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Managing Risky Bodies: From Pregnancy to Vaccination

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Abstract and Keywords

Health risk is increasingly calculable, often with new ways to surveil the body, in hopes of enacting change that might treat, manage, or lower that identifiable risk. Nowhere is this more evident than in pregnancy management and childhood vaccination. This chapter examines how women encounter discourses of risk during pregnancy as well as when they consider childhood vaccination and make decisions for themselves and their children. Using two case examples from a larger qualitative study of perceptions of risk and vaccine refusal, this chapter shows how women's decisions reflect the ways their pregnancy and parenting decisions are driven by perceptions of risk that are embodied, subjective, and contextual, and that reflect different social locations and processes of management.

Keywords: risk, pregnancy, birth, vaccine, medical expertise, expert knowledge, disease, health care, body, embodiment

Increasingly, risk is perceived to be calculable and subsequently mitigatable. This logic emerges as new technologies identify patterns between the conditions of bodies and negative health outcomes. With new ways to surveil the body, risk can be calculated in hopes of enacting change that might treat, manage, or lower risk (Lupton 1999). We see examples of this in health education campaigns, home health testing, or commercial genetic screening (Annas and Elias 2014). Genetic evaluation may identify pre-existing risks, while lifestyle or environment may introduce new kinds of risks, depending on the behaviors and exposures of bodies (Shostak 2013). These new ways to calculate risk and surveil aspects of behaviors and bodies provide a means of judging, classifying, and disciplining bodies in hopes of normalizing them (Foucault 1995). These dynamics take health management out of the hospital, clinic, or even the doctor-patient relationship (Armstrong 1995) and place it within individuals' daily lives and homes. There, health and the proper management of illness and risk become individual moral responsibilities (Crawford 1980) "to be fulfilled through improved access to knowledge, self-surveillance, prevention, risk assessment, the treatment of risk, and the consumption of appropriate self-help/biomed-

ical goods and services” (Clarke et al. 2003, 162). Health no longer then is a state of well-being or illness, but rather, is something to continually work toward, manage, and control (Conrad 1992). As individuals become vigilant against risk, they transform into what Timmermans and Buchbinder (2012) call “patients in waiting” or what others term “the worried well” (Wagner and Curran 1984). Even when healthy, disease risk is omnipresent, requiring vigilance and active management of the body.

Pregnancy, Parenting, and Risk Management

The discourse of perpetual risk is universal in the United States, woven tightly into the fabric of education, health care systems, and public health promotion efforts. It is also in many ways most evident among women and children. Parents are defined as responsible for children’s outcomes and well-being, with the majority of responsibility falling on mothers. Cultural expectations are that parents generally and mothers specifically intensively invest in their children in ways that are labor intensive, financially expensive, wholly child centered, and self-sacrificing (Elliott, Powell, and Brenton 2013; Hays 1996). These expectations are policed by professional organizations and state programs, which have, since the inception of pediatrics, focused on monitoring children’s health and development and providing feedback to parents on how to manage their care better (Apple 2006; Halpern 1988). Yet, as seen in much scholarship, mothers are held responsible for children’s outcomes and are uniquely blamed for children’s illness, disability, or shortcomings (Blum 2007; Ladd-Taylor and Umansky 1998). Women’s decisions and choices before, during, and after pregnancy all present risk to their future children, with medical management and self-control the touted remedies (Flavin 2008; Waggoner 2013). What to eat or how to sleep, for example, become not just lifestyle choices but also health optimization strategies for women’s own bodies and for their fetuses.

Ideologies and practices of parenting also reflect class privilege. If experts argue that raising children to become successful adults requires active management and adult intervention, often with the investment of significant resources, then some parents—those with time and money—are better situated to appear to be good parents, committed to their children’s success (Lareau 2003). Yet parental efforts to manage risk and protect children can also be seen as excessive. When parents are perceived as working too hard to protect their children or continue to intensively intervene as their children enter adulthood, they will be criticized for presenting different risks to their children’s growth, maturity, and resilience, as they are labeled “helicopter parents,” “snowplow parents,” or blade-wielding “lawnmower parents” (Hyman and Jacobs 2010).

Parents’ consumption choices on behalf of their children represent their desire to adopt strategies they believe best protect their children from potential harm or, alternatively, improve their children’s health and bodies, which they see as pure and uncontaminated at birth. Technologies can be used in ways parents feel manage, support, or improve the natural state of the body (Turner 2007), or can be perceived as presenting risk of damage to the body (MacKendrick 2018; Reich 2016).

