There is evidence that patient involvement in decision-making is related to improved outcomes and greater patient satisfaction with their medical experience (Anderson et al. 1995; Beach et al. 2007; Joosten et al. 2008), but patients may also be less adept than physicians at assessing the risks, often underestimating the chance of adverse outcomes (Reyna 2008).
Increasing patient involvement in medical decision-making contributes to the ideal of highly personalized care. In this model, the patient expects to be treated as an individual with distinct qualities that warrant tailored treatment. However, personalized care can also have unintended consequences, namely that patients may view recommended care as inappropriate for their individual bodies or circumstances. For example, anti-vaccination advocates often claim that doctors should consider the individual genetics and predispositions of each child before administering each vaccine (Reich 2016a), leading to reduced vaccination rates nationwide. The personalized care model also contributes to a growing focus on the politics of “risk,” and the notion that individuals are responsible for their health via the management of their distinct “risk factors” (Aronowitz 2015). The focus on risk, in turn, casts a moralistic light on what patients choose to do – or not do – in pursuit of “wellness,” and disregards the role of social inequality in health outcomes (Wikler 2012).

Class and Race in Clinical Interactions

Researchers consistently find that patients of higher socioeconomic status (SES) experience better health over the life course (Marmot 2004). For example, studies find that higher income (Case, Lubotsky, and Paxson 2002; Pampel, Krueger, and Denney 2010), education (Grzywacz et al. 2004; Schnittker 2004), and occupational status (Elo 2009; Braveman, Egerter, and Williams 2011) all contribute to better health, a link that begins in early childhood (Hayward and Gorman 2004; Haas 2008). Though researchers disagree about which (and when) status factors impact health the most, Link and Phelan’s (1995) notion of “fundamental causes” of
health disparities suggests that examining SES as a “metamechanism” is worthwhile in and of itself, as it allows for what they call a “massive multiplicity of connections” (2005: 1331) between causes and effects.

Despite the trend towards shared medical decision making, social status impacts the degree of involvement that patients wish to have in the judgments made regarding their own care (Deber, Kraetschmer, and Irvine 1996; Mansell et al. 2000; Barry 2002). Young, better educated, and female patients are the most likely to want a say in their medical decisions (McKinstry 2000; Adams, Smith, and Ruffin 2001; Say, Murtagh, and Thomson 2006), while men, older patients and those with less education are less likely to seek involvement (Beaver et al. 1996; Bastiaens et al. 2007).

Differences in patient involvement are intimately tied with the quality of care that patients receive. Studies have found that uninsured low-income patients are at higher risk of incurring injuries due to substandard care (Burstin et al. 1992), and experience less respectful and informative interactions with doctors (DeVoe et al. 2009; Jensen et al. 2010; Verlinde et al. 2012). Some scholars attribute the root of these disparities to unequal healthcare access (Adrulis 1998; Huguet 2008), making equitable entry to care a centerpiece of public health advocacy.

Much like socioeconomic status, studies of race and ethnicity reveal that they are an additional factor in health and healthcare. Research has consistently shown that racial and ethnic minorities experience poorer health than their white counterparts, including measures of birth weight (Lu and Halfon 2002), life expectancy (Hawyward & Heron 1999), late stage breast cancer (Chlebowski et al. 2005), and chronic conditions like hypertension, diabetes, and kidney problems (Williams et al. 2010). These disparities are partially attributable to unequal access to the resources that impact the risk of poor health. For example, racial and ethnic minorities are
frequently residentially segregated (Charles 2003; Williams and Collins 2001), and are more likely than whites to live in neighborhoods with unsafe physical conditions, lacking access to healthy food, and characterized by few spaces to be exercise (Cohen et al. 2000; Giles-Corti and Donovan 2002; Browning and Cagney 2003; Gordon-Larsen et al. 2006). Furthermore, race and ethnicity shape health through the experience of discrimination (Williams, Neighbors, and Jackson 2003). For example, experiences of discrimination are a factor in chronic stress (Grzywacz et al. 2004; Nuru-Jeter et al. 2009; Williams and Mohammed 2009), and mental illnesses like depression and anxiety (Brown et al. 2000; Karlsen and Nazroo 2002), as well as poor self-reports of physical health (Williams, Spencer, and Jackson 1999; Schnittker and McLeod 2005).

Importantly, however, race and ethnicity are key factors in the quality of medical treatment. Indeed, racial disparities in the timing and quality of care are well documented (Nelson, Stith, and Smedley 2002; Williams and Mohammed 2009). For example, studies find that blacks are less likely than whites to receive certain diabetes tests and procedures when presenting similarly at the same clinic (Heisler et al. 2003), and that black women are less likely to receive adjuvant care for early stage breast cancer (Bickell et al. 2006). Blacks and Hispanics are both less likely than whites to receive treatment for depression (Algeria et al. 2008), and receive poorer care for coronary heart disease (Fincher et al. 2003).

Balsa and McGuire (2003) outline three mechanisms through which health disparities may arise from the doctor-patient relationship: prejudice in the form of doctors being less willing to interact with minority patients; clinical uncertainty due to doctors interpreting the same symptoms differently between patients of different racial backgrounds; and stereotypes that doctors have about the health-behaviors of each racial group. Other research agrees, finding, for example, that doctors perceive black patients more negatively than their white counterparts (Van
Ryn and Burke 2000). Racial minorities are more likely than whites to mistrust their physicians (LaVeist, Nickerson, and Bowie 2000), and are less likely to change their perception following a change in the physician’s behavior (Schnittker 2004). All patients are more likely to report higher satisfaction with their care when they have a doctor of the same race, but clinical diversity remains limited (LaVeist and Nuru-Jeter 2002; Cooper et al. 2003). Patient satisfaction is itself a risk factor for poor health, as those who report low satisfaction are less likely to adhere to prescribed treatment and further recommended appointments (Carlson and Gabrel 2001; Beach et al. 2007).

Class and race shape the doctor-patient relationship by creating unequal health risks, access, and resources. My study seeks to extend past findings by showing how social disparities in medical interactions shape patients’ decision-making, particularly around refusals of conventional treatment.

Medical Non-Adherence

In light of this personalized and risk-centered model, it should be no surprise that patients are increasingly concerned with how and what they choose to help them stay healthy. Perhaps, counter-intuitively, however, individualized healthcare does not necessarily lead to greater adherence to recommended treatment regimens. In fact, one of the largest bodies of research in medical decision-making is called “non-compliance” or “non-adherence,” both terms that describe the failure of a patient to follow and/or complete the course of treatment recommended by a doctor. Rates of non-adherence

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10 The term “non-compliance” has traditionally been used to describe situations in which patients do not pursue or complete care as recommended by their doctors. However, in recent years, scholars have
vary by ailment type, but reviews suggest that 30-50% of patients are partially or totally non-adherent (Vermeire et al. 2001; Lacro et al. 2002). Non-adherence is typically considered a problem in the medical community because of adverse outcomes for patients (Sendt, Tracy, and Bhattacharyya 2015), medical system costs (Julius et al. 2009), and the possibility of drug-resistant pathogens (Bangsberg et al. 2000).

Research finds that most non-adherent patients fail to follow doctors’ orders for material reasons, including concerns over the cost of care (Briesacher, Gurwitz, and Soumerai 2007; Bengle et al. 2010; Wade et al. 2017), the complexity of dosage or treatment guidelines (DiMatteo 1994; Vermeire et al. 2001; Weng et al. 2005; Sajatovic et al. 2009), or distress about side-effects (Donovan and Blake 1992; Soyka 2000; Kaplan et al. 2004; Gardner et al. 2007; Perkins et al. 2008). Contextual factors such as work arrangements (Huijer and Van Leeuwen 2000; Ayanian et al. 2003; Ma et al. 2008), living apart from family (Gilmer et al. 2004; Sajatovic et al. 2009), or depression (Jindel et al. 2003; Wang et al. 2002; Gonzalez et al. 2004) also reduce adherence, while well-coordinated care (Lacro et al. 2002; Day et al. 2005; Alverson et al. 2007; Byerly et al. 2007) and social support (DiMatteo 1994; Gonzalez et al. 2004; Sher et al. 2005; Simoni, Frick, and Huang 2006) lead to better adherence. Research suggests that, overall, young patients, patients of color, and those with lower socioeconomic status are less likely to adhere to recommended medical treatment than are older patients, whites, and those with higher education (Jindel et al. 2003; Loghman-Adham 2003; Kaplan et al. 2004; Julius et al. 2009; Puskas et al. 2011).

suggested that the term carries a paternalistic or compulsory tone, and have shifted to the more judgment-neutral “non-adherence” (Aronson 2007; Julius, Novitsky and Dubin 2009).
While these studies offer a great deal of information on adherence outcomes, they provide only hints as to why patients may actively choose to refuse conventional medicine, and how those decisions may be shaped by sociodemographic factors. Understanding more about the nature and formation of these beliefs is sociologically important because they can tell us more about how individuals come to resist social norms – in this case, the norm of using conventional medicine.

**Alternative Understandings of Health: Complementary and Alternative Medicine**

The models of medical decision making discussed above all privilege a Western biomedical understanding of health. Whether or not one is adhering to doctors’ recommendations, those models assume that the treatment to be accepted, rejected, or debated rests on a foundation of shared understandings regarding how the body works, what causes illness, and what a cured patient would look like. However, biomedicine is not the only framework in which to understand the body, illness, or health. Indeed, alternative etiologies of health have existed for as long as modern medicine. In the current environment of fractured authority and accessible information, these alternative etiologies are growing in popularity.

A considerable body of research explores these etiologies, typically called complementary and alternative medicine (CAM). CAM is an umbrella term that includes a wide range of healing techniques, including prayer, spiritual touch therapy (also called the “laying on of hands”), meditation, visualization, energy healing, acupuncture,
chiropractic or osteopathic manipulation, massage, yoga, herbal supplements, and specialized diets (Richardson et al. 2000; Barnes, Bloom and Nahin 2008; Poloma and Green 2010). Though the CAM community is tremendously diverse (discussed in further detail below), users tend to share alternative understandings of health, meaning beliefs about how the body, health and wellness function that differ from those proposed by modern medicine. The broadest version of these beliefs is that health should be considered holistically, meaning that CAM users reject exclusively biomedical understanding of illness in favor of a perspective that considers emotional and spiritual components to wellness, and privileges competing explanations for the cause and cure of disease. Unlike those who believe that they cannot impact the outcome of their illness, CAM users do feel that they can impact their own health, but believe that conventional medical interventions are not the only, or even the best, way to do it.

Below I discuss two forms of CAM: divine healing and natural healing. Both are broad terms that refer to holistic, non-medical systems of belief and treatment for the body. Divine healing is based in religious belief, and particularly the belief that God can effect healing, while natural healing is non-religious, and typically refers to beliefs and interventions based on bodily manipulation and herbal remedies. Though both are tremendously popular forms of alternative healing, we know very little about if or how they operate in relation to non-adherence, particularly ideological resistance to conventional medicine.
Natural Healing in the United States

Most of what the average American would think of as “alternative medicine” is what I term “natural healing.” I use this term to distinguish it from religiously motivated CAM (i.e. divine healing, discussed in the next section) and to highlight that most forms of non-religious CAM are rooted in views of healing as part of a “natural” process, meaning that it does not require synthetic chemicals or other interventions deemed man-made (Bobel 2002; Reich 2016a). Natural healing as I use it here indicates all non-religious forms of CAM, including herbal supplements and remedies, chiropractic manipulation, massage, acupuncture, and energy healing techniques such as Reiki.

One challenge of the natural healing literature is that most studies do not distinguish between religious and non-religious CAM, making it difficult to accurately report the number of Americans who use natural healing. However, evidence suggests that CAM use overall is increasing. Nationally, use of CAM grew from 33.8% of Americans in 1990 to 42.1% in 1997 (Eisenberg et al. 1998; see also: Kessler et al. 2001), and was 47% just a few years later (McCurdy et al. 2003). One study found rates of CAM use to be as high as 66% (Stern, Canda, and Doershuk 1992). Another study that did separate religious from non-religious forms of CAM reported that 68.7% of cancer patients used at least one natural healing method over the course of their treatment, while that proportion increased to 83.3% when the authors included divine healing techniques (Richardson et al. 2000).11

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11 Richardson et al. (2000) acknowledge that the sample overrepresented whites and the college educated, both groups that are more likely to use natural healing. I return to the issue of demographics and natural healing use in a later section.
Because natural healing interventions are so diverse, summarizing a singular belief system would be impossible. There are, however, unifying perspectives that natural healing users share. Perhaps the greatest of these is the view that nature has perfected the body, and that we as individuals need to learn how to listen to and follow what our body tells us to do for wellness (Bobel 2002; Abramson 2015). In practice, this means a focus on nutrition, herbal remedies, and interventions that are believed to support the body’s existing immune system rather than unbalance it as conventional medicine is expected to do. Natural healing users are also more likely than non-users to believe that health should be viewed holistically, meaning that there are emotional and spiritual components to wellness that must be respected (Furnham and Foley 1994; Astin 1998). Conversely, natural healing users often report that conventional medical interventions weaken one’s natural immune system (Scherman and Lowhagen 2004; Reich 2016b), a belief that informs the decision to avoid treatments such as antibiotics (Bucks et al. 2009), and vaccines (Offit et al. 2002; Reich 2016a; described in more detail below). At the same time, it can be hard to determine if a naturalistic view of the body shapes patients’ orientation towards conventional medicine or the other way around. For example, those who use CAM are more likely to report distrusting their medical providers (Yaqub et al. 2014; Mesch and Schwirian 2015) and to have had negative experiences with conventional medicine (Furnham and Forey 1994; Dimmock, Troughton, and Bird 1996). Conversely, users report that natural healing helps them “feel hopeful” (73%), is perceived to be gentler or “non-toxic” (48.9%) and because CAM interventions provide more “control” over their medical care (43.8%) (Richardson et al. 2000).
However, it is difficult to know if patients’ negative experiences and poor rapport with a physician made them seek an alternative explanation for their illness or if their seeking of alternative explanations made them distrustful of conventional medicine. Certainly, patients overall do not seem to expect that their doctors will understand or accept their usage of natural healing methods: Between 31 and 54 percent of patients using natural healing never report or discuss such interventions with their doctors, typically fearing that they will be dismissed as useless or foolish (Eisenberg et al. 1998; Adler and Fosket 1999; Peebles et al. 2000), despite evidence that most medical students would like more information about CAM methods in general (Chaterji et al. 2007).

So who are these natural healing users? They are more likely than not to be women, affluent, white, have more than a high school education, be between 30 and 50 years old, and live in the western or northeastern areas of the United States (Astin 1998; Richardson et al. 2000; Burgmann, Rawsthorne, and Bernstein 2004; Jain and Astin 2001; Barnes, Bloom and Nahin 2008; Bair et al. 2008). Importantly, however, natural healing users are not the same thing as the “non-adherent,” though some natural healing users certainly also refuse conventional medicine. Remember that overall, the non-adherent are more likely to be non-white, working class or poor, and under age 30 (Puskas et al. 2011).

In fact, the degree to which using any form of CAM represents an active rejection of conventional medicine is unclear, and is one of the central weaknesses of the current literature. As the term “complementary and alternative medicine” suggests, CAM research investigates interventions that are intended to be used with modern medicine –
i.e. complementary strategies – as well as those that are intended to be used as an alternative to modern medicine. The vast majority of research focuses on patients who use CAM methods in addition to conventional biomedicine, likely because over 95% of those who use such methods do so in conjunction with conventional treatment (Astin 1998), and may even think of CAM interventions as luxuries rather than necessary health interventions (Bishop, Yardley, and Lewis 2008). The small proportion of people who use alternative medicine exclusively are significantly more likely than complementary or conventional medicine users to distrust modern medical systems, to express a desire for control over their healthcare, to feel dissatisfied with conventional medical practitioners, and to place a high value on one’s inner life and experiences (Astin 1998). I discuss more about those who actively refuse conventional medicine in a later section about resistance to cultural norms.

Divine Healing in the United States

Divine healing, or the belief that God can intervene to heal ailments and improve one’s overall health, is tremendously popular in the United States. Those who practice divine healing use prayer, either alone or with others, to ask God for healing, and may engage in rituals like reading scripture, or the laying of believers’ hands on an ill person to channel spiritual energy into the body (McGuire 2008). Studies find that seventy to eighty percent of the total US population believe that spiritual or religious practices may impact healing (Poloma 1991; Brown 2011), and that forty-five percent have reported praying about their health (Bell et al. 2005). Fourteen percent of respondents in one
random sample reported experiencing healing from a serious illness that they attributed to
prayer or regarded as divine healing (Johnson et al. 1986). Overall, those using divine
healing are more likely to be older, low-income women, and those with less education
(Johnson, Williams, and Bromely 1986; Glik 1988; Poloma and Green 2010; Cartledge
2013).

Pentecostals, who comprise over a quarter of the nation’s Christians (Pew 2011),
are the single largest group to use divine healing in the United States, with as many as
ninety-eight percent reporting that they have prayed with others for healing, ninety-three
percent claiming to have personally experienced an “inner or emotional healing,” and
seventy percent report healing from a physical illness due to prayer (Poloma and Green
2010). Additionally, eighty-five percent of Pentecostals have “witnessed a miraculous
healing in the lives of family members and/or friends” (Poloma and Green 2010).

Divine healing represents an alternative view of health that challenges Western
medical models of health as located only in the physical body, seeking instead to
conceptualize wellness holistically as spiritual and emotional (Poloma and Hoelter 1998;
McGuire 2008). Those who use divine healing reinterpret the meaning of illness and
recovery through the conversion of physical or psychological ailments into what Geertz
(1973) would deem “cultural symbols” that serve as an “expression of [believers’]
concerns for meaning, moral order, and individual effectiveness and power in the social
world” (McGuire 1988:6). Divine healing thus contests the exclusive expertise of modern
biomedicine (McGaw 1980; McGuire 1988, 2008; Barnes & Sered 2005) and seeks to
assert believers’ authority over their own bodies (Glik 1988; Poloma & Green 2010; Stolz 2011).

Indeed, subscribing to alternative understandings of health means that the very cause and effect of illness may differ from that proposed by biomedicine. More devout divine healing believers conceptualize illness as the result of interference from Satan (Glik 1988, Csordas 1988, Stolz 2011) or of personal or collective sin (McGuire 1988). Healing, therefore, becomes a spiritual process, and may contain multiple dimensions of recovery that lack the objective or quantifiable improvement prized by biomedicine. Though there is some evidence that faith healing may “work” to some extent in terms of measurably improved health outcomes (Koenig 1998; Levin 2001, Cartledge 2013), there is no consensus as to if and how causality has been established (Oman and Thoresen 2002, Sloan 2006). Healing in the religious context, however, may very well not mean a return to one’s state of health prior to illness, but rather a perceived improvement in mood or pain management, or as spiritual growth (Watts 2011, Csordas 1988). Lack of improvement may be interpreted as obstruction by the Devil or as a lack of faith on the part of the believer (Hughes 2004, Stolz 2011). Some advocates of divine healing further distinguish between the healing itself and the experience of the healing, suggesting that the healing has already occurred but the person has not yet experienced it because he or she has failed to “claim” it (McGuire 1988).

Importantly, though most research reports divine healing as the practices and outcomes of individual practitioners (Brown 2011), there is evidence that the social experience of being in a religious group can play a role in divine healing as well.
Certainly, individuals can use personal prayer or solitary rituals to address the spiritual
element of their illness, but they can also harness group energy in the pursuit of healing.
Several scholars point to the power of religious communities to normalize divine healing,
and the subtle socialization at work in many healing contexts, particularly those that
example, Stolz (2011) points to a number of "social techniques” that bolster divine
healing, such as the repeated suggestion of potential healing, emotive music, a large and
engaged audience, the probability of at least one person in the audience perceiving a
healing, and the selection effect of who is permitted to testify.

Active group resistance to conventional medicine in favor of divine healing is
something quite different from group healing rituals, however, and is far less studied. The
key distinction is that while most CAM users – including divine healing believers – view
conventional medicine as complementary (Astin 1998), religious groups that actively
reject some or all conventional medicine do so on ideological grounds. We might think of
these ideological grounds as constituting a cultural schema that prioritizes a specific
religious understanding of the body to the exclusion of other interpretations.

Christian Scientists and Jehovah’s Witnesses are two groups notable for their
rejection of some or all conventional medicine in favor of a belief system that emphasizes
Biblical interpretations of the body and healing. Jehovah’s Witnesses accept most
conventional medicine, but typically refuse blood transfusions on the basis of a Biblical
interpretation, though even this prohibition remains contested among some current and
former members of the church (Elder 2000; Muramoto 2000). Research suggests that
Jehovah’s Witnesses refuse blood transfusions as both a way to draw boundaries between themselves and other groups and as a way to maintain an understanding of the body as spiritually pure of outside intervention (Singelenberg 1990), particularly in light of their belief that the end of the world is coming soon (Holden 2002). By contrast, most Christian Scientists refuse conventional medical interventions in favor of healing techniques administered by trained Christian Science practitioners (Nudelman 1986; Manca 2013). Christian Science healing is based on an alternative view of health that operates from the belief that physical illness is unreal and can be ameliorated with prayer (Swan 1983; Badaracco 2007). As such, believers adhere to a different model of risk than that used by biomedical experts, understanding health crises as having an exclusively spiritual dimension (DesAutels, Battin, and May 1999). Studies suggest that Christian Scientists who do receive conventional medicine experience it as a stressful event that reflects a loss of group support (Nudelman and Nudelman 1972; Nudelman 1986), and seeking such help is actively discouraged by the community (Swan 1983). Poloma (1991) argues that groups like Christian Scientists, who actively reject (rather than incorporate) conventional medicine for religious reasons, do so because they share an understanding of health as “monistic” vs. “dualistic.” She defines this difference as the perspective of health as centrally a spiritual concern that can only be healed through spiritual means (monistic), versus the view that both faith and conventional healing view health as having both physical and spiritual components (dualistic), and requires both spiritual and medical authorities to be treated.
Despite a great deal of research detailing the widespread use of divine healing, we ultimately don’t know much about if or how divine healing is related to either general medical non-adherence or active resistance to conventional medicine. Studies that examine groups resisting conventional medicine remain rare, and most scholarship on Jehovah’s Witnesses and Christian Scientists concerns the ethics of clinical care and the specter of medical neglect cases (Swan 1983; Richardson and DeWitt 1992; Merrick 1994; Schoepflin 2003; Hughes 2004; Woolley 2005; Remmers and Speer 2006). This gap means that my study can offer significant new information on the role of religion in shaping the rejection of medicine (see chapter 5).

Refusing Conventional Medicine: Cultural Schemas and Collective Resistance

To explore why individuals may actively reject conventional medicine in favor of CAM, it is important to consider how they come to believe what they believe, and how their membership in social groups influences their decisions. The literature of cultural schemas offers us one key way to think about logics of belief and action that shape individuals’ behavior in the context of larger social groups.

Cultural schemas are “both representations of knowledge and information-processing mechanisms…that simplify cognition” (DiMaggio 1997: 269). Famously described as “cultural toolkits” that define “strategies of action” (Swidler 1988: 273), schemas are “interpretive processes that mediate our understanding of the world” (Garro 2000: 285) and act as a network of beliefs that shape the behaviors we deem appropriate,
or even possible, in a given situation (Strauss and Quinn 1997; Nishida 2005). The notion of schemas helps us understand how a particular choice – for example, the choice to refuse conventional medicine – could have larger meanings about one’s status as a parent, an educated person, a consumer, or anything else.

Because they are shaped by cultural context, we absorb cultural schemas early in life through our social networks (DiMaggio 1997; Garro 2000; Nishida 2005). As such, schemas are powerful drivers of our decisions and behavior, and powerfully shape our judgements of morality, value, and what is the “right” thing to do in a given context. Schemas also shape our ability to accept and process new information, meaning that individuals are more likely to accept information that fits with their existing schemas, can recall schema-affirming information more easily and accurately (DiMaggio 1997). This gas important implications for medical decision-making, as patients may be more likely to pursue the kind of care that fits with their current worldview.

Though some schemas are broadly held – for example, national schemas (Garro 2000; Hui 2005) – sociologists typically conceive of schemas in terms of shared notions specifically held by smaller groups that operate in ways shaped by gender, race, or class. For example, one study found that workers rarely take flexible hours when offered by their employers because it disrupts the “workplace devotion schema” (Williams, Blair-Loy, and Berdahl 2013), which equates long work hours and a singular focus on work with moral worthiness. Importantly, however, schemas can be mediated by race, class, and gender. In the case of schemas around work, at least two studies found that workplace devotion is most salient for middle and upper class workers (Padavic and
Reskin 2002; Jacobs and Gerson 2004), and particularly men, who experience a heavier stigma for transgressing a schema of devotion to work than women (Berdahl and Moon 2013; Rudman and Mescher 2013; Vandello et al. 2013). Outside the workplace, cultural schemas of parenting (Lareau 2011) and education (Calarco 2011) differ by class, such that middle class parents and children value behaviors like assertiveness and help-seeking over the more deferential relationships to authority enacted by working class families.

Given the range of schemas, it seems likely that there is a kind of “medical decision making schema,” even if researchers haven’t discussed it as such. The work of Jennifer Reich (2014; 2016a,b) stands out as an important exception. She argues that health beliefs and the decision to refuse vaccines are shaped by class and gender. Reich shows that those who refuse vaccines match the same demographics as those who use natural healing – namely, that they are more likely to be white, have a college degree, and earn over $70,000 per year (McNutt et al. 2016, Reich 2016a). Furthermore, she finds that vaccine refusal is a way for middle class parents, particularly mothers, to demonstrate their commitment to intensive parenting by engaging in extensive research into the immune system and health technologies. Armed with information, parents define their children’s bodies as “naturally perfect” and vaccines as an artificial (and potentially sinister) technological intervention. They do significant emotional and institutional work to resist social (and sometimes state) pressures to follow conventional medical recommendations (see also: Buttenheim et al. 2015), searching for pediatricians who will accept unvaccinated children into their practices and learning about local laws to file the appropriate waiver paperwork with schools. Furthermore, their distrust of conventional
medicine means that mothers often assume the work of managing their child’s healthcare
themselves, including preparing special, organic foods or taking steps to “boost” their
child’s immune system with things like homemade herbal remedies (see also: Bobel
2002). As they work to care for their children in ways that align with their beliefs and to
resist institutional pressures to vaccinate, parents position themselves as experts on their
children and signal that they cannot be treated within the construct of a “one size fits all”
model (Reich 2014, 2016b).

Importantly, Reich does not examine middle class parents who don’t refuse
vaccines. This means that she is unable to explain why the parents she interviewed are
different from the mainstream. However, Reich’s work suggests a shared middle class
script that anti-vaxxers have merely tweaked. She shows that rather than totally rejecting
the schema of middle class intensive parenting, anti-vaccine parents have developed a
narrative of anti-vaccination advocacy as one version of good parenting. Indeed, anti-
vaccine parents who tout their extensive research, their expertise on their children as
individuals, and particularly their comfort challenging physicians’ authority, are
amplifying the values of intensive middle class childrearing (Bobel 2002; Lareau 2011).
In fact, Wang (2015) found that even those parents who did ultimately choose to
vaccinate their children had done significant research on vaccines, reinforcing the
exploration of vaccine choice as part of what it means to be a good middle class parent
and lessening the social stigma of not vaccinating. Studies suggests that becoming
engaged with a group of similar believers strengthens the schema, such that vaccine
refusals are socially clustered among parents trading information and support for their
choices (Buttenheim, Jones, and Baras 2012; Brunson 2013; Reich 2014; Yaqub et al. 2014; Weiner et al. 2015; Stahl et al. 2016).

Considered more broadly, resistance to cultural norms is in fact a significant component of modern parenting, particularly for the middle class. For example, scholars have documented the homeschooling movement as an important example of parents resisting social norms, in this case casting collective education as unable to meet the needs of their individual families and children. Like Reich’s work, these authors discuss the role of (mothers’) emotional labor as integral to collective resistance (Lois 2013; Stevens 2009), though others have pointed out that mothers undertake a good deal of labor in interacting with children’s schools (Griffith and Smith 2005) and extracurricular activities (Vincent and Bell 2007).

Though long the purview of middle class mothers, these days intensive parenting is increasingly a cross-class model for how to raise children. For example, Elliott, Powell & Brenton (2013) find that low-income, black single mothers pursue similar goals of time-intensive parenting, and extol the same kinds of parental sacrifice for their children. The difference is that they do so without the larger social support for their efforts, and at great cost to their own well-being. Still, as the ideal of intensive parenting extends its reach, it is likely that the behaviors and values found by Reich and others will only continue to grow in importance.
Conclusion

Clearly, much work has been done on medical choices, both conventional and alternative. In spite of this vast, literature, however, we lack an understanding of how and why patients arrive at different decisions when coming from similar backgrounds. My contribution is to show, using a comparative study design, why parents from similar backgrounds make different decisions. In doing so, I build on past research concerning models of decision-making, social inequality in medicine, medical non-adherence, and CAM studies. I add to our understanding of medical decisions by revealing them to be a shared social process that draws on community ties for the meaning and support to collectively resist medical norms.
CHAPTER 2: ENTITLED SKEPTICS

Introduction

Sociologists and medical researchers agree that the most likely demographic to refuse key modern medical interventions like vaccines are middle class white mothers (Buttenheim et al. 2015; McNutt et al. 2016; Reich 2014, 2016a). Yet clearly not all middle class white mothers refuse modern medicine, and not all people who refuse modern medicine are middle class white mothers. In this chapter, I handle the first part of that statement, showing how some middle class women – from a variety of racial backgrounds, and overwhelmingly mothers – become skeptical of conventional interventions like vaccines, obstetrical childbirth, antibiotics, and even critical treatments like chemotherapy.

The stories of these women, whom I term Entitled Skeptics, illustrate key factors that influence how patients from all backgrounds make choices about health. I have chosen to discuss their experiences first because their social position means that they are the most entitled to make the choices that they want to make. In other words, they face the fewest barriers to choosing (or refusing) their desired treatments, and as such represent a kind of “ideal type” in medical decision making.

I argue that the key determining factor in patients’ medical decision making is their community. Specifically, I find that Entitled Skeptics make health decisions in the context of communities that give social and cultural meaning to their choices. Coming from a middle class orientation, these Skeptics expect to be treated as educated medical
consumers who possess expertise on their own bodies, health, and experience. When that expertise is disrespected or contradicted, Entitled Skeptics interpret the incident through the lens of their community, which supports a set of alternative health beliefs that privilege Skeptics’ expertise over that of conventional clinicians. Their integration into these networks creates a kind of cycle, in which Entitled Skeptics who express alternative medical beliefs face more challenges from conventional doctors, which in turn further incentivize their involvement with an alternative medical community. Skeptics become embedded in communities that provide the respect for their expertise and experience that are lacking in interactions with the conventional medical establishment.

I do not mean to imply that Entitled Skeptics are delusional, nor that they demand constant deference from doctors. As I show below, many of them have experienced terrible interactions with medical professionals. Such negative experiences were especially impactful when they occurred around pregnancy and childbirth, powerful points of social and personal transition during which women were keenly attuned to losing control over their bodies and faced a mountain of new decisions (medical and otherwise). After these interactions, it is quite reasonable that they would seek out something better. The key is what “something better” means for them. Skeptics’ communities prime them to interpret their experience as a systemic problem with the medical system as a whole, and to view alternative treatment as viable. Knowing even one or two people already using CAM could help a patient view it as a reasonable option, and begin the process of drawing the patient into a community supportive of alternative medicine. For others already embedded in such a network through family, friends, or
neighbors,\textsuperscript{12} drawing on the values and interpretations of that group felt natural. In either case, Entitled Skeptics felt that fellow CAM users valued their own experience, and more importantly, their expertise.

