VACCINE SKEPTICAL MOTHERS IN THE UPPER MIDWEST AND THEIR KITCHEN-BASED CARE PRACTICES

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The Supervisory Committee certifies that this ***disquisition*** complies with North Dakota State University's regulations and meets the accepted standards for the degree of

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ABSTRACT

While many Americans view vaccination and medical intervention as benefits to society and for the greater good, vaccine skeptical mothers not only reject vaccinations but most biomedical interventions as well. In place of biomedical interactions vaccine skeptical mothers here focused on daily care practices centered around a healthy diet and eating whole foods. Further, they then create alternative forms of care that are founded in their kitchens and based on their own expertise as mothers, rather than with the expertise of biomedical experts. Based on nineteen months of in-person and virtual ethnographic research in a mid-size Upper Midwestern city in the United States, this research sheds light on the broader relationships between mothers who reject biomedicine and their caregiving in contemporary America.

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A very special thanks to my husband, Ali, who has spent many hours extending encouragement and motivation, including support in negotiating the balance of life throughout the process of my master thesis research and writing. I also want to include special acknowledgement to my daughters who were watching from the sidelines while I was occupied with in-depth conversations or focused on writing, often hearing, “just one more page” of writing to do before my attention was free for them.

I offer my appreciation to the mothers in my research, who opened their homes, lives, daily routines, and their deepest thoughts and memories.

DEDICATION

I dedicate this research to my daughters, watching and learning how women must constantly negotiate and explain their choices and decisions in life. May you always be confident and strong.

I dedicate this research to my husband, a constant support in my life and eternal cheerleader for my success.

I dedicate this research to all women and mothers making tough choices in life and parenting.

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LIST OF ABBREVIATIONS

CAM .....Complementary and Alternative Medicine

CDC .....Centers for Disease Control

VPD.....Vaccine Preventable Disease

NICU.....Neonatal Intensive Care Unit

OTC.....Over the Counter

UTI.....Urinary Tract Infection

LLL .....Le Leche League

1. INTRODUCTION

On March 18th, 2021, I received my Covid-19 vaccination. As I walked away from the vaccine clinic, my husband noted how interesting it was that I was wrapping up my thesis on vaccines, during a pandemic. After nineteen months of immersing myself in the world of vaccine skepticism, I then had to decide for myself whether to get the brand new Covid vaccination. While superficially, it may seem that researching attitudes toward vaccination during a global pandemic would be ideal, it was also a challenge. I faced a constant barrage of information and discussion on my research topic all day, every day. While emerging conversations on the topic of vaccination were plentiful and helpful, where other student researchers may have had the ability to turn their research mind "off" for a break, I found that I could not. Anthropologists typically immerse themselves into the lives of their interlocutors, and I did as much was safely possible. Doing this while also keeping up with the news on the release of studies on vaccination safety, side effects, and the public's reactions to it all meant that the research process was constant and exhausting.

When I started this research journey, discussions on vaccine skepticism were not normal everyday conversations, not for my interlocutors nor for the public. Throughout 2020 and thus far into 2021, vaccination has become a daily topic for nearly everyone. While some people who previously had been extremely pro-vaccination suddenly felt some vaccine skepticism about what was perceived to be a rushed approval process for Covid-19 vaccines, others who were previously against vaccinations suddenly questioned their vaccine skeptical tendencies. What I saw emerge in my research is that contrary to popular belief, mothers who are vaccine skeptical cannot be described by any one characterization, idea, or stereotype, which means that generic campaigns to promote vaccination based on these concepts will surely fail. These vaccine

skeptical mothers did not see themselves as the often-repeated stereotypes such as anti-science, dumb, or uncaring. My interlocutors spent hours researching and reading about health. They spent time very intentionally caring for their families in the best ways that they could, by promoting health in lieu of vaccination. Each mother saw their family's health as unique, rather than fitting into the one-size-fits-all healthcare model.

As a mother with children, I have routinely sought connection with other mothers through in-person playdates, activities, and online parenting support groups. I have always been aware that there were some mothers who chose not to vaccinate their children. It was a point that I did not think about often and it was not regularly discussed in playgroups or online parenting forums. But it was sometimes brought to light by an innocent question from a new mother and I soon learned that it was a hotly contested parenting topic. Never one to shy away from a controversy, I knew I wanted to use my research to pursue the topic of "those mothers," the mothers who refuse childhood vaccinations for their family.

I immediately conducted preliminary research to determine if it would be possible to find vaccine skeptical mothers willing to participate in this research in this geographic area in the limited time frame that I had. It soon became clear to me that there was a plentitude of mothers who were not only willing to partake in this research, but excited to talk to someone who would be willing to listen to their stories. I dove into in-person and online local mothering groups focused on Complementary and Alternative Medicine (CAM) in place of vaccination or other biomedical interventions. Additionally, I discovered a broader online world of social media groups and events relating to parents who question the safety of the typical vaccine schedule and later learned of the newly termed "health freedom" and "medical freedom" movements.

Throughout this research, my intention was to listen to vaccine skeptical mothers' stories to understand how and when they decided to shun vaccination. My goal was to find the elusive reasons *why* mothers choose not to vaccinate. I was interested in their seeming mistrust of clinical health professionals. To situate my findings, I first outline the broader context of social and cultural ideals about mothering in contemporary U.S. society. I then look at ideas about care as context, which includes examples of mothers providing care based in the kitchen. Finally, I review concepts of risk and trust in biomedical healthcare settings and how mothers who have experienced paternalistic, demeaning, and dismissive biomedical interactions now view all biomedical interactions and interventions as a risk. I argue that when mothers reject biomedicine, they become the perfect neoliberal consumer.

1.1. Background

According to the Center for Disease Control and Prevention (CDC) website, vaccines contain a weakened, killed, or fragmented version of the same bacteria or virus that causes a disease. Vaccines stimulate the immune system to produce antibodies as if you were exposed to the actual disease, creating immunity without having had the disease (CDC 2012).

Vaccine skepticism is not a new phenomenon (Reich 2016; Yochim and Silva 2013). In 1905 the Supreme Court heard arguments in the case *Jacobson v. Massachusetts*. A man named Henning Jacobson challenged the state compulsory vaccination law refusing to receive the mandated smallpox vaccine and presenting arguments about its lack of efficacy and safety, as well as the probability of harm (Reich 2016). By the time of the announcement of the polio vaccine by Jonas Salk in 1953, there had been both underlying skepticism and out-right refusal to participate in state-led large-scale public health vaccine campaigns (Conis 2013; Hausman 2019; Olpinski 2012; Reich 2016).

Modern vaccine skepticism has similarly focused on the powers of the state and medical institutions, with an added suspicion of "Big Pharma" (Conis 2013; Poltorak *et al* 2005; Reich 2016; Yochim and Silva 2013). Early vaccine skepticism based on suspicions of state and medical powers laid a foundation for second-wave feminists to question the same presumed overreaches of power in their healthcare experiences.

Although early vaccine opponents were men, women picked up the cause in the 1960s during second-wave feminism as a part of their rallying cry against patriarchal social institutions. They continued on a similar thread of suspicion of state powers, the medical establishment, and big pharma, adding that big business and science did not believe in their expertise as women or as mothers (Craven 2005; Davis and Craven 2016; Reich 2016; Yochim and Silva 2013). During this time, women demanded more health autonomy based on their expertise, pushing back against the biomedical model that doctors know best (Conis 2013; Craven 2005; Yochim and Silva 2013). Women demanded a right to choose their medical providers and the types of care they received, as well as to know the potential side effects of drugs and vaccines for their children (Conis 2013; Craven 2005; Yochim and Silva 2013).

At the same time women were questioning the patriarchal healthcare system, the American neoliberal healthcare system based on individual responsibility was also growing (Trnka and Trundle 2014). According to anthropologist Carole Browner (2019) the "neoliberal medical industrial complex" dates back to the 1960s. During this time, a network of corporations started to provide healthcare services for excessive profit rooted in "competitiveness, self-interest, and decentralization" (Reich 2016, 342). Neoliberalism involves such fundamental ideals such as shrinking state mandates, deregulation, increasing privatization, and confidence that markets will govern the healthcare system (Trnka and Trundle 2014). A neoliberal

healthcare market stresses individual responsibility through personal choice and freedom and maintains that individuals should actively manage themselves through "informed decision-making" (Reich 2016, 342; Trnka and Trundle 2014). The neoliberal healthcare consumer performs actions such as self-education, comparison, and research on healthcare providers and health options. Such "good" consumer behavior is also related to what counts as "good" mothering in the contemporary United States (Kaufman 2010; Reich 2016; Sobo et al 2016).

The responsibility of engaging in the neoliberal healthcare system typically falls upon women (Reich 2016). And while the critical healthcare consumer is considered a positive within a neoliberal healthcare economy, negative perceptions abound of women who are critical of biomedicine and express their desire for something different as they make care decisions for their families (Conis 2013; Craven 2005; Reich 2016; Varman and Vikas 2007; Yochim and Silva 2013). For example, writing about vaccines from the perspective of feminist literature, Bernice Hausman (2019) notes that between the years of 2005 and 2010, public discourse about vaccine skeptical mothers had become more inflammatory and more aggressive (2019). More recently, public commentary in various sources such as journalism, clinical vaccine campaigns, and social media have labeled non-vaccinating mothers as "anti-vaxxers" (Hausman 2019; Kitta 2019). "Anti-vaxxer" connotes not just antipathy toward vaccination but also suggests that these women are anti-science, irrational, ignorant, and irresponsible (Conis 2013; Hausman 2019; Kitta 2019). When there is a VPD (vaccine preventable disease) outbreak, circulating rumors often blame anti-vax individuals or families (Kitta 2019; Poland and Brunson 2014). During the Disneyland measles outbreak in 2015, for example, initial reports in mainstream media outlets circulated that patient zero might have been a young woman with an incomplete or absent vaccine history (Kitta 2019). In contrast, news in anti-vaccine circles suggested that this person had been vaccinated

but that the vaccine did not work (*ibid.*). Patient zero's identity is still a mystery, leaving the public to speculate which "side" of the vaccine debate is correct (*ibid.*).

1.2. Research Significance

Nearly every publication on vaccination has an introductory statement that cites vaccines as one of the greatest medical inventions of all time. Vaccination has resulted in a dramatic decrease in VPD's, particularly in middle- and high-income countries (Brunson 2013; Kaufman 2010; Omer et al 2009; Poland and Brunson 2014; Williamson and Glaab 2018). It seems self-evident that families would choose vaccination, yet there is a growing number of well-educated parents who choose not to vaccinate their children (Brunson 2013; Poland and Brunson 2014; Sobo 2015; Sobo et al 2016). Some non-vaccinating mothers feel that potential side-effects from vaccination creates a risk that outweighs the benefits (Brunson 2013; Poltorak et al 2005; Sobo 2015; Williamson and Glaab 2018).

Notions about why families do not vaccinate and ideas about how to get them to do so have circulated through various disciplines, including public health (Brunson 2013; Omer et al 2009; Poland and Brunson 2014; Sobo 2015). But vaccine refusal demands an anthropological approach to address the issue holistically by attending to its cultural, social, and political aspects.

From an anthropological perspective, vaccine skepticism provides a way to think through the tensions between the moral expectations of motherhood and a neoliberal healthcare model which emphasizes individual responsibility. Individual responsibility is publicly approved, but only when an individual makes the "right" healthcare choices. When mothers exercise their right to choose what kind of health care they want, the mainstream medical system pushes back in ways that come across as paternalistic and disempowering. For such mothers, it is easier to chart their own paths outside of what they see as a paternalistic healthcare system.

Such anthropological insights are important as clinical and public health professionals continue to grapple with vaccine skepticism. These insights are especially critical as the global medical community attempts to gain public trust of the new Covid-19 vaccines. By taking the perspectives of mothers who refuse vaccination seriously, we can glean a more thorough understanding of vaccine skepticism when we need it most.

2. LITERATURE REVIEW

2.1. Mothering

Anthropology has long recognized mothers as unique transmitters of culture, kinship, family, and reproduction in society (Barlow and Chapin 2010). Mothers are tasked with not only ensuring their children's survival into adulthood, but also their ability to thrive out in society (Conis 2013; Reich 2016). Expectations about mothering are publicly polarizing in terms of moral judgements of what is good or bad mothering (Kitta 2019; Reich 2016; Yochim and Silva 2013).

Anthropologist Christa Craven notes that medical discourses around women's and family health care practices often overlap with state discourses about what practices are deemed good or "respectable" (2005, 194). Ideas about respectable and acceptable health care are assimilated into American principles which impact mothers who defy dominant health trends (Craven 2005). In her research, Craven collected health histories and stories of women's experiences with biomedicine during prenatal and birth interactions and found that nearly all of them had experiences of "dangerous and disrespectful" treatments, which led to feelings of disempowerment (Craven 2005, 204). Ultimately, research has shown that when mothers stray from a set of ideals about the "right" medical choices for themselves and their families, they are pressured into choices that align with social standards (Reich 2016).

Idealized standards of what mothers should and should not be doing are created by society and governments with a healthy child symbolizing a good mother, while mother blame is cited for children's failures (Barlow and Chapin 2010; Craven 2005; Reich 2016; Yochim and Silva 2013). When things go wrong, mothers find themselves caught in "a culture of mother-blame" (Singh 2004, 1201), blamed and shamed for their poor parenting skills (Conis 2013;

Yochim and Silva 2013). Public discourses exude pressure onto mothers and emphasize power dynamics, which mothers must constantly negotiate to claim successful mothering (Barlow and Chapin 2010; Craven 2005; Yochim and Silva 2013).

Claiming authoritative knowledge based on their personal experience and identity as mothers is what Emily Yochim and Vesta Silva (2013) call "expertise of the everyday". Expertise of the everyday considers lived experiences as justification for mother's individual choices and interventions about health and childrearing (Conis 2013; Yochim and Silva 2013). The consequences of external pressures to be a good mother creates an increased desire for thoroughly researching medical options and decisions based on numerous types of knowledge and expertise (Yochim and Silva 2013). This illustrates a shift from credentialed experts to a "feminine expertise of the everyday", which Yochim and Silva define as "authority based on experiential knowledge and instinct" (2013, 409).

During second-wave feminism, which spanned three decades between the 1960s and the early 1990s, a women's health movement also emerged that challenged ideas about who were the experts of women's bodies (Davis and Craven 2016). The result was a repositioning of expertise within the individual rather than mainstream institutions of authority, including government and medical institutions (Barlow and Chapin 2010; Davis and Craven 2016, Reich 2016, Yochim and Silva 2012). The feminist health care movement challenged medical institutions by demanding less medicalization in healthcare and reforming ideas of birth practices, sexuality, and the family (Craven 2005; O'Riley 2004). During this time, government efforts to expand immunization stressed maternal responsibility, while at the same time women were questioning the mainstream paternalistic structure of medical institutions and the safety of drugs (Conis 2013, Reich 2016).