Sometimes the same technologies are at different times imagined to be risk generating and risk mitigating, depending on context. For example, medical interventions in birth can be seen as disempowering to women or increasing risk to women and babies. Critiques of the medicalization of birth often highlight how births with lower technological intervention often end more “naturally” and with lower rates of surgical birth than are highly monitored technological births (Malacrida and Boulton 2013). Simultaneously, medical intervention into birth can reduce maternal mortality and has allowed for many newborns to survive conditions that might have otherwise been fatal (Hallgrimsdottir and Benner 2014). For women with low-risk pregnancies, home birth is no riskier than hospital birth (de Jonge et al. 2009), even as proponents of medically managed birth argue that technologies that monitor and assess risk allow those who might otherwise experience deleterious outcomes to survive (Grünebaum et al. 2015).

Similarly, parents may imagine vaccines at different times to be beneficial or risky. When risk of infection is high, parents often seek out vaccines, while at other times, parents may see vaccines as presenting an unknowable long-term health risk, which when stacked against perceived low risk of infection, seems unnecessary (Reich 2016).

These constructions of risk and intervention are powerful and ubiquitous, making them simultaneously omnipresent and invisible in their daily machinations. They also illustrate how risk is embodied and contextual. In the chapter, I explore specifically the intertwined meanings of embodied risk and medical management to show how they emerge and are managed by women in their daily lives. Specifically, I use the stories of two mothers to discuss the processes of evaluating risk and making decisions about pregnancy, birth, and childhood vaccines. Throughout, I illustrate how meanings of risk are contextual and emotional, and result from evaluation of bodies themselves.

Methods

Qualitative data used in this chapter were collected during in-depth interviews with parents who oppose vaccines. These data are taken from a larger study that includes data from ethnographic observations and interviews with health care providers and other key informants (Reich 2016). I interviewed 34 parents who live in Colorado (29 mothers and 5 fathers) who challenge expert recommendations on vaccines for their children, either by opting out completely or by providing consent to some vaccines on a schedule of their own devising. Colorado has among the lowest rates of vaccination in the United States, and it remains one of the states with the highest rates of parents claiming nonmedical exemptions (CDPHE 2015).

Despite epidemiological data that treat parental rejection of vaccines as dichotomous, in reality it is less clear. Parents constantly reassess whether vaccines are necessary based on shifting perceptions of need and risk. They consider each child in the family differently, at different ages. They may opt out entirely or consent to vaccines on a schedule other than that recommended by federal advisory bodies, state law, and physician organizations. Parents may consent to vaccinate their first child but not their other children, or

they might deliberately choose vaccines that protect against a risk they perceive as serious while rejecting others. These strategies demonstrate how parents dynamically assess risk and benefit and make vaccine decisions based on their experience, research, or perceived needs of each child.

Parents who opt out of vaccines are different from those whose children are undervaccinated because of lack of resources or access to a regular care provider. Children with significant delays in receiving all vaccines are more likely to have mothers who are unmarried, don't have a college degree, are black, and rely on publicly funded vaccine providers (Luman et al. 2005). In contrast, those who are unvaccinated by choice are most likely to be white, college educated, and have a family income over \$75,000 (McNutt et al. 2016; Smith, Chu, and Barker 2004). These patterns underscore the ways resources shape parental strategies.

Participants for the larger study were recruited using convenience sampling: by email, on listservs, or by others familiar with the study. Semistructured interviews lasted between 1 and 4 hours and were recorded and transcribed verbatim. Questions were open ended and explored a wide range of topics, including parental history, education, employment, health care experiences, relationship and family formation, family planning and pregnancy, parenting practices, interactions with health care providers and schools, sources of information and care for children's health and vaccines, process of coming to question vaccines, and views of vaccination in general.

Transcripts were initially coded and analyzed thematically, and then as patterns were identified, I employed what Charmaz (2002) calls constructivist grounded theory where data are collected and analyzed "to learn participants' implicit meanings of their experiences to build a conceptual analysis of them" (678). In aiming to elucidate the ways these parents understand and manage risk and embodiment, I have chosen two cases for this chapter that are illustrative of broader themes that emerged throughout the interview data from parents. Like nearly all of the participants of the larger study, both women featured here are white. They are politically and religiously different, with one identifying as an Evangelical Christian who homeschools her children and the other as a self-identified political progressive who seeks out a private elementary school focused on an experiential child-guided curriculum. Yet in discussing risk, parenting, and vaccines, both women described their parental strategies in similar ways and draw on shared understandings of their children's worlds and their ways to manage them. All names are pseudonyms.