\textbf{Health and Medicine in Childhood}

First, I want to show how the middle class mothers with whom I spoke became Entitled Skeptics. I say “became” because very few started out as Skeptics. Despite academic accounts of the fracturing of medical authority since the 1970s (Conrad 2005), most middle class parents reported that their doctors were trusted sources of information in their families. The vast majority—both eventual Entitled Skeptics and Believers—characterized their parents’ interactions with doctors as unquestioning, and the doctor as the clear authority on matters of health. Ellen, a Korean-American stay-at-home mother of three who was raised by adoptive white parents, recounted her family’s orientation to doctors, an orientation that she no longer shares:

[My parents] just listened to the doctor. Whatever they told them to do, they never questioned anything. [We did] all of the standard vaccinations and if we got a cough, they’d give us cough medicine. If we had a fever, they’d give us Tylenol.

\textsuperscript{12} It’s worth noting that these social networks are often geographically close (Yaqub et al. 2014). For example, some neighborhoods have more shops that offer services like herbal remedies, Reiki, crystal healing, or others. In such an environment, CAM services become normalized, and even those with little interest in CAM may be tempted to try it. It’s also true that the presence of CAM businesses indicates a sufficient client base, meaning that people living in these areas may be more likely to know people who use CAM. Indeed, many of the participants I spoke with lived in such neighborhoods and had friends or family nearby. However, none mentioned the presence of CAM businesses as being a key factor in their medical decisions (though having access to services certainly helped). Thus, I don’t emphasize it in my findings, but the neighborhood effect of CAM remains an interesting line of inquiry.
There wasn’t a lot of thought in it — Not in a bad way, it’s just this is what we do, because it’s what the doctor says to do. That’s fine. We’re all healthy.

Another skeptic, a white professor of education with one child, and pregnant with her second, described her parents’ compliance with doctors’ orders in similar terms:

If we ever had, like, a pediatrician appointment, [Mom] would bring us. Or the dentist, or eye doctor, or things like that. It was all the standard yearly things… Everything was very, very traditional. No questioning of anything a doctor says.

The notion of following a doctor’s orders “without question” came up frequently, an allusion to the absolute authority with which they used to view medical professionals. Consider the case of Naheed. Naheed is a 36-year-old black woman who worked as a nurse before leaving her job to stay at home with her three living daughters. However, Naheed also had another daughter, her first, who died at six years old after suffering from apparently congenital disabilities that included the inability to sit, eat solid food, or speak. Though her first daughter’s condition – which she came to believe was caused by vaccines – eventually spurred her to seek out alternative medicine, as a young mother Naheed described herself as being in her childhood mindset towards medicine:

At that time, I knew nothing about alternative medicine. Whatever the doctor says, I’m doing, because he’s the doctor…I did all the vaccines; whatever the doctor said, I’m doing.
That is not to say that all respondents grew up with parents who rushed them to the doctor for every fever or scrape. Many reported that their parents preferred to wait it out when they were ill, providing lots of soup, orange juice, and sometimes Tylenol. And a few participants even grew up using alternative medicine. The respondents who grew up with CAM viewed it as normal, and saw no contradiction in it being mixed with conventional medicine. As Mariah, a black mother of two and an art teacher in her early thirties, told me:

Ever since I was little my family has gone to traditional medicines, like going to a chiropractor, an Ayurvedic doctor when they couldn't figure out what was wrong with themselves or what was wrong with me. This was growing up. So my mom still went to a regular doctor but she also sought out these other medicines because I was getting really bad rashes, I was gaining weight and we couldn't out figure why. So there was an Ayurvedic doctor that someone had recommended to my aunt, and so we started taking different probiotics and treating certain points of the body, and we had an acupuncturist across the street from our house where I grew up hanging out as a babysitter. So she would treat me without the needles and she would treat my mom with the needles. I grew up with these kind of medicines in my repertoire, so I could go deeper and understand that that's more the way that I'd rather go.
A white mother of two, as well as a nurse and social worker in her mid-thirties named Emily described a similarly complementary approach to medicine in her family growing up:

My mom grew up normal [with conventional medicine]; I think she just found natural medicine through her education and because she lived in Vermont. [We were the same as] my other friends' families, it was just like this hippie natural parenting thing. So she was a little more extreme with health food and way more, yeah, super-intense about nutrition and that kind of thing. I didn't get vaccinated. I think I got the polio vaccine because my dad wouldn't budge on that one because it was more of a scare. But I did have antibiotics every year because I got tonsillitis every year and it was always that bad that I needed them.

Emily’s experience of her mother’s “mix and match” approach to medicine is a good example of the fluid nature most Entitled Skeptics bring to their health choices. Interviewing Emily’s mother, Lois, later, she described seeking out a responsive doctor after encountering several who were not willing to discuss her interest in alternative medicine:

We went to a doctor who would pretty much listen to us. I do tend to go to doctors to get an opinion or a diagnosis. Then I go home, [and think] where do I
go with this?... I have moments of clarity when I’m calm, trusting myself. I just hate that we have to be experts.

Lois’s perspective reflects many skeptic mothers who remained willing to get a doctor’s opinion, but felt that they were ultimately responsible for determining if that recommendation was best. Some mothers found this process exhilarating, while others, like Lois, found it exhausting. Still, it is notable that skeptic mothers believed they could and should synthesize information from multiple sources to make health decisions, indicating a diffuse view of medical authority.

Aamira, a black woman in her late twenties in graduate school for community education (one of the few respondents without children), similarly described the coexistence of conventional and alternative medicine in her house, even as her parents were both involved in medical professions:

I had a really nice childhood. Really happy, me-centered childhood, and like a really insular family. We’re very much attached to our extended family…My mom’s a nurse and my dad works in mental health. He usually worked nights when we were growing up…He’s self-taught in more esoteric sciences like astrology, palmistry, numerology, iridology, like reading the eyes, so he’s very holistically based. [Reading eyes] is a newer skill that he acquired more in my teen years through an herbalist he actually knows in our neighborhood. It’s like your skin, if you know what you’re looking for, your eyes can tell you what’s ailing you. You might have seen little posters or memes where people, okay, if
you have acne here it means this—it’s the same thing with other parts of your body.

Participants whose parents used some form of CAM for themselves or their children were likely to use it themselves. Similar to the medical believers I discuss in the next chapter, they approached the medicine of their childhoods with an attitude of, “if it ain’t broke, don’t fix it.” In other words, participants who grew up using CAM were likely to continue using it unless they felt there was a reason not to. Importantly, however, the level of commitment that parents expressed towards using CAM over conventional medicine was moderated both by their experiences with conventional medicine (no matter how limited), and by the medical norms of their communities.

**Interactions with the Medical Establishment**

If most participants grew up with conventional medicine, why, then, did so many ultimately come to refuse some – or even all – of it in favor of alternatives? Entitled Skeptics typically described coming to alternative medicine as a process. For most, it began with negative or disrespectful experiences in a conventional medical setting, particularly when those experiences were related to childbirth or the respondent’s child. In the face of those negative interactions, Entitled Skeptics turned to their communities for support, where they found an interpretation of their experience as a fault of modern medicine. These networks validated their understanding of themselves as educated medical consumers and experts on their own health. Having felt that understanding to be
challenged by conventional medical professionals, they were more likely to seek out alternative explanations and practitioners that would acknowledge and honor their expertise.

Experiencing disrespect from conventional medical professionals was a key event for many parents who have become Entitled Skeptics, and one that galvanized their interest in pursuing alternative routes. Many felt that doctors disregarded patients’ knowledge of their own or their children’s bodies, of their medical history, or the information that they had found on their own (typically on the internet). Parents understood doctors’ reactions as indicating that patients were not a knowledgeable source of information about their own bodies. Allison, a white mother of a ten-month-old son and a history professor, explained how a doctor responded poorly to her reports of repeated pain in her hip, the result of her earlier career as a ballet dancer:

I guess I question [conventional medicine]. I’ve had a lot of bad relationships with surgeons specifically, like them telling me that they know what’s happening in my body when I feel like I have a fairly good anatomical understanding of how things work and what is causing pain. The first doctor that I saw for that hip injury on the second visit when I said I was still having pain and couldn’t do these things he brought a resident in and said, “This is why you can’t listen to patients, because they don’t know body parts they’re talking about.” He said I didn’t know where my hip was. It felt like he wasn’t listening, like he was going to do what he was going to do, but I had no say in the process even though it was my body that he was sort of at work on… Just the fact that he was not listening to the input and
I think there’s a lot that you can—by perceiving what’s happening in your body, you can actually share a lot of information.

Others reported that when they had questions about their conventional care, they encountered dismissive responses from medical personnel, and particularly the sense that doctors were not listening to their concerns. Respondents understood doctors’ unwillingness to listen as a refusal to acknowledge their bodily experience, and, perhaps just as importantly, an unwillingness to incorporate information that they as patients were providing into their clinical assessment.

For example, Mariah, the black mother of two and an art teacher at a local private school who grew up with some alternative medicine, described how her doctor was unwilling to engage with her when she had questions about environmental health concerns:

I think that HPV shows up from the chemicals in tampons. I heard that those chemicals are the same things that are in baby diapers that are linked to cervical cancer for girls. I'm talking to my doctor and my doctor's like, ‘There's nothing proving that,' and just shutting every single thing down. Whereas instead of having a conversation with me about it, they're just shutting me down and I'm like, ‘But this is what I'm hearing from news or other sources, and this is what my body is feeling.’ I feel that when I have an eczema flare up, that could be caused by me eating wheat but I'm also showing up positive for an abnormal pap smear. So I feel like these things are connected, but you're saying there's no proven
science that's saying that these things are connected, and you've giving me some kind of medicine that is not gonna actually stop the problem from happening.

This respondent felt that her doctor’s unwillingness to listen was a refusal to consider her bodily experience – as she described it, “what my body is feeling.”

Mariah said that she rarely goes to doctors now, but described how she approaches them when she does, and how she draws on what she learned in childhood:

When I do go to the doctor…I’m not shy about the fact that—I don’t say that I don’t have any faith in medicine, but I’m very much aware that doctors are no longer scientists. I watch people become doctors, too, go through med school, and I’m like, ‘You just get taught to treat symptoms and say, okay, if you have x, y, z symptoms, you must have this,’ which is how you misdiagnose, and people get misdiagnosed left and right. And then on top of that, even if you rightly diagnose me, and you suggest I take x, y and z, you can’t tell me what’s in it, you can’t tell me what it does, you can’t tell me exactly how it helps me… A benefit I had growing up in the household I did was I don’t feel like the doctor knows everything. I feel like really I know everything because it’s my body and I just have to learn how to [heal it]. If we all learned how to listen to our body and just recognize those signs like your skin, your eyes, whatever, your mood, then we could be treating ourselves. I’m already coming to [the doctor] with this knowledge, I’m telling you that I know I don’t need this [medication].
Summing up how she approaches medicine now, Mariah told me:

I think for what I know of myself and other people who've switched to alternative it's that we've lost traditional with the traditional Western allopathic system because it's failed us in so many ways or there's so many side effects of what they're treating that it's not getting to the root of the problem and symptoms are still persisting and they're not telling us why. And a lot of the stuff like with my own child, my daughter would've been pumped with medication if I didn't trust my own intuition, which is what I think allopathic and Western doctors are pushing away from because they can be sued if they don't get it right. So most of where we've gone with a lot of these sciences is away from the trusting of ourselves and our own bodies and having someone outside of them.

Mothers also expressed frustration that conventional doctors wouldn’t engage with them in considering multiple choices to treat a specific issue. A conversation recorded in my fieldnotes between three women at a Mothers for Sustainable and Alternative Parenting (MSAP) meeting illustrates the challenge parents face when they feel ignored by conventional doctors, but also unsure about the safety of alternative practices. The discussion took place at a public library during a presentation of “winter wellness tips” presented by a young white woman named Casey who introduced herself as an herbalist.
Diana and Robin are talking with Casey about the skin issues that they have faced with their respective daughters. Diana – a short white woman with dark hair and tortoiseshell cat-eye glasses – says that since her daughter experienced extremely dry skin, she no longer uses shampoo on any of her children and “can’t remember the last time anything other than water touched my daughter’s head.” She launches into a bit of a rant, then, about how skin is “our largest organ, I mean, right?!?” She looks at us for validation, and we all nod quickly. Diana says that she is “frustrated that we don’t have more options” when she takes her children to the doctor. “We go to the children’s hospital because it’s supposed to be the best, but it doesn’t feel like we have any options when we talk to them” beyond interventions she considers too harsh, like steroids or antibiotics. Robin nods slowly, focused intently on what Diana is saying. She is a tall, heavyset black woman in her early thirties with her hair combed into a large bun on top of her head. She has one daughter the same age as Diana’s oldest, and reports similar skin problems, saying that both she and her daughter have “very sensitive skin – we can really only put anything on our skin that we could ingest, or digest.” Unlike Diana, however, she has essentially given up on going to doctors for skin care, though she doesn’t recount any particularly bad experiences with doctors. Instead, she uses aloe from her mother’s garden (“she just grows it because it looks pretty,” Robin laughs) for burns and for her hair. She describes funneling the liquid from the plant into ice trays and freezing it, and then thawing it when they need it. “I had read online that I shouldn’t put it in the fridge,” Robin says.
modestly, “but that freezing it was okay. YouTube University, right?” she says, joking that the online video service is its own form of education.

As Diana and Robin’s case illustrates, doctors’ unwillingness to discuss alternative options that these mothers view as less “harsh” or “toxic” can push parents away from conventional medicine and onto the internet, where they seek advice that aligns with their own experience and beliefs. Diana and Robin are also a key example of how medical experiences and community ties can create a cycle that pushes parents towards alternative medicine. By seeking alternatives online and discussing them in a group with other parents, mothers like Diana and Robin take a less than ideal experience with a doctor and put it in the context of a larger journey towards finding answers for their health concerns, regardless of where those answers come from.

For others, the hospital setting itself was enough to push them away from conventional medicine entirely. Aamira, the young black woman without children quoted above who grew up with alternative medicine, told me that she had suffered from depression and anxiety, and ultimately checked herself into an in-patient psychiatric program. Unfortunately, she came to feel that the care she received was deeply flawed:

It was like a prison…You’re kept in this box. There’s not enough social workers, not enough time with the psychiatrist. It’s just like, ‘Okay, time for your drugs, time for your drugs, time for your drugs.’ And everybody just takes them. And people are still tripping and flipping out and crying, because it’s a depressing place as it is. You come with your own issues and then the only thing they have
for you is to sit around and talk to everybody else, which is really good, and then just dope you up with more medication.

The most common site of dissatisfaction in the doctor/patient relationship, however, was during childbirth. The case of Jacqueline, the white professor of education and mother of one quoted earlier as growing up with conventional medicine, is instructive in how interactions with medical professionals around the birth process could push patients away from the conventional health system. After years of debilitating back issues that were finally helped by yoga, Jacqueline had become interested in exploring more alternative medicine, and ultimately decided to give birth at home. After enduring a long labor, however, her midwife found that Jacqueline was experiencing some complications, and transferred her to a hospital. Jacqueline described the hurtful response of hospital staff, noting how it pushed her further away from conventional medicine:

The doctors and nurses, the way that they were talking to me like, ‘well, this is what you get for trying to do a home birth.’ Like it was just—it was really horrible. And they wouldn’t trust what my midwife was saying about what had happened until they saw that that was the case. It was just really insulting and obnoxious. They kept being like, ‘Oh no, that’s not possible. Your cervix isn’t swollen. That’s not possible.’ …And then I went back to nine and a half centimeters and my cervix started swelling and they were like, ‘Oh, you’re not getting past nine and a half centimeters and your cervix is swelling.’ I was like, ‘Really? Because that’s what we told you six hours ago.’ So anyway I’ve just had
a lot of these experiences that have made me feel less and less excited about the
sort of traditional, medical establishment.

Indeed, many respondents reported negative experiences with conventional
medicine around childbirth. These seemed to be particularly impactful because for many
women, as for many childbirth was their first sustained contact with the medical system,
and coincided with a huge and emotional life transition. Ellen, the Korean-American
mother of three who, much like Jacqueline, reported growing up with conventional
medicine, described the birth of her first child as tremendously negative:

[My first birth experience] was, you know, just short of traumatic [chuckles].
Because everything like I didn’t end up with any interventions, so it ended up like
okay, but if they had had their way, like I would have been on the operating table,
because it took 17 hours...[The doctors and nurses] were not supportive. They
were not happy if I was too loud, because I’d scare the other mothers that were
laboring. They didn’t want me to move around because then the sensors would
fall off...The doctor had a really bad attitude. [While giving birth] I tore a little bit,
so [the doctor’s] like, ‘I’m going to give you a local [anesthetic] so I can put these
stitches in.’ And she’s like, “Unless you don’t want that either.’ I was like, ‘Okay,
I just had a baby. Cut me a little slack.’

Kathy, a white social worker and mother of two girls in her late thirties, declared that
giving birth at the hospital led to interventions she believes were unnecessary:
The hospital was not a good fit for us. It was too much, if you don’t do this, this could happen or this. Okay, settle down. My first baby was eight pounds, twelve ounces, and she lost seven or eight ounces in the hospital and they convinced us to give her formula. We were so tired and we were new parents and we did. She would have been fine. I was so stressed that my milk hadn’t come in right away. We did do vitamin K [for the baby when she was born, but] we definitely opted out of the eye stuff, because we had talked to our doula about that. The whole premise of some of those practices, like these are for people who might have STD’s. It’s a common practice across the line, because if it’s really bad and you have syphilis it could mess with your baby’s eyes, but I don’t have syphilis, so I don’t have to shove this crap in my kid’s eye. I don’t, so I’m not…They come out the way they need to. We realized okay, we have a say. We can handle this, we got this.

Later, Kathy described her experience with childbirth as a turning point in her journey towards using alternative medicine. When asked how she would describe her approach to medicine these days she said:

[I’m] skeptical. I think since we had kids, that’s what it was. Kids were the cornerstone. Where it was like, ‘You don’t tell me; I research and then I can tell you what I want. I have choices, I have decisions.’ I think we didn’t realize.
Others echoed the feeling that having children changed their sense of what they wanted from their doctors. For many, having children made them want more information about medical treatments as a way to provide the best possible care for their children, even if that meant refusing recommended interventions. Mariah, the black mother of two quoted earlier for her concerns about the chemicals in diapers, described how she has pushed back against doctors, seeking out different providers if they will not address her concerns:

I feel like these questions [about conventional medicine] have been coming up for me and the doctors are seeing me as a rebel or what-not because I'm fighting it. I had my daughter and I'm like, ‘No, this is my little baby and I want to take care of her.’ So I'm gonna go to you [the doctor] for certain things or I'm gonna find my own doctor who’s more willing to talk to me about these things. And that's when you go to seek other things.

Mariah’s comment reflects the attitude of many Entitled Skeptics, who view themselves as medical consumers entitled to either choose selectively from their provider’s recommendations or to shop around for a provider who shares their own perspective.

**Community Ties and Medical Decision-Making**

Negative experiences with conventional medicine pushed Entitled Skeptics to consider their alternatives. The key factor that determined middle class participants becoming Entitled Skeptics was being or becoming part of a community that encouraged
medical skepticism and CAM use. In its simplest form, this meant knowing someone who already used CAM, and particularly someone with experience in the intervention the respondent herself could use. The community factor is key, because though negative experiences with conventional medicine were important, communities were what gave the negative experience meaning, determining how respondents understood what had occurred. In other words, one’s community was the difference between having a negative experience and believing that the doctor was a bad doctor, and having a negative experience and believing that the medical system was a bad system.

Community ties were often the first way that participants learned about alternative options for healthcare. Kathy, the white mother and social worker who described children as the “cornerstone” of her interest in alternative medicine, recounted how she was initially unaware of non-obstetrical options for care during her first pregnancy:

I was in yoga with my first kid, prenatal yoga when I was pregnant. I met up with this one girl who is just awesome. She said, ‘You have a doula.’ I’m like, ‘What’s a doula?’ I had no idea about any of that stuff. She said, ‘with the midwives.’ I’m like, ‘What do you mean?’ I had a traditional OB-GYN, where you go to the appointment; you wait for like a year and a day. You do an ultrasound. They tell you to come back in so many weeks. It’s kind of impersonal and very factory driven. You’re like, ‘Ok, this is how we have a baby.’ You just didn’t know.

After initially seeing an obstetrician, this mother later sought out a midwife-assisted homebirth and midwife. Through the support team that she assembled for her home birth,
Kathy described being further drawn into alternative practices. For example, she recalled learning about placenta encapsulation, the process of having the placenta made into vitamin-sized capsules after birth to help postpartum women with hormone regulation:

[I found out about placenta encapsulation from] the second doula and the birth photographer. The photographer actually did it. She’s the one I had come over. She had the home birth, she lives not too far away, she had a small house. I’m like, ‘Alright, if you did it, I can do it.’ Kind of identifying with someone who’s similar to you. She was telling me about that. The doula thing, some of those things come up too. What do you want to do with the placenta? Some people have cord burning ceremonies, some people will do placenta art. There are all these different things that really go on. I’m like, ‘I don’t know what I would like to do. I hadn’t thought about that.’ She did it, I thought let me try it; I didn’t feel great after my first pregnancy. Let me see what happens.

Kathy noted that her doula presented a number of possible uses she might have for the placenta and/or cord after birth. Simply by offering options, Kathy felt that it was reasonable to consider an alternative intervention that she was not considering on her own.

Since having the positive experience of her second birth, Kathy has become more and more interested in alternative medicine. She described going to a local chiropractor as a positive development that helped her tap further into the alternative medical community:
The chiropractor was super helpful. He would never push anything with his ideas but you could tell he had experience. He has had four kids and he has had them all at home. I think his last one might have even been an unassisted birth. He and his wife and then they had a midwife that they could go to, that kind of thing. Just that idea, ‘Oh, you can do this. You’re not just some crazy person if you do it.’

Like Kathy, several respondents reported that the notion of a home birth was initially scary, and that knowing someone else who had gone through it helped them make the decision. Cheyenne, a homeschooling mother of three boys discussed how the idea of home births came to seem normal:

My cousin had a home birth. She lived in California, so I wasn’t there or anything, but she was the first person I knew who had a home birth and then I started learning about it. Some of the people that I had known from the chiropractor, there was a mom’s group that I got connected with and some of them had home births and it just felt like the right thing for us. Also, I don’t really trust [doctors]. (Chuckles) I don’t always believe what they say. I have trust issues…So again, I read up and I looked at the risks on both sides and I just decided that I felt like I was not at risk. I didn’t have any high blood pressure issues. I didn’t have any reasons that I felt like I would need a hospital.
As Cheyenne suggested, the decision to refuse conventional medicine often stemmed from multiple beliefs, such as the perception that doctors are untrustworthy or that the risks of conventional medicine outweighed the benefits. Still, the process of actively learning about home birth was facilitated by a family member.

Respondents also acknowledged, however, that what they were finding out from their communities had to resonate with what they intuitively believed about health and their own bodies. As Gail, a chiropractor in her forties without children, said:

Chiropractors are a supportive community. It’s one of the reasons I leaned more towards that rather than going into medicine. Already medicine wasn’t really resonating—I even remember when they wanted to put me on birth control. I did it for a few years and then I was like, ‘I don’t like the idea of popping pills every day.’ I know that obviously I didn’t want to get pregnant when I was young, but there was something about it that just never really felt right to me.

Mariah similarly told me that information from her community was helpful, but also needed to be vetted through a process of research as well as her own intuition:

I feel like you just kind of have to tap into those resources. I was invited into a play group when my daughter was really little and all of those mothers were into the same kind of naturopathic, herbalistic alternative medicines so they offered sound boards. Yoga studios too…There is a lot of information and it's like, ‘How can you trust that kind of stuff?’ [It’s] the same thing you would do for all your
research: check the sources where they're getting their information. Is it a traditional practice? Who is putting it out there? And then there's also trusting yourself and being like, ‘That doesn't sound right,’ or, ‘That sounds really right and I'm gonna go with it.’

As Mariah recounted, rejecting conventional medicine was not a single event but a longer process of listening to friends and family, conducting one’s own research, and ultimately “trusting oneself.” In this way, respondents described their decision to use alternative medicine as a journey towards respecting their own intuition over an outside authority like doctors.

For many middle class mothers, the medical decision making process also involved drawing on formal educational resources. Entitled Skeptics were proud of their educational background, and were often eager to make clear that they were not gullible consumers of wild theories, but rather methodical researchers. The work of researching medical options was a job that Entitled Skeptics took seriously, and being able to share that information provided valuable assurance that they were making the right choice.

Fieldnotes from a monthly meeting of Mothers for Sustainable and Alternative Parenting (MSAP) illustrate both the pride and entitlement middle class mothers bring to the task of medical decision-making. The example of Ashley, a white woman and stay-at-home mother to one daughter with another on the way, is instructive:

Ashley has the look of a tightly controlled, type A woman, who stands out next to the more “artsy” types around her. She is very slim despite the basketball of
pregnant belly on her front, and her butter-blonde hair is pulled into a smooth low bun. She is wearing black jeans and a soft-looking salmon-pink sweater with a diamond pendant necklace made of three stones that curve in an S-shape at the end of a chain. Ashley speaks in clipped, no-nonsense sentences that suggest a confident decisiveness. Talking to the small group of mothers assembled around the table in a busy suburban Whole Foods, she says that she has opted to “pick and choose” vaccinations for her two-year-old daughter. Ashley declares that reading up about each one made her feel like she was “back in grad school.” She says it neutrally, but her quick glance down and slight smile suggest a hint of pride in the time and care she has taken to be an educated medical consumer on her daughter’s behalf. Someone asks her how she has handled vaccination requirements for her daughter’s school, as the state she lives in allows only medical and religious exemptions. Ashley’s response is casual: She says that there’s a church you can join online that is against vaccines. You don’t have to actually participate in the church, but once you pay your membership fee, they will provide paperwork that you are part of the church, which parents can submit as proof of their religious objection.

Though some Constrained Skeptics (working class participants who are skeptical of medicine) were also aware of similar “churches” that would provide the necessary documentation to submit vaccine waivers to schools (see chapter 4), middle class mothers were much more likely to be tapped into communities that facilitated these relationships. Specifically, middle class mothers were more likely to be part of an official network like
MSAP, which provided an official, semi-institutional veneer to the sharing and dissemination of tips like the church membership Ashley noted above.

Naheed described the process of seeking out health information with similar notes of pride. Recall that Naheed is a black mother of three living daughters and one daughter with severe disabilities who passed away at age six. Like many Entitled Skeptics, Naheed noted that having children spurred her interest in alternative medicine. This was particularly true because Naheed believed that vaccines were the cause of her first daughter’s disabilities. From early experiences with her daughter’s disabilities, Naheed drew on her formal education to seek answers:

I’ve always been interested in medicine, [but] I definitely was not as into it as I am now. Kids brought that forth—kids bring things out of you that you do not know are there and I definitely had that experience. Especially with [my first daughter], the vaccine thing just took a turn. …[At the time] I was working on my Bachelor’s, last leg; I had access to college library and also subscription-based medical journals. I would look at that. I would read the actual study that the laws were based on, I would look at those. I was not convinced. I wasn’t convinced with like half of them…I definitely wasn’t as much into it as I am now, but yeah, I guess it was a combination of having access to the studies and I’m always a researcher. You can’t Wikipedia me. You can’t “angrymom.com” me; like, I’m not going to be roped in by a blog. I’m going to listen to personal stories, but I want to see numbers. I mean, I’ve always had strengths in math and science but I
need to see like evidence-based, concrete [information], I need the research. And
I just wasn’t convinced based on the research.

Still, most CAM users approached alternative measures as essentially
complementary, and were rarely all-or-nothing in their approach to medicine. Consider
Emily, the white mother of two in her early thirties who described growing up with
alternative medicine in Vermont. Her own mother turned to alternative medicine after
several harrowing experiences of sexism in the conventional medical establishment of the
1970s. Now with children of her own, however, Emily has not had reason to remain
passionately committed to CAM practices, and tends to pick and choose the interventions
she feels are appropriate with little concern:

It was funny, the other day my coworker called me to ask, 'Do you have any
Tylenol?' I mean I'm not that extreme, but I didn't have any. I'm like 'No, I've
never given my son Tylenol just because, I don't know, I think with fevers are part
of healing. I don't strictly follow homeopathy or strictly follow anything. I'm
pretty not strict on any of that…If I get a sore throat, I'll like drink tea and take
Echinacea, or I have my go-to herbs that I use. I just don't think to take Sudafed or
whatever when I get sick.

She was similarly casual in her explanation of how she decided to give birth to both
children at home, noting the importance of her social circle without suggesting that she
felt pressured into her decision:
I really had no second thoughts about it. None. With my son I was thinking about my really good friend growing up who had already had her son at home. Two of my friends had already had kids at home. That one friend's older sister had already had kids at home. It was just totally a standard thing. And I don't think my decision was based on anything other than, like, if something's wrong I'll go to the hospital, but otherwise I know that it is very safe and I feel safer at home. I feel more comfortable at home.

However, Emily did acknowledge that her mother could be judgmental about her choice to use some conventional medicine, including her decision to vaccinate both children. Emily attributes the choice to vaccinate as due partially to her time in nursing school, and in her belief that there was no real reason not to.

It's hard to back up why not to vaccinate your kids… [Nursing school] changed my view a little bit. I think it was just exposing me to the real world. Growing up, I think that I was just really surrounded by a lot of people who didn't vaccinate and were against vaccines or whatever for no actual reason.

Importantly, Emily attributes her shift towards more conventional medicine in terms of her changing social circle, and more specifically the medical norms of this new community. While home birth still feels “totally standard” and something that she can do safely (with a backup hospital plan), not vaccinating in her current milieu feels
unreasonable. Emily did acknowledge that her children’s current pediatrician can be condescending because she has labeled her an “alternative mom.” However, she has had better experiences with other practitioners in the past, and does not seem to feel that her choices are either radical or under attack.

Similarly, Mariah (who, recall, grew up with CAM and reported her earlier doctors as being dismissive of her alternative beliefs), was happy to report that she has found a conventional doctor whom she feels is more willing to communicate with her.

At that time [our new doctor] was transitioning from her practice to making her own practice and so she was doing workshops at the Co-op and it was on introducing naturopathic or herbal medicine to your children, or probiotics. I was like, ‘Oh my god, she's talking alternatives and she's a traditional doctor who takes my health insurance. I'm gonna go to her.’ …She now knows our family and she knows how we want to do an alternative science and so she'll talk to us in that way. She came in and she assumed automatically we were not doing vaccines, which, we didn't have that conversation but she kind of knew me and she kind of read [my partner]. ‘You guys aren't, and so I'm gonna talk to you in this way,’ but it wasn't putting us down the way that a lot of doctors do…She's a good doctor, she's a professional.

In addition to knowing others who used CAM, respondents’ positive experiences with CAM procedures and professionals encouraged them to continue pursuing alternative medicine. This was particularly true when the alternative medical experience
contrasted with the conventional medical experience. Ellen, who earlier described her
doctor’s sneering attitude towards her choice to labor without an epidural, described her
later experiences with home childbirth:

The next two [children] I had at home and a midwife, and they both were very
different [from the birth in the hospital]. My second’s birth was beautiful. It was
so long, but we have a labor tub, and my husband at the time got in and then after
the baby was born, my son got in [too], he was 18 months. It was really great.
Very peaceful welcoming to the world. Very different [from the hospital birth].

She went on to describe the positive – and specifically, respectful – interactions that she
has had with CAM practitioners.

I’m kind of protective about my body and sometimes I feel like I have
information that [doctors] are not necessarily willing to take into account or listen
to, and I’ve never had that experience with an acupuncturist or a chiropractor or a
naturopath, but I have it all the time with a doctor. It’s hard for me to then trust
my care to them. Plus, you know, the alternative treatments that I’ve sought have
been really effective.

Indeed, respondents often described their CAM experiences in terms of how they
contrasted with conventional medicine. Though most felt that medical doctors had
important services to offer, they were nearly unanimous in rejecting what they viewed as doctors’ authoritative monopoly on matters of health.