Embedded near the beginning of second-wave feminism, in the 1970s and 1980s, vaccine rhetoric revealed how women critically questioned medical advice, scientific expertise, the risk of prescription drugs, and abuses of power in the medical community and advocated for more information about vaccine risks (Conis 2013; Davis and Craven 2016). These feminist-based movements led to a critical analysis of vaccine recommendations, including women's rights to fully informed and independent health and vaccine decisions for their families (Conis 2013). Furthermore, the feminist movement and the scrutiny of clinical medicine challenged medicine's traditional paternalism (Conis 2013, 409; Reich 2016; Yochim and Silva 2013). Modern vaccination campaigns were based heavily on gendered assumptions of women as child-bearers, primary caretakers for their children, mothers, and members of the work force reinforcing constructed gendered norms (Barlow and Chapin 2010; Conis 2013; Yochim and Silva 2013). Mothers were seen as a gateway to children's health and were encouraged to vaccinate either from a sense of shame or duty based on their role as mother to protect their children or from danger (Conis 2013; Craven 2005). If mothers did not vaccinate their children, they were labeled as failures, reckless, poor, ignorant, and uneducated (Conis 2013).

Mothers were pressured with a "persistent ideology of moral motherhood," meaning that they were responsible for all aspects of their children's lives, including as primary caregivers (Conis 2013, 412). The informal and gendered responsibility of mothers to care for their children, becoming an obligation and a labor of love (Silverman 2013). Caregiving is intellectually difficult and emotionally demanding, yet due to its association with women, remains undervalued (Silverman 2013; Turrini 2010).

2.2. Care

Multiple authors have described care as what it means to be human and consists of considering the well-being of another during the everyday basic aspects of life (Heinemann 2013, Kleinman 2015). Care also gives meaning to, sustains, and builds relationships which are embedded in local worlds (Kleinman 2015). Care practices are formative to a social person and involve on-going work of resolving social bonds, while also playing a role in the development and sustainment of personhood (Buch 2015; Turrini 2010). Care involves social construction and reproduction with the goal of sustaining both social and biological life through generations (Buch 2015).

Although care and caregiving have been addressed in numerous fields, anthropology offers more depth to caregiving discourse with a focus on human connectedness (Heinemann 2013; Kleinman 2015). Caregivers attend to practices and intentions, values, and beliefs which are in response to social and cultural contexts (Heinemann 2013; Kleinman 2015). These care actions intend to preserve, sustain, and restore our worldview to continue daily life as well as possible while attending to the needs of those for whom we take accountability and responsibility (Heinemann 2013; Kleinman 2012). Ultimately, care is a moral obligation, which outside the healthcare structure goes unpaid (Heinemann 2013). The result of gendered structures, especially in domestic life, is that care labor is invisible labor frequently bestowed and socialized upon women (Silverman 2013; Turrini 2010).

Care practices are also a negotiation of independence which emphasizes interconnectedness of both moral meanings and political economies and markets, of which, national policies influence (Buch 2015; Kleinman 2012). Care strategies influence and are influenced by the neoliberal market-based commercialization of healthcare, especially in

combination with state healthcare services (Chudakova 2016; Kleinman 2012). This combination of neoliberal and commercialized healthcare with the promotion of healthy lifestyles creates a form of individual risk management (Chudakova 2016). Chudakova notes that in post-socialist Russia, for example, pluralistic wellness discourses are grounded in the cultivation of health for moral pursuit, and that understanding self-care strategies should not be analyzed as noncompliance of clinical medicine or failures at "risk reduction" (2016, 81). Here, practices of care include the ability to be well-fed and financially secure, but also living a healthy lifestyle by growing one's own food and medicinal plants and sharing recipes, all presented as folk wisdom (Chudakova 2016).

Anthropologists Emily Yates-Doerr and Megan Carney (2016) propose that the kitchen is "a site of care" used by women in Latin America. It is in the kitchen that women cultivate and nourish health and provide care through food. Yates-Doerr and Carney suggest that although kitchens are not biomedical sites of healthcare, they are sites that produce and respond to health. Furthermore, Yates-Doerr and Carney encourage us to think about CAM practicing outside the realm of conventional medicine while also pushing for biomedical recognition and value in alternative medicine. They claim that this would make sense if medicine were "de-medicalized," resulting in food being recognized as medicine, as well.

Care is intertwined with morals and the economy, formed through politics and social processes and affects immediate social relations (Cubellis 2020; Kleinman 2012; McGranahan 2017; Sobo 2016). Additionally, in the presence of feelings of anxiety or grief, another care strategy emerges: refusal. Anthropologist Ashanté Reese (2019) has written about an experience with an informant who was once eager to participate in an interview but then abruptly refused. For Reese, this informant's decision demonstrated both a request to be seen but also respect for

the right to refuse. Reaching the point of enough, making the choice of refusal becomes a care practice in and of itself (McGranahan 2017; Reese 2019).

2.3. Risk and Trust

Anthropology can offer context to what shapes conceptions about risk through attention to social interactions, discourses, practices, memories, cultural beliefs, power relations, and trust in institutions of science (Boholm 2003; Kaufman 2010; Panter-Brick 2014; Poltorak et al 2005; Sobo et al 2016). In addition, anthropology can offer nuanced models of health seeking behaviors and risk perceptions using cultural narratives and life histories to situate risk in local social and moral worldviews (Brunson 2013; Panter-Brick 2014; Poland and Brunson 2014; Poltorak et al 2005).

Risk invokes thoughts of binaries including pure or impure, good or bad, moral or immoral, lay or scientific (Alaszweski 2015; Boholm 2003; Douglas 1966; Panter-Brick 2014). In anthropology, risk is defined as an uncertainty based on cultural contexts, scripts, and variations that social groups use to manage future threats (Alaszwski 2015; Beck 1992; Boholm 2003; Douglas 1966). Anthropological risk research has focused on risk assessments and mitigations, environmental/ecological risk, economic risk, medical risk, and risk perception (Beck 1992; Boholm 2003; Douglas 1966; Hunt, Castaneda and Voogd 2006; Little 2012; Panter-Brick 2014).

Risk theory has been examined in social sciences since the 1970s when shifts in industrialization, globalization, and second-wave feminism were prominent (Conis 2013; Davis and Craven 2016). Risk has been addressed in terms of social, historical, and political structure and function by numerous scholars, including Ulrich Beck, Mary Douglas, and Anthony Giddens. Beck (1986) famously coined the term “risk society” and addressed risk paradigms and

management in modern society. Douglas (1966) addressed ideas of danger, purity, and pollution in relation to moral risk choices. Giddens (1999) added that to analyze risk, there must be distinctions to separate risk from danger and hazard. Extending Beck's definition of "risk society," Giddens further, argued that risk society is not more dangerous or hazardous but instead more preoccupied with the future and safety.

Risk has also been noted in close relation to power and trust, especially in healthcare settings (Grimen 2009, Hunt, Castaneda and Voogd 2006, Panter-Brick 2014). Addressing risk in healthcare interactions is especially timely as clinical medicine focuses on patient-centered medicine and patient autonomy in the clinical encounter. In clinical medicine, risk factors are presented in numerical ratios and percentages, which refer to groups rather than individual cases (Hunt, Castaneda, and Voogd 2006, 212, Panter-Brick 2014). Significantly, this creates grey areas that are not particularly meaningful to patients who do not have a relationship with statistical concepts or risk modeling (Hunt, Castaneda, and Voogd 2006). Medical risks may not be relevantly connected to personal risks and cultural narratives of risk can eclipse clinical or medical risk (Panter-Brick 2014). By embracing data and definitions that are beyond Western contexts, clinical professional can better understand cultural conceptions of risk inform patient choices (Hunt, Castaneda, and Voogd 2006, Panter-Brick 2014).

Harold Grimen (2009) notes that risk has become routinized and remains steady at the core of modern medicine because it is providers with autonomy and power who determine risk. In healthcare, he writes, even the most well-informed patients must trust others to assess health risks, and in doing so, they delegate power. Furthermore, topics of power, paternalism, autonomy, choice, informed consent, and empowerment are absent from provider-patient discussions. Paternalism is not a new tactic; in combination with negative rhetoric, it decreases

trust in the medical establishment and increases resentment of biomedicine (Conis 2013; Craven 2005; Kitta 2019; Poltorak et al 2005). To remedy this point, Grimen (2009) suggests the feminization of medicine values, the democratization of knowledge, and structural characteristics of the role of provider.

Additionally, power imbalances are created in the patient-provider relationship as healthcare providers become gatekeepers to medical knowledge (Grimen 2009; Hunt, Castaneda, and Voogd 2006; Poltorak et al 2005). Grimen (2009) further details three sources of structural inferiority in medicine: knowledge differentials/knowledge gap, forced loyalty to gatekeepers of healthcare services, and provider-patient interactions which are not normal due to confusion, stress, and shock. Furthermore, healthcare professionals and patients carry different worldviews and hold varied, contrasted, and complex meanings of risk, which often undermines communication (Grimen 2009; Hunt, Castaneda and Voogd 2006; Panter-Brick 2014).

Through differentiating the divergent risk concepts between clinical and medical professionals and lay patients, ethnographic research can situate worldviews specifically in the local and moral. Mothers who are uncertain about risks related to vaccination also report experiences that have promoted distrust in the provider-patient relationship including paternalism, coercion, and with-holding of medical care (Conis 2013; Grimen 2009; Kaufman 2010; Poltorak et al 2005; Williamson and Glaab 2018). Feelings of uncertainty or doubt, in combination with ideas of risk and noted experiences that promote distrust, lay the foundation for mothers to pursue their own research on alternative interventions, ultimately leading to their refusal of vaccination and biomedical care.

3. METHODOLOGY

The intention of this research was to gather in-depth health and life narratives of vaccine skeptical mothers' regarding why they do not vaccinate their children. Additionally, engaging them in their decision making about vaccination and biomedical interactions to gain a deep understanding of when and why they have chosen to refuse or stop vaccinations. Furthermore, observing their home health and care practices to determine if there are consistent themes in home-based health care provided in lieu of vaccination and biomedical interactions. The first part of this research was completed in-person, and later due to the Covid-19 pandemic, the methodology was adapted and modified to virtual observations and interactions for safety, while keeping a foundation based in anthropological standards, as detailed below.

This ethnographic research took place from October 2019 through April 2021 in a mid-size city in the Upper Midwest of the United States. This study includes seven mothers who had children that they stopped vaccinating or did not vaccinate at all. I was able to spend time engaging in in-person participant observation with semi-structured and open-ended interview time with five mother informants pre-Covid-19 and later these five mothers also engaged in virtual hangouts. I engaged in exclusive virtual hangouts, or virtual participant observation with semi-structured and open-ended interviews, with two mother informants starting March 2020 and continued during the on-going Covid-19 pandemic.

The unique methodology of anthropological research considers a holistic approach, considering the human condition across time and space (Bernard and Gravlee 2015; McElroy and Townsend 2015). Additionally, anthropological research is focused on participant observation in the field (Bernard and Gravlee 2015; Emerson, Fretz, Shaw 2011; McElroy and Townsend 2015). Anthropological research requires an immersion into the life and lifestyle of

the interlocutors allowing for direct interaction with participants to note subtle behavior, physical, and vocal responses or changes in answers and observational activities which provides perspectives not directly solicited from the researcher (Bernard and Gravlee 2015; McElroy and Townsend 2015). In the process of immersion, the anthropologist defamiliarizes themselves of prior beliefs or understandings of and within the group, looking beyond the confines of our own society's norms (Bernard and Gravlee 2015; McElroy and Townsend 2015). The researcher also focuses on developing trusting and open friendships with the interlocutors. The results of the research is then compared and contrasted to patterns in the larger social systems (Bernard and Gravlee 2015; McElroy and Townsend 2015).

This research employed standard anthropological methods of both in-person and virtual participant observation, engaging mothers in their at-home health and care practices to gain a clearer understanding of the symbolic meaning of material health items, locations, and health rituals used by vaccine skeptical mothers in their at-home health and care practices, which they have developed in lieu of biomedical interactions. Additionally, engaging mothers in in-person and virtual semi-structured interviews with a prepared question schedule (Appendix C & Appendix D) regarding their health and life histories leading to open ended discursive health narratives. Finally, analyzing the data, another immersion process to look for consistent themes in mother's health and vaccine narratives (Borken 1999; Emerson, Fretz, Shaw 2011).

3.1. Preliminary Research and Community Entry

Starting in the fall of 2019, I started exploring various online social media groups that focused on mothering and alternative health. My intention was to connect with and immerse myself into all aspects of a vaccine skeptical mother. Through these first online connections, I

soon became aware of four vaccine related public events, the first which helped me to solidify this topic for research and gain community entry.

The first event I attended and made contact with vaccine hesitant mothers was a public screening of a documentary called, "*Vaxxed II*" at a local movie theatre in October 2019. I found the event for this event on a social media group that I had recently joined. In addition to attending the documentary, there was a planned pre-movie meet and greet dinner scheduled at a near-by local restaurant. I used this event as preliminary research to determine if there were enough mothers willing to participate in this research project, but also to determine if I could gain quick acceptance and rapport for entering the vaccine skeptical community. Additionally, I wanted to make connections with parents, specifically mothers, and determine if there were at least five or more who may be interested in participating in this research study with me. After attending this event, I determined that the possibility to conduct this research topic was promising, with several mothers excited to discuss the topic of vaccinations with me at the well-attended pre-movie dinner. From the connections made at this event I was also invited onto other social media and online platforms for vaccine skeptical parents and learned of upcoming medical and health freedom rallies. Although titled medical and health freedom rally, the main underlying theme was vaccine skepticism and refusal.

As a result of my new social media group invites, I was able to see other medical and health freedom or vaccine skeptical events. Two medical freedom rallies were scheduled to take place regionally, one at the Minnesota State Capitol and weeks later at the North Dakota State Capitol. These were scheduled as a part of a broader medical freedom group and organization that had planned rallies at state capitols across the United States. While the public engagement was focused on the ability to have freedom for individual choice and decision making in all

medical situations and interactions, the main underlying premise was based on the right to refuse or modify the CDC's vaccine schedule. I attended the medical freedom rally at the Minnesota State Capitol the afternoon of February 20th, 2020, just as news about the pandemic was starting to take hold in the United States. At that rally, I was able to observe group dynamics and rally chatter, and additionally talk with 7 attendees of the rally. While I was also planning on attending the Medical Freedom Rally at the North Dakota State Capitol later, by the time that rally was scheduled to happen the pandemic precautions were in place and I decided not to attend. Through my access to the medical freedom online groups, I was able to see that the event did take place but had low attendance.

The last event that suggested that I would have an easy acceptance into the vaccine skeptical groups for this research study, was the discussion of a potential regular event that was going to be started by a local mother who ended up becoming one of my mother participants. She intended to start a monthly vaccine movie and social discussion night. Inspired from the *Vaxxed II* documentary premier which she helped organized, she intended to gather vaccine skeptical mothers in her home once per month for vaccine themed movies, documentaries, books, and other media with social time. Unfortunately, her intention of starting these meetings also happened at the same time that Covid-19 emerged and therefore did not materialize.

