

The Social Organization of People's Experiences Enhancing Health for their Young Children  
after Declining Vaccines

by

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RN Diploma, Lethbridge College, 2002

B.N., Athabasca University, 2010

M.ScN., University of Northern British Columbia, 2015

A Dissertation Submitted in Partial Fulfillment  
of the Requirements for the Degree of

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University of Victoria

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We acknowledge and respect the Ləkʷəŋən (Songhees and Esquimalt) Peoples on whose territory  
the university stands, and the Ləkʷəŋən and W̱SÁNEĆ Peoples whose historical relationships  
with the land continue to this day.

**Supervisory Committee**

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## Abstract

In this publication-based dissertation, I describe a Ph.D. research project with three manuscripts that seek to form a better understanding about people's activities to enhance their family's health after declining routine childhood vaccinations. My experiences as a registered nurse working with people who choose not to vaccinate their children ignited my interest in this topic. After not fully vaccinating, people have described contributing substantial amounts of time, effort, and financial resources towards activities that aimed to thwart vaccine preventable diseases in their families and enhance their children's health. Declining vaccines was not just a choice, or a perspective confined inside of people's minds. Their efforts to do "health work" for their family can be observed in different families and communities, at different times. Recognizing that what people *do* is as intensive as it is invisible has led me to engage in a dissertation that seeks to form awareness about this facet of vaccine refusal.

Using Institutional Ethnography, my dissertation research began illuminating how institutions within ruling relations influence the social organization of people's experiences of health work that aims to enhance the health in their children while protecting their rights to choose which health treatments their children will receive. In this work, a JBI qualitative systematic review, a key informant interview, and a meta-ethnographic exploratory synthesis provided rich descriptions of informant's health work for their children. My goal was to produce an understanding that assists people and healthcare providers, like nurses, to recognize potential influencing factors of vaccine hesitancy that may have gone unnoticed. From this understanding, I hope that healthcare providers and researchers recognize that respect for people's "health work" can exist in tandem with a difference in opinion on the topic of vaccines.

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## Glossary

<b>Term</b>	<b>Definition</b>
Actuality/ies	The world outside of texts to be explored in Institutional Ethnography; always more than what can be described, named, or categorized (Smith, 2005)
Discourse	The translocal relations coordinating the practices of individuals talking, writing, reading, and watching, in particular local places at particular times (Smith & Griffith, 2022)
Disjuncture	The feeling of being caught between the experiences of everyday life and institutionalized work processes; recognizing that two subjectivities co-exist, two different versions of reality, whereby something is known from a ruling (institutional) perspective versus an experiential perspective (Campbell & Gregor, 2004; Smith, 2006)
Experience	What people come to know that originates from their bodily being and action (Smith, 2005)
Institutions/institutional	The complexes embedded in ruling relations that are organized around a distinctive function, like health care or education (Smith, 2005)
Institutional capture	Occurs when both informant and researcher are familiar with institutional discourse, know how to speak it, and the interview loses touch with the informant's experientially-based knowledge (Smith, 2005)
Institutional circuits	The displacing of what is actually going on in people's lives when they are caught up in the textual representations of institutional order; shown through standardized representations that conform to language and framing of governing or boss texts (e.g. theories, laws, procedures, policies, rules, regulations) (Smith & Griffith, 2022)
Institutional Ethnography	Explores the social relations organizing institutions as people participate in them and from their perspectives (Smith, 2005)
Map/mapping	A map or mapping brings together different work knowledges, from different positions, and includes an account of the texts coordinating work processes in institutional settings (e.g. work-text-work sequences) (Smith, 2005)

Problematic	How the ethnographer/researcher's concerns and interests organized their research direction (Smith & Griffith, 2022)
Processing interchange	Used to identify an institutional chain of action or work process where a text enters an individual's work setting, then it is processed into a new text to become the focus of another or others' work (Smith, 2005)
Ruling relations	Draws attention to distinctive translocal forms of social organization. How the everyday of our lives is organized and coordinated, we participate in ruling relations while they impose objectified modes of action upon us (Smith, 2005; Smith & Griffith, 2022)
Social Organization	When different forms of coordinating peoples doings emerge and are reproduced again and again (Smith, 2005)
Standpoint	The positioning of research, a way of directing attention to the starting place of the inquiry (Smith & Griffith, 2022)
Texts/textual resources	Material objects (electronic or print) that have various messages that coordinate what people do across multiple sites and times (Smith & Griffith, 2022)
Work/workful activities	A generous conception of work; what people do intentionally that takes time and effort, done under definite conditions (Smith & Griffith, 2022)

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*Deep down inside most of us would like all stories to be simple because we want real life to be like that, too. But communities are like ice, not water. They don't suddenly flow in new directions because you ask them to, they change inch by inch, like glaciers.*

*Sometimes they don't move at all.*

(Backman, 2019 in *Us Against You: A Novel*, p. 380)

*Let us give up the illusion that 'we humans' rule the world. Let us refrain from distinguishing endlessly between people who are able and people who are not. For as it is, each time our attempts at control fail again, we are caught unprepared. So let us care instead.*

(Mol, 2008, p.108)

## Chapter 1: Foreword

### Engaging with this Topic

Engaging and exploring the “health work” of people who have declined routine childhood vaccines is undoubtedly rooted in my embodied experiences as a nurse and as a mother to two children. I remember the first parents I worked with who declined a measles-mumps-rubella vaccine for their one-year-old son, 15 years ago. They were fearful of him developing autism and relayed the findings of a published, then subsequently retracted, research paper by Andrew Wakefield that purported a causal link between the two (Allan & Harden, 2015). At the time, I was astounded by their choice. The country we were living in was experiencing a measles outbreak due to low vaccine uptake because of an interruption to public health vaccination programs during a violent conflict in the prior decade. The parents’ fears of the vaccine prevailed regardless of the assurances and information my colleagues and I shared. I struggled to find research that could inform my practice in how to engage with families that have fears about vaccines and choose to delay or avoid this preventative health intervention for their children.

This experience, in tandem with my studies in a family nurse practitioner (NP) graduate program, led me to complete an integrative literature review capstone project on the topic of vaccine hesitancy (Huel, 2015). The most recent, formal definition of vaccine hesitancy was developed by The World Health Organization as: “...a motivational state of being conflicted about, or opposed to, getting vaccinated; this includes intentions and willingness” (WHO, 2022). This definition is inclusive of people who are conflicted about their choice to vaccinate along with those who are opposed to receiving all or some vaccines. More importantly, it portrays vaccine hesitancy as a motivational state rather than a behavioural one that is linked to their

specific actions surrounding vaccines (Bedford et al., 2018). These actions could include feeling hesitant yet still vaccinating your children, refusing some vaccines but not others, and/or refusing all vaccines. In short, there is expressing vaccine hesitancy, and there is acting upon it.

My master's degree integrative literature review endeavored to provide some direction to primary care providers about how to intervene when families express hesitancy about vaccinating their children. Its findings, along with my continued engagement with unvaccinated families in primary care practice, produced more questions for me than answers. Namely, I wondered if healthcare providers and researchers understood enough about all the “moving parts” and circumstances that could influence a person's vaccine choices? Did we understand enough to make recommendations that could alleviate people's fears and increase childhood vaccine uptake?

These questions were cultivated through my conversations with people who were both vaccine hesitant and chose not to fully vaccinate their children. Their questions and concerns about vaccines were much more difficult and nuanced than what the literature purported their perspectives to be. In a research landscape that connects a lack of trust towards a primary care provider with a feeling of hesitancy about vaccines (Dubé et al., 2018; Kempe et al., 2011; McGregor & Goldman, 2021), one may conclude that if patients trust you, they will choose to vaccinate their children. However, my nurse practitioner practice revealed that people's trust was not an all or nothing phenomenon. People could simultaneously feel mistrustful about health providers' vaccine recommendations—yet trust them with other matters pertaining to their family's health.

I felt comfortable listening and communicating about vaccines with people, the conversation rarely felt contentious, yet people frequently still declined my recommendations. It

seemed that my patients did not have a problem with me, but they *did* have a problem with my sources of information to substantiate claims that vaccines were safer than the illnesses they protect against. People discussed their perspectives on corrupt, greedy governments and “Big Pharma.” They noted how research purporting vaccine safety, when it originated from the manufacturing pharmaceutical company, is inherently biased due to profit motives.

I surmised that other nurses, could be asking the same types of questions as myself. What if the necessary measures to cultivate trust in childhood vaccines includes a consideration of the origin points of people’s fears at the institutional level? These questions added to my understanding of the nursing practice implications related to people’s vaccine hesitancy, and the development of questions framing my dissertation research which are outlined on page seven.

### **Introduction to a Disjuncture**

My experiences left me asking some substantial questions about how healthcare providers and academic disciplines practice and conduct research about highly contested and thorny issues. According to sociologist and institutional ethnographer Dorothy Smith, research can begin with a disjuncture that a healthcare provider or researcher experiences (Smith, 2005). This is when two subjectivities co-exist, two different versions of reality, whereby something is known from a ruling (institutional) perspective versus an experiential one, or “how it actually happens” (Campbell & Gregor, 2002). Nurses may experience a disjuncture in practice when the way their work is described in research (nursing standards, practice guidelines, or the discourses they use to describe what they do), does not fit with what they are experiencing or observing.

My disjuncture began with a hard, judgemental statement and question from a primary care colleague. It was valid question that represented a ruling (institutional) perspective<sup>1</sup> about people who are “non-compliant” with healthcare providers’ recommendations— but one that made me acutely aware that the way healthcare providers discussed people’s decisions about their children’s vaccine status did not always fit with the efforts and contributions they made to their health.

What follows is a detailed description of the context and encounter with primary care colleagues that underpinned my disjuncture. I had just completed a well-baby appointment with a young family and during that visit, the baby’s family caregivers/parents chatted with me about their efforts to nail down the perfect yogurt culture to enhance their family’s gut flora. Their baby wore cloth diapers, had been fully breastfed to seven months. When they introduced solid foods, the parents had only provided the baby with organic, non-GMO, home-cooked food. The baby’s caregivers planned to provide this diet and continue breastfeeding for as long as they both remained happy and healthy, with no end in sight.

I knew from prior appointments, that this young family struggled with their finances, they went without many luxuries to budget for their health and well-being. In addition to allopathic<sup>2</sup> primary care visits, the family was also connected to a naturopathic doctor and a local homeopath. They rarely ate out and dedicated much of the warmer seasons to growing fruits and vegetables in their garden. During clinic appointments, I could see that the baby was healthy and cared for. The caregivers were fully committed to their children’s health as demonstrated by the

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<sup>1</sup> The term institutional refers to the complexes embedded in ruling relations that are organized around a distinctive function, such as education and healthcare (Smith, 2005).

<sup>2</sup> Allopathic healthcare refers to Western, conventional, and orthodox medicine that forms the basis of many of the world’s modern health systems (Uher et al., 2020).

amount of work and resources they expended to do things that they perceived would be beneficial for their family's well-being.

After booking the next well-baby appointment, and saying goodbye to the family, a colleague asked me about how I could tolerate working with such "negligent" people. My colleague also knew that this family had declined most routine childhood vaccines for their children due to their beliefs about vaccine efficacy, safety, and necessity. The baby was completely unvaccinated and nearing their first birthday. My colleague warned me that it was only a matter of time before the family presented to the clinic with children sick from measles or whooping cough. There had been recent outbreaks of these illnesses in the area. They also feared that this family would spread vaccine preventable diseases (VPDs) amongst unvaccinated young infants, immunocompromised people, and elders that attended the same clinic.

The disjuncture I experienced was the feeling of being caught between two subjectivities. The first was the "ruling" or institutional version of reality that organizes the recommendations and care provided to infants and children in primary care practice and public health vaccination programs (BCCDC, 2020), that would support my colleague's views and strongly disagree with the family's choice to not vaccinate their children. The other subjectivity was the reality I experienced when I worked with this family and saw the many other ways the caregivers were dedicated to their children's health. Undoubtedly, an outbreak of a VPD within this family, and the risk of its members experiencing significant illness or even death, is only one facet of the consequences they could face due to their decision. The family spreading a VPD to vulnerable, unvaccinated, or non-immune people could impact a community and the local healthcare system on a much larger scale.

Nurse practitioner and physician colleagues understandably expressed their frustrations with people who questioned the safety of vaccines and refused to fully immunize their children. In this example, our community was situated in a geographic area that was known to have some of the lowest rates in the province of British Columbia for “fully vaccinated” status in two-year-old children. From 2011–2020, the percentage of two-year-olds that had received all recommended routine childhood vaccines ranged from 51–66%, compared to the provincial average of 67–74% (BCCDC, 2021). My colleagues’ perceptions about people who declined vaccines echoed what I read in literature that addressed this issue. People’s viewpoints have been called misperceptions (Whyte et al., 2011), poor knowledge (Wu et al., 2008), contained no scientific evidence (Hilton et al., 2006), and uninformed (Lehmann et al., 2017).

Regardless of the contested notions of risks surrounding VPDs or perceived risks of infant and childhood vaccines a question persisted: were these parents or other family caregivers who declined vaccinations *negligent* in caring for the health of their children? From my interactions with this family, I worried that the parents were investing so much time, money, and effort on their health, that they were forgoing other pleasures that could contribute to their quality of life aside from their steady focus on health. I knew that this family, and other families in her community, had been ostracized by health care providers, teachers, friends, and other family members for not vaccinating their children. Some families avoided allopathic healthcare providers and hospitals altogether, even when their children were significantly ill.

I wondered what it felt like to decide not to fully vaccinate your children, engage in workful activities<sup>3</sup> to enhance your family’s health in response or in tandem with this choice, yet

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<sup>3</sup> Workful activities or work are anything that people do that takes time, effort, and intent; not exclusive to the work that people are paid to do (Smith, 2005).

still be considered negligent by members of your community, including healthcare providers. This led me to ask the following questions: What were people's experiences of enhancing their children's health after declining routine childhood vaccines? Also, was their work to enhance their children's health invisible to healthcare providers and researchers, due to a persistent spotlight on their decisions and opinions about vaccinating?

My experience of this disjuncture has led me to embark on a dissertation project that is based on my developing *problematic* and was guided by Dorothy Smith's Institutional Ethnographic (IE) approach. In IE, the problematic identifies how the researcher will take up inquiry from a standpoint in the everyday world (Campbell & Gregor, 2002). My problematic arises from my experiences in nursing practice, listening to people describe how they prevent communicable disease and enhance their children's health after forgoing all or some routine infant and childhood vaccines. It also arose from my recognition that few of my healthcare colleagues spoke about a family's health efforts —discussions were centred on scientific arguments to counter people's defective viewpoints *and* decisions. Literature on this topic echoed my experiences, as qualitative research has overwhelmingly favoured inquiry that is centred on people's decisions, ideas, and opinions about vaccinating their children. In contrast, this problematic identified how I would engage in my research topic differently. It was formed by my experience of disjuncture and has served as the entry point into this dissertation inquiry.

### **Dissertation Purpose & Approach**

The purpose of my publication-based Ph.D. dissertation was to address two overarching research questions: How do people experience their work of caring for their children and family's health after making the decision to decline all or some vaccines from the recommended immunization schedule? What work do they do to protect or care for their children?

A significant shift in my doctoral journey occurred when I could see the link between the unsettling feeling I was having during my work as a nurse practitioner and my reaction to reading qualitative research about caregivers' vaccine *decision-making* and *vaccine hesitancy*. This shift has led me to pursue a dissertation that uses an IE approach for exploring the “health work” of people who decline routine infant and childhood vaccines. For this dissertation, people’s “health work” or “care activities” are the terms used to describe an array of actions they might enact to protect their children against VPDs or enhance their health. However, from the onset of research, I did not stipulate what exactly “health work” or “workful” care activities may entail, to keep these terms “empirically empty” and open. In the research context described in this dissertation, the word “work” refers to anything a person may do that takes time, effort, and intent, instead of the traditional definition of what one is paid to do (Smith, 2005).

To the best of my knowledge, an IE approach to research on this topic is a novel way to explore this controversial issue in healthcare. There are examples of research on vaccine hesitancy that have proliferated judgmental discourses about people who make the decision to decline children’s vaccines (White & O’Doherty, 2023). In turn, this research problematizes people’s viewpoints while offering suggestions to healthcare providers on how to accrue evidence to counter people’s claims and the best way to disseminate it (Edge, 2009; Suk, 2010). The IE approach to my dissertation research started from the standpoint of people, to focus on developing an understanding about the “health work” they do after declining vaccines. People’s experiences presented an “entry-point” from which this research commenced (Campbell & Gregor, 2002).

Though I began my nursing doctorate program with the aspiration of researching vaccine hesitancy, I have made a substantial pivot to utilize a novel approach to explore my problematic.

My problematic has evolved to focus on the invisibility of vaccine hesitant people's health work for their children after declining all or some vaccines. Also, within my problematic, is the concern that the invisibility of people's health work could indicate that there's a lack of understanding about how their efforts are socially organized. Understanding this component can provide researchers and healthcare providers with a unique awareness surrounding ruling relations that are connected to both people's work and vaccine hesitancy. To date, I am unaware of any qualitative research that uses an Institutional Ethnography (IE) approach to understand this problematic. Therefore, my dissertation research presents a novel way to investigate what is happening.

My dissertation research treated my key informant as a knowledgeable, embodied expert in their own experiences of enhancing their children's health. IE requires an ontological shift away from treating participants in research who refuse vaccines as the *object* of research. This project navigated a departure from studies that focus primarily on people's viewpoints and how they make vaccine related decisions. Instead, I hope my dissertation research raises awareness about the empirical realm of observable "health work" activities to show what it is that people do to enhance health in their families.

### ***Diverse Methods of Inquiry***

A more in-depth overview of each manuscript is presented at the end of this chapter. In this section, I differentiate how the methods of inquiry I used for my dissertation supported my inquiry into this topic. The three papers that are submitted for publication include: 1) a JBI qualitative systematic review protocol, 2) a JBI qualitative systematic review, and 3) a meta-ethnographic exploratory synthesis research paper. The third paper examines the findings of a

key informant interview synthesized within the context of participant's illustrations from the systematic review.

Two different paths of inquiry were engaged to provide a more fulsome picture on this topic. This was an important entry point as I am not aware of existing research that has explored how people's "health work" after declining vaccines for their children is socially organized.<sup>4</sup> A JBI systematic review of qualitative evidence is underpinned by a philosophy of pragmatism. This is reflected in the Institute's assumptions about what constitutes evidence; that it needs to be practical, appropriate (given the ethical or cultural context), meaningful to patients because it is associated with an intervention or activity, and it needs to achieve an intended effect (Jordan et al., 2015). In comparison, IE is philosophically most closely linked to being a "variant of constructionism" because its claims of truth about the social world assert that social activities happen in concert with sequences of action amongst other people, that potentiate a world in common (McCoy, 2008; Smith, 1987, 2005). However, IE is a method of inquiry that resists philosophical or theoretical labels in favour of being informed by theory and staying grounded in how social realities are organized and knowledge about what is going on is constructed (Rankin, 2013).

From an IE approach, JBI systematic reviews would likely be interrogated for their adherence to standardized methods, a rigid process, and the extraction of findings (versus participants' descriptions) for forming categories and meta syntheses. In IE, the researcher attempts to show people how the social world is organized, rather than interpreting people's descriptions as themes to form conceptual categories (Campbell & Gregor, 2002). Forming

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<sup>4</sup> When people's doings are coordinated by distinct forms that are reproduced again and again, in IE this is called social organization (Smith, 2005).

conceptual categories is avoided in favour of material evidence of what is happening. This approach to data analysis is meant to circumvent abstracting and disembodiment of informants' descriptions.

A JBI qualitative systematic review was completed first to facilitate awareness of the qualitative research landscape. Regardless of the two different philosophical underpinnings between JBI and IE, both maintain a focus on empirical evidence. I maintained an IE approach while completing the qualitative systematic review, by continuing to focus on qualitative participants' illustrations and researcher's findings related to the work they do to care for their children. I also remained critically attuned to how qualitative studies examined this topic by questioning: 1) how people were represented, 2) which types of theoretical framing guided the research 3) who the participants were, and 4) how the researchers presented people's work within the findings of their study.

The IE approach to a literature review framework is unusual, though not completely new. In a previous study, an IE "inflection" was applied to a scoping review framework to highlight examples of caregiver's information work and provide insights on how the research surrounding a particular topic is socially organized itself along with the rigorous review framework (Dalmer, 2020a, 2020b). I hoped to generate a picture about what people are doing for their children's health from current qualitative research and identify ways that research about this topic is socially organized. My dissertation research is the starting point in developing a future program of research that helps to foster an understanding that assists people who care for unvaccinated children. Knowledge generated would help healthcare providers, including nurses, to recognize potential influencing factors surrounding people who decline vaccines for their children that may have gone unnoticed.

### *A Note About Language*

In this dissertation, I have struggled with appropriate language in referring to those who make decisions about vaccines and care for their children's health. I considered women, mothers, parents, caregivers, and family caregivers as potential terms to refer to the informants of interest. Finally, the decision was to refer to this population as "people." Admittedly, any of these terms could work for some people but inevitably left others out or could be subject to misinterpretations.

A fellow Ph.D. student from Quebec, who is completing research on a related topic, told me that the term "family care giver," when directly translated into French, reflected a paid home-health worker for children or elders (Malo, personal communication, February 23, 2023). In addition, while reviewing a draft of my qualitative systematic review, a Ph.D. classmate and co-author, who is a steadfast ally to the 2SLGTBQIA+ community, asked if I could use a more inclusive term than "parents" in the manuscript (Haghiri-Vijeh, personal communication, August 6, 2023). Specifically, could I use a term that better reflects the diversity of family units and those who care for children. I struggled to select a name for this population that was indicative of their role in making decisions about dependent children's health, but also inclusive of the many people who provide care to the children in their lives.

Readers will find a variety of terms used in this dissertation. "Parents" was used to name the population of interest in the JBI systematic review protocol and qualitative systematic review (details to follow). Due to feedback from peer reviewers on the original protocol publication (Huel et al., 2022), there were relevant concerns from the peer reviewers and journal editor about how "caregivers" may be translated and understood by readers whose first language was not English. Therefore, in the description of the JBI methodology in this chapter and in the

manuscripts of Chapters Two and Three, “people” are referred to as “parents.” Also, in Chapters Two and Three, the term used to describe what people do for their children’s health after declining vaccines is “care activities.” The terms more reflective of the IE approach we were using in our analysis: “work” or “health work,” were also questioned during the peer review process for the systematic review protocol. Though we maintained an IE approach during the process of completing the qualitative systematic review by placing our attention on the informants’ descriptions of their “work” of caring for their children’s health after declining vaccines, we agreed to refer to their work as “care activities” during the peer review and editorial processes.

To acknowledge those who do not call themselves parents yet care for children and make decisions about their vaccine, I have tried to keep their work and experiences as *people* embodied within their descriptions.

### ***Women’s Work or People’s Work?***

Like the adaptations that were made to the language used to describe the people and work I was interested in exploring, other shifts in my project have taken place during my doctoral studies. My journey has been a fluid one where I embraced my role as a researcher, but still held strong to my embodied experiences as a registered nurse working with unvaccinated families. As I gained more knowledge about this topic and spoke with other researchers, my inquiry, as described below, began to reflect new perspectives and advice. These changes were made in collaboration with my Ph.D. committee, and subject to their approval.

My original research proposal detailed a project that was focused on understanding the social organization of *women’s* experiences of enhancing health in their children after refusing vaccines. The choice to focus on women’s experiences was well matched with an IE approach to

research. Specifically, IE is a method of inquiry theoretically informed by feminism and Marxist materiality and has been helpful in exploring topics related to women's work (DeVault, 1991, 1999; MacKinnon, 2006). In addition, qualitative research about people who do not vaccinate their children will often refer to informants as parents, but the study demographic information demonstrates that the majority of people who participated in interviews were women (Attwell et al., 2018; Brunson, 2013; Enkel et al., 2018; Sobo et al., 2016c; Wang et al., 2015; Ward et al., 2017). Qualitative research has also indicated that healthcare decisions, including choices about children's vaccines, are clearly "gendered processes;" firmly rooted in maternal terrain despite the use of the gender-neutral term of "parents" in literature about this topic (MacKendrick, 2014; Reich, 2014).

Making the decision to use an IE approach to research, coupled with my knowledge that most informants in studies about vaccine hesitancy identified as being female, initially led me to pursue a project where I recruited women. However, my experiences in nurse practitioner practice and my knowledge of my community at that time, led me to question this choice. I had encountered people in practice who were vaccine hesitant, identified as male, and cared for young children. Also, I was aware of people who were active in a local vaccine advocacy group who identified as being male. I wondered if people who identified as male were less likely to be a research informant, yet still be vaccine hesitant with their children.

Discussions with Shannon MacDonald, a member of my committee and an experienced vaccine researcher, and Devon Greyson, a vaccine researcher from the University of British Columbia, solidified my decision to talk to "people" about enhancing their children's health after declining vaccines. I preferred to let informants' identified genders speak for themselves rather than stipulating a preferred gender for research informants during recruitment.

## **Background and Context**

Feeling hesitant about infant and childhood immunizations involves an immense spectrum of opinions, ideas, and fears that ultimately determine how people make choices about preventing communicable disease in their family. Vaccine hesitant people may feel worried about vaccines, delay their acceptance, or completely refuse all or some immunizations despite the availability of vaccination services in their community (MacDonald, 2015; WHO, 2022).

People who refuse all or some vaccines for their children may believe that vaccines are ineffective and harmful to an infant's immune system, and adverse effects from vaccines are under-reported and lack proper healthcare follow-up (Lyren & Leonard, 2006; Nield & Kamat, 2008). They could also believe that supporters of vaccination are motivated by corporate profit margins and will therefore intentionally overlook vaccination dangers in clinical trials (Ward et al., 2018). Some people may think that VPDs are not harmful for children or might consider them to be helpful to children's development, providing superior immunity to vaccines (Fallet, 2017; Harmsen et al., 2013; Tombs-Heirman, 2009). Finally, people may think that mandatory childhood vaccine schedules are a violation of civil liberties (Lyren & Leonard, 2006; Nield & Kamat, 2008). Regardless of what decisions they ultimately make for their children, people who feel hesitant about vaccines are thought to have spent a great deal of time and attention weighing the perceived benefits and risks of vaccinating their children (Damnjanović et al., 2018). They have made a conscious decision based on their beliefs that they are protecting their children's health and well-being (Brunson, 2013; Dubé et al., 2016; Peretti-Watel et al., 2019).

### ***“Health Work” of Declining Children’s Vaccines***

Research about people who decline vaccines for their children also describes that long after their initial decision is made, they make substantial efforts to prevent their children from

catching a VPD (Blaisdell et al., 2016; Carrion, 2014; Reich, 2014). They also work to enhance their children's health by promoting a stronger immune system, by modifying diet and lifestyle choices, to make it less likely that they will contract a VPD or become seriously ill from one (Wiley et al., 2022). Studies have also found that decisions about vaccinating are rarely a one-time event. After initially choosing not to fully vaccinate, people have continued to re-evaluate their decisions, their children's health, and emerging information about vaccines, to determine if their current choice remains the best option (Helps et al., 2019; Poltorak et al., 2005; Sobo et al., 2016c; Ward et al., 2018).

Within research that describes people's efforts to avoid VPDs, enhance their children's health, and make decisions about vaccines, their work has been described as processes (Blaisdell et al., 2016; Brunson, 2010; Glanz et al., 2013), experiences (Carrion, 2018), behaviours (Enkel et al., 2018; Glanz et al., 2013), intensive mothering practices (Reich, 2014), and responsabilisation<sup>5</sup> (Ward et al., 2018). Notably, the terms that researchers have assigned to people's workful activities do not match how they discuss their efforts, within the illustrations they have described to researchers.

People have also conveyed their capability in managing their children's health without vaccines due to their efforts to successfully enact natural living lifestyle choices (Reich, 2016). Natural living lifestyle choices have been reported in other research and conceptualized as "salutogenic parenting"<sup>6</sup> (Ward et al., 2017). This term is used to describe the practices that non-vaccinating people take up, under the auspice that they can minimize the risk of their children

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<sup>5</sup> Describes the conditions in which responsibility for certain functions, which used to be provided by the State, are taken on by individuals. People enact "responsibilisation" when they consider vaccines an individual choice or decision (Ward et al., 2018).