Managing Risky Bodies and Motherhood

Lauren Tate is a white married mother with four children. She identifies her Christian faith as important to her and as a driving force in her decision making. As a former home health care worker, Lauren feels comfortable with medical terms and systems. However, she opts not to consent to any vaccinations for her children and rejects medical interventions in favor of more natural remedies whenever she perceives it is possible. Her experi-

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ence with four complicated pregnancies illustrates how she evaluates and manages risk in and out of health care systems.

Lauren's first pregnancy, she explains, was fine until 30 weeks (of the 40 weeks of pregnancy). "And then I just went into full-blown preterm labor. They couldn't stop the contractions—they were every 2 minutes. And they couldn't stop them. They gave me shot after shot after shot of Terbutaline," a muscle relaxer used to stop contractions.¹

After 24 hours of contractions, the obstetrical team noted that her cervix showed no signs of dilating. Realizing that further testing might increase risk of amniotic rupture, they sent Lauren home. Lauren endured painful contractions and unpleasant medications for those last 10 weeks of pregnancy, trying to manage risk of preterm labor on her own. "It kind of would ebb and flow. I was on complete bed rest and I was in and out of the hospital. I had to go to the hospital many times and get shots of Terbutaline and I couldn't sleep so I was just basically delirious." She remembers those weeks as agonizing, but ultimately successful: "The contractions were so painful they woke me up every 2 minutes forever and ever, but he made it full term." Her first son was born healthy at a hospital after 1 hour of labor. Despite the physical misery she experienced, Lauren never questioned the importance of managing her body with the use of medical interventions and indeed takes pride in having successfully done so. She also sees herself and her treatment team as collaborators in her birth of a healthy baby.

Her second pregnancy 2 years later was worse than her first. She again had contractions, but this time starting at 20 weeks, 10 weeks earlier than with her son, and before viability. Unlike in her first pregnancy, she was beginning to dilate. Filled with fear and facing the inability to manage the risk as well as she had with her first pregnancy, she recalls that she and her health providers identified their shared goal as simply getting to 28 weeks of pregnancy when the fetus would have a higher chance of survival. She again opted for high levels of medical management to get there. To maintain that pregnancy, Lauren was again physically miserable, "in and out of the hospital, on Terbutaline the whole time, bed rest the whole time." Her husband who worked nights and weekends as the sole earner was able to manage a flexible schedule to care for their toddler son. Toward the end of that pregnancy, her mother came to help. She again remained on bed rest until 28 weeks, and then, when she did not go into labor, was cautious until she ultimately delivered a full-term baby. Her daughter was born after only 30 minutes of labor but spent 10 days in the neonatal intensive care unit (NICU) with trouble breathing. Disappointed and concerned, she accepted this technological intervention was necessary.

After two difficult and medically managed pregnancies, Lauren came to see how health care providers perceived her body, not as facing risk, but as the source of risk, and as presenting inevitable risk to future offspring. She remembers physicians and nurses insisting, "'Don't have anymore.'" No one asked her what her reproductive goals might be, which included a commitment to having a large family. She felt pressured by medical staff. "Every doctor, every nurse [asked], 'Well you're never gonna have another baby, are you?'" Owing in large part to these admonitions, she decided she would not have another

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baby in a hospital. Instead, Lauren hired a midwife to plan a home birth for her third pregnancy, even as she describes it as “definitely a scary decision.” In choosing a midwife, she felt scared “because that means bucking the whole system and not using the Terbutaline because [midwives] can’t get prescriptions for Terbutaline.” Yet it also meant feeling supported and respected for her knowledge of her own body.

Lauren’s midwife, referred through her church, provided her prenatal care. She reportedly came to her house and “still did all the blood work and sonograms, [and] did the normal 20 week sonogram—where they measure everything.” Without access to prescriptions, the midwives used herbs, which she says worked, though she began experiencing contractions at 16 weeks, much earlier than in the prior pregnancies. With particularly strong contractions one night, Lauren chose to go to the hospital for help, a choice she regrets. “It was so bad, I went to the hospital and they just, like, freaked out on me.”