Jacqueline, the mother and professor who faced complications during birth, was passionate in her rejection of this authoritative monopoly. She described a mysterious illness that was plaguing her four-year-old son, and how it improved immediately after seeing a naturopath. Nonetheless, she expressed how frustrating it was to still have to contend with family and friends questioning their choices when the CAM intervention had been so much more successful than the conventional treatment:

He had this horrible rash that wouldn’t go away for like a year, and this cough that wouldn’t go away, and instantly they’re both gone. And it was another moment I was like, how many doctors did we see in the last year? How much money did we spend on this? And like with all these things, it’s so frustrating how doctors and doctor’s opinions are put up so highly and like never questioned. When we do things differently, people around us question it, and anyway, so it’s sort of like we are feeling like—we figured things out and feel good about our approach, but it’s still hard living in this world that doesn’t really value a holistic approach to health… I mean, my parents are much more likely to, ‘oh, he has this, give him this medicine.’ Just sort of instant. Or well, the doctor said this so you should follow that. And if we don’t, they’re questioning it.

Entitled Skeptics felt that experience had proven the effectiveness of CAM interventions, yet still struggled to explain their decisions to doctors, family, and friends who wished to
dissuade them. Respondents like Jacqueline vehemently questioned doctors’ authority as supreme, advocating at the very least for greater acknowledgement of multiple types of expertise. They believed strongly in their own capacity to research options and act as educated medical consumers, and tended to respond positively to practitioners who treated them as such. For example, one monthly meeting of the Women’s Health Consortium (WHC), an alternative health support and interest group, highlighted how validating patients’ own expertise strengthens their commitment to alternative medicine. At this meeting, a middle aged white woman named Deborah presented on her work as what she termed a “hypnotherapist.” Her goal was to provide information about “self-hypnosis” and how it could be used as a stress relief technique. An excerpt of my field notes explain how she validated participants’ own expertise:

Deborah is a tall woman, with an hourglass figure and straight, reddish brown hair. She wears a sapphire blue blouse with bell bracelet-length sleeves and an open neckline, and silver necklaces and bracelets jangle as she speaks expressively with her hands. Her eyebrows are frequently raised behind black rectangular framed glasses. “Okay,” she says matter-of-factly, “We’re all educated here, so I’m not going to tell you exactly what to do. You know how to deal with stress.” However, she notes, hypnotherapy, including self-hypnosis, can be a good way to handle stress and physical pain in your life. She says that the first step to self-hypnosis is to reset your beliefs by saying ten times per day, “I’m

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13 Despite the group’s name, it is welcoming to both men and women. Attendance fluctuates from month to month, but at any given meeting there are about three men and twenty women.
calm, I’m relaxed, and I’m full of energy,” noting that she had a co-worker who used to say that to her every day and always seemed incredibly content. I see several women around the room intently scribbling this directive into notebooks or on the back of wellness flyers. “The more empathetic you are, the more stress you carry,” Deborah says, the note of gravity in her voice suggesting that everyone in this group is very empathetic.

It would be easy to interpret Deborah’s comments as somewhat pandering, and it’s certainly true that most people like to be told that they are smart and empathetic. Still, Deborah’s entire presentation was geared towards giving participants the tools to act directly in their own health, and to do so based on self-knowledge. For people who feel that the conventional medical establishment has shunned this knowledge, it is important to understand the power of having that knowledge validated and even encouraged.

**Conclusion**

Entitled Skeptics did not describe a unified set of health beliefs that led them to reject doctors’ recommendations. Indeed, the conventional interventions that they refused, either for themselves or their children, ranged from stiff opposition to interventions like vaccines and antibiotics to more limited refusals of epidurals or allergy medications. Respondents were unified, however, in viewing conventional medicine as worthy of questioning. Parents with whom I spoke reported negative interactions with medical staff that led them to question the science behind doctors’ recommendations, and subsequent research led them to believe that many conventional interventions were
unnecessary or even harmful. When asked more about how they made the decision to refuse specific treatments, respondents were quick to note their independent research, but also spoke of making decisions that “resonated” with them, or “felt right.” As such, Entitled Skeptics’ decision-making reflected the eroding authority of conventional medical professionals and the increasing role that middle class patients expect to have in their own healthcare. Ultimately, however, Entitled Skeptics highlighted the importance of their community ties for normalizing and supporting the refusal of conventional medicine in favor of alternative treatment.
CHAPTER 3: BELIEVERS

Introduction

Compared to Entitled Skeptics, those parents who used all conventional medicine faced fewer moments of conflict, confusion, or crisis in their medical decision-making. Importantly, however, this doesn’t mean that they never had negative experiences with conventional medical interventions; many did. Rather, medical believers’ communities primed them to interpret these experiences in terms of a “bad egg” instead of a bad system. Though they may have disliked a specific practitioner (and indeed, some did switch doctors in response to poor care), it didn’t make them question the nature of conventional medicine overall.

Health and Medicine in Childhood

Like Entitled Skeptics, Believers overwhelmingly grew up using conventional medicine. Their comments sound nearly identical to those of Skeptics in their description of doctors as an authority. Kylie, a white woman with one young son who works in community health education, described her experience with medicine as a child:

If it was a rash or something, we went to the pediatrician pretty often. I took my son to my former pediatrician; she’s still alive. He got to meet her. She’s a pretty good pediatrician. Stays updated with recent medical news, so she was good. If there was anything, she would pick it up…I loved her. She had lollipops for me.
loved candy, so that’s one thing I remember about going to her office.

Meghan, a white mother of one in her mid-thirties who works in human resources at a large company, recalled that her parents were unquestioning of doctors:

[My parents] were definitely very doctor oriented. Everything was definitely very much like, ‘We don’t care if you like it, you’re going to do this, because the doctors know what’s best and this is how we’re going to handle it.’

When asked if she recalled her pediatrician, Meghan was emphatic:

He was wonderful. Honestly, when something went wrong, I could easily go to him to figure it out. He wasn’t one of those doctors who says, ‘Go to this specialist, go to that specialist, you need to do this, you need to do that,’ unless he needed tests done or something. There was an instance I had really bad stomach issues and ended up in the ER, and he was the doctor to figure out what was wrong, not the hospital doctor.

For most Believers, their trust in doctors seems to have been rewarded with quality care. For some, however, the experience was more mixed. Sophie, a white mother of three who works in campus ministry, seemed ambivalent about her pediatrician:
We did not go to the pediatrician often. It had to be a major fever that lasted many
days. I was prone to strep throat. I knew when I had strep throat. ‘I have strep
throat.’ And then we would go to the doctor…I saw the same doctor consistently
starting in elementary school through high school. I thought she was okay. I
remember she was a middle-aged woman. I remember when I was in seventh
grade she called me hefty. She gave me a lot of sheets about losing weight. That
was a bad scene. Otherwise, she was kind and very professional.

For others there were unequivocally negative experiences with doctors. Their parents’
responses were instructive of the different orientations of Entitled Skeptics and Believers.
Take the case of Elisa, a white woman and jewelry maker with one kindergarten-age son:

When I was really little, I had ear infections a lot. I probably had ear infections a
lot until I was in eighth grade. At one point, I had so many ear infections that I
became part of a study…I had to take something like all season long to keep my
ears drained. I had to get tubes in my ears. I think with the ear infections, it was
pretty much like, ‘Okay, let’s go to the doctor.’ And the doctor would be like,
‘Hi, oh, okay, here you go.’ It would be the same medicine over and over and
over again. I just remember that pink, chalky medicine. Then we moved to [a
new town] and we went to a doctor who was like, ‘Okay, let’s do this.’ It was,
like, drink water, hold your nose, blow out your ears…He was very forceful and
scared me, and I was just crying and it hurt intensely. My mom was like, ‘Okay!’
in a warning tone. And we never went to that doctor again. We just went right
next door; there was a different pediatrician. We just went to that one for the rest of my time in that town.

Elisa’s parents disliked the doctor, but given their history with frequent (apparently positive) visits to other physicians for ear infections, they attributed the incident to a bad practitioner, not a bad system. Though they might have interpreted the doctor’s behavior as disrespectful in light of Elisa’s recollection that he was “forceful” and frightening, they appeared to regard the experience as isolated, and easily moved on to another doctor.

**Interactions with the Medical Establishment**

Moving into adulthood, Believers continued to use conventional medicine with relatively little trouble. Their comments reflect a continued trust in conventional medicine. For example, Bea, a white mother of two in her late thirties who works as an architect, described her response to being diagnosed with a rare form of cancer after the miscarriage of her first pregnancy. She traced her commitment to prompt care partially to watching her father (a doctor!) delay his own care for prostate cancer. Though her situation was extreme, her orientation towards conventional medicine exemplifies the commitment that many Believers shared:

So when I found out that I had those tumors in my lungs, I didn’t need to think about it for that long. I was like ‘I want to start the chemotherapy now.’ The second I sat down with the oncologist and I knew that was probably where things
were headed, I said, ‘I don’t know if you get this very frequently, but I’m ready to start chemotherapy. Can we do this now?...Unless you’re telling me that I’m going to lose my fertility and there’s some reason to wait, I want to do this now.’…The faster you do it, the easier it’s going to be, and the quicker you can get the recovery over. My father had prostate cancer the year before, and he had really waited to get tested even though his father had died [of] prostate cancer…Seeing my dad wait it out, and then my mom having to go through dealing with basically somebody being a giant baby because they’re not taking care of themselves, my attitude is once you know it’s serious, you got to do something about it. There’s no point in delaying because it just gets worse.

Bea was adamant that conventional medicine was the first, best, and only solution for health problems, and that a patient’s job was to seek treatment as soon as possible. She echoed this perspective for the much less critical matter of her infant son’s tongue-tie, a common and treatable condition in which a baby’s tight frenulum hinders breastfeeding. Referencing her statement that “there’s no point in delaying” care, Bea told me, “That’s why when we found out about the tongue tie, it was like, ‘Call the doctor!’ We had an appointment the next day.”

In contrast to many Entitled Skeptics, more Believers had positive childbirth experiences. Lauren, a white mother of one who works from home part time, described her birth story:

It was great…Got to the hospital at 5:30 in the morning and she was born at 7:55
in the morning, so it went very quick…I was early, a couple weeks early and I
didn't know what I was doing. I think I stayed home too long…because it was a
couple weeks early, I wasn't expecting it and I was like, ‘This isn't real.’ … They
gave me an epidural [because] I was just so scared of not knowing how bad it was
gonna get, [but] looking back on it, I probably could've done it without it…It was
a great experience. I definitely hope to do it again.

Lauren’s story is notable for its positive, straightforward nature. She recalled her doctors
as supportive, the labor as relatively quick, and the overall experience as “great.”

Sydney, a white mother of three in her early forties who works as a physician,
happily described having a planned cesarean section for her second and third births after
having an emergency cesarean section for her first, an experience that she described as
upsetting and something she had to process for a long time. The planned cesareans,
however, brought logistical convenience and a calmer atmosphere that she enjoyed:

[My second child] was a scheduled C-section. He was just like he is now, easy,
breezy. My husband always describes [a C-section] as like you’re going on a
plane ride: You show up, you check in, you have to wait a little bit, you get
delayed a little bit, you go in the OR, 20 minutes later you have a baby, you’re
done. Compared to our first experience, we were like, whoa, this is amazing.
This is awesome…It was my doctor. We did the 11 o’clock appointment,
dropped [our daughter] off at daycare first, and went in. It was awesome.
Sydney had no qualms about choosing a surgical birth. She made no mention of viewing it as less “natural,” as many Entitled Skeptics did, though she did note that her first (emergency) C-section was hard in part because she expected to have a vaginal delivery. Still, for Sydney the disappointment of that experience was related to its outcome being unexpected; it was not that she opposed C-sections.

Unfortunately, not all Believers had such positive experiences with doctors, including during and after childbirth. Angela, a white mother of one who works in addiction counseling, recounted the emotional pain of the postpartum period, made worse by suffering as a single parent:

[That time] was terrible. I had post-partum depression and anxiety…I got a lot of help, but it came much later than it should have ideally come. [The doctors] give you questionnaires [about your mental health] to fill out. They give you one at the hospital. They give you one at the doctor’s office. They give you one at the pediatrician’s office. No one ever followed up with me about any of them. And I know my answers were indicating a problem, so I don’t even know what they did with them. I was already feeling so isolated that I just didn’t have the energy to call them and say, ‘Why aren’t you doing a better job? You had me fill this out.’

Though Angela eventually found a more responsive doctor, she was disappointed that it took so long. I was not surprised to learn later that she had eventually sought out a postpartum doula, whom she viewed as more responsive than conventional doctors. Though she never refused any conventional care for herself or her son, I speculate that if
she were to meet more CAM-friendly friends she could be a good candidate to pursue alternative medicine. As it stands now, Angela has one friend who has given her herbal remedies, but she remains somewhat ambivalent about them, saying, “I think they work, especially if you believe that they will… But I also call the pediatrician and say, ‘This is not going to interfere with anything, is it?’

Rosalyn, a 36-year-old white mother of two also described her doctor as withholding:

My doctor, I don’t even know…She’s so weird. I feel like I have to be like, ‘Tell me what you think about my health.’ She doesn’t volunteer anything. She’s like a vault. I don’t need a doctor only for the flu shot.

Rosalyn expected to be involved and informed in her healthcare, and balked at a doctor who wasn’t forthcoming. It is telling that Rosalyn demanded information from her doctors – her concern was not whether her doctor would share information but that she had to ask. Rosalyn’s reaction suggests that her doctor’s reticence came across as a breach of the relationship between physicians and middle class patients.

Importantly, however, regardless of the nature of their interactions with doctors, Believers were similar to Entitled Skeptics in their propensity to research health issues and approach doctors with questions. In that way, both groups brought distinctly middle class orientations to their interactions. Believer parents were simply more likely to see their perspective on healthcare as aligning with that of their doctors. In fact, a handful of respondents specifically used the term “evidence-based” to describe the kind of health
advice that they sought out, regardless of whether they found it through their doctors, in books, or on the internet. For example, Rosalyn responded forcefully when I asked if she had ever refused anything recommended by her child’s pediatrician:

No, absolutely not. The doctors all have a reason for recommending what they’re recommending. They have protocols that they follow. It’s not like a whim…I know that whatever they’re recommending is within the range of what is recommended by the forces that be.

Believers were also vocal in their perspective that their medical choices have a larger public health benefit, specifically referencing vaccines. Several respondents drew on their medical knowledge, or even direct experience, to frame their medical decisions as a moral choice. Becca, a white mother of one in her early thirties currently working on her PhD in education

I had worked in the pediatrics out-patient clinic in North Carolina before we moved to New Jersey, and was pretty onboard with vaccines from my time there… I remember seeing a few kids were medically fragile who couldn’t have vaccines and [feeling] that we’re in this together, people who can vaccinate their kids, should – for the benefit of everybody. A little greater good. I look out for other people’s kids, too; not just my kid.
Farah, a white mother of two in her early forties who works in public relations, answered similarly when asked if she and her husband had opted for all the recommended vaccines for their two children:

I mean I thought twice about it and might have researched it but I also think that the immunizations are in place for a reason and it's not just for my child's safety but for the safety of the children who can’t get them…It's never fun when kids have to get several shots at once but I think it's much more important that everyone stay healthy.

Believer parents sometimes faced the same concerns that more skeptical parents reported, including questions around vaccines. In these instances, respectful communication from a medical provider could make a huge difference in the final decision of whether or not to vaccinate a child. Isabelle, a white mother of a two-year-old son and a psychologist, recounted her early discussion with their pediatrician:

I research everything when stuff like this is happening. Same thing with the vaccines. I read several books. I went into my pediatrician and I was like, ‘okay, this is the plan. This is what I think I want to do based on everything I’m reading.’ I was like, ‘I know I’m going to be that annoying parent, but can you just talk to me about the thought process and give me your two cents and not make me feel like I’m trying to undermine you, because I’m not, I just want to be informed.’ She was great. She talked to me—and I ended up adjusting my point
of view after talking to her. I think it was Hep B was one of the ones that I was concerned about…and she told me that it has nothing to do with [the sexually transmitted nature of hepatitis B], it has to do with the fact that the child can contract a liver disease if they don’t have it. And her aunt, actually, had the liver disease. So when she told me the whole story, I was like, ‘let’s do it. Thank you for making this make sense for me.’ I think also at the end of the day as a parent it’s like, okay, if I’m going to place gravity on other people’s points of view, what do I place the gravity on? Some books where I don’t even really know these authors, I don’t know their whole story? Or the physical doctor sitting in front of me who I basically think is a really good person and I trust her.

Though Isabelle had a positive interaction with her doctor, other believer mothers found that they didn’t care for their children’s pediatricians. At such moments, their solution was not to seek alternative medicine, but to find another doctor better suited to their tastes. Vanessa, a Latina mother of one who works as a researcher in clinical psychology, recounted the instrumental approach she took while seeking a doctor for her daughter:

We once saw a pediatrician [for my daughter’s eczema] who directed questions only to me and used a baby voice with my daughter, which I dislike. But I knew she knew a lot about eczema, and so I actually got a nice [treatment] plan and I was like, ‘Great, I'm never gonna see you again because I hate the way you talk to my child and my husband.’ To me that's kind of deal breaker; you need to
recognize that my husband is a huge part of this, and don't talk to my two-year-old like she's a puppy.

It’s notable that though Vanessa was immediately turned off by the physician’s communication style, she had done the research to know that the doctor was a well-respected specialist. Vanessa felt comfortable implementing the treatment plan the doctor recommended without any follow-up visits, allowing her to tailor the medical experience to be useful for her daughter without subjecting herself to a provider she didn’t like. This notion of having – and deserving – control over a clinical encounter was evident with both Entitled Skeptics and Believers.

**Community Ties and Medical Decision-Making**

Believers, like Entitled Skeptics, drew on their communities for support, validation, and interpretation of their medical choices. In some ways, the support component was less visible, as Believers had less need for it – they were conforming to cultural norms around medicine, not resisting them. Resistance typically requires more encouragement from like-minded community members. Still, it was evident that Believers interpreted medical decisions through the lens of beliefs, values, and meanings shared by their social circles. For example, Becca, the white PhD student and mother of a three-year-old daughter recounted to me who she turns to for advice when her daughter gets sick:
There are several girls that I graduated from high school with, and we’re all still really close, just friends for years. There’s five of us now that all have kids, and we will often bounce stuff off one another. I think we’re all kind of similarly minded and that we’re pretty pro evidence-based medicine. We all have graduate degrees. I think we think of the world generally in the same way. If I had a question about something, I would bounce it off them. One of my girlfriends has a sister who’s a yoga teacher and very anti-vaccine and gives her kids essential oils and the whole thing and is kind of a running joke. ‘Oh, my daughter has an ear infection. Give her essential oils and it’ll be fine.’ We can kind of joke about that a little bit. Yeah, I mean, I don’t tend to read a bunch of things on the internet.

Despite approaching health decisions from a thoroughly conventional medical framework, believer parents were not shy about asking questions of their doctors, and often felt entitled to do so from a place of expertise. Importantly, however, middle class believer parents often mentioned drawing on specialized resources that aligned with conventional medical knowledge. Thus, the knowledge that middle class believers brought to interactions with their doctors was much more likely to be viewed with respect by medical professionals. Sydney, a white mother of three in her early forties, told me about how she researched her son’s heart condition before speaking with his doctor, despite being a physician herself:

So the tech told us he had this condition. I was like, ‘give me my cell phone.’ I was reading about it…I wanted to know what to ask [the doctor], what to be
worried about. I read up about it so that when I met with the doctor things that caught my attention I could then ask him about…But I have access to Up-to-Date, which is this medical resource that most people use, so that’s very helpful. I understand the language of it. I think in that sense, it is helpful for me to read things that I have a good resource. I’m not looking up things on Wikipedia. I’m looking at something that’s pretty respected, it’s all evidence based. What do the studies show? I know I’m reading something that’s not written by just like anybody. It’s somebody who has credentials.

Meghan, the white mother of one in her early thirties noted above who works in human resources, was diagnosed with irritable bowel syndrome in her early twenties. She also drew on her education in biology to speak with her doctor:

I think I was pretty stubborn with doctors in general and always have been where if I’ve got my mind made up about something, that’s the way it’s going to be done and that’s it. When I knew I had to change my IBS medication for when I was going to breastfeed, I did all the research myself, figured out what the alternative was, and basically went to the doctor and said, ‘here. Here’s the change you need to make. And this is the dosage.’ My doctor was at that point, because they knew I knew, biology, knew that I was so on top of everything; they could just be like, ‘Okay.’
In addition to their familiarity with medical education, Believers were also far more likely than Entitled Skeptics to have family and friends who are doctors. These medical professionals provided an important source of health information, but perhaps just as importantly, they humanized and engendered trust in the medical system for those who knew them personally. For example, Lauren, a white mother of one who works part time in payroll preparation, is married to a doctor. Her father is also a doctor. She reported how they handle illnesses in their one-year-old daughter:

She's gotten sick a couple times. Basically what happens is my husband freaks out, calls every one of his pediatrician friends, asks them what to do. We had to take her to the hospital twice. [She got really sick while we were on vacation in Las Vegas.] Whatever the doctor said there, my husband then called his doctors here to make sure that Las Vegas doctor was saying the right things and doing the right things.

Sydney, a doctor herself, noted that she will seek advice on specific questions from her friends who are specialists in other areas:

My son was really, really sick once. I have a friend who’s a pediatric cardiologist – his wife is actually my good friend – I texted her and was like, ‘What respiratory rate should I watch out for?’ She said, ‘You don’t have to worry about that. You just sort of look at how is he acting, how is he looking?’ He was doing okay… My other friend, the pediatrician, is helpful for rashes or initially for what
Tylenol dose I can use, what Motrin dose I can use. That kind of stuff. I haven’t used her recently, but it is helpful.

The impression from Sydney and others was that conventional medicine was a language they could speak. In some cases, this was because they were indeed medical professionals. But in a broader sense, Believers exuded a kind of ease with and about clinicians that indicated comfort in their position. These participants were not concerned about pushback from their doctors because they fundamentally agreed with doctors’ expertise, but they also felt educated and socially connected enough to exert their own influence over medical experiences.

Importantly, community ties were also vitally important for maintaining a believer’s connection to conventional medicine when she had experienced extremely negative interactions with doctors. A believer’s community was key for supporting her decision to continue using conventional medicine in the face of a negative experience, and for supporting a framing of alternative medicine as illegitimate. Kara, a black mother of one in her early forties who works as a Christian minister, recounted her early experiences with doctors as nothing short of traumatic:

I remember my first pelvic exam being horrifying. It was painful. I didn’t know what to expect. I just had never even ventured into dealing with feminine health and reproductive stuff whatever… I was a virgin, but I remember she [the doctor] accusing me of being sexually active…I remember her having a thick accent, and I remember her having a very gruff disposition.
Kara’s early experience was so bad that she didn’t go back for a pelvic exam again until her mid-twenties. She began tearing up as she told me about undergoing more painful experiences before finding a truly gentle and empathetic clinician:

As a young woman [I had] anxiety [about doctors] because I had had such a painful experience that I just didn’t want to enter into that space again. I literally had to breathe and stay calm. I would cry, tears! It makes me tear up now thinking about how challenging that was…Whenever I would have to see a doctor about it that I would kind of explain, ‘Hey, I’ve had really bad experiences where [gynecologists] are concerned. Please be patient with me. This is really hard for me.’ Because I used to feel like okay, they’re going to think I’m just this big baby. They would try to walk me through it, but I didn’t necessarily feel like they were super sensitive about it. Until there was a doctor that I had who she was recommended by my girlfriend. She was youngish, like close to my age, maybe even a few years younger than I was, but I remember she was a Christian, and she had a gentleness about her that I never had, and it almost makes me want to cry even now. I had never had a good healthcare experience like I had with her… I remember her just empathizing and being gentle. The other doctors would walk me through it, ‘Okay, you’re going to feel a pinch here.’ [But] she was like, ‘I’m so sorry it hurts.’ She was the first healthcare provider that I felt cared and really understood that.
Kara’s experience would seem to make her a prime candidate for shifting to alternative medicine, given her negative interactions with doctors that centered on a dismissal of her physical and emotional pain. However, Kara maintained that she remained distrusting of alternative measures. When asked about exploring alternative medicine, Kara described CAM users and practitioners in a way that placed them firmly outside her social orbit:

Alternative medicine, just I’m not completely comfortable with, because I don’t know how vetted it is, so I just have a discomfort entering into that…I’ve never had a trust factor [with alternative medicine], because it isn’t traditional medicine…My husband, he’s never had a comfort level with that [too]. He wants to know, what is the diagnosis, what do the professionals say? A lot of the homeopathic people that we know are just real crunchy and weird. They just smell like essential oils. Really strange people. They bike everywhere. Nothing wrong with biking. It just is a different life.

Kara’s assessment of people who use alternative medicine suggested that she sees them as culturally distinct. Though she didn’t mention race, her description has overtones of the stereotypical upper-middle class white CAM user. As I have shown, there is certainly a community of black women who use alternative medicine, and it’s possible that Kara would include them in her description of CAM users. What is clear, however, is that Kara feels culturally different from those who use CAM, and thus would not take into the meaning or the social support that such women might offer in light of her medical
experiences. I discuss the intersection of race and class and medical decisions more fully in chapter 5.

**Conclusion**

Compared to Entitled Skeptics, Believers faced fewer concerns when making health decisions. Declaring proudly their allegiance to “evidence based medicine,” these parents framed their decisions in terms of a commitment to science and the greater good. Unlike Skeptics, they faced negative experiences with conventional medicine as an instance of a bad provider, rather than a bad system, a position that was supported by their friends and family. Indeed, believers’ communities were often peppered with medical professionals to whom they could turn for advice and second opinions.

Ultimately, however, the differences in Entitled Skeptics’ and Believers’ choices mask the fact that they are coming from the same orientation: namely, that patients must be informed medical consumers who are acting in the best interests of themselves and their children. I find that individual experiences are moderated by community norms, which create an interpretation of specific events as either challenging patients’ authority or confirming it. When it challenges their authority, Skeptics are more likely to see out an alternative medical framework that will better acknowledge/honor their expertise. For Believers, those who do not see a specific medical experience as challenging their authority will be unlikely to seek out that alternative framework.
CHAPTER 4: CONSTRAINED SKEPTICS

Introduction

Compared to middle class parents, past research shows working class parents are less likely to refuse conventional medicine in favor of alternative medicine, or to report using treatments complementarily (Barnes, Bloom and Nahin 2008; Bair et al. 2008). These findings, however, taken from large scale survey data, hide a complex reality in which class and race constrain medical choices. I show that the same factors that matter for middle class families’ decisions – namely, how parents’ communities mediate and interpret their interactions with medical professionals – matter for working class families as well. However, I also find that class (and race, which I discuss in chapter 7) operates in distinct ways to shape working class parents’ ability and willingness to push back against conventional medical norms. Indeed, it is the additional barriers that working class parents face when making medical decisions that lead me to call them Constrained Skeptics.

Below, I first briefly discuss how Constrained Skeptics approached health while growing up. I show that, like Entitled Skeptics, Constrained Skeptics grew up using primarily conventional medicine, though some used a combination of conventional and alternative remedies. However, I found that when Constrained Skeptics described using alternative medicine as children, it was framed as a matter of “tradition” and cost savings rather than as an ideological rejection of more conventional treatments. I did not find any
working class families who opposed conventional medicine in the way of Emily’s or Mariah’s families, discussed in chapter 2.

I then move on to discuss how Constrained Skeptics have come to distrust the medical establishment in interactions with clinicians. Compared to Entitled Skeptics, I find that Constrained Skeptics were more likely to recount that doctors have disregarded or underestimated their pain (though, like Entitled Skeptics, they also felt that doctors had at times been disrespectful of their knowledge or experience). Some participants explicitly viewed these negative experiences as tied to their class position.

Finally, I turn to how working class communities influence medical decisions, finding that Constrained Skeptics were much more likely than Entitled Skeptics to view themselves as a “lone soldier” in pursuing CAM use, meaning that they had a very limited community to support their choices. They were also more likely to discuss finding support for their medical choices online, a strategy that is helpful, but which also has limitations for getting actionable, local advice for refusing specific conventional interventions like vaccines.

**Health and Medicine in Childhood**

Constrained Skeptics reported a wide range of experiences with medicine growing up. All reported that they used conventional medicine, though the frequency with which their parents sought out clinical care varied. Much like middle class families, some took a “wait and see” approach, while others were more aggressive about treatment. Commonly, working class families took their children to the doctor for serious illnesses, but otherwise
tried to manage healing at home. Nancy, a stay-at-home mother of five in her early 50s, told me that in the small town where she grew up, people were fairly self-sufficient:

We would go to the doctor if we were very ill, but for the most part, it was Tylenol or some type of fever-reducing medication, not too much natural anything, just over-the-counter stuff more than anything. If we had to go to the doctor, there was a little country doctor that we went to…but that was very few times.

Others reported a more proactive approach to seeking care. For example, Gabriela, a Latina mother of three in her late thirties who works at a funeral home, described an upbringing similar to that of many middle class respondents:

In the doctor setting, it was like, you follow what the doctor says. If he was giving us the antibiotics, the pink medicine, you would take it because this is what the doctor says. Ear drops, the doctor said you’re going to follow that, so we followed that. That was law.

Notably, Gabriela differed from many working class respondents in that she grew up middle class – her father was an attorney with a small private practice. She experienced downward mobility since dropping out of college at age 19 to have her first son, and she and her husband, a truck driver, have struggled financially for years.
Several women noted that their parents valued going to the doctor because it made them feel cared for or special. Paula, a stay-at-home mother in her early 50s with four children, felt that her mother’s relationship to medicine was partially what sparked Paula’s interest in alternatives:

My mom had headaches and pains and she was on all kinds of medication. She loved going to the doctor. She was a hypochondriac. She loved the attention of it. That was another reason why I started looking into natural remedies earlier. I didn’t want to end up being like my mother on medications and dependent on other stuff to create this whole sense of what she would call health. I just didn’t want that for myself. I didn’t want my kids’ lives starting out that way, so we really didn’t use a whole lot [of medicine for our children].

Though no working class medical skeptics described using primarily alternative medicine as children, several mentioned receiving “traditional” remedies. Interestingly, these were not framed as an explicit refusal of conventional medicine, but rather as an inexpensive alternative that drew on the family’s history of self-sufficiency. For example, though Nancy described her mother as enamored with conventional medicine, she also reported learning about “natural remedies” from her grandparents, which her mother occasionally used:

[My mother] did use some natural remedies, because she grew up in a different world where that was a kind of thing. She grew up in the country. My
grandfather, her father, is a full-blood American Indian, so I think that a lot of that historically went back to the late 1500s, early 1600s. It was very impressionable on me when I got to know my father’s side of the family, his cousins and stuff that lived in Virginia on the farm where he had grown up. I learned a lot of natural things from my cousin. Like black tea, instead of using sunscreen, you use black tea as sunscreen.

Note that Nancy didn’t describe her family’s CAM use as a rejection of conventional medicine, so much as medicine from a “different world.” She tied it to a kind of rural knowledge and self-sufficiency that she claimed as part of her family history. Nonetheless, the notion of drawing on traditional or ancient knowledge would be familiar to many Entitled Skeptics, who valorize earlier, especially non-European, ways of healing.

For those who used primarily conventional medicine, the experience was not always positive. As an extreme case, 31-year-old Alexis, a white stay-at-home mother to four children under age 13, recounted the pain and frustration of growing up under the shadow of her mother’s Munchausen’s syndrome by proxy:

Alexis: My dad’s always been into natural medicine, but my mom actually had Munchausen disease by proxy. It’s where you make yourself sick for sympathy and attention. And by proxy it's where you make those around you, like the elderly or your children, sick for attention and sympathy. So my mom always had us on amoxicillin or some sort of prescription, some sort of medication
when we didn’t really need it… It wasn’t really until I was a parent myself that I realized it. But I always knew something was wrong with her because I knew that I wasn’t really sick… We wouldn’t even have to go to the [doctor’s] office, she would just call him and get a prescription for amoxicillin, tell him we’re sick and he would send in a prescription.

Lindsay: Now do you feel that he was unethical, or do you think he was just trying to be responsive?

Alexis: I don’t believe what he was doing was unethical. I think he was trusting a parent to know when their kid was sick, not realizing the degree in which she had a disease herself… But that is kind of the reason I don’t take medicine or over-the-counter anything now… I lived kind of a normal life with my dad and then that craziness with my mom.