Immediately after I attended the *Vaxxed II* documentary event, I placed a recruitment ad in a local social media mothering group (Appendix A.). Mothers interested in participating in the study either made a note of interest on the recruitment post or sent me a private message through the social media site. After mothers expressed interest, I sent a follow up message with details about the depth and commitment of participating in this study. An example of a typical script for the follow up message as follows:

> Hi! Thanks for your interest in participating in my research. I wanted to let you know that if you would like to participate fully, I will immediately assign you a pseudonym which will be used to refer to your identity in all of my notes and typed papers. Further, any other identifying factors of yourself or your family will also be changed to maintain utmost privacy. I would like to talk with you about your health history and when and how you decided to stop vaccinations or not vaccinate. I am hoping to spend time with you observing how you provide care to your family and keep them healthy in place of vaccinations. This may include observing special dietary preparations and protocols in your kitchen or where you keep things in your home that you use to keep you and your family healthy or treat illness. Also, it would be fun for me to follow you to health activities you do for yourself or family to keep healthy or treat illness, and grocery or supplement shopping trips. It would be ideal for me to attend public gathering or activities relating to health or vaccination with you, too. I have [usually 3-4 dates of my availability spanning over a 3-week period] open for a first meeting. Please let me know what day and time of day would work for you.

After the emergence of Covid-19 prohibited in-person contact, I modified the above script to include observation through "participation of virtual hangouts via Zoom". I choose to use the term "virtual hangout" instead of "Zoom meeting" because I wanted to encourage the kind of causal spontaneous conversation that would have occur during an in-person coffee date.

Initially, there were eleven positive respondents to the recruitment ad, one targeted recruitment, and two snowball recruitments for a total of fourteen potential participants. In the end, four respondents did not reply further after their initial expression of interest to participation, two later rescinded participation after the pandemic started sharing that they were going through a divorce, and one declined participation after the start of the pandemic because they refused to meet via Zoom and would only meet in-person without a mask requirement. As a result, the final number of mother informants participating in this research study was seven. All participants were English-speaking mothers with children whom they have chosen to not vaccinate at all or started vaccination but then stopped completely. I had a minimum of two extended interactions with each participant. I was able to engage in in-home participant observation with three mothers, engaged in exclusive virtual participant observation with two

mother participants, and finally both in-person and virtual engagement with four mother participants. I attended in-person health appointments with one mother and spent time attending outdoor activities with one other mother participant. I attended two public vaccine skeptical events.

I gained rapport with mother informants through various ways. Foremost, being a mother of two children myself and also trying to be "the best" mother and make the best parenting decision possible with the resources available to me. Additionally, while I fully accept and use Western biomedicine, I have also struggled with chronic health issues and have explored and experienced relief from use of Complementary and Alternative Medicine (CAM). In this way, I was able to connect with other mothers using other alternative methods of health and treatment, listen to their stories without judgment of their choices, and openly empathize with the health-related choices they have made. Other ways of gaining rapport with vaccine skeptical mothers included engagement through social media in alternative health or mothering groups, attending public health and vaccination events, and finally through participant observation, or spending time with mothers, both in-person and virtually.

3.2. Pre-Covid-19

In preparation to the first in-person participant observation, I would gather paper items related to the first time spent with the informants. These included the demographic information worksheet (Appendix B.), parental question prompts (Appendix C.), and later an additional packet with question prompts related directly to Covid-19 (Appendix D.). In addition to these items, my field notebook, 2 pens, and my password protected cell phone for audio recording and photos was included in the items needed for visits.

I drove to participants homes or public meeting spaces of their choosing. Upon arrival, I would take hand-written jottings about the drive to their homes or meeting locations, noting the weather, neighborhood descriptions, and exterior and interior descriptions of the destination. When meeting with a participant in a public space, such as a coffee shop or outdoor park, noting the dynamics within the store or park area, how many people were also using the space, and where we were located in the space. Once the mother informant and I were settled in the public space, I provided the informed consent forms, verbally giving an outline as they read and signed. Immediately after, I offered the demographic worksheet. Demographic questions included number of people living in the household and range answer options for ages of household members, household salary, highest level of education for each parent, and political and religious affiliation. During the time informants spent filling in the papers, I made quick notes in my field notebook about initial dynamics and descriptors of the mother, dynamics of the space- including who was there and how the space was used. As they finished the paperwork, I would inquire about their desired time commitment for the research visit, wanting to always be respectful of their time, I kept a close eye on accommodating their suggestion and needs.

When visiting participant homes, I noted objects and items in the outdoor and indoor spaces. Once inside participant's homes, and after greetings, I would suggest going over the informed consent packets immediately. Typically, we then sat at either a living room couch or dining table where I would give the informants the informed consent packet and reiterate the points verbally. After giving informants time to read and sign the informed consent packet, I would hand them the demographic information worksheet, which they would fill out then as well. During the time the informants were reading and filling in papers, I jotted notes about the physical space we were in and descriptors of the informants. As paperwork was filled out, we

also engaged in casual conversation, and I showed the mother informants by field notebook with brightly colored tabs, noting that I would be taking extensive notes in here during the process. In whole, this first step normally took 20 to 30 minutes.

Next, during in-person participant observation in homes, I tried to initiate as much of a causal encounter as possible by first asking the mothers to give me a home health tour, letting them lead me to locations where they kept items that they used in health maintenance and illness treatment. The items of their at-home health maintenance and illness treatment would consistently include items such as special foods or supplements, primarily located in the kitchen. I would use my phone to photograph the health objects in the specific locations, while also taking hand-written jottings to describe the location in the house and what other items were located around the health objects. In addition to audio recordings, noting specific terms or short quotes mothers verbalized during the home health tour in my field notebook. The home health tours varied in time from 30 to 45 minutes.

Both in-person participant observation and later, virtual hangouts, engaged mothers on various levels. At all times, mothers were also engaged in their normal routines including making snacks for their children, re-directing them in activities, or for one mother, observing her routine of making and maintaining sourdough bread on numerous occasions. At the time such routine daily activities were taking place, I would watch carefully and note the dynamics of activities and interactions, as well as catch up on jottings and prepare to transition to a new topic or the prepared question prompts. Often, at this point when the home health tours were concluding, mother informants and I would settle into an area in their home to begin deeper discussions and narrative collection. Examples of prepared parental questions include significant health care experiences or memories spanning the time of youth to current day, how or when they made

decisions about vaccinations and other biomedical healthcare, familial or social support in their vaccine decisions, and their at-home health care practices and protocols. Additionally, questions about their role as a mother and caregiver and how they see, manage, or mitigate risk in their lives. After the start of the Covid-19 pandemic, I included question prompts about the pandemic for all informants and inquired if experiencing a pandemic has changed their minds about vaccination, including questions about Covid-19 vaccinations.

The ethnographic interactions varied from 1 to 3 hours. Mothers often reported feeling excitement to be discussing their health experiences and vaccination decisions. Some expressing surprise at how some of the question prompts made them think about their past and connect it to their current health decisions and lifestyle.

3.3. Covid-19 Protocol Adaptions

Once Covid-19 emerged in the world, we all paused momentarily. At some point, it was clear that the research must go on and that adaptions were necessary for that to happen. Using a Zoom account provided by the University, I intentionally labeled the virtual experience with mother informants as a "virtual hangout", to set a foundation of casualness that would normally emerge spending time in the mother's homes during in-person participant observation. Due to the unique circumstances of experiencing a once-in-a-lifetime pandemic while researching vaccines, I added an additional section of question prompts specifically related to Covid-19 with broad topics such as health understandings, feelings, and personal response to the CDC recommended lifestyle and safety protocols and the announcement of multiple new Covid-19 vaccines. Importantly, focusing on any connections to social experiences and new at-home health and care practices in response to Covid-19.

One week prior to the first scheduled virtual hangout I would email mothers the informed consent form and demographic worksheet. Mothers would fill the informed consent forms and demographic worksheet and would scan or photograph them and email back to me prior to the first virtual hangout. In preparation to the first virtual hangout, I would open Zoom and check my computer audio and volumes, gather my parental question prompt packet and specific Covid-19 question packet, my field notebook, 2 pens, and my password-protected cell phone for audio recording, all placed in front of my computer on my desk. Just as in-person participant observation was not video recorded, I did not video record the virtual hangouts, but relied on the same fieldnote jottings and audio recordings as I did for in-person observations. Similar to in-person participant observation, virtual participant observation hangouts included time for semi-structured and open-ended interviews leading to in-depth health and life narratives and virtual home health tours which included a guided tour lead by mothers of their home health spaces. In place of me being in the home and taking photographs of health items and locations with my cell phone, I made a list of items and places I would like photographed from the participant observation session. At the end of our virtual hangout mothers would photograph items and locations we had discussed and email, text, or message me with the photos, often including descriptions with their photos.

Additionally, once COVID-19 emerged, I asked all participants to keep "picture diaries" of their home health areas, food purchases and prep, and other notable health situations. Adding notations and descriptions when they sent me the pictures via messaging or email. The picture diaries requested that mothers take photos of a typical healthy meal, starting from documenting their groceries purchased at the store to being unpacked at home and then where they stored their food items. Finally, some mothers documenting a prepared meal that their family consumed. The

same request was submitted to them for supplements or health items they purchased, from tea to herbs or vitamins. Beyond purchases, I asked mothers to send me message updates about any health issues or procedure changes in their household. For instance, one mother sent me photos of immune boosting supplements and whole food juices she purchased when someone was feeling “under the weather”, then she continued to update me about supplements, foods, and her lifestyle. These specific changes permitted the continuance of standard anthropological ethnographic interactions and data collections.

During the first virtual hangout we would have introductions and causal chatting as I verbally confirmed they understood points in the informed consent forms. Then, I asked what their expected time commitment for the research interaction for the day, wanting to keep track and remain respectful of their time. I next transitioned to explaining what I envisioned for a virtual hangout. I explained that typically I would have liked to spend time talking, observing their daily activities, and routines in-person. Since we were engaging virtually, I wanted to have a foundation that was as normal in their home behaviors, interactions, and activities as possible while also remaining cognizant of them needing to hold onto and bring their phone or laptop device everywhere, too. Additionally, I asked for their input about how they envisioned this causal virtual hangout. Then, I held my field notebook up to the camera to show them my brightly colored tabs, noting that I would be taking lots of notes. This first part of the virtual interaction typically took 20 to 30 minutes.

In the new normal of Zoom meetings, a causal virtual hangout was easier for some mothers than others. Some mothers preferred to stay stationary and engage in a more formal format typical of online meeting encounters. This led me to start some semi-structured question prompts immediately, with hopes of creating a causal environment for them to adjust to. Yet,

other mothers embraced the virtual hangout and brought me with them throughout their home redirecting their children, getting them snacks, or setting them up with games or crafts so they could give me tours of their kitchen and their health items and objects. During the virtual home health tours mothers would show me locations of health items and objects and describe to me where they were located and what they were and what they were used for. Throughout the virtual hangout I was audio recording the participant observations on my cell phone and taking more extensive jottings in my field notebook. In my field notebook I noted physical descriptors of the interior home and different rooms, paying attention to objects and items in each room and its layout or locations. Also noting specific terms or descriptions that mothers used to describe objects or locations and short quotes. Each virtual hangout lasted from 1 to 3 hours.

3.4. Data Analysis

Data analysis began in the fall of 2020. At this time, all the in-person field notes and interview question prompts were typed, and virtual hangouts were being scheduled. As I read through the in-person fieldnotes, I used the foundations of the "immersion/crystallization" process (Borkan 1999). The "immersion/crystallization" process entails immersion into the data collected through detailed reading and examination, then suspending the "immersion" for reflection on the analysis experience to identify patterns or themes (Borkan 1999).

The first step in my immersion process included re-reading typed fieldnotes and identifying different themes that emerged in multiple observational fieldnotes, messages, and photos (Emerson, Fretz, and Shaw 2001). I electronically highlighted each theme in a different color. The initial list of themes, which was informed from the literature, included mothering, mother's intuition, care, care through food, care based in the kitchen, care items or objects,

health, medical experiences, and risk. Once all observation-interactions were complete, I completed the same process with typed virtual hangout fieldnotes.

Through this process, it became clear to me that there were very specific emerging themes among mother participants. Once these themes were clear, I temporarily suspended my deep immersion of the data to then contemplate and reflect on the process of theme patterns (Borken 1999). These theme patterns consistently showed that first, mothers revealed specific health narratives of a dismissive or disrespectful biomedical provider interaction. These health experiences consistently occurring either as a child or in early in motherhood which led to these mothers to not only lose trust in biomedicine, but question vaccinations and other biomedical interventions. Next, mothers provided care based in the home kitchen focused primarily on food or healthy eating. Here mothers created an alternative medical home based in their home kitchen using herbal and folk products for health maintenance and illness treatment.

3.5. Limitations

This research methodology was adjusted due to the Covid-19 pandemic. Although the adjustments were satisfactory, they posed not only a different level of participant engagement, but also a different level of participant control. With mother interlocutors in control of where the camera is pointed during participant observations, subtle details that may have been noticed by the researcher in-person, may have been missed. Additionally, mothers were more in control of the photos sent for the requested photo diaries and some may have wanted to present “the best” grocery and supplement options purchased or possibly leaving out sweets or junk food that didn’t align with the dietary protocols that they shared in virtual hangouts. Yet, at the same time, while the changes in methodology could be spun as a negative, it could also become another new

normal. The changes to methodology are in line with knowledge and research trends of becoming more collaborative.

4. STUDY RESULTS

The research period spanned nineteen months, from October 2019 through April 2020 with in-person and virtual participant observation of seven mothers who stopped vaccination or have not vaccinated their children. Mother participants were in the age range of 30-50 years old with 2, 3, or 6 children and were either married or with a long-term partner. After content, discourse, and thematic analysis of the data, overarching themes in the mothers' narratives emerged. First, when prompted to think about their own personal health history, each mother interlocutor shared specific memories of negative interactions with biomedical health providers, either as young girls or as new mothers. These negative experiences ultimately resulted in the mothers shunning or rejecting biomedical interventions and interactions, including childhood vaccinations. These mothers, becoming vaccine skeptical as a result of negative biomedical provider experiences over time.

In response to rejecting biomedicine, these mothers consistently focused on caring for their children and keeping them healthy based on food and diet, and when needed vitamins, herbs, and folk remedies. All health activities and health items were reliably located in the kitchen. Emily Yates-Doerr and Megan Carney (2016) have recently pointed to the significance of "the kitchen as a site of care," and as I demonstrate in the narrative data below, my research similarly demonstrates how that works in practice for these vaccine skeptical mothers. I argue that these vaccine skeptical mothers have very specific care practices and at home health processes based in the kitchen which they have established in response to viewing biomedical interactions, and vaccinations, as a health risk.