Lauren understands that the staff perceived her to be someone who had not had reliable prenatal care, who had ignored medical advice by again becoming pregnant, and whose pregnancy they saw as too risky for home birth. Lauren explained to disapproving staff that despite contractions, neither of her children had actually been born premature. However, she felt the doctors and nurses refused to take her own assessment of her care seriously—her embodied sense of pregnancy—or to see her as capable of making informed decisions about how to manage risk. Having been through two complicated pregnancies, Lauren felt capable of evaluating what she most needed; they did not. At the hospital she received medications that temporarily stopped the contractions long enough to be discharged.

Unlike many other women who voice certainty (Klassen 2001), Lauren was unsure that home birth was the right decision. She explains, “I was not comfortable with it, I was very nervous about it, and I felt like I was like stuck, you know? Between a rock and a hard place by making a decision.” She elaborates that on one side was a home birth, without access to medical interventions she might need, while on the other side, a hospital birth “meant going with doctors who were going to do nothing but just say, ‘Your baby’s gonna die, your baby’s gonna die.’” It seemed she could not have both medical tools to manage risk and emotional supports that might do the same.

Lauren says she understood the risk of a preterm birth without medical intervention but felt she could manage it. She explains, “You know, I have faith and—there’s nothing I could do. It’s out of my control and if I’m panicking it’s going to make it worse.” Lauren’s third child was born healthy and 2 weeks late, at 42 weeks gestation, at home after a 20-minute labor.

Lauren was committed to having a fourth child, which did not feel particularly risky after her success in her first three pregnancies. Yet this pregnancy carried different challenges. During the first month, Lauren was diagnosed with Celiac disease. Managing it seemed to prevent preterm labor, and this pregnancy progressed easily to 37 weeks. One night, Lauren had just finished putting her three young children to bed when she tripped on a toy and fell. Initially, she didn’t think much of it and went to bed. When she woke up

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several hours later, she thought her water had broken but discovered she was soaked in blood. Panicked, she went to the hospital. "I just thought the baby was dead at that point. And I go to [the hospital] and they're like 'No, your baby's fine.' " The emergency room physician conducted an ultrasound, which he said did not show anything out of the ordinary. Knowing she had used a midwife for her prenatal care, the doctor told her, "You're in early labor. Go home and have the baby."

Lauren explained that she knew something was wrong. Claiming credibility by invoking her experience as a home health care aide, she insisted, "No, you don't understand how much blood came out. I used to work in health care. I'm not exaggerating the amount of blood." She told the doctor in the emergency room, "I just have a really bad feeling. You need to get the baby out. I'm 37 weeks." Lauren requested that her midwife fax over all of her records "so that they could see that my due date was right. I had the 20-week ultrasound, I had all the paperwork in line." The doctor, unconvinced, sent her home.

Reflecting on how little credibility she had with the emergency room staff, she explains that medical providers seem to hold "the opinion that if you're having a home birth you're stupid [or] you're trying to hide something." In these interactions, Lauren's lived experience with preterm contractions, her prior birth experiences, and her certainty something was wrong were devalued. Instead, she understands that medical providers viewed her as someone whose behaviors or choices increase risk and jeopardize their goals for a healthy baby.

After leaving the hospital, Lauren's midwives came over. She recalls their sense of panic as they felt certain she had suffered a placental abruption, where the placenta separates from the wall of the uterus, depriving the fetus of oxygen and nutrients and causing severe and potentially life-threatening bleeding in the pregnant woman. They debated whether to wait for a shift change or send her to a different hospital, but the bleeding stopped and the sense of urgency faded. One week later, the bleeding started again and Lauren returned to the emergency room only to find the same doctor working. She remembers him telling her, "You do not have a placental abruption... . Don't come back unless you're sitting in a pool of blood." Lauren begged to be admitted to the hospital, where she could be induced. Unsuccessful, she called doctors who provided care during her first two pregnancies. As she recalls, "They all told me basically, 'You've decided on a home birth. That's your choice. You're stuck with it.'"

It is worth noting here that obstetricians face intense pressure for good fetal outcomes and have among the highest rates of malpractice insurance of all medical specialties, which underscores expectations they must manage fetal risk perfectly (Morris 2013). Although we cannot know why they approached Lauren as they did, these pressures logically predict against them welcoming a patient late in pregnancy who believes she is experiencing a serious complication. According to Lauren, none agreed to take her case.