Though Alexis didn’t blame her pediatrician, she still associated the “craziness” of her mother with conventional medicine, and distrusts that it was good for her. Meanwhile, her father was a much more stable figure, and after his divorce from Alexis’s mother became a proponent of some natural medicine, including herbal remedies. Later in the interview she described first learning about herbal remedies from him. Alternative medicine, in this context, seemed like an eminently reasonable choice, while conventional medicine was clearly imperfect.

For most eventual Constrained Skeptics, healthcare growing up was something of a non-issue. Still, as Nancy’s and Alexis’s experiences show, for some the seeds of alternative medicine were planted early, ready to blossom in the right circumstances of
social support and medical disillusionment.

**Interactions with Medical Establishment**

Like Entitled Skeptics, Constrained Skeptics I spoke with recalled negative interactions with medical professionals that contributed to their later medical choices. These events were not necessarily a neat, linear progression of cause and effect, but they either spurred interest in alternative medicine or contributed to an already existing curiosity.

Several Constrained Skeptics reported interactions with doctors that sounded very similar to those of middle class moms. Take Dawn, 38, mother of two and a daycare worker, who described her doctors’ unhelpful response to her belief that she has an autoimmune problem called “leaky gut:”

So many of the books I’ve had [on leaky gut], a lot of them have a test in the back, and I rated pretty high off the charts. [But] when you bring it up to the doctors they’re just like, ‘Oh, you have to be careful with that.’ I’m recognizing these elements of my body, these reoccurring, constant, daily things, and the doctor just wants to tell me I’m stressed and give me a pain pill or an antidepressant. It would be nice to have a real diagnosis of what is truly going on with my body.

Asked what her relationship is like with her doctor now, she simply shook her head: “It’s not very good… The doctors are not very personal at all. I’ve been to two through the
past couple of years, [and] they’re just not very nice.” Much like the middle class mothers, Dawn faulted doctors for disregarding things she’s “recognizing in [her] body.”

Stories of doctors failing to listen were not limited to questions about alternative measures, however. Some Constrained Skeptics felt that their doctors didn’t listen to them, even when they were requesting interventions. As Gabriela, the Latina mother of three quoted above, reported that after she told her doctor she wanted a natural birth, the doctor didn’t seem interested in listening to further requests as her labor progressed badly. She told me:

When I came into the hospital in labor, I was five to six centimeters dilated. I’m doing my breathing techniques, and I think within about an hour I was at eight centimeters, but it stopped. I just knew something was wrong. The doctor was like, ‘No, just keep going. Keep going.’… I remember telling them, ‘Something’s wrong. I’m going to die.’ I told my husband, ‘Take care of the baby, because I’m dying. Take care of our kids, because this is something that’s really wrong. If [they] don’t take the baby by C-section, I’m going to die. Something’s wrong.’ So the doctor did actually take me in to do a C-section, and he was like, ‘Oh, this is why the baby didn’t want to come out. She was sideways.’

Gabriela couldn’t remember whether the doctor had taken steps to check on the baby’s position or if medical staff were otherwise incorrectly informed about her labor. Years later, she was left only with the perception that the doctor didn’t listen to how she felt,
and that her gut feeling was borne out as correct. For Gabriela, the experience was a key instance of her knowledge and her bodily experience trumping clinical experts, and it had a lasting impact on how she viewed medical authority.

In some cases, working class mothers didn’t necessarily want alternative treatment, they simply wanted to feel that they were being respected enough to make a choice. As Jasmine, a black stay-at-home mother of eight children in her early forties, recalled:

Jasmine: I just got to get educated on certain things. I’ve learned, too, when you have babies, you can keep your stuff [like the placenta]. See they never really pushed that issue that you can keep your umbilical cord, afterbirth, they don’t really tell you that.

Lindsay: Did you end up keeping them?

Jasmine: No, because they didn’t tell me I could.

Lindsay: What would you have wanted to do with it, do you know?

Jasmine: I would have wanted to be able to have that option more than anything. At least give me that option to be able to say yes or no. That’s it, because if what I have inside me can help someone else, I’m all for it; however, just give me the option to be able to say no or yes. That’s it. Just give me my option.

In other cases, women felt that they had not been offered options for pain management, an apparent negligence of medical duty. Tammy, a 47-year-old mother of three, described giving birth to her first child as a teenager, saying that she “screamed and cried through every contraction that there ever was.” When asked why she didn’t choose
I don’t think I was offered it. I was only 19 when I had my first baby, and it was a very traditional, old hospital, and I don’t think they even offered it. That was back in 1990. And I don’t know, I can’t prove it, but I was also on [welfare], so I don’t know if the doctor just said, ‘Well, let’s just see how she progresses.’ I was on Pitocin\textsuperscript{14}…You would think just putting Pitocin on, the first thing out of their mouth would be, ‘Hey, do you want an epidural? Because we’re going to make your life really miserable here in about ten minutes.’ Like I said, it was so long ago. I should have written a book when I had the chance.

Tammy believed that using state assistance marked her as less deserving of effective pain management during childbirth. Though it’s impossible to know if she’s correct in this instance, past research does show that doctors frequently disregard the intensity of self-reported pain among those they view as low status (Trawalter, Hoffman, & Wayts 2012).

For many working class women, as with middle class women, the experience of childbirth was a turning point in their journey towards alternative medicine. They reported experiencing medical professionals as cold, disrespectful, or disinterested in their wishes. For example, Nancy, now in her early fifties, described her interest in giving birth to her first of four children without pain medication:

\textsuperscript{14} Pitocin is an intravenous medication that speeds up labor by bringing on stronger and more frequent contractions.
Well, at the time natural birth wasn’t a popular thing. The doctor was not happy with us wanting a natural birth. After the birth we found out he had a reputation of being called “the butcher.” There were thirteen women who went into labor the same time I did. We were all in the delivery area. It was like he wanted to rush everything. Also, he did not believe that I could have a baby at my size [because I am so small]. He made me go get an x-ray. Having labor pains, I had to go get an x-ray of my pelvic area to see if the baby’s head would fit. Then when he did the episiotomy, it was major. It was huge and unnecessary…My midwife is the one who actually clued me in on it. She said, ‘oh, my goodness, child, you did not need that.’ We felt very rushed. And actually, my husband was about to deck him because he did not want to let him into the delivery room and it was all planned that he was going to be at the delivery. They tried to really keep him out, and he was very adamant with him and said, ‘no, I’m going in one way or the other.’

After that, Nancy’s interest in a natural birth developed further, so that she went from wanting to give birth in a hospital but without pain medication to avoiding hospitals altogether.

The hospital birth was stressful. The whole atmosphere when I was having a child, they put you on a very cold, sterile table, and poured very cold liquid on you and you’re trying to relax and have a child it was like, no. So after talking with a friend of mine who had the natural delivery, she explained about it, and I
was like, “yah, we’re going to do that. It was such a difference from my first child that there was no way I was going back unless I had to.

Taylor, a 41-year-old mother of four who works in retail, told a similar story, even using the same language of hospital birth as “cold” and “sterile:”

My first was a hospital birth. It was horrible. There was not even a doctor available, the nurse kept yelling at me to not push until the doctor got there, but my body wasn't listening [laughs]. I gave birth alone in an empty, sterile, room. My second and third were completely different, born at my midwife's birth center and home. I felt loved, cared for, important. Her delight with my babies was almost as great as my own. My fourth was planned to be at the midwife's home, but unfortunately, the week before I went into labor, my midwife's daughter was in a fatal car accident, so I had to go to a local hospital again. It stressed me out so badly, I finally locked myself in the bathroom, got in the shower, and birthed my baby alone in there.

Gabriela, the Latina mother of three quoted above who told her doctor she needed a C-section, drew on her past work as an administrative assistant in a hospital to explain why she believed doctors should take her knowledge into account:

I used to work in hospital administration, so I would see sometimes the errors. I
think it was called the M&M committee,¹⁵ where they would discuss the patient deaths and what could have been done to prevent it and those things. And I remember one time going up in an elevator with two doctors and them having a discussion about a patient and me listening and the one doctor saying, ‘Well, in my opinion, x, y, z.’ And the other one was like, ‘Okay, I’ll put it in my perspective, it’s a, b c.’ So they had two completely different diagnoses of the same patient – same symptoms and they completely felt that they were each right, but how can they both be right if they’re completely different opinions? I was just like, I think a lot of times with medical doctors, it’s their best guess, and does their best guess equal the truth, necessarily? Is it really what’s correct? Because your best guess might be subject to your experience, but that might not be the right answer for that one person. I’m like, ‘Wow, there are times that people do die because it’s just a guess.’ It’s like, okay, I have wisdom, too, and I have to separate out what I feel is the right thing for me, what I feel is the right thing for my family. I listen [to doctors]. Okay, I want to hear what you’re saying, but then I have to make the best choice. I have to advocate for what I believe is the right choice for my family and I don’t think medication is always the answer.

Gabriela also described coming to distrust medical professionals after a nurse failed to tell her about an important chain of side effects that could impact her son:

¹⁵ M&M stands for “morbidity and mortality,” and refers to a committee or conference held periodically by clinicians in each medical department to discuss adverse patient outcomes. Whether held weekly, bi-weekly, or monthly, the purpose of these committees is to determine whether there are changes that hospital staff can make to prevent those adverse outcomes in the future.
With my oldest, when he was on the medication [for ADHD] he had a side effect where he couldn’t go to sleep at night, so the doctor told me to put him on Benadryl every night. I’m like, okay, I put him on Benadryl, but the doctor forgets to tell me that there’s a side effect to Benadryl, which is it dehydrates you… [so] you get constipated. I didn’t know this. So he must have been on the Benadryl for a month or so before he started having stomach pains. He would start screaming and clutching his stomach. I’m like ‘Why is this happening?’ The doctor’s like, ‘Oh, it’s probably from the Benadryl.’ I was mad. I was really mad, because then I had to actually take him to see a GI doc. He had to get on this drug where it’s a solvent that I would have to put in his drink every single day. Because of all this, he developed a bacteria [sic] in his stomach. He had to get an endoscopy. All of this because he was on this medication. But no one thought to tell me the side effects of what could happen until he started experiencing them. My God. So I think after seeing that, too, I’m always much more careful. What are the potential side effects here that we need to talk about this before I just rush in and do anything? Because you don’t know what can of worms you’re opening up.

Gabriela’s comment exemplifies the concern Skeptics feel about medical authority. Coming to see that authority as subjective and fractured, she described how she now feels more able to stand up to doctors:
Doctors listen to me. They have to. What I have found with medical doctors, you cannot let them walk all over you. If you do, they will. You just have to say, ‘No.’ Just say, ‘This is the way I’m going to do it.’ They’ll say, ‘Okay’ because they can’t do it otherwise.

I was surprised by Gabriela’s comment, which disregarded potential state intervention that other working class parents were so cognizant of (and which is discussed further below). Still, Gabriela admitted that she faces pushback from doctors over things like vaccines, which she believes require compromise. For example, when Gabriela refused the Gardasil\textsuperscript{16} vaccine for her children, she recounted the back and forth conversations with her doctor that resulted:

Every time I’ve gone in, there’s a little more pressure that’s put upon me and I felt that. The last time the doctor and I had a conversation, he was like, ‘You have to go to the American Academy of Pediatrics,’ to the two websites that he felt were the right ones to go to. I’m like, ‘Okay, I’ll do a little bit more research. But until I do all that research and I feel comfortable, I’m not giving Gardasil.’ So that was my compromise, I’ll do my research. But I’m not going to do more research because Gardasil, literally, from what I’ve heard, it only protects you from a couple of strains of the HPV virus and there’s thousands of strains of the HPV virus. What are the chances that my children are going to encounter those two

\textsuperscript{16}Gardasil is a vaccine intended to protect against several strains of the human papilloma virus (HPV), which can lead to cervical cancer. It is typically administered to both boys and girls around age eleven.
strains? And is it going to be worth it when it’s such a new vaccination? So with vaccinations, sometimes they’re actually putting the virus into your body, even dead, so that you can develop this immunity towards it. What if your body can’t handle that? What if it awakes in you and then you confront that?

In voicing her concerns about Gardasil, Gabriela touched on many of the most common concerns that parents have about vaccines, including the perception that the disease poses little threat to their children, distrust in newly developed vaccines, and worries that the vaccine will contain live virus and/or overwhelm the immune system (Reich 2016a). Unlike most Entitled Skeptics, however, Gabriela did not feel comfortable refusing the vaccine, which is not required for school, outright. Instead, she avoided the issue by promising to research it further, while maintaining that she has no intention of doing so.

Certainly, not all interactions with the medical establishment were bad. Consider Alexis, the 31-year-old stay-at-home mother of four. She felt that her doctor was supportive of her unmedicated birth plans:

I had all of my kids [at the hospital], completely natural with no medication. [My doctor] was supportive of that. We did agree that unless the child or myself was in danger, that he would let me do it naturally, so we were on a very good common ground on that. Luckily, everything just went smoothly… As far as epidurals, the risk of it just did not outweigh the risk of a natural birth. I mean, women have been doing it for years.
Alexis’s account echoes those of Believers who shared their doctor’s perspective. Without a difference of opinion there was no power struggle between doctor and patient, and the experience was a positive one.

For many Constrained Skeptics, their interactions with doctors – and the feasibility of using alternative medicine – were shaped by access to quality health insurance. Those who did have insurance expressed frustration that most alternative treatments were not covered, which pushed them away from CAM use. However, for those who didn’t have insurance, the alternatives were often less costly than paying for conventional medicine out of pocket.

Paula, a white stay-at-home mother of four in her early fifties quoted earlier, chose to have her first baby at a birth center not because she hoped to avoid conventional obstetrical birth, per se, but because it was cheaper:

I went [with the birth center] because I got pregnant at 18. I wasn’t married. I really had few alternatives. I didn’t qualify for any kind of Medicaid or anything like that, or at least I didn’t apply for it because I didn’t think I’d qualify for anything. So I sought out alternatives and it was $850 to have him, with all my prenatal visits and to have him was $850 cash, that’s it. I opted to do that. It was fine. It was a fine experience.

Even with insurance, Dawn, the white mother of two who works at a daycare center, described the challenge of seeking treatment while worrying about the cost of co-pays:
If you’re sick, of course, you got to go pay the copay. Physicals or the recommended checkups, that of course is another copay. With my company, if I have an urgent emergency, in order to be covered I would have to go to their facility, where the emergency room out here which is 20 minutes away. I’m not covered [at a closer hospital], so I would have to pay $100 copay, or go to the local Urgent Care, which is very unpleasant. Not trying to sound judgmental, but I mean, they treat you like most of their other patients that come there that are low-income. I’m not trying to sound mean, but it’s not that they’re low-income, it’s that there’s a lot of users in this area and they go there, and it’s been very uncomfortable to sit there with my child when somebody is loud and talking about how they’re coming down [from a high]. They need medicine. It’s a little uncomfortable. Everybody has their story, and I’m sure it hasn’t been an easy life… I don’t know.

Dawn’s experience exemplifies the situation many working class families find themselves in, trying to juggle the logistical and financial costs of seeking health care. I found that when conventional medical costs added up, alternative treatments that a participant was curious about could become more intriguing, and lead to further research on the benefits of refusing standard care.

Gabriela also reported challenges associated with co-pays and the quality of care, drawing on her deep religious faith to explain how her family has managed to get by:
We haven’t always had health insurance. When we don’t have health insurance, there’s a lot of prayer. There’s a lot of prayer that goes in. I just feel like the times that we haven’t had insurance, though, we’ve been under the grace of God that we haven’t gotten ill. You know what I mean? We’ve just been blessed during those times. [But] now we have insurance off my husband, [who works as a truck driver]. His insurance, when we go to the doctors, we have to pay $25 copay, so I feel like it’s a lot of money to just go and be told, go home and do a, b c, and we’re already doing a, b, c. So I’m really particular about going. I have to feel like there’s legit something that we need the doctor to help us with for us to go and spend that, but yeah, so I think it’s probably a lot more prayer that goes in when we don’t have health insurance.

Much like Dawn, Gabriela was cognizant of how her family’s class status impacted the quality of their care. She strategized to mitigate what she views as the adverse impact of being on Medicaid:

There was one time where we were in a place where we didn’t have insurance and we got Medicaid insurance. So when that happened, although we did have Medicaid, we had to switch PCPs,\(^1\) my kids, we had to switch pediatricians, which I wasn’t happy about, but I looked and I’m like okay, we’re going to find one that’s in a good area, that’s not hopefully not accepting a lot of Medicaid patients, so hopefully we don’t have a wait a long time, so we did have to switch.

\(^1\) Primary care providers
during those times. But when we came back to the insurance, like when my husband got the insurance, we switched back to the pediatrician, we switched right back.

For Madison, a twenty-six-year old white mother of two who is interviewing to do office administration for her midwife, the inadequacy of conventional care in her rural area strengthened her interest in having a home birth. She told me:

We’re insured. When I was pregnant with my youngest, I actually had to file for a network adequacy appeal. It’s this very irritating process where you have to essentially prove exceptional need for a practitioner to be considered an in-network provider. I was with a midwife, and as we’re doing our interview, I come to find out that she’s actually the only OB provider in my entire county. There’s gynecologists. There’s one doctor at my clinic that does IUDs. But she’s the only OB provider. They closed down the labor and delivery ward here at my hospital in 2008, so they had not delivered a baby in this town in ten years…It would be about a 33-mile drive. I’d have to cross state lines, and I would have to go through about an 1800-foot elevation change through an exceptional grade…It was interesting that [the insurance company] tried to fight that even though it fit the bill. I was going to go with [the midwife] anyway, but it’s not like I had much other option. [I wanted] to have a choice in my birthing process. I don’t want to have to drive a half hour, 45 minutes while I’m in labor. When I was speaking to 90 percent men, in the medical field…[sighs, trails off]. I got approved.
For this young mother, the inadequacy of conventional medical coverage coupled with the insurance company’s early refusal to cover her midwifery care, strengthened Madison’s interest in alternative medicine. Noting that the medical field was dominated by men, she felt that conventional providers were insensitive to her needs as a pregnant woman. Certainly, her situation might have been no different as an Entitled Skeptic – after all, the key to her battle with the insurance company was that she lives in a remote rural area without many doctors. Nonetheless, it remains important that health insurance, and the challenges it could present for working class families, were uniquely instrumental in promoting participants’ interest in alternative medicine over conventional.

**Community Ties and Medical Decision-Making**

When it came to learning about and supporting alternative medical decisions, Constrained Skeptics reported a much smaller network of likeminded friends than did Entitled Skeptics. They were less likely to live near businesses catering to CAM users, and were more likely to have learned about alternative medicine from one family member or friend, rather than the broader network that Entitled Skeptics frequently mentioned.

Gabriela, for example, reported that she knew about home births, midwives and doulas through internet searches and television. Though she was ultimately decided against a homebirth, she overcame financial obstacles to find a doula because of the information she uncovered:

I’ve always been a Googler, so I found out about midwives and stuff like that… I
watch [home births] on TLC shows – I love watching those shows. I think a lot of that I saw there, just doing research. So what I did was I found out is that doulas, when they’re in training, will actually help for free, because they have certain like requirements that they have to meet to be certified, so I just went on Craigslist and looked for a doula-in-training and I found one. She was so good. She knew how to deal with the hospital staff versus my husband and my mom, who were more quiet. She’s like, ‘No, we’re going to get her some ice chips. We’re going to get this and get that. Just different things that she knew to do, and somehow pulled them in and got them involved. I really enjoyed having her there.

Part of what Gabriela alludes to here is the kind of middle class entitlement that her doula was able to bring to her birth, particularly when her mother and husband did not know how to help. As noted before, Gabriela’s borderline class status may have made her better able to seek out and harness those resources.

However, Gabriela’s sense that she was somewhat alone in the process of finding and learning about CAM was echoed by others. Alexis, 31, took a light-hearted tone as she described how her friends and family view her:

People joke and call me the witch doctor, so yeah, I’m kind of a lone soldier around here [with alternative medicine], but I use a lot of social media to connect to others like me. I enjoy it. I like putting in my knowledge and I like being able to ask for other people’s knowledge.
Most respondents, however, originally learned about CAM through their in-person contacts. Paula passionately recounted the positive impact that alternative medicine had had on one of her close friends:

I had a friend who had an accident while she was on a vacation over in New Zealand and after five surgeries still had probably 98 percent paralysis from her right elbow all the way down to her hand. It was like that ten or twelve years, and 5 surgeries later, she still had paralysis. The doctor told her he couldn’t do anymore surgeries, there was nothing they could do, the nerve damage was extensive and it was permanent, blah, blah, blah. Using the essential oils, by topical application, ingestion and meditation revived her arm and hand entirely. Needless to say, that was all the proof I needed that that stuff worked. I have since used it on myself, my kids, friends, strangers. I’ve seen it reverse COPD. I’ve seen it reverse cardiovascular disease. Using oils, people have regained their health.

Paula’s claims were among the most incredible I heard, but their veracity is less important than the fact that they convinced Paula to seek out alternative medicine herself. Such an impressive account of healing from a known friend validated Paula’s interest in pursuing CAM treatments for herself and her four children.

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18 COPD stands for Chronic Obstructive Pulmonary Disease, an umbrella term for a range of progressive illnesses that affect the lungs.
Tammy, in her late forties with three children, described how she came to learn about CAM when seeking help for her young daughter:

My daughter kept getting urinary tract infections when she was about 2. I said, Ooh, my goodness, this is the third time she’s been on antibiotics. This is crazy. There has to be another way.’ My pastor and his wife, they didn’t have health insurance, and they said, ‘Well, we’ve got this chiropractor that really does some different things. You really should go check with him and see what you think.’ It was a little expensive, but I thought, you never know. The first thing I learned was that carrot juice is an antibacterial in the urinary tract or in your bladder; when you store your urine in your bladder, a lot of times that bacteria will grow, and carrot juice will actually really, really help it. So basically that was my first step with this alternative-medicine type kind of thing…I was actually seeing a naturopath who was a chiropractor. Anyway, he was my start with that. Then I found homeopathy through him.

Tammy described a kind of stepping stone approach to learning about alternative medicine, going from one contact to another. It’s notable, in the context of the discussion about health insurance above, that the pastor and his wife were seeing a chiropractor as part of their attempt to manage health without insurance, something that appealed to Tammy as an uninsured adult.

Tammy went on to recount a mysterious inflammatory illness that she began experiencing in her mid-thirties, which at times confined her to a motorized wheelchair.
I was really losing my mobility. I’d have flareups. I’d call them arthritis flareups, like I couldn’t even lift my arm correctly, because I just had all this inflammation in that particular joint. Then two or three days later, it would be in my hips or it’d be in my knees. My family thought I was losing it, like it was all in my head, but it was very, very painful... My naturopath basically said with our society people overdo gluten, sugar, and dairy; 90 percent of people are somewhat sensitive to that. He goes, ‘I won’t even do any tests especially since you don’t have health insurance to cover it.’ He said, ‘Let’s just do an elimination diet.’ So basically, I went on this very bland diet for several weeks...It was really hard to follow it. Nobody I knew ever knew what it was like not to be on sugar, except for my pastor’s wife, but I noticed such great health benefits from that. I lost a bunch of weight. I had better energy. I didn’t have this mysterious arthritis that I was having.

In fact, a lot of working class respondents overall noted poor diet as a contributor to health problems, but, like Tammy, were also more likely than middle class respondents to characterize diet changes as challenging. For some, it was the lack of social support, as their friends and family were unlikely to be making similar dietary changes (but which would be at least familiar to most middle class families). Tammy also attributed what she perceives as broader cultural disinterest in good nutrition to financial conflicts of interest:

Doctors still don’t do a whole lot of nutritional type [education]. In fact, I
listened to an article the other day that said doctors are only required to get seven hours every two years of nutritional information training. I’m just like, ‘You’ve got to be kidding me.’ So, you got somebody depressed and all they want to do is give them antidepressants instead of saying, ‘Why is this person really depressed?’ Okay, well, they’re 400 pounds overweight. Well, how can we help them lose weight? Well, they don’t have any motivation to lose weight. So we just give them a pill…Something needs to be changed here. But see, Big Pharma’s got their hand in the kitty so much that if they can’t make money helping you lose weight then why would they help you lose weight? They’re not going to say, ‘hey, drink more water. Stay away from the sugar and get some exercise.’ That doesn’t make anybody any money…They give you a pill pretty much every time you go in [to the doctor] for this, that, and the other thing; it’s just crazy. There are people who like to go to the doctor just because they trust them, and they think, ‘well, my doctor will know what to do.’ Well, unfortunately, they don’t know about everything.

Tammy echoed the sentiments of Gabriela and others that if doctors “don’t know about everything” there must be room for her own knowledge and alternatives.

Paula was similarly incensed at what she perceived as the lack of training for physicians. After a naturopath diagnosed her daughter with a vitamin deficiency that was contributing to seizures – a deficiency that the conventional doctor did not recognize as legitimate – Paula turned away from conventional medicine completely:
What [was shocking] for me was how little doctors actually know. Then I researched what they’re taught in school, and they’re not given nutritional medicine. They don’t know anything about it basically other than eat well. What does that mean? According to them, it’s ‘Eat according to the food pyramid,’ which isn’t always correct, and it’s not always correct for all people. It doesn’t take me long to put the puzzle pieces together, either, once I’ve got the pieces that I need. I’m done with all of this. We don’t go to doctors.

For others, regardless of whether or not they agreed with conventional dietary guidelines, changing the family’s diet was largely a financial concern. Dawn, the 38-year-old mother of two who works at a daycare center, told me that she felt the kids in her care were sick too often and remained unhealthy using conventional medical care:

I’d been a daycare teacher for the past 14 years, so working in that environment and seeing the children on that base eating the USDA plan what like the average American eats, and they’re all vaccinated, and their parents rely heavily on Tylenol. I’m really trying hard to turn away from that.

Still, as she contemplates making different dietary choices for herself and her children, she acknowledges that it can feel prohibitively expensive:

I grew up with very processed food, taking meds from the doctors. I’d say probably about eight years ago, right before I had my daughter, I started getting
really sick with a lot of food, I noticed, and it was probably stress, too. One of my good friends, she was vegetarian and started kind of introducing me to more like holistic things and documentaries, so it kind of sparked my interest in changing my diet and things like that. [But] the fact is that I’m a single mother, and I have my children that I’m trying to take care of. I get paid fairly well, above minimum wage – like greatly above minimum wage – but I would like to try to figure out how I could maybe go into a business aspect of [nutrition] or even just down to cooking. I greatly cut out a lot of processed things already… and that kind of set off a [mindset of] ‘buy nothing but organic’ for a huge amount of time, but I’ve had to balance it with some things. I’m learning, okay, maybe this isn’t as bad as that one, especially as long as it’s not genetically modified.

Dawn exemplified the tension that working class women felt when trying to make health choices outside of the mainstream. She remains stuck between relevant social circles: On the one hand, many of the people in her community that use alternative medicine are middle class, and she doesn’t feel a connection with them. On the other hand, her friends tease her for using alternative medicine. As Dawn told me:

They have some alternative medicine practitioners, like acupuncturists, out here. I just feel a little bit unsure. I live near Joshua Tree, so it’s very holistic. It’s just, there’s also that side of it that’s the snooty, artsy side. So it’s kind of hard. I want to embrace that lifestyle, but I don’t know why I’m not cool enough—I’m just a mom. But everything else is kind of far, so you got to tack on gas and the price of
it, and insurance doesn’t help cover any of those costs, so it makes it really hard.
I definitely would love to find somebody [that does alternative medicine] though.

Dawn noted that alternative practitioners were not only cost prohibitive, but connoted an elitist, “snooty” culture in which she didn’t feel at home. At the same time, she faced the double-bind of feeling alienated from her working class friends and colleagues. Though Dawn reported turning to the staff of a health food store for advice, she said that because the store isn’t in her town it’s “usually just me researching stuff,” or posting questions in Facebook groups devoted to alternative medicine. Among her in-person community, Dawn felt that her health viewpoint was not appreciated:

I’m definitely the kooky one when it comes to my friends. People like to make jokes…Sometimes it hurts my feelings a little bit…because sometimes it was some of my friends and I felt like, I’m not trying to force my lifestyle on you, but when I say no to something and you are peer-pressuring me in front of other people and putting me down, it makes me feel like you’re a toxic person. I don’t know if they were thinking I was trying to be thin. I just wonder what they think my ulterior motive was, so it made me think, ‘What should I say different or do different?’ [sic] So now… I just say, ‘Oh, no thanks, I’m good.’…I just try to make a joke out of it. I have to admit, it does kind of hurt your feelings when people are very, very closeminded.

Contrast Dawn’s experience with the networks that middle class moms described, in
which their health choices were more broadly supported. Mariah, for example, the art teacher and black mother of two, described knowing a large community of families making similar medical decisions. She met them through a yoga studio, a local children’s center, her partner’s shiatsu training program, her children’s private school, and at the local co-op grocery store. In short, she was immersed in an environment that facilitated these connections and made her feel exceedingly normal. Dawn, who has made far fewer radical changes to her own or her children’s healthcare, felt judged and isolated for her choices.

Many working class skeptics reported doing research on their own and facing criticism from friends or family. Alexis, 31, reported that her family is sceptical of her health choices:

They kind of roll their eyes at me or think I’m weird sometimes, and what I tell them is, ‘Well, if it doesn’t work, I wouldn’t suggest it.’ The only things I do suggest are the things that I do know that have worked for us. [And] when I do suggest something, it’s for them to do their own research, even if it’s only Googling it, so that it backs up my word.

Similarly, Nancy, 54, and mother of four, said that though she feels her friends “generally get it” now, it has been a long process to explain to them why she is interested in alternative medicine. She described learning about naturopathy from a friend, whose “no-nonsense” attitude and strong Christian faith assuaged Nancy’s fears that alternative medicine could be too “weird:”
A friend of mine was going to the naturopath with her daughter. I had never heard of anything like that. The friend is a no-nonsense person and she’s very cautious about anything weird, so when she started going, I said, ‘Okay, well, this lady must be okay.’ Then I started reading about it myself. Once I went, the lady has become a very good friend of mine now. She’s a very strong, Christian lady. Her passion is to make people well with natural remedies, with common sense.

Now, Nancy says that she continues to share an interest in naturopathy with her likeminded friend, but that they do face questions and criticism from others who do not understand their interest in alternative medicine.

[My other friends] were like me; they’re very unfamiliar with natural remedies or anything like that, because of what is put out there through the media, or doctors, even. At first, when I recommend this naturopath to people…they’ll look at [my friend and I] like we’re into witch craft or something. We just quit. We don’t even tell them anymore. I understand where they’re coming from, but I do kind of have to explain what happened, kind of our testimony of what we did and how it succeeded and how much it helped us, and explain what she does and the difference.

Nancy was one of several working class skeptics who noted the importance of their religious communities in introducing and legitimizing the use of alternative medicine. As
I discuss in the next chapter, religion can sometimes provide the meaning behind refusing conventional medicine. In most cases, however, the communities built on faith simply provided support for a narrative of living “outside the mainstream” that contributed to using alternative medicine. For example, Nancy later explained to me that her role as a Christian homeschooler prepared her for being viewed as a little “out there:”

I got pushback [for using alternative medicine] at first, but I was used to it, because I did homeschooling. My husband’s family weren’t [into it], and still really aren’t. None of my children had major issues, so they kind of shut up, but from homeschooling to the choices we made there, and doing natural stuff, they weren’t real keen on it.

When I asked about the role of other homeschooling parents in health decisions, Nancy was clear:

Most of the information I got was from other homeschool moms. That was both for homeschool material and health material. We were very driven… and very concerned with the education of our children and our health, so we all did our work, did our homework, and helped [one another].

Religious communities occasionally provided the alternative healing itself. Though middle class mothers sometimes talked about praying for good health, they were clear that they did not see prayer as a genuine response to illness, at least not as a separate
Several working class mothers, by comparison, talked about prayer as a direct intervention. Gabriela recalled an especially vivid experience of divine healing:

I would have this back pain. It was difficult for me to walk or sit in the car. At church, I was just like, ‘Yeah, I’m having this back pain. It’s been getting on my nerves.’ It wasn’t a pastor, it was just somebody else that came up and put hands on me and prayed for me. I remember feeling like heat—I could feel heat coming out of her hands. I was like, ‘Wow, this is so cool.’ After she stopped praying for me, I still felt that heat on there. It was like a different kind of heat. It was like relaxed and my back was fine. I’ll never forget that. I’m like the pain is gone. I haven’t had any more issues.