Below I begin with sharing the narrative of Hannah. Since her son was born prematurely, she has been "deep in the medical field," becoming a lay expert in his health needs and

conditions, sharing her experiences that led her to distrust biomedicine and vaccination. I end with sharing the narrative of Kate. Kate shared numerous dismissive and demeaning biomedical experiences that led her to shun and refuse biomedical interventions and vaccination, yet found herself questioning those decisions and changed her mind, starting vaccinating for herself and for her family during the pandemic.

4.1. Mothers' Narratives

4.1.1. Hannah

Hannah is in her 30's and is married to her husband who is also in his 30's. They have two children, both in the age range of two to five years old. Both Hannah and her husband, Adam, have Bachelor's degrees. Adam works outside of the home and Hannah stays at home with their children, offering at-home daycare services to a few families for additional income. Since Hannah has her degree in education, she found that this was the best way for her to have an income, provide the mothering and care that she wants to provide for her children, and use her degree. Hannah and Adam have a combined annual household income in between $70,000-$90,000. They are active participants in their Evangelical Lutheran Church and describe their political affiliation as conservative.

In Hannah's response to the recruitment ad, she immediately noted that her son, Jake, was born prematurely at 24-weeks gestation, so they "were deep in the medical field", adding that she felt that sharing his story was important. Hannah has had extensive experiences with the biomedical community and incredibly strong opinions of the biomedical healthcare system. In the past, Hannah was fully accepting of and believing in biomedicine and biomedical providers, accepting all procedures, interventions, and treatment without question, adding that she thought "the medical industry was there to help people." That changed when Jake had a reaction to a

commonly recommended shot for preemie babies, Synagis. Synagis is a therapy injection which prevents Respiratory Syncytial Virus (RSV) (Drugs.com, "Synagis", accessed Jan. 20, 2020, https://www.drugs.com/synagis.html). At the time Hannah wanted to accept this therapy injection because "with his weak lungs, I thought it would be a good idea", but at the same time she was questioning whether she felt comfortable giving her son this injection plus the recommended MMR shot at the same time. Hannah decided to go forward with the Synagis protocol and wait temporarily administer the MMR vaccine. In the middle of the Synagis protocol, which included 6 separate injections, Jake came down with head-to-toe pinpoint rash, including eczema on his forehead and toes. When this developed, Hannah was terrified and immediately called a pediatrician from their time in the NICU, describing their feeling toward him as "an old, trusted friend, old because he is 80 years old!" He explained that Hannah's son was having an allergic reaction that could lead to anaphylactic shock and possible worse with future doses, so for safety, they should stop.

As Hannah describes this, I could see she was shaken and with wide eyes explains this point as the beginning for her "quest for research" about Synagis reactions which lead to reading about vaccine reactions and eventually led her to discontinue vaccinations for both of her children completely. While Hannah recognizes that her son needs biomedicine, she still has hesitations about any biomedical interactions, Hannah has to "ask myself if the benefit is worth the risk, especially when it comes to decisions with my son."

During a virtual hangout Hannah started discussing when they lost trust in biomedical care. She was on her couch and her husband, Adam, was sitting at the other end of the couch with their son. Adam would quietly add supporting comments here and there from the background, out of the vision of the screen. When we started talking about a specific health story

that Hannah had shared with me previously, Adam spoke out louder and asked if it was ok that he say something too. The story was about when their son experienced mishandling and abuse in a local hospital's NICU which included "accidental drowning" and broken bones, the latter of which went undetected until later, when they were at a children's hospital in Minneapolis. Now I saw Adam fully in the screen, once adding quiet affirmations in the background of our virtual hangout, suddenly was speaking louder, determined, and visible upset. As roles switched, I could hear Hannah quietly confirming and adding points as Adam spoke. During their time in the NICU, they were constantly told how the nurses and patient advocate were supposed to be helping them, telling Hannah and Adam:

> " 'we're doing everything we can… everything we can to help you.' But then they have lawyers in the room, and everyone stops talking to you, and the story changes to cover up for the nurses. Letting them go, relocating them behind the scenes. How are we supposed to trust them?! With anything?! They abused and almost killed our son."

Hannah quietly adds, "They didn't care. His life was nothing to them."

From this point, both Hannah and Adam were sharing health narratives together, in a flowing conversation, shifting the phone screen back and forth. They shared an example of care through food. While Jake was at the Children's Hospital in Minneapolis, he had to have a feeding tube and per hospital protocol, feed him an approved liquid diet. Now, both Hannah and Adam are constantly "on guard" in any clinical setting for fear of their son being hurt. They looked at the liquid diet containers and were dismayed that it was all chemical based. After plenty of tense meetings with various hospital personnel and "big-wigs", and Hannah spending dozens of hours online researching whole food based liquid diets for young children in hospital care, Hannah and Adam eventually found a replacement they felt would be able to provide better whole food nutrition. They provided "lots of documentation and research" and were allowed to give their son the whole foods liquid diet they wanted.

Figure 1. Hannah's nutrient dense groceries.

During my time with Hannah, she shared numerous experiences in which through exhaustive research, she was able to provide documentation and research to doctors which would change the protocols or interventions initially recommended, "bringing information to a specialist who should know this, and I end up knowing more than them." These experiences have lead Hannah and Adam that feel that biomedical interaction is a risk they won't take unless absolutely necessary. Their trust in the biomedical healthcare system is gone.

Now, Hannah spends "hundreds of dollars a week" on whole food groceries (Figure 1). She also spends lots of time in the kitchen making as much of their meals from scratch as she can. She wants to keep their bodies and "gut" as healthy as possible. "If your gut is healthy and strong you can digest more nutrients from foods." Hannah sees providing nutrient dense foods to her family as a form of care, adding that this is their first line of health maintenance and illness defense. Next, if someone in the household comes down with anything, she increases vitamin C foe everyone, and adds elderberry syrup and iodine to their daily routine. All of which are for helping the body's ability to fight off infections. "Our cupboards are always packed!" Hannah confirms with a video tour and pictures where the fruit and veggies groceries from her latest shopping trip are kept. Next, Hannah pulls numerous bottles out of her fridge, mostly kept in the

door and one top shelf, here are the health maintenance and illness treatment supplements that need refrigeration (Figure 2).

Figure 2. Examples of Hannah's home health items. L to R: cod liver oil, elderberry syrup, liquid vitamins, liquid vitamin C, Umcka ColdCare.

Additionally, Hannah has 3 kitchen cabinets that each have one shelf reserved for various supplements. A pull-out drawer in a pantry that has vitamin bottles and powdered smoothie additives. The next cabinet is mostly "kid-safe" vitamins like multi-vitamins and vitamin C, elderberry, and some teas (Figure 3). All homeopathics are kept separately behind a small narrow cabinet door. In the bathroom, Hannah has a "medicine" cabinet with essential oils and salves (Figure 4).

Figure 3. Extra kid's vitamins, extra vitamins.

Lastly, Hannah sees her role of a mother as having fun with her kids, teaching them, giving them quality time, keeping them clean, while also considering their social needs, too. She is glad to be able to stay at home, "so I can raise my kids, me, I want to raise them. I want to be a part of their life and be their main care-giver." To Adam, being a parent means protecting them, advocating for them, and keeping them safe. After our virtual hangout, Hannah sent me a message telling me that Adam told her how nice it was to be able to "actually talk about" the serious health situations they have had to deal with, with someone who listened to their pain and their distrust of the biomedical field, and how their eyes opened to a new type of risk.

Figure 4. Hannah's bathroom medicine "cabinet". Essential oils, toothpowders, and homeopathy.

4.1.2. Janis

Janis is in her 30's and lives with her partner, also in his 30's, in their modest shared house. Janis has two children. One daughter in the age range of 6-10 years of age and the second daughter is in the range of 3-5 years of age. The older daughter is from a previous relationship and Janis' younger daughter is with her current partner. Janis works full-time at a regional distribution company. Janis and her partner have an annual combined income in the range of $70,000-$90,000. Both she and her partner have completed high school. Janis describes herself

as following agnostic or spiritual beliefs while her partner is atheist. Their political affiliation is liberal, democratic socialist, and independent.

I officially met Janis at the screening of *Vaxxed II* during my preliminary research. She was ready to participate immediately. Janis was one of the mother informants that I spent the most time with. I attended two CAM health appointments with Janis and had in-person interactions with her at her home and virtually also. She also was the most interactive often sending messages of health updates, food preparations, and checking in on how the research was going. She messaged me curious about how the health freedom event that I attended at the Minnesota State Capitol went, asking for pictures, the turn out, and what I thought. Janis was also a very active participant in the other vaccine skeptical and medical freedom groups that I joined online.

Janis shared her health narrative while we sat in her living room, coloring books on the table we sat at, and a shelf along the wall behind me, dedicated entirely to games and crafts. Janis has not had health insurance consistently and therefore has extensively used CAM for health maintenance and illness treatments, adding that she would rather spend her money to stay healthy then pay a health insurance premium "just in case". If she or her family ever needed emergency care, she has no problem paying the bill for services when they are needed. Just 3 days prior I had accompanied Janis on an extensive CAM health session. We both relaxed in a warm infrared sauna, wrapped in towels and listening to meditative music on YouTube from Janis' phone. In the small wooden and glass box, Janis was able to change the mood lighting, guided by a laminated sheet giving prompts of why one might choose a certain color for health (Figure 5).

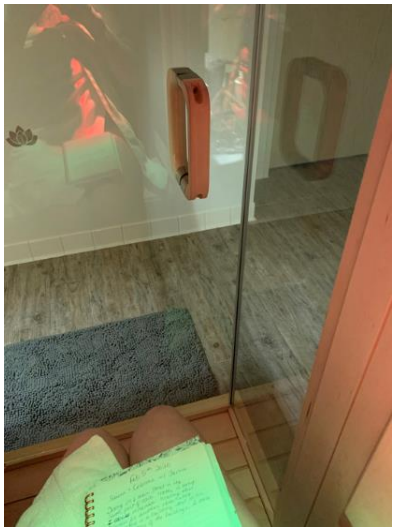

Figure 5. Inside the sauna.

Janis chose blue and closed her eyes and rested her head back against the wooden wall. As Janis relaxed, and I started sweating, I tried to finish my fieldnotes, but my pen stopped writing on the damp paper, so I tried to imitate Janis in relaxation as much as possible.

After the infrared sauna, I went to the waiting room while Janis transferred to the colonics room (Figure 6). This was one of the many colonics appointments Janis had already, with more scheduled for the future. In a large open tiled room, Janis laid on a massage like table, draped with a sheet.

Figure 6. The colonics room.

Next to the table was a rolling stool where they colonics attendant sat, and large metal rectangular device attached on the wall. Within the device on the wall, was a smaller narrow part that was glass. Inside the glass was a tube filled with water. Below this area were knobs and gauges. During the session, the colonics attendant would check in with Janis about how she felt, pressing on her abdomen periodically, then turning and adjusting the knobs as needed. The knobs controlled the water pressure and temperature. As I learned from both Janis and the colonics attendant, this treatment was beneficial for cleaning out the colon, removing old and compacted "debris", leaving your colon in better shape for optimal nutrient absorption. Janis claims she feels "better, lighter, and less bloated" after having these sessions. As she explained this to me, I wondered how do we measure "better and lighter" in terms of health research?

Janis also sees a chiropractor regularly, does "some yoga at home", and does other "body type appointments" when needed, like energy cleansing. She does have a biomedical provider that she spent time reading about, getting other mother's experiences with this doctor before making an appointment and keeping this biomedical doctor in her pocket for when she or her girls may need biomedical care. Dr. A became a regularly mentioned biomedical contact in my research. This doctor is known in the vaccine skeptical community to be friendly to families who do not vaccinate or modify the vaccine schedule.

Both Janis and her partner were vaccinated as children, "but there were much less vaccines on the schedule then." Janis started questioning vaccines during her first pregnancy, specifically triggered by an unwanted message from her aunt questioning that she was "going to vaccine, right?" Adding that if Janis did not vaccinate and her kid was bit at daycare, they could get Hepatitis B. Her aunt then followed up with "a bunch of stuff to read." Instead of Janis feeling encouraged to vaccinate, this encounter encouraged her to start reading about vaccines,

with a critical eye. Janis spent “hundreds of hours” during her first pregnancy reading books and websites about vaccine research, ethics, safety, ingredients, and side-effects. Admitting that still now, she spends a few hours per week reading on biomedical health ethics and standards. Another significant health memory related to vaccination that Janis shared was a prenatal appointment where the nurse asked if she wanted the flu vaccine. Janis and her partner had never had the flu vaccine and did not think twice about declining it. Janis describes the nurse “becoming really abrasive” telling them stories of babies and moms dying. Janis reflects that the same interaction for other new moms could be extremely terrifying, and some moms may “choose to get the flu vaccine from fear, not proper informed consent they should get.” Janis talks about the risk she sees with vaccination, specifically. She believes that science should accept and analyze anecdotal evidence, particularly relating to adverse vaccine reactions, more. “Anything foreign that is injected into our bodies is a risk and I’m not going to take that risk.”

Janis strongly believes that the best way for her daughters to be and stay healthy is through diet and whole foods. She not only buys mostly organic fruits, veggies, and meats, but most condiments and any food or body related product is organic as well. Janis take time to get up early every school day to pack a homemade lunch for her daughters, making sure to include all major food groups (Figure 7).

Figure 7. Example of two school lunches Janis makes for her daughters.

An example she gives me is either peanut butter or turkey sandwich on whole grain bread, cheese, carrot or cucumber sticks, any variety or mixture of fruit, seeds or nuts, maybe avocado. Additionally, she makes sure to pack any special or favorite foods for her daughters. Even though Janis works full-time outside of the home, she also makes sure to have full homemade meals most evenings and on the weekends. During the summer months they will go to the local farmers market to get as much local organic produce as they need for the week. Additionally, during the winter months and to supplement the farmers market produce, Janis has spent time determining which grocery stores have the specific organic food and body items she wants, at the best price.

During an in-person participant observation, Janis gives me her home health tour, starting in the kitchen. Here, Janis provides care through food. I see light brown eggs sitting on her kitchen counter that she picked from the hens she has in her well used backyard. She shows me a picture that she took on her cell phone of cracked eggs in a pan. One has a deep dark orange yolk, and the other is a yellow-ish orange yolk. She boosts that the deep orange yolk is from eggs from her backyard hens and the yellow-ish orange yolk is an organic egg from the grocery store. When Janis' first line of health defense, the natural whole food diet that she provides isn't enough to keep them healthy and they become ill, Janis then turns to her well researched arsenal of herbal supplements, vitamins, teas, and homeopathics.

Figure 8. Fridge door shelf. Contains probiotic, CBD oil, probiotic, stevia liquid sweetener.

Janis shows me where she keeps her health maintenance and illness treatment items that are stored in the kitchen. She has a dedicated shelf in the door of the fridge for products such as probiotics and CBD oil (Figure 8). Next to the fridge above her coffee maker is a narrow cabinet with 3 shelves (Figure 9). Each shelf has a type of vitamin or supplement. The bottom shelf has ginger tablets, elderberry syrup, and a natural water sweetener. The middle shelf has homeopathic pellets and liquids and natural throat lozenges. The top shelf has a probiotic gummy and bags of loose teas.