<sup>6</sup> Engaging in practices that are believed by people to equip their children's immune systems with general health and resilience (Ward et al., 2017).

becoming critically ill from a VPD, including breastfeeding, eating organic and/or home-grown food, cooking from scratch to reduce exposure to food preservatives, and reducing exposure to household toxins (Ward et al., 2017).

Wherever a person sits along the spectrum of immunization viewpoints and actions, at any given time, three elements prevail; (a) workful activities, to prevent communicable disease and enhance the health of children who are not fully vaccinated, are happening, (b) these workful activities represent a heavy burden of responsibility and effort on the part of the caregiver over an extended period of time, not just at the point that the decision to vaccinate is made, (c) current literature on this topic has described and conceptualized people's work, however, I am not aware of an effort by another researcher to understand how workful activities are socially organized.

### **Method of Inquiry: JBI Qualitative Systematic Review**

To address the three elements listed above and the gap in literature on this topic, my dissertation research began with a JBI qualitative systematic review and protocol. The following section provides a short overview of the JBI methodology and process with more in-depth material being provided in Chapters 2 and 3 and in Appendices A–D.

### ***Joanna Briggs Institute (JBI) Qualitative Systematic Review and Protocol***

The initial approach to my dissertation research began with a JBI qualitative review protocol (Chapter Two) with an overarching review question of: how do parents experience the specific activities involved in caring for their under-vaccinated or unvaccinated young children after refusing routine scheduled vaccines due to concerns about safety and efficacy? (Huel et al., 2022) In addition, our review team added the following sub questions:

1. How do parents control their young children's exposure to communicable diseases?

2. What activities do parents implement to protect their young children from serious illness that might result from exposure to vaccine-preventable diseases?
3. What specific care activities do parents use when their young children become ill with a vaccine-preventable communicable disease?
4. What is the parental experience of providing this care? Where do parents obtain information or support? Who provides most of this care within family units? What are the risks and/or benefits (emotional, physical, financial) associated with this care?

The development of a review protocol was an essential, early step, as it predefined the objectives and methods of the systematic review in order to increase transparency and decrease the chance of bias (Aromataris & Munn, 2017). It also demonstrates to readers how the findings and recommendations in the main body of the systematic review were determined (Aromataris & Munn, 2017).

The key components of the qualitative systematic review included the title, review objectives/questions, background, inclusion criteria, search strategy, critical appraisal, data extraction, data synthesis, narrative summary, references, and appendices. Chapter Three of this dissertation contains the second manuscript, a JBI qualitative systematic review, that provides further details about the findings and meta-synthesis, and constitutes the main body of this component of the dissertation (Huel et al., in press).

**Background.** The method for the systematic review protocol and qualitative systematic review was guided by JBI, an international collaborative supporting evidence-based practice in nursing, medicine, and allied health fields (Aromataris & Riitano, 2014). Systematic reviews, as a bibliographic research methodology, have long been associated with searching for, appraising, and synthesizing findings from primary studies (Dixon-Woods et al., 2006). As qualitative

research began to proliferate within disciplines such as the humanities, social sciences, and nursing, so did recognition that synthesis of its findings could be beneficial for better understanding human experience, cultural and social phenomena (Jordan et al., 2006). Broadly speaking, qualitative research aims to give a voice to the patient/client or healthcare provider to assist in decision-making processes in healthcare, however, it does not quantify or statistically present data about healthcare. Qualitative systematic reviews allow for the synthesis of qualitative data derived from methodologically diverse primary research studies. JBI has developed a method of qualitative synthesis that is guided by a meta-aggregative approach. This approach endeavours to remain sensitive to the practicality and usability of the primary author's findings instead of re-interpreting findings, which is present in other methods of qualitative synthesis (Lockwood et al., 2020).

**JBI Philosophical Assumptions.** The philosophical stance of JBI is pragmatism. A year after the institute was established, JBI's founder Alan Pearson, began to break away from a focus on systematic reviews for synthesis of data from effectiveness studies (Jordan et al., 2015). Instead, he decided to consider other types of evidence that could help to inform patient healthcare. Pearson wrote: "The Institute regards the results of well-designed research studies grounded in any methodological position as providing more rigorous evidence than anecdotes or personal opinion" (Jordan et al., 2015, p. 117). Though the foundations of JBI Systematic Reviews are rooted in a post-positivist, scientific philosophy, the institute has made some headway in expanding what constitutes "evidence" to include qualitative research and other forms of knowledge.

JBI assumes that with a rigorous, transparent method, which includes explicit reporting of methods used in searching and synthesis, a wide-ranging unbiased synthesis of studies can

provide evidence to inform clinical decision-making for healthcare questions (Jordan et al., 2015). Therefore, its epistemological assumption deems knowledge to be tangibly real—something that within a transparent, systematic, and comprehensive search strategy can be sought for and identified.

With the addition of a review team to formulate database searches, independently screen sources, and collectively determine which papers progress to further steps in the review process, JBI attempts to reduce researcher bias. This also lends evidence to JBI's assumption of knowledge being objectively real, whereby a reviewer remains impartial and transparent throughout the process, to avoid an analysis and synthesis of data that is reflective of their own stance. The goal is a clear, expansive, unsullied “knowledge product” that can be relied upon for clinical decision-making. Ultimately, the JBI Model of Evidence Based Healthcare (2019) directs how evidence is transferred and implemented at the point of care in local settings with a goal of achieving improved health and health equity on a global scale.

**Rigor.** A fundamental aim of systematic reviews is to provide a wide-ranging, unbiased synthesis of many studies in one document that uses rigorous and transparent methods (Aromataris & Munn, 2017). Uncovering all the relevant evidence relating to a research question and relying on the quality of the evidence synthesis, depends on adherence to a systematic review method. Following a rigorous systematic review methodology is crucial in reducing the risk of error and bias during the process; it also distinguishes a systematic review from more traditional literature reviews (Aromataris & Munn, 2017). Our review team<sup>7</sup> made a concerted effort to explicitly report the methods used in searching and synthesis throughout each step of the

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<sup>7</sup> Chapter Three contains more details about the roles of the systematic review team, and who was involved in each stage of the process.

process. The search strategies for each database can be seen in Appendix A. To keep our searches up to date, two were completed during the study, to make sure we were not missing any new literature.

During all steps of the process, I kept a word document to track all searches and transfers between databases and used tools that have been developed to assist with data management, including Covidence (Veritas Health Innovation, Melbourne, Australia), and data analysis and report writing software: JBI SUMARI (JBI SUMARI; JBI, Adelaide Australia). Any discussions about papers where there was a difference in opinion about inclusion between two reviewers, were tracked in a document with the rationale for the final decision. Finally, all hand searching and forward searching of reference lists was also documented to demonstrate how any papers included from these searches, could be linked back to the original document in which the article had been cited. JBI instructs that because systematic reviews are used in healthcare to guide decision-making, they require the same level of rigor that one would expect to encounter in all research (Aromataris & Munn, 2017). As I do want the findings of this qualitative systematic review to guide healthcare providers who work with vaccine hesitant people, my review team and I made every effort to adhere to the methodology.

The following are the steps we took to ensure that a thorough, structured, research process was undertaken by our review team and to confirm that the results of the systematic review are reliable and meaningful to knowledge users (Aromataris & Munn, 2017):

1. Formulating a review question.
2. Defining inclusion and exclusion criteria.
3. Locating studies through searching.
4. Selecting studies for inclusion.

5. Assessing the quality of studies.
6. Extracting data.
7. Analysing and synthesizing the relevant studies.
8. Presenting and interpreting the results, potentially including a process to establish certainty in the body of evidence.

While completing a rigorous SR, these steps helped to demonstrate a systematic, transparent, and comprehensive process for each stage of the JBI methodology. Systematic reviews should be completed in a way that renders the reviewer in a neutral stance. Therefore, the process could be replicated by another researcher following the same searches, compiling of data, and analysis, rendering similar conclusions (Lockwood, 2020)

**Ethical Considerations: JBI Qualitative Systematic Review.** The research completed in our systematic review was *secondary research* of previously published studies. Therefore, no ethical approval was required for this component of the dissertation.

### **Second Method of Inquiry: An IE Approach to Investigating People’s Experiences of Health Work after Declining Vaccines—Key Informant Interview**

The next section of this dissertation details the approach I took to completing an in-depth key informant interview with an IE approach. It is important to mention that I did not complete a full IE study. My IE approach to my dissertation research was to investigate descriptions of people’s health work as empirical evidence of what is going on and identify institutional traces or processes within their illustrations that could represent viable avenues for further IE exploration. A full IE study would not stop at this point, the research would continue with mapping texts and processes, and observing work processes, while keeping the institution “in view.” Chapter Four provides more information about the key informant interview. In response

to significant recruitment challenges detailed below, I invoked an emergent approach to my dissertation research. What started with an intention to do a small IE approach investigation into people's experiences of health work and a research report on this study morphed into a different process. Instead, I completed an in-depth key informant interview and then began a meta-ethnographic exploratory synthesis of the descriptions shared during this interview in comparison to illustrations identified in the JBI qualitative systematic review.

### ***Research Questions***

In this second study that followed the completion of the JBI qualitative systematic review, I spoke with a key informant who had declined all or some vaccines for her young children about her experiences enhancing health for them. It began from her standpoint and together, we explored her family "health work" to enhance her children's health. The data gleaned from the interview was analysed using an IE approach. The research questions for this study were:

1. How do people experience their work of preventing communicable disease in their children after making the decision to decline vaccines or deviate from the recommended immunization schedule? What work do they do to protect their child/children?
2. How do people experience their work of enhancing their children's health, with consideration for the possibility of illness, after deciding to refuse all or some vaccines? What work do people do to care for their children?
3. How do societal discourses, and institutional work processes, embedded within ruling relations, influence the social organization of people's activities that seek to prevent, promote, or treat vaccine-preventable communicable diseases?

The third paper of this dissertation, found in Chapter Four, describes an exploratory meta-ethnographic synthesis that compared participants' verbatim illustrations from our extensive JBI qualitative systematic review to the descriptions from a descriptive, rich, key informant interview with Amy (a pseudonym). The goal was to gain awareness and insights from these two empirical research approaches by conducting an exploratory synthesis of the descriptions of "health work" in both studies with a critical lens. At the end of the Chapter One I will provide more insights into how the research took place and interesting challenges I experienced in the process. This reflection will help to frame the following chapters/manuscripts included in my dissertation.

### ***Philosophical Underpinnings of Institutional Ethnography***

Dorothy E. Smith, a Canadian sociologist, founded and developed IE to support researchers to better understand the features of contemporary social organization that creates problems for people (Rankin, 2013; Smith 2005). Research that uses an IE lens endeavours to expand people's knowledge about their everyday worlds; extending beyond their understandings that are formed through their routine participation. IE research also aims to develop knowledge of institutional processes and understand ruling relations by maintaining focus on the material world, what people do, with whom they are doing it, and the conditions under which their activities are carried out (Luken, 2008). The aim of IE research is to look closely at people's activities and their problems and form an understanding about how these are coordinated.

**Ontology.** Institutional ethnography as a method of inquiry for research, is considered a variant of constructionism because its origins contain some of the same intellectual precursors as constructionist research and shares a similar ontology (McCoy, 2008). The social world is

practiced, enacted, activated, and always embodied in people's doings (Smith, 2005). The ontological assumption is that what happens in the social realm, as people's activities, is real.

The ontological stance within IE research is shared with phenomenologists, symbolic interactionists, and ethnomethodologists who also share constructionist philosophical underpinnings. Social constructionism centres on the belief that there is no objective knowledge that humans can aspire to discover separately from other individuals. Instead, truth and meaning exists in and out of our interaction and involvement with the realities of the world (Crotty, 1998). IE research examines how social realities are organized and aims to develop knowledge about how "what is going on" is constructed but does not align itself under the philosophical umbrella of constructionism. Institutional ethnographers wish to avoid the category label of "constructionist" in order to establish a project of inquiry that is grounded in the actualities of people's embodied lives rather than one that is underpinned with a philosophical or theoretical school (McCoy, 2008). Therefore, the motivation for an IE approach to research is inquiry and discovery of the social in people's lives and their doings as they would explain them.

**Theoretically informed.** Though IE is a method of inquiry that eschews aligning with philosophical or theoretical labels, it is theoretically informed. Institutional ethnographers draw from theory that is derived from sociological traditions to discover social relations that organize a particular setting (DeVault, 1999). Ethnomethodological approaches have been linked to IE; in that both engage in a precise analysis of how interactions are coordinated among members of a setting and are interested in what people do in specific situations (DeVault, 1999). IE analysis is also informed by Marx's theory of historical materialism (Smith, 1987). The researcher does not consider or treat the setting that informants describe as just "there" (DeVault, 1999). Instead, consideration is given to how the settings of interest have developed from a particular history—

how it has happened that people's activities are organized in one way rather than another (DeVault, 1999).

**A Feminist Sociology.** The most notable perspective informing IE is underpinned with Smith's entry into developing a feminist sociology as a critique to mainstream sociology (Smith, 1987; Stanley, 2018). Smith's awareness surrounding the routine repression of women's activities helped to form her critique of the traditional, positivist practices of sociology that categorized people into designated groups and aimed to explain and theorize about their activities, behaviours, and culture (Smith, 1987, 2005; Stanley, 2018). Smith saw this categorization as a repressive act because it formed ideologies rather than actual knowledge about the people researchers were interested in understanding. For example, Smith (2005) noted that ideologies formed about single mothers or housewives perpetuated oppression and discrimination against women. She noted that established sociology gave a consciousness that looks at society, social relations, and peoples' lives as if one could stand outside them, and form an understanding about them, while ignoring the particular local places in the everyday/every-night contexts in which we live our lives (Stanley, 2018).

Smith's critique of sociology from a women's perspective led her to form a feminist sociology detailed in her book *The Everyday World as Problematic: A Feminist Sociology* (Smith, 1987). It detailed a feminist alternative to the prevailing social ontology and conceptualizations of conventional sociology. The book also specified working practices for researching and writing the social within a feminist framework (Stanley, 2018). Smith did not call her suggestions for sweeping changes within sociological research "a method" or "methodology," she instead referred to it as an "alternative sociology." She described the

fulcrum of a sociology for women as beginning with the standpoint of the subject or the standpoint of women (DeVault, 1999; Smith, 1987, 2005)

### ***Key Informant Recruitment***

Recruitment for the IE approach to investigating people's experiences of health work study was widespread. It has been one of the most challenging components of my doctoral research experience for several reasons related to the timing of my research following the SARS-CoV pandemic and to the introduction of more advanced artificial intelligence (AI) tracking of social media platforms. I used purposive sampling to recruit English-speaking informants living in Canada, who have infants or young children, and have refused all or some vaccines from their province's immunization schedule. Ultimately, the difficulties I faced with informant recruitment changed the nature of my dissertation research. What started as an intent to do a small IE approach investigation into people's experiences of health work and complete a research report on this study, ended with one in-depth key informant interview and a meta-ethnographic exploratory synthesis with rich findings (Chapter Four).

Early in the process of recruiting, I met a fellow Nursing Ph.D. student from York University, who relayed her concerns about recruiting informants for topics related to vaccines (Sessa, September 27, 2023). She mentioned a recent master's thesis whose author detailed substantial difficulties in recruiting people who do not fully vaccinate their children via social media or other online modalities (Seiter, 2023). This served as my initial indication that study recruitment could be difficult for topics related to vaccination.

Initially, I began with social media recruitment. Due to complications described below, I shifted to emailing information to healthcare provider practices, day-cares, and independent schools, asking if they would either share information about the study or put up the poster in an

area where potential informants might see it. Appendices F, G, and H contain my recruitment poster, letter, and draft of the eligibility email I sent to respondents. The following list details the measures taken to recruit informants to participate in my study:

1. recruitment posters on public access parenting group social media sites, (Facebook, BabyCenter, and Reddit) after permission from the site's administrator
2. recruitment poster shared on my personal Facebook page and posted on family, friends, and Ph.D. classmates' own Facebook feeds
3. private Facebook parenting sites, via administrator sharing the poster on the private feed; included: Homeschooling Ontario, Attachment Parenting Canada, Parent Life Network, and Catholic Families of Ottawa
4. word of mouth through family nurse practitioners in British Columbia (former colleagues, and classmates) working for the Primary Care Network, not a Provincial Health Region
5. word of mouth through friends and family members who shared details with people they knew had not fully vaccinated their children
6. physical copies of recruitment poster posted on public message boards in Creston, Nelson, and Rossland, British Columbia
7. two midwifery practices, one in Rossland and the other in Nelson, posted the recruitment poster in their waiting rooms
8. forty midwifery practices and 48 naturopathic clinics across Canada were emailed with PDF poster and details about the study

9. three professionally printed posters mailed via Canada Post to 3 midwifery clinics requesting physical copies for their waiting rooms
10. all Waldorf Independent schools in Canada, except for Quebec, emailed a PDF of the poster and an introduction the study.
11. recruitment posters and introductory letter sent via email to Vaccine Choice Canada, this organization has multiple chapters and supports people who decline vaccines (<https://vaccinechoicecanada.com/>).
12. Emailed posters and introductions to Waldorf Preschools throughout Canada and several community preschools in British Columbia and Alberta.

**Fake Bot Informants.** Immediately after the social media posts went up on Facebook, I began to receive numerous, strange emails from potential informants addressed to the contact email account listed in my social media poster. The email addresses all followed the same format: last name, first name, a number, @gmail.com. The emails were short, much like a text message, and the grammar was incorrect, for example:

1. Hi Am reaching out to you regarding your study, I will be well pleased if elected for participation.
2. Hello, I solicit to participate in the upcoming interview session.
3. Hello, It'll be my possible best to participate in the interview study about parents experience.

I contemplated that I could be receiving emails from people who are learning English. I also considered that younger people may write response emails similar to how they would text message. However, the first and last names of potential informants were indicative of a person originating from a country where English would likely be spoken as a first or second language.

For example, several of the respondents had the last name of Smith, Jones, Scott, and James. In the beginning, I replied to all emails that requested information about study participation and did receive several replies from my initial response. However, as the communication continued, I became concerned.

Disturbingly, I noticed that the syntax of the respondents was changing as the email traffic progressed. The word choice, sentence structure, and punctuation improved substantially, and becoming more complex. I also noted that simple questions I asked the respondents would get answered (e.g., how many children do you have?) while others would glean no response (e.g., which vaccines has your child received from your Provincial Immunization Schedule?). Twice, the email traffic progressed to the point where respondents signed a consent form and provided a time to meet via Zoom. However, once I sent the Zoom link and asked if I could deposit the honoraria into an email linked to a Canadian bank account, the emails stopped, and the informants never joined the Zoom meeting. I began to suspect that the respondents were originating from AI bots because each time my poster went up on a public Facebook site, soon after I would receive three to 10 replies, one to two minutes apart, in succession with the same format of email and short message with incorrect grammar and word choice.

Recent articles have indicated that AI bots are complicating study recruitment and survey data that takes place online or through social media (Lawrence et al., 2023; O'Donnell et al., in press; Ridge et al., 2023; Xu et al., 2022). Initially, most of the literature I found described the challenges of AI infiltrating research that takes place through online surveys and questionnaires (Browning et al., 2023; Lawrence et al., 2023; Xu et al., 2022). However, I was interested in looking for direction on how to screen the onslaught of questionable emails I received, so that I did not exclude legitimate respondents for a qualitative research study.

The guidance I needed came from two editorials where the authors raised concerns about human bots attempting to infiltrate health-related studies (O'Donnell et al., in press; Ridge et al., 2023). The authors of one of these articles detailed the waste of time and scarce resources consumed when receiving 150 fraudulent expressions of interest in less than 24 hours (O'Donnell et al., in press). I could commiserate with this experience, however the anecdotal advice I received from these proved very valuable to my recruitment. The authors warned against emails that did not include a preamble that described their interest in the study, whose email addresses followed a generic format across multiple inquiries, and whose medical details appeared vague (O'Donnell et al., in press).

These warnings confirmed my concerns and helped with screening the numerous emails I was receiving. I also spoke with a friend with an extensive background in IT and bot detection (Marjanovic, October 8, 2023), he advised that some advanced fake bots were extraordinarily adaptive. They would be able to use the sentence structure and word choice from the recruitment poster to adapt the email in a way that would appear more “human.” Others would progressively adapt as you respond to the initial emails, mimicking your written response to produce more complex and human-like email responses.

A recent publication about bot-detection in online psychological research echoed this information, in explaining how bots' abilities can range from simple script to advanced bots with greater capabilities for natural language processing (Casalheira, 2023). This was an unanticipated hurdle in my recruitment that made this step frustrating and time consuming. It also opened my mind to the possibility of writing further about this experience, or completing a scoping review about this perplexing challenge, to bring awareness to other qualitative researchers who wish to recruit via social media.

**Informant Fear of Participation.** Once I felt confident screening fake bot respondent's emails, I faced an even greater challenge to my study. Regardless of the different ways I was trying to reach potential informants, even increasing the honoraria through an amendment to my ethics approval, I was not getting much interest for my study. I did receive some emails from administrative teams at Waldorf Schools expressing interest in the study and mentioning that they were going to share details at parent's council meetings. However, they replied telling me that people were very hesitant to engage in any research related to vaccines after their experiences during the COVID-19 pandemic. The parents they spoke to had learned about the ability of governments to mandate vaccines and "punish" those who refused so were now concerned about what could be on the horizon for those who declined routine childhood vaccines.

I was told by respondents, social media platform administrators, and colleagues that people did not want to speak with researchers, particularly a nurse practitioner, who could report their identity to the public health authorities, police, or to the provincial ministry for children and families. I reiterated the University of Victoria Ethical Standards that governed my study. I also stressed that my research was not exploring their vaccine decisions, my interest was on the work they do to care for their children's health. To my surprise, respondents argued that my professional standards also required mandatory reporting in any situation where I suspect child abuse or neglect. They questioned if I would consider their vaccine choice a form of child neglect. I was taken aback by how knowledgeable potential respondents were to these elements of nursing practice and the perceived risks they contemplated when considering participation in my study.

Healthcare providers who were sharing my study invitation with their patients also echoed these fears back to me, that in a post-COVID-19 research scape, the topic of declining vaccines had sent potential informants underground in a bid to protect their families from the institutional gaze. One respondent who I emailed back-and-forth with said that because I was taking a “softer” approach to this topic, she felt even more suspicious that I might be trying to “entrap” informants under the auspices that I am on their side. Comments like these hurt to receive. I have long considered myself to be a nurse who tries to build bridges to patients who may feel marginalized for their choices. I believe strongly in relationship-centred patient care, and understand that who I am does play a role in my patient’s healing (Kuhl et al., 2017). It felt like my aims of building a bridge to this cohort of caregivers, by engaging in this topic, were already thwarted by a protective wall constructed to keep families and their vaccines choices safe and to keep me out. I was extraordinarily appreciative of the key informant who decided to reach out to me and participated in the study.

### ***Key Informant***

One key informant was recruited through purposive sampling. My key informant chose the pseudonym, Amy. She identified as female, had a male partner, and had two children, aged six and eight. Demographic information was obtained from a questionnaire before the informant interview (Appendix I). Amy worked both in and outside of the home in a professional role. Neither of her children had ever experienced a VPD, nor could she recall a VPD outbreak in their community.

To maintain a higher level of confidentiality, I am not sharing the gender of Amy’s children. Amy lived in Ontario; she was recruited through a poster I sent to a Waldorf-Steiner School in her community. Amy’s eldest child had received their first series of routine infant

vaccines at 3-months-old and presently had an up-to-date tetanus vaccine. Her younger child had received no vaccines since birth.

### ***Data Collection Methods***

Amy and I had an audio and video recorded Zoom Meeting in Fall 2023. The Zoom platform provided a transcription of the interview, and I took notes throughout the interview. Opener interview questions are noted in Appendix J. In an IE investigation, interview questions can evolve as the interview and/or study proceed (DeVault & McCoy, 2012). Therefore, the opener interview questions served as a beginning point to our conversation but did not structure the topics we explored.

### ***Data Analysis***

The transcript from Amy's interview was examined using an IE lens to identify institutional threads and mentions of texts and conceptual resources. It was overseen by Karen MacKinnon who guided my lens in identifying institutional traces provided in Amy's descriptions. I was particularly interested in how descriptions of her experiences were socially organized in the local setting and how these experiences might reflect ruling relations or institutional priorities.

### ***Rigor and IE***

Rigor in IE research begins from an analytical stance that commits to gathering evidence to develop an account of how something in the world is being socially organized for particular people (Rankin, 2017). IE is differentiated from other methods of inquiry in that rigor is not ascertained from the techniques used in sampling or analysis; instead, the corrigibility of the developing map of social relations provides more insight into the thoroughness of an IE study (DeVault & McCoy, 2012). The analytic goal of IE is to find and describe ruling relations that

*can be shown* to extend beyond study informants; ideological practices may be experienced by people across the country or the globe (Rankin, 2017). Finding how problems are linked and how people experience similar tensions and contradictions in their everyday work is described as *generalizing relations* (Smith, 2005). The generalizability of the descriptions provided by informants rests on finding and demonstrating how ruling relations exist in and across many local settings, that organize their experiences (Campbell & Gregor, 2002). The rigor of my study also rests in my ability to view my key informant as an expert in her own life and provide descriptions that are not abstracted from her material, everyday experiences (Smith, 2005).

### ***Ethical Considerations***

**Key Informant Interview.** Ethics approval was obtained for this part of the dissertation research through the University of Victoria Human Research Ethics Board (HREB). I wrote the ethics application independently with advice from my supervisor and committee members. I also received valuable feedback on my recruitment materials, specifically my recruitment letter and social media poster, from Benjamin Malo Ph.D.(c) and Ève Dubé at Laval University who have extensive research in informant recruitment for topics related to vaccine hesitancy. Appendix E includes the study's University of Victoria HREB Certificate.

### **Overview of the Manuscripts**

The results of my dissertation are presented in three papers. One is a published protocol, another is a manuscript accepted for publication, and the third paper will be submitted for publication. The first paper (Chapter Two) is a qualitative systematic review protocol. I am the primary author of this paper; however, it is co-authored with members of my review team. The second author on the protocol manuscript is my Ph.D. supervisor Karen MacKinnon who provided feedback on all steps of the protocol process. Co-authorship is a JBI requirement to

assure a minimum of two reviewers confer on screening articles and extracting findings along with the addition of a research librarian (Carol Gordon) to assist with database searching. The protocol was independently written by myself, with support from my supervisor. I also received feedback from three members of the review team on the completed draft before it was submitted to the journal *JBI Evidence Synthesis*. The manuscript used the JBI template for systematic review protocols to best reflect the preliminary process that precedes any full systematic review. The protocol includes sections dedicated to the background, review questions, inclusion criteria, methods, and a preliminary search strategy. The manuscript was peer-reviewed and underwent an editorial review prior to being published (Huel et al., in press)

The second paper (Chapter Three) is the completed qualitative systematic review which has been peer and editorially reviewed by *JBI Evidence Synthesis* and accepted for publication with minor revisions (Huel et al., in press). This manuscript was also guided by the JBI template for qualitative systematic reviews. The manuscript was co-authored with Karen MacKinnon, and four other members of the review team which included one of my committee members, Shannon MacDonald. The entire manuscript draft was independently written, with support from my supervisor, and feedback from the four other members of our review team.

The third paper (Chapter Four) will be submitted for publication to *Global Qualitative Nursing Research*. This paper describes a meta-ethnographic exploratory synthesis of participants' illustrations from our extensive qualitative systematic review along with the descriptions from the key informant interview. The goal was to gain awareness and insights from the two empirical research studies through an exploratory synthesis of the descriptions of "health work" in both studies with a critical IE approach.

Chapter Five, the Afterword section of this dissertation, discusses the significance of the participants' descriptions from both the qualitative systematic review and the key informant interview and what knowledge was generated from both studies. I will also highlight the “next steps” my research can follow, using an IE lens, to follow a narrative thread linked to textually based resources shared by the key informant.