Gabriela also described how her family uses prayer as a first line of intervention against illness:

Typically, in our home, we do prayer for anything. So if you have a headache, you feel like you have a stomach ache, we’re going to pray first before anything else…If they feel better, then we just leave it alone. If they don’t feel better, then

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19 One exception was Cheyenne, the stay at home mother of three who became an evangelical Christian in adulthood. She described experiencing divine healing and viewing God as deeply connected to her medical decisions. Notably, Cheyenne’s class background is the mirror image of Gabriela’s: Though Cheyenne graduated from a four-year college, her husband and parents did not. Her husband works in construction and house painting, but the work is intermittent, and they struggle with money. Like Gabriela, Cheyenne’s faith played a role in mitigating the anxiety that she felt about the family’s lack of health insurance, and helped her feel supported in making alternative medical decisions.
at that point, what are we going to do? Now, since I’ve been getting into the oils, our next step is oils.

Recall that Tammy, 47-year-old mother of four, described how the wife of her pastor put her in touch with her chiropractor, and her attributed her growing interest in alternative medicine to the pastor’s wife:

My pastor’s wife, she got me really started down this direction [with alternative medicine], and then that chiropractor that I’ve been seeing [too]. Unfortunately, about five years ago he moved on, so I’m kind of on my own now. But there’s a gentleman on the internet, on YouTube, and his name is Dr. John Bergman, and he really pushes the chiropractor direction. If your body is in alignment, it can function a whole lot better.

Note that Constrained Skeptics, particularly those outside of cities, were less likely to have more than one option for alternative medical care. In the absence of practitioners, these women often reported seeking out information online. Certainly, searching the internet for health information was something that parents from all classes did, but for working class skeptics, Google was often the only or best source of information, as they had few opportunities to check their findings against a practitioner. Instead, most reported that they tried to gauge the legitimacy of that information by comparing sites to see if they said the same thing. Alexis told me that, “Most of [the information online] is fairly reputable. I mean, most of the time all the natural sites are on the same page, all on board.
They say the same things. The same benefits of whatever herb there is. I’ll Google that.”

However, Madison, the stay-at-home mother of two in her mid-twenties, acknowledged the shortcomings of online research. When asked about where she finds health information, she replied:

My mother-in-law, Angela, she has been a great resource, as well as her various literature. My grandma, my maternal mother, she is into a lot of the more naturalistic medicine and has been very encouraging of that. Some Facebook groups, surprisingly a couple mom groups. The internet is always an interesting supplement of resources and connections. It sort of feels for the most part the middle road doesn’t get announced as much. They’re not quite as vocal as they outliers. It can be difficult to find someone I can share several similar points with. Moms at home birth, there tends to be very self-fulfilling sort of stereotype, anti-vaxxers, mixed into the quote, unquote ‘natural’ moms, and then spaced vaxxers. Finding someone that has a little bit of everything [is hard].

To combat the challenges of the internet, some participants turned to trusted key sources. Nancy agreed that she had a few regular sources of information, but noted that one of the most important, interestingly, was her daughter who worked as a paramedic:

The bio-kinesiologist that I used, she’s a naturopath, she’s the one that I go to for the most part to find out anything like that. So she’s my primary [source of information]. For the most part, it’s the naturopath or the internet is usually where
I get my information. Now that my daughter is a paramedic, she and I will do research; she’ll look stuff up on the internet, or I will.

In line with supporting her daughter’s work as a paramedic, Nancy was clear that conventional medicine has its place. She succinctly described her approach to using conventional medicine as a complement to alternative, noting that “serious” illnesses require visits to a doctor:

If you need a doctor, you go to the doctor if it gets that bad. We just experienced [that] here, because my second daughter, we had some kind of weird viral thing come through, and we haven’t been sick like that in years. It knocked us pretty bad. She started on a program with the natural stuff, but that evening, she started breathing really funny, so we went to the ER. Probably could have waited, but she was just so exhausted. In order to do the natural stuff, your body needs to be rested somewhat, and not as drained as we were. I knew she needed an antibiotic, a pretty strong one to get her back on her feet, so you go when you have to, but doctors are a last resort for us. We try to be careful what kind of doctor we get, because there’s just some that are not as conservative as others. The doctor she got at the ER was very conservative, and didn’t put her on an unnecessary treatment; he put her on just what she needed, and that to me is what we’re after.

Tonya, a black mother of three and office administrator in her mid-forties, told me about a friend who has served as her key resource for alternative health information:
I met [this friend] at baseball with our sons, so we’re just sitting there and we connected. We just started talking about natural healings and herbal stuff. Then she said, ‘I can send you some stuff.’ I said, ‘Okay.’ So we exchanged numbers. She had to ask me if I was comfortable to talk about women things. I said, ‘Oh, that’s fine.’ Before it was all, like, colds, just other types of sicknesses…certain herbs and stuff like that, but just never on that level, women’s private things. She just texted me last night a whole long article on cleansing—how can I say this without being graphic—women cleansing yourselves or personal area, so she sent me an article on that, and a chair that you sit down, and it’ll cleanse you. You put the herbal stuff in steam, so whatever’s in that stuff is going to steam up and then it’s going to purify your insides.

Though Tonya described her friend as a wealth of information, she was only one person, and also a person with whom barriers of politeness and reservation were just beginning to come down. Such a relationship is unlikely to provide the kind of support that mothers like Mariah describe as coming from all directions. Tonya uses herbal remedies almost exclusively for herself, but she was clear that she’s never actually refused something for herself or her children, and was unclear whether she ever would.

For Tonya, refusing conventional medicine felt too risky. For others, however, partial refusals – particularly of things like vaccines – allowed parents to manage perceived health risks while choosing alternative medicine. Madison, a white 26-year-old mother of two, echoed the middle class mothers of Jennifer Reich’s 2016 study in making
vaccination decisions on the basis of perceived risk:

Pretty much the big [vaccines] we stuck with are if it could kill you. If the disease it’s vaccinating again could kill you. We never did anything with the flu vaccine. We weren’t interested in the chicken pox vaccine, things like that, but [we did] polio, DTaP, diphtheria, pertussis, tetanus. [We refused the rotavirus vaccine] mostly upon researching it and deciding it wasn’t necessarily appropriate for our situation. We live in an industrial, first-world nation, with clean running water and access to quality medical care. The likelihood of her getting dehydrated to that point, needing hospitalization was so incredibly small, and even then, IV fluids, a course of treatment, is very easily accessible. It didn’t feel necessary. It felt like it was more pressure on her and her little body and immune system than it would be to [watch her]. Because I’m very judgmental right now; I’m just an observant parent and making sure my child’s not getting that dehydrated. As a stay-at-home mom, there really wouldn’t be any excuse not to catch the signs.

Tammy noted a similar perspective when discussing her choice to see a midwife at her local hospital to give birth. She explained her interest in pursuing the natural route in medical setting as a way to manage risk:

I went through this midwife, [who] was supervised through a hospital, so she did everything naturally. However, when there was a problem, we were at the hospital, and so I felt fully comfortable that a doctor could walk in in ten minutes
and fix everything if I really needed it. It wasn’t like I had a home labor and all that. Well, so while I was in labor, they found I had a staph infection in that area down below. I wish I would have asked more questions about it, because now I understand what staph is and that sort of thing. [But] we really didn’t have any other alternative except I had to go on an IV for antibiotics or otherwise they said it’s very, very dangerous to have a staph infection and have natural childbirth, so I went with what my midwife said.

Despite Tammy’s concerns about conventional medicine, she trusted the doctor to be able to “fix everything in ten minutes” if needed. Interestingly, however, Tammy then opted out of the interventions for her baby after birth, including vaccinations, noting, as Reich (2016a) finds among middle class anti-vaccination advocates, that the risks did not feel applicable in her life situation:

Now, [the baby] did not get the Vitamin K and she didn’t get the ointment in their eyes. The reason we put that ointment in their eyes is because they’re worried about a sexually transmitted disease when they pass through your birth canal.

Well, I had been married to my husband for almost 20 years. I had not shown any, and granted, I could have been harboring an HIV virus or whatever, but it’s like, we still do all these things from 50 and 100 years ago that are probably outdated. Does my baby need to be injected with Hepatitis B immunization when they don’t have contact to body fluids or bloods? I believe the thinking behind that is, you’ve got the kid in there for immunizations anyway, let’s just do them all. I
understand that makes sense, but I’m not sure it makes sense for an 8-pound baby to have 6 or 8 immunizations within 2 days of being born. That’s where I came up with that, yeah, I’m done with immunizations.

Ultimately, Tammy’s decision about vaccines led her to keep her children away from the doctor, feeling that doctors’ visits were only an excuse to push vaccination:

I never did [take my kids to the pediatrician]. The first one, I think I took him up until he was about five years old, and then that was it. I was just like, this is ridiculous, all they’re going to do is nag me about why aren’t I immunizing. Or the big thing, too, they want to look at their height and weight, and it was like, ‘I’m feeding my children, they all look healthy.’

Though Tammy eventually decided to partially vaccinate her children on a delayed schedule, she continued to believe that medicine should be used only when absolutely needed, meaning what she determined to be an emergency. Though she was clearly willing to take the doctor’s recommendations for things like antibiotics (at least when her midwife was in agreement), she continued to make each choice on an individual basis of perceived cost/benefit.

**Conclusion**

Constrained Skeptics shared many of the same medical experiences as Entitled Skeptics, from negative interactions with healthcare providers to a growing interest in the
possibilities presented by alternative medicine. Where they differed, however, was in the strength and nature of their communities. While middle class skeptics usually had a range of friends, family, and practitioners who used alternative medicine, Constrained Skeptics were much more likely to have only a few like-minded friends or an online-only support group. These limitations meant that Constrained Skeptics felt hindered in their ability to make alternative medical choices, and socially isolated from assigning a collective meaning to those choices. With less social support for their medical decisions, working class families hoping to refuse conventional medicine had to do more legwork for the education and resources they wanted, without the validation of a likeminded community.
CHAPTER 5: THE CASE OF FULL TRUTH

Introduction

It’s not impossible for working class families to refuse conventional medicine in favor of alternative medicine, particularly for white working class families. But it is harder than it is for middle class families. It’s harder because these Constrained Skeptics feel that they are operating as “lone soldiers” when it comes to finding information on alternative medicine and making the decision to refuse a conventional treatment. Though most Constrained Skeptics know one or two other people who are making similar choices, they lack the broader social support networks that Entitled Skeptics enjoy. Refusing conventional medicine for alternative medicine is also harder because working class parents (regardless of their medical decisions) face institutional barriers and the threat of state intervention in a way that middle class parents do not. Middle class parents bring an entitlement to their interactions with school and medical professionals that most working class parents cannot match. Even when working class parents voice similar reasoning and entitlement to their choices, they note awareness of agencies like Child Protective Services (discussed in chapter 7), which not a single middle class parent did. Working class families’ weaker social support for alternative medical choices coupled with stronger institutional barriers to such choices mean that they face more constraints in making the same decisions as middle class families.

But: As I said, it’s not impossible for working class families to choose alternative medicine over conventional. In this chapter, I discuss the case of Full Truth Calvary
Church, a non-denominational fundamentalist Christian congregation whose members refuse all conventional medicine in favor of prayers for healing.\textsuperscript{20} As an overwhelmingly white, working class community, members of Full Truth show how families with fewer material and educational resources can draw on social and institutional resources to reject medical norms. Indeed, I show that Full Truth members are able to refuse conventional medicine in favor of prayer because their church community offers the support and meaning necessary to make these choices as working class families. The depth of this meaning and the strength of the social support give members what they need to refuse conventional medicine in a way that most working class families are unable to do.

The Setting: A Short Overview of Full Truth Calvary Church

As I will show, Full Truth Calvary Church is an unusual community. It is a prime example of how the extreme case can reveal social mechanisms at work in more moderate cases (Katz 2012). In this case, the exceptional beliefs and social support that Full Truth members use to support their refusal of conventional medicine show the factors more subtly at work for other working class families. However, as an outlier in many ways, it is important to outline the context of this community so that the reader understands how and why it relates to other groups choosing alternative medicine over

\textsuperscript{20} Note that prayer falls under all commonly used definitions of CAM. Typically understood as part of “divine healing,” prayer and other divine healing methods like “the laying on of hands” (in which a spiritual leader touches the ill person and asks God to operate through him or her) are a type of health intervention. For those unfamiliar with strong religious faith, it may seem that those who pray for healing are simply refusing conventional medicine without using a true alternative treatment in the way of someone who, for example, mixes herbal remedies or goes to an acupuncturist. It is important to understand, however, that for those who use divine healing, prayers for healing are very much an active intervention that penitents are making to get well. It is not enough to simply abstain from conventional medicine; the key is to pray to God for healing, and in doing so to repent for sins and reaffirm tenets of their faith.
conventional.

Full Truth Calvary Church was founded in the early 1920s by a man named Julius Burke (a pseudonym). Mr. Burke started the church as a separatist faction of another nondenominational Christian church called First Christ Chapel (also a pseudonym) after being ousted from the leadership over doctrinal differences concerning salvation. About a third of the congregation followed Burke to the new church.

From the start, Full Truth was a strong fundamentalist Christian church, part of a conservative Christian movement in the 1920s that grew in opposition to the emerging scientific worldview of mainstream America. By framing modern society as morally relativistic, church leaders stressed the importance of a literal, unchanging interpretation of biblical morality to which all members should ascribe. As part of this interpretation, Pastor Julius Burke emphasized that members must avoid what members call “human means” for getting life’s necessities, meaning anything that is accomplished by an individual’s own agency rather than that of God. In practice, avoiding human means meant that members were instructed to trust God for health, employment, and other basic needs. Thus, instead of seeking care from a doctor or actively inquiring about jobs, members learned to pray for healing when they became ill and to pray that others would offer them a job (or inquire as to whether they were in need of a job) when they were out of work.

Today, leaders at Full Truth Calvary Church maintain the emphasis on rejecting human means. Melvin Burke, a grandson to Julius, is the current pastor, having inherited
the position from a succession of his uncles in the early 1990s. He continues to urge the community’s 500 working class and overwhelmingly white members to reject all forms of modern medicine. Treatments considered off-limits are quite wide-ranging, including painkillers, surgery, antibiotics, and dental care,\(^{21}\) as well as safety precautions like seatbelts or prescription eyeglasses. Sitting in church, one sees evidence of these prohibitions in the form of growths that protrude from faces, legs, or abdomens, in missing teeth, and in the hymnals held up to compensate for poor eyesight. Members also reject contraception, leading to large families of commonly six to twelve children.

Members spend a significant amount of time in church; because the vast majority of members attend all of the three weekly services, they hear institutional messages, including those about divine healing, for at least four hours a week. When combined with time for private prayers and Bible reading in the morning and evening, as encouraged by church leaders, it is not uncommon for members to spend 15–20 hours per week in religious activities. Combined with time spent in the church-run school (which nearly all children of church members attend) and in work at businesses run by church members, the Full Truth community is both close and closed. Perhaps because of this closeness, the community does not perform its beliefs in ways that outsiders might expect. For example, members pray for healing alone rather than publicly in worship services. The tone of those services remains quiet, respectful and even somewhat sleepy.\(^{22}\)

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\(^{21}\) Interviews with former members revealed that some members quietly sought dental care as a matter of hygiene rather than medical care. However, most members considered dentistry off-limits.

\(^{22}\) Most groups that engage in divine healing use charismatic worship practices such as shouting during the sermon, speaking in tongues, or writhing on the ground. Full Truth members are unusual in that they do
experience of others’ healing is when the assistant pastor reads testimonies of recovery
that have been submitted anonymously through an online form.

Still, Full Truth members are not fully separate from the world outside. Despite
refusing modern medicine, members have otherwise kept pace with current American
life, using smart phones, dressing in typical clothing, and working at jobs in retail, food
service, and manufacturing. Members earn their drivers’ licenses as teenagers, eventually
commandeering large vans to accommodate their growing families.  

Members live in small but tidy family homes in a working class neighborhood, remaining close to other
church families but by no means separate from their non-church neighbors. Though
members don’t typically have friends outside of Full Truth, they report being comfortable
with outsiders, and frequently interact with them in work settings or while out doing
errands. Almost all members are born into the congregation; the few who have joined as
adults are former members of First Christ Chapel, Full Truth’s sister church, which
maintains the same beliefs on divine healing.

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23 Because of the prohibition on corrective lenses, members with severe vision problems are unable to
obtain a driver’s license. In such cases, members arrange rides with other family members. However,
members with only minorly impaired vision may take the written component of the driving test (which
includes an eye exam) multiple times until they pass. Members typically submit an anonymous testimony
praising God when they pass the driving test, which the assistant pastor reads during Wednesday evening
services. In such testimonies, members describe their success in the vision exam as due to God’s
intervention to heal their eyes. They typically do not comment on the current state of their vision, though
they may acknowledge that they are continuing to pray for the “full healing” of their eyesight.

24 For more information about Full Truth Calvary Church, and findings from data collected earlier in this
study, see Glassman (2018a) and Glassman (2018b).
The Study at Full Truth Calvary Church

My findings from Full Truth draw on an independent data collection, which differs from the interviews and observations described in the past three chapters. Findings in this chapter come from observations conducted between March 2014 and March 2017 at Full Truth Calvary Church, and supplemented with member interviews and church publications.

For three years I attended an average of two of the church’s three weekly services. Each service lasted about an hour and fifteen minutes, and followed a set pattern of prayers, hymns, member-submitted notes of praise read by the assistant pastor, and a sermon message delivered by the head pastor. Including informal social time before and after services, each observation session lasted about two hours in total. In addition to church services, I observed church social events to which members invited me, such as picnics, bridal showers, and women’s game nights, and spent time in members’ homes and at outings for activities like miniature golf. For all observations, I recorded audio-notes on the way home from the event, and wrote detailed notes from my recordings. I coded those notes using Atlas TI software, paying special attention to how and when members and church leaders discussed healing, the meanings that they attached to healing, and any specific practices that I witnessed, such as private prayers for improved health.

The second component of my data collection was a review of church literature in the form of pamphlets, which were written and printed by the pastor and assistant pastor twice a month. Many were almost direct transcriptions of recent sermons. I collected
pamphlets from display sets at the church and received new tracts in the mail. I also received older pamphlets from a member who had saved them from the mid 1990s through the present. Altogether I reviewed and coded approximately 70 pamphlets, paying particular attention to how they described health and illness, and the relationship between healing practices and religious faith.

The third and final component of my research method was interviews, both formal and informal, with adult church members and former church members. I recruited respondents for formal interviews by explaining that I was interested in learning about how they “figure out God’s direction for them,” and emphasizing that I was interested in their personal experience. Despite quite positive relationships with church members, I found that many were hesitant to sit down for a formal interview, even when assured that responses were confidential and that there were no “right answers.” Due to the insular nature of church life, I found that members were not accustomed to discussing their faith – among insiders, faith is an assumed commonality, while with outsiders, members are not encouraged to proselytize. Ultimately only one third of current church members whom I asked agreed to speak formally, for a total of eleven interviews with ten church members. Former members were challenging to locate, as current members did not always have or wish to share current contact information of those who had left. However, once located, former members were much more willing to speak with me, and I ultimately conducted interviews with eight out of ten people I contacted.

Among church members, I conducted formal interviews with seven women and three men. The women ranged in age from nineteen to sixty and were all white. Three
were married and four were unmarried. The men were between the ages of forty and sixty-eight; two were white and one was black. Two of the male respondents were married and one was widowed. Six out of the ten respondents had children. Each interview lasted between ninety minutes and three hours and all but one were audio recorded with the respondent’s consent. One respondent did not wish to be recorded, so I wrote notes during our interview and wrote a lengthy summary of the interview immediately afterwards. Among former church members, I conducted formal interviews with five women and three men. Four out of five women were married; all were white and ranged in age from thirty-seven to sixty-six. All three of the men were married; two were white and one was black, and they ranged in age from forty-one to fifty-nine.

In addition to the eighteen formal interviews, I conducted thirty-three informal interviews during social time spent with church members. Over the course of my time at Full Truth, I got to know about thirty people in seven families quite well, and spent significant time with them outside of church. Time spent with these families included organized group activities such as bridal showers, “girls’ nights” (similar to a bachelorette party), church women’s nights (social events meant to help women meet others from church they might not know well), and semi-annual church picnics, as well as more intimate social activities such as carol singing, pie baking, miniature golf outings, theater outings, dinners at home or at restaurants, and funerals. I was invited to participate in all of these activities, and felt welcome at all events. All church members are familiar with who I am and that I am conducting a study about religion and family life.
Of these informal interviews, seven occurred with men and twenty-six occurred with women. Male respondents ranged in age from their early twenties through late fifties, while female respondents ranged from their early twenties through mid-eighties. In informal situations, I felt that it was inappropriate to talk to men for long periods of time unless it was in the context of a conversation that included their girlfriends or wives, as most social events were either sex-segregated or were intended for couples and families.

All formal interviews were audio recorded and transcribed, while all informal interviews were recorded in field notes following the conversation. I coded all interview data using AtlastTI software. In coding, I paid particular attention to members’ overall beliefs, their practices around healthcare, and specific anecdotes regarding health problems.

**The Meaning of Health Choices at Full Truth**

Full Truth members make health choices as part of their religious faith, which dictates that refusing modern medicine demonstrates trust in God to heal. In other words, health decisions have a specific, institutionally shaped meaning that is integral to members’ identity as good Christians. Much as Entitled and Constrained Skeptics’ community ties shape the interpretation of their health choices as moving away from a disrespectful and unnatural system towards a more holistic alternative, Full Truth members live in a community that interprets their health choices through the lens of
religious meaning and identity. This interpretation creates a strong incentive for members to refuse conventional medicine in favor of prayer.

To understand the significance of health decisions at Full Truth, I do not begin with childhood experiences, as I have in previous chapters, because these participants weren’t starting from a different orientation towards (the way that Entitled Skeptics or Constrained Skeptics were). I’m not charting a transformation, but rather the meanings that church members give to health decisions from birth. Instead, it’s important to show what medical decisions mean in the context of this group, because that meaning is important for both why they make the decisions they do and for how they ultimately generate the necessary social support to do so.

Full Truth members say that their key goal in life is to follow God’s will. Field notes from one Wednesday evening sermon illustrate the message that members hear nearly every service, complete with vivid descriptions of the consequences for those who fail to heed his message:

Pastor Burke leans forward again, and declares that, “God has provided a message of how we're supposed to live through His son, Jesus Christ.” Squinting his eyes and furrowing his brow, hands on the lectern, he says that “the world wants you to be proud of your accomplishments; God wants you to be humble… The worldly way is to focus on the self—exclusively!”—here he raises his eyebrows and lifts his right fist in a motion of emphasis—“while the Godly way is to focus on others
and on the Lord Jesus… Look around, it’s worse now than it’s ever been—almost every city in the country is a Sodom and Gomorrah!” He continues with a tone of resignation, “We know that God has wiped out the unrighteous before, as He did through the great flood, and Sodom and Gomorrah—we know that He will do it again.”

Pastor Burke’s exhortations starkly outline the destruction awaiting those who fail to follow God’s will. He also suggests that following (his interpretation of) the Bible is the only way to ensure one is following that will.

Importantly, church leaders’ interpretation of the Bible specifically links the process of following God’s will with health behavior. More specifically, they suggest that both the cause and the cure to an ailment are indicative of one’s relationship with God. Speaking from the pulpit, Pastor Burke frequently described the choice to use divine healing over modern medicine as the choice to trust God. As recorded in field notes from one Wednesday evening sermon, titled “Choosing to Live in Faith”:

Pastor Burke declared that, “Millions profess to believe in Christ but almost none of them rely on him! The devil’s greatest wish is that we will rely on any plan but God’s.” He looks out at us, deadly serious, while saying in low tones that “health plans” are “tools of the devil” designed to prevent us from having faith in God.
He adds that one of the things the devil uses to get us to not rely on God is “safety equipment” because it interferes with God’s plan for us.

The pastor describes illness as a form of spiritual warfare, in which one’s health experiences and decisions align the member with either God or Satan. In doing so, members are encouraged to think of their physical health as an important part of their faith, intimately intertwined with their own spiritual health.

Similar messages emerged in many pamphlets, which are condensed versions of sermons that summarize church teachings. For example, one 2011 tract declared that, “A genuine surrender to God is a total commitment to trust Him for healing, no matter how serious the oppression, without trusting any human remedy, doctor, medication, or drug.” Another said similarly:

Anyone who lives by faith in God will be putting His Word into practice – a Word that gives advice and instruction on every detail of life – explaining what to do, and how to meet every situation. Trusting God each day means… no family doctor.

Yet another reminded members that, “Obeying the Word just shows evidence of believing faith in God’s power – to heal, protect, provide, and save.” Again and again, the
institutional message was that members’ choice to avoid conventional medicine in favor of prayer is a key way that they can demonstrate trust in God above all others. As such, Full Truth members have a clear framework in which to interpret their medical choices as vitally important, even when they present challenges.

Interviews and observations revealed that members follow these institutional messages closely. I found that members not only took the steps of praying for healing and refusing modern medicine, but also understood their behavior in terms explicitly defined by the church. In particular, members aligned with institutional teachings by describing incidents of illness or injury as the result of personal failings, particularly the failure to follow God’s will. Such alignment was particularly obvious in hypothetical scenarios, in which members used church logic to describe what was happening. For example, Suzanne, a bubbly grandmother of ten in her early sixties, summarized her understanding of illness while we rocked in the armchairs of her cozy living room one hot summer afternoon:

All good things come from above; all bad things come from the devil. And it may be that there’s something that God wants you to [know] if He allows the devil to give you a pain or attack you in some way… We see that as God’s way of saying, um, “Excuse me! You were supposed to turn left back there!” Or “You were supposed to go straight, not turn left!” A lot of times it’s something we know we’re doing.
Lewis, a 64-year old widower and local truck driver with two grown sons, said similarly:

If we don’t get the results from God that we wanna get, it’s because of something wrong in our hearts. God is enabling us to realize that things in us need to be changed so that we can be right with Him.

As Suzanne and Lewis suggested, members understand physical pain in spiritual terms, interpreting ailments as both chastisement and communication from God. By extension, how they respond is understood as nothing less than a test of faith – will the member demonstrate faith in God by praying for healing, or turn away from Him to seek modern medical help? In contrast with many working class skeptics from chapter 3, Full Truth members did not have to determine for themselves why they were making the choices they did. Instead, they had a powerful framework for their decisions that gave meaning to health as a key indicator of one’s relationship with God.

Beyond hypotheticals, members recounted specific stories of injury or illness as opportunities to evaluate their relationship with God. In these instances, refusing conventional medicine was a signal to God and the community that they were committed to the faith. Divine healing (in place of conventional medicine) offered the opportunity to strengthen their relationship with God. Wilson, a 68-year-old cabinet-maker with thirteen
children and over forty grandchildren, described an incident from his own life that illustrated this point well. He grew thoughtful as he described an accident while working at his cabinetry business. With his eyes downcast, and his normally buoyant attitude subdued, Wilson told the story:

I had one serious accident at the shop where a saw blade went right through my hand. Right through …[shakes his head and pauses, remembering]. I just felt the Lord had got my attention at a serious level. I mean I could've bled to death but one of my sons taped it up, took it over to another old guy and he taped it up a little more and the Lord healed it.

Wilson held out his hand for me to see the pale, jagged scar across most of his palm. It had faded in color, but still revealed a dent of puckered skin where the blade had been. He continued:

It didn't really hurt a whole lot, but it was a serious injury… It came to my mind, will I trust the Lord to save my life? My hand? Or will I get in a car and go to some hospital and say, “Fix it any way you can?” Not only for myself, but for the family, I knew that my only choice would be to trust the Lord…God had blessed our family over the years in a lot of ways, and you become proud of your situation
a little bit -- So it renewed my interest and effort to live a life that was pleasing to God. But He got my attention.

Wilson recognized his injury as a moment of spiritual reckoning in which he felt he was receiving a clear communication from God. Implying that his injury was due to sinful pride in his family’s success, Wilson’s refusal to ask doctors to “fix it any way you can,” was an important way that Wilson could show his renewed faith in God.

Alice, a single food service worker in her late 30s, recalled a moment of hardship in which she felt that God wanted her attention. Saying that, “It’s only by the mercy of God that I’m here,” she began by telling me that she had her menstrual period twice in two weeks, and that the second time, the bleeding became extremely heavy and painful. Despite feeling weak, Alice got into her car to run errands. She told me:

The last thing I remember was getting back in the car. All of a sudden, I came to, and I was sitting, stopped, with my foot on the brake, at a green light a couple of miles away. And there was no traffic in any direction. And I just started crying out, “God is good! God is good! God is good!” and the moment I did that, the bleeding stopped. I’ve had my period like normal ever since. I came to feel that the whole thing was a testimony to me of divine healing, of how I need to trust in the Lord. And ever since then, I’ve known that divine healing is real; no one can
tell me otherwise. Now I know that I can always be healed; I’ve just gotta keep my eyes on the cross.

Alice described her faith as the result of a specific experience of divine healing. Though the incident occurred privately, she drew on church teachings to explain the religious meaning of her ordeal, aligning herself with the church’s interpretation of divine healing as part of what it means to “trust in the Lord” rather than the interpretation of those who would “tell [her] otherwise.”

Lori, a mother of seven with another on the way, recounted a time that a health crisis in her family served as a reminder to trust God. While her young sons played in the background, she explained that her husband struggled for years with chest pains and difficulty breathing. Her eyes misting over, Lori told of one evening when the problem reached a crisis point:

There was a time when I thought I lost [my husband]. He told the kids “bye” and everything. It was horrible… He was laying right here on the floor and he could hardly breathe, and it was that choice in life: What was he gonna do? Was he gonna depend fully on God or go to man for help? And I knew that he wanted to depend on God. He made that choice no matter what: we’re gonna depend solely on Him. He passed out and I thought we lost him. I just sat there and prayed with him, and prayed over him. My parents came and my dad prayed and it was just
like, all of a sudden he was awake, and he talked to us, and God was there; it was really amazing… You know, God just wants us to look to Him, and then all the glory goes to Him…And that’s what happened that night.

Lori’s account suggests that the family was primed by the church to assign a specific meaning to her husband’s illness. Saying that the crisis made them face “that decision in life” [emphasis added] of whether or not to trust in God, Lori underscored how members are prepared to interpret suffering in spiritual terms put forth by church leaders, even when the experience is intensely personal. Lori’s story further points to how health decisions are an opportunity to reinforce faith even for those who are not experiencing the illness directly. Even though it was her husband’s illness, the crisis required her to engage in specific behaviors like prayer and a religiously salient interpretation of the outcome.

The key point is that Full Truth members attach a specific, strong, and institutionally supported meaning to their health decisions, which I found that Constrained Skeptics do not. That is not to say that Constrained Skeptics don’t know why they’re refusing conventional medicine in favor of an alternative – they expressed a range of reasons, from concerns about toxic ingredients in vaccines to the belief that the body’s immune system will be weakened by antibiotics. However, they did not share a unified narrative of why their decision was important, nor if or how it related to their core values.
For Full Truth members, by contrast, the shared interpretation of their medical choices goes to the core of what it means to be a member of the group and a good Christian.

**Full Truth as a Social Support Network**

I’ve demonstrated that the religious meaning behind Full Truth members’ health decisions is important to them, and that it sets them apart from other Constrained Skeptics who tend to have a less cohesive and value-laden framework for their choices. Now I turn to how church members give and receive social support for those decisions, and how that support makes possible the kind of medical resistance that is otherwise difficult for working class families.

Social support at Full truth falls into two categories. The first is what sociologists typically think of as social support, i.e. material or emotional assistance for an individual or family undergoing challenges. Certainly, given that Full Truth is its own social world, it is not surprising that members support each other by creating tight networks that offer help (for a fuller discussion of material support between members, see Glassman 2018b). What I will discuss here, however, is the second kind of social support, which is the work that the group does to support itself as a matter of social reproduction. By this I mean the work that members do to affirm that the group functions as they expect it to, and that their medical choices are the right thing to do.