Figure 9. Health items located in a kitchen cabinet. Top: probiotic gummy's, stevia sweetener, loose leaf tea. Middle: Lozenges, homeopathics, chewable digestive enzymes. Bottom: ginger, elderberry syrup, oregano capsules, amino acid, stevia sweetener drops.

Janis brings me back through the living room into a small hallway that connects the bathrooms and bedrooms. Here is a storage closet with shelving. On one shelf she has a re-used carboard box with expired vitamins. On the same shelf she has extras of bathroom supplies such as tubes of natural toothpaste, organic hand soaps, bodywashes, and shampoos. On a shelf above this Janis has a clear plastic storage container. She takes it out and lifts is up into the air, revealing how she stores the homeopathic bottles in such a way that she can see the labels from the bottom and know where to grab when she opens the container (Figure 10).

Figure 10. Homeopathics in a clear plastic storage container to easily read the labels.

Additionally, Janis has a robust supply of essential oils that she also uses for an array of health maintenance and illness treatment. Her essential oils are kept in the hall storage closet, and they are stored in well-made wooden boxes specifically designed for holding essential oil bottles (Figure 11).

Figure 11. Essential oils stored in a wooden box.

In addition to providing health care to her family, first through a healthy food diet then by use of CAM, Janis also notes that they make changes in their lifestyle is someone is not feeling well, too. They do not go to work or school and "conserve our energy" as much as possible by spending extra time sleeping or napping, reading books or watching extra T.V. or movies. During this time, Janis will also adjust their diets to be "simple and easy" for digestion. This means lots of fruit, some steamed veggies, less breads and carbohydrates, and no sugar. At the same time, Janis acknowledges that biomedicine does have a place in health care, primarily for major health issues and emergency care. One time, both of her daughters came down with pneumonia within days of each other. Janis followed her protocol of adjusting to a simple diet and added herbs, supplements, teas and salves on their chests. After observing for a day, she noticed no change and knew that now, she had to evaluate the potential risk outcome of them not getting better with her CAM care at home. Janis decided this was the time to use emergency care, she brought both daughters into Urgent care and got a prescription for anti-biotics, which they took and recovered soon after. Janis sees her role of mother as being a "protector, promoter

of health, wellness, and wellbeing", having a duty to be sure they are well balanced in health but mentally and socially as well.

4.1.3. Layla

Layla is in her 30's. She is married, and her husband is also in his 30's. Layla has two children. Her oldest is in the age range of 11-15 and her youngest is in the age range of 6-10. Layla is very open about the relationship she had with her first child's father, which she describes as abusive, manipulative, and demeaning. Layla's second child is with her husband. Layla is currently finishing her undergraduate degree with intention of immediately joining a graduate program. Her husband is an essential healthcare worker. Their combined annual household income is $60,000-$70,0000. She describes herself as holistically spiritual and holding radical left political beliefs. Layla is a well-known parenting blogger advocating for gentle parenting, radical schooling based on activism, and informed consent in all facets of life.

Layla grew up between some of the larger cities in North Dakota and spent the middle part of her childhood in Minneapolis. She does not have significant or any memories of going to the doctor as a child but knows that it was always an option. The only memory she remembers is getting a UTI when she was younger and feeling she could not explain what was wrong to her mother. Then Layla experienced that same feeling again in her twenties. Then, she found natural ways to treat the UTI by changing her diet and taking certain supplements. Growing up, Layla's diet consisted of "a standard American diet- lots of cereal, candy, pizza." She laughs, "do you remember those plastic 'juice' bottles with the foil top? What was that?! It wasn't anything real!"

The first time Layla started to feel skepticism about vaccines was when she brought Sophia into a routine pediatrician appointment, one which vaccination would be occurring, Layla was hesitant because she heard "there may be risks" and asked if vaccines were safe. Her doctor

told her that the only risk people talk about was that vaccines caused autism, “which has been debunked a while ago.” Layla was not comfortable with giving Sophia vaccines but also did not feel confident to say she did not want to do them either, so she brought Sophia in for the first few vaccination appointments. “I felt really gross about it. Like I was leaning on someone else to mother for me, because I did not have my own power. It was like relying on someone else took away my intuition, my protective gift.” Soon Layla stopped seeing that pediatrician and then she started to feel better about those “gross” feelings. Having to figure things out on her own, she started to feel more confident and felt her motherly intuition come back.

Before the pandemic I visited Layla for an at home participant observation. I knocked on the backdoor and Layla answered, then waved me in. She walked back into the kitchen to the task she was working on. Once in the kitchen I could see that Layla was in the process of making something. She asked if when her “breakfast cake” is done, I would like some. I could not refuse. Suddenly, her younger son, Roman, popped into the kitchen and asked if he could help. “Of course! Then, I would like you to go play in your room and let Kim and I talk in private.” Roman happily agreed and started mixing a bowl with a wooden spoon. Inside the bowl is almond and coconut flours. Kali adds maple syrup because she is out of her organic cane sugar. Then, they pour the batter into a glass baking dish and adds to the top, an already prepared crumble mixture and puts the baking dish into the preheated oven. Then, she turns to Roman saying that it was time “to give the adults time” and she would call when the cake is done.

Layla immediately starts on her next kitchen task: making sourdough bread. She asks if its ok that we chat while she works. I explain to Layla that it is ideal for me to observe her doing what she does every day. Layla explains that she found that her family’s body reacts to eating gluten with bloating, cramping, and upset stomach, but through the sourdough fermentation

process which breaks down the proteins in the wheat flour, they can eat this bread. So, Layla keeps the dough active every day and consistently makes homemade bread for her family. I watch as Layla intuitively poured some ingredients, but also weighed others, then mixed the flour, water, sugar, and yeast into two separate glass bowls which already had a blob of her sourdough starter (Figure 12).

Figure 12. Baking items used for breakfast cake and sourdough maintenance.

I know that Layla is a well-known activist parenting blogger, so I ask her how her writing is going. As a writer with a strong feminist tone, she has received numerous death threats, one recent one included a severe written threat and attached images of a woman's body "with bruises and cut to pieces." Noting that her pro-feminist stance "seems to anger a lot of people." Additionally, Layla has written about vaccines and the importance of informed consent, the politics and money behind vaccine development, and a mother's right to choose the best health care for her family. Writing about these topics has resulted in frequent written threats to her body

and family, adding that she is done writing about vaccinations because she is "done looking at dismemberment photos of women."

> "This is why this stuff matters, people are really violent about these topics, and this shouldn't be happening. As a society, we should be able to have a civil discourse on these topics. Pro-vax people typically don't argue from a science base, they always rebuke with, 'that's been debunked', because they actually don't know anything else to say. But will often respond to me with comments such as 'you're just a stupid mom blogger' or 'your kids should be taken away'. Everyone should have safe options."

Furthermore, Layla believes that sometimes choosing not to vaccinate falls under bigger issues about healthcare coverage, access, and a mistrust of health services. Layla feels strongly that when moms bring questions and concerns to doctors or providers about their children's health or concerns about vaccines, that they should be taken seriously and not dismissed, and when the doctors or providers "discount the observances and questions from a mother, it's basically saying that moms don't know their own kids and that is super fucking misogynist."

To keep her family healthy, Layla first focuses on making all meals from scratch covering all food groups and focusing on a "simple and clean diet." This means that the food in her kitchen is completely free from artificial sugars and never has any processed foods, food with additives, or food dyes. Eating simple and clean also means eating organic locally raised meats raised without hormones, buying veggies from local Community Supported Agriculture (CSA's) or the seasonal farmer's market. It also means she spends time making and tending to her sourdough bread at home.

Her next step in illness prevention care draws from what she calls "folk medicine". She prefers this term to alternative or natural medicine because of the negative stereotypes associated with those words. In the corner of her kitchen was a raised counter space shaped like a triangle (Figure 13). Here Layla has quick access to her arsenal of bottles of liquid herbal tinctures or sprays, salves, vitamins, and other supplements. The herbal tincture bottles have dark amber

brown with soft dropper tops, while most of the vitamins are in opaque plastic bottles. Some are grouped together in re-used plastic food storage containers, while some remain loosely scattered. Additionally, if they do come down with an illness, Layla makes sure that they rest and do not go out in public, prevention spread of illness. Their diets change by eliminating all carbohydrates and adding lots of homemade bone broth, which has minerals that are important for the body. Layla may add some Vitamin C or D, or herbal teas, too.

Figure 13. Layla's health items located in the kitchen.

Finally, Layla shares a story about how she treats illness or injury at home. Two summers ago, Layla's preteen daughter, Sophia, was playing in their backyard and got a "long deep scrape" on her finger. She could see it needed some intervention, so immediately started her at home protocol for treating this injury. First, Layla thoroughly observed the condition of the finger and then soaked the finger in an Epsom salt soak. After a quick trip to the store to get food-based supplies for treatment, such as fresh garlic cloves, oregano oil, and herbal salves. When she got home, she re-assessed the injury and drew a circle around the border of the red

area with a marker to have a clear indicator if infection spread and they would need biomedical care. Then she had Sophia swallow small whole garlic cloves, continue regular Epsom salt soaks and apply oregano oil and other folk herb based salve products. Each health item, Layla picked for their natural antibiotic or antimicrobial properties. The next day, Sophia's finger was "significantly better", leaving Layla relieved. But, during this process Layla also contacted her trusted doctor and explained what happened, what she was doing at home, and that she knew she would come in for biomedical treatment if she did not see improvement. Layla didn't want biomedical treatment first, for many reasons. First, she did not "want that bill." Living for many years without healthcare insurance, she:

> "… can't have additional bills most months. If I can treat at home, I do. If I need urgent care, I will go no doubt. But even though I called our doctor and told her every single thing I did, if I blogged about this, people would go nuts! I would be chastised for not running to the doctor because people see that as risky but going to the doctor and getting antibiotics when not needed could be riskier. People just want to trust doctors no matter what."

Through all of this, Layla has a "great relationship" with the doctor she and her children see now, Dr. A, one of the well-known doctors in the area who are friendly to vaccine skeptical families. Every year, Dr. A. still asks Layla if she would like to vaccinate and Layla politely declines, but they agree to have a discussion if Layla's lifestyle changes, such as traveling overseas which may warrant some vaccines.

Ultimately, Layla sees her role of mother as a:

> "Teacher, healer, supporter. My role as a mother is to teach my kids about life as much as arithmetic, and support their personalities and their growth, and help heal any issues that come up. My role is that of a caregiver, and my goal is to five the best care I can to help nourish gentle individuals who will benefit their corner of the world."

After Covid-19 emerged Layla and I had a conversation about what I saw emerging in the local and national online vaccine skeptical groups, whether focused on mothering, health, or

medical and health freedom. Layla felt really dismayed by the new "anti-vax propaganda," adding that just because she does not vaccinate, it does not mean she believes the other stuff happening relating to Covid-19 pushback. She does not understand vaccine skeptical people.

> "not wanting to wear a mask, which is much less invasive way to prevent the spread of sickness and disease... especially compared to a vaccine which is injected intramuscularly. Covid is real and a lot of people are falling for propaganda, which leaves me feeling like I need to keep reviewing the vaccine stuff."

4.1.4. Ursula

Ursula and her husband are both in their thirties and have three boys. The first in the 11–15-year range, the second in the 6-10-year range and the last was born at their home with a midwife right before the Covid-19 pandemic. Their combined annual household income is in the range of $60,000-$70,000. Ursula has attended some college and her husband has a bachelor's degree. Ursula describes her husband's religious and political affiliation as Christian and Republican while she is agnostic and "in the middle."

I met Ursula at the *Vaxxed II* documentary, first at the meet and greet held in a local restaurant before the movie, then witnessed her as "organizer" for getting the movie here and arranging a Q and A session after in the movie theatre. Ursula, like other mothers at the *Vaxxed II* movie premier were excited to talk to someone wanting to hear their stories and reasoning for being vaccine skeptical.

When I arrived for an in-person participant observation to Ursula's house, I noticed a pleasant scent right away. At the top of the stairs from the entrance I saw a candle burning and something on her stove top. Sensing my curiosity, she explained she was making apple cinnamon tea, with real apple slices and cinnamon sticks, asking if I wanted some (Figure 14).

Figure 14. Ursula's apple cinnamon tea boiling on the stovetop.

After adding local honey to the teacups, we sat on her sectional couch to chat about her health experiences. I noticed immediately upon arrival that Ursula was pregnant [I did not recall noticing during the *Vaxxed II* meet and greet or movie], and baby supplies such as car seat, swing, and stroller were lined up right along the back of the living room wall. Ursula has three specific health experiences that remain strong in her memory and that influenced her decision to not vaccinate.

The first experience was connected to getting the annual flu vaccine. The first time Ursula received the vaccine she had the side-effect of typical flu like symptoms. The second flu shot she got was during her first pregnancy and she felt "really awful" which scared her enough that she thought to herself that she would not get the flu shot again. Next, during a routine prenatal checkup, the certified nurse midwife was performing a pelvic exam and asked Ursula if she wanted her membranes stripped to sped up labor since she was "already down there." Ursula felt extremely "vulnerable" making a quick decision in a compromising position. It was not a conducive time or place to talk about the pros and cons of the procedure. Ursula thought, "I should just do it, I know he has a busy schedule and I want to have him as my provider through the whole process… let's just go for it." Later, when Ursula was thinking about and processing

how interaction went, she felt that it was not normal, not consented, and presented in situation that was an uncomfortable power dynamic. Ursula shared her last story which led to her vaccine skepticism. It happened during a routine prenatal check-up with her second pregnancy. The nurse stated that they "were going to do DTAP and flu shot today" in a way that Ursula felt that it was not a choice, it was just going to happen. Ursula shared her bad experiences with the previous two flu shots with the nurse and that she did not want to do it anymore. The nurse replied that if she did not, she would be a health threat babies and other people, basically "fear-mongering."

Ursula used to keep regular health check-ups with Dr. A, the vaccine skeptical friendly doctor in town. She really liked Dr. A's more "natural mindset" and holistic approach to health care by giving Ursula natural options first rather than "jumping to prescriptions." She also liked that Dr. A did not "shut down" questions Ursula brought up in appointments. Ursula also felt that she gave clear informed consent to all procedures, especially related to her children's check-ups. But, when Ursula mentioned travel plans in a check-up appointment, Dr. A recommended that they consider getting the MMR vaccine. Ursula did not like that suggestion, and that is when her appointments with Dr. A "began to taper off."