## Chapter 2: Qualitative Systematic Review Protocol

*Huel, C., Harding, J., MacKinnon, K., Gordon, C., & MacDonald, S.E. (2021.) Parental experiences of caring for their preschool children after declining vaccines: a qualitative systematic review protocol. JBI Evidence Synthesis, 20(1), 196–203.*

### Review Title

Parental experiences of caring for their preschool children after declining vaccines: a qualitative systematic review protocol

### Reviewers

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### Acknowledgments

This review forms a component of the requirements for the completion of a Doctorate of Philosophy in Nursing for CH.<sup>8</sup>

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<sup>8</sup> Chapters Two and Three were originally submitted as manuscripts in Vancouver Style format. They have been adapted to APA for consistency within my dissertation.

**Abstract**

Much of the current qualitative research literature on parents who hesitate or refuse to vaccinate their young children focuses on parental perceptions about the safety and efficacy of vaccines and decision-making. However, limited attention has been paid to measures taken by parents to help their young children avoid contracting communicable diseases, promote resistance, and enhance their children's health.

***Objective***

This review will explore the experiences of parents after making the decision not to vaccinate their young children. This review aims to help health care providers understand parents' specific care strategies for their under-vaccinated or unvaccinated young children.

***Inclusion Criteria***

This review will consider qualitative studies that describe parents' experiences of caring for their young children, aged 0 to 6 years, after making the decision not to vaccinate. Studies undertaken in any context will be considered. Studies that focus on young children who are unvaccinated or not fully vaccinated for reasons not related to parental refusal will be excluded.

***Methods***

The JBI methodology for systematic reviews of qualitative evidence will be followed. Databases will be searched from 1998 onwards, and will include Web of Science, MEDLINE, CINAHL, PsycINFO, Google Scholar, and ProQuest Dissertations and Theses, with no language limits. Following critical appraisal, findings that describe parental experiences and the care activities they perform related to their young children will be extracted. The JBI process of meta-aggregation will be used to identify categories and synthesize findings. The ConQual approach will be used to assess confidence in the findings.

Systematic review registration number: PROSPERO CRD42021241781

Keywords: *childhood communicable diseases; decision-making; immunization; parenting; vaccine hesitancy or refusal*

## **Introduction**

Feeling hesitant about or refusing childhood immunization reflects a vast spectrum of opinions, ideas, and fears that ultimately determine how parents endeavor to prevent communicable disease in their family. Parental decision-making is complex and context-specific, varying across time, place, and vaccines (MacDonald, 2015). Parents may feel worried about vaccines, delay their acceptance, or completely refuse all or some immunizations despite the availability of vaccination services in their community. Researchers believe that parents are influenced by factors such as complacency, convenience, and confidence (MacDonald, 2015).

Some of the concerns or suspicions that parents may have include the following: vaccines are ineffective and harmful to a child's immune system; adverse effects from vaccines are under-reported and lack proper follow-up; companies producing vaccines are motivated by profit margins and will therefore intentionally overlook vaccination dangers; vaccine-preventable diseases are not harmful and provide superior immunity to immunizations; and mandatory childhood vaccine schedules are a violation of civil liberties (Lyren & Leonard, 2006; Nield, 2008). Regardless of what decision they ultimately make for their children, parents who are hesitant about vaccines or refuse them altogether are thought to have spent a great deal of time and attention weighing up the perceived health benefits and risks of vaccinating their children, and have made a conscious decision based on the belief that they are making the best decision to protect their child's well-being (Damnjanović, 2018).

Research on this topic has described how parents who refuse all or some vaccines take measures to prevent communicable diseases, enhance their children's health, and reevaluate their decisions long after the choice to forgo immunizations has been made. It has been reported that parents who refuse vaccines have expressed their capability to manage their children's health without vaccines through efforts to make natural living lifestyle choices that enhance their children's health and well-being (Reich, 2016). "Managing" children's health after refusing vaccines has been reported in other research and is known as "salutogenic" parenting (Ward et al., 2017). This concept has been used to describe care activities that are perceived to minimize the risk of a child becoming critically ill from a communicable disease. This includes avoiding daycare, breastfeeding, eating organic and/or homegrown food, cooking from scratch to reduce the intake of food preservatives, and reducing exposure to toxins (Carrion, 2018; Dubé et al., 2016; Peretti-Watel et al., 2019; Reich, 2014; Ward et al., 2017; Ward et al., 2018).

Parents who choose not to vaccinate or fully vaccinate their children but who put substantial effort into making decisions about vaccines, preventing communicable disease in their families, and enhancing their health have had their care described as "experiences" (Carrion, 2018), "intensive mothering practices" (Reich, 2014), "responsibilization" (Ward et al., 2018), "processes" (Brunson, 2013), and "behaviors" (Enkel et al., 2018).

The phenomenon of parental vaccine hesitancy or refusal has been studied in numerous ways. However, most qualitative research on this topic typically falls into two categories. First, there are studies that focus on parental perceptions surrounding early childhood vaccines and how these ideas have been formed (Carrion, 2018; Dubé et al., 2016; Peretti-Watel et al., 2019; Mendel-Van Alstyne, Nowak, & Aikin, 2018; Reich, 2014). Second, there are studies that focus on how parents make decisions about early childhood vaccines (Austin et al., 2008; Austvoll-

Dahlgren & Helseth, 2010; Brunson 2013; Corben & Leask, 2016; Danchin et al., 2016; Sobo et al., 2016c). These qualitative studies have provided a substantial body of knowledge on why parents refuse to vaccinate their children and their decision-making in this regard. However, within this research, there is a plethora of narrative examples describing what parents do to ensure their children's health following their decision to refuse all or some vaccines (Brunson 2013; Carrion, 2018; Enkel et al., 2018; Glanz et al., 2013; Reich, 2014; Ward et al., 2018).

Wherever a parent sits along the spectrum of immunization viewpoints and actions, a notable observation from qualitative research data is that care activities to prevent communicable disease and enhance children's health represent a substantial burden of responsibility and effort on the part of the parent. This occurs over an extended period, and not just at the point when the decision is made to forgo all or some vaccinations. However, much of the research maintains a steady focus on parents' viewpoints and opinions, rather than on the descriptions of what the parents actually do for their children following their immunization decision (Ward, 2018). The choice not to vaccinate exceeds the scope of viewpoints and opinions; instead, it extends to actual care activities of parents in response to their children not having all or some immunizations. Understanding what parents are doing as an alternative to vaccination informs health care providers about the practices that parents value as well as conveys information that parents deem important in terms of preventing communicable diseases.

As this protocol was being written, researchers were anticipating that parents who refuse all or some vaccines for their children will likely refuse the COVID-19 vaccine (Dubé & MacDonald, 2020). Examining this issue is essential to better understand what parents are doing in lieu of vaccinating. Such an approach moves the focus away from what parents are *not* doing (i.e., not vaccinating) and their perceptions about this.

A preliminary search for existing qualitative systematic reviews on this subject was conducted in the following databases: PROSPERO, CINAHL, MEDLINE, Epistemonikos, *JBIEvidence Synthesis*, and the Cochrane Database of Systematic Reviews. The search identified qualitative systematic reviews on caregivers' or parents' decision-making and viewpoints on vaccination. These include systematic reviews on parents' beliefs about childhood vaccines (Gidengil, 2019); parental decision-making and childhood vaccines (Allan & Harden, 2015); factors that promote vaccine uptake, hesitancy, delay, or rejection in parents (Forster, 2016); and parents' views and experiences of routine early vaccination communication (Ames, Glenton & Lewin, 2017). None of these reviews have specifically extracted data on the actions parents take after deciding not to vaccinate or fully vaccinate their child.

This review will examine parents' specific care activities for under-vaccinated or unvaccinated young children in all countries. The purpose of this review is to consider the findings of existing research to help health care providers and researchers better understand the care activities parents use to ensure their young children's health following the decision not to vaccinate them.

### **Review Questions**

The primary review question is: How do parents experience the specific activities involved in caring for their under-vaccinated or unvaccinated young children after refusing routine scheduled vaccines due to concerns about safety and efficacy? The sub-questions are as follows:

1. How do parents control their young children's exposure to communicable diseases?

2. What activities do parents implement to protect their young children from serious illness that might result from exposure to a vaccine-preventable communicable disease?
3. What specific care activities do parents use when their young children become ill with a vaccine-preventable communicable disease?
4. What is the parental experience of providing this care? Where do they obtain information or support? Who provides most of this care within family units? What are the risks and/or benefits (physical, emotional, or financial) associated with this care?

## **Inclusion Criteria**

### ***Participants***

This review will consider studies that involve parents of young children aged 0 to 6 years who refuse some or all routine vaccines for their children. The choice to focus on young children, inclusive of infants, toddlers, and preschool children, was made because this cohort is recommended to receive the greatest number of routine vaccinations over the shortest period of time. The review will exclude studies that focus only on parents' perceptions or opinions about vaccination or on health care providers' perspectives on vaccine refusal and preventing communicable disease. This review will focus on parents' health-related care of young children following their decision not to vaccinate. Studies that focus on parents who have declined vaccines for their children due to concerns other than those linked to safety and efficacy, such as religious beliefs, will be excluded.

### ***Phenomena of Interest***

This review will consider studies that explore parental experiences and care activities that parents describe when caring for their young children after refusing all or some routine vaccines, due to concerns surrounding safety and efficacy. For the purposes of this review, we have defined “care activities” as all the everyday activities that parents carry out to ensure their children’s health and safety, following their decision to forgo all or some vaccines. These specific care activities may include breastfeeding, modification of diet, use of organic products, avoiding daycare, and being wary of environmental toxins. The activities also include parents’ efforts to prevent their young children from contracting a vaccine-preventable communicable disease and to enhance their children’s health to minimize the risk of critical illness from a communicable disease. “Enhancing health” refers to practical care activities to improve children’s health to minimize the possibility of them contracting a vaccine-preventable illness. Parental care of a sick child who has contracted a vaccine-preventable illness also addresses the overall review question.

### ***Context***

This review will consider studies published in all languages and undertaken in all contexts where this topic has been explored through qualitative research.

### ***Types of Studies***

This review will consider studies presenting qualitative findings including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research, and feminist research. Relevant findings will include descriptions, examples, or stories about how parents prevented vaccine-preventable communicable disease in their young children and/or cared for their children’s health after choosing not to vaccinate or fully vaccinate them.

## **Methods**

The systematic review will be conducted in accordance with JBI methodology for systematic reviews of qualitative evidence (Lockwood et al., 2020).

The protocol is registered in PROSPERO (CRD42021241781).

### ***Search Strategy***

The search strategy will aim to locate both published and unpublished studies. An initial limited search of MEDLINE and CINAHL was undertaken to identify articles on the topic. This search yielded five qualitative studies for inclusion (Dubé et al., 2016; Glanz et al., 2013; Mendel-Van Alstyne, Nowak & Aikin, 2018; Ward et al., 2017; Ward et al., 2018).

The text words contained in the titles and abstracts of relevant articles, and the index terms used to describe the articles, were used to develop a full search strategy for CINAHL via EBSCO (see Appendix I). The search strategy, including all identified keywords and index terms, will be adapted for each included information source. A comprehensive search using all identified keywords and index terms will then be undertaken across all databases as part of the review. The reference lists of all included reports will be screened for additional studies. All identified reports will be subject to forward citation searches to ensure the search is as far-reaching as possible. The searches will be updated prior to the final analysis. Any further studies identified will be considered for inclusion.

The databases to be searched include Web of Science, MEDLINE (Ovid), CINAHL (EBSCO), and PsycINFO (EBSCO). The search for unpublished studies or gray literature will include Google Scholar and ProQuest Dissertations and Theses.

Studies published in any language will be considered for inclusion. Study titles and abstracts will be translated using Google Translate to determine whether they meet the inclusion

criteria. Although resource limitations preclude full translation of most non-English publications, when a translated abstract suggests that the study may be relevant, it will be reported in a table for future research consideration.

Although the establishment of an anti-vaccination movement dates back to 1882, the starting point for the more modern “anti-vax” movement is attributed to a published, then subsequently retracted, research paper by Andrew Wakefield, which purported a causal link between the measles, mumps, and rubella vaccine and autism in 1998. Therefore, studies published from 1998 onwards will be included.

### ***Study Selection***

Following the search, all identified citations will be collated and uploaded into EndNote X9 (Clarivate Analytics, PA, USA) and duplicates removed. Titles and abstracts will then be screened by two independent reviewers using Covidence (Veritas Health Innovation, Melbourne, Australia) for assessment against the inclusion criteria for the review. Potentially relevant studies will be retrieved in full, and their citation details imported into the JBI System for the Unified Management, Assessment and Review of Information (JBI SUMARI; Adelaide, Australia) (Munn et al., 2019). The full text of selected citations will be assessed in detail against the inclusion criteria by two independent reviewers. Reasons for exclusion of full-text studies that do not meet the inclusion criteria will be recorded and reported in the systematic review. Any disagreements that arise between the reviewers at each stage of the study selection process will be resolved through discussion or with a third reviewer. The results of the search and the study inclusion process will be reported in full in the final systematic review and presented in a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram (Moher, Tezlaff & Altman, 2009).

### ***Assessment of Methodological Quality***

Eligible studies will be critically appraised by two independent reviewers for methodological quality using the standard JBI critical appraisal checklist for qualitative research (Lockwood, et al. 2020). Authors of papers will be contacted to request missing or additional data for clarification, where required. Any disagreements that arise between the reviewers will be resolved through discussion or with a third reviewer. The results of the critical appraisal will be reported in narrative format and in a table. All studies will be reviewed for methodological quality before undergoing data extraction and synthesis (where possible).

### ***Data Extraction***

Qualitative data will be extracted from papers included in the review by two independent reviewers using the standardized data extraction tool in JBI SUMARI (Munn et al., 2019). The data extracted will include specific details about the populations, context, culture, geographical location, study methods, and the phenomena of interest relevant to the review questions. The findings and their illustrations will be extracted and assigned a level of credibility. Any disagreements that arise between the reviewers will be resolved through discussion or with a third reviewer. Authors of papers will be contacted to request missing or additional data, where required.

### ***Data Synthesis***

Qualitative research findings will, where possible, be pooled using JBI SUMARI with the meta-aggregation approach (Munn et al., 2019). This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings and categorizing these findings on the basis of similarity in meaning. These categories will then be subjected to a synthesis in order to produce a single comprehensive set of

synthesized findings that can be used as a basis for evidence-based practice. Where textual pooling is not possible, the findings will be presented in narrative format. Only unequivocal and credible findings will be included in the synthesis.

### ***Assessing Confidence in the Findings***

The final synthesized findings will be graded according to the ConQual approach for establishing confidence in the output of qualitative research synthesis and presented in a Summary of Findings (Munn et al., 2014). The Summary of Findings will include the major elements of the review and details how the ConQual score is developed. Included in the Summary of Findings will be the title, population, phenomena of interest, and context for the specific review. Each synthesized finding from the review will then be presented, along with the type of research informing it, the scores for dependability and credibility, and the overall ConQual score.

## Chapter 3: JBI Qualitative Systematic Review

### **Review Title**

Parental experiences of caring for their preschool children after declining vaccines: A qualitative systematic review

### **Abstract**

#### ***Objective***

The review synthesizes qualitative research findings about the experiences of parental caregivers after making the decision to not vaccinate their preschool children. This review aims to help healthcare providers understand the parental work involved in caring for under or unvaccinated children.

#### ***Introduction***

Much of the current qualitative research literature about parents who are vaccine hesitant or decide not to vaccinate their children focuses on parental perceptions about the safety and efficacy of vaccines and decision-making. However, limited attention has been paid to measures taken by parents to help their young children avoid contracting vaccine-preventable communicable diseases, promote resistance, and enhance their children's health.

#### ***Inclusion Criteria***

This review considered qualitative studies that describe parents' experiences of caring for their young children, aged 0 to 6 years, after making the decision not to vaccinate. Studies undertaken in any context were considered. Studies that focused on young children who are unvaccinated or not fully vaccinated for reasons not related to parental refusal were excluded.

## ***Methods***

The JBI methodology for systematic reviews of qualitative evidence was followed. Databases were searched from 1998 onwards, and included Web of Science, MEDLINE, CINAHL, PsycINFO, Google Scholar, and ProQuest Dissertations and Theses, with no language limits. Following critical appraisal, findings that described parental experiences and the care activities they performed relating to their young children were extracted. The JBI process of meta-aggregation was used to identify categories and synthesize findings. The ConQual approach was used to assess confidence in the findings.

## ***Results***

Forty papers, representing 30 studies, met the criteria for inclusion. The studies were conducted in 14 countries located in four continents, with approximately 676 informants. From these studies, 115 findings were extracted and combined to form 12 categories based on similarity in meaning. Three syntheses were derived: (a) Parental care strategies took place in the home with measures that aimed to protect children's health and inform ongoing decision-making about vaccines; (b) Children's health was supported by parents who actively managed, responded to, and anticipated difficult relationships within their social networks and community, in addition to forming relationships with like-minded peers for information and support; (c) Parents' care activities extended to protecting their vaccine decisions through challenging societal discourses, and they also anticipated and planned for how their families would respond to punitive measures from governmental agencies as a penalty for not vaccinating their children.

## ***Conclusions***

The major conclusions from this review highlight the laborious activities that parents enact to care for their family's health after declining vaccines. Care activities extended from the

household and into the community, encompassing a myriad of anticipatory and reactive measures. Parents demonstrated a strong commitment to their family's health and well-being while responding to stigma they experienced amongst their friends, children's teachers, and healthcare providers. While facing or expecting penalties related to their vaccine choices, parents reached out to likeminded peers for support and planned which next steps to take should punitive measures become overwhelming.

Systematic review registration number: PROSPERO CRD42021241781

**Keywords:** vaccine-preventable disease; decision-making; immunization; parenting; vaccine hesitancy; vaccine refusal

**Abstract word count:** 491

**Bibliography:** Huel, C., MacKinnon, K., Harding, J., Haghiri-Vijeh, R., Gordon, C., & MacDonald, S. E. (in press). Parental experiences of caring for their preschool children after declining vaccines: A qualitative systematic review. *JBI Evid Synth.*

**Title:** Parental Experiences of Caring for Their Preschool Children After Declining Vaccines: A Qualitative Systematic Review

### Summary of Findings

Synthesized finding	Type of research	Dependability	Credibility	ConQual score	Comments
<p><b>Parental care strategies in the home: Focusing on the individual and family.</b> Parents enacted specific care strategies in the home that were meant to protect their children from vaccine-preventable diseases, enhance their health, strengthen their immunity, and inform their ongoing decision-making about whether or not their children should be vaccinated. Parents also described how they would care for a child who has contracted a vaccine preventable disease or how they did care for</p>	Qualitative	High (No downgrading)	Moderate (Downgrade one level)	Moderate (Downgrade one level)	<p>Dependability: 18/27 studies scored 4 and 5 for the questions relating to appropriateness of the conduct of the research. 8 studies scored 3 for the questions relating to location of researcher culturally or theoretically and acknowledging researcher influence on the research.</p> <p>Credibility: Downgraded one level due to mix of unequivocal (U) and credible (C) findings.</p>

Synthesized finding	Type of research	Dependability	Credibility	ConQual score	Comments
their child(ren) while they were ill. 64 findings from 27 research reports.					U=41, C=23
<b>Parental care strategies in the community: Managing social interactions and community networks.</b> Parents actively managed, responded to, and anticipated difficult relationships with members of their community who disagreed with their vaccine choices. This included local healthcare providers, teachers/schools, their friends, and family members. However, parents also reached out to like-minded peers to receive support and information to better inform their care activities and gain further knowledge about vaccines. 32 findings from 11 research reports.	Qualitative	High (No downgrading)	High (no downgrading)	High (no downgrading)	Dependability: 10/11 studies scored 4 and 5 for the questions relating to appropriateness of the conduct of the research. One study scored 3 for the questions relating to location of researcher culturally or theoretically and acknowledging researcher influence on the research.  Credibility: Downgraded one level due to mix of unequivocal (U) and credible (C) findings. U=31, C=1
<b>Parental care strategies at the systems-level: Challenging societal discourse and institutional work processes.</b> Parents laboriously worked to protect their vaccine decisions and their families from punitive measures from governmental agencies. In addition, they planned next steps should penalties become overwhelming, and reported their efforts to stand their ground on the topic of vaccinating. 19 findings from 8 research reports.	Qualitative	High (No downgrading)	Moderate (Downgrade one level)	Moderate (Downgrade one level)	Dependability: 7/8 studies scored 4 and 5 for the questions relating to appropriateness of the conduct of the research. One study scored 3 for the questions relating to location of researcher culturally or theoretically and acknowledging researcher influence on the research.  Credibility: Downgraded one level due to mix of unequivocal (U) and credible (C) findings. U=16, C=3

U: unequivocal; C: credible

## Introduction

Feeling hesitant about or refusing childhood immunizations involves a vast spectrum of opinions, ideas, and fears that ultimately determine how parents make choices about preventing vaccine-preventable diseases (VPDs) in their family. Parental decision-making about vaccination

is complex and context specific, varying across time, place, and vaccines (MacDonald, 2015). Parents may feel worried about vaccines, delay their acceptance, or completely refuse all or some vaccines despite the availability of vaccination services in their community. Researchers believe that parents are influenced by factors such as complacency, convenience, and confidence (MacDonald, 2015).

Researchers have identified parental concerns about the following claims: that vaccines are ineffective and harmful to children's immune systems; that adverse effects from vaccines are under-reported and lack proper follow-up; that companies producing vaccines are motivated by profit margins and will therefore intentionally overlook vaccination dangers; that vaccine-preventable diseases are not harmful and provide superior immunity to immunizations; and that mandatory childhood vaccine schedules are a violation of civil liberties (Lyren, 2006; Nield & Kamat, 2008; and Damjanović et al., 2018). Regardless of what decision they ultimately make for their children, parents who are hesitant about vaccines or refuse them altogether, are thought to have spent a great deal of time and attention weighing the perceived health benefits and risks of vaccinating their children and have made a conscious decision based on their belief that they are making the best decision to protect their children's well-being (Damjanović et al., 2018).

Research on vaccine refusal has described how parents who decline all or some vaccines continue activities to prevent VPDs, enhance their children's health, and re-evaluate their decisions, long after the choice to forgo immunizations has been made. It has been reported that parents who refused vaccines expressed their capability in managing their children's health without vaccines because of their efforts to make natural living lifestyle choices that enhance their children's health and well-being (Reich, 2016; Ward et al., 2017). "Managing" children's health after refusing vaccines has been reported in other research and called "salutogenic"

parenting (Ward et al., 2017). This concept has been used to describe practices that are perceived to minimize the risk of their children becoming critically ill from a VPDs and include breastfeeding, eating organic and/or home-grown food, cooking from scratch to reduce intake of food preservatives, and reducing exposure to toxins (Carrion, 2018; Dubé et al., 2016; Peretti-Watel et al., 2019; Reich, 2014; Reich, 2016; Ward et al., 2017; Ward et al., 2018). Parents who choose to not fully vaccinate their children put substantial effort into making decisions about vaccines, preventing VPDs in their families, and enhancing their health. Their work has been described by researchers as “processes” (Brunson, 2013; Glanz et al., 2013), “experiences” (Carrion, 2018), “behaviours” (Enkel et al., 2018), “intensive mothering practices” (Reich, 2014), and “responsibilisation” (Ward et al., 2018).

The phenomenon of parental vaccine refusal and hesitancy has been studied in numerous ways. However, most qualitative research studies on this topic typically fall into two categories. First, there are studies that focus on parental perceptions surrounding early childhood vaccines and how these ideas have been formed (Carrion, 2018; Dubé et al., 2016; Mendel-Van Alstyne et al., 2018; Peretti-Watel et al., 2019; Ward et al., 2018). Second, there are studies that focus on how parents make decisions about early childhood vaccines (Austin et al., 2008; Austvoll-Dahlgren & Helseth, 2010; Brunson, 2013; Corben & Leask, 2016; Danchin et al., 2018; Sobo et al., 2016c). These qualitative research studies have provided a substantial body of knowledge surrounding why parents are not vaccinating their young children and their decision-making process. However, within this research is also plethora of narrative examples describing what parents do to ensure their children’s health following their decision to refuse all or some vaccines (Brunson, 2013; Carrion, 2018; Enkel et al., 2018; Glanz et al., 2013; Reich, 2014; Ward et al., 2018).

Wherever a parent sits along the spectrum of immunization viewpoints and actions, a notable observation from qualitative research data is that care activities to prevent VPDs and enhance children's health represent a substantial burden of responsibility and effort on the part of the parent. This occurs over an extended time, and not just at the point when the decision is made to forgo all or some vaccinations. However, much of the research maintains a steady focus on parents' viewpoints and opinions, rather than on the descriptions of what the parents do for their children following their immunization decision (Ward et al., 2018). The choice not to vaccinate exceeds the scope of viewpoints and opinions; instead, it extends to actual care activities of parents in response to their children not having all or some immunizations. Understanding what parents are doing as an alternative to vaccination informs health care providers about the practices that parents value as well as conveys information that parents deem important in terms of preventing VPDs.

As we write this systematic review, researchers continue to explore the reasoning of parents who refuse the COVID-19 vaccine for their children (Rhodes et al., 2020). Refusal of this vaccine has happened in tandem with an estimated 6,943,390 people dying from a COVID-19 related illness and an estimated 767,984,989 cumulative cases of people contracting the COVID-19 virus (World Health Organization, 2020). Many of these people are at risk for long-term disability as a result of COVID-19 viral sequelae (Baskett et al., 2023). Therefore it is increasingly difficult to argue that personal exposure to vaccine-preventable illnesses and diseases will compel parents to provide the COVID-19, influenza, or any routine immunizations for their children. Forming a more expansive understanding about what is known about this issue is of utmost importance to develop knowledge about what parents are doing in lieu of

vaccinating, rather than placing predominant focus on what they are not doing and their perceptions about it.

A preliminary search for existing qualitative systematic reviews on this subject was conducted on the following databases/sources: PROSPERO, CINAHL, MEDLINE, Epistemonikos, the JBI Database of Systematic Reviews and Implementation Reports, and the Cochrane Database of Systematic Reviews. No current or in-progress systematic reviews on the topic were identified. There are qualitative systematic reviews that have compiled information about caregiver's/parent's decision-making and viewpoints on vaccination. They include systematic reviews on parents' beliefs about childhood vaccines (Gidengil et al., 2019); parental decision-making and childhood vaccines (Allan & Harden, 2015); factors that promote vaccine uptake, hesitancy, delay, or rejection in parents (Cooper et al., 2021; Forster et al., 2016); and parents' views and experiences of routine early vaccination communication (Ames et al., 2015). None of these qualitative systematic reviews specifically extracted research data on the actions parents take after deciding not to fully vaccinate their children.

Our review examined parents' specific care activities for under-vaccinated or unvaccinated young children in all countries. The purpose of this review is to consider the findings of existing research to help health care providers and researchers better understand the care activities parents use to ensure their young children's health following the decision not to vaccinate them. The synthesized findings of our review will shed light upon the information and practices parents do trust in relation to their children's health. This will help to further inform healthcare providers' approaches when working with this cohort of parents.

**Review Question(s)**

How do parents experience the specific activities involved in caring for their under-vaccinated or unvaccinated young children after refusing routine scheduled vaccines due to concerns about safety and efficacy?

In addition, our review examined evidence on parental experiences of the following:

- How do parents control their young children's exposure to communicable diseases?
- What activities do parents implement to protect their young children from serious illness that might result from exposure to a VPDs?
- What specific care activities do parents use when their young children become ill with a vaccine-preventable communicable disease?
- What is the parental experience of providing this care? Where do they obtain information or support? Who provides most of this care within family units? What are the risks and/or benefits (physical, emotional, or financial) associated with this care?

**Inclusion Criteria*****Informants***

Studies that involved parents of young children aged zero to six years who refused some or all routine vaccines for their children were considered. The choice to focus on young children, inclusive of infants, toddlers, and preschool children, was made because this cohort is recommended to receive the greatest number of routine vaccinations over the shortest time period. We included studies that had informants who reported having at least one child aged six years or younger. We also included studies that did not provide the ages of informant's children, due to concerns regarding their confidentiality in smaller communities, but whose informants had declined vaccines that would be on the infant and young child immunization schedule. Our

review excluded studies that focused only on parents' perceptions or opinions about vaccinations or on healthcare providers' perspectives on vaccine refusal and preventing VPDs. Our research team looked for parents' health-related care of young children following their decision not to vaccinate in studies that identified this as their phenomena of interest, and in studies where these findings were spontaneously reported by informants answering questions about other matters related to not fully vaccinating their children. Studies that focused on parents who declined vaccines for their children solely due to religious beliefs, but had no concerns about vaccine efficacy or safety, were excluded. We also excluded studies about parents who refused vaccines for older children, namely the human papillomavirus (HPV) vaccine, and for those who refused seasonal influenza or COVID-19 vaccine for their children.