Specifically, because church teachings frame ailments as the result of sin, members not only pray for healing, but also actively seek to atone for their wrongdoing.
as part of the healing process. These atonement efforts reproduce group solidarity by resolving social tensions in a religiously meaningful way.

For example, Jeremy, a 44-year-old contractor and father of seven, described this process as it occurred during the birth of his last child about three years ago. After a full day in labor at home, his wife was becoming tired and increasingly delirious, despite the prayers being said around her by family members and, as the night wore on, church leaders who arrived at Jeremy’s request. Jeremy was calm, and his speech measured, as he explained that:

You know, our belief is that we went through this [difficult childbirth experience] because there was a spiritual cause somewhere in her life or my life, since we’re married. So during that time… we made phone calls to people and told them that we’re sorry for whatever. There may be people out there that we don’t have the greatest relationship with, or something went on where we didn’t treat them the way we should have, or held a resentment, or had an issue with them, or whatever, so we apologized to ‘em…Both of us prayed that if there’s anything that we’ve done that’s not pleasing to God, that He show us.

Soon after the phone calls, Jeremy’s wife delivered a healthy girl in their home, a result they both attributed to their successful atonement.
Jeremy went on to explain that it can be difficult to be on the receiving end of these atonement calls, because the recipient is often unaware that he or she has been wronged. As Jeremy told me:

We all believe similarly. So I think when people get the call they sort of feel bad, because I’m holding resentment towards this person, [but] they’re probably not holding it towards me; they’re probably holding it towards somebody else, and down the line. When I get [the call] I’m like, “Well, there’s nothing on my end. I’m good, but I’m more than willing to accept your apology.”…In reality, I need for them to be victorious as much as they need me to be, because we’re all in this together.

In Jeremy’s telling, such calls may feel unnecessary to the recipient, but are nonetheless important for reinforcing the group’s identity and the righteousness of their medical decisions. When the illness (or in this case, difficult labor) is successfully resolved, church members feel validated in their choices.

Sharing these narratives publicly is also a way to share the idea that divine healing has significance beyond the person being healed. Much as Lori described the health crisis of her husband as having spiritual significance for the whole family, members understand illness in children to be an indication of parents’ spiritual failing. One anonymous member testified about a time when plans with friends were disrupted at
the last minute, leading to frustration. The member explained how his child’s injury helped him identify the error of his ways:

I should have immediately gone to God in prayer, asking Him to control my attitudes, words and emotions, but I let frustration creep in, and let it fester to the point of bitterness and resentment. Since I wasn’t on Scriptural grounds at this point, Satan seized the opportunity to get in, and our young child fell and cut her head, causing much bleeding. I knew immediately that I needed to make things right in my heart with God. After crying a while, the child said she was better, and the bleeding stopped almost completely, for which we praise God. Apparently, there must have still been some hidden resentment or bitterness in my heart, because the very next day, I received a text from my wife saying that this same child was complaining of an earache…I realized that I still needed God to search my heart even deeper, and to totally give everything over to Him…Not long after, I received another text telling me that the child was much improved!

The writer described the child’s illness as caused by his sin of frustration, and framed the child’s healing as the result of his atoning prayers. Even though he was not the one experiencing pain, this member used divine healing practices in alignment with the church’s interpretation of health as having spiritual meaning. Such testimonies are important because they make the personal practice of atonement into a public
demonstration of faith that reinforces group interpretations of what it means to avoid modern medicine.

**Full Truth vs. The State**

Where social support at Full Truth really matters, however, is in conflicts with the state. Though they ideally hope to avoid it, members’ medical choices do sometimes put them in the judicial crosshairs. The most common cases were the result of care withheld from children, which occurred when an outsider brought an untreated childhood illness to the attention of government authorities like Child Protective Services (CPS). State laws vary, but generally parents may forgo medical care themselves, but may not withhold it from their children if doing so poses mortal danger to the child. Once authorities intervene, families may undergo home inspections and court hearings to determine the nature of the child’s illness and the degree to which withholding medical care endangers the child. At Full Truth, most families ultimately complied with court orders to provide medical care to their children, but compliance did not indicate acceptance of the government’s perspective.

When facing such conflict with the state, Full Truth members face competing institutional messages about the meaning of their health choices, and must reckon with an interpretation of those choices as negligent or even abusive. Members do significant emotional work to determine if and how those interventions can be interpreted as part of religiously meaningful healing practices. In fact, members are able to accept medical care
when it is perceived as occurring under duress, either from a judge’s order to provide
treatment for children or from outsiders intervening to summon emergency care.
Members interpret forced interventions through a lens of religious persecution, contesting
medical explanations and treatments as flawed or even dangerous, and framing the
experience as yet another way to reinforce – and reproduce – their faith. As such, while
outside institutions may impose medical care, the language of these interventions as
“forced” allows members to support one another in viewing the events as religiously
meaningful. These narratives of religious persecution bolster members’ faith in the long
run, even if they did have to accept medical care in the short run.

Both members’ court appearances and the way they handle them are at odds with
more typical, non-church Constrained Skeptics with whom I spoke. These participants
certainly voiced their concerns about potential interventions from CPS. Yet it is
important to note that none of those Constrained Skeptics had actually faced a CPS case –
though they worried about how their medical choices could be perceived by the state,
charges of negligence or abuse never materialized.

Full Truth members, on the other hand, have dealt with the state again and again.
In doing so, they have developed collective strategies to accommodate these interventions
without actually changing their behavior in the long term. This means that as religious
Constrained Skeptics, they can continue to resist conventional medicine even in the face
of state intervention.
Over half of the respondents with whom I conducted formal interviews had had some experience, in either their immediate or extended families, with government institutions mandating medical care for children. Their detailed knowledge of these incidents was important because it contributed to perceptions of religious persecution, and revealed a shared interpretation of how compliance with state intervention does not necessarily weaken the practice of divine healing. Wilson, for example, described how the family stayed faithful during a time that his two-year-old granddaughter, Lyla, was in the court system:

With the situation with Lyla, we had never been in a situation like that before. We went down there [to court]. The baby had a bad rash, itchy, couldn’t sit still. Went into court. The judge was ferocious…[My son and daughter-in-law] went in with the understanding that whatever this guy says, that’s what we got to do… They did that. The baby spit out the antibiotic. They called the doctor. The doctor says, “Just forget it.” [Lyla] spit it up two times. “Try one more time.” Spit up again. Didn’t even hardly swallow it. Spit it right up. ‘Alright. Forget about that.’ Over a period of time, she got well. Visibly well. They waited four more months, went back down again; [the judge] could see she was fine. Case is closed. And I really felt that they were blessed for doing what the Bible says, which is doing what [the court] says you got to do.
Wilson noted that Lyla’s parents were following the biblical injunction to obey the government,\textsuperscript{25} an important element of the narrative members use to interpret the religious validity of accepting medical care. By linking the couple’s obedience with anecdotes about Lyla’s (admittedly unwitting) resistance to the medicine, Wilson implied that the child was still divinely healed because even without swallowing the medicine she “got well over a period of time.”

Alice’s family faced a similar court order when her niece Macy experienced fluid-filled bumps on her head as a baby. After the court ordered initial treatment, Alice’s brother, the child’s father, was informed that he would need to seek medical care promptly in the future. Alice explained what happened next:

My brother was put on trial the same way [as others], and he was told if Macy ever got sick or had a problem he had to seek medical attention for her. And that happened. Macy got sick. It was Thanksgiving; it happened while the child was in my arms, so he took her back to the hospital… and it was a medical mistake, you know. The tube was supposed to drain the fluid away from her brain; instead it was retaining it to her brain. So it was miracle that she is still here…She’s done fine ever since, thank God.

\textsuperscript{25} Full Truth members trace their belief that the government must be obeyed to Jesus’s exhortation to his followers to “Give unto Caesar what is Caesar’s,” meaning that they should pay taxes because Caesar’s face appeared on the gold currency. The phrase appears in Matthew 22:21, Mark 12:17 and Luke 20:24.
Again, Alice highlighted the failings of modern medicine, suggesting that Macy might have never experienced a second negative event if she had not had the tubes inserted in the first place. In this narrative, Alice and her family followed the law while remaining committed to divine healing, critiquing the framework of modern medicine as unnecessary or even harmful.

Less frequent but still noted were stories of adult members who received medical care under duress. Not having made the choice to transgress church boundaries, members could interpret the event as a trial from “worldly” forces, meaning a form of religious persecution. As Suzanne explained:

My sister Marion, she was giving birth and having difficulties. Her husband’s worldly sisters called the EMTs, and they took her to the hospital. They gave her a Cesarean and they told her husband that she wasn’t going to make it. The reason she wasn’t going to make it was because she got pneumonia after they took her to the hospital!... They asked Marion what she wanted [to do], and around those tubes [in her nose and mouth] she came to enough and said, “I want to go home.” And the doctors, told her husband, “Well, she’s probably going to die in a few days, I just want to prepare you because she’s got serious pneumonia.”... And so she came home, and she did not die. She actually had another baby.
Suzanne described the experience of her sister as a case of medical care being forced upon her by outsiders (“worldly sisters” meaning biological sisters who do not attend Full Truth), and stressed the faults of medical intervention at every step. In doing so, she removed the responsibility for these interventions from her sister, while simultaneously contesting medical interventions as helpful or necessary. She further suggested that Marion’s choice to reject medical care when given the chance was a testament to her continued belief in Full Truth teachings, and framed her resistance as a vote of confidence in the community.

When Full Truth members independently chose to receive care, however, the narrative of religious persecution did not hold. Voluntary care was understood by both current and former members as a rejection of Full Truth teachings on the body. When members rejected divine healing it typically signaled that they were leaving the community. Indeed, former members of Full Truth described the process of leaving as intimately linked with experiences of poor health, and with the feeling that the church’s interpretation of the ill vs. well body increasingly did not reflect their own beliefs. Importantly, however, while former members specified that they no longer agreed with Full Truth teachings, the experience of getting medical help did not lead them to reject religion altogether. Instead, the vast majority of former members continue to be heavily involved in other Christian churches, suggesting that embodied practices like divine healing are shaped not by religious faith itself, but by the institutional meanings with which they are associated.
For example, contrast the way Alice described the voluntary medical care her sister-in-law received with her earlier story of court-mandated care for Macy. Alice explained how medical care featured in the declining faith of her brother (not Macy’s father but another brother) and his wife after their father became ill and passed away in his 60s, followed just months later by a third brother in his 30s. She looked resigned, her eyes downcast as she explained what had happened:

With my brother Kurt and his wife Ellen, they believed their whole lives, but after everything with my dad and my brother, Kurt just stopped believing. He felt like it wasn’t right. And then when his wife was having their fourth child she just got really, really scared. And he said, “Well, you know I don’t believe anymore; we can go to the hospital.” So they did. [The birth was] totally normal. But she just got scared for some reason. And you can’t have faith if you have fear… After they had the baby [Kurt’s wife Ellen] came back a few times, but then she stopped. And he had already stopped.

While Alice viewed Macy’s court-ordered care as ultimately conducive to religious belief, she described her sister-in-law’s treatment as based on fear, and therefore as a breach of the community’s values.

I interviewed Kurt about a year after speaking with Alice, and he described the same incident in very different terms. Kurt told me that after hours of pushing, his wife
was exhausted. Despite the protests of his mother-in-law and the church’s midwife, Miss Betty,\(^\text{26}\) he felt that it was “time to get a professional in here.” Kurt went on:

I asked Miss Betty to leave, and she was saying "No, no, no! You're making the wrong decision! You need to just pray about it and everything is going to be okay!" I said, "Yes, yes, yes, it's time for you to leave; we're taking another step."… So, I called 911. Ellen’s mother got upset, obviously; she decided she was gonna leave too. It was hard for Ellen… [The ambulance] took her to St. Anne’s Hospital. And on the exam table, the doctor came in and said, "Here's the problem! The water bag wasn't broken yet. You're dilated enough." Poked the water bag and whoosh! And the next contraction, out came the baby! So it was just something as simple as that. To me, that's not stepping in front of God, that's just common sense.

In Kurt’s telling, he rather than his wife initiated the medical care, based not on unfounded fear but on exhaustion and the feeling that the birth was not progressing normally. The moment of conflict with Miss Betty revealed that Kurt explicitly rejected Full Truth’s teaching that prayer would make “everything okay,” but he was equally clear that he did not view calling 911 as rejecting God. Instead, he understood their decision to

\(^{26}\) The church “midwife” is an older woman and member of Full Truth who has attended many church members’ births. She is called a midwife out of respect, but has no formal training. Kurt maintained that she never did any kind of internal exam on his wife, and believes that she has no medical knowledge, including an understanding of cervical dilation.
seek medical care as a “common sense” measure that did not diminish his faith or signal that he was not a Christian. His telling reflects a moment in which Full Truth’s institutional messages about the meaning of the ill body lost their salience specifically because he no longer agreed with the church’s interpretation of what it means to be a good Christian.

Divergent explanations of the same event came up in other conversations as well. Kathleen, a single woman and office manager in her early forties, explained the case of one of her sisters who has since left the church:

Well, [my sister Sarah] is going elsewhere for help [with problems in her life] now, so she would be considered an unbeliever because she's not believing that God will do things today for her…Like, she's had stuff done at the hospital, and that goes against what I believe. She was praying about her eyesight for a lot of years, and then she just figured God didn't want to heal her, so she went and got something done about that.

For Kathleen, the crux of the transgression was that her sister chose to get care. Kathleen equated her sister’s eventual choice to go to a hospital with a deliberate rejection of their faith. For Full Truth members, rejecting the faith is synonymous with withdrawing support the medical choices that are so central to their beliefs.
Kathleen’s sister Sarah viewed the choice differently, however. Far from the somewhat offhand nature with which Kathleen believed Sarah went to a doctor about her eyesight, Sarah recounted doing so only after a lifetime of suffering from vision problems. When I spoke with her almost two years after interviewing Kathleen, Sarah told me that she had memories as young as four years old of not being able to see the hands on the clock in a room or understand what the teacher was writing on the blackboard. Sarah described her fear of getting glasses while she was a member of Full Truth:

My parents were like, “Well, you just have to pray, and ask Jesus to heal your eyes.” So from the time I was four or five until I was twenty-nine I was like, “What could I be doing wrong my whole life that I can't get this prayer answered?” And the thing was, for someone to get glasses [at Full Truth] was not having faith in God. They were taught that out of fear because they were afraid that you wouldn't go to heaven if you didn't trust in God and you trusted in something man came up with… At that point I would have been terrified to [get glasses] because I would have felt like I was going to be struck down by lightening or something.

Later, however, Sarah began to question church teachings, partially from reading the Bible closely and finding passages that she believed contradicted Full Truth’s
messages on divine healing. She felt that church leaders took scriptural passages out of context, and used small snippets of passages to build the argument that they wanted to make rather than letting the passage guide their teachings. Eventually, she came to see her eyesight problems differently:

I was born with my eyes the way they are. It's not a defect, it's just the way that I was made and I just need glasses… My whole entire life changed when I got glasses. I was like, “whoa, I can actually see!” I just felt so exposed all of a sudden. “People can see me as good as I can see them! There’s cracks in the sidewalk!” [sic]. I felt like such a little child; it was so crazy.

Sarah defined her eyesight not as a “defect” or the result of ongoing sin, but merely as a fact of her birth that came without larger spiritual meaning. Learning how much she had been missing in the world without clear vision, she continued to explore faith outside of Full Truth, and now attends an evangelical church with her husband, an outsider whom she met as she was leaving the church. She described her faith to me today:

I'm a Christian now. All of that [divine healing at Full Truth], I want nothing to do with it. I believe that that's wrong. I do have genuine faith now, and it's so contrastingly different from what I grew up with. So now my belief is that Jesus
died for my sins. I believe that; I accept that. I have forgiveness for my sins so I know when I die I'm going to heaven. That's what I believe; it's that simple.

In describing her current beliefs, Sarah disconnected her health behavior from her religious identity, and therefore from the church community. Because members rely on shared performances of medical refusals as a form of social support, publicly and willingly accepting medical care was a slap in the face for this tight-knit group.

**Conclusion**

As these experiences of medical care reveal, members defined voluntary and involuntary treatment in very different terms. Members viewed forced care through a narrative of resistance to persecution. In such instances, mounting even limited opposition to medical care created a narrative of struggle that reinforced Full Truth teachings on health without inviting undue legal trouble.

By contrast, former members of Full Truth spoke candidly about the process of coming to reject divine healing, and the role that seeking modern medicine played in their defection from the church. Though I have recounted the stories of only two former members here, all eight of those with whom I spoke echoed similar sentiments: They typically agreed with current members’ assessments that their choice to get care was a sign that they no longer agreed with church teachings, but they strongly disagreed that their break with Full Truth teachings meant that they were no longer Christians. Instead,
most described the process of leaving Full Truth as a journey towards a closer, more loving relationship with God. The embodied practice of divine healing was so linked to the institution of Full Truth that former members felt they could no longer be a part of the community while using modern medicine, even though they did feel that they could be good Christians.

Full Truth members are an exception to the general rule of Constrained Skeptics, which is that their working class position hinders the ability to resist conventional medicine. While most Constrained Skeptics make medical choices in an environment of limited resources and social support, Full Truth members show that working class families can resist conventional medicine if they only have enough encouragement from the community. Indeed, this tight knit congregation reveals that by sharing accounts of trusting God rather than doctors, they reinforce both the religious salience of their health decisions and the social validation of those choices.
CHAPTER 6: COMPLIERS

Introduction

I’ve shown how Constrained Skeptics approach medical decisions in an environment of limited social support and financial resources. In these restricted circumstances, members of Full Truth Calvary Church stand out as an exception to most Constrained Skeptics because their religious beliefs and strong community provide the robust social support working class families need to resist conventional medicine. In this chapter, I turn to the case of working class participants who use all conventional medicine, and who do not express any desire for alternatives. I call this group “Compliers” because, unlike the middle class Believers, they did not approach medical decisions as consumers. In other words, Compliers did not research their options, question their doctors, or otherwise engage with their medical care as collaborators. And when faced with substandard care, they were more likely to continue with it rather than seek out a new doctor. Thus, I argue that Compliers face some of the same barriers to independent medical choices as Constrained Skeptics, including a more limited community, but that because they comply with conventional medicine their constraints are less visible.

Health and Medicine in Childhood

Like Constrained Skeptics, Compliers grew up using primarily standard conventional medicine, including Tylenol, antibiotics, and regular doctors’ visits. They
also mirrored Constrained Skeptics’ experience of drawing on CAM treatments that they described as “traditional.” Compared to Constrained Skeptics, however, Compliers grew up with more positive memories of conventional medicine, and specifically with their doctors. While most Constrained Skeptics described their doctors in general terms—“fine,” “no problem,” “okay”—Compliers were more likely to tell me about individual doctors and to recount specific things that they liked about the experience of getting medical care. 33-year-old Nicole, a white mother of one who works as a nanny, noted that she still sees her childhood doctor, who works as a family physician:

>[As a kid my doctor] was Dr. Kowalski, who I still go to because he was the family doctor. I still go to him for [any] issues. I actually liked the pink medicine [amoxicillin, an antibiotic]. I think it kinda tastes like candy cigarettes, which I still like to this day – I like candy cigarettes.

April, a black mother of two in her early forties who works as an administrative assistant, smiled as she described her doctor growing up, extending her positive regard to the local city hospital where she continues to go to this day:

My pediatrician was one of my favorite doctors. Dr. Ramirez. I had him for years at Roosevelt General. I was born at Roosevelt. My kids were born at
Roosevelt. My mom went to Roosevelt. Half my family goes to Roosevelt. [Dr. Ramirez] was just a gentle giant. He was a really big guy, but he was so nice. In the beginning, I used to be scared of shots, so he always made you feel good about it. He didn’t rush you through anything.

Brittany, a black mother of three in her late forties who works as a nanny, brought her typically sunny attitude to her description of doctors, saying: “I always loved my doctors. I never had no problems with my doctors. They tell you the truth. They take the time to talk to you and stuff. I never had problems going to the doctors at all.” Brittany’s characterization was unusual for being so unequivocal, but it’s notable that when she described liking her doctors, her primary reason was related to open and honest communication. This perspective is a contrast to Entitled and Constrained Skeptics, who often reported that they distrusted doctors based on either their own experiences or those of people in their networks.

Interestingly, Compliers mentioned the presence – or absence – of health insurance as children more frequently than did Constrained Skeptics. Though we’ve seen that Constrained Skeptics consider health insurance part of their decisions now, none mentioned it as an issue growing up. This is not to say that it wasn’t an issue, but Compliers seem to have thought about it more in relation to childhood health. For those who had insurance, it was a point of pride to use it. April, the black mother of two noted

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27 It is also worth noting that my participants live primarily in and around an urban area with exceptional health care, particularly for children. This could provide more positive experiences for participants of all class and race backgrounds than would be the case on average nationwide.
above, recalled her own mother’s attitude:

My mom would always say – she lived for doctors – ‘Nope, [we] have insurance, that’s what it’s for. Take them to the doctors.’ I kind of have the same mindset, even if there’s a problem…if I’m concerned, I will call. I will definitely call. I keep up with the shots. I keep up with the dental. I started at two years old. I’m probably better with them than myself. I know I am.28

For these working class families, using health care signaled that they could provide an important service to their children. Compliers with health insurance today expressed a similar pride that they have the resources to provide their children with prompt medical attention, and considered it a badge of honor that they were able to “keep up” with all of the check-ups and shots that young children require.

For others, however, insurance was intermittent if the family had it at all, resulting in fewer visits and clinic settings that prevented establishing a relationship with one practitioner. Carmen, a Latina mother of three who works in catering, described going to a series of storefront clinics as a child. When asked if she had any particular feelings about doctors when she was young, she told me that she rarely saw the same doctor

28 Interestingly, the same perspective was echoed by middle class respondents who grew up working class. For example, Kara (a black mother of one and Christian minister) and her husband (a union electrician) both grew up working class, and are happy to have access to the high quality health insurance that his union job affords. As Kara told me: “My husband, his first response if I tell him I’m not feeling well, I’m having pain again, his first thing is, ‘I have the best health insurance in the city. Go. Do you want to go to the ER?’ He’s into utilization.”
twice. At the time it didn’t bother her, but looking back now, she understands that her medical care at local storefront clinics was dictated by her parents’ limited resources:

[When] I grew up that’s what I knew; I didn’t know any better…I grew up and that’s where I went if I was sick – I didn’t know any different. I didn’t know I could have a pediatrician and you could call them up, you can have a primary doctor, I didn’t know that. We would go to whoever. Where we lived there were these doctors that you can pay $15 or $20, very low, and you could see them. They were doctors that had a little storefront. I don’t know if they were associated with any hospital, I couldn’t tell you that. All I know is that we would go to them and almost like a small-town doctor, they’re not really associated, but it was just a business, it was a little place, it wasn’t nothing big. So that was an option for us if we were sick.

Many reported taking a “wait and see” approach, much like middle class parents. Amber, a black mother of five and working in retail, recalled her own mother’s approach growing up:

When we were sick, my mom calls it the ‘Jewish penicillin,’ which is like the chicken noodle soup. She’d make chicken noodle soup. She had the whole house
smelling. She had everything lined up on the table. Nyquil, Benadryl, Tylenol, had everything lined us. She was just like, ‘Okay, come on.’ We’d try that first. If that didn’t work, then we’d go to the doctors. For the most part, we weren’t sick like that. We were the kids in the wintertime that had the whole snowsuit all bundled up like the Christmas Story; you couldn’t walk.

Compared to Believers, Compliers were much more likely to use CAM in addition to conventional treatment. However, while Compliers recounted instances of their parents using alternative medicine, they were clear that these treatments were simply “traditional” and/or inexpensive rather than some kind of statement. They discussed these alternative practices casually, and did not view them as in any way a rejection of conventional medicine. Dominique, a black mother of one daughter in her mid-twenties who works as a legal assistant, described some of the remedies her mother used:

My mom, she wasn't one to always bring us to the doctor for every little thing. She had like home remedies or give us medicine from the store or stuff like that. So most of our medicine was herbs because she's definitely into natural herbs and healthy stuff. So when we'd get fevers and stuff she would do the onion method when they cut up onions and put them on you. Like, when you have a fever you cut up onions and put them on your skin and it’s supposed to break the fever. Like in your shirt and stuff, like on your body, on your body. Like you put on like a
shirt and you tie it around so it can stay in place and it's supposed to break your fever. That's one of the home remedies she used to do.

Lucia, a 38-year-old Latina mother of three who is currently looking for work, recounted an alternative remedy that her family used while she was growing up: “[My family is] Puerto Rican, so they just take a bath in alcohol and some stuff like that. You get a thing of alcohol and you pour it in the water. It's supposed to take the fever away.”

When asked if she does the alcohol bath for her own children, she nodded, but said that she also uses over-the-counter medications like Tylenol and Motrin, “if I have it around.”

Pressed for the difference, or why she chooses one over the other, Lucia shrugged nonchalantly:

Lucia: Yeah, it depends on how irritated I am at that point, maybe that means, like, how sick they are, how really, really sick they are. I know how really sick is; I've seen that.

Lindsay: So if she's really sick, you do more Motrin instead of the alcohol bath?

Lucia: Yeah.

Lucia’s logic mirrored that of many Entitled and Constrained Skeptics who turn to conventional medicine if an illness is particularly severe. However, Lucia also voiced
making decisions partially a matter of convenience and how she as a parent was faring in the moment. Though is likely how many parents approach medical decisions, most did not reference their own needs in the context of health choices, and I appreciated Lucia’s candor. I was struck that she did not view the interventions as categorically different, but simply had different benefits and drawbacks (based on cost, treatment strength, and amount of parental labor). Though she has used alternative medicine as many would define it, she was not skeptical of modern medicine so much as drawing on her own experience from childhood and using the resources she had at hand in a given moment.

Interactions with the Medical Establishment

For as many Compliers who talked about their positive feelings towards doctors as children, few reported seeing medical providers with any frequency as adults. Reduced medical care was typical of participants from all class and medical orientation backgrounds, as participants reported having little time to get routine care while in the flow of parenthood and work. However, Compliers had exceptionally limited interactions with doctors. Amber, the black mother of five who works in retail, described a common approach when she gets sick:

29 One other participant who mentioned her own needs as part of medical decision-making was Sydney, the Believer mother of three who works as a physician. She described how challenges with her work schedule dictate how she treats her son’s frequent fevers: “We’re so busy. I don’t get sick days. My husband doesn’t get sick days. We have to just make it work. With our son, he’s a real fever kid. I realize this now. So he would get sent home from daycare a lot. I’d be giving him Motrin in the morning, mixing Tylenol in his yogurt that I was sending to school, and be like, ‘You’re going to have that about noon, that should get me to 3, and then I can come get you at 3, if I have to.’ Because like we don’t have—I don’t have wiggle room.”
When I get sick, I kind of go into survival mode so that I can just do what I have to do. I tend to myself, so I already know if I feel it coming on, ‘Okay, go get your soup, go get your ginger ale, go get your medicine, because you’re going to be no good to the kids.’ And even though [my husband is] helpful, you know how men are—he’s helpful to just what he needs to be helpful to, and it’s just like you still have to be mommy and still do this and do that. It gets done. It’s rough, but it gets done.

When asked what types of treatments she uses for herself, Amber replied:

Tylenol/Motrin/Nyquil, whatever medicine, for whatever need it is, but I always—I’m a mom—I always make a pot of soup, get the house smelling, all the vapors, all the humidifier. I have the purifier over here now. The purifier, the humidifier, whatever you need. The Vicks inside it. I’m doing everything.

Amber noted that when she did seek medical care for herself or her children, she had good experiences with the doctors themselves, but was wary of the environment in which they received medical care as a working class family.
I’m not crazy about [going to] the doctors. They have been really good. I have been able to talk to them. Even though they have [our] records, I still give them the run down from myself about the kids, so they can get a better understanding and they have been really good with that. I think it’s just—I don’t know—I think it’s the appearance of the office sometimes, and like I said, the clientele, not so much the people that actually work there or nothing like that, it’s just the people that go there. They’re not as nice.

Recall Dawn, the working class medical skeptic who complained that her family’s limited healthcare coverage meant they had to visit a clinic frequented by patients suffering from drug addiction. Though she spoke of these patients compassionately, she also noted that she didn’t like her children to see the pain of opioid withdrawal. Regardless of their medical choices, working class families dealt with barriers to quality medical care that middle class families simply did not have to consider. For Compliers, however, these barriers did not drive them away from conventional care (or towards alternatives) as a whole, but did sometimes have the impact of reducing their contact with medical professionals.

As with women from all backgrounds, Compliers had the most to report about their experiences with childbirth and seeking care for their children. Compared to the Constrained Skeptics, however, they reported much more positive labors and deliveries.
Dominique, the black legal assistant in her mid-twenties with one child, recounted a remarkably positive birth story:

Dominique: [Pregnancy and birth] were great. I had a good small pregnancy, no complications. The only thing out of it probably was like maybe having trouble gaining weight. Labor was good, she came out quick. 'Cause the whole [pregnancy], see, I walked. I walked literally the whole pregnancy, and then when my water broke, I didn't go to the hospital right away, I just waited. 'Cause if you go right away, if you're not ready to push they send you home, so I wanted to stay home. So I stayed home and I got to the hospital when it was almost time for me to push, and then when I got there, I only did like four pushes so she was out in 15 minutes or so.

Lindsay: Did you do an epidural?

Dominique: No. I couldn't because it was too late by the time I got there. I got there too late so I had to have her natural.

Lindsay: Did you go into labor thinking that you didn't want to do an epidural or you were kind of--

Dominique: I really didn't put that much thought into it because I felt like I probably won't go off for the pain. If the contractions was hurting real bad then
maybe I would've got it but if not, then I probably would've been fine [sic]. But I did the whole labor in the house so there wasn't really no point for me to get the epidural…I was fine. I just stayed there, I stayed in the house until I couldn't take the pain no more and by the time I couldn't take the pain anymore it was time for me to push.

Dominique’s story is notable for being free of the angst and confusion that many women reported feeling during childbirth. Though Dominique by nature seemed to be a naturally calm and happy person (with a high pain tolerance!), it is notable that she did not go into the labor and delivery process with strong ideas about how she wanted it to go. This attitude was much more common among all working class participants – both Compliers and Constrained Skeptics – than middle class participants. Though Dominique’s attitude echoes other research showing that working class patients tend to expect less of a say in their medical care (Beaver et al. 1996; Bastiaens et al. 2007) – a troubling finding, given that involved patients tend to have better outcomes (Beach et al. 2007; Joosten et al. 2008) – other studies have found that mothers who do not have a strong commitment to a “birth plan” are more likely to report their experience as positive (Mei et al. 2016).

Unfortunately, not every story of pregnancy and childbirth was so positive. Marielle, a Latina mother of two who works at a local after school program, described how a sudden spike in blood pressure during her first pregnancy led to a near-death experience. Her story is notable for its horror, but also for the fact that she did not turn to
alternative medicine over conventional after undergoing the trauma. She recounted the story:

My pregnancy went normal. My blood pressure was fine, everything was fine. Then I got sick. I went to my normal doctor. He took my blood pressure. He goes, ‘You might want to tell your other doctor that you have high blood pressure right now.’ The next day I went to [the obstetrician] and she was like, ‘No, your blood pressure is fine.’ My blood pressure was normal. I was like, ‘Oh, okay, maybe it was something I ate.’

But it turned out that Marielle’s blood pressure was not stable, and by the next day she was extremely sick. Although she “kept calling them” she reports that they said, “No, you’re fine. You probably got the flu or something.” Marielle continues:

I started losing vision in one of my eyes. My vision got blurry. Since they kept telling me I’m fine, I’m fine, that weekend I ended up going to a graduation party, which was crazy, because I’m sitting there driving like this [covers one eye].