At 40 weeks of pregnancy, Lauren again began bleeding heavily. When she could not immediately reach her husband by phone, she panicked and called for an ambulance, an action she now describes as "the worst mistake ever." When she arrived at the hospital, she

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was told that the baby was in distress and needed to come out. Already at 6 centimeters and caked in blood, she was told she was having contractions she could not feel. After a hospital delivery she had not planned, the obstetrician told Lauren that she had suffered a 25 percent placental abruption, where 25 percent of the placenta had detached from the uterus.

Although she was relieved the baby was healthy, she felt persecuted as hospital staff confronted her in hopes she would confess how she had caused the abruption. In these interactions, she could feel competing definitions of risk and blame. She recalls one nurse who rejected Lauren's accounts, noting, "The only way that this could happen is for you to use cocaine or get in a car accident. You can't get this by tripping and falling on the carpet."

Underscoring the nurse's perception of risk, Lauren and her newborn son were drug tested, which, although negative, was noted in their medical records. Friends tried to convince Lauren that the test results exonerated her, but she felt humiliated. She remembers that the nurses "were watching me like a hawk because I'm sure they thought, you know, 'She's totally guilty. She's gonna bolt,' and they didn't even leave me alone basically."

The baby was large for gestational age and his blood sugars were aggressively monitored, which is another form of risk management. Lauren had lost a significant amount of blood and was unable to stand unassisted but wanted to breastfeed. She objected to them taking the baby out of the room for several hours at a time or offering him formula. Once her baby's pediatrician arrived and said he was well and could go home, Lauren in her weakened state discharged herself against medical advice. Lauren reflects on her experience: "It confirmed all my fears about hospitals."

Lauren's relationship with medical care and physicians structures how she approaches vaccinations. In general, Lauren trusts her judgment more than she trusts the views of experts. Just as she identified what she needed in pregnancy and found medical providers dismissive of her self-assessment, she expects that they will disapprove of her health care choices so she only seeks care when she perceives it as essential for her children's well-being. She has rejected all vaccines for her children, except the vaccine against tetanus because she believes that since the bacteria that causes the disease is in the environment, it presents a real risk. In contrast, other vaccines seem unnecessary, particularly since she homeschools her children, limiting their social contacts—and possible infection risk. She most particularly objects to the Hepatitis B vaccine, a disease transmitted through blood and bodily fluids, since she can't see how her children who she is raising to share her Christian beliefs and lifestyle will face risk of infection.

Lauren does not wholly object to medical care. She has taken her children for myriad procedures, including adenoid removal, casting of a broken arm, treatment for a scratched cornea, ear infections, strep infections, and digestive problems. Each of these conditions, like the demand for intervention when she perceived fetal distress in pregnancy, presents a risk she sees as legitimate and manageable with medical technologies. In each, she assesses risk and decides the correct course of action, which as a mother she feels uniquely qualified to determine. Even having refused virtually all vaccines for her children, she

says she is open to revisiting that decision as information or circumstances change. She explains, “We are not, definitely not anti-, you know, we fall on the spectrum that we kind of see, ‘Well, what’s going to happen as the kids get older? Do we need to do something and vaccinate them?’” In these ways, vaccine decisions, like other health care decisions, require careful risk assessment and deployment of technologies as they are necessary to manage that perceived risk.

Managing Future Risk and Present Uncertainty

Katie Reynolds is a white mother of two who works hard to manage risk in her children’s lives. She describes herself as someone who reads everything to make decisions and, as a freelance writer, has the time and flexibility to do so. For example, when it took 6 or 8 months to conceive her first pregnancy, she decided she needed to become more deliberate in her efforts. Identifying her body (and not necessarily her partner’s) as the barrier to conception, she recalls, “I had the books out about, like, timing everything and I was like, ‘Okay, scientifically I should be able to do this in a month. So of course I was reading.’”

In her first pregnancy with her son Julian, she remembers working hard to educate herself. “I did everything, like, went out and bought *What to Expect When You’re Expecting*.” She followed the lead of friends who already had babies and sought care from the obstetrician they used. During her pregnancy, Katie says she read “a lot and researched a lot on childbirth” and began questioning the medical care she was receiving. Despite her efforts to gather formal information, she trusted her intuition more: “Intuitively it seemed to me that there’s—I felt like there’s way too much intervention and women didn’t have enough power in the process or enough say over what was happening to them and so I was sort of questioning some of the practices.” She hired a doula, a lay birth attendant, in hopes of having as “natural, as unmedicated of a birth as possible.”