### ***Phenomena of Interest***

For our review we synthesized findings from qualitative studies that explored experiences and care activities that parents reported doing for their unvaccinated preschool children after choosing to refuse all or some routine childhood vaccines due to concerns surrounding safety and efficacy. We defined "care activities" as all the everyday activities that parents carry out to ensure their children's health and safety, following their initial decision to forgo all or some vaccines. Initially, we identified that these specific care activities may include breastfeeding, modification of diet, use of organic products, avoiding daycare, and being wary of environmental toxins (Huel et al., 2022). We also stipulated that care activities may include parents' efforts to prevent their young children from contracting a VPD and to enhance their children's health to minimize the risk of critical illness from a VPD.

However, as our research team delved into the qualitative research landscape, we recognized that care activities expanded from the "hands-on care" that parents provided within

the home to enhance their children's health. It included the efforts that parents took to support and protect their vaccine choices. We reflected upon this as a substantial benefit of engaging in a qualitative systematic review, as our understanding of the phenomena of interest (care activities) expanded with a deeper engagement with the relevant research. "Enhancing health" both referred to the practical care activities to improve children's health to minimize the possibility of them contracting a vaccine-preventable illness, and the initiatives parents engaged in to evade vaccinations and being stigmatized by members of their community. For example, although we were interested in the care activities of parents to young children aged 0-6, we determined that parent's efforts to address issues related to schooling was directly related to their decision not to vaccinate their preschool children before they entered primary school. Parents also worked to avoid being marginalized for their decisions at the governmental level. Our research team acknowledged that even though some parents' care activities were aimed at preventing VPDs, others reported encouraging their children to contract vaccine-preventable diseases due to perceptions about how this could enhance their overall health. Therefore, studies with findings that reported parents' efforts or intention to help their children contract a vaccine-preventable disease and the work of caring for sick children with a VPD, also addressed our overall review question.

### ***Context***

Studies published in all languages and undertaken in all contexts where this topic has been explored through qualitative research were considered for our review.

### ***Types of Studies***

Studies presenting qualitative findings including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research, and feminist research were

considered by the research team. Relevant findings will include descriptions, examples, or themes about how parents prevented VPDs in their young children, how they protected their choice to not vaccinate, and how they enhanced their children's health after choosing not to fully vaccinate them.

## **Methods**

Our systematic review was conducted in accordance with JBI methodology for systematic reviews of qualitative evidence (Lockwood et al., 2020). It was conducted in accordance with an *a priori* protocol that was published in 2022 (Huel et al., 2022), and registered in PROSPERO: CRD42021241781.

### ***Search Strategy***

Our search strategy aimed to locate both published and unpublished studies. A three-step search strategy was utilized in this review. First, an initial limited search of MEDLINE and CINAHL was undertaken to identify articles on the topic. This search yielded five qualitative studies for inclusion (Brunson, 2013; Reich, 2014; Reich, 2016; Ward et al., 2017; Ward et al., 2018). The text words contained in the title and abstracts of the relevant articles, were used to develop a full search strategy for CINAHL via EBSCO (see Appendix I). The search strategy, including all identified keywords and index terms, was adapted for each included information source. A comprehensive search using all identified keywords and index terms was undertaken on February 15<sup>th</sup>–24<sup>th</sup>, 2022 and updated on January 30<sup>th</sup>–February 7<sup>th</sup>, 2023. All identified reports were subject to forward citation searches and reference lists of all included reports were screened for additional studies to ensure that the search was comprehensive. Systematic reviews that included qualitative reports, were of a similar topic, and were found during the database searches were screened for relevant included studies. All database search strategies, including

search terms, subject headings, keywords, and MeSH headings were approved by a university research librarian with experience doing JBI systematic reviews and database searching.

No language limits were used in our search strategy. Study titles and abstracts were translated using Google Translate to determine whether they met inclusion criteria. Resource limitations made full translation of non-English publications impossible; however these studies were reported in the table as “full-text not available” for future research consideration. Studies published from 1998 onwards were included. This particular year was chosen because despite the establishment of an anti-vaccination movement dating back to 1882, the starting point for more modern hesitancy and refusal of vaccines is attributed to a published, then subsequently retracted, research paper by Andrew Wakefield. It was published in 1998 and purported a causal link between the measles, mumps, and rubella vaccine and autism (Allan & Harden, 2015).

The databases that were searched included Web of Science, MEDLINE (Ovid), CINAHL (EBSCO), and PsycINFO (EBSCO). Sources of unpublished studies and gray literature searched included Google Scholar and ProQuest Dissertations and Theses. Search results in Google Scholar were limited to the first 150 results and ordered by relevance, as results were 3000+ and had no relevance to the topic after 100–200 results.

### ***Study Selection***

Following our search, all identified citations were collated and uploaded into EndNote v.X9 (ClarivateAnalytics, PA, USA). All duplicate studies were removed. Titles and abstracts were screened by two independent reviewers using Covidence (Veritas Health Innovation, Melbourne, Australia) for assessment against the inclusion criteria for the review. Potentially relevant studies were retrieved in full and their citation details imported into the JBI System for the Unified Management, Assessment, and Review of Information (JBI SUMARI; JBI, Adelaide,

Australia) (Munn et al., 2019). Full-text studies that did not meet the inclusion criteria were excluded. Reasons for their exclusion are provided in Appendix II. Any disagreements that arose between two members of our research team were resolved through discussion, or with a third reviewer.

### ***Assessment of Methodological Quality***

Our eligible research reports were critically appraised by two independent reviewers (CH, KM) on our research team for methodological quality using the standard JBI critical appraisal checklist for qualitative research (Lockwood et al., 2020). For a study to be selected for inclusion, we completed a preliminary review of the report for Questions 2 (congruity between the research methodology and the research question), 3 (congruity between the research methodology and the methods used to collect data), 4 (congruity between the research methodology and the representation of the analysis of data), and 8 (informants and their voices are adequately represented), which our team deemed as necessary. Our plan was that papers not meeting all four criteria would be excluded. However, all included studies met these criteria and none were excluded due to methodological quality. Those meeting these criteria were reviewed using the 10 questions from the JBI critical appraisal checklist (Lockwood et al., 2020). Any disagreements between the two reviewers (CH, KM) were resolved through discussion with two other reviewers (JH, RHV). Our plan was to contact the authors of papers to request missing or additional data for clarification when required, however, we did not need to take this action.

### ***Data Extraction***

Data were extracted from studies included in the review by two of our independent reviewers (CH, KM) using the standardized JBI data extraction tool (see Appendix III) (Lockwood et al., 2020) Our inclusion criteria stipulated that the study must include parents of

young children who had declined all or some routine childhood vaccines. As some of the studies also included informants who did vaccinate their children, or had no children, or were pregnant with their first child, only the findings linked to the illustrations shared by non-vaccinating parents were extracted. Companion studies were compared to ensure that their extracted findings and illustrations were unique to each paper. When more than one research report was included from a single study (same informants and sample size), then we looked to see if the supplementary reports provided additional findings or used a unique analytical lens or novel way to analyze the data collected. If so, we extracted these additional findings when they addressed our review question. If not, these additional research reports were excluded as duplicate reports. Findings and illustrations were extracted if the informant had a child(ren) aged 0–6 years and had declined all or some routine young childhood immunizations. However, some relevant papers did not give specific ages of informants' children. If the paper mentioned an age range of children that was inclusive of 0–6 years, it discussed parental refusal of vaccines that are on the immunization schedule for infants and young children, or the paper mentioned the inclusion of informants with young preschool children and infants, then we extracted the findings from the study.

Results from each of our reviewers were cross-checked, and any differences in data extraction were discussed and clarified to reach an agreement on final findings. Our initial extraction included data relevant to the phenomena of interest, the populations, study methodology, findings, illustrations, and specific objectives related to the review questions. Findings were verbatim extractions of the authors' analytic interpretations (commonly themes), along with relevant illustrations (informant quotes or fieldwork observations), if available. The reviewers on our research team assigned a level of credibility to each finding; these included:

unequivocal (evidence beyond a reasonable doubt), credible (an intention or plan that's plausible considering the data and theoretical framework), or unsupported (findings that lack illustrative data. Any disagreements that arose between us were resolved through discussion or with a third reviewer on our team (JH or RHV).

### ***Data Synthesis***

Qualitative research findings were, where possible, pooled using JBI SUMARI with the meta-aggregation approach (Munn et al., 2014). As this review was part of a doctoral dissertation for CH, the majority of the data synthesis process of grouping and categorizing findings was completed by CH, and discussed with KM. Feedback was also received from the other two reviewers (JH, RHV) on two occasions to create the final synthesis. This involved the aggregation or synthesis of 115 findings to generate a set of statements that represented that aggregation, through assembling the findings and categorizing these findings based on similarity in meaning. Our categories were grouped and assigned titles based on similar meanings, illustrations, the review questions, and the phenomena of interest.

Theoretical guidance informed our process and was derived from Dr. Dorothy E. Smith's writings about Institutional Ethnography and illuminating the invisible, every-day, every-night work of parents and family caregivers (Smith, 2005). (For our review, we focused on parents' "care activities" after declining all or some vaccines, as embodied work experiences demonstrative of what they do for their children's health. The notion of "work" oriented us to parents' care activities that involved acquired skills and conscious intent; it included their emotional thought work as well as their physical labour and communicative action (Smith, 1987). Our goal in aligning data synthesis with this theoretical guidance was to uncover the work of parents, often not the primary focus in qualitative research on the topic of "vaccine hesitancy,"

in order to shift healthcare providers' understandings from what they are not doing (vaccinating), to what work these parents are doing.

Our categories were then subjected to a meta-synthesis to produce a single comprehensive set of synthesized findings that could be used as a basis for evidence-based practice. Where textual pooling was not possible, our findings were presented in narrative form. We have provided additional details in narrative form when required to foster understanding of findings. Only unequivocal and credible findings were included in the synthesis. A timeline of each step of the review and a journal was kept by CH to trace all decisions made during the meta-aggregation.

### ***Assessing Confidence in the Findings***

Our final synthesized findings were graded according to the ConQual approach for establishing confidence in the output of qualitative research synthesis and presented in a Summary of Findings table (Munn et al., 2014). The Summary of Findings (SoF) includes the major elements of the review and details how the ConQual score was developed. Included in the table is the title, informants, phenomena of interest and context for the specific review. Each synthesized finding from the review is presented, along with the type of research informing it, scores for dependability and credibility, and the overall ConQual score. We noted the variation in methodological quality of each companion report about the same study when we reviewed the ten questions for the JBI critical appraisal checklist. To assess the dependability of a qualitative study based on the five specific questions from the critical appraisal scores, we took an average from each of the included reports to make one score for the entire study to contribute to the ConQual score. CH and KM conferred on this decision, determining that due to the different qualitative analytical lenses the study authors used for each of their reports, taking an average

score, rather than using the report that demonstrated the study's highest score, would provide the most accurate assessment of dependability. All our grouped companion papers scored 4, 4.5 or 5, out of the five specific questions from the critical appraisal, for dependability.

## **Results**

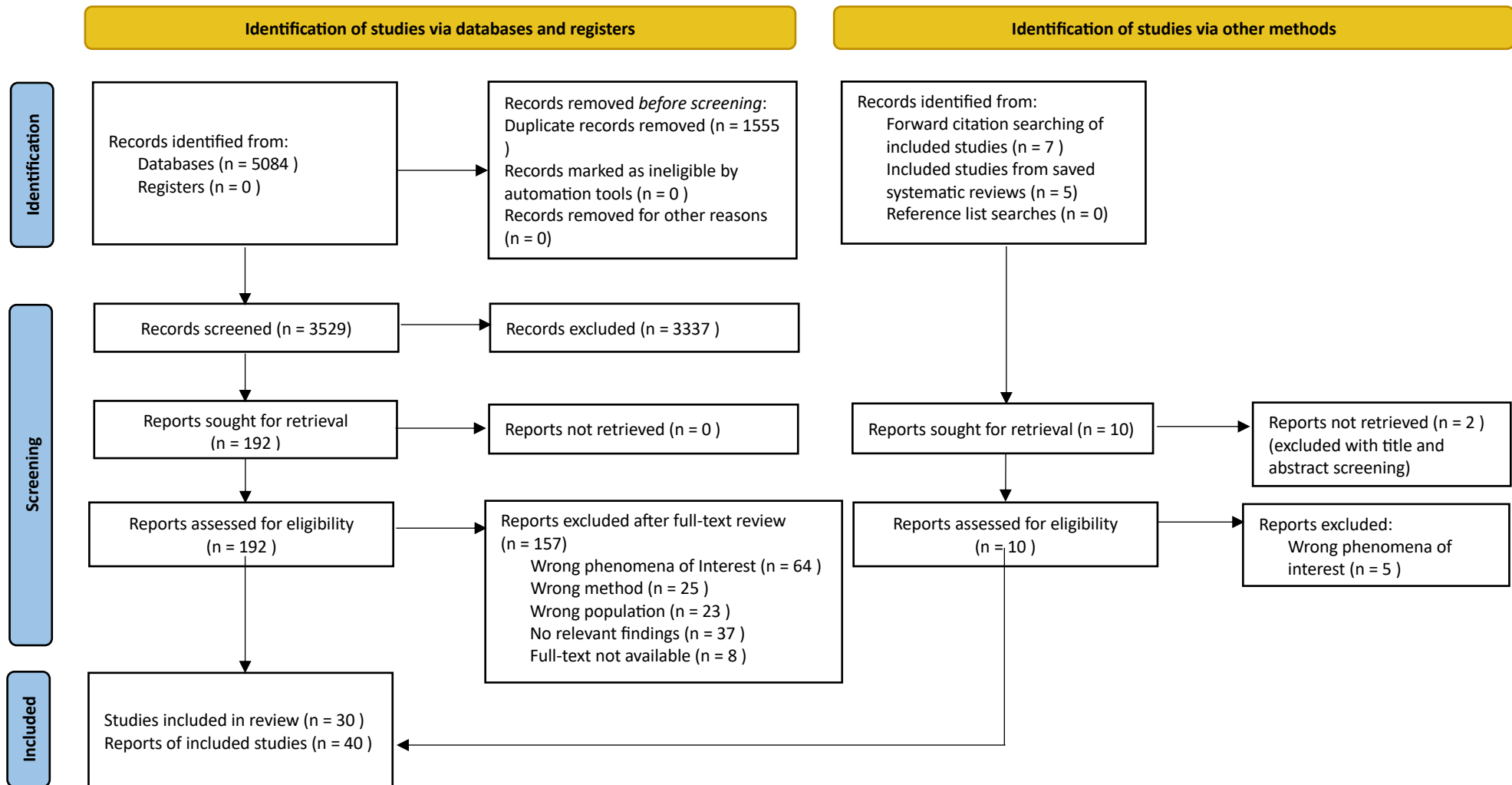
### ***Study Inclusion***

As shown in the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) flow diagram (Figure 1), we identified 5084 records from a detailed search process across selected databases including Google Scholar and ProQuest Dissertations and Theses from searches completed in February 2022 and February 2023. After duplicates were removed, 3529 were eligible for screening. All were screened for inclusion based on their title and abstract, and 3337 were excluded. Seven records were identified from forward citation searching. Five records were found through review of included studies from systematic reviews found in the search process. Two of the records found via other methods were excluded after their abstracts were reviewed. A total of 202 records (including 180 articles, seven systematic reviews, eight doctoral dissertations, six master's theses, and one book chapter) were assessed for inclusion through full-text review. The seven systematic reviews were excluded but saved in a separate file for citation searching as mentioned above. One hundred forty-seven articles, seven systematic reviews, six doctoral dissertations, and two master's theses were then excluded after the full-text review (Appendix II provides information on excluded studies and the reasons for exclusion).

Forty research reports, reflecting qualitative research from 30 studies, met our pre-established required criteria for methodological quality and were accepted for study inclusion and data extraction. These included 33 journal articles, four master's theses, two doctoral dissertations, and one book chapter.

Figure 1

Search results and study selection and inclusion process (Page et al., 2021)



### *Methodological Quality*

We appraised 40 research reports were for methodological quality. The methodological quality of the 40 included research reports varied slightly, all scored a “yes” in the essential criteria for review inclusion; i.e. Questions 2, 3, 4, and 8 (Table 1). The essential criteria was not included in the priori protocol (Huel et al., 2022). Overall, the methodological quality of the reports included was quite high with all scoring “yes” for question ten. Fifteen reports scored “yes” to all ten criteria (Brunson, 2013; Carrion, 2014; Fallet, 2017; Haarstick, 2021; Helps, Leask & Barclay, 2018; Helps, et al., 2019; Nurmi, 2021; Sobo et al., 2016c; Sythes & Bedford, 2022; ten Kate et al., 2021; Tombs-Heirman, 2009; Reich, 2014; Vandenberg, 2013; Wiley et al., 2020; Wiley et al., 2021). This was attributed to the fact that five of the studies were qualitative research reports from master’s and doctoral theses and contained more in-depth information (Carrion, 2014; Fallet, 2017; Haarstick, 2021; Tombs-Heirman, 2009; and Vandenberg, 2013). Ten reports met nine criteria (Attwell et al., 2018; Attwell, Meyer, & Ward, 2018; Deml et al., 2022; Ejuma, 2019; Reich, 2018; Reich, 2020c; Thornton & Reich, 2022, Ward et al., 2017; Ward et al., 2018; Wiley et al., 2022), and five reports met eight criteria (Byström et al., 2014; Gross et al., 2015; Harmsen, 2013; Reich, 2016; Reich, 2020b). Nine studies in nine reports met seven criteria (Atasever et al., 2021; Blaisdell, et al., 2016; Duchsherer et al., 2020; Hsu, et al., 2023; Kuan, 2022; Nurmi & Harman, 2022; Sumengen et al., 2021; Tomljenovic et al., 2022; Zin et al., 2022), but one report met five out of ten criteria (Martinez-Diz et al., 2014). Overall, the studies scored the lowest on the stated philosophical perspective (Q1), a statement locating the researcher culturally or theoretically (Q6) and addressing the influence of the researcher on the research (Q7), with total responses at 60% for these criteria. Sixteen reports received a “no” or “unclear” for question one about philosophical perspectives (Atasever et al., 2021; Attwell et

al., 2018; Blaisdell, et al., 2016; Byström et al., 2014; Duchsherer et al., 2020; Harmsen, 2013; Hsu, et al., 2023; Nurmi & Harman, 2022; Kuan, 2022; Martinez-Diz et al., 2014; Reich, 2020b; Sumengen et al., 2021; Tomljenovic et al., 2022; Ward et al., 2018; Wiley et al., 2022; Zin et al., 2022). If the statement about the philosophical perspective underpinning the study was absent or was not clearly stated in a way that the reviewer would definitively understand the author's connection to the research methodology, the report would receive a "N" or "U." Sixteen reports received a "no" or "unclear" for Question 6 about the cultural or theoretical location of the researcher(s) (Atasever et al., 2021; Blaisdell, et al., 2016; Byström et al., 2014; Deml et al., 2022; Duchsherer et al., 2020; Gross et al., 2015; Harmsen, 2013; Hsu, et al., 2023; Martinez-Diz et al., 2014; Nurmi & Harman, 2022; Reich, 2016; Sumengen et al., 2021; Tomljenovic et al., 2022; Ward et al., 2017; Zin et al., 2022). If the researcher(s) did not provide this information or the reviewer felt uncertain that the researcher's description was meant to locate their cultural or theoretical location, the report received a "N" or "U." Finally, sixteen reports received a "no" or "unclear" regarding Question 7, addressing the researcher's influence on their research (Atasever et al., 2021; Attwell, Meyer, & Ward, 2018); Ejuma, 2019; Hsu, et al., 2023; Kuan, 2022; Martinez-Diz et al., 2014; Nurmi & Harman, 2022; Reich, 2016; Reich, 2018; Reich, 2020b; Reich, 2020c; Sumengen et al., 2021; Tomljenovic et al., 2022; Thornton & Reich, 2022; Zin et al., 2022). If the researcher(s) did not address their influence on the research or vice-versa, or it was unclear if the statement(s) they provided were clearly meant to address this component of qualitative research, the report received a "N" or a "U." One report received a "N/A" designation for Question 9 about ethics approval due to the fact that the researchers engaged in qualitative analysis of content that was openly available on the internet, and therefore did not require ethical approval (Duchsherer et al., 2020).



Citation	Q1	Q2*	Q3*	Q4*	Q5	Q6	Q7	Q8*	Q9	Q10
Nurmi & Harman, 2022	U	Y	Y	Y	Y	N	N	Y	Y	Y
Reich, 2014	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Reich, 2016	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Reich, 2018	Y	Y	Y	Y	Y	Y	U	Y	Y	Y
Reich, 2020b	U	Y	Y	Y	Y	Y	U	Y	Y	Y
Reich, 2020c	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Sobo et al., 2016c	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Sumengen et al., 2021	U	Y	Y	Y	Y	N	N	Y	Y	Y
Sythes & Bedford, 2021	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
ten Kate et al., 2021	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Thornton & Reich, 2022	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Tombs-Heirman, 2009	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Tomljenovic et al., 2022	U	Y	Y	Y	Y	N	U	Y	Y	Y
Vandenberg, 2013	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Ward et al., 2017	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Ward et al., 2018	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
Wiley et al., 2020	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Wiley et al., 2021	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Wiley et al., 2022	U	Y	Y	Y	Y	Y	Y	Y	Y	Y
Zin et al., 2022	U	Y	Y	Y	Y	N	N	Y	Y	Y
%	60.0	100.0	100.0	100.0	97.5	60.0	60.0	100.0	95.0	100.0

\*required criteria to move to full critical appraisal

Companion papers are colour-coded in Table 1 to demonstrate their relationship to one another.

Y = Yes, N = No, U = Unclear

JBI critical appraisal checklist for qualitative research:

Q1 = Is there congruity between the stated philosophical perspective and the research methodology?

Q2 = Is there congruity between the research methodology and the research question or objectives?

Q3 = Is there congruity between the research methodology and the methods used to collect data?

Q4 = Is there congruity between the research methodology and the representation and analysis of data?

Q5 = Is there congruity between the research methodology and the interpretation of results?

Q6 = Is there a statement locating the researcher culturally or theoretically?

Q7 = Is the influence of the researcher on the research, and vice-versa, addressed?

Q8 = Are informants, and their voices, adequately represented?

Q9 = Is the research ethical according to current criteria or, for recent studies, is there evidence of ethical approval by an appropriate body?

Q10 = Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

### ***Characteristics of Included Studies***

The 30 qualitative studies described in 40 reports were published over a 10-year period spanning from 2013 to 2023. Fourteen countries across four continents were represented in the studies: USA (Blaisdell, et al., 2016; Brunson, 2013; Carrion, 2014; Duchsherer et al., 2020; Ejuma, 2019; Haarstick, 2021; Reich, 2014; Reich, 2016; Reich, 2018; Reich, 2020b; Reich, 2020c; Sobo et al., 2016c; Thornton & Reich, 2022), Australia (Attwell et al., 2018; Attwell, Meyer, & Ward, 2018; Helps, Leask & Barclay, 2018; Helps, et al., 2019; Ward et al., 2017, Ward et al., 2018; Wiley et al., 2020; Wiley et al., 2021; Wiley et al., 2022), Turkey (Sumengen et al., 2021; Atasever et al., 2021), Switzerland (Deml et al., 2022; Gross et al., 2015), The Netherlands (Harmsen, 2013; ten Kate et al., 2021), United Kingdom (Tombs-Heirman, 2009; Sythes & Bedford, 2022), Finland (Nurmi, 2021; Nurmi & Harman, 2022), Canada (Vandenberg,

2013), Croatia (Tomljenovic et al., 2002), Malaysia (Zin et al., 2022), Norway (Fallet, 2017), Spain (Martinez-Diz et al., 2014), Sweden (Byström et al., 2014), and Taiwan (Kuan, 2022). Sample sizes ranged from four to sixty informants. The total aggregate sample size was around 676 informants. This is not an exact number because one report conducted qualitative analysis of online content and did not provide informant numbers for their research (Thornton & Reich, 2022). Five reports did not provide the genders of their informants (Blaisdell, et al., 2016; Duchsherer et al., 2020; Ejuma, 2019; Harmsen, 2013; Hsu, et al., 2023). In six reports, researchers reported on the genders of the informants, but did not specify the genders of the non-vaccinating parents in their study (Brunson, 2013; Byström et al., 2014; Deml et al., 2022; Fallet, 2017; Kuan, 2022; Sobo et al., 2016c). Of the studies that specifically reported on the genders of non-vaccinating parents, 324 informants identified as female, 56 identified as male, and one informant asked that their gender identity not be divulged. To our knowledge, none of the parents identified as transgender, nonbinary, or gender diverse.

All studies used a qualitative methodology for data collection and analyses. Three studies completed qualitative analysis of online content including websites, blogs, social media posts, and comments (Duchsherer et al., 2020; Reich, 2016; Thornton & Reich, 2022). Thirty-four reports described interviews with one or two parents (Atasever et al., 2021; Attwell et al., 2018; Attwell, Meyer, & Ward, 2018; Brunson, 2013; Byström et al., 2014; Carrion, 2014; Deml et al., 2022; Ejuma, 2019; Fallet, 2017; Gross et al., 2015; Haarstick, 2021; Helps, Leask & Barclay, 2018; Helps, et al., 2019; Kuan, 2022; Martinez-Diz et al., 2014; Nurmi, 2021; Nurmi & Harman, 2022; Reich, 2014; Reich, 2016; Reich, 2018; Reich, 2020b; Reich, 2020c; Sobo et al., 2016c; Sumengen et al., 2021; Sythes & Bedford, 2022; ten Kate et al., 2021; Tombs-Heirman,

2009; Tomljenovic et al., 2002; Vandenberg, 2013; Ward et al., 2017; Ward et al., 2018; Wiley et al., 2020; Wiley et al., 2021; Zin et al., 2022).

In twenty-two reports, interviews were completed in-person (Atasever et al., 2021; Attwell, Meyer, & Ward, 2018; Attwell, Smith & Ward, 2018; Brunson, 2013; Byström et al., 2014; Deml et al., 2022; Fallet, 2017; Gross et al., 2015; Helps, Leask & Barclay, 2018; Helps, et al., 2019; Martinez-Diz et al., 2014; Reich, 2014; Reich, 2016; Reich, 2018; Reich, 2020b; Reich, 2020c; Sobo et al., 2016c); ten Kate et al., 2021; Vandenberg, 2013; Ward et al., 2017; Ward et al., 2018; Zin et al., 2022), four involved interviews held in person and over the telephone (Nurmi, 2021; Nurmi & Harman, 2022; Tombs-Heirman, 2009; Tomljenovic et al., 2002), two were only over the telephone (Carrion, 2014; Sythes & Bedford, 2022), two were in person and online (Haarstick, 2021; Kuan, 2022), two were a combination of telephone, online and in-person (Wiley et al., 2020; Wiley et al., 2021), and one report described only online interviews (Sumengen et al., 2021). Three reports included in-person focus group interviews (Blaisdell, et al., 2016; Hsu, et al., 2023; Martinez-Diz et al., 2014), and one had online focus group interviews (Harmsen, 2013). Six reports described studies involving in-person, ethnographic observations (Deml et al., 2022; Haarstick, 2021; Kuan, 2022; Reich, 2014; Reich, 2016; Reich, 2018), one had online observations (Haarstick, 2021), and one report detailed researchers completing fieldwork for their data collection (Tombs-Heirman, 2009).