When Marielle continued to be lethargic and sick, her husband insisted she go to the hospital. Five days after her first high blood pressure reading, he drove her to the
As soon as we pulled up, I went into a seizure. Thank God we got to the emergency room when I had a seizure…I honestly don’t remember any of this. That’s probably good…They said my blood pressure sky-rocketed and they had to take the baby out. They thought either I was going to die, or the baby was going to die. They asked [my husband], ‘If we have to save one, which one do we save?’ It was that bad. He said, ‘My wife. We can have another baby.’ They took her out, and then they put me in intensive care and she went to NICU. While I was in intensive care, they drew blood, they had me on all kinds of medicines to lower the blood pressure.

In addition to the negative OB experience, Marielle described her other doctors as unhelpful:

The eye doctor, he was like, ‘Oh, this is horrible. You lost your vision. I don’t know if it’s going to come back.’ …My mom was pissed. She was like, ‘Get out and don’t come back’…I did have to wear glasses for a little bit, but the retina's repaired. He said it wouldn’t.
Despite her traumatic experience, Marielle was not angry with the doctor, but rather with the nurses and also herself. When I asked if she was angry with the doctor because she had been calling earlier about feeling sick, she said:

Oh, yeah, I was angry. But honestly, I think it was the nurses that I was talking to. I didn’t have that experience with the doctors. They were all friendly and nice when I would go in, but I guess whoever answered the phone was the same, mean lady that was like ‘Oh, you’re fine. We just saw you the other day. Nothing’s wrong with your blood pressure. You probably have the flu.’ That’s it. We were pretty upset. Apparently, I wasn’t fine. Now, losing the vision that was my fault. As soon as I realized my vision was getting blurry, I probably should have went to the emergency room. I didn’t. I was like, ‘Oh, I’ll just lay home and I’ll be okay.’ I wasn’t.

Regardless of who is responsible for Marielle’s experience, her claim of some personal culpability fits with previous research showing that members of the working class are more likely to identify themselves as accountable for their own misfortune (Silva 2013). It is hard to imagine any of the middle class parents I spoke with not responding furiously (and litigiously) in Marielle’s shoes. Indeed, Marielle chose to return to the same hospital and OB practice for her second pregnancy.
Marielle also didn’t express entitlement in interactions with her children’s specialist doctor. When her second daughter developed problems with eating and appropriate growth, she was unhappy with the doctor they saw first, but she made no move to switch. In fact, it was only because an older female physician noticed her dislike of him that they eventually transferred to a doctor she liked much better:

The first doctor, he was okay. I guess he was new, he was learning, he was a resident they said, and then when my daughter ended up in emergency one day and stayed for a week at the hospital, this older doctor looked at me—[our doctor] was there, and I guess [the older doctor] realized I wasn’t too fond of him. She’s like, ‘It’s okay, I can talk to him and you can switch to somebody who’s older.’ He wasn’t making decisions; we were stuck in the hospital, and the older lady was like, ‘No, we need to do this now.’ He was just, ‘Oh, let’s wait it out.’ We don’t want to be in the hospital any longer. She gave me another doctor and she’s great. I love the other lady.

It is fortunate that Marielle’s daughter ended up with a doctor that Marielle liked better, but the way that it happened is telling. Unlike middle class parents, or even many of the Constrained Skeptics, it didn’t seem to occur to Marielle that she could be entitled to switching doctors. Though most Complied did not report negative experiences with the medical system, Marielle’s experience suggests that the working class may feel more constrained in their interactions with doctors, regardless of their own health beliefs. Such
constraint could limit the types of medical treatment that patients even consider, including alternative medicine.

**Community Ties and Medical Decision-Making**

As with all participants, Compliers drew on their relationships with friends and family to make medical decisions. In many cases, social connections mattered for simple things like finding a doctor or asking advice on a child’s illness. April noted a network of sources she draws on for medical advice:

I have a good friend who has six kids and she’s been through everything. I call her the child whisperer. I’ll ask her, and I’ll just call the doctor. Then of course, I ask my mom: ‘You need to call the doctor, did you call the doctor?’ And she’ll kill me until I do it.

While Believers talked frequently about drawing on the knowledge of doctors in their communities, Compliers strove to get information from doctors through friends and family who worked in a medical setting. In most cases, this meant contacts who worked as administrative assistants in doctors’ offices, or sometimes as nurses’ assistants. For example, Amber summed up her approach:
I have a few friends that are in the health field and a few family members that are in the health field, so I would talk to them and ask them questions about what they knew of anything like that, [especially] asthma, and then go from there.

Similarly, Carmen, the Latina mother of three who works in catering, noted that she draws on resources from a local university to find what she deems insider information on the best doctors:

Carmen: Any specialist, we just try to look for someone that’s good, that’s rated really good. Try to look that up. Thank God I have a sister-in-law who works at the university, so she actually will get me information on doctors and things like that.

Lindsay: She works in the hospital system?

Carmen: No, she actually works in the university, but for doctors, so actually professors, so she can go in the system and really tell me this person’s good and things like that. She’s helpful with that. So if we need a specialist, I’ll call her, but only for specialists. I just used it for my daughter, because my daughter was having rapid heartbeats and she was feeling really faint a few times, so I called my sister-in-law immediately. I said, ‘I don’t want to play around with doctors, because there’s an issue
in the family,’ so she recommended a specialist and I went all the way
downtown to Central Hospital. I was like, ‘Yeah, I’m not going to any
doctor around here.’

Carmen was adamant that a good specialist would be in the central, wealthy part of town,
rather than in the medical centers closer to her working class neighborhood. It is unclear
exactly what information her sister-in-law has access to, but to Carmen this connection to
the university validated her recommendation.

Certainly, as with all participants from all class backgrounds and medical
orientations, working class medical believers looked up information online. Kim, a black
mother of two who works as an office administrator, provided a quick rundown of how
she seeks out health information:

I kind of do all of it. I don’t have a lot of time, unfortunately, so most of the time,
I guess I’ll just Google it really quick. If it’s something that I really have a
question about, a lot of times I’ll write it down and then the next time I see the
doctor or talk to the doctor I’ll ask them if it’s not life or death. If it’s life or
death, I just call the doctor. But if it’s just something like a rash or something,
usually I’ll just Google pictures of different kind of rashes. If I don’t really get an
answer there, then yes, I’m part of a mom’s group on Facebook and I’ll post a
question, or I’ll ask a friend.
Nicole, the white mother of one in her early thirties who works as a nanny, also reported drawing on medical advice through a combination of friends as well as family who work for doctors:

I have a bunch of nannies [I ask about health issues], and then I have my mom, [and] especially my Aunt Jan. My Aunt Jan is like the go-to person. She's got three kids of her own, and her husband had eight, nine kids before her so she has a lot. And she's been working at a daycare since she was 19 and she's well into her 40s. [So] she's the first one I go to. She's done it, been there… [My mom,] she's an administrative assistant for pediatricians, so if I have a question, like right now if I had a question, I'd call her and be like, 'Mom, ask Sue or Brianna [the doctors] what I should do.'

As Nicole shows, Compliers trust conventional medicine in much the same way that Believers do, but find that their communities keep them more distant from doctors themselves. While Believers were not shy about seeking out more information or a second opinion – often through the doctors in their communities – Compliers were happy to get recommendations through a friend or family member connected in any way to a clinician.
Conclusion

Overall, Compliers approached medical care with few of the demands so apparent among Believers, but facing some of the same challenges as Constrained Skeptics. They approached medical providers with little sense of entitlement, instead complying with doctors’ orders not as collaborators but as passive recipients. This is not to say that Compliers received medical treatment against their will; on the contrary, many were proud to have the resources, including insurance, to seek treatment. Yet contrary to Believers, for Compliers, medical care remained an essentially passive, personal endeavor. Compliers did not speak of any health decisions, such as vaccines, in terms of public health or the greater good, something that Believers mentioned frequently. I speculate that the difference is because working class parents overall were less aware of anti-vaccination advocacy as a phenomenon. Indeed, not a single Complier reported that they had researched vaccines before accepting them for their children, something that many Believer parents did. In other words, many middle class parents were keenly aware that some parents refuse vaccines, and felt that they should read up on them to make sure that they felt comfortable. Complier parents accepted them as a matter of course. Thus, Compliers’ more limited interaction with doctors wasn’t simply that they agreed with conventional medicine – Believers also agreed with conventional medicine, but still tended to seek second opinions, research their conditions, and ask their doctors lots of questions. Instead, Compliers tended to follow doctors’ order and to keep the same doctor (even in the face of poor care). Those decisions reflect the lack of entitlement that Compliers bring to their medical encounters, suggesting that they do not see themselves as the kind of educated consumers that Constrained Skeptics do. The difference, I argue,
is that Compliers’ communities don’t provide a connection to, or support of, alternative medicine. Constrained Skeptics, by contrast, are able to tap into the more privileged orientation of alternative medicine users, and the narrative of personal agency and advocacy that they promote.
INTRODUCTION

The case of Full Truth Calvary Church showed that racial privilege can moderate the role of social class in making medical decisions, and more specifically, can protect working class parents who face pushback from institutions like Child Protective Services. The purpose of this chapter is to explore more broadly how race intersects with class in the process of making medical decisions. I find that race constrains participants’ capacity to choose alternative medicine, and especially to take the necessary steps to make those choices in light of institutional regulations around medical care for children. I focus on interactions with institutions because I find that the impact of race is most salient in these encounters, as well as in the anxiety and preparation engendered in the prospect of such encounters.

Importantly, however, the impact of race on medical decisions and institutional interactions differs by social class. For middle class participants – both Entitled Skeptics and Believers – parents of all races reported feeling entitled to make medical decisions freely. Not a single middle class participant raised concerns about their ability or right to challenge their child’s school, nor mentioned Child Protective Services (CPS) or other government institutions. However, several middle class black participants – again, both Entitled Skeptics and Believers – noted the role of historical medical abuses of African
Americans in their perception of the conventional health system. Referencing the Tuskegee experiment, negative stereotypes of black sexuality, and racist medical negligence, these participants reported bringing reservations to their interactions with clinicians. Though in most cases these reservations didn’t lead to rejecting conventional medicine outright, they could impact decisions in other ways. For example, black participants described their efforts to find black healthcare professionals in a new city, or the need to do additional research on the quality of their doctor.

Among working class participants, the impact of race was strikingly different. Notably, for working class participants, the race distinction was most salient among Constrained Skeptics only (not Compliers). I found that Constrained Skeptics from all racial backgrounds were aware of, and concerned about, institutional interactions, including those with the public school system and agencies like CPS. However, white Constrained Skeptics tended to respond with a degree of entitlement, telling me adamantly that they knew their rights and were not afraid to push back against anyone who challenged their medical choices. Black Constrained Skeptics, on the other hand, showed more restraint in their interactions with institutions. They noted concerns about keeping a record of their contact with the conventional medical system, and were compliant with school regulations about vaccines. Research shows that they were right to be concerned – black families face interventions from CPS and related social services at a much higher rate than white families (Fluke et al. 2003; Lu et al. 2004). The result, however, was that Black Constrained Skeptics almost never outright refused any conventional medicine. Instead, they demonstrated distinct strategies to manage the risk.
of encounters with the school and judicial systems – essentially strategies of conciliation – while continuing to explore CAM options.

In fact, I found that the black and Latina working class women with whom I spoke were so hesitant to outright refuse conventional medicine that I ultimately stretched my criteria for classifying Constrained Skeptics: I defined black and Latina working class participants as Skeptics if they identified as being interested in, and using, CAM, while also expressing a *desire* to refuse some form of conventional medicine, even if they ultimately did not. I hope that in the stories below, it will become clear why I ultimately classified these respondents as Constrained Skeptics, and what they show about the unique barriers facing black and Latina patients who wish to make alternative health choices.

**Similar… but Different: How Race Impacts Medical Decisions Among Entitled Skeptics**

Entitled Skeptics from all racial backgrounds spoke similarly about their relationship to institutions. In many cases, this meant reading between the lines, as these middle class participants had little to discuss about their interactions with institutions like the school system or doctors’ offices, and nothing at all to say about agencies like CPS.

As illustrated in chapter 2, Entitled Skeptics spoke easily about pushing back on facets of medical authority like school vaccination requirements. Maura, a white woman in her early thirties who stays at home with her two children, spoke about refusing
vaccinations at the pediatrician’s office, and then obtaining vaccine waivers for her children’s daycare and school. She spoke about the process nonchalantly:

Maura: With the pediatrician, she asked the first time, and I said, ‘No.’ She has not asked again. The nurses, they kind of are like, ‘Well, why aren’t you vaccinating? Are you going to vaccinate? What are you going to do for school?’ I get it every single time, but otherwise, the pediatrician, she’s very cool.

Lindsay: What do you say when they ask?

Maura: I just say, right now I’m not vaccinating, and they’ll be like ‘Well, what about later?’ I’m like, ‘We’ll think about later.’

Lindsay: And how does not vaccinating work for their schools?

Maura: They do require vaccinations, but they allow religion as an exemption. There is a place locally that you can actually get a religious exemption. It’s literally [an online church]. It’s $75, I think, for a lifetime membership. You just send [the school] your membership with a seal and everything. I handed it in to my one daughter’s daycare, and they didn’t ask any questions. There’s no meeting place or anything [for the church]…They have them in every state. It’s called-- Let me look it up. Congregation of Universal Wisdom. My chiropractor is a member and told me about it, and then I realized my naturopath had joined it [too]. He
has older kids and he has never had a problem with school. So we’re into it. I’m not declaring it as my religion, but [it works for the schools].

Maura approached the issue of vaccine waivers as a bureaucratic hurdle that required paperwork, but no real stress. She was unconcerned about claiming a religious exemption without holding any medically related beliefs, and was honest that her church membership was an instrumental move that helped her make the desired medical choices. At no point did she express concerns about what the school, doctor, or other authorities might think about her choice to avoid vaccines.

Mariah, the black mother of two who works as an art teacher, spoke about her search for a doctor who would support her choice to avoid vaccines and antibiotics while feeding her children a strict vegan diet. Recall from chapter 2 that Mariah found a pediatrician that she liked by asking around in her social circles. Notably, this pediatrician was helpful for facilitating Mariah’s potential interactions with other institutions, like a hospital, with the fewest possible roadblocks or misunderstandings.

But she [the pediatrician] now knows our family, and she knows how we want to do an alternative science [of medicine] and so she'll talk to us in that way. She came in and she assumed automatically we were not doing vaccines. We didn't have that conversation but she kind of knew me and she kind of read [my partner]. 'You guys aren't [going to vaccinate], and so I'm gonna talk to you in this way,' but it wasn't a putting down in the way that a lot of doctors do. Yeah, it was like,
‘If you go to an emergency room, you need to tell them this because your child doesn't have the traditional vaccines that another child would and you need to tell them this is what you want to do because of that.

Mariah described the pediatrician offering advice for how to handle emergency room doctors not as a matter of legal liability but rather as a way to keep the staff informed of their past decisions and current wishes. The doctor’s recommendations supported Mariah’s understanding of herself as fundamentally in charge of her children’s medical care, a perspective shared widely by middle class parents.

Entitled Skeptics were also careful to model authoritative interactions with medical professionals for their children. Take Shannon, a white mother of two in her early forties who became a personal wellness coach after improving her health drastically with alternative medicine. She recounted letting her eleven-year-old son decide if he wanted to receive the Gardasil vaccine, which is designed to protect against a sexually transmitted virus that can lead to cancer:

I had been very critical about the actual study that was done [about Gardasil]. I was kind of pissed. So I really had an in-depth discussion with the doctor in front of my son. I could tell the doctor was a little bit irritated by the questions, but in the end, I let my son make the choice, and he said, ‘Yeah, mom, if it’s something that would prevent me from potentially getting cancer, I want it.’ I was like,
okay. It’s your body. It’s your choice. But I’m glad he saw me have a very open
discussion with the doctor. And I was glad that she was ready to answer my
questions.

Far from any concerns about appearing noncompliant in front of the doctor,
Shannon felt that it was important her son see her questioning the doctor and making an
informed decision. Just as Lareau (2011) found in her study of social class and child-
rearing, middle class parents encourage their children to act independently and
confidently with authority figures from an early age. Shannon’s interaction with the
doctor was explicitly meant to foster her son’s sense of autonomy in relation to medical
professionals.

Black Entitled Skeptics were similarly unconcerned with others’ perceptions of
their compliance. Naheed, a black mother of three in her early thirties who worked as a
nurse before leaving to stay home with her children, described her response when her
middle daughter swallowed glue recently:

She vomited it up. I called Poison Control, the whole shebang. And they were
like, ‘Bring her to the children’s hospital.’ However, this was five days after I had
given birth [to my third child]. I did not feel like-- I guess if it was more severe I
would have been more frazzled and taken her in, but I just Googled what the
ingredients were and the main ingredient was alcohol, so okay, we’re looking for
alcohol-poisoning. I know the signs of alcohol poisoning. I know what happens when you’re intoxicated. None of that happened to her. So it was just like, put your thinking cap on. It helps if you have a medical background.

It’s noteworthy here that Naheed did not feel that she had to heed Poison Control’s recommendation to go to the hospital. Though Poison Control doesn’t have the ability to follow up on what callers do, nor any kind of compulsory treatment mandate, it is telling that Naheed felt comfortable asking for a recommendation and then immediately disregarding it. Though I don’t have a clear comparative case of a Constrained Skeptic calling Poison Control, it seems clear that Naheed’s class position, coupled with her medical background (which is itself classed), made her comfortable rejecting medical advice. Indeed, Naheed expressed no anxiety interacting with the medical system despite refusing all vaccines for her three daughters, and using exclusively herbal medications. When they did need to see a doctor – for example, when one daughter had a persistent gastrointestinal issue that the family naturopath could not resolve – Naheed had no qualms about doing so.

Where race did seem to make an impact for middle class participants was in the differential awareness of past medical abuses towards black patients. Several black participants, both Entitled Skeptics and Believers, told me that they were sometimes wary of the medical system because of the way doctors have treated black patients in the past. Take Danielle, a black woman and Believer in her mid-thirties without children who is an administrator at an affluent private school. Sitting in her brightly decorated office, she spoke clearly about her misgivings with white doctors:
I actually am very intentional to only get black doctors or doctors of color moving forward 'cause I don't really trust white doctors. I've come to that understanding… Basically, I just feel like there's more empathy. I think the older I've gotten and when you read stuff and you read articles and you read different things about people who are charged with being your protectors per se, like health, and then they have no exposure to people of color or no exposure to differences, they see you oftentimes like less than or not really in need or something. So there's a lack of trust. I really prefer those people [of color as doctors] 'cause then I feel like I can make a personal connection with them. So interestingly connected to that, I've got this conference where it was black educators and they were talking…about, you know, back in the day they used to do all these experiments on black people, the Tuskegee Institute, and do all these things where they would use us like subjects to practice studies…So I am actually more aware of they see me as a specimen, not actually a person, human. So I wonder if that's tied in there. That's not an active thought but I'm very aware of it. Like Henrietta Lacks, you know the things which the science world has done, the achievements they've accomplished at the expense of folks who don't look like them; I'm aware of that.

Asked more about what she does to locate doctors of color, Danielle recounted the strategies she used when she moved to a new city:
I asked around when I first got here trying to find out where all the black female
doctors were, or just the black doctors in general. You can go online and look for
a list of black doctors and stuff… Just type black everything, like black churches,
black doctors, black whatever that I'm looking for… And then I'll ask people.
Now, they don't always show their picture so you have to call and ask, ‘Do you
have a black doctor, do you have a black dentist, do you have black people on
staff?’ And then they'd say, ‘Yeah.’ Or you can hear from their voice, like, ‘Oh,
it's a black receptionist so most likely if it's a black receptionist, it's also maybe
gonna be a black doctor… Some of the [receptionists] have been trained to say,
‘Our doctors are diverse,’ blah, blah, blah, and I'm like, ‘No, I said is there a black
doctor.’ … So some places you call, but I also think about the neighborhood in
which I'm looking for doctors too. The doctor I found happened to be in [an
affluent neighborhood], but at first I was thinking there's not gonna be any people
of color and doctors in [that area]. But I found one.

Danielle’s efforts to find black doctors, dentists, and other professionals, underscores the
importance of race for a shared basis of understanding. Though Danielle did describe
several positive interactions with a white doctor, she was adamant that black doctors
would be more empathetic and better able to treat her as a full person. Such concerns
were never raised by middle class white participants.

Victoria, a black mother of three in her late thirties who works as a grant writer
for a non-profit organization, provided a unique perspective on the issue of race in
medical interactions. Raised in Jamaica, she moved to the United States for college and
stayed when she married a man she met at her Ivy League university. Victoria, an Entitled Skeptic, described a troubling period in her life when she had unexplained stomach pain. Though the pain eventually resolved itself without ever being diagnosed, Victoria was shaken by the experience:

I don’t know what that [pain] was about, but subsequently, I felt that the default of medical professionals I met with was to assume that I knew nothing. [They felt] that they were superior in knowledge, and whatever they told me I should take at face value, because they were the MD and I was the plebe off the street. That was bizarre to me. I’m not used to that at all. I’m totally used to people bringing me on the inside of their logic and explaining why they’re making this diagnosis, giving me a couple alternatives, because usually my doctors were kind of friends or people I was familiar with. People who respected my parents, because they all went to college together, so this dynamic was bizarre.

Victoria told me that the experience made her acutely aware of US racial dynamics. She gave a quiet, rueful laugh as she explained:

Of course, it’s funny, because at the time, I didn’t even think it could be anything racialized or even gender, but now in retrospect I think that may have also played a role like, ‘Oh, here’s this dumb black girl, she doesn’t know anything, let me tell you what you’re going to do that’s going to cure you.’ …I was like, what is this? This is so odd. As a result, with our pediatricians, we kind of went into the
process proactively saying, ‘Hey, hi, how are you doing? Here’s who we are. Here’s what we’re about. If you’re not able to work with us in this way, we’ll just fire you and get somebody else, because doctors are a dime a dozen.’ That really served us well, because Dave, who is our primary pediatrician, he had a very similar approach. He’s like, ‘We are diagnosing all of this together. So you’re telling me observations, suspicions, hypotheses, I’m telling you what I think based on my knowledge and then we’re deciding together about a course of action’… [It’s like,] we’re all educated humans, we have a certain expertise, what do we think?

Victoria was frank that her medical experiences in Jamaica were informed by her upper-middle class position and a social circle that included lots of physicians. Being outside of that environment and thrown into the US context of race and class, Victoria was sad and angry to find that she was not accorded the respect she had come to expect. However, by marshalling the resources of her class position, she was ultimately able to find a doctor who matched her understanding of her role as a co-decision-maker in matters of health. Victoria clearly views this doctor relationship as close and equal; she noted their discussions as giving each party equal weight, and repeatedly used the doctor’s first name.

Kara, a black mother of one and a minister in her mid-forties, recounted a lifetime of anxiety around doctors, despite being an avowed Believer. Recall from chapter 2 that Kara had a terrible experience during her first pelvic exam when the doctor, gruff and lacking gentleness, accused Kara of lying about being a virgin. For years afterwards,
Kara avoided doctors, particularly gynecologists, until eventually finding one whom she described the first empathetic provider she’d ever seen. After moving to a new city, however, she was horrified to encounter more physicians who seemed uncaring. She described going to see a male gynecologist after the birth of her daughter because she was still experiencing severe vaginal pain at four months postpartum:

I had some spots that had not healed on the inside of my vaginal wall, so between the spasms from the trauma [of birth] and the lesions that had not healed, [the doctor] said that they were going to have to cauterize those spots. Honey, you’ve not had pain like that before in your whole life. It was an office procedure…He gave me local anesthesia but didn’t give me enough anesthesia. Lindsay, I cried. [Afterwards, the doctor] never came to see about me. I had to go back because I was still in pain and I ended up seeing him, because he was the one who was available, and he admitted to me that he had not given me enough anesthesia. He apologized then. Well, shoot, you should have told me that then!…Especially now, historically, seeing how from the slave era black women were experimented on by slave owners and doctors. Even a lot of the gains we have in medicine in women’s reproductive health are because black women were abused and misused in that way. [There are] articles that affirm my suspicions that practitioners think that you just don’t experience pain, so that just kind of bleeds into the larger discussion of really, are black people human? We are human. We do experience
pain.\textsuperscript{30} So my experience kind of helps me understand all of those historical experiences. I don’t want to say it informs how I view healthcare, but I do have a suspicion, just a side eye, that I probably just didn’t have before. You just kind of trust, ‘Oh, they know the best and all that kind of stuff.’ Truth is, they don’t. They’re going through and trying to figure things out just like anybody else. They just have training to go with that.

As someone on the border between working and middle class – she was the first in her family to go to college, and the family lives on a modest income – Kara is keenly aware of how race and class impact parents’ interactions with authority. She told me about an incident last Thanksgiving in which her then-three-year-old daughter wandered out of the house while Kara was in the bathroom. The little girl made it halfway around the block before a neighbor saw her and brought her home. It gave both mother and daughter a scare, but everything was otherwise fine. However, Kara specifically noted that had she not been middle class and living in their tidy neighborhood, the same incident could have turned out differently:

I think had we lived in the city, my experience with [my daughter] leaving Thanksgiving Day, she would have probably been taken by CPS and into the foster care system. I read an article the \textit{New York Times} or \textit{Washington Post}, the same thing that happened to me, happened to a single mom. The mom was exhausted, fell asleep in the bathtub, wakes up, cannot find her daughter

\textsuperscript{30} Past research echoes Kara’s experience, finding that doctors consistently underestimate black women’s experience of pain (Staton et al. 2007).
anywhere, because her daughter didn’t know she was in the tub, so she left the apartment building looking for her. ‘I’m going to go to grandma’s house, because I don’t know where mom is.’ CPS was called. She lost her daughter for a while. Had that happened not in this suburban neighborhood, we would have had the same experience…My eyes are wide open.

Ultimately, Kara’s awareness of the role race and class play in daily life has impacted her medical choices. Like Danielle, Kara became committed to finding a black female doctor, but was ultimately disappointed that the physician she found wasn’t more empathetic. Still, she was aware that experiences of racism can hinder the very closeness she was hoping to find in a doctor/patient relationship:

I got a black female doctor, [and I thought] ‘She’ll be able to understand,’ but I didn’t feel like that at all… I actually have not had the experience with her that I was hoping for… I don’t know if she, as a black doctor, is feeling like, ‘You wanted a black doctor, why, so I can cosign your foolishness?’ She didn’t say any of those things. But when I told her I was really excited to have a black doctor, she just raised her eyebrows and just kept it going. I don’t know if she’s had the experience where maybe people have not respected her as a professional because they think shared culture breaks down barriers and they can just talk in any way. My doctor is probably a little younger than I am. She’s probably in the mode of maintaining her professionalism, just a different season of life. Often, we feel like we have to be the top and perfect at whatever it is we do, because
we’re discounted because we’re black. I dealt with that in corporate America, being young, where people would not hear what I had to say even if it was the right thing. I always had to make sure I was on top of everything.

Despite her desire for greater affinity with her physician, Kara felt that the experience of being black in America continued to shape her interactions with medical professionals. Though finding a black doctor was a step in the right direction, it did not remove race as a key factor in the way she receives care.

**Racial Constraints and Racial Privilege: How Constrained Skeptics Interact with Institutions in Medical Decision-Making**

One of the biggest contrasts between Entitled Skeptics and Constrained Skeptics was their orientation to institutions and institutional pushback against specific medical decisions. Though both faced decisions like whether to file a vaccine exemption form with their children’s school, Entitled Skeptics didn’t mention it as a source of stress, but rather an administrative hurdle that they felt confident they could overcome. Constrained Skeptics, on the other hand, were more anxious about the prospect of challenging the school system. Importantly, parents’ ultimate decisions about, and approach to, this step were shaped by race.

Taylor, a 41-year-old white mother of four who works in retail, described the mixture of worry and entitlement that she brought to a roadblock in the vaccine waiver process at her daughter’s new school:
My daughter's school didn't want to accept her vaccine waiver at first. I walked into the office of the school board, and told them I would sit there until I could talk to someone. I had printed a copy of the state law and had it with me. I went in all prepared for a battle.... only to have the very sweet lady tell me, she didn't know there was a provision for vaccine refusals, it was only her first year there and no one else had ever brought it up. We ended up having a very nice two-hour conversation about vaccines, laws, and health care in general.

However, Taylor did specify that she has had to make choices in the past that brought her into conflict with institutions.

South Carolina told me I would not qualify for their WIC program if I did not vaccinate my child. I walked out. It was a hard time, as my husband was out of work on workers comp and had two surgeries ahead of him, and the extra food would have been nice. But we got by without it, even though I went hungry many days in order to make sure my kids had enough.

Taylor faced consequences to her choices that would be unthinkable for Entitled Skeptics. Importantly, however, Taylor felt able to refuse conventional medicine without
significant concerns that she might face additional sanctions. Indeed, though white
Constrained Skeptics reported concerns about institutional interventions, compared to
their black counterparts they felt relatively empowered to refuse treatment. Dawn, a 38-
year-old white woman and mother of two who works at a daycare, told me matter-of-
factly how she approached the issue of vaccines for her children:

I did take my kids to their checkups and well checkups, but I pushed to space their
vaccines big time, because that was a scary thing. [I was] watching information
about vaccines, so that was something that really scared me. I always got flak
from [the doctors], but I mean, I didn’t care…I don’t trust what’s in those shots at
all. I’ve researched it, and to go to the CDC website and to see those ingredients
is mind blowing that people would think that’s okay to insert in your body…[The
doctors] are just trying to make you. ‘No, it’s not like that. We’ve eradicated this
or that due to the shot’…Even when I say to them, ‘This is against my beliefs,’
They’re so shocked by it.

Asked if she’s ever faced pushback from her children’s school based on her selective and
protracted vaccination schedule, Taylor sighed, seemingly resigned:

[The school administrators] are looking at you like you have neglected your child,
and I’m like, ‘My child has been to the doctor; this is my choice.’ I do not want my child slammed with these shots. Their bodies are growing. It just seems very strange to put these foreign things in… I just stated my beliefs and told them, ‘You have your right to an opinion and so do I, but I’m going to go off of facts from the CDC website because they’re listing the ingredients or listing the injuries. So you can argue that it’s a small percentage, [but] that’s still somebody’s life and that is still somebody’s child. If that was you, you’d have a totally different outlook on it.’

Taylor’s reasoning reflects the language of risk aversion and individualized medical decision-making that Reich (2016a) found among the middle class, predominantly white mothers she spoke with. Though Taylor has far fewer resources than the average medical skeptic, she brings a similar logic to healthcare decisions for her children. Notably, however, the strict vaccination exemption requirements for her state mean that she ultimately “had to play catch-up,” in her words, when her children started kindergarten. Working at a daycare and recently divorced, Taylor lacked the resources to send her children to a private school (with more lenient vaccination requirements), or homeschool her children, both options that middle class women in her state embraced.

Paula, 52 and white, was adamant that the school system in her home state of Florida honor the vaccine waiver for her youngest daughter, age fourteen:
She has a [vaccine] exemption. The schools are not allowed to question you. They might try to bully people, but it’s against the law. Down here if you have an exception, they can’t question it. You turn it in in the one year and it follows them through their school years. The only time you need to reapply it is if they go somewhere new… I did a religious exemption, to be honest with you, just because when you walk in, because of the religious freedom, they can’t question you. They can’t even say, ‘Well, what religion are you following?’ They can’t do that. You walk into the county health department down here and you request a religious exemption. You just say, ‘I need a vaccine exemption.’ You literally give them the information on your kid, your name and your ID. You don’t even have to provide your kids’ birth certificates or anything like that. You just give their social security numbers and they create the paperwork and they hand you back a copy of the vaccine exemption.

Paula presented her use of the religious exemption process as the easiest route to obtaining the waiver she wanted for her daughter. In fact, a religious exemption is the only non-medical exemption that Florida permits, but Paula seemed unconcerned about claiming a religious liberty unrelated to her actual religion.