Now, Ursula uses a "natural at home" approach for health care maintenance and illness prevention. To start with Ursula is strict about teaching her kids about the importance of handwashing; before they leave the house, immediately when returning home, before eating at school or daycare and when finished. Also encouraging them to wash their hands numerous times when out at other places and doing other activities. Ursula also teaches her kids how to cough and sneeze into their arm creases, not hands or open air. Ursula routinely opens the window of their house to get fresh air circulation during all seasons. One of the main health maintenance protocols Ursula follows is eliminating food dyes from their diet after she noticed

behavior issues when her kids ate food with food dyes, specifically Red 40. They try to eat healthy, but not necessarily all organic. Ursula focuses on making sure her kids eat a balanced diet throughout the day, including proteins, minimal carbohydrates, fresh fruits and vegetables.

One time when Ursula dropped her kids off at bible school, she heard a child "coughing really bad and loudly." She was upset that another parent would send their kids out when they are not well. If they are sick, they stay home and do not go anywhere. When someone shows signs or symptoms of illness, Ursula's goal is to find the root cause of what is wrong or out of balance, then find how to balance that problem. She asks then where in their body they do not feel well and investigates and observes from there. For instance, if their head hurts, she may take temperature and physically check their head and neck structure for abnormalities and offer a cool towel for their head or neck. If their stomach hurts, she will gentle feel their abdomen and ask what they have recently eaten or when they last went to the bathroom and offer mint tea to settle and relax the stomach.

Figure 15. Elderberry syrup, liquid silver, liquid vitamin D, powdered vitamin C.

If one of her children have a cold or illness, she will "boost their immune system" through doses of elderberry syrup, vitamin C and D, and liquid silver (Figure 16). Ursula shows

me where she keeps her at home health care items. Ursula pulls out some jars and bottles from a cabinet space that also contains glasses and to-go mugs near her kitchen sink, and places them on the kitchen counter, in a row. These include elderberry syrup, liquid silver, liquid vitamin D, and vitamin C powder. In a cabinet near the stove, where there are also boxes of tea, Ursula has jars of honey that is used in home health care. Notably, Ursula seems to have a hierarchy of honey which is used as an at home illness treatment protocol (Figure 15). The white label local raw honey is given freely and used as a sweetener for food and drinks. Then, YS brand raw honey is given with any symptoms of cold or illness, lastly, the orange label Manuka honey, which is expensive, is reserved for more fevers and serious colds or illness.

Figure 16. Local raw honey for everyday use, orange label Manuka honey for most severe symptoms, purple label manuka honey for use at start of cold symptoms.

Ursula admits that she is not as “natural” as some moms and also has a shelf in the hall closet of OTC (over the counter) medications, too. She seemed embarrassed to admit this, so I assured her that I also have OTC medications at home, too. Here, she kept natural ear oil and cough lozenges, in addition to OTC children’ liquid Tylenol, throat spray, nighttime cough syrup, and Benadryl (Figure 17).

Figure 17. OTC medications stored in hall closet. Also contains herbal ear oil and natural lozenges.

I was also able to engage in participant observation of a postpartum midwife appointment at Ursula's home in March. Lilith is a popular midwife in the area, whom I had also met at the *Vaxxed II* documentary event. There, she noted to me that she wants people to make their own decisions about vaccinations, but for that to happen there needs to be transparent informed consent. I could hear Ursula and Lilith chatting when I entered the home. As directed by a sign on the door, I went straight to the bathroom to wash my hands. What was significant about this observation was that Lilith, wearing surgical gloves and taking notes on a clipboard was very intentional with her eye contact and questions. After every question about mother or baby's health or lifestyle adjustments to a new baby, she peered over her glasses to make direct eye contact, which were perched on the end of her nose watching *how* Ursula answered.

> "Looks great! Oh! An outie!... Do you have any concerns?... How many wet diapers per day?... Spitting up concerns?... How are you doing?... How is going to the bathroom?... How is your postpartum bleeding?... And sleeping?... How many poops?... How big are they?... How many wet diapers?... How often are you nursing?..."

Then Lilith looked down to write notes. If Ursula did not give a complete answer, Lilith asked another question, then smoothly re-asked the same question in a different way, sometimes repeating questions to make sure the answers were the same.

Suddenly, the room was quiet, and Ursula shed some tears because she wasn't sleeping or eating enough. Lilith offered some advice:

> "It is overwhelming to adjust to a new baby while trying to care for other children… It's hard when women have a lot of pressure and responsibility… You have to let something slide to take care of the newborn… Women need help, we can't do it all".

Adding that Ursula should try to get outside for fresh air once this week, and twice the next week, and so on. If she needs a break, to ask her husband, mother, or father for help. Most importantly, she needs to rest and not try to do it all.

The appointment finishes with Lilith checking Ursula's abdomen and uterus location while Ursula lays on the couch. At the same time Lilith adds that the baby's blood panel from the state laboratory would be back soon and the birth certificate will be back in two weeks. At that time, Lilith will do a hearing check for baby. After Lilith left, I spent a short amount of time chatting with Ursula about her homebirth. It was the best birth she had experienced, loving the freedom of having her home environment and the midwife who encouraged her to explore positions and asked what she wanted to do during the process of labor. Ursula liked Lilith's hand on birth experiences but also her gentle non-invasive labor and birth protocols. Ursula felt more comfortable and more respected.

4.1.5. Karen

Karen and her husband are in their 40's. Karen's husband, Dan, is retired from the military and they both have strong opinions about the mandatory vaccines he was required to have during his service. They have two children together. One teenage daughter and one son in

the age range of 6-10. Both Karen and her husband have master's degrees and have an annual combine household income of $70,000-90,000. Karen describes their religious affiliations as Christian Lutheran, although she grew up Catholic which heavily influences her vaccine beliefs. When asked about her political affiliation, she said, "no".

Karen responded to the online recruitment ad. I had two public setting chats with her and attended one of her business seminars online. Both of Karen's children are mostly vaccinated, but she is now a supporter of informed consent for everyone, especially for vaccines. Karen's aunt had polio and was told she would never walk again. Karen's grandmother felt that was "bullshit" and worked with Karen's aunt every single day with exercises and stretches which resulted in the ability for Karen's aunt to become mostly mobile herself.

Karen learned that she was the product of rape to her biological mother and was adopted as a baby. She grew up in a small town with her adoptive, and very real to her family. Karen was "a super sick kid", which she relates to the trauma involving her conception, biological mother's birth, and adoptive process. As a child she constantly had fevers and infection, at 5 years of age she had a thyroid goiter, in 5th grade Karen was diagnosed with stomach ulcers. As a young adult Karen was "often dealing with pneumonia, bronchitis, or migraines."

Growing up, Karen felt that vaccinations were very important. But when she had kids, she had questions about vaccines "in the back of my head." Even as she went forward following the vaccination schedule with her oldest daughter, Britta, she started reading about vaccines more and specifically, "why do we get these things?" When Karen had her son, William, she also followed the vaccine schedule until kindergarten. Then, Karen started struggling with her son, noticing that he was also really struggling with health, attention, and behavior. One night she was

scrolling through old photos on her phone and noticed all the screen shots of vaccine information she had saved from years ago, prompting her to "dive into information about vaccines."

At the same time, Karen met Trisha. Trisha had been a mental health counselor for 20 years and was distraught by all the trauma she witnessed in clients and the barriers of Western medicine protocols she felt prevented some people from getting better. Trisha developed a system of getting to the root cause of people's problems and issues, based on energy medicine. In using this system, Trisha suggested that the problem with William was related to fetal cells. Karen had no idea why fetal cells would be a problem, so she went home and googled, "what are fetal cells in" with a hit of fetal cells being a vaccine ingredient. As a Catholic, Karen was "disturbed to learn that fetal cells could be involved in the vaccination process." Britta had her 7th grade vaccinations coming up and when they went to the doctor Karen noted her concern and saying she didn't want to do them. The doctor replied, "you don't have a choice" which led Karen to leave the appointment and "evaluate a lot of things in my life." She started with eliminating chemical products from her home and cutting down on standard processed foods. "I don't consider myself anti-vax, but rather pro having a choice. Anything to do with a body should be a choice."

Now, Karen homeschools William while Britta is in public school because each option is the best for that child. While they eat healthy at home, Karen isn't strict about it either, wanting her kids to have freedom of food choices while promoting healthy eating. For health maintenance and illness prevention, they regularly have fruit smoothies with healthy vitamin smoothie powders added. Everyone goes to a monthly chiropractor appointment, and they do regular outdoor walks and at home exercises. Karen herself, goes to regular acupuncture appointments and cryotherapy appointments "to keep energy flowing in my body" and because if

she “is not healthy, I can’t keep my family healthy.” Further, adding that “to maintain my family’s health, we stay as far away from hospitals as we can.” If they need a sports physical for school, they go to the Urgent care clinic and request one.

Karen sees her role as a mother as different than when she first became a mother. Now, her role involves helping her kids be healthy in mind, body, and spirit. Guiding them to be contributing members of society. She also feels that her role of mother includes care- caring for her family and caring for herself so that she can be the best mom possible. Sometimes that means taking a nap or ordering pizza.

4.1.6. Charlotte

Charlotte is in her 30’s and her husband is in his 40’s. They have three daughters, in the age range of 18 months to 6 years old. Charlotte had completed nearly all of her bachelor’s degree before stopping when she had kids. Her husband has his master’s degree. They have a combined annual household income of over $90,000. Charlotte describes her religious beliefs most closely associated with paganism, believing that there is an “inherit connectedness and sacredness of all things.” She said they are not specifically political but would align more closely with democratic ideals.

Charlotte was a snowball recruitment and exclusively a virtual participant. She was excited to participate and an excellent informant, engaging in the virtual hangouts with comfort and further keeping me updated with health and food photos. Charlotte was always thoughtful and honest in all of her discussions. Charlotte always started the virtual hangout in a large open room that on the right side of the screen contained a kid play area, long bookshelf, and storage unit and on the other side a piano and guitar, both of which she plays (Figure 18).

Figure 18. Wooden play area for Charlotte's children.

Charlotte grew up here and her experience with doctors was that they “knew all and we do whatever they say.” As a child she went to the doctor anytime she had a sniffle, cough, or cold and would take anything recommended for treatment, adding that all the treatments were “physical, nothing mental or emotional was addressed.” She remembers having strep throat a lot as a kid and even had high fevers that resulted in hallucinations more than once, though she felt she could not describe to her mom what was going on. At 9, Charlotte felt some anxiety and brought up to her mom that she felt weird or that something was not right, but at the same time didn’t really know how to describe it. Charlotte’s mom brought her into a psychologist, and she was given and anti-depressant. When Charlotte was 11, she had bad acne and was “really medicated” with acne medicine. Later, she read a teen magazine article suggesting that acne could be related to diet. When she showed her mom, her mom “blew off the idea.” Later that year, the doctor suggested birth control might help the acne and Charlotte became very stressed, wondering if she “can get pregnant at 11?” At the same time, while Charlotte did not enjoy going

to the doctor or taking medications, “deep down” she really liked being sick. Because then her mom would have to stay home from work, so when she was sick her “mom would stay home and care for me.” Charlotte pauses with her thumb and finger on her chin, gazing off she adds, “gosh, I haven’t thought about this stuff in a long time. This is so crazy!” Charlotte adds that she “absolutely” believes that her childhood experiences have influenced how she parents her children now.

Charlotte has very specific health experience memories which led her to become vaccine skeptical. Her first daughter, Ashley, is partially vaccinated, the second daughter, Brinley, is less vaccinated, and her last daughter, Sara, is not vaccinated at all. During the birth of Ashley, she prepared the birth with excitement. When it was time for newborn vaccinations, just hours after birth, Charlotte felt that she wanted to vaccinate, but just wanted “to wait a week.” She was thinking “this is too soon; she was just born.” She asked the nurse if she could talk about it with her doctor and ask some questions. For Charlotte, this clinical interaction quickly took a turn from acceptable to uncomfortable and included conversations “being shut down” and lists of all the bad things that would happen if she did not vaccinate. Soon, numerous nurses started rotating into her birthing room trying to coax her into vaccinating. The nurses even encouraged her parents to come into the room to “try and talk to her”. She felt “overwhelmed and powerless and really pressured”, eventually agreeing to the vaccinations. For Charlotte, this experience was the first of many biomedical clinical interactions where she felt her power was taken away and “defeated.”

Her next two health experience memories and examples are also both relating to Ashley when she was a baby. Ashley was having reoccurring UTI’s, and the constant antibiotic prescriptions were not helping. Charlotte started reading in health books and reaching out to

friends and learned about the bacteria that makes up the microbiome. She brought up her concerns and what she learned at the next appointment and the doctor became "really dismissive to my concerns, but offered more tests, which showed nothing." Later, Ashely had a consistent bad diaper rash. Again, after many appointments, nothing was helping or changing the rash. At this time, Charlotte started going to Le Leche League (LLL) meetings and when she brought up her daughter's diaper rash, another mom at the meeting asked Charlotte how much dairy she was consuming. "That's all I ate! Cereal with milk all day." In desperation she immediately cut out all dairy and soon, the diaper rash cleared up. Charlotte had a doctor appointment coming up for the rash and was excited to go and share how she figured out the solution to the diaper rash. When she got there, she had a younger male physician who was not her regular doctor and when she mentioned her story and discovery, he replied, "no, that's not why it went away. I'm a doctor and I've never heard of that." That's when Charlotte decided, "I'm in charge of my health and my family's health and I'm not going to listen to what that man in the white coat is telling me anymore."

Now, Charlotte is a full time stay at home mom and she homeschools her children, too. Additionally, Charlotte makes all their meals from scratch, buying food with the least ingredients and uses whole and fresh foods, because "the main thing is food and diet." She also has a "focus on prevention by eating the colors and eliminating sugar." If a health issue or illness happens, she then looks at the issue and does research to determine the best way for her to address getting better, which usually includes diet changes and immune boosting herbs and tinctures. Above Charlotte's stove is a cabinet which contains jars of dried herbs and spices (Figure 19). Additionally, there are empty jars for filling with other herbs or spices when she gets them, or for

homemade tinctures. Recently Charlotte and her oldest daughter took an online herbal tincture making class from a local herbalist.

Figure 19. Dried herbs and spices.

Charlotte's typical treatment protocol includes elderberry, vitamin C, raw garlic with honey, and gingerroot. These are for "pushing the cold out." Then, she observes the issue and looks for changes. If she sees positive changes, she continues the protocol. If she does not see changes or things get worse, Charlotte will make an appointment with their trusted chiropractor or naturopathic doctor. Charlotte gives me a tour of where she keeps her at home health items. In the kitchen, she sets up Sara in a highchair and gives her a cup of cut pineapple. Charlotte then brings me to a small counter space between her fridge and a tall white cabinet where yellow boxes of tea and jars of powder containing healthy whole food supplement additives for fruit smoothies reside within quick reach (Figure 20).

Figure 20. Spices, smoothie powders, cod liver oil, honey, teas.

On the very top shelf in the tall white cabinet on the other side of this counter were two long and narrow black plastic baskets. One contained supplements and vitamins prescribed for her husband by a Naturopathic doctor, and the other with her own vitamins and herbal supplements. Here, she also takes out a basket of kids' vitamins that are given regularly (Figure 21).