The methods of inquiry described in the studies included sixteen grounded theory reports (Blaisdell, et al., 2016; Brunson, 2013; Carrion, 2014; Fallet, 2017; Helps, et al., 2019; Martinez-Diz et al., 2014; Reich, 2014; Reich, 2016; Reich, 2018; Reich, 2020b; ten Kate et al., 2021; Thornton & Reich, 2022 ; Tombs-Heirman, 2009; Vandenberg, 2013; Wiley et al., 2020; Wiley et al., 2021), three ethnographic (Haarstick, 2021; Nurmi, 2021; Nurmi & Harman, 2022), two

phenomenological (Ejuma, 2019; Sumengen et al., 2021), three interpretive (Gross et al., 2015; Ward et al., 2017; Ward et al., 2018), one pragmatist and epistemological (Tomljenovic et al., 2002), two inductive (Harmsen, 2013; ten Kate et al., 2021), three inductive and deductive (Ward et al., 2017; Ward et al., 2018; Hsu, et al., 2023), and one online dialogue group methodology (Wiley et al., 2022). Six reports gave minimal description on which specific qualitative methods were assumed (Atasever et al., 2021; Attwell et al., 2018; Attwell, Meyer, & Ward, 2018; Byström et al., 2014; Deml et al., 2022; Zin et al., 2022). One study used rapid assessment techniques to facilitate data collection from busy parents by combining a few short surveys (including a demographic survey) with a quick or “five minute” in-person interview involving a single, highly focused question: “How do you know you’ve made the right decision with regards to vaccinating your child/ren?” (Sobo et al., 2016c).

While all of our included reports had parental perceptions surrounding refusal of routine childhood immunizations and/or parental decision-making surrounding vaccines as the phenomena of interest, few specifically focused on parents’ care activities for their children after declining all or some routine childhood immunizations as their initial phenomena of interest. Of the reports that explored care activities at the onset of their study, the researchers investigated attitudes and behaviours related to the Australian “No Jab, No Pay” policy and financial impact (Helps, Leask & Barclay, 2018), how parents craft claims to use vaccine exemptions in order to get their children into school (Reich, 2018), how parents pharmaceutically manage their children’s health (Reich, 2020b), parental strategies to avoid mandatory vaccination (Tomljenovic et al., 2002), parents’ health promoting illness preventing practices (Haarstick, 2021; Nurmi, 2021; Tombs-Heirman, 2009), parent’s choice of alternative protection methods over vaccines (Sumengen et al., 2021), and how mothers formed social capital and managed

stigma (Reich, 2020c). Our remaining reports included findings related to parental care activities at the outset of their data analysis based on their informant's illustrations. However, the phenomena of interest at the onset of their research included six reports describing maternal experiences of refusing vaccines (Carrion, 2014; Reich, 2014; Reich, 2020c; Sythes & Bedford, 2022; Thornton & Reich, 2022; Vandenberg, 2013); nine about making decisions about vaccinations (Brunson, 2013; Deml et al., 2022; Ejuma, 2019; Harmsen, 2013; Nurmi, 2021; Fallet, 2017; Haarstick, 2021; Sobo et al., 2016c; Vandenberg, 2013); 16 reports about understanding parental reasoning, beliefs, and values related to vaccines, vaccine preventable diseases, and vaccine refusal (Atasever et al., 2021; Blaisdell, et al., 2016; Ejuma, 2019; Gross et al., 2015; Helps, et al., 2019; Hsu, et al., 2023; Martinez-Diz et al., 2014; Nurmi & Harman, 2022; Reich, 2016; Sythes & Bedford, 2022; ten Kate et al., 2021; Thornton & Reich, 2022; Ward et al., 2017; Ward et al., 2018; Wiley et al., 2022; Zin et al., 2022); two reports described connections between feeling hesitant about vaccines and complementary and alternative modalities (Attwell et al., 2018; Deml et al., 2022); three reports explored non-vaccinating parents' experiences with healthcare providers (Nurmi, 2021; Sythes & Bedford, 2022; Thornton & Reich, 2022); two reports focused on the lived experiences of non-vaccinating parents (Attwell, Meyer, & Ward, 2018; Wiley et al., 2021); and six reports were about the social contexts and processes of non-vaccinating parents (Duchsherer et al., 2020; Kuan, 2022; Reich, 2014; Reich, 2020c; ten Kate et al., 2021; Wiley et al., 2020).

We examined our companion papers carefully for their overall contribution to this review. Research reports from one researcher, Dr. Jennifer Reich, a well-established sociological expert in this field of study, collected extensive data from 2007 until 2016 and then published five analytic papers that were included in this review (Reich, 2014; Reich, 2016; Reich, 2018; Reich,

2020b; Reich, 2020c). We also noted that two researchers, Dr. Katie Attwell et al. and Dr. Paul R. Ward et al., combined their two studies into a single study early in their research program and then used differing analytic lenses to explore their combined data more deeply in subsequent reports (Attwell et al., 2018; Attwell, Meyer, & Ward, 2018; Ward et al., 2017; Ward et al., 2018). The following table is intended to provide clarity and enhance transparency about the 15 research reports that included 10 companion papers from five studies. Additional details about these studies and research reports are included in Appendix III: Characteristics of included studies.

**Table 2***Companion Papers*

Citations	Data collection location	Informants/ Time period	Qualitative Analytic Lens
Attwell et al. 2018; Attwell, Meyer, & Ward 2018 Ward et al. 2017; Ward et al. 2018	Fremantle, Western Australia, and Adelaide, South Australia	29 to 32 parents Sept. 2013–December 2015	Attwell 2018 examined vaccines & CAM; Attwell, Meyer & Ward drew on Bourdieu’s concept of “Habitus” and “Capitals.” Ward 2017 analysis used a logic of care; Ward 2018 focused on risk, responsibility & trust.
Helps et al. 2019; Helps, Leask & Barclay 2018	Byron Shire, NSW, Australia	31 parents 2014–2015	2018 analysis focused on impact of government financial penalties; 2019 paper focused on improving clinical encounters through understanding.
Nurmi 2021; Nurmi & Harman 2022	Southern, western, and central Finland	34 to 38 parents 2016–2019	Nurmi 2021 focused on human-microbe relations; Nurmi & Harman focused on reasons parents refused vaccines.
Reich 2014, 2016, 2018, 2020c, and 2020b	Colorado, USA	25 mothers (2014) 34 parents (2016) 34 parents (2018) 34 parents (2020c) 28 mothers (2020b) 2007–2016	2014 paper focused on neoliberal mothering; 2016 focused on dichotomies of natural & artificial; 2018 analysis focused on managing compulsory vaccination laws; 2020c analysis focused on parental control & ambivalence; 2020b analysis focused on social capital & stigma management.
Wiley et al. 2020 and 2021	Five of Australia’s eight states and territories	21 parents 2020, 2021) Sept. 11, 2017–Feb. 20, 2019	Wiley 2020 focused on social processes of parental vaccine refusal; Wiley 2021 focused on lived experience of non-vaccinating parents.

### ***Review Findings***

Our review included a total of 115 findings that were extracted from the 40 papers describing 30 studies (Appendix IV) and combined to form 12 categories based on similarity of meanings found in the qualitative data. The categories were combined into three synthesized findings (meta-syntheses). One synthesis finding demonstrated how parents provided care activities for their children within the home environment; a second synthesis contained categories related to how parents cared for their children through forming social networks and managing risks and relationships with healthcare providers and school personnel in their communities; a third category was formed to amalgamate categories associated with how parents cared for their family at the social institutional level by protecting their vaccine decisions from punitive measures from governmental agencies and their efforts to stand their ground on the topic of vaccinating. Table 3 depicts the findings from each of the categories and connect them to the three synthesized findings categories to demonstrate the overall synthesis process.

**Table 3***Results of Meta-Synthesis of Qualitative Findings*

Synthesized Finding	Categories	Findings <sup>1</sup>
<b>1. Parental care strategies in the home: Focusing on the Individual and Family</b> Parents enacted specific care strategies in the home that were meant to protect their children from vaccine-preventable diseases, enhance their health, strengthen their immunity, and inform their ongoing decision-making about whether their children should be vaccinated. Parents also described how they would care for a child who has contracted a vaccine preventable disease or how they did care for their child(ren) while they were ill.  64 Findings from 27 research reports.	1.1 Ongoing information seeking	9 Findings (7 U, 2 C)
	1.2 Living healthy, natural lifestyles	21 Findings (16 U, 5 C)
	1.3 Acquiring natural immunity through exposure to diseases	11 Findings (2 U, 9 C)
	1.4 Using complementary and alternative modalities	11 Findings (9 U, 2 C)
	1.5 Assuming responsibility for treating vaccine preventable diseases	8 Findings (3 U, 5 C)
	1.6 Reducing exposure by providing a low-risk environment	4 Findings (4 U)
	<b>2. Parental care strategies in the community: Managing Social Interactions and Community Networks.</b> Parents actively managed, responded to, and anticipated difficult relationships with members of their community who disagreed with their vaccine choices. This included local healthcare providers, teachers/schools, their friends, and family members. However, parents also reached out to like-minded peers to receive support and information to better inform their care activities and gain further knowledge about vaccines. 32 findings from 11 research reports.	2.1 Managing risks and relationships with healthcare providers
2.2 Managing stigma, confronting critics, and staying silent		7 Findings (6 U, 1 C)
2.3 Home-schooling and schooling responsibilities		6 Findings (6 U)
2.4 Forming social networks with like-minded parents		7 Findings (7 U)
<b>3. Parental care strategies at the systems-level: Challenging Societal Discourse and Institutional Work Processes</b> Parents laboriously worked to protect their vaccine decisions and their families from punitive measures from governmental agencies. In addition, they planned next steps should penalties become overwhelming, and reported their efforts to stand their ground on the topic of vaccinating. 19 Findings from 8 research reports.		3.1 Challenging societal discourses and institutional policies
	3.2 Managing punitive measures at the systems-level	12 Findings (12 U)
Total synthesized findings: 3	Total categories: 12	Total findings: 115 (88 U, 27 C)

<sup>1</sup>For more details about the findings with accompanying illustrations, please see Appendix IV. U: unequivocal; C: credible

### **Synthesized Finding 1: Parental Care Strategies in the Home: Focusing on the Individual and Family**

This meta-synthesis contains six categories and 64 findings. Parents enacted specific care strategies in the home that were meant to protect their children from vaccine-preventable diseases, enhance their health, strengthen their immunity, and inform their ongoing decision-making about whether their children should be vaccinated. The major findings were that parents enacted a multitude of care strategies for their children, after declining vaccines, that included direct health strategies for the children and within the home environment. To enhance their children's health, parents used complementary and alternative health modalities. They also willingly exposed their children to vaccine-preventable diseases (VPDs), due to a belief that this conferred superior, longer-lasting immunity over immunizations and that the illness convalescence was important for their growth and development. Parents reported living natural lifestyles and fostering a healthy environment in their home to decrease the risk of their children getting a VPD and so that their children would have stronger immunity to suppress symptoms. Parents also detailed that a healthy, natural lifestyle could decrease the severity of VPD symptoms should their children become ill. They conveyed their confidence and intention to take responsibility in caring for children who become ill with a VPD, mainly because of a perception that the severity of these illnesses was negligible. Finally, parents reported that the decision not to vaccinate was not a final choice. Instead, parents described an intensive, ongoing process of searching for information that would either confirm their suspicions about vaccines or disprove them, in which case they may reconsider their decision.

**Table 4**

*Synthesized Finding 1: Parental Care Strategies in the Home:  
Focusing on the Individual and Family*

Categories	Findings
1.1 Ongoing information seeking	<p>Stasis, reassessment, and ongoing assessment. (U)</p> <p>Research as ongoing. (U)</p> <p>Ongoing risk assessment. (U)</p> <p>Individual strategies and selective use of medications/vaccines: Like many parents who reject vaccines, she (Astrid) envisions individual parents as responsible for evaluating risk and making informed decisions, rather than following advice from providers that seems generic. (U)</p> <p>Standpoint mobility: Rather than sticking to a single standpoint, informants moved from vista to vista. [...] (U)</p> <p>Questioning science/shifting evidence. (U)</p> <p>Risk assessments. (U)</p> <p>Making choices to protect their child: This illustrates how a mother who has declined vaccination for her children continue to evaluate the risk of vaccine up against the risk of disease, and if circumstances alter, possibly make a different choice to protect her children or family. (U)</p> <p>Changing their minds: Some were completely firm in their stance and said that they would never change their minds, whereas others had a more nuanced approach, admitting that they would be open to new information and potentially accepting future vaccines depending on the context and the individual needs of their child. (U)</p>
1.2 Living healthy, natural lifestyles	<p>Current health and healthy lifestyle. (U)</p> <p>The costs of intensive mothering: This is related to the paradigm of intensive mothering, which suggests that the healthy growth and development should be the central focus of the mother's identity. (U)</p> <p>Should focus on natural interventions instead of chemical ones. (U)</p> <p>Lifestyle: Informants mentioned that their healthy lifestyle promotes their children's health, and therefore the risk of getting an infectious disease is reduced. (U)</p> <p>Underpinning beliefs—shared: The suite of behaviours that accompanied non-vaccination such as eating organic food, breastfeeding, minimal screen time, using complementary medicines and cloth nappies appeared to be derived from this same understanding. (C)</p> <p>Intensive parenthood: Informants who did not trust vaccines sought to improve their children's health through everyday practices. (U)</p> <p>Feeding as health promotion. (U)</p> <p>Natural living as immune-promoting. (C)</p> <p>Natural methods/additive-free nourishment. (U)</p> <p>Positive healthcare options/what they did to keep their child well: All the respondents actively searched for and provided what they saw as positive healthcare options in; childcare, nutrition and lifestyle. (U)</p> <p>Salutogenic parenting—Comprehensive health promoting and illness preventing activities: Parents' activities included managing nutritional intake</p>

Categories	Findings
	<p>during pregnancy, breastfeeding, feeding their children organic and/or home-grown food, cooking from scratch to reduce preservative consumption, reducing their children's exposure to chemicals and toxins and promoting physical activity and play-based learning. (U)</p> <p>Responsibilisation: Most parents in this study adhered to a salutogenic parenting pathway including eating organic food; reducing the ingestion of, and exposure to, chemicals in their environment; limiting children's time on 'screens'; and encouraging physical and emotional development through creative play. (U)</p> <p>Reciprocal obligations fulfilled: ...nonvaccinating parents do not owe society anything because of the lengths they already go to in raising healthy children who can withstand the diseases that vaccines are intended for. (C)</p> <p>The strength of the naturally acquired immune system: Many parents argued that the strength of the immune system can be built up by healthy food. Moreover, breastfeeding was often mentioned as a sufficient measure to protect infants particularly in the early phase. (C)</p> <p>Fulfilling the role of responsible parent: "Informants were highly attuned to their children's health, wellbeing and developmental needs. Many invested significant time and resources into providing, taking active responsibility for meeting those the best environment for their children. (U)</p> <p>Healthy eating. (U)</p> <p>Care through food. (U)</p> <p>Attending to diet and whole foods. (U)</p> <p>Simple clean diet. (U)</p> <p>Natural at home. (U)</p> <p>Lifestyle: These lifestyle choices included long-term breastfeeding, avoiding formula milk, eating raw and/or organic food and following a vegan lifestyle. (C)</p>
1.3 Acquiring natural immunity through exposure to diseases	<p>Microbes as unpredictable agents: ...well-functioning immune systems were perceived as limiting the disease-inducing agency of microbes while simultaneously co-producing immunities. (C)</p> <p>Perceived advantages of having the disease. (C)</p> <p>It is beneficial to undergo the natural course of the disease, as part of a new way of life. (C)</p> <p>Natural infection and the quest for varicella. (U)</p> <p>Rejecting vaccines as an unnatural mode of absorption. (C)</p> <p>Positioning in the healthcare field: Parents often chose the option that they perceived to be the most natural or the measure that respected or supported a natural approach the most. (C)</p> <p>Positive effects of illness and the purpose of illness. (C)</p> <p>Natural health beliefs: Study informants expressed strong beliefs in natural health, which include beliefs that the body was created to sustain itself and deal with diseases through its complex immune system, and vaccines and other unnatural substances interfere with the immune system. (C)</p> <p>Health perceptions and practices: They often stated views and attitudes alternative to the mainstream understanding of health and illness; for instance,</p>

Categories	Findings
	<p>they talked about VPDs serving a purpose in strengthening the immune system. (C)</p> <p>Letting 'nature' run its course. (U)</p> <p>Immunization as an intrusion into natural bodily orders. (C)</p>
1.4 Using complementary and alternative modalities	<p>Conventional/Alternative Treatment Modalities. (U)</p> <p>Alternatives to vaccination. (C)</p> <p>Alternative medicine as complementary or as primary healthcare. (U)</p> <p>Self-directed and practitioner led use: CAM use went beyond simply visiting and trusting a practitioner. It involved CAM providers being information sources, applying friends' CAM advice, or personal study. (U)</p> <p>Engagement with CAM. (C)</p> <p>Beliefs in alternative practices. (U)</p> <p>Using immune boosting herbs and tinctures. (U)</p> <p>Using supplements to boost the immune system. (U)</p> <p>Health maintenance and illness treatment supplements. (U)</p> <p>Using CAM for health maintenance and illness treatment (U)</p> <p>Folk medicine. (U)</p>
1.5 Assuming responsibility for treating vaccine preventable diseases	<p>Treatment is available. (C)</p> <p>Parental control over risk. (C)</p> <p>Treatability of VPDs. (C)</p> <p>Responsibility: Parents in our study had to navigate through the frame of responsibility for their decision, particularly if anything was to go wrong either way. (U)</p> <p>Dealing with the outcome: When asked how they cope with the risk of their child being infected with a disease, several informants seemed to lack any strategies of dealing with the risk and reported they have never so far considered it, therefore displaying only vague strategies related to this issue (C)</p> <p>Home remedies: 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. (U)</p> <p>Promoters of natural immunity. (C)</p> <p>Controlling risk. (U)</p>
1.6 Reducing exposure by providing a low-risk environment	<p>Living in a low-risk environment. (U)</p> <p>Managing the risk of travel. (U)</p> <p>Managing risk from imagined gated communities. (U)</p> <p>Individualism and Control: Many informants felt they could control their child's exposures and infection risk, and therefore, tailor their vaccination schedule according to their child's circumstances. (U)</p>

### ***Category 1.1: Ongoing Information Seeking***

Nine findings (7 U, 2 C) were combined to form this category which captured the ongoing, intensive nature of parental information seeking about vaccines even after the initial decision to forgo a routine childhood vaccine(s) is made. Parents expressed their feelings of being responsible for evaluating risk and making informed decisions that are specific to their children's health (Sobo et al., 2016c; Reich, 2020b). Parent's information seeking involved finding new research about the safety and efficacy of vaccines included on their childhood vaccination schedule (Carrion, 2014). In addition to this, parents reported extending their information gathering, to seeking research about brand new vaccines that could be added to the existing schedule (Brunson, 2013; Carrion, 2014; Sobo et al., 2016c). They also examined evidence surrounding health-promoting and illness preventing care activities they undertook with and for their children (Ward et al., 2017). Parents acknowledged that if circumstances should change in their community, either an elevated risk for a VPD or a decline in nutritious food and environmental sanitation, they would take this factor into consideration and contemplate vaccinating their children (Helps, et al., 2019; Ward et al., 2018). This statement was supported by findings that demonstrated parents were not only evaluating scientific evidence about vaccines; they were also doing continuous risk assessments from their household looking out towards the health of the greater community.

Owen (SA) talked about the difficulties involved in searching for and synthesising evidence in order to make the best possible decisions for his children, and how he is open to new information, "to me it isn't a closed door ... it's an enquiry about a lot of things, but that's kind of my life; it like takes up a lot of RAM, all this questioning ... I'm grasping with it, you know, to make the best decision because all of my things are about

making the best decision. You know, about the vaccinations ... I haven't been able to let go totally of it and say 'oh fuck that.' There's still a question ... it's bloody challenging. I know it's a done deal for my wife but I'm not a closed—you know, I'm still wondering” (Ward et al., 2017, p. 7).

### ***Category 1.2: Living Healthy, Natural Lifestyles***

Twenty-one findings (16 U, 5 C) described how parents closely monitored their children's health and promoted a natural lifestyle to both lessen their risk of getting a VPD, and to decrease the severity of symptoms should they contact one. Within the thirteen findings and the accompanying illustrations, parents did not mention only one practice that could contribute to their children's healthy lifestyle. Instead, living a healthy, natural lifestyle that contributes to a decreased need for vaccines involved a host of health-related practices that extended from pregnancy and beyond (Blaisdell, et al., 2016; Carrion, 2014; Reich, 2016; Wiley et al., 2020). These measures were seen to naturally boost immunity to infection by decreasing the risk for a child contracting a VPD (Wiley et al., 2022). These included a toxin-free household, breast-feeding, decreasing screen-time, exercising, and keeping a calm and happy home (Ejuma, 2019; Gross et al., 2015; Harmsen, 2013, Helps, Leask & Barclay, 2018, Kuan, 2022; Sythes & Bedford, 2022; Ward et al., 2017; Ward et al., 2018). Parents discussed a healthy diet as being central to promoting immunity and essential for recovery from illness (Reich, 2014). A healthy diet was described as having minimal sugar, non-processed, organic, preservative-free, home-grown, prepared from scratch, nutritious, containing lots of vegetables and fruit, being whole, and not including takeout (Haarstick, 2021; Sumengen et al., 2021; Sythes & Bedford, 2022; Tombs-Heirman, 2009; Ward et al., 2018). Parents meticulously monitored and managed their

children's health and accepted agency for the responsibility in ensuring their children's healthy development and well-being after making the decision to not fully vaccinate them.

There are other ways to make sure your children have a strong immune system. We work hard to reduce our little ones' toxic exposure and prepare their bodies to fight against any pathogens they might encounter naturally. This isn't just with the things that enter their body, this is with everything that comes into our home from floor cleaners to detergent and toothpaste. We eat an organic diet and limit things that might harm their immune systems in any way (Ejuma, 2019, p. 75).

### ***Category 1.3: Acquiring Natural Immunity Through Exposure to Diseases***

Eleven findings (2 U, 9 C) were grouped to form this category. Parents detailed how VPDs were not to be feared (Byström et al., 2014; Fallet, 2017; Nurmi, 2021). Instead, VPDs allowed children to strengthen their immunity in a natural way (Fallet, 2017; Martinez-Diz et al., 2014; Nurmi & Harman, 2022; Vandenberg, 2013). Vaccine injections were described as an unnatural or undesirable way to build immunity (Gross et al., 2015; ten Kate et al., 2021; Vandenberg, 2013). Parents explained that avoiding vaccines and contracting a VPD, provided life-long immunity instead of relying on vaccination boosters over a lifetime (Fallet, 2017; Harmsen, 2013). Parents described this measure as promoting "natural immunity" (Byström et al., 2014; Gross et al., 2015; Reich, 2016). Some parents also detailed how children's immune systems need to be trained by the VPD which also confers other health-related and developmental benefits (Fallet, 2017; Tombs-Heirman, 2009). The experience itself of contracting a VPD and going through the disease without medical intervention was both essential for developing the immune system and the emotional well-being of the child (Martinez-Diz et al., 2014; ten Kate et al., 2021; Tombs-Heirman, 2009). Most illustrations mentioned one of the

following illnesses: varicella (chicken pox), measles, mumps, rubella, and whooping cough, as the VPDs that could potentiate better health for their children (Fallet, 2017; Nurmi, 2021; Reich, 2016).

If someone sneezes on me or I let my child get chickenpox by itself, or mumps, rubella, whatever these things are, even polio, now my body says, “Oh, that’s already gone through the lymph channels. It’s already gone through the mucus channels. It’s already gone ... so by the time it hits the blood stream, the immune system says, “Hey, we’ve already weakened this germ to the point where now we can kick its butt ... And now once your body defeats that bug naturally ... anytime anything else comes at the immune system, that first string gets released immediately, and now you have lifetime immunity. You don’t need boosters. You don’t need anything, because you’ve got it (Reich, 2016, p. 107).

#### ***Category 1.4: Using Complementary and Alternative Modalities***

Eleven findings (9 U, 2 C) were combined to form this category. Parents reported that they utilised, learned about, and accessed practitioners of complementary and alternative modalities (CAM) for their children’s healthcare (Atasever et al., 2021; Attwell et al., 2018; Haarstick, 2021; Martinez-Diz et al., 2014; Tombs-Heirman, 2009; Zin et al., 2022). This was done to prevent VPDs, treat VPD symptoms, and boost their children’s immunity (Attwell et al., 2018; Martinez-Diz et al., 2014). Parents listed herbal products, tinctures, propolis, homeopathic vaccines and homeopathy, probiotics, liquid silver, super-foods, colostrums, bone-broth, and apple cider vinegar of examples of the CAM modalities they were using with their children (Atasever et al., 2021; Haarstick, 2021; Martinez-Diz et al., 2014; Zin et al., 2022). Though some parents reported that they accessed CAM practitioners as their first choice in accessing health

care for their children, others reported that they went to a CAM provider as an alternative if their biomedical/allopathic provider was not providing treatment options that were not amenable or agreeable to them (Attwell et al., 2018; Tombs-Heirman, 2009). Parents discussed CAM as a health modality that made them feel like they were taking a proactive role in their children's health by enhancing their ability to manage VPD risks by informing their knowledge on how to treat VPD infection symptoms (Attwell et al., 2018).

Questioned whether she would be worried during an outbreak of measles or diphtheria, Kavita (SA/CV) would trust in her son's "body to be strong enough to fight that" and "probably just do some probiotics and some colostrums and some bone broth and a bit of Reiki and some hippie stuff, apple cider vinegar in the bath" (Attwell et al., 2018, p. 108).

#### ***Category 1.5: Assuming Responsibility for Treating Vaccine Preventable Diseases***

Eight findings (3 U, 5 C) addressed how parents took responsibility for treating VPDS contracted by their children as an extension to their choice not to vaccinate them. Parents detailed their nonchalance about their children becoming ill from a VPD and repeatedly expressed confidence in their ability to treat their children's symptoms (Blaisdell, et al., 2016; Tomljenovic et al., 2002; Ward et al., 2018). Confidence in their ability, or prospective ability, to care for an unwell child was substantiated by beliefs that VPDs pose a minimal amount of harm to their children's overall health due to their treatability and low severity (Blaisdell, et al., 2016; Tomljenovic et al., 2002; Ward et al., 2018). Some parents reported not considering any strategies for dealing with the outcomes of a VPD infection in their family (Tomljenovic et al., 2002); where others reported that they had confidence in allopathic physicians' abilities to care for their children's symptoms when they need to seek care outside of the home environment (Blaisdell, et al., 2016; Haarstick, 2021; Tomljenovic et al., 2002).

If she gets diphtheria, that's fine, she's going to throw up, she will just drink water. If she doesn't drink water, we will take her to the hospital, they will give her an IV, so we didn't (vaccinate), we based our rationale on risk (Blaisdell, et al., 2016, p. 484).

### ***Category 1.6: Reducing Exposure by Providing a Low-Risk Environment***

Four findings (4 U) were grouped to form this category. Parents strategically planned to reduce their children's risk for contracting a VPD by isolating their children geographically to avoid exposure. This involved limiting social interactions with other children, avoiding local areas with disease outbreaks, and avoiding international travel (Blaisdell, et al., 2016; Carrion, 2014; Reich, 2014). Some parents discussed the challenge of managing/limiting their children's social contacts if they were required to travel or wished to go abroad (Blaisdell, et al., 2016; Reich, 2014). They admitted that if this were the case, they would need to embark on a separate VPD risk assessment of the country they wish to travel to and possibly reconsider their vaccine decisions (Reich, 2014). Controlling their children's risk exposure meant keeping them close to home and avoiding risk of disease from outsiders.

We don't send them to daycare. I felt like they weren't exposed to a lot of different kids all day long, or for long periods of time without me around watching and keeping them safe. It doesn't mean that they are not gonna get a disease, it also means that they have a less chance (Blaisdell, et al., 2016, p. 484).

### **Synthesized Finding 2: Parental Care Strategies in the Community: Managing Social Interactions and Community Networks**

The second meta-synthesis finding was formed from four categories and 32 findings. It's reflective of the descriptions in qualitative research that detailed how parents' care activities after declining vaccines extended broadly from the "hands-on" care they provide in the home and

expand into the greater community. Their decisions lead them to anticipate difficult relationships with members of their community who may disagree with their vaccine choices. Parents discussed how they would actively and passively respond to and manage relationships with healthcare providers, teachers/schools, friends, and family members. While guarding themselves from animosity, parents concurrently reached out to like-minded peers for support and information to guide the hands-on care they provided their children and to continue gaining knowledge about vaccines.