Despite voicing her rejection of medical interventions, Katie gave birth in a hospital. This choice represents both her resentment of medical systems, which she feels do not place women in control of their care, and her desire to access medical technologies and experts if a complication were to arise. In the former, she sees medical practitioners as imposing excessive assessments of risk and unnecessarily managing her body, and in the latter, sees those same practitioners and having skills and technologies to manage significant and unexpected risk. Her description of her labor experience illustrates her resentment of restrictions in the hospital she chose:

Everything was fine, but it was like, I was in the bathroom sneaking things to eat during labor because I wasn’t supposed to be eating ... so it was just kind of like a lot of sneaking around; they wanted to give me Pitocin to speed up my labor, and I didn’t want it, and there was a lot of people trying to intervene when I really didn’t want intervention.

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In these examples, Katie sees medical efforts to manage risk—of long labors or ingested food that could create challenges should a caesarean section delivery become necessary—to be excessive and restrictive. As such, she challenged them, even as she chose to be in a hospital in case other risks became compelling to her.

Katie works hard to make informed decisions. When she doesn't conduct her own diligent reading, she sees those subsequent decisions as inferior ones. For example, Katie consented to have her son circumcised because her husband was insistent they do so, a decision she regrets. "To me that was an example of where I sort of didn't make a decision, let somebody else make the decision for me, and it didn't turn out right."

A similar decision was made immediately after Julian was born. As she remembers, a medical care provider at the hospital informed her that her immunity against measles, mumps, and rubella was low and recommended a booster, given in one injection as the MMR vaccine, to protect her and her baby, as well as future pregnancies that could be devastated by exposure to measles and rubella. Katie did not hesitate. "I didn't question that at all. I just sort of was like, 'Oh, okay. Give me the shot so I can leave.'"

Katie did not think about that vaccine until just before her son's first pediatric appointment when she would be asked to consent to the first round of routine vaccines against childhood illnesses. "So then 3 months passed and ... it was like the night before he was getting his first round of immunizations and I thought, 'Oh, I should probably ... I just felt like I had made a lot of decisions without really researching them.'"

Katie turned to *Mothering Magazine* and its accompanying website, a publication that self-references as "the home for natural family living." There she came across information that concerned her.

I was always really worried about autism to begin with. There was some study that was done where children whose mothers had received the MMR vaccine while they were nursing, the child went on to develop autism in like 20 out of 25 cases in some study in England... . So I was freaking out about that, because I thought, here I am worrying about his vaccines and I totally agreed to do that and didn't think twice about it.

She sees this decision as an example of a having failed to identify and manage risk. She explains, "Here I won't take an aspirin while I'm nursing, but I did that, you know? So I was really freaking about it and calling everybody I knew ... so at that point I was like, 'I'm not getting him the shots.'"

Katie's mother attended that first appointment with her and, insisting that she worries too much, convinced her to consent to the first round of vaccines. Julian did not have an adverse reaction, which quelled her fears. Yet as Julian's first birthday approached, Katie became increasingly concerned about the upcoming MMR vaccine. As she recalls,

Now around this time one of my friends who was sort of into all these questions too told me she had read something and I guess the crucial thing with this study with the MMR booster and the mother was the child developed autism after receiving their own MMR booster. So that was sort of like the trigger... . At that point I said to my husband, "If I get hit by a bus tomorrow, the one thing you have to remember is do not give Julian the MMR booster" because I kept thinking, to me that was gonna be, that would be the trigger.

Katie believes her MMR booster carelessly introduced risk and, as a result, she must be vigilant. "Maybe if it hadn't been for me getting the MMR, I would have done all [vaccines] and not questioned it." As Katie perceives it, this intervention into her body introduced risk to her son's body, as pregnancy and breastfeeding link their health and well-being.

Katie works to manage her son's health. However, his health issues suggest some are beyond her control. Julian developed "a lot of allergies, eczema, definite immune system issues," all of which made Katie more cautious. He also, she explains, "has sensory processing dysfunction and potentially is on the spectrum for Asperger's—for autism, although we haven't really pursued a diagnosis. As she considers his health, she notes, "He's very high functioning, but he's got some quirks." These health issues, she imagines, place him at increased risk for autism, so she guards against a possible trigger.