Others found ways to explain their religious exemption in terms of individual belief. As Tammy, 47, noted:
You can’t take a philosophical exception in Iowa, but you can do a religious exception. That’s what I claimed because the MMR immunization – somebody somewhere – I’ve done a lot of research on it, but that’s the one that I specifically have known that they have used stem cells from aborted baby tissue to manufacture that at some point in time. They may not anymore, but my point is, I’m not even going to mess with that. I also feel like, if I started immunizing my kids now, if I ever had to stand before a judge he would say, ‘well, why are you immunizing them now when you couldn’t before?’ So I’m trying to keep that continuity—whatever you call that. And I think there’s just so much out there that I don’t trust…Again, it’s all about what you feel and like I said, I don’t pretend to know it all. I just know bits and pieces and when I hear bits and pieces enough, it’s like, you know what, I think I’ll just hold off on this for now until I can get better information. Because once you’ve given that kid an immunization, too late, there’s nothing more you can do, I mean, then it’s already in their blood.

This isn’t to say that white Constrained Skeptics didn’t worry about state intervention. Tammy, in fact, brought it up several times, describing a time that her daughter’s arm was blistered in a laundry accident and Tammy was scared to take her to the emergency room because “I don’t want them to think I was being terrible to my daughter.” Instead, she called a friend who brought over a kind of powdered clay, which she wet and applied to Tammy’s daughter’s arm, and then wrapped it in plastic. Tammy declares that this worked perfectly. Another time, however, when her youngest daughter
caught whooping cough, she did take the child to the doctor, saying that “the only reason I brought her is because I didn’t want anybody to try to turn me into Social Services for not treating my daughter.” In any case, she said, the doctor wasn’t able to do anything since the illness had all but run its course.

Nancy, a 54-year-old white woman, reported in starker terms her concerns about government intervention on the basis of medical decisions. She complained that conventional doctors were dismissive of any alternative medicine, and that as a young mother she had been afraid to even bring it up:

You get when you have young children you’re even scared to ask [the doctor about alternative medicine] because you don’t know if they’re going to be very watchful and call Child Protective Services on you or something like that. You have that feeling, always had that feeling when they were young if I was using natural products to even say anything in the doctor’s office for fear of retribution from them. I almost had that happen with my daughter when she was having problems with the asthma. We had been using a natural product somewhat. We didn’t say anything to [the doctor] about what we were doing, but he said something to the effect of you know you need to go do this. Probably, ‘You should have gone to the ER,’ or something like that.

It’s unclear exactly what happened next, but the doctor was apparently unsatisfied with
her response:

He just looked at me, and he said, ‘I can put her in the hospital if I have to to make you do these things.’ That didn’t go over real well. Yeah, so we steer clear as much as possible…I do fear for future generations; it’s like at least if [doctors] could just respect our wishes to use natural and at least learn enough about it to listen. I don’t expect them to be trained in it, but at least respect it enough as a method, not just blow it off as something whacky.

For white Constrained Skeptics like Nancy, the presence of the state was very real, even if she did approach it with a degree of resistance. Still, Constrained Skeptics who were black and Latina mothers faced deeper concerns about state intervention, concerns that are borne out by research finding that mothers of color are more likely to face government intervention in their family lives (Roberts 2009). Jasmine, the black mother of eight in her early forties, outlined the concerns she has had when considering refusing vaccines for her younger children:

I started getting a little concerned, because I’m low income; I don’t want it to be looked at as negligent. That’s the worry that I have is that they’ll say I’m neglecting my children, and then the next thing you know, I’m going to get in
some type of trouble. So that’s the worry. I’m still trying to do homework on that, but also I know my rights, too, I really don’t have to take them, so I’m trying to get paperwork, because it is in black and white, I just have to get a little bit more education in it and basically walk around with it every day. I do have a choice. I do have a right of not taking it, but if you don’t know that, then they can come to you, ‘oh, it’s neglect.’ How can you really tell me that I can’t do this, but it also goes back to how when you have your children, that’s why it’s very important to get full custody, because when you do give birth, the state owns them. Technically speaking, they really own whoever comes into this world, the state owns them. I just got to get educated on certain things.

As a result, despite discussing at length her interest in alternative medicine and her desire to avoid many conventional treatments, Jasmine has been extremely diligent in taking her children to the doctor, and has not ultimately refused anything the doctor recommends. When I asked if any of her children had ever been to the hospital, her answer was instructive:

Jasmine: The emergency room [has] just [been for] typical stuff, the boys playing, fighting, getting little cuts and stuff like that, and just CYA — cover myself, just go. Oh, this is what happened. But other than that, no.

31 “CYA” stands for “cover your ass.” It typically refers to avoiding liability for a potentially negative outcome.
Lindsay: You mean for state stuff or covering yourself just in case they get infected?

Jasmine: I guess both. More so the state, now, because we have band-aids, and alcohol and peroxide for certain stuff, but just that [it’s on record]. I don’t care too much for the government, but I respect it. That’s it. It’s part of the rules. You know what I’m saying? You got to live by the rules. If not, just more stuff going to just accumulate, and I don’t need that in my life.

Tonya, on the other hand, a black mother of three in her early forties who works as an administrative assistant, acquiesced to school regulations as a matter of course, despite her passionate commitment to herbal remedies and misgivings about vaccines. Asked if she gave the full vaccine schedule to her children, now in elementary and high school, she shrugged resignedly:

For the kids I do [all the vaccines]. It’s a requirement. They won’t even let you in the school if your stuff is not done. They get all of that. I don’t particularly want them to, but I’m only doing it because I think it’s required.
Tonya’s concerns about school regulations dictated her medical choice despite not “particularly want[ing]” her children to receive every vaccine. While white Constrained Skeptics in her position often described pushing back against school vaccine requirements, Tonya had not felt entitled to challenge school administrators the same way.

Importantly, however, class and race do intersec, and sometimes moderated one another. Gabriela, for example, used her latent middle class status (remember, her father worked as a private attorney) to fight her son’s school over his ADHD medication, which he had taken from first through sixth grade. At that point, however, he began complaining of heart palpitations, and Gabriela began looking into the background and testing procedures of the medication:

It just started to make me feel a little uncomfortable, because I’m like, what if my child is essentially like a lab rat or a guinea pig and they won’t know until something goes wrong? So at that time, our pastor just randomly, I think maybe two or three times he called if any children have ADHD, bring them up to the front, we’re going to pray for them. [My son] went up to the altar a couple times, and they prayed over him. I felt God was putting it on my heart, like, if you believe he’s healed, then you need to take him off the medication. You need to have faith. So I took him off the medication and it’s a big thing. It’s a really big thing, because in school he was really having a terrible time. I had to sit down
with the principal and the social worker. This was a Catholic school. They were like, ‘why did you take him off the meds?’ I’m like, ‘because he was healed by God.’ This just doesn’t register to them. They were like, ‘what do you mean, healed by God?’ I remember the principal telling me, ‘If he had diabetes, you wouldn’t be able to take him off his medication. You’d have to keep him on.’ I’m like, ‘Yeah, if he had diabetes, you could give him a blood test and / he has diabetes.’ The ADHD, you fill out a survey, and then you come to the conclusion that he has this, and I’m telling you that he’s been healed. So anyhow, it was fine. What we did was we came up with this agreement that we get to see a counselor, we get to see a therapist that would help him, work with him on behavior modification.

The experiences of institutional conflict for these black and Latina Constrained Skeptics would be unrecognizable to their white counterparts. For example, Paula, the white mother of 2 in her early fifties, was adamant that patients have to be the ones to hold doctors accountable for their poor training, a position that highlights a certain sense of entitlement:

VACLIB.org has all of the state links to each of the websites and all their requirements. There’s no excuse for us not to get an exemption if you are opposed to vaccinations for any reason. And it’s not even opposition…it’s about
being pro-choice and informed choice. And doctors today aren’t informing. They don’t inform. They threaten, they do everything except inform. If you ask questions, they get belligerent in many cases if you question their authority. The problem is, they’re not being educated in medical school. They’re told here’s the vaccine schedule and here’s why you give it. They don’t even know what a vaccine injury looks like in most cases, and if they do see one, they’ll deny it.

Paula’s insistence that anyone with concerns about vaccines should be willing and able to refuse them overlooks the constraints that women of color face when trying to make similar choices. She rightly points out that contesting conventional medicine is often viewed, by both doctor and patient, as a challenge to medical authority. For Paula, that is a necessary part of being an informed medical consumer. For black and Latina women, however, any entitlement they might feel is on much shakier ground.

**Conclusion**

Race was a key factor in how participants made medical decisions, but its precise impact varied by social class and medical orientation. For middle class participants, both black Entitled and black Believers felt empowered in their decision-making, but remained keenly aware of the medical establishment’s history of racial abuse. As a result, black middle class participants remained reserved in their interactions with doctors, and sometimes sought out black doctors to feel more comfortable. For working class
participants, however, race seemed to matter more for those who were skeptical of medicine than those who were not. Indeed, though all Constrained Skeptics were aware of state intervention and wary of institutional pushback on their medical decisions, white Constrained Skeptics approached these interactions with a degree of defiance and entitlement, while their black counterparts avoided confrontation. As a result, black Constrained Skeptics rarely actually refused any conventional treatments, choosing instead to use alternative medicine while saying they were unable to opt out of the conventional.
CONCLUSION

By most accounts, we are living in an age of unprecedented health. In industrialized countries like the United States, life expectancy has risen sharply over the course of the twentieth century, while rates of infectious disease and maternal mortality have declined (Guyer et al. 2000; Oeppen & Vaupel 2002). When we do fall ill – with anything from a stomach bug to cancer – we find that modern medicine is more often than not able to treat us with sophisticated interventions, some of which may not have existed even a generation ago. This is not to say that the medical establishment has finished its work; to the contrary, public health crises like the unfolding opioid epidemic have impacted numerous (heretofore positive) morbidity and mortality trends nationwide (Dowell et al. 2017). Yet the fact remains that modern medicine remains a triumph of the scientific age, changing the human experience of birth, health, illness, and death in immeasurable ways.

So why do some people refuse it? I find that while most studies frame non-adherence in terms of individual choice (Dubé et al. 2013), people make health decisions as part a larger social process, in which they draw on the resources and support of their communities to determine the best choice. Though interactions with medical professionals matter, the most important factor determining if a patient will refuse conventional medicine is how a patient’s social groups give meaning to, and support for, their experiences and choices. Thus, if a patient is embedded in a community in which
alternative medicine is used, respected, and shared, she will be more likely to consider CAM a legitimate healthcare option. Indeed, when faced with negative medical experiences, that patient is more likely to draw on her community to seek out advice on alternative care. The process of undergoing those treatments may in turn attract her further into a community of CAM users, thereby solidifying the values and interpretation that first encouraged her to consider alternative medicine. Ultimately, patients’ trust – or lack thereof – in medical professionals is tied to the information and support they receive from their communities, and mediated by the privileges or constraints afforded them by race and class.

**Summarizing the Four Participant Groups**

I have discussed four main participant groups, whom I call Entitled Skeptics, Constrained Skeptics, Believers, and Compliers. These groups represent differences in orientation towards conventional medicine as they are shaped by social class. All groups operate in an environment of eroding medical authority, but the degree to which they are able to challenge, co-opt, or negotiate that authority varies.

The Entitled Skeptics are middle class participants who refuse some or all conventional medicine on the basis of their skepticism towards the authority and efficacy of the modern health system. I term them “entitled” because they approach interactions with health professionals – whether conventional or alternative – with the expectation that they will be respected as educated medical consumers with expertise on their own
bodily experience. They view their health as a collaborative process. When Entitled Skeptics experience negative, and specifically disrespectful, interactions with clinicians, they draw on the knowledge and support of their community to interpret those incidents as reflective of flaws in the conventional medical system. As middle class patients, Entitled Skeptics can rely on their privileged position while questioning their doctors, seeking other opinions, refusing care, and seeking out alternative treatments. They feel empowered to engage with institutions like the public school system or hospitals, and do not worry about state intervention in medical choices for their children.

Believers share the privilege of a middle class position, but approach conventional medicine as supporters. Like Entitled Skeptics, Believers expect doctors to treat them as educated and as worthy of engaging collaboratively on healthcare options. However, Believers differ in their relationship to medical authority, which is fundamentally trusting. In fact, I call them “believers” because they actively pursue conventional medicine as the best source of expertise on health matters. Though they often want to ask doctors questions, seek out additional opinions, and research information independently, they approach conventional medicine without skepticism that doctors can help. The difference in Believers’ orientation to conventional medicine lies in their communities, which differ substantially from Entitled Skeptics in that they support medical authority as “evidence-based” and as in the public interest. For Believers, accepting interventions like vaccines is a way to demonstrate their commitment to a scientific worldview, which they equate with being responsible, educated citizens.
Constrained Skeptics are so called because, despite their skepticism of conventional medical authority, their working class position constrains their ability to challenge doctors’ orders with the same ease Entitled Skeptics display. Some reported facing disrespectful interactions with clinicians that they attributed to their status as low-income or using government assistance; these experiences were humiliating but Constrained Skeptics sometimes lacked the resources to seek different care. Constrained Skeptics also belonged to more limited communities of CAM users, frequently reporting only one or two friends with an interest in alternative medicine. For some, online groups on platforms like Facebook were their own source of support for using alternative medicine. As “lone soldiers” trying to resist conventional medicine in favor of alternative, Constrained Skeptics recounted being criticized or teased by their friends and family who didn’t understand their choices. This pushback took a toll on Constrained Skeptics, who felt less empowered to make decisions independently.

Notably, however, not all working class participants who refuse conventional medicine were constrained: Members of Full Truth Calvary Church, a white, working class, fundamentalist Christian church, are able to reject all conventional medicine in favor of prayers for healing. I argue that they are able to make these choices – even in the face of state intervention – because their faith community provides both the comprehensive meaning for their choices and the rock solid social support for doing so. Thus, when faced with pushback for their (admittedly extreme) choices, these working class members have a narrative of religious persecution and the will of God to bolster their perseverance.
Finally, Compliers are working class participants who use all conventional medicine. Importantly, however, their orientation differs from Believers (their middle class counterparts) in that they do not feel entitled to question or collaborate with their doctors. Though they fundamentally trust medical authority, Compliers are less empowered to advocate for themselves by, for example, switching to a new doctor when they don’t like the care they receive. Still, members of their communities support continued use of conventional medicine, encouraging Compliers to take their children to the doctor and giving advice on drugstore remedies.

Within these four general groups, which are based on social class and medical orientation, race continues to be a mediating factor. I find that among middle class participants, race did not impact participants’ perceived ability to make medical choices, but it did impact the context in which they made those decisions. Specifically, middle class black women – both Entitled Skeptics and Believers – reported being keenly aware of historical medical abuses of black American, referencing the Tuskegee experiment, negative stereotypes of black sexuality, and medical negligence due to racism. These participants had reservations in their interactions with medical professionals, and several spoke about seeking out black doctors in an effort to feel more comfortable in clinical settings.

Race impacted medical decisions quite differently for working class participants. First, while race differences held constant across the two middle class groups, working class participants showed racial differences only if they were skeptical of conventional medicine. That means that Constrained Skeptics experienced medical decision-making
differently by race, whereas Compliers of all races shared similar experiences. Specifically, while all Constrained Skeptics reported awareness of state intervention in their medical choices, white participants and participants of color differed in their responses. White Constrained Skeptics approached the possibility of government intervention with a degree of entitlement, or even defiance, striving to make their alternative medical choices despite financial and institutional barriers. Black Constrained Skeptics, on the other hand, experienced the threat of institutional acutely, and were much more hesitant to actively refuse conventional care.

**Contribution to Sociology**

Past research, notably that of Jennifer Reich (2016a,b; 2014), has found that people who reject interventions like vaccines are most likely to be white, college-educated, and middle- or upper-middle class parents (see also: McNutt et al. 2016). As Reich argues, parents refuse vaccines as part of individualistic and intensive childrearing, in which medicine is ideally personalized. For her participants, the work of making what they would describe as informed individual choices is heavily bound up with an understanding of themselves as committed parents doing what’s best for their individual child. Parents’ insistence that they are experts on their own children, and that medical care should be personalized to their perceptions of what those children need, forms the basis of their resistance to medical authority.
I find, however, that without looking at middle class parents who do use vaccines, Reich misses the central mechanism that dictates medical choice. Though her findings about intensive parenting were also evident in my own study, intensive parenting cannot truly explain why parents reject vaccines because, simply put, most middle class parents engage in intensive childrearing, but very few refuse medicine. I agree completely that a schema of individualism and intensive parenting lends meaning to medical choices, and that both lead parents to expect that medical professionals should accept their choice as inviolable. But these choices are also centrally about trust – trust in experts, trust in medical professionals, and trust in our communities. The key difference between those who are skeptical of medicine and those who find it trustworthy is not a distinction in parenting approaches or class ideology. Indeed, middle class parenting strategies remain relatively constant across the divide of medical views, meaning that Entitled Skeptics and Believers raise their children in similar ways. (For example, Believers mirror Entitled Skeptics by engaging in intensive parenting when they pursue individualized care, seeking out second opinions, specialists, and new doctors if they were not satisfied with their experience.) The key difference is that Entitled- and Constrained Skeptics have fundamentally lost trust in medicine as the system exclusively and best able to heal them. Conversely, Believers and Compliers fundamentally trust the system, even as they may draw on class privilege to work inside that system to secure the best possible care.

I am not the first to make the connection between medical choices and trust (c.f. Benin et al. 2006; Smith et al. 2006), nor to suggest that the social context of medical choices (particularly vaccines) matters (c.f. Bish et al. 2011; Streefland, Chowdhury &
Ramos-Jiminez 1999). However, my study is unique in showing that trust in medical authority is both shaped by social ties, and mediated by the privileges and constraints of race and class. My findings also capture a broader, qualitative perspective on trust in medicine, extending the importance of trust beyond the question of vaccines and towards a larger orientation that influences how parents approach medical authority.

Yet in the midst of these differences, it is important that they not obscure the commonalities participants share. I found that everyone wanted to be treated with respect by their doctors, and everyone wanted to feel like they have a say in their care. All participants valued clinicians who listened to them, and who took patients’ own experience into account when developing treatment. Furthermore, all participants wanted the best for their children. Whether or not they ultimately agreed to vaccinations, antibiotics, or anything else, parents made medical decisions that aligned with what they believed, in the context of their communities, to be in their child’s best interest. Whatever the state might say, I did not encounter any instances of child negligence. Though I did not always agree with their choices, I took participants at their word that they believed they were making the right decision.

**Contribution to Medicine**

The participants I spoke with are making medical choices in the context of new and growing options. Today, what was formerly “alternative” is becoming increasingly mainstream as hospitals and insurance companies offer treatments like acupuncture,
chiropractic adjustments, meditation, and yoga. On the one hand, it appears that medical professionals are coming to appreciate the legitimacy of some CAM interventions (at least as a complement to conventional care), which may help more patients feel respected and promote positive relationships with between doctors and patients. On the other hand, we might understand this shift as largely about hospitals catering to medical consumers and trying to keep white middle class dollars in the conventional healthcare system.

Yet the growth of complementary medicine doesn’t mean that relations between doctors and avid CAM users – particularly those who also refuse conventional medicine – are necessarily positive. Instead, doctors report anxiety and frustration in what they perceive as a surge in non-adherent patients whom they must (try to) convince that their recommendation is worthwhile (Kempe et al. 2015; Mohanty et al. 2018). Adding to the challenges they face, a review of interventions with hesitant patients finds little data to support the best approach for doctors seeking to assuage patient anxiety (Jarrett et al. 2015). In the absence of better recommendations, doctors facing non-adherent patients typically focus on the individual relationship, engaging in one-on-one efforts to address their concerns (Dubé et al. 2013; Opel et al. 2013).

My findings suggest that doctors are not, however, dealing with individual non-adherence, but rather with a larger community that gives meaning to medical decisions as a marker of good parenting and educated medical consumption. Building off of large scale interventions that address group-specific hesitancy (such as the World Health Organization’s “Guide to Tailoring Immunization Program”) it is now the task of those working at the intersection of social science, public health, and epidemiology, to develop
practical recommendations for health providers that address community-based skepticism. To develop trust at the community level, clinicians must be willing to genuinely engage with parents’ anxiety about medical risk, and the role that their social ties play in medical decision-making. The better able clinicians are to treat patients with an understanding of their social context, the more successful they will be in providing the meaning and support we crave in the health setting.
APPENDIX: RECRUITMENT AND POSITIONALITY IN THE FIELD

The purpose of this Appendix is to provide further detail regarding participant recruitment and data collection for my dissertation. As part of that information, I discuss the larger context of the study, including how my own position as a white, upper-middle class, married woman (and later mother) impacted the study. I explore these issues separately for data collection related to Full Truth Calvary Church and to secular participants not involved in the church. I separate my discussions because each site presented a distinct environment with unique challenges, which determined how my positionality influenced data collection in different ways.

Full Truth Calvary Church

My data collection began with members of Full Truth Calvary Church. I first became acquainted with Church members in 2011 when my family hired several church members to repair their kitchen. The members worked with a contracting firm, and my family was not aware of their church affiliation when they began working. We learned of their beliefs over time by asking about the music they were listening to (the local Christian radio station), their children (five for one worker, eight for another), and inquiring about doctors’ orders when one man mentioned shoulder pain (there would be no doctor visits). They never volunteered information about their church, but answered questions forthrightly when asked. In 2014, when I was beginning to explore issues of religious vitality and sociology, I reached out to one of the contractors to explain my
interests and asked to join his family at upcoming services. He agreed, and facilitated my entry to the community by introducing me to the pastor and several other families.

As a young, white woman, I blended into the congregation with relative ease, mimicking the modest skirts, high heels, and limited makeup of other women. Members were often interested in my own religious background, and I readily shared my identity as a lifelong Quaker. The shared Christian affiliation was helpful in establishing a rapport. However, lacking family ties to anyone in the congregation, I also keenly felt my status as an outsider. Full Truth members are overwhelmingly born into the congregation (the few exceptions being people who have married in from Christ Chapel, Full Truth’s sister church), and live in a complicated web of extended family relationships. Being outside these networks, I found it challenging to keep track of such dense bonds. For example, someone might tell me about a cousin or aunt who was likely the sister, mother, or granddaughter of someone else with whom I had recently spoken. However, my ignorance was also an asset in data collection, as I could ask detailed questions about family trees and personal relationships that could have otherwise seemed intrusive. In fact, I found that many participants were eager to share information about family networks, joking about how impossible it must be for an outsider to understand all the connections.

I found that I became closest with single women in their 30s and 40s, a development I attributed to the fact that though I was/am married, I did not have a child at the time, and was attending church alone. These qualities meant that I functioned like a single woman in the Full Truth community. Single women had more time to speak with
me after church, or to text or talk by phone, while married women were often
preoccupied with children and family duties. Single women were also employed, and so
had more in common to discuss, while married women typically stayed at home after the
birth of their first child. I became friendly with several men in their 60s, but these
relationships were generally more formal, and were limited to our interviews and short
conversations after services. I did not approach young men due to concerns that I would
be perceived as pursuing them romantically. This concern was reinforced when I learned
that the wife of one older participant, Wilson, had been upset about an interview that
occurred without her presence. From that point on, I was exceedingly careful about
keeping my interactions with men public, innocuous, and inclusive of partners. As a
result, I knew only a few young men, and even those I knew as the husbands or
boyfriends of women with whom I was more familiar.

Though my race did not make me stand out at Full Truth, my class position did.
Because church members knew my parents and had worked in their home, it was public
knowledge that I grew up in a relatively affluent neighborhood and that my parents are
college-educated. I took care to dress appropriately – both as a matter of cost and
modesty – and minimized discussion of things like travel. Still, one participant once
referred to me in passing as “fancy,” as in, “My kids said you were real nice, that you’re
a fancy lady and real nice.” It was intended as a compliment, but it made me aware of
that church members viewed me as different, and not only because I did not grow up in
the church. I don’t believe that my class position presented any significant problems, as
Full Truth is such a closed social network that being working class would not have
provided much additional affinity. In other words, though my life experience is different from church members, so is the life experience of most white, working class city dwellers.

I recruited respondents for formal interviews in person or by phone only after we had been acquainted for several weeks. Six of my respondents were female and white, of whom five were unmarried and one was married. The remaining three respondents were men, two white and one African American, of whom two were married and one was a widower. Respondents ranged in age from eighteen to sixty-eight. The gender, racial and age breakdowns approximately mirrored the demographics of the congregation, which was evenly split between men and women, covered the full age spectrum, and was almost entirely white. My respondents were disproportionately unmarried, which was due, in part, to the greater ease of recruiting respondents without childcare duties.

In the summer of 2015 I began recruiting former church members for interviews. I located these former members in two key ways. One was through current members who remained in contact with friends or family who had left the church. In four cases, current members explicitly introduced me to former members, knowing that I was interested in meeting some people who had left Full Truth. In one case, I met a former member at a bridal shower for her sister, a current member. She friended me on Facebook

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32 Former church members who have left the community typically remain in limited contact with their friends and family remaining in the community. Some current members told me that they would have nothing to do with someone who left (a sentiment that some former members shared), but most were willing to keep in touch, albeit at a distance. For example, one participant told me about continuing to follow her brother, a former member, on Facebook, noting that he had just had another baby. She was not sure if or when she would meet her new niece. For others, former members might be invited to events around the holidays or birthdays. I didn’t meet anyone who maintained a close relationship with a former member. For more information about the process of leaving Full Truth, see Glassman 2018a.
shortly after, and I recruited her for an interview through social media. In the remaining three cases, I snowballed from former members I had already interviewed to locate new participants.

Ultimately, I conducted formal interviews with five women and three men who were former members of Full Truth. Four out of five women were married; all were white and ranged in age from thirty-seven to sixty-six. All three of the men were married; two were white and one was black, and they ranged in age from forty-one to fifty-nine.

I expected that my class position would impact interactions with former members the same way it did with current members, as former members remained universally working class. However, I found that former members were generally delighted to speak with an “outsider” who understood the Full Truth community. Several described it as a “relief” to be able to talk about aspects of the church that they found frustrating or troubling with someone who has no connection to the church beyond research. In these cases, I found that any barriers presented by class differences were mitigated by a shared understanding of their former community.

The last thing to note regarding my position at Full Truth was the role of pregnancy. In the summer of 2016, I became pregnant with my son, and was surprised to discover the extent of positive impacts it had on my interactions with members. I expected that mothers I already knew would be more open about their own pregnancies and family lives, hoping to give me advice as a first-time mother. What I did not expect was how much additional attention and goodwill I would receive, particularly with
women. Mothers and grandmothers who had never spoken to me before came up to congratulate me, ask how I was feeling, and offer advice. Women told me stories from their own pregnancies and labors. Even children, particularly girls, seemed excited for me, asking when my baby was coming. Full Truth is a very family centered place, and perhaps it shouldn’t have been surprising that being pregnant raised my visibility – and status – so much. Still, the experience made me acutely aware of the status that the community confers on mothers, and the limited opportunities for recognition women without children face.

**Secular Participants**

I initially conceived of observing and interviewing non-church parents who refuse conventional medicine as a comparison to Full Truth members. I told myself that I was looking for “people who make similar choices (as Full Truth members) for non-religious reasons.” The goal was to understand how religion impacts the decision to refuse conventional medicine, and to explore the many reasons that people have for making the health choices they make.

Several problems presented themselves fairly quickly. The biggest was that finding secular people who refuse conventional medicine as completely and passionately as Full Truth members was nearly impossible. In fact, I found only one person who is as hardline in her beliefs about the evils of medicine as Full Truth members. Instead, when I went looking for people who refuse conventional medicine, I found a number of loosely
interrelated communities that refuse interventions like vaccines, obstetrical hospital birth, and medications like antibiotics and anti-histamines. They did not share an institutional affiliation or single set of beliefs. Though they were largely white and middle class, they presented more race and class diversity than Full Truth members.

This is not to say that I was shocked at the diversity of perspectives and backgrounds I encountered – I knew that I was unlikely to find anything as cohesive as the Full Truth community. Still, I was surprised not to find a more coherent organization, meet-up group, something. My decision to attend meetings of Mothers for Sustainable and Alternative Parenting (MSAP) and the Women’s Health Consortium (WHC) was largely in hopes of findings that kind of close community. Though each group had a consistent core of attendees, even these core participants lacked a shared set of decisions or an explanation for the decisions they did make. I located MSAP through a web search of local parents’ groups interested in alternative medicine (using words like “natural,” “homeopathic,” and “holistic”), home birth, anti- or slow-vaccination advocacy, or any combination thereof. I learned about WHC from a respondent, who referenced it as a supportive community for resisting conventional medicine.

I signed up for newsletter and social media notifications from both groups and began attending their monthly meetings. Both groups had fluid attendance, and no one was surprised to see a new person. My race and class position helped me fit right in with other attendees, who were overwhelmingly white, middle class mothers. When I started attending meetings I was already visibly pregnant, which also helped break the ice with other attendees.
However, in meetings it became apparent that members varied widely in their decisions, their level of commitment, and their reasoning for individual medical choices. Faced with this diverse community, and with the support of my committee, I pivoted to a different comparative model that would allow me to focus on medical decision-making more broadly. In this new study design, I decided to compare those who refuse conventional medicine with those who use it to determine why patients from similar backgrounds make different decisions. I stratified my sample by social class, and maintained racial and religious diversity in each of my study groups.

Recruiting secular participants was much easier than recruiting Full Truth members. I located participants through my social networks, beginning with acquaintances whom I know refuse conventional medicine in favor of alternative. I also emailed a local parents listserv and posted about my study on local parent Facebook groups. In these recruitment emails and posts, I explained that I was looking to interview parents of young children for my dissertation, and that I was interested specifically in “exploring how they made medical decisions for themselves and their families.” I indicated that I was looking for people who made any kind of health choices, from using a “regular” doctor to alternative medicine, and anything in between. I received over one hundred responses, and responded to all of them. Though some people did not ultimately follow through on establishing a meeting time, no one who initially reached out refused to participate after learning more about the study.

Middle class mothers were the first and most common volunteer participants. The social media and email networks I am a part of center on my neighborhood, which is full
of young middle class families. Between online recruitment and snowball sampling from existing participants, I interviewed over forty middle class mothers in about six months’ time. Working class parents who use conventional medicine (i.e. Compliers) were also relatively straightforward to recruit through my social networks and neighborhood social media, and I snowballed from the early working class interviews. By far the hardest secular group to recruit was working class parents who do not (want to) use conventional medicine (i.e. Constrained Skeptics). I found several participants through snowballing, but not enough, partially because Constrained Skeptics are relatively rare (Bobel 2010). Ultimately, I decided to join three Facebook groups dedicated to refusing conventional medicine (particularly vaccines) and to using herbal or other alternative remedies for health problems. I posted about my study, specifying that I was looking for mothers who had “chosen to parent or work after high school,” noting that I was interested in hearing from all kinds of mothers about how they have made health decisions for themselves and their families. Those Facebook groups proved helpful; of those who responded to my posts, only one did not ultimately fit my criteria (because, though she had worked for ten years after high school, she ultimately returned to college and went on to earn a PhD!).

The role of my race and class in interviews with secular participants varied. I had the closest cultural matching with Believers (middle class participants who use conventional medicine), though I also felt very comfortable with Entitled Skeptics (middle class participants who refuse some/all conventional medicine). With black Believers and Entitled Skeptics, my whiteness did not seem to discourage them from sharing their concerns about racism in medicine. By contrast, black Compliers and
Constrained Skeptics seemed more reticent with me overall, and did not bring up experiences or concerns of racism unless directly asked. White Compliers and Constrained Skeptics varied, but were generally forthcoming, particularly those I interviewed by phone. I speculate that the ease of these phone interviews was due to anonymity and lack of knowledge about regional accents.\(^{33}\)

For interviews across all class and race backgrounds, being pregnant, and then later having a baby, provided a positive, shared affinity. Many participants were in the same phase of life, and were happy to commiserate with someone undergoing the same joys and challenges.

Ultimately, I don’t believe that my findings would be significantly different if my race and class positions were different. It is possible that black participants, particularly working class black participants, would have shared more with me if I were not white, but given that I found black patients to face overall more negative experiences and constraints, it’s likely that any difference would be in degree rather than type.

\(^{33}\) When I say “lack of knowledge about regional accents,” I am referring to the fact that many white Constrained Skeptics I interviewed lived in other states, and didn’t know what a working class accent in my area would sound like. This felt important, because they could not tell my class background as easily as they would be able to in an in-person interview, or as easily as a participant from my city would be able to by listening to my voice.


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