**Table 5***Synthesized Finding 2: Parental Care Strategies in the Community:**Managing Social Interactions and Community Networks*

Categories	Findings
2.1 Managing risks and relationships with healthcare providers	Resisting social opposition: Relatedly, many informants discussed calling healthcare providers in advance in order to screen for potential disagreements about policy or choices. Likewise, informants actively sought healthcare providers who shared similar perspectives on health, especially those who were willing to take a more “holistic” or “homeopathic” approach to care. (U)
	Managing institutional insistence: Parents who aim to meticulously manage their children’s health are often baffled when their children become sick, despite good nutrition, healthful living, and good parenting. They face both an inability to control health and limits on their power to treat illness. (U)
	Interactions with health professionals: How the respondents handled their GP’s, practice nurse’s or health visitor’s attempts to persuade them to vaccinate their children, varied enormously. (U)
	Responses and reflexivity: ... we widen the scope of parental risk engagement to consider risks to social relationships and medical care, considering that parents must also deal with the potential risk of unwelcome responses and problematic encounters. (U)
	Vaccination avoidance behavior—Not being truthful. (U)
	Vaccination avoidance behaviour—Stalling and avoiding contact with clinicians. (U)
	Vaccination avoidance behavior—Deceit. (U)
	Affect: Emotions and social proximity: Parents commonly described experiences with healthcare providers in emotional terms. They cited affect or their general sense of comfort or discomfort, as important elements of clinical encounters...some parents discussed negative emotional and affect experienced in interactions with their children's doctors. (U)
	Self diagnosis: Data in transcripts were coded with self-diagnosing whenever a mother mentioned that they identified the origin of their child’s illness without the help of a medical professional. (U)
	Healthcare professionals: Before, during and after the decision-making process, interactions with healthcare professionals and health institutions were important for non-vaccinating mothers. (U)
2.2 Managing stigma, confronting critics, and staying silent	Trust: Trust is an important component of relationships with healthcare professionals and more widely with institutions and government. (U)
	Refusal and the risk of state sanctions—Healthcare providers: In particular, mothers identified healthcare providers who are mandated reporters as particularly high-risk encounters, and at times recommended avoiding them. (U)
	Resistance: Overall, mothers in this sample were highly self-conscious of the public perception and discourse about non-vaccinating mothers. (U)
	Strategies for managing stigma: As mothers share their sense of stigma because of their vaccine choices, social support from their network provides strategies with which to challenge or manage it. (U)

Categories	Findings
	<p>Social capital in the face of stigma: The decision to reject some or all vaccines is often met with criticism from those outside of the mothers' sympathetic networks. Parents who reject recommended vaccines encounter negative feedback from peers, doctors, schools, or even their own family members. (U)</p> <p>Confronting critics: In contrast to those who suggest smiling and keeping quiet, others insist mothers who reject vaccines need to speak out about their choices to educate others. (C)</p> <p>Social networks: Other mothers spoke of feeling isolated by their decision and unable to tell those around them, highlighting the differing experiences of non-vaccinating mothers: Some felt supported and able to build a network, whereas others were alone with their decision. (U)</p> <p>Status loss and discrimination at an interpersonal level. (U)</p> <p>Responding to stigmatization: doing what it takes to defend my child. (U)</p>
2.3 Home-schooling and schooling responsibilities	<p>Interactional negotiations: Some parents found themselves in negotiations with organizational actors, like school personnel and healthcare providers, who challenged their autonomy. (U)</p> <p>On vaccinations and schools. (U)</p> <p>Removing children from school. (U)</p> <p>Interactional negotiations: Negotiating Quarantine: Carolyn's choice to reject vaccines became an issue at the school when an outbreak of rubella was reported. (U)</p> <p>The privilege of vaccine refusal— Homeschooling. (U)</p> <p>Vaccination avoidance behaviour—Avoiding school. (U)</p>
2.4 Forming social networks with like-minded parents	<p>Using social capital to support alternative ways of knowing: Many of the mothers in this study referenced the importance of building a network of other mothers who share their experiences or views. (U)</p> <p>Quest for 'the real truth': Most parents in the study mentioned Facebook groups as a source of sharing with other parents who choose not to vaccinate. (U)</p> <p>Destabilized Habitus: This shift started with a questioning of their current parenting practices (which were similar to other parents in their social group at the time) and a quest for new practices, which were more similar to those in a different social group. (U)</p> <p>Habitus Tug (pull toward an alternative social group with different caregiving practices). (U)</p> <p>Disjunctive Habitus: Her 'habitus tug' was home birth, but she found vaccine rejection to be a jarring fit within the social network she entered—a form of 'disjunctive habitus.' (U)</p> <p>Building credibility: Many of the mothers who shared that they conducted research on vaccinations and vaccine injury indicated that main sources of information included those within the VR/ H community, namely other VR/H parents and advocacy groups. The strength of the VR/H community was cited at times to bolster individual mothers' claims of credibility. (U)</p> <p>Finding new supportive social groups—social contacts. (U)</p>

### ***Category 2.1: Managing Risks and Relationships with Healthcare Providers***

Twelve findings (8 U, 4 C) made up this category that demonstrated how parents actively and passively managed relationships with their children's healthcare providers as part of their care activities related to their vaccine decisions. Parents reported feeling anxious about attending their children's healthcare appointments (Deml et al., 2022; Sythes & Bedford, 2022). They managed relationships in anticipation of unwelcome responses from healthcare providers who disagreed with their choices (Deml et al., 2022; Sythes & Bedford, 2022; Tombs-Heirman, 2009; Tomljenovic et al., 2022; Ward et al., 2018). Passively, parents called healthcare providers in advance to screen for potential disagreements, or to seek those who may share similar holistic perspectives on health (Carrion, 2014; Deml et al., 2022; Tomljenovic et al., 2022). They also avoided contact with clinicians who could be mandated reporters of families with unvaccinated children, or simply did not disclose their choices regarding vaccination (Carrion, 2014; Deml et al., 2022; Tomljenovic et al., 2022; Ward et al., 2018).

Actively, parents reported that they handled their healthcare providers' attempts to persuade them to vaccinate while still maintaining a good relationship with them (Tombs-Heirman, 2009). Others discussed deliberately deceiving healthcare providers regarding their reasons for not vaccinating, forging vaccine medical documents, or bribing them to provide the certificates needed for their children to enter kindergarten (Sythes & Bedford, 2022; Tomljenovic et al., 2022).

Some parents discussed the conflicted feelings they experienced while addressing the demands of healthcare providers (Reich, 2020b). While they felt it was their moral imperative to meticulously and individually manage their children's health as per healthcare providers' expectations, this approach contradicted generic public health vaccination schedules for all

infants and children (Reich, 2020b). Avoidance also meant that parents pursued “self-diagnosis;” they privileged their own knowledge of their child’s illness over a formal medical diagnosis or explanation (Duchsherer et al., 2020). When children did become ill from a VPD and their wellness efforts did not lead to their anticipated outcome, parents felt baffled (Reich, 2020b; Sythes & Bedford, 2022). Despite healthy lifestyle initiatives, they had not thwarted illness and lacked the ability to manage their child’s symptoms without the assistance of the healthcare providers they had made concerted efforts to avoid (Sythes & Bedford, 2022).

When he first became ill, we didn’t worry so much at the start but then we did and we took him to the doctor. That was a horrendous experience with that doctor. He was absolutely terrible. He was blaming me; it was my fault that Billy was ill. He said, “It’s probably measles.” Well, he had no spots. He looked inside his mouth and his tongue was coated white. “Are they Koplick [sic] spots then?” I asked. He said, “Yes” (brusquely). They weren’t. It wasn’t measles. He listened to his chest and told me it was clear! He had pneumonia! It was far from clear! This guy was basing it on pure prejudice. No science behind it all. He was very aggressive with me. He blamed me, for not having vaccinated my child! He wanted to have this long blaming conversation in front of my ill child when it had absolutely nothing to do with it. I mean even if I’d poured boiling water all over this child I wouldn’t expect a doctor to stand there and blame me like that. It made me feel awful (Tombs-Heirman, 2009, p. 144).

### ***Category 2.2: Managing Stigma, Confronting Critics, and Staying Silent***

Seven findings (6 U, 1 C) addressed the ways that parents provided care for their families through managing, avoiding, and preparing for opposition from friends and family members in relation to their vaccine-related decisions (Carrion, 2014; Reich, 2020c; Wiley et al., 2021). Like

the prior category detailing how parents managed relationships with healthcare providers, parents reported both active and passive measures to respond to criticism from friends and family members. Passively, parents described purposely staying silent when the subject of vaccinating came up in conversation amongst their peers (Reich, 2020c; Wiley et al., 2021). Actively, they prepared themselves by acknowledging the stigma in the media and online discourse surrounding parents who choose not to vaccinate and rehearsed how they would manage interpersonal confrontations (Reich, 2020c; Wiley et al., 2021). Some parents took a proactive stance and discussed how they would speak out about their choices openly and confront their critics directly.

I've decided that if anyone should outright attack me, I am going to "baaaa" them. I'm going to just not bother w/justifying myself and just tag them for what they are: "Oh, sheeepy, sheeepy, sheepole, so sad that you're a sheeepy. Baaaaa, baaaaa" (Reich, 2020c, p. 6).

I'm actually having a hard time too, especially with sharing our choice if anyone ever asks, most of my really close friends and family just respect it and leave it alone (maybe secretly think we are nuts, but i'll take that) ... I'm tired of feeling nervous or anxious about this conversation coming up with play groups or new friends, parents who may be uncomfortable, or attack me because "their kid is in danger" (Reich, 2020c, p. 5).

### ***Category 2.3: Home-schooling and Schooling Responsibilities***

Six findings (6 U) were combined to form this category that demonstrated parent's care activities related to their children's schooling. After declining all or some vaccines for their children, parents discussed their choice to home-school for varying reasons (Thornton & Reich, 2022; Tombs-Heirman, 2009; Reich, 2020b). Some parents were forced to because of laws that restrict unvaccinated children's access to public schools (Thornton & Reich, 2022; Reich,

2020b). Others removed their children from school out of fear that their children would catch a VPD from newly vaccinated children, whom they considered potentially infectious (Tombs-Heirman, 2009). Parents also avoided or removed their children from school due to concerns surrounding scrutiny or stigma from staff and students towards their family due to their choices (Tomljenovic et al., 2022; Reich, 2020c).

Some parents discussed the fact that home-schooling unvaccinated children was a benefit enjoyed by white, privileged parents with the resources to enact this choice (Thornton & Reich, 2022). Families of Colour who declined vaccines for their children and experienced inequalities, lacked the benefits of a legally permissive environment enjoyed by those whose privileges facilitated both vaccine choices and schooling options (Thornton & Reich, 2022). Finally, parents of unvaccinated children reported that sending their children to school meant they may face a challenge to their autonomy as parents to direct their children's health choices. School personnel and parents were feared to be potential organizational actors who could force their children into a mandatory quarantine in the event of a VPD outbreak (Reich, 2020b; Thornton & Reich, 2022; Tomljenovic et al., 2022).

She recalled, "So I went to the field trip and there was two nurses that were mothers of the kids in the class and so they went and called the health department to send me home. And when they did, they tacked something on my door that said we're quarantined for a week." Carolyn saw this gesture as an effort to humiliate her and force her to acquiesce to state agencies promoting vaccines. "They knew themselves that I was not any more contagious than anybody else. It just—we did not comply, so we got spanked" (Reich, 2020b, p. 119).

#### ***Category 2.4: Forming Social Networks with Like-minded Parents***

Seven findings (7 U) made up this category that collectively addressed how parents form social networks with their peers who have also chosen not to fully vaccinate their children (Attwell, Meyer, & Ward, 2018; Duchsherer et al., 2020; Helps, et al., 2019; Reich, 2020c; Sythes & Bedford, 2022; Wiley et al., 2021). Parents described their engagement with like-minded peers, both in-person and online, who supported and informed their new/alternative health-related practices (Helps, et al., 2019; Sythes & Bedford, 2022; Wiley et al., 2021). Parents found that choices in birthing and lifestyle naturally led them to social groups who also refused and questioned vaccines (Attwell, Meyer, & Ward, 2018; Reich, 2020c). Within these communities, parents sought to establish their credibility as an informational source for others who refused or felt hesitant about vaccines (Duchsherer et al., 2020). While some parents felt uncomfortable with the inherent link between birthing choices, alternative lifestyles, and anti-vaccination, others appreciated the support they received in maintaining their lifestyle choices and gaining a further source of vaccine-related information (Attwell, Meyer, & Ward, 2018; Helps, et al., 2019; Reich, 2020c; Sythes & Bedford, 2022).

I actually ended up living close to kind of a small mommy group, like walking group ... [One woman in it] didn't vaccinate her baby and he was 24 months old when I first met her. And what she did was she had these, I guess it was like some kind of drops, like vitamin drops or whatever, and something else ... And then she also took him to the chiropractor once a month, which I think is crazy. Like taking a baby to the chiropractor? Like do they really need—like they have such flexible joints anyway but she's like, "No, it really helps and, you know, that affects everything in their body." So yeah, I definitely listened to what she had to say ... (Reich, 2020c, p. 4).

### **Synthesized Finding 3: Parental Care Strategies at the Systems-level: Challenging Societal Discourse and Institutional Work Processes**

This meta-synthesis was created from two categories and 19 findings reflecting the broadest scope of parents' care activities for their children in response to their decision to not fully vaccinate. Parents discussed how they would work to protect both their choices and their families' overall well-being from real and perceived punitive measures directed towards them by governmental agencies. Parents approached this by planning next steps, namely describing what they would do if penalties became too overwhelming. They also reported their efforts to stand their ground and challenge societal discourses that undermined their rights as parents to take ownership of their children's health along with pushing back against systems-level punitive measures.

**Table 6**

*Synthesized Finding 3: Parental Care Strategies at the Systems Level:  
Challenging Societal Discourse and Institutional Work Processes*

Categories	Findings
3.1 Challenging societal discourses and institutional policies	Holding my ground: Concerns were expressed about further punitive measures that may be imposed upon families who continued to decline vaccination. (C)
	Decentering medical care: "These networks extend social capital to members who aim to reconceptualise vaccine-preventable diseases in ways rejected by allopathic medicine. (C)
	Reactance to system inflexibilities: Elements of psychological reactance were evident in these parents' accounts when their desire to make the best decision for their child was met with inflexibility in the immunisation schedule or health system. (C)
	Vaccine avoidance behavior—Moving out. (C)
	Advocacy: Mothers in this dataset seemed to feel a personal responsibility to spread the word about the dangers of vaccination and suggested specific platforms for sharing this message. (U)
	Finding new supportive social groups—reacting to stringent government policy: Relatedly, some informants described

Categories	Findings
	<p>reacting to the more stringent government policies by doubling down on their resolve and becoming more vocal and engaged with like-minded people. (U)</p> <p>Parental activist blogging: 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 healthcare for her family. (U).</p>
3.2 Managing punitive measures at the systems-level	<p>Minimising impact of the “No Jab; No Pay” policy: Families who were currently, or expecting to be, affected by the inability to lodge exemptions and receive family tax benefits and child care subsidies had to re-evaluate how to manage financially without this assistance. (U)</p> <p>Ownership of child's health: Having the ability to take ownership of their child's health emerged as a strongly communicated consideration among parents in both informant pools. (U)</p> <p>Refusal and the risk of state sanctions— Avoiding Child Protective Services (CPS). (U)</p> <p>Refusal and the risk of state sanctions—Signing exemptions. (U)</p> <p>The privilege of vaccine refusal—Getting childcare. (U)</p> <p>Refusal and the risk of state sanctions—Impact on social programs. (U)</p> <p>Vaccination avoidance behavior—Informed consent: In regard to the consequences of avoiding vaccination, some parents experienced being asked to sign an informed consent about the refusal, being referred to a talk with an epidemiologist, or being legally prosecuted, as well as receiving financial fines and not being able to enroll the child into kindergarten. (U)</p> <p>Strategizing interactions with the state: Parents—both those who have permitted some and those who have rejected all vaccines—laboriously manage information about their children’s care for fear of jeopardizing claims to an exemption. (U)</p> <p>Claiming a right to know: ... all states have some legal mechanism for opting out of vaccinations while maintaining access to schools or childcare settings. (U)</p> <p>Crafting claims to exemptions. (U)</p> <p>Challenging state power. (U)</p> <p>Status loss and discrimination at a systemic level: In these parents’ accounts, systemic status loss was experienced as differential treatment of their families, through policies excluding unvaccinated children from early childhood education and federal financial assistance. (U)</p>

### ***Category 3.1: Challenging Societal Discourses and Institutional Policies***

Seven findings (4 U, 3 C) were combined to form this category. Parents expressed an intention to emigrate from the country they reside in if system-level restrictions were imposed upon their family or exclude themselves from public schooling if restrictions did not allow for their children to attend (Helps, Leask & Barclay, 2018; Helps, et al., 2019; Tomljenovic et al., 2022). Parents pushed back and challenged societal discourses that questioned their rationale by reconceptualising VPDs as strengthening to the body rather than harmful (Reich, 2020c). They established roles as advocates for vaccine choices and informed consent and blogged about parental rights on online public platforms, sometimes this was at a risk of their family's safety being threatened by "pro-vax" people (Duchsherer et al., 2020; Haarstick, 2021; Wiley et al., 2021). Parents provided information and affirmations about their choice and tried to change the way people think about VPDs, as something not to fear and potentially beneficial for children's health (Duchsherer et al., 2020; Haarstick, 2021; Reich, 2020c; Wiley et al., 2021).

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 (Haarstick, 2021, p. 48).

### ***Category 3.2: Managing Punitive Measures at the Systems-level***

Twelve (12 U) findings illustrated how parents protected their vaccine decisions and their families by addressing perceived and real risks from government agencies that threatened their

access to schools, childcare, financial assistance, and nutritional programs (Ejuma, 2019; Helps, Leask & Barclay, 2018; Reich, 2018; Thornton & Reich, 2022; Tomljenovic et al., 2022; Wiley et al., 2021). Some of the parents described being subjected to fines related to not vaccinating their children (Tomljenovic et al., 2022). Concerningly, parents worried that their unvaccinated children could be apprehended by child services (Thornton & Reich, 2022). Care activities that parents enacted for their children involved filing exemptions and managing household finances; namely cutting back in response to the loss of family tax benefits and nutritional social programs (Ejuma, 2019, Helps, Leask & Barclay, 2018; Reich, 2018; Thornton & Reich, 2022; Wiley et al., 2021). Parents reported being cautious about signing vaccine exemption forms in order not to make their family visible to state agencies along with avoiding surveillance from child protective services (Thornton & Reich, 2022). They also struggled to find childcare due to providers not accepting non-medical exemptions and because of a decrease to financial resources (Helps, Leask & Barclay, 2018; Thornton & Reich, 2022; Wiley et al., 2021). Finally, parents discussed consequences of avoiding vaccination that included being referred to speak with an epidemiologist, sign an informed consent form about their refusal, or being legally prosecuted (Tomljenovic et al., 2022).

The first report was at the hospital, I had to sign a paper which said I refuse to vaccinate and that I am informed about the benefits of vaccines (...) After a few weeks, I got a call to go to an informative talk with the epidemiologist, so the doctor can talk to me “about vaccines” and that I get better acquainted. She turned us in to the sanitary inspector, who is by duty obligated to file a court lawsuit, by which we get a fine, and you can get a fine for every vaccine you decline (Tomljenovic et al., 2022, p. 6217).

## Discussion

Our research team's qualitative systematic review was conducted to better understand the care activities of parents who aimed to enhance their children's health after declining vaccines. Our synthesized findings were formed as meta-syntheses that revealed how parents' care activities extended into three broad contexts, within the home, in the community, and at the societal level. Forty reports including 33 published articles (Atasever et al., 2021; Attwell et al., 2018; Attwell, Meyer, & Ward, 2018; Blaisdell, et al., 2016; Brunson, 2013; Byström et al., 2014; Deml et al., 2022; Duchsherer et al., 2020; Gross et al., 2015; Harmsen, 2013; Helps, Leask & Barclay, 2018; Helps, et al., 2019; Hsu, et al., 2023; Kuan, 2022; Martinez-Diz et al., 2014; Nurmi & Harman, 2022; Reich, 2014; Reich, 2016; Reich, 2018); Reich, 2020b; Reich, 2020c; Sobo et al., 2016c; Sumengen et al., 2021; Sythes & Bedford, 2022; ten Kate et al., 2021; Thornton & Reich, 2022; Tomljenovic et al., 2022; Ward et al., 2017; Ward et al., 2018; Wiley et al., 2020; Wiley et al., 2021; Wiley et al., 2022; Zin et al., 2022), four master's theses (Fallet, 2017; Haarstick, 2021; Tombs-Heirman, 2009; Vandenberg, 2013), two doctoral dissertations (Carrion, 2014; Ejuma, 2019), and one book chapter (Nurmi, 2021), that detailed thirty research studies, were included in this review.

Parents from 14 countries provided illustrations to researchers that examined their contributions through qualitative approaches and methods for data collection and analysis. We interpreted the level of the evidence, using ConQual, to be high for one of the synthesized findings (Parental Care Strategies in the Community), and moderate for two of the synthesized findings (Parental Care Strategies in the Home and Parental Care Strategies at the Systems-Level). Our credibility ratings of the 115 findings included 88 that were unequivocal and 27 that were credible. The findings of our review provided rich and insightful perspectives surrounding

the labourious care activities parents engage in to protect their family's health while safeguarding their right to make decisions about their children's vaccine status.

### ***Controlling Vaccine-Preventable Disease Exposure***

The process of completing our qualitative systematic review revealed unexpected information about parents' care activities that challenged our team's pre-emptive expectations about how they control exposure to VPDs. As described previously, we approached this systematic review with two underlying assumptions. First, that parents' care activities would only be detailed in their descriptions of the hands-on work they did for their children within the home. Secondly, that parents' care activities would only include what they did to reduce their children's exposure to VPDs.

When our team asked the review sub-question: "How do parents control their young children's exposure to vaccine-preventable communicable diseases?" (Huel et al., 2022), we anticipated that parents would report trying to avoid or lessen the risk of their child contracting a VPD. While findings related to home-schooling (Tombs-Heirman, 2009), ongoing information seeking about VPD outbreaks (Helps, et al., 2019), and reducing VPD risks by controlling children's social exposure (Reich, 2014) did substantiate our assumption, eleven findings also described how parents pursued VPDs based on beliefs that it would improve their children's health and immunity (Fallet, 2017; Martinez-Diz et al., 2014; Nurmi & Harman, 2022; Vandenberg, 2013). This finding alerted our team to discuss and determine if this review was meant to demonstrate parents' care activities from their perspectives of what is healthy, or if it was aligning with our teams' assumptions about what they would do to enhance children's health after declining vaccines. Taking up the standpoint of parents who did not fully vaccinate their children meant that other forms of work they described in the research (Smith, 2005), outside of

the home context, would need to be considered in order for our team to effectively answer the systematic review research questions.

### ***Focusing on Parents' Care Activities***

CH, as the project lead on this review team, was inspired to pursue her doctoral research topic on parental care activities from her experiences in family nurse practitioner practice. She has worked closely with parents and caregivers who did not fully vaccinate their children, but noted the positive health choices and pursuits they engaged in for their family's benefit. Parents and caregivers were enthusiastic to share their experiences of their care activities with her. Two studies in this review also demonstrated that parents were happy and engaged to shift from descriptions of decision-making, becoming hesitant or refusing vaccines, to providing illustrations of the work they do for their family's health (Haarstick, 2021; Ward et al., 2017). CH contemplated what it was like to work very hard at enhancing your children's health, yet still be called negligent, anti-vax and misinformed. She also wondered why allopathic medicine, pharmaceutical companies, and government-led public health programs had become so untrustworthy to some parents, when some profit-driven natural health/CAM companies and providers still enjoyed the trust of many parents who refuse vaccines.

Interestingly, the lack of direct focus on parent's care activities after declining vaccines was echoed in the studies we included in this review. Nine of our studies initially endeavored to explore parents' care activities. However, findings directly related to this were often spontaneously reported by informants in research that began with a focus on a different phenomenon of interest (Brunson, 2013; Ward et al., 2017; Wiley et al., 2021). The care activities that parents engaged in found its way into research that was meant to explore their decision-making and perceptions surrounding vaccines. It served as empirical evidence of their

efforts to respond to their decisions about vaccines, by enhancing their children's health and protecting their rights, rather than just explaining their reasoning. Parents' descriptions of their care activities shifted the focus away from contestable topics related to immunization risks and re-routed the issue towards examples of how they are committed to their children's health through other modalities instead of vaccines (Haarstick, 2021; Ward et al., 2017). This aligns with recommendations from research that encourage an exploration of vaccine refusal from a positive, salutary, generative pole in order to ask better research questions about social and cultural lives (Sobo, 2016a).

Utilizing an Institutional Ethnography (IE) lens to bring forward the examples of parents' care activities or work from qualitative research, was considered a necessary paradigm shift for our research team (Sobo, 2016a; Ward et al., 2017). Parents' efforts rose to the forefront, rather than their rejection or their steps in refusing. Our team tried to stay as close to the illustrations that parents gave, while understanding that the extracted themes (findings) from research could also provide descriptions of parents' care activities. This is not a critique of qualitative thematic analysis, or concept development. Rather, it reflects our specific intent to use an IE lens, drawing attention to the embodied experience of parents' care activities as they happened. A wish to place focus on parents' strengths, both in practice and in research, was foundational to our team's approach.

### ***The Impetus of Parents' Care Activities***

A thought-provoking component of our systematic review were the discussions amongst our research team surrounding the onset of care activities in relation to the decisions parents made about vaccinating. One of the included review studies drew our attention to the reality that care activities related to health, that involved natural living, exercise, diet, and birth practices had

preceded some parents' decision not to vaccinate their children (Attwell, Meyer, & Ward, 2018). Namely, if a person was already engaged in these activities before pregnancy, some element of that activity(ies) could lead them to decline all or some vaccines and continue with these care activities for their children's health afterwards. The care activities parents discussed may not actually be a response to their vaccine decision and more closely linked to their perceptions about health and risk before having children.

Researchers have detailed how the neoliberal rise of the modern-day health consumer, empowered to enact choice to direct their own health, has impacted what constitutes good parenting (Hamilton, 2016; Steiner & Bronstein, 2017). Notions of "good parenting" have compelled parents (predominantly mothers), towards enacting a style of raising children that is emotionally absorbing, labour-intensive, and financially expensive (Hays, 1996). Of the studies that provided demographic information about the gender of the informants, more than 85% (n=324) of the 380 informants included in our systematic review identified as mothers, with the remaining 15% (n = 56) identifying as fathers. The predominance of mother's role in good parenting and making health decisions is also reflected in studies indicating that vaccine decisions, hesitancy, and refusal are gendered issues situated in predominantly maternal terrain (Thornton & Reich, 2022); Reich, 2014).

"Intensive mothering" or more specifically, intensive parenting strategies related to health and well-being have become the predominant norm in North America and are closely associated with natural parenting (Minnotte, 2023), breastfeeding (Avishai, 2007), consumptive behaviours (MacKendrick, 2014), and decisions about vaccines (Reich, 2014; Steiner & Bronstein, 2017). However, the introduction of neoliberal ideals into parenting does not necessarily begin with childbirth. Care expectations related to "intensive mothering" arising from neoliberal ideology

have been shown to be present in the practice of nurses, midwives, and birth workers who shape mothers' identities towards self-sufficiency and individual responsibility before their children are even born (MacKinnon, 2006; McCabe, 2016). Research that is unrelated to vaccination but has explored mother's work in caring for their children to avoid chemical toxins, sheds some light on the context in which parents anticipate and address threats to their children's health (MacKendrick, 2014). This research has detailed how "precautionary consumption" is used to mediate children's exposure to chemicals found in food, consumer products, and the home (MacKendrick, 2014). It represents a costly burden of caregivers' time and money in order to mitigate environmental degradation that is occurring as a larger social problem outside of mother's control (MacKendrick, 2014). From our review "Category 1.2: Living healthy, natural lifestyles" (p. 24), illustrated precautionary consumption activities used by caregivers to eliminate the influence of toxins on their children's developing bodies (Carrion, 2014; Ejuma, 2019; Kuan, 2022; Reich, 2014; Tombs-Heirman, 2009). Parents also described the additional costs of this time-consuming approach to avoiding environmental toxins in household products and foods for their children's health (Attwell, Smith & Ward, 2018; Carrion, 2014).