Katie's description of her son communicates both affection and sadness. "My son is very, he's probably ahead for his age intellectually or cognitively, but you know his language skills, his motor skills, and other things are a little behind." She continues, noting the times he struggles. "Like, when he's the only kid who doesn't get invited to a birthday party at school or when people say, 'Oh, why does he drool all the time?' Or, you know, stuff like that."

Katie agonizes about how to make sure her son succeeds and perceives she is responsible for his well-being. She visited more than fifteen preschools before choosing one. She conscientiously manages her family's diet and nutrition. She consults a variety of specialists, including a pediatrician who touts holistic care, an allergist, a craniosacral practitioner, and a homeopath. "I've tried everything to try to help him because he doesn't—because he kind of falls through the cracks in terms of understanding what's going on with him. Nobody can quite put their finger on it so that's why I've tried different routes."

Katie's perception that her son's health is difficult to understand is notable in light of her resistance to having him diagnosed by pediatricians or special education service providers. Rather, she sees her son as a complex person and thus resents how diagnostic processes might place him in a proverbial box that masks his uniqueness.

Evaluating situations to decide how to best manage risk for her son is, as Katie sees it, her responsibility. She explains, "I feel like I have to be his advocate and figure out what situation's gonna work for him." This extends to his education, diet, services, and health

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care. She fears vaccines could present risk to him but also fears some infectious diseases, which she understands are prevented through collective strategies to vaccinate.

My preference would have been not getting any of them, granted understanding that that's a purely selfish decision. But the decision I made is that, "Yeah, pertussis is dangerous, but if my child gets the measles it's not the end of the world." So it was not just weighing the risk of the vaccine, but weighing the risk of the vaccine versus the risk of [infection].

Katie describes her efforts to manage her son's health to be all-encompassing and exhausting. She spends countless hours gathering information and expending significant emotional energy. Katie compares herself to her sister, who follows expert recommendations "by the book." She describes the difference. "Every vaccine she got I had to agonize about it, agonize about what should I do? What should I not do?" She admits, "I feel like I get burned out."

Some of this exhaustion emanates from her decision to take Julian to different providers who, she says, each ask for her son's history in an effort to evaluate risk and find possible explanations for his challenges. In these efforts, they often focus on whether Katie created or failed to manage risk. She explains with exasperation, "I don't want to hear anybody else, I don't want to tell—or have to talk to anybody else or talk about his birth again or—'Did you have a long labor? Did he have any birth trauma? Um, what did you do wrong when you were pregnant?' You know, just going on and on, and usually it involves something I did wrong."

These lines of inquiry remind Katie that children's outcomes are mothers' fault (or occasionally, credit) with obligations to manage risk starting even before they have become mothers—during pregnancy or even before conception. These questions over time have shaken Katie's confidence, making her wonder whether she did unknowingly introduce risk to her son. "When people are always asking you questions about it all too ... you start thinking, 'Well, maybe I—I thought I had a really easy pregnancy, but maybe I didn't; let me think. Maybe I ate a lot of tuna at the beginning of the pregnancy. Maybe that was it.' I think about the mercury in the tuna, you know?"

Katie's willingness to accept blame extends to her emotional state during pregnancy, which she fears may have primed her son for challenges. "One of the things I wonder with my son too is he was born a month after 9/11, and I was just a basket case the whole month before he was born." Katie says she better managed emotions during her pregnancy with her daughter, born 4 years later, which may have contributed to her easy-going nature. "I tried to do so much yoga and stuff when I was pregnant with her. Maybe that did something." Katie accepts that her behaviors, decisions, and feelings could have causally shaped her children's health and well-being. As such, she insists on remaining vigilant and examining each decision closely. Yet she finds decisions do not become easier to make over time.

You would think by that point I would have a clear view one way or the other, but I still haven't a clue. I mean, I sit there and question, like, cod liver oil or fish oil, you know? What should I get? But what about the pollution of the oceans? I sit there and second-guess everything.