Figure 21. Tall closet for storing supplement baskets. Contents of one basket: Kid's probiotic, liquid vitamin C, Kid's multi-vitamin gummy's, turmeric capsules, echinacea tincture from local Naturopathic doctor.

Turning around 180 degrees, Charlotte opened a lower cabinet drawer in the kitchen island. Here, her children could access healthy snacks, such as dried fruits and nuts, individually packaged fruit cups, and other quick food choices, such as chickpea pasta.

For Charlotte, her role as mother means that her "gut is always right" and that she is "a guide to little humans, to keep them safe til they can develop their own intuition."

4.1.7. Kate

Both Kate and her husband are in their late 40's and have 6 children. Two adult children, one is in the age range of 16-18 years old, two are in the age range of 11-15 years old, and one in the age range of 6-10 years of age. Kate has completed some college and her husband has a bachelor's degree. They have a combined annual household income of $40,000-50,000. Kate grew up Methodist and her husband grew up Lutheran but they both converted to Catholicism 22 years ago, because they "believe very much in the social justice aspect of faith and the responsibility of humanity to the most vulnerable." She describes their political affiliation as independent but leaning towards moderate liberalism.

Kate was a snowball recruitment and an excellent exclusive virtual participant, providing lots of information, photos, and health update messages and photos. Kate shared numerous stories of what she experienced as medical abuse and trauma that were very personal and emotional, eliciting tears as Kate recounted them. Yet, she was determined to share as much as she could with me in the amount of time we had. She packed our long virtual hangouts with a plentitude of health and life narratives, feeling encouraged that anyone would be asking and listening to why she chooses not to vaccinate her children. She added that the time for these discussions, in the midst of the pandemic, is critical for health providers to reach out to vaccine skeptical mothers. Adding that she, like others she surmises, are teetering on the fence of

vaccination acceptance. Kate started her kids back on a schedule of vaccines during the pandemic, getting the Covid-19 shot herself.

Kate grew up in a small town and spent her childhood moving around to other small midwestern towns. While Kate was growing up, she had plenty of biomedical encounters and tests due to a mysterious health issue. She was in and out of school with spells such as light-headedness, passing out, slurred speech, severe headaches, shaking, stumbling, and extreme weight loss. By 2nd grade Kate had a "huge thick medical file." She was diagnosed with pleurisy and tonsilitis. Which, after treatment, she felt a little better but still felt that "something was wrong, I was always sick and bumbling behind my peers." In 4th grade, Kate was extremely thin and not gaining weight. A doctor told her she had an eating disorder and recommended eating "two desserts, twice as much butter, and that should be eaten in front of the T.V." When Kate was 14, another doctor wanted to enroll her into a study that was exclusive to 40-year-old women. She had to drink a large amount of "some liquid that made me feel really sick." While sitting in the doctor's office waiting for the testing after the drink, Kate's "leg's stopped working" and she felt like she was going to throw up. She fell to the floor where the doctor slapped her on the butt with his clip board telling her to "Get up! There is nothing wrong with you!" Kate said this was the first of many biomedical experiences that "left a bad taste for medical doctors."

Finally, as a senior in high school, after a "bad spell of headaches, slurred speech, and bad handwriting" at school. Her mysterious health illness made the school and local newspaper, and she became known as the "girl with crazy health stuff." Soon, her health problems were connected to the schools' major renovations. When Kate was in proximity to the part of the school where the remodeling was taking place, she had these symptoms. After time outside in

fresh air, they would lessen. The school tried to accommodate her by allowing windows open in her classrooms and she was allowed extra time between classes to go outside for fresh air, but she was still sick. Kate ended up schooling at home, labeled as "home-bound." She finally received her diagnosis of "multiple chemical sensitivity disorder" after seeing a specialist in Washington because she was "not believed by any general medical person here." This diagnosis meant that Kate's body severely responded to exposure to any chemicals such as paints, glue or adhesives, or chemicals in cleaning or beauty products.

Even after having a diagnosis and taking precautions with her health, Kate's health experiences did not improve. Kate was "pretty traumatized" after experiencing mono, pre-eclampsia, and a seizure which led to an emergency c-section during the first of her six pregnancies which eventually lead to her being diagnosed with PTSD. After this terrifying pregnancy and birth experience, Kate's post-natal biomedical appointments consistently included missed health issues and problems and she was lacking support from clinicians as a first-time mom. After her first pregnancy and delivery, Kate explored midwifery care to get the extra help and support she felt she did not get and needed, in addition to the biomedical care she used. Kate had numerous positive experiences balancing the use of a midwife for pre- and post-natal care along with "only the basic medical help."

The experience that led Kate to question and stop vaccinations was when her first son had a febrile seizure after his 18-month DTP vaccination. After this vaccination, he ended up having a total of 5 petit mal seizures where he would stare off into space, have a stiff body, and be unresponsive. She feared that he would get worse if they did any other shots, so she declined the vaccinations at her next appointment. The pediatrician said that Kate would need a doctor's note to stop vaccinating, and she would not be the one to give her one. In this time period, Kate had

her second son, and she was afraid to do vaccinations for him, thinking the same might happen, so she expressed that if she did vaccinations for him, she wanted to wait in the clinic for an hour to observe him to be sure he did not have a reaction like her first son, to which the pediatrician responded that Kate was "ridiculous." "They lost their chance, that's when they lost me." After that, she "just stopped going" to the doctor appointments and stopped getting vaccinations. Kate she remembers back and forth confusing messaging on the radio and television ads regarding polio, chicken pox, and the changing of the DTP vaccine to DTAP from the time her kids were little in the 1990's to now, leading her to the conclusion that:

> "They mock us, then change the story. The trust level doesn't exist there. If they really cared about kids, why wouldn't you change and improve the vaccines? It seems like it's all about profit. But I also felt like if illness happens to my kids, it happens, but if I inflict that [through vaccination], I'm going to feel horrible."

Then, Kate started "reading lots of books." Kate also bought a lot of books, most of which she still has. Kate takes her laptop to their "library" and shows me shelves and shelves of books (Figure 22).

Figure 22. Kate's bookshelf.

Her library includes CAM books on health maintenance and illness treatment, but also biomedical health books and homeschool curriculum books. As we look at her bookshelves, she

seems deep in thought. “I was a good mom. My job as a parent is to find the best doctor, the best schools, the best daycares and I learned the hard way that *I* was the best.”

Although Kate stresses healthy eating, she also feels that to follow a strict healthy or organic foods diet is based on economic privilege. With six family members remaining in the house their grocery budget is tight, so Kate has to determine which food items to purchase organically (Figure 23). She tries to follow the list of the “dirty dozen and clean fifteen.”

Figure 23. Grocery trip. Fruit and vegetables, frozen foods, snacks.

This list is compiled by an environmental organization and lists the fruits and vegetables that have the least amounts of pesticides, the clean fifteen, and the ones with the highest levels of pesticide use. The highest-level ones are called the dirty dozen and should be purchased organic. More, Kate tries to focus on a balanced diet and not eating too much of one thing. Kate sent me part of a photo diary with images and descriptions of her typical grocery trip from two different grocery stores. Kate explains the need for covering carbohydrates, proteins, fruits, and vegetables and also get regular dairy milk in addition to a milk alternative for one child and one grandchild who both has diary allergies (Figure 24). She buys meat, but also tofu, food items for making meals at home and fun snacks for her kids (Figure 24).

Figure 24. Dairy and non-dairy "milk." Snacks- cheese sticks, meat sticks, bars. Tofu, tea, and drinks.

Now Kate follows the saying, “treat the child, not the fever” when using CAM at home, although she does still keep OTC medicine to treat a fever or other illness, if necessary. Kate has very specific locations for her at home health treatment items. Some of the reasoning behind the locations of the health items is that they live in a “very small house with lots of bodies so space is limited.” Items such as Vit C, D, Zinc, and nasal sprays are in the dining room where the kids can access themselves. Kate keeps any health items related to herself in her bedroom, either in shoebox sized plastic totes under the bed or a drawer in her dresser (Figure 25).

Figure 25. Under bed storage. Contents of plastic storage container- extra supplements, lozenges.

Since Kate also has diabetes, she has her diabetic biomedicine in a separate bag and space- on a bookshelf in her bedroom. In the hall closet is where Kate keeps “the rest of our health items” and has been organized into numerous plastic baskets (Figure 26).

Figure 26. Hall closet storage for health items.

Here she has “cough drops, hand sanitizers, allopathic medicine, natural remedies, and a nebulizer.” At home fever reducing treatments Kate does before using OTC medicine includes putting wet socks on hands and feet, cold cloth on foreheads. Other at home remedies include alternating hot shower steam and opening the windows in the winter for coughs, adding chest percussion and echinacea. These treatments are what Kate used when her family had whooping cough.

Kate marks the experience of whopping cough as when she “started to feel challenged” about whether she should continue not vaccinating or start again. One day at church Kate heard a family coughing and thought “that doesn’t sound good.” Soon after, one of her daughters got sick, then another and another child were sick, and they were coughing all the time. She brought them into the clinic. Kate knew that if the entire could get quick antibiotic treatment, it could

help the infection spread. She asked the doctor who said no. Then the doctor said, “Oh, we know it’s not whooping cough because you’re vaccinated, right?” Kate replied that no, they did not vaccinate. Then the doctor responded, shocked, “Oh! Then it is whooping cough!” Whooping cough went through Kate’s entire family, with her 17-month-old coming down with symptoms last, which she describes as a “traumatizing experience.” Twice her 17-month-old son stopped breathing, requiring hospitalization once. The day and night caring for her 6 kids with constant coughing fits over three months was “absolute hell.”

Another experience that pushed Kate one step closer to accepting vaccinations was when Kate’s mom died of an aneurysm. After her mom’s death Kate went to her house and collected all of her medications and things. She noticed *a lot* of unused blood pressure medication and knew her mom was hesitant to take prescriptions regularly, which made her think that if her mom had just taken her prescription medicine, maybe she would still be alive. Then, after Kate and her family got regular healthcare coverage through the Affordable Care Act, she found a doctor that was “for the first time, nice! And respectful! And having labs available and covered were so nice!” Kate, tearing up, wiped her eyes on her T-shirt sleeve, adds that this doctor was good and not mean or demeaning about her use of natural medicine at home.

Finally, in addition to the experience of having whooping cough in her family and her mother’s death, Kate felt the final push to consider vaccinations again was that when the Covid-19 pandemic hit and “the world went crazy!” Kate pauses a moment, “I’ve gotta stop and breath about this”, Kate pauses before continuing on

> “The masks! Why are people opposed to masks! They are as natural as cloth diapers! Do these people even read? Or actually read medical studies like they claim?! Then I saw they became Trump loving and then find out they were racist, so then I knew it wasn’t me, it was them.”

Kate no longer feels that she knows what is true or not. She feels that both of the "anti-vax and pro-vax" arguments are similar, stuck firmly in their beliefs and neither are willing to be open to hear "the other side." Kate has noticed that in the past few years, the "pro-vax comments were getting really nasty", then she "realized that there are some anti-vaxxer's that are that crazy!" Once Kate put all of these extremely deep and personal experiences together, along with the world going crazy, she felt "insulted by all of it" coming to the realization that all of these experiences have led her to believe that vaccinating is now right for her family.

Minutes after my first virtual hangout with Kate had ended, I got a notification on my phone of a message from her.

> "One thing that struck me as I got off the phone .... I feel like mainstream medicine doctors have an opportunity with me and many others right now. This is simply because the conspiracy theory, anti-mask version of the anti-vax community sound so crazy that we are open right now to mainstream medicine because they sound less crazy. I hope they don't blow this opportunity. Seriously ... treat us with respect and dignity. Give us actual informed consent. Listen to questions and respond with studies and thoughtful replies. Respect if the patient makes a different decision. Because otherwise, we will just be driven away yet again. So that's what I would say to them. Don't waste this opportunity. I really enjoyed meeting you and chatting. I hope you are able to make sense out of all my ramblings. Lol. Talk to you soon!"

Kate's quick message to me exemplifies the importance of this research. Vaccine skeptical mothers encompass the spectrum of hesitancy, refusal, and skepticism. Vaccine skeptical mothers are not all holding firmly to the ideas of never vaccinating or using biomedicine blindly. For clinical medicine and public health to make connections to remedy low vaccine uptake, it cannot be assumed that all vaccine skeptical mothers live in the same science, or anti-science, reality. As my research demonstrates, some mothers are well aware of the benefits to using biomedicine, but they have experienced negative and demeaning interactions, and in some instances abusive interactions and experiences, which in turn have resulted in them losing trust and respect for biomedicine, in general.

4.2. Covid-19

A few months into the pandemic, in the late spring of 2020, I sent my interlocutors messages checking in and asking them if they were making changes to their at-home-health maintenance or illness prevention routines. Initially, all mothers responded that they were making sure they were following strict healthy eating at home along with adding supplements and herbs that had immunity boosting properties. Additionally, most of the mothers were following recommended precautions such as staying home and avoiding contact outside of their household and washing hands frequently. Some mothers had also started using standard hand sanitizer versus natural based ones they would typically use, and also started using standard chemical-based cleaning wipes to their routine of wiping hands, items, grocery, and household surfaces. These cleaning wipes were typically never used in these households, but these vaccine skeptical mothers saw the benefit of using them temporarily when little information was known about Covid-19. By the summer of 2020, all mother interlocutors had stopped using standard hand sanitizers and chemical-based cleaning wipes for items and household surface cleaning, and instead switched back to natural based hand sanitizers and their typical natural based cleaning products and routines.

Notably, the topic of mask wearing became a contested issue in online vaccine skeptical, and medical and health freedom groups, including the local online group where I had posted my recruitment script. Initially, most mother interlocutors were accepting of and wore masks. But soon I noticed online postings in medical and health freedom groups charge that forced mask wearing was akin to forced vaccination. From that moment two of my seven mother interlocutors also took a hard stance against mask wearing claiming reasons of health freedom. The other five remained steadfast in the importance of mask wearing as a noninvasive intervention to stop the

spread of disease to others and protect themselves. Further, the online discussions in the local mothering group became inflammatory, accusatory, and angry with a clear and hard divide revealed in the once cohesive group based on the commonality of vaccine skepticism, all stemming from the topic of mask wearing. Some became more anti-science while others became more willing to engage with science during this unique time explaining to the group that changes in protective, preventative, and safety measures was actually good science. What was abundantly clear was that this local online mothering group and all of my mother interlocutors were not static or homogeneous in their vaccine skeptical beliefs as the media portrayed all anti-vaxxer's as also anti-maskers. Some were capable and willing to change their minds, by following good science. What this revealed was that despite their connection of vaccine hesitance, these vaccine skeptical mothers diverged drastically in response to mask wearing during a pandemic.

In the end, most mother interlocutors held tight to their vaccine skepticism regarding Covid-19 vaccines, citing distrust in the quick approval process and lack of long-term studies as major factors in why they will decline getting vaccinated for Covid-19. Proving to be products of their social and cultural environment, another layer of skepticism regarding Covid-19 vaccines was their distrust for medical institutions and providers based on their negative experiences. Kate was the one outlier in the research group. She and most of her family received one dose of Covid-19 vaccination during the research time period.