Precautionary consumption is reflective of how parents try to mitigate risk to their children's health in the home. However, this work is also enacted in healthcare settings, where parents are encouraged to take on the responsibility of questioning some of the advice they receive from healthcare providers. A researcher from the University of British Columbia, Dr. Devon Greyson (2019), has identified that changes to healthcare and the activation of patients to become empowered, medically informed, and involved in their health, may be sending mixed messages to the public. On the one hand, shared decision-making and consideration of personal preferences could improve health outcomes. This has led to public health campaigns encouraging

“activated patients” to question their primary care provider about the safety and necessity of antibiotic prescriptions, out of a fear of ongoing anti-microbial resistance (Greyson, 2019). However, activated patients experience “the activated patient paradox” where they are expected to be empowered and informed about some topics related to their health, but unquestioningly follow medical advice about routine infant and childhood vaccines.

This paradox was reflected in papers included in this review that illustrated parents’ confidence and self-advocacy skills in questioning their healthcare provider’s diagnosis and treatment choices for their children (Deml et al., 2022; Reich, 2020b; Tombs-Heirman, 2009). Parents also strived to reconceptualise vaccine-preventable disease in ways that are rejected by allopathic medicine, by reframing VPD infection as a way to strengthen the body and extended this message through social networks to decrease members’ fears about illnesses (Reich, 2020c). Some parents progressed to avoiding healthcare providers altogether, determining their own diagnoses and treatment regimens to support their children’s health (Duchsherer et al., 2020; Haarstick, 2021). Illustrations from the review papers both reflected how activated parents were in taking control of their children’s health, and also demonstrated the reactions from healthcare providers who responded to their vaccine choices by blaming them for illnesses unrelated to VPDs (Tombs-Heirman, 2009), calling them an “unfit mother” (Deml et al., 2022), and a terrible, irresponsible mother (Sythes & Bedford, 2022).

As described above, neoliberal notions of health empowerment and responsibility have had a marked influence on activating patients, “intensive mothering practices,” and “precautionary consumption activities.” These influences have been shown to impact people’s beliefs about health, risk, and responsibility, even before they become parents; therefore, our research team was left with the question: What came first, the “responsibility” to live a natural

lifestyle to circumvent the risk of harms like toxicity, or the decision not to vaccinate? In many of the included review studies, parents framed vaccines and other allopathic medical treatments as toxins in their own right (Carrion, 2014; Ejuma, 2019; Reich, 2020b; Reich, 2020c). More concerning, we questioned if there are an assortment of health beliefs, practices, and expectations, exalted by health and government institutions, that naturally lead parents towards the choice to not vaccinate their children, while at the same time authorities are recommending or mandating them to do so.

### ***Self-care Activities and Mistrust as the Gateway to Vaccine Refusal?***

Engaging in self-care activities related to improving personal and family health and birthing has also been linked to parents feeling hesitant about or refusing vaccines. Researchers have suggested that experiences of childbirth self-advocacy in prenatal education and adherence to alternative diets (vegan/vegetarian, non-GMO, and organic) have a relationship to subsequent vaccine refusal (Dolin, 2022; Reich, 2020a). A recent meta-synthesis examined articles that detailed the key elements involved in childhood vaccine hesitancy (Crescitelli et al., 2020). The authors condensed their findings to categories that were directly related to vaccines and VPDs; for example, *perceived risk of target diseases* and *perceived risk of the vaccines*; they also had categories that were related to vaccine hesitancy, but not necessarily linked to the vaccines themselves (Crescitelli et al., 2020). These categories included mistrust towards health/pharmaceutical institutions, mistrust towards healthcare provider competencies and integrity, beliefs about childhood immunity, and “a life without toxicity” (Crescitelli et al., 2020). The categories included examples like, breastfeeding, avoiding chemicals and toxicity, and suspicions about the relationship between government and the pharmaceutical industry. Beliefs

surrounding these key elements of vaccine hesitancy, could have likely proliferated well before a parent considers whether to vaccinate their children.

In recent years, people are inundated by media reports about unethical pharmaceutical practices, toxic drug-supplies, the opioid-misuse epidemic, and environmental spills of toxic chemicals into water supplies. The contributions of the governments, economic systems, and the petroleum industry to climate change with an increasingly evident impact on human health also raises questions about how trustworthy these institutions are and may give rise to beliefs about the benefits of natural living to avoid “contamination” and the decision not to “inject toxins” into one’s children. For this review, we chose to keep our focus on the care activities that informants reported as being directly linked to their vaccine decisions rather than examining an overall lifestyle approach. However, we were intrigued by the possibility for further research that could examine if vaccine-related decisions for young infants and children begin well before pregnancy and childbirth and are associated with adherence to dietary and lifestyle choices, and with a lack of trust towards allopathic healthcare providers, public health programs, pharmaceutical companies, and governmental leadership. While these factors contributed greatly to the informants’ articulation of their vaccine choices in our review, we focused on a goal of enhancing healthcare providers’ understanding of how much work these parental caregiving activities entail (Attwell, Smith & Ward, 2018; Carrion, 2014; Deml et al., 2022; Duchsherer et al., 2020; Helps, et al., 2019).

People’s efforts to improve their health and avoid environmental contamination, despite being linked to vaccine avoidance, are largely considered positive health attributes that are encouraged by allopathic and naturopathic providers alike. Healthy eating, breastfeeding, exercise, avoiding unnecessary use of antibiotics, avoiding foods and drinks that contain

preservatives, excess sugar, and artificial ingredients—these are part of a repertoire of health recommendations that permeate all levels of healthy living education. Whether it's one-one-one with a healthcare provider, or as part of a social media public health announcement, the actions and concerns of parents who refuse vaccines are not fundamentally different from the health advice provided to all. With respect to this notion, healthcare providers are challenged to come to terms with an association between lifestyle, birthing, and infant feeding choices that are both beneficial for health, and inherently linked to mistrust of allopathic medicine, government, industry, and the perceived need for people to protect their health through avoiding vaccines.

### ***Toeing the Neoliberal Line While Fighting Stigma and the Threat of Penalties***

Findings related to parental care activities in the home, the “hands-on” work of caring for children’s health and illness, made up most of the findings in this review. However, parents’ negative experiences, or the risks of providing these care activities, were most clearly articulated in studies whose findings contributed to the community and systems-level synthesized categories. Parents often framed their commitment to care activities within the home in a positive light. They reported that quitting their work outside of the home, cooking, growing their own vegetables, and tuning into their children’s health, as a beneficial change to their lives, rather than a work-intensive health project (Blaisdell, et al., 2016; Carrion, 2014; Harmsen, 2013; Kuan, 2022; Reich, 2014; Tombs-Heirman, 2009; Ward et al., 2017; Wiley et al., 2020). Three studies touched upon informants’ financial stress of providing natural, health foods and complementary and alternative modalities for their children (Attwell et al., 2018; Carrion, 2014; Haarstick, 2021). However, the emotional and financial stresses that parents most frequently reported experiencing was related to managing stigma they experienced from friends, family, and neighbors (Reich, 2020c; Wiley et al., 2021), anticipating and experiencing negative reactions

from healthcare providers (Carrion, 2014; Deml et al., 2022; Sythes & Bedford, 2022; Tombs-Heirman, 2009), and when trying to protect their family from punitive government penalties (Reich, 2018; Thornton & Reich, 2022; Tomljenovic et al., 2022; Wiley et al., 2021). This was where emotional labour and care activities merged to demonstrate a palpable toll of anxiety, fear, anticipation, and social isolation.

Parents responded to this emotional and financial stress in different ways. What was clear from the findings was that harsh punitive penalties, or the threat of them, was not met with parent's adherence to vaccine schedules. Instead, parents alone, or in consultation with like-minded peers, strategized about how to get around mandates. Their actions included avoiding healthcare encounters (Thornton & Reich, 2022; Tomljenovic et al., 2022; Ward et al., 2018), lying to healthcare providers (Tomljenovic et al., 2022), bribing providers (Tomljenovic et al., 2022), and falsifying vaccine documents (Tomljenovic et al., 2022). At the systems-level, parents learned how to craft exemption claims (Ejuma, 2019; Reich, 2018), they managed financial hardship due to loss of federal assistance (Helps, Leask & Barclay, 2018; Thornton & Reich, 2022; Wiley et al., 2021), and paid fines (Tomljenovic et al., 2022). The studies that reported on parents' reactionary and anticipatory care activities to protect their vaccine decisions lends evidence to the reality that vaccine mandates may not work—parents who are committed to their decision will find ways to avoid both vaccinating their children and punitive penalties; even if it means that they need to move their family to a different country (Helps, Leask & Barclay, 2018; Helps, et al., 2019; Tomljenovic et al., 2022).

While reflecting on the research that describes intensive mothering and vaccine refusal, and the findings of this review that demonstrate the unwavering focus parents have on their children's health, the informants in this review represent a neoliberal societal and governmental

ideal in parenting. If governments and health systems are aiming for parents to take charge of their children's health, evaluate risks, self-sufficiently fund healthy lifestyles and CAM, avoid costly hospital visits, homeschool, and independently educate themselves about health and wellness—those who decline or refuse vaccines for their children represent model citizens. Regardless of the care activities parents enacted for their children's health, because of their choice to not fully vaccinate, they are paradoxically engaged in a laborious health project for their children, while simultaneously pushing back against the institutions that threaten their right to decline vaccines but have encouraged their empowerment to independently make health choices in the first place.

### ***Intersectional Oppressions for Parents who Refuse Vaccines***

Being judged as a parent at a time where 'intensive mothering' practices have become the norm in child rearing is challenging, but relatively easy when you are financially stable and can avert institutional gaze. Notions of "good mothering," despite the physical, financial and emotional costs, have been shown to influence institutional birth and breastfeeding policies that are used to evaluate all families regardless of the inequities they experience (Hamilton, 2016; Minnotte, 2023). Parents who can homeschool or send their children to private schools that don't enforce vaccine mandates, who can live on one salary while one parent stays home, and who are not dependant on government financial assistance or programs can live unencumbered by risks of penalties that other parents face.

Studies in our review that included parents who were economically advantaged indicated that they did experience stigma and social isolation from members of their community based on their vaccine decisions (Reich, 2020c; Wiley et al., 2021), however, they were able to maintain their choices without fear of governmental punitive interventions. Parents who were

economically or racially marginalized would face the same stigma, yet their illustrations placed more focus on care activities needed to thwart punitive measures.

Two papers in this review brought the realities of gender-based, economic, and racially marginalized people to our attention, demonstrating that vaccine refusal amongst some parents added another intersectional barrier to those already struggling with discrimination (Helps, Leask & Barclay, 2018; Thornton & Reich, 2022). In one study, parents considered dropping out of university, taking their children out of daycare to reduce costs, and asking family for assistance in order to address the loss of government financial assistance due to their vaccine decisions (Helps, Leask & Barclay, 2018). In another study that explored the experiences of Black mothers in the United States who declined vaccines for their children, the reactionary measures were extraordinarily stringent (Thornton & Reich, 2022). Unlike some of the parents in the other review studies that strategized on how to complete vaccine exemptions to get their children into public school (Ejuma, 2019; Reich, 2018), mothers in this study who experienced gender-based, economic, and racial discrimination, avoided signing exemptions in order to avoid making their family visible to state agencies (Thornton & Reich, 2022). The mothers negotiated loss of public assistance eligibility to supplemental nutritional programs, childcare, and healthcare access (Thornton & Reich, 2022). Well-child visits were missed in order to avoid healthcare providers who may be mandated reporters of their vaccine status, to minimize the risk of state intervention (Thornton & Reich, 2022). Black mothers in this study frequently mentioned the risk for state surveillance through Child Protective Services (CPS), whereby homeschooling, home birthing, or declining vaccines could be deemed child maltreatment by social workers who subjectively made determinations relying heavily on assumptions about race and gender (Thornton & Reich, 2022). Mothers in this study lamented the freedoms that white parents had in their State to make

autonomous vaccine decisions due to their ability to homeschool their children (Thornton & Reich, 2022).

Choosing not to vaccinate their children led mothers in this study to be discriminated against for their decisions, on top of the other intersecting axes (racial, gender, poverty) they embodied. Their experiences are shrouded by a prevailing consideration regarding the issue of parents declining vaccines for their children. Many of the informants in the review studies reported their feelings of mistrust towards government. However, amongst parents who are Black, Indigenous, or People of Colour, and/or belong to diverse gender identities, gender expression and/or sexual orientation communities and have experienced racism and systematic discrimination by people and programs that represent governments, a greater reason exists not to trust vaccination programs recommendations originating from the institution(s) that have subjugated them. Other research has indicated that policies to address conscientious objection to immunisation disproportionately affects lower income families, particularly single-mothers, leaving socio-economically advantaged parents free to exercise their vaccine choices (Glassman & Czymzak, 2022; Li & Toll, 2022).

Historical and modern-day precedence form a deeper-seeded consideration about what it means to trust governments in making the best suggestions for your children's health. When your experiences and history demonstrate evidence to the contrary, parent's mistrust is justified and understandable. Researchers exploring mothers' perceptions of childhood immunizations in First Nations Communities of the Sioux Lookout Zone in Canada, found that Elders in the community had anti-immunization beliefs because of experiencing forced vaccination and a lack of trust in the healthcare system was due to negative experiences (Tarrant & Gregory, 2001; Tarrant & Gregory, 2021). Other studies that have looked at COVID-19 vaccine hesitancy amongst

Racialized Minorities and Indigenous Peoples have noted that it stems from a long history of medical experimentation, structural inequities in government institutions, forced or coerced sterilisation, residential school experiences, and unethical research by institutions that promote vaccination (Mosby & Swidrovich, 2021; Opel & Peek, 2021).

There is no doubt that awareness of the stigma already experienced by parents who belong to Racialized and/or marginalized communities, and choose not to vaccinate their children, is important for improving health services. Further research exploration could be helpful to foster healthcare providers' understanding of these health experiences from the standpoint of this group of parental caregivers. However, research would need to proceed in a culturally safe manner; directed by, in collaboration with, supported, and agreed upon with communities that have experienced historical and present-day injustices. A topic like vaccine hesitancy in Racialized and marginalised communities of parents, that is so strongly connected to institutional power, and the risk for punitive penalties, would need to proceed in a respectful and collaborative manner that doesn't perpetuate further stigma or additional family work to avoid sanctions.

### ***Rarely a Final Decision***

Regardless of when parents made their decision not to vaccinate their children, the findings of this review suggested that it is rarely a one-time, final decision on the matter. Of the review studies that reported on their informant's vaccine decisions, most parents had given some, but not all vaccines. Although some parental caregivers completely refused all vaccines for their children this choice was not reflective of most parents. The findings that made up Category 1.1: Ongoing information seeking (p. 86) indicated that after making an initial decision not to vaccinate their children, parents continued to contemplate the circumstances and evidence that

would change their mind (Blaisdell, et al., 2016; Carrion, 2014; Helps, et al., 2019; Reich, 2020b; Sobo et al., 2016c; Sythes & Bedford, 2022; Ward et al., 2017; Ward et al., 2018). Parents discussed new evidence about vaccines (Brunson, 2013; Carrion, 2014; Sobo et al., 2016c; Sythes & Bedford, 2022), family member's health or choices making them vulnerable to VPDs (Fallet, 2017; Reich, 2020b), and VPD outbreaks (Helps, et al., 2019; Ward et al., 2017), as reasons for why they may reconsider their decisions. This finding replicates what other researchers have determined about how parents make vaccine decisions, in that vaccine uptake resides on a continuum (Piltch-Loeb & DiClemente, 2020). In this review, information, circumstances, and children's health status determined parents' decisions about their children's vaccine uptake. The ongoing information seeking process parents engaged in, as a care activity, seemed never-ending as the parents frequently questioned whether or not they had made the correct decision (Brunson, 2013). This indicates an inroad or path for exploration, that healthcare providers who maintain respectful relationships with families who decline vaccines, can re-engage, discuss, and provide support.

### ***Limitations of the Review***

The following limitations should be taken into account when considering the findings of this review:

1. Due to resource limitations, studies published in languages other than English could not be included in this review.
2. Most of the studies, except for Australia, were located in the Global North. Our findings might not be reflective of experiences in Africa, Eastern Europe, and South America.

3. Exclusion of studies that discussed vaccines for older children, namely the human papilloma virus (HPV) vaccine, the seasonal influenza vaccine, and the COVID-19 vaccine, that could have also detailed parents' care activities.
4. The included studies reported varying amounts of demographic information about informants, some only referred to them as "parents." This made it difficult to adequately describe the informants who discussed their care activities. However, some authors reported that informants felt more comfortable having less information shared about them due to fears about anonymity and their choices about vaccines.
5. Many studies reported on parents' care activities but did not focus specifically on it as its phenomena of interest. Findings were found from careful reading of reports that described studies that explored other topics related to vaccine hesitancy.

## **Conclusions**

The following table presents a summary of the three synthesized findings from this review.

**Table 7***Summary of Synthesized Findings*

1: Parental care strategies in the home: Focusing on the individual and family.	2. Parental care strategies in the community: Managing social interactions and community networks.	3. Parental care strategies at the systems-level: Challenging Societal Discourse and Institutional Work Processes.
<p>Parents enacted specific care strategies in the home that were meant to protect their children from vaccine-preventable diseases, enhance their health, strengthen their immunity, and inform their ongoing decision-making about whether their children should be vaccinated. Parents also described how they would care for a child who has contracted a vaccine preventable disease or how they did care for their child(ren) while they were ill.</p> <p>64 findings from 27 research reports.</p>	<p>Parents actively managed, responded to, and anticipated difficult relationships with members of their community who disagreed with their vaccine choices. This included local healthcare providers, teachers/schools, their friends, and family members. However, parents also reached out to like-minded peers to receive support and information to better inform their care activities and gain further knowledge about vaccines.</p> <p>32 findings from 11 research reports.</p>	<p>Parents labouriously worked to protect their vaccine decisions and their families from punitive measures from governmental agencies. In addition, they planned next steps should penalties become overwhelming, and reported their efforts to stand their ground on the topic of vaccinating.</p> <p>19 findings from eight research reports.</p>

Our qualitative systematic review had a moderate to high level of confidence in the findings based on the ConQual analysis. For this review, knowledge about the experiences of parents caring for their preschool children after declining vaccines has been clarified, corroborated, and reinforced. The 30 studies detailed in 40 reports, and 115 findings from 14 countries have provided a rich understanding of the care activities parents do after declining vaccines for their young children to enhance their health and protect their parental rights. The major conclusions of our review highlight the laborious activities that parents enact to care for

their family's health after declining vaccines. Care activities extended from the household and into the community, encompassing a myriad of anticipatory and reactive measures.

Parents demonstrated a strong commitment to their family's health and well-being while responding to stigma they experienced amongst their friends, children's teachers, and healthcare providers. While facing or expecting penalties related to their vaccine choices, parents reached out to likeminded peers for support and planned which next steps to take should punitive measures become overwhelming. Parents also pushed back and challenged societal discourses that questioned their rationale. They established roles as advocates for vaccine choices and informed consent and blogged about parental rights on online public platforms. Some parents provided information and affirmations about their choice and tried to change the way people think about vaccine preventable diseases, as something not to fear but rather potentially beneficial for children's health. Parents' care activities for their children were as intensive as they were invisible to the healthcare providers that placed their focus on the vaccine choices their patients were not pursuing. However, parents' choices to decline all or some vaccines may be linked to perceptions about health empowerment, responsibility and independence that are solidified well before the birth of their children.

### ***Recommendations for Practice and Policy***

The Summary of Findings within this review reported high dependability, and moderate to high credibility of the findings included. Using the ConQual approach (Munn et al., 2014), confidence levels for the synthesized findings were assessed as moderate for Synthesized Findings 1 and 3 that focused on parental care strategies in the home, and parental care strategies at the systems level; but high for the Synthesized Finding 2 that described parental care strategies

in the community. The following practice and policy recommendations have been graded according to the JBI Grades of Recommendations (JBI, 2014):

1. Healthcare providers should maintain their relationships with parents who decline all or some vaccines for their children; parents rarely choose to refuse all vaccines and are actively seeking information about vaccine safety, VPD outbreaks in their community, and the health of their family to determine if they should vaccinate. These are opportunities for healthcare providers to maintain relationships and not assume that parent's decision is final. Ostracizing parents drives them towards like-minded communities that confirm their fears rather than offering support, and divergent advice for them to consider. (Grade A)
2. To foster a relationship with families that is not primarily focused on the rejection aspect of their decisions about vaccines, healthcare providers should inquire about what they do to enhance their children's health. Ask about what informs their care activities and what makes these information sources trustworthy for parents, over other sources of information. Give positive attention and acknowledgement to the work they do for their children's health. (Grade A)
3. Healthcare providers should recognize how anxious and fearful parents are to approach them about their questions about immunizations and when their children are ill, due to differences of opinions about vaccination. Some parents are actively avoiding healthcare encounters, even when their children are very ill for fear of being called negligent or unfit. Parents spend time and effort mentally preparing themselves for healthcare encounters that may seem like a snapshot in time for the provider but leave a lasting impression on parents when they have a negative experience. When parents avoid taking

a sick child to seek medical attention due to fear, a child's health is at risk. Healthcare providers should avoid interactions with parents that might lead them to forgoing needed medical attention. (Grade A)

### ***Recommendations for Research***

Based on study characteristics and limitations, the following recommendations focus on areas for further inquiry as well as methodological approaches.

1. Further research that specifically looks at what parents are doing to enhance their children's health and protect their rights to make vaccine-related decisions, after declining all or some vaccines. Specifically looking at the attributes of the information sources they draw upon to inform their care work. What makes this information more compelling or trustworthy than sources that provide evidence of vaccine safety and efficacy?
2. Further research that pinpoints when information, beliefs, and experiences led people to become hesitant about vaccines and consider declining vaccines for their future children.
3. Further inquiry is needed to examine Racialized and marginalized parents' experiences of declining vaccines for their children using an intersectional lens. This entails exploring the issue of mistrust in parents who's cultural or community's history and experiences with institutional powers leads to greater feelings of mistrust towards health-related recommendations.
4. Nurses who engage in the issue of vaccine hesitancy from a policy and practice perspective should continue to grow their voices in research on this topic. Few academic disciplines have the historical legacy of developing and delivering immunization programs, providing the vaccines to infants and children, and forging relationships with

families and communities. Our understandings are unique and can provide much-needed support to other researchers who are engaged in the topic of why people question vaccine safety, necessity, and efficacy.

## Chapter 4: Meta-Ethnographic Exploratory Synthesis

*Huel, C., MacKinnon, K. A., Bruce, A. & MacDonald, S. E. The everyday experiences of people enhancing their children's health after declining vaccines: An exploratory synthesis. [unpublished manuscript].*

### Abstract

An Institutional Ethnography (IE) approach can provide nurses and other health professionals with a nuanced understanding about the experiences of people who decline routine childhood vaccines for their children. We took the enriching descriptions from a key informant interview and compared them to participants' illustrations from an extensive qualitative systematic review. Our goal was to combine both studies' empirical research illustrations of people's "health work" through a meta-ethnographic exploratory synthesis of their experiences caring for their children. Peoples' choices to decline all or some routine vaccines for their children are not only reflected through their opinions and decisions about vaccines. Our exploratory synthesis demonstrated that people's efforts to enhance their children's health, protect their rights to make choices about vaccines, and navigate difficult relationships with those who disagree with their decision, are made visible through descriptions about what they do. Recognizing peoples' health work can illuminate how institutions within ruling relations can influence the social organization of their everyday experiences related to their vaccine choices. Within a neoliberal political and economic landscape that may seek to subjugate people who refuse childhood vaccines, engaging in this ongoing research provides an opportunity for nurses to recognize people's intensive health contributions and identify possibilities for change at the institutional or ruling level.

*Keywords:* vaccine hesitancy, vaccine refusal, institutional ethnography, meta-ethnography; Canada

## Introduction

People who feel hesitant about or refuse infant and childhood vaccines for their children describe a vast spectrum of opinions, ideas, and fears that eventually influence how they make choices about protecting their family from vaccine-preventable communicable diseases (MacDonald, 2015). The World Health Organization has defined vaccine hesitancy as: "...a motivational state of being conflicted about, or opposed to, getting vaccinated; this includes intentions and willingness" (WHO, 2022). People who are vaccine hesitant and refuse all or some vaccines for their children may have concerns that: vaccines are ineffective and harmful to an infant's immune system and adverse effects from vaccines are under-reported and lack proper healthcare follow-up (Lyren & Leonard, 2006; Nield & Kamat, 2008). They may also believe that supporters of vaccination are motivated by corporate profit margins and will therefore intentionally overlook vaccination dangers (Ward et al., 2018) Finally, people may think that vaccine-preventable diseases (VPDs) are not harmful and provide superior immunity to immunizations and that mandatory childhood vaccine schedules are a violation of civil liberties (Lyren & Leonard, 2006; Nield & Kamat, 2008).

To date, few studies have specifically looked at the activities that people enact to care for their children's health after declining all or some vaccines for them. However, examples of people's efforts to enhance their children's health have been spontaneously elicited in qualitative research studies where the researchers were initially interested in their beliefs and values related to vaccines and VPDs (Reich, 2016; Sythes & Bedford, 2022; Ten Kate et al., 2021; Ward et al., 2018; Ward et al., 2017; Wiley et al., 2022). Research on this topic tends to focus on peoples' perceptions about children's vaccines and how they are formed (Carrion, 2018; Dubé et al., 2016; Mendel-Van Alstyne et al., 2018), or how people make decisions about vaccinating their

children (Austvoll-Dahlgren & Helseth, 2010; Brunson, 2013; Corben & Leask, 2016; Danchin et al., 2018; Sobo et al., 2016). The efforts enacted by people who have chosen not to fully vaccinate, yet enhance their children's health in other ways, are not often explored as a phenomenon of interest in qualitative research. For this reason, we decided to undertake a meta-ethnographic exploratory synthesis of the descriptions shared by a key informant interview and synthesize them with participants' illustrations from a recently completed, extensive, qualitative systematic review (Huel et al., in press). Our key informant had two children, one had received a few vaccines in early infancy, the other had received none. She provided us with an expansive description of her efforts to enhance their health, along with the information sources she accessed to inform the care she provided to her family.

Our exploratory synthesis is representative of an emergent qualitative research project. Due to unforeseen challenges, we were responsive to how we could look at the rich data we had collected in a different way (Bruce et al., 2016; Smith & Griffith, 2022). We began with the intention of completing two separate research projects. First, in a Joanna Briggs Institute (JBI) qualitative systematic review, we looked at qualitative research studies that reported findings on vaccine hesitant people's efforts to enhance their children's health after declining vaccines (Huel et al., in press). Second, we had planned to complete an independent IE approach primary research study, by recruiting informants to investigate people's efforts to enhance their children's health after declining vaccines. However, after completing a fulsome interview with a key informant and facing extensive recruitment challenges, we decided to synthesize our key informant's illustrations from the interview, along with descriptions shared by qualitative research participants from the systematic review, to explore the interesting and relatable accounts of people's activities for their children's health after declining vaccines.

## **Exploratory Synthesis**

The process of completing our meta-ethnographic exploratory synthesis included identifying empirical research illustrations of people's health work for their children in both our key informant interview and those found during our prior systematic review (Huel et al., in press). We used a seven-step process for conducting a meta-ethnography that is discussed further in this paper (Britten et al., 2002; Noblit & Hare, 1988).

Researchers conducting meta-ethnographies typically start their synthesis of different qualitative research findings through identifying the main concepts or themes developed by the study authors (Britten et al., 2002). In qualitative research analysis, first-order constructs are the informant's own words. We use the terms *illustrations* or *descriptions* in this paper to describe their first-order, verbatim accounts. Second-order constructs are the primary author's *interpretations* of the first order constructs, often expressed as themes, concepts, or findings (Toye et al., 2017). Third-order constructs, are reviewer's interpretations of second-order constructs from primary research studies, often seen in qualitative systematic reviews (Toye et al., 2017). For our meta ethnographic exploratory synthesis, we placed our focus on vaccine hesitant participants' first-order constructs, their verbatim descriptions of their efforts to enhance their children's health. We stayed close to participants' descriptions to facilitate awareness about their efforts, from their standpoint. Further discussion of this process is discussed in the methods section of this paper.