Katie's laborious efforts to manage risk and her inability to do so perfectly are palatable and are most visible when she questions whether she could do more for her son. Yet she also seems certain that her intense efforts to make good decisions are important. Despite her uncertainty about the outcomes of her decisions, Katie nonetheless advises other mothers to trust their instincts, as she aims to do. She insists mothers should claim ownership of decisions and trust these decisions become easier over time. "Like for all the experts who will tell you what to do, just don't do it. Do what works best [for you]. I feel like I'm much more intuitive about the way I make decisions now than I was [when Julian was born]." Katie sees herself as making good decisions, even as she agonizes over them, fearing that a bad decision will introduce risk to her children that she can't manage. Yet she reiterates that mothers are best able to make these decisions for their children and should do so.

Making Sense of Embodied Risk and Parenting

Perceptions of risk are subjective, even as they are co-constructed by medical experts. Prenatal care, pregnancy, birth, and parenting are moments that demand calculations of risk and intense calls for bodily management. Women face scrutiny; they also demonstrate a willingness to evaluate their own choices and behaviors in terms of the degrees to which they manage or invite risk—both alongside and against medical guidelines. The experiences of both Lauren and Katie illustrate willingness to seek expert input and also an insistence on a right to reject expert opinions when they don't resonate with their own perceptions and embodied experiences of risk, need, and benefit.

Vaccines are a technology to protect against a hypothetical future exposure to bacteria or viruses that can cause disease. Children's bodies are perpetually at risk of the most serious outcomes of exposure. In making vaccine decisions, mothers estimate the chance of encountering a disease that could have been prevented, the seriousness of the disease, and their ability to manage that illness should their children become infected. They then stack that against perceptions of vaccines as causing other health risks that may not be fully anticipatable. Despite volumes of evidence that vaccines are safe, parents often feel uncertain about those claims. As they see themselves as uniquely able to assess necessity and risk for their children, they sometimes reject vaccines. Lauren's story illustrates how women trust their own embodied experience just as Katie's story demonstrates the importance of mothers' knowledge of their children's needs, vulnerabilities, and risks that emerge within their bodies.

From pregnancy through parenting, mothers, who are disproportionately responsible for health care decisions and almost entirely blamed for children's illnesses, consider how to manage their own bodies and those of their children. Yet their choices are situated within

larger understandings of medicine, health, risk, and necessity. Medical knowledge increasingly measures risk, beginning before conception (Waggoner 2013), and suggests innumerable ways to mitigate that risk through individual management, even as much disease risk is in fact environmental and beyond individual control (MacKendrick 2018; Shostak 2013). The result is that the body becomes not just susceptible to risk (and the beneficiary of management strategies) but the source of risk itself.

In considering how the body carries these dual meanings, it is important to focus on how they are indelibly connected to perceptions of mothers as managers of risk, filtered through systems of gender, race, class, religion, and embodiment. Women's increasing willingness to challenge health care providers and rely on their own judgment or intuition illustrates how expert knowledge becomes democratized and contested (Barker 2008). This often leads to competing understandings of the relationship between risk and the body and conflict in care strategies. Ironically, these tensions arise from public health education campaigns, which increasingly insist on greater individual responsibility for health and patient self-advocacy.

As children's health outcomes are attributed to mothers' behaviors, women will increasingly accept responsibility and make decisions independent of experts. Katie's fears of autism and her perception that she is solely responsible for her child's health illustrate this, as does Lauren's efforts to manage pregnancy and birth outside medical systems, even as they both want medical systems to be available should they decide they need intervention. Yet the ability to move in and out of medical management highlights how those with the greatest amounts of social capital will be most able to define their own goals and exercise them to the limits of their resources. Katie and Lauren both had families in which they did not need to work for wages, giving them more time and resources with which to manage their children's care. Vaccine refusal and demedicalization of pregnancy are two examples of how this manifests. While more privileged women may experience disapproval from providers, those with the greatest access to resources are still best situated to refuse medical expertise. For some with less capital, refusal will result in more formal social sanctions, including referral to criminal or civil systems of punishment (Flavin 2008; Reich 2005). In these ways, risky bodies—in definition and management—inevitably reflect individual social location and will thus be viewed, assessed, and managed unequally. Yet for all, the willingness to refuse the disciplinary gaze, which aims to measure and manage risk, will reveal the tensions between expert knowledge, power, and individual autonomy.

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Notes:

(1.) Terbutaline is an asthma medication that causes muscle relaxation and has been used to limit contractions. In 2011, the FDA issued guidelines about its off-label use for preterm labor. See <http://www.healthline.com/health/pregnancy/preterm-labor-terbutaline>.

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