5. DISCUSSION

Initially I believed that mothers who are vaccine skeptical would latch onto ideals presented during second-wave feminism, which scrutinized medicine's paternalism and called for a women's right to have informed consent and medical choice (Conis 2013; Craven 2005; Davis and Craven 2016). Yet only one of the seven interlocutors strongly claimed feminism as an influence on her vaccine skepticism and biomedical refusal. Layla strongly believed that issues of informed consent and medical choice regarding vaccinations were "absolutely a feminist issue." She added that biomedical practitioners dismissing mothers' questions about vaccine safety or demeaning them for bringing up their hesitance is "misogynistic." In contrast, when I asked the other mothers directly if feminist ideals directed their vaccine decisions, they responded similarly to Janis, who said, "I wouldn't call it feminism." Yet, similar to second-wave feminism, all mothers noted their distrust of clinical medicine and "Big Pharma." Janis believed that clinicians received financial incentives to administer vaccines, which was one reason not to trust them. And all of the mothers wanted informed consent and medical choice, especially when it came to vaccines and prescription medicine.

I also thought that ideas about medical risk would play a role in mothers' vaccine skepticism. While each mother mentioned the potential risk of negative side effects from vaccination and other biomedical interventions, risk did not play a major role in their narratives. Rather, each mother saw the risk of potential side effects as lying in a grey area, not a binary statistic often provided by biomedical health providers (Hunt, Castaneda, and Voogd 2006; Panter-Brick 2014). Before Layla's first vaccination appointment, for example, she had heard that "there may be risk" associated with vaccines. She also felt that prescription medicine "could be riskier" than trying to maintain health through her folk medicine.

One point that became abundantly clear throughout my research was that paternalistic, demeaning, and dismissive biomedical experiences directly led to their vaccine skepticism. Harold Grimen (2009) notes that issues of power and trust are deeply embedded in clinical medicine and when combined with paternalism and negative rhetoric, decreases trust, and increases resentment. This point was evident as each mother shared a clear memory of a negative clinical encounter that led her to lose trust in the biomedical relationship. When Charlotte's desire to "just wait" with newborn vaccinations "shut down," she felt "overwhelmed and powerless," eventually succumbing to the pressure. Ursula felt extremely "vulnerable" when a medical provider asked her questions about procedures in the middle of a vaginal exam. She felt the power dynamic created a situation in which she "couldn't say no." After Hannah and her husband Adam endured their son's medical experience, they saw biomedical interventions as risks not worth taking, noting their trust in the biomedical health care system is "gone." On the whole, these mothers felt that continuing interaction with biomedicine created more of a health risk for their families than a benefit. While Hannah recognized her son's need for biomedical care, she still asked herself "if the benefit is worth the risk."

When medical experts cannot be trusted, to whom do these mother's turn? In my research, the women relied on their own research, education, and everyday mothering experiences to shift the locus of experience. Every mother with whom I spoke claimed authoritative knowledge based on her personal experiences as a mother (Conis 2013; Yochim and Silva 2013). In this way, mothers moved medical care out of the clinic and into the home- and specifically into the kitchen. Mothers described ways that each child's health needs were unique, resulting in individualized care through food, health maintenance options, and illness treatment protocols. Akin to Yates- Doerr and Carney's (2016) work on the kitchen as a site of

care in Latin America, I soon realized that the focal point of these mothers' caring practices was also in the home kitchen. Layla tended to easily digestible sourdough bread in her kitchen every day, in addition to making all food and snacks from scratch. Janis woke up early every morning to pack balanced homemade lunches for her girls and herself. The kitchen was where mothers spent the bulk of their time preparing food, whether it was special health-boosting food or food to treat illness and finally it was where they also kept most of their CAM and folk herbal remedies.

My interlocutors consistently described various ways that they, as mothers, provided care for their children. A key component of their care was time. They spent time researching "the best" options for diet, food, alternative or folk supplements, and medical providers. Janis spent "hours every week" reading about health studies, reputable supplement brands, and food nutrition. Additionally, the mothers took time to shop for the best food and supplements, and they spent time preparing homemade meals every day. Such attention to food preparation also meant spending time with their children and getting to know each child's unique wants and needs, especially their individual health needs. Hannah chose to provide daycare services in her home so that she could both "have an income and provide care." Charlotte was grateful to be a stay-at-home mother to her children, providing them with support and love in a way she felt that her mother, who had worked full-time outside the home, could not.

Finally, for each of my interlocutors, within their married or long-term relationships, childrearing was their primary responsibility, and they saw as it as incredibly important. Conis (2013) and Reich (2016) have discussed the substantial pressure on mothers not only to ensure their children's survival into adulthood, but also to consider their well-being as individuals and as considerate members of society. My interlocutors saw the role of mothering to consist of more

than providing basic necessities, such as food and shelter. They also spent quality time with their children in hopes of raising healthy, respectful human beings. Charlotte, for example, felt that providing support to encourage her daughters to have strong intuition and "follow their gut" was important. For Janis, being a mother means that she was a "protector and promotor of health, wellness and wellbeing." Layla, reflected on the many responsibilities she had as a mother, which included;

> "[being a] teacher, healer, supporter… to teach my kids about life as much as arithmetic, support their personalities and their growth, and help heal any issues that come up. My role is that of a caregiver, and my goal is to give the best care I can to help nourish gentile individuals who will benefit their corner of the world."

5.1. Summary

What all of these narratives show is that these mothers are concerned about health in ways that far exceed the potential risks of vaccination, even though that is what public health professionals, biomedical providers, and the media tend to focus on. Rather, these mothers, took an expansive approach to health and wellness that included alternative interventions that could and did exist alongside biomedical options. To be sure, while biomedicine was never the first choice, it was *a* choice, and it was one that mothers were open to if circumstances warranted it. Until it came to that, however, they saw themselves as providing good preventive care through the most intimate and practical of ways: the everyday dietary choices they made for their children in the kitchen. They created their own medical homes based in their kitchen. At home they observed their children's health needs and made changes based on their everyday expertise as mothers and caregivers. When they noticed their children's health was not optimal, or if food proved inadequate to maintain health or prevent illness, they sought out a variety of alternative, natural, or folk health resources, which they saw as less invasive and less risky than biomedical care.

Further, these mothers consistently and exhaustively research the best food, supplements, health options, and CAM practitioners. They claimed they were doing what was right for themselves and their children, taking full responsibility for their health. In other words, they followed the spirit of the neoliberal healthcare model, yet their choices were not approved by the public. How, then, can clinical medicine and public health, which simultaneously encourage and discourage personal responsibility for one's own health, connect with mothers who embrace neoliberal healthcare consumerism? This is where the value of ethnography shines. By placing each of the mothers within her personal and social context, we can see them as true people, not as stereotypes, who have their reasons for questioning biomedicine.

In particular, stories from these mothers revealed that their vaccine skepticism and general distrust of biomedicine stemmed from negative experiences with biomedical practitioners. To gain back their trust, there needs to be renewed focus on patient-centered medicine. What does "patient-centered medicine" mean if not taking the opinions and experiences of patients seriously? When these mothers went to their clinical providers with questions or hesitation about vaccination, they were "shut down" and made to feel that their concerns were not important. What these mothers desired was open and respectful discussion regarding their concerns and questions.

During the current pandemic, as public health officials struggle to connect with vaccine-skeptical American, campaigns based on gaining their trust, rather than shaming their decisions, may be more effective. If public health officials acknowledge that vaccine skepticism stems not from ignorance but from unhealthy biomedical encounters, they may be able to initiate vaccine conversations with these mothers. Importantly, while vaccine skeptical mothers are concerned about community health- they stay home when ill, for example- they were also unwilling to

sacrifice their own children's health for the greater good of the community. Campaigns focusing on protecting neighbors or others fall short of connecting with these mothers, who see protecting their family's health as one of their primary responsibilities. It is crucial for clinical and public health professionals to recognize that stereotypes of "anti-vaxxers" are incomplete. As Kate told me, "This is the time to reach us." Given the unprecedented nature of the Covid-19 pandemic and vaccination campaign, now is the time to reach out to vaccine skeptical mothers.

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APPENDIX A. ONLINE RECRUITMENT SCRIPT

Hello parents! I am a student at NDSU working on my master's degree in Anthropology. I am aware of some people in this [social media group] choosing modified CDC vaccine schedules, or not vaccinating at all. I would like to interview parents from 10 families who are willing to discuss this topic to learn when and why you have made these choices about modified or no vaccination for your family. I am also interested in what you do to stay healthy during the cold and flu season, including alternative health care providers you see for help, health, or advice. I would also like to know of any personal conflict you or your family have experienced based on your vaccination choices, whether with health care providers, other social events, or other interactions. This research is open to families from all levels of vaccination refusal. I am also looking for 3 families to participate further by allowing me to observe at home health preparation and wellness activities. Please note that all participation is voluntary, and any direct personal information collected will be modified or removed completely.

APPENDIX B. DEMOGRAPHIC WORKSHEET

Number of adults (18+ years old) in your household _____

Your age (please circle one):
20-29 30-39 40-49 50-59 60-69 70+

Age of your partner (please circle one):
20-29 30-39 40-49 50-59 60-69 70+

Number of children within the following age groups:

0-2 years ____ 3-5 years ____ 6-10 years ____ 11-15 years ____ 16-17 years ____

Approximate annual household income (please circle one)

$10,000-29,999 $30,000-39,999 $40,000-49,999

$50,000-59,999 $60,000-69,999 $70,000-89,999 >$90,000

Your highest level of education (please circle one):

High School Trade School or Community College Some College

Bachelor's Degree Master's Degree Doctorate/MD/JD

Your partner's highest level of education (please circle one):

High School Trade School or Community College Some College

Bachelor's Degree Master's Degree Doctorate/MD/JD

Do you, your partner, or family have a religious affiliation or beliefs? If so, how would you describe your religion or spirituality?

Do you or your partner have a political affiliation(s)? If so, how would you describe your political affiliation(s)?

APPENDIX C. PARENTAL QUESTION PROMPTS

Health History and Information

Past experiences

Have you always lived in in this area?

- If not, where

What was your experience with health, illness, and doctors growing up?

- How did your family stay healthy?
- How did your family treat illness/what happened if you were sick, as a child?
- Did your family go to doctor appointments?
- Did your family see other health providers/alternative health care?

What kind of memorable health or illness experiences have you had?

What kind of health provider experiences have you had?

Current experiences

Do you see a biomedical health provider? (Dr, NP, Fam Prac Dr.), or alternative health care provider? (Naturopath, etc).

- Do you inform health care providers of home health practices?
- What has been your experience with any provider that you have seen? (W. Dr./NP, or Natropath) both POSITIVE and NEGATIVE
- What would your ideal health provider experience look like? Who would be involved?
- What knowledge would they have?

How do you manage illness in your family?

- -Prevention: What methods of wellness (prevention) do you participate in?

- Treatment: What methods or routine do you use when someone becomes ill or sick?
- Whom do you turn to for medical or health advice when needed?
- How does your life/lifestyle change in these instances (of illness/sickness), or not at all?

How long have you been using alternative home health practices/remedies?

- How long have you been seeing CAM health providers?

Where/who have you learned the most of what you know about alternative or natural health care treatments, remedies, methods, etc?

- How do you know what to do, when?

Have you ever been without health insurance coverage? How long?

Vaccine Q's

When did you make the choice to do a modified schedule of vaccines, or no vaccines?

- How were the conversations between you and your partner in making this decision?
- Was there hesitance from either person regarding this topic?
- What were the most important factors in making your decision?
- What specific factors or information essentially helped to finalize your decision?

Where do/did you get most of your information on vaccines?

- Family/friends?
- Did they provide specific resources?
- Medical or other health provider? (specify)
- Self-research? (specify)
    - Library/hard copy literature, books?
    - Site specific online sources/websites?

- Social Media -Other

How do you evaluate the information that you find/read/hear? Do you "double check"?

Are you and/or your partner vaccinated?

- Are all of your children vaccinated/not-vaccinated in the same way? Why or why not?
- Does anyone in your family receive the yearly flu shot?

What if your children decided that at 18 years of age (or older) that they want to get vaccinated?

- Or participate in other health methods not aligned with what your family practices now

What are your thoughts on/what do you know about herd immunity?

What do you think about the statement that the autism link to vaccines has been debunked?

Are you familiar with celebrity anti-vaxxer's, such as Jenny McCarthy?

- What are your thoughts about her experience, campaign, and anti-vax book?

In your opinion, could a vaccine ever be made safe?

- Safe enough you would consider vaccinating?

What does vaccinating mean to you in terms of your body?

- Your children's bodies?

What does NOT vaccinating mean in terms of your body?

- In terms of your children's bodies?

What does vaccinating mean to you politically?

What does vaccinating mean to you socially?

Social support

Do you and your partner have extended family support? Are they aware of your vaccine choices?

Yes-> In what ways do they express and show support? Have they always been supportive? If not, how and when did their minds change? How does this make you feel?

No-> What challenges do you face with family members that are unsupportive of your choices? How do you mitigate the differences/conflicts? Can you give me an example of a negative interaction?

Do you have the support of friends?

- Do some, none, or all of your friends know about your vaccine choices? Why or why not?

Have you gained friendships through your vaccine decisions?

- If so, in what ways have these friendships been supportive or beneficial?

Have you lost friendships based on your vaccination decisions?

Public/Social Interactions

Are there any activities that your family members attend, which ask for, or "require" vaccine information? (School, activities)

- How do you manage this when interacting with other people, groups, and organizations?

Do you have any social "support" groups? Those who share your beliefs on vaccination and you spend time with them or go to them for support or advice

- Online or in-person?

Are you familiar with any vaccine conspiracy theories? (from mainstream media, social media, etc.) Which ones do you believe or not believe? Why?

What is your opinion of people who:

- Do not vaccinate at all?
- Do a modified vaccination schedule?
- Do a full recommended vaccine schedule as recommended by their doctor or CDC?

Are there other health or lifestyle subjects/topics that you are passionate about/actively pursuing information that is counter to mainstream ideas or beliefs about children and family health?

APPENDIX D. COVID-19 QUESTION PROMPTS

COVID-19 Questions

What do you know about COVID-19?

Where have you learned/heard about COVID-19?

Have you made any lifestyle changes since the outbreak of COVID-19?

- Specifically, related to:
    - health/wellness
    - illness prevention
    - at home treatment preparation

What are your thoughts and feelings about the COVID-19 vaccines?

Would you consider/accept administration of a COVID-19 vaccination?

- Why or why not?

I've noticed that mask wearing/not wearing has become a popular/hot topic in non-vaccinating social media groups, but also becoming a dividing issue in some anti-vaccine social media groups.

- What is your stance on mask-wearing and how does this connect, OR NOT connect, to your ideas about vaccinating?