## **An Institutional Ethnography Approach**

We used an Institutional Ethnography (IE) approach to both the qualitative systematic review and during our key informant interview, in that we maintained our focus on verbatim descriptions participants provided about the work they did to promote their children's health after

choosing not to fully vaccinate. Dr. Dorothy E. Smith, a Canadian sociologist, founded and developed IE to support researchers in forming a better understanding about the features of contemporary social organization that creates problems for people (Rankin, 2013). IE aims to expand people's knowledge about their everyday worlds that extend beyond understandings that are developed through their routine participation in social relations<sup>9</sup> and their work. Research using IE also aims to develop knowledge of institutional processes and an understanding of ruling relations.<sup>10</sup>

IE is distinct from other research approaches in the way it treats the people who inform the research. Social researchers outside of IE have typically thought of informants' interviews as sources for learning about individual experiences (DeVault & McCoy, 2012). From here, the researcher recognizes the knower's (informant's) location as being biased and looks for themes in what other knowers share about their experience to make sense of what is said, substantiate it, and develop theory about it (Campbell & Gregor, 2002). IE takes up a different approach by treating informants as knowledgeable subjects, experts in their every-day and every-night activities. Research begins by taking the "standpoint" of those being ruled, this is the entry point for the researcher to position themselves in the everyday, expert knowledge of people's activities and work on behalf of those who are experiencing the problems (Bisaillon, 2012).

By treating informants as knowledgeable and taking up their standpoint within the problems that they experience, IE seeks to go beyond merely understanding but to also empower

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<sup>9</sup> Social relations orient the researcher to considering people's doings in local settings as attached to sequences of action that connect them to what others have been doing in other places and different times (Smith, 2005).

<sup>10</sup> Ruling relations refers to a distinctive way that institutions organize society through discourses and textually mediated knowledge practices, not how they are directly dominated (Stanley, 2018).

people. A lack of understanding about how people's everyday experiences are socially organized is quite common. From an IE perspective, people's experiences reveal something about whose interests are being served and therefore reveal issues related to power (Campbell & Gregor, 2002). For our research, we described what people do for their children's health as "health work." The notion of work is central to IE (Smith, 2005), and in this research keeps what people do for their children's health embodied within the experiences they share. It is considered work because their activities take time, effort, and intent, both inside and outside of the home, and require knowledge (Smith, 2005).

Rather than trying to understand the concept of health work and focus on meaning of the term, we left the term "empirically empty" in order to leave space for informants' experiences and to draw our attention to the institutional relations that shape the activities people engage in while enhancing the health of their children (Mykhalovskiy & McCoy, 2002). We wished to draw attention to this workful activity within the actualities it represents, rather than lifting it out of the social practice that it encompasses. Recognizing people's health work can illuminate how institutions within ruling relations can influence the social organization of their everyday experiences—in this case, related to vaccine choices.

### **Getting Started: A Disjuncture**

In IE, a researcher can begin with a disjuncture<sup>11</sup> that they or others have experienced as an impetus to their exploration (Smith, 2005). In addition to noticing how fears about children's vaccines had become so widespread, I (CH) found that people in my community who did not

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<sup>11</sup> A disjuncture occurs with the recognition that two subjectivities co-exist, two different versions of reality, whereby something is known from a ruling (institutional) perspective versus an experiential perspective (Campbell & Gregor, 2002).

vaccinate their children, were often considered negligent by healthcare providers despite the significant amount of money, time, and effort they invested on their family's health.

My disjuncture was a feeling of being caught between two subjectivities. The first subjectivity is the ruling or institutional version of reality that is linked to primary care practice, public health vaccination programs, healthcare education, and research. This reality would strongly disagree with a family's choice to not vaccinate their children. The second subjectivity came with the recognition that many of the people I worked with, in the absence of vaccinating, cared deeply for their children's health and worked hard to promote it.

This "bifurcated consciousness"<sup>12</sup> invoked a feeling of being pulled between the knowledge of these families, their personal circumstances, how they cared for their children's health, and institutional requirements where the focus would remain steady on what they were not doing (vaccinating) rather than what they were doing (Smith, 2005). From a research perspective, as nurses and researchers, we wondered what it felt like to decide not to fully vaccinate your children, engage in workful activities to enhance health in your family in response or in tandem with this choice, yet still be considered negligent, ill-informed, "anti-vaxx," and/or anti-science by members of your community—including health care providers. This disjuncture led us to two preliminary research questions at the heart of our research: what were the experiences of people/parents/family caregivers enhancing their children's health after declining routine childhood vaccines? Was their work invisible to nurses and healthcare researchers due to a pervasive spotlight on their opinions about vaccinating?

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<sup>12</sup> Also called 'line of fault,' experiencing a lack of fit between categories and the actualities of your own experience of the everyday world (Stanely, 2018).

## **Methods: Synthesis of Two Data Sources**

### ***How are the Data Sources Related?***

As described earlier, prior to our key informant interview, we completed a JBI Qualitative Systematic Review of the Literature (Huel et al., in press). We took descriptions from participants' illustrations identified in this qualitative systematic review and compared them with descriptions from the key informant interview. What follows is a brief description of these two data sources.

Our overarching systematic review question was: how do parents experience the specific activities involved in caring for their under-vaccinated or unvaccinated young children after refusing routine scheduled vaccines due to concerns about safety and efficacy? This initial step was taken to inform what we know about the topic and how the topic had been studied by other researchers (Huel et al., in press).

Completing the qualitative systematic literature review provided access to multiple studies and the verbatim accounts of participants which we have utilized as part of the synthesis for this paper. As per the JBI Methodology for Reviews of Qualitative Evidence (Lockwood et al., 2017), we generated findings and extracted examples of illustrations from primary research studies to form categories based on similarity in meaning. Categories were then grouped and collapsed into three meta-syntheses (Lockwood et al., 2017). We found that people's health work was linked to the contexts in which the work was taking place: (1) health work happening in the home, (2) managing social interactions and community networks, and (3) challenging societal discourse and institutional work processes.

The second source of data in our exploratory synthesis was a key informant interview, with details to follow later in the paper. When we compared the first-order descriptions found in

qualitative research studies to the rich and in-depth descriptions discussed by our key informant, we found strong similarities. For example, our key informant's descriptions of her health work also occurred within the workful contexts we had highlighted in our systematic review meta-syntheses (Huel et al., in press). For this reason, we have used our meta-synthesized findings from the qualitative systematic review to frame the “exploratory synthesis of combined findings” section of this paper.

### *Qualitative Systematic Review*

In this section, we share details of our systematic literature review (Huel et al., in press) as an overview of what is currently known from qualitative researchers about vaccine hesitant people's health work for their children. We included 40 papers that described 30 research studies. The studies took place in 14 countries within four continents and included approximately 676 informants. We extracted 115 findings from qualitative research and formed 12 categories based on likenesses of their meaning. From this, we formed three meta-syntheses that helped to articulate understandings about parental care activities for their children and what this work involved. We considered the writings of sociologist Dorothy E. Smith for guidance when extracting findings from qualitative research, in keeping our focus on empirical descriptions of people's activities (Smith, 1987, 2005).

Qualitative research studies exploring topics related to refusal of childhood vaccines have used a variety of methods to form understandings about people's experiences. Methods of inquiry have included grounded theory (Blaisdell et al., 2016; Brunson, 2013; Helps et al., 2019; Martinez-Diz et al., 2014; Reich, 2016; Ten Kate et al., 2021; Wiley et al., 2020), ethnography (Haarstick, 2021b; Nurmi & Harman, 2022), and phenomenology (Ejuma, 2019; Sumengen et al., 2021). Within this body of research, findings from qualitative research have also described

how people who decline vaccines for their children may also engage in laborious parenting practices, as a response to their decision not to vaccinate, and in order to keep their children healthy (Ward et al., 2017). With consideration to this concept, we hoped to build our exploration on what people described doing for their children's health in their own words and as a response to their vaccine choices.

**Health Work Happening in the Home.** People have described their efforts within the home to build up their children's immunity, protect them from vaccine preventable diseases (VPDs), and enhance their health in the absence of vaccination. Qualitative research participants described breastfeeding (Reich, 2014; Ward et al., 2018); eating only organic, non-GMO foods (Attwell, Smith, et al., 2018; Reich, 2014; Ward et al., 2017); and preparing homemade meals sourced from their own gardens and chickens (Ward et al., 2018). They willingly exposed their children to VPDs because they believed that this provided better immunity and contributed to their children's growth and development (Fallet, 2017; Nurmi, 2021; Tombs-Heirman, 2009). People also discussed assuming responsibility for treating VPDs when their child became ill (Blaisdell et al., 2016; Haarstick, 2021; Ward et al., 2018).

Participants described using and learning about complementary and alternative modalities to prevent VPDs, treat VPD symptoms, and boost their children's immunity (Attwell et al., 2018; Haarstick, 2021; Tombs-Heirman, 2009; Zin et al., 2022). Mistrust and acrimonious relationships with conventional (allopathic) healthcare providers also led participants to choose complementary and alternative health modalities to enhance their children's health (Haarstick, 2021b). Interestingly, research participants described that after their initial decision to decline vaccines, they continued with ongoing efforts to search for information that would either reaffirm their choice to withhold vaccines or cause them to reconsider (Brunson, 2013; Carrion,

2014; Sobo et al., 2016c). Finally, within the home, research participants discussed planning to reduce their children's risk for contracting a VPD by isolating their children geographically (Blaisdell; 2016; Carrion, 2014; Reich, 2014).

**Health Work Happening in the Community.** Qualitative research has also described how people care for their children's health within their communities by managing difficult relationships with healthcare providers (Deml et al., 2022; Sythes & Bedford, 2022; Tombs-Heirman, 2009; Tomljenovic et al., 2022; Ward et al., 2018). Research participants also managed, avoided, and prepared for criticism from friends and family members (Carrion, 2014; Reich, 2020; Wiley et al., 2021). As part of their health work related to the decision to decline vaccines, participants reported homeschooling their children because they did not have completed immunization records required to enter public schools (Harmsen et al., 2013; Thornton & Reich, 2022). They also described avoiding or removing their children from school due to stigma related to their vaccine choices that caused difficult relationships with students and staff (Reich, 2020; Tomljenovic et al., 2022). Research participants also reported removing their children from school due to concerns that they would catch a VPD from newly vaccinated child (Tombs-Heirman, 2009). In contrast to people's health work to manage difficult relationships, people also reported their efforts to cultivate relationships and form social networks with like-minded parents to share health related information and receive it from others (Attwell et al., 2018; Duchsherer et al., 2020; Helps et al., 2019; Reich, 2020; Sythes & Bedford, 2022; Wiley et al., 2020).

**Health Work Happening at the Systems Level.** The final major finding of our qualitative systematic review was created from qualitative research findings that detailed the broadest scope of people's health work for their children (Huel et al., in press). Research participants described how they would protect their right to make vaccine-related choices and

addressed real and perceived governmental punitive measures related to their decisions that included emigrating from their country (Helps et al., 2018; Tomljenovic et al., 2022). In addition, research participants detailed their roles as advocates for vaccine choices and informed consent (Duchsherer et al., 2020; Haarstick, 2021; Wiley et al., 2021). People discussed how they paid fines for their children not being vaccinated (Tomljenovic et al., 2022), and their worries about their children being apprehended by child protective services (Thornton & Reich, 2022).

Research participants described health work that involved filing vaccine exemptions, struggling to find childcare, and managing the loss of tax benefits and nutritional social programs (Ejuma, 2019; Helps et al., 2018; Reich, 2018; Thornton & Reich, 2022; Wiley et al., 2021).

Our qualitative systematic review was predominantly focused on extracting the findings or themes derived from participants' descriptions of their health work. In keeping with our IE approach, we decided to stay close to verbatim illustrations for the meta-ethnographic synthesis described in this paper. Having taken an expansive look at qualitative research evidence using a rigorous systematic review process, we now describe how it aligned with a key informant IE approach interview, and then discuss using a meta-ethnographic synthesis to further look at what people described about their health work.

## **Key Informant Interview**

### ***Recruitment***

Diverse recruitment strategies were used, including a recruitment poster that was sent to multiple independent schools and daycares in Canada. Some schools posted a physical copy in their building, while others posted on their Facebook page. Other strategies included social media posts on Facebook and Reddit, and sending digital and hard copy posters to midwifery practices and naturopathic physician's clinics throughout Canada.

Nevertheless, research recruitment of people who question vaccines, or who don't vaccinate themselves or their family members, has become increasingly difficult since the COVID-19 pandemic (Seiter, 2023). Many potential informants for this study made initial contact but voiced fears about being recorded in any way. Despite reassurances, they expressed concerns about their identity being provided to social service and public health agencies. In the end, we were able to recruit one informant, whose pseudonym was Amy, for our key informant IE interview.

### ***Context***

Amy identified as a Canadian cisgender woman with a male partner and two children. At the time of the interview, both of her children were under the age of eight. Her younger child had received no vaccines. Her older child had received their first round of vaccines in early infancy but had not received any other routine vaccines since, apart from an up-to-date tetanus vaccine. Amy and her family resided in an urban setting in the Province of Ontario. She and her partner worked both in and outside of their home. Her children attended an independent school that was understanding and supportive of people's choice not to vaccinate their children. Amy's children had never experienced VPDs, nor had her community experienced an outbreak of one. In Amy's community she had access to an allopathic healthcare provider (a general practitioner) and practitioners of complementary and alternative health care for meeting her family's healthcare needs.

### ***Data Collection***

Data collection took place in October 2023 and included a 90-minute recorded, online Zoom interview with Amy. Questions began with asking her to describe a situation or recent day when the work of caring for her children's health was amplified, increased, or more difficult

because her children were not vaccinated. Amy was also asked about what she did to help keep her children healthy after she and her partner decided not to vaccinate. Our conversation built upon these preliminary questions and was responsive and emergent to the information and descriptions. This approach is congruent with IE whereby conversations with informants seek to expand understanding rather than stick to a predetermined set of questions (Campbell & Gregor, 2002; Smith, 2005).

### *Analysis*

Analysis of the interview used an IE approach to show how people's health work is socially organized in order to explicate how in the local setting, particular understandings and explanations come into being (Campbell & Gregor, 2002). We repeatedly listened to the audio recording of the Zoom interview and re-read the transcript, keeping in mind how Amy was describing her health work. In addition, we reviewed documents related to the descriptions Amy provided, alongside field notes written following the interview and an ongoing reflective journal. We also listened carefully for traces of institutional discourse and work processes mentioned by our key informant.

Our transcript was generated through the Zoom Meeting interview platform. After downloading, we listened to the audio-recording and compared it to the transcription to ensure accuracy. We looked for traces of social organization in Amy's descriptions of her health work as enacted through her efforts to enhance her children's health, such as her work done to receive a vaccine exemption in order to enrol them in daycare and school. We asked about books, documents, webpages, and social media platforms that were linked to the health work she was describing and how these informed her efforts. Relevant documents were obtained and analysed; these included a book about raising unvaccinated children and governmental documents for

obtaining a vaccine exemption. The “exploratory synthesis of combined findings” section of this paper takes a closer look at what our key informant described about doing health work for her children. Our exploratory synthesis joins two very different but empirical approaches to generating knowledge and awareness.

### ***Ethical Considerations***

Ethical approval for the study was obtained from the University of Victoria Human Research Ethics Board (22-0252). Informed consent was obtained from Amy, who participated voluntarily and was free to withdraw at any time. The study was funded by the University of Victoria Faculty of Human and Social Development Graduate Student Research Award.

### **Meta-Ethnographic Exploratory Synthesis**

What follows is a description of the steps taken in conducting the exploratory synthesis guided by a meta-ethnographic approach (Noblit & Hare, 1988). The synthesis included and compared the two sources of data: 1) illustrations from a key informant interview, and 2) an extensive qualitative systematic review (Huel et al., in press). Our goal was to compare both studies’ empirical research illustrations of people’s health work of caring for their children.

Noblit and Hare (1986) outline a seven-step process for conducting meta-ethnography: getting started, deciding what is relevant to the initial interest, reading the studies, determining how the studies are related, translating the studies into one another, synthesising translations, and expressing the synthesis (Britten et al., 2002). We linked the studies together based on the population of interest they investigated and extracted illustrations that informants shared about health work. As per the steps for completing a meta-ethnographic synthesis, the studies were translated into one another by comparing the metaphors and concepts in the first-order verbatim accounts of health work that informants shared (Britten et al., 2002) As we had already

completed the prior qualitative systematic review, we were acutely aware of what types of evidence were relevant. We were interested in synthesizing both verbatim illustrations of people's health work from the systematic review along with one key informant's descriptions from our IE investigation.

For this paper, and using an IE approach, we made a departure from the typical meta-ethnographic approach. Unlike many meta-ethnographies that focus more on conceptualizing rather than describing (Toye et al., 2017), we focused on the illustrations provided by all participants that detailed their efforts. We compiled these illustrations and then reviewed the transcript of our own informant's interview. The participants from qualitative research studies along with our key informant were all people who cared for young children, had declined all or some routine-infant and early childhood immunizations, and had made their vaccine decisions based on concerns surrounding vaccine safety, efficacy, and necessity.

In the exploratory synthesis of combined findings section of this paper, we have framed participants' descriptions of health work with the third-order interpretation (synthesis) of our qualitative systematic review (Huel et al., in press). In that, people's health work is strongly linked to the context in which that work takes place: in the home, in the community, and at the institutional (societal) level. The next section of this paper takes a closer look at what our key informant described about doing health work for their children. Our exploratory synthesis does not seek to form concepts about people's health work or generate a theory on how or why it is done. Instead, we want to cultivate healthcare providers' awareness about people's efforts for their children's health, aside from their vaccine decisions, and consider their standpoint as caregivers. Ultimately, IE investigations are done to help people identify where change might be

possible within institutions, such as health care, or to challenge societal discourses and institutional work practices.

### **The Results: Exploratory Synthesis of Combined Findings**

The findings from the qualitative systematic review were echoed within the descriptions that Amy provided about the health work she does for her children. However, Amy's key informant interview provided greater depth to the textual resources<sup>13</sup> she accessed for guidance for her health work. Once people activate texts, by incorporating them into their doings, in essence, texts are enacted as people's doings. We stayed close to verbatim illustrations for the exploratory synthesis. Illustrative excerpts from qualitative research that contains traces of institutional discourses or processes have been underlined.

#### ***Health Work Happening in the Home***

**Living a Healthy, Natural Lifestyle.** Qualitative research participants described health work strategies that focused on the health of their children and were enacted within the home environment (Huel et al., in press). For example, findings related to living healthy, natural lifestyles demonstrated how people worked to boost their children's immunity and decrease their chances of developing a VPD by having a toxin-free household, breastfeeding, decreasing screen time, and keeping a calm and happy home (Ejuma, 2019; Gross et al., 2015b; Helps et al., 2018; Sythes & Bedford, 2022; Ward et al., 2017):

There are other ways to make sure your children have a strong immune system. We work hard to reduce our little one's toxic exposure<sup>14</sup> and prepare their bodies to fight against

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<sup>13</sup> In IE "texts" or textual resources cue the researcher to materials in a form that can be reproduced. They can be printed or electronic and produce the stability and replicability of an organization or institution, in that they enter and coordinate people's doings (Smith, 2005).

<sup>14</sup> Underlining highlights institutional threads, including textually mediated discourse and work processes for further consideration and analysis.

any pathogens they might encounter naturally. This isn't just with the things that enter their body, this is with everything that comes into our home from the floor cleaners to detergent and toothpaste. We eat an organic diet and limit things that might harm their immune systems in any way (Ejuma, 2019, p. 75).

All of my choices are currently aimed to give my children a peaceful basis for life: choose to breastfeed (about 1.5–2 years), raise children in a small-scale home, part-time work, first half year no childcare, minimize shopping/traveling with young children, All kinds of things that do not overcharge the immune system (Harmsen et al., 2013, p. 3).

The way I see it is that ... parents who choose not to vaccinate their children do actually offer quite a lot in return. They choose to breast feed their children longer, they choose to minimise sugar and processed foods and they choose to keep their kids as healthy as they can so that, when they do contract an infection, then obviously their symptoms are going to be less ... they generally keep their kids home when they're sick.... These decisions to not vaccinate are not made in a blasé way and they really work hard to keep their kids home, look after them properly and ensure that their disease doesn't progress to something that's dangerous. And in doing so they're protecting the population (Wiley et al., 2022, p. 1683).

Participants also discussed a healthy diet as being imperative for promoting immunity and illness recovery (Reich, 2014). Recommendations for what constituted a “healthy diet” were extensive. Having minimal sugar, organic, preservative free, nutritious, being “whole” were just a few examples of how healthy diets were described by research participants (Haarstick, 2021b; Peretti-Watel et al., 2019; Sumengen et al., 2021; Sythes & Bedford, 2022). Health work related

to providing children with specific foods needed to be balanced with other household and occupational responsibilities along with setting aside financial resources to source and afford organic foods (Haarstick, 2021b; Huel et al., 2024).

Like the illustrations from qualitative research participants, findings from our key informant echoed the efforts taken to provide a healthy diet for her children. Amy described how her children eat high quality, wholesome foods and are given prebiotic and probiotic foods like sauerkraut to promote their “gut health.” Some of the measures their family took to provide homegrown fruits and vegetables began before she and her partner had children through establishing a permaculture food forest in their back yard:

My life before kids, our backyard, that's when we spent all of our time installing our permaculture food forest for us in our backyard. And so we now are reaping the benefits of it all. So we have lots of fruits and vegetables that happen on their own out there. And I would say since I've had children, because it's been so intense, and because I care a lot about what they eat, I would say I make a lot less of it and I buy it instead. So I buy a lot of fermented foods from people that are locally doing it.

I just have the philosophy of life in general that like, less is more and so we do a lot of ... I would say we do like, a lot of proactive health care decisions. Like, we choose to feed our children high quality, wholesome foods. So really, like, basic high-quality food. So, you know, a lot of fruits and vegetables, and we, we have always given our children a lot of probiotics. We really believe in a lot of gut health, so we've given a lot of pre and probiotic foods. So, we started our kids eating sauerkraut at a young age and a lot of yogurt and when they have been sick and ill.

**Complementary and Alternative Health Modalities.** Participants who did not vaccinate their children reported using complementary and alternative modalities (CAM). This was a major finding of our qualitative systematic review (Huel et al., 2024). Research participants discussed utilizing, learning about, and accessing practitioners of CAM to prevent VPDs, treat VPD symptoms, and boost their children's immunity (Attwell, Ward, et al., 2018; Martinez-Diz et al., 2014). Modalities were wide ranging, with participants treating their children both independently and with the assistance of a CAM provider (Attwell, Ward, et al., 2018; Tombs-Heirman, 2009). Participants reported that CAM helped them to feel proactive in their children's health by improving their ability to manage VPD risks and treat VPD infection symptoms. They also accessed CAM practitioners as an alternative to their allopathic provider if treatment options were not agreeable to them:

Like I mean, since then we have all been ok and haven't been to a doctor. I go to the homeopath if something doesn't clear up by itself. My homeopath will also advise me over the phone. I don't panic a lot but I do like to talk to my homeopath. Like something like earache, I mean my oldest son had earache badly and it clears up very quickly with homeopathy (Tombs-Heirman, 2009, p. 161).

I use chamomile water, carob molasses, celery, honey, sage, and antibiotics. I buy propolis from herbalists. I care about hygiene (Atasever et al., 2021, p. e99).

There are more effective methods of preventing or treating disease. I would get vaccinated with (homeopathic) vaccines that were absolutely safe.... (Martinez-Diz et al., 2014, p. 374).

Amy spoke extensively about the “blended approach” to healthcare that her family used to enhance their health and treat illnesses. This included practitioners of the “western medical system” (the family’s GP), a naturopathic physician, a homeopathic doctor, and a chiropractor. She spoke directly about how her viewpoints about vaccines did not equate to her being “anti-medical system.” Instead, her family determined which provider (allopathic or CAM) they would access based on diagnosis of the illness and potential treatments:

Our first line of defense has typically been taking them to a naturopathic doctor. Well actually, sorry, I don’t know if this is quite answering the question, but we usually go to the western medical system for diagnosis and we typically solve the issues more naturally if possible. So, typically we’ll turn to homeopathics. A lot of people know about homeopathics, so we have a homeopathic doctor we go to. We also ... I just feel like it’s not one or the other. It’s kind of like a blended approach. It’s not like one’s better than the other. They’re all just really useful and helpful.

I connect to my community and ask questions and then I go to the places that feel best. Like, it might be my doctor, it might be my naturopath, it depends on what the problem is that they’re presented with. And I’m like, “less is more” so I don’t ... it’s kinda like wait and see a lot of times. You know, it’s like, I use my intuition to make a lot of decisions. I’m like: “Okay, you’re clearly very sick. We need to go to the hospital,” or ... “You’re not that sick, I think we’ll just like, give it a moment.” You know?

**Assuming Responsibility for Treating VPDs.** Participants who chose not to vaccinate their children discussed their role and responsibility in caring for a child who had contracted a VPD (Huel et al., in press). Their responses to the potential for illness varied. Some were nonchalant about VPDs because they reported feeling confident that they could care for their

children while they were sick and did not consider VPDs particularly dangerous for their health (Blaisdell et al., 2016; Tomljenovic et al., 2022; Ward et al., 2018). Other participants shared that they would trust an allopathic physician to care for their children's VPD symptoms if they required in-hospital care (Blaisdell et al., 2016; Haarstick, 2021b; Tomljenovic et al., 2022):

I know that there is a risk for complications but I personally believe that the risk for complications is very small, if you take care of the disease in a good way and make sure to gain that knowledge. I mean that it may be important not to give a pyretic and to allow for rest and care (Byström et al., 2014, p. 6756).

It stinks because back when this used to be a regular childhood illness that everyone got, like chicken pox was for us, people would pass down remedies. But now, we don't know them anymore so we have to go online. I'd probably go online and look up a home remedy for measles (Blaisdell et al., 2016, p. 484).

Amy's children had never experienced a VPD, and at the time of the interview she did not know of any VPD outbreaks in her community. Similar to the illustrations provided by qualitative research participants, Amy discussed what she had learned about caring for VPDs, and which information sources guided her. She also surmised about the healthcare providers she could contact for advice and support if her children became ill:

But I've learned a lot about them (VPDs) ... I have a really interesting book called Raising Vaccine Free Children that has been helpful for me. I also want to add one piece, is that our Chiropractor Group ... probably shouldn't name who it is, she is also very helpful with us around ... you know, she's like, "Call me if the measles or the whooping cough come, I can support you in this," you know? 'Cause I think, I mean to be honest, like, I'm not loud and proud about raising vaccine-free children.

So if they were to get really sick from illnesses and childhood diseases, if they have an illness, I would probably be anxious and afraid. Of like: “Oh shit, like I could have ... I could have prevented this by giving them a vaccination.” But I don't know, I have this trust ... it's gonna be well.

When we asked if there was anyone that Amy would go to for help, aside from her chiropractor, for support or information about caring for children with a VPD, she indicated that she would go to her family doctor. Though she did not follow her doctor's recommendations about vaccines, Amy relayed how she trusted his ability to diagnose illness in her children, and treat them, if she agreed with the proposed solution. Amy determined at what point she felt the need to go to her doctor, and also decided upon which treatments would be appropriate for her children. This was based on her voiced belief that the medical system would be quick to intervene rather than allowing her children's bodies to intuitively heal themselves:

My family doctor ... I feel, I feel supported by him. Like, I remember very clearly when I took them [key informant's child] to him for the first time and I got them vaccinated and I went back and was like: “[Doctor's first name], I just, I don't want to do this anymore.” and he's like: “Okay, no problem. I can't advise you against that. I legally have to tell you. But I am not going to shame you and make you wrong for it.” And so, I would go to my family doctor.

Like, your body's smart and intuitive, and it knows, and it's wise, and it can do a lot of healing if we give it the nutrients and the support that it needs look after itself. So when my kids have a super high fever, unless it's like high for a long period of time, it's sustained over many days, I don't really touch it. I let the body do its thing until it's like,

actually no, “Now it's time you need to go to the doctor.” Like, I’m not opposed. I'm not anti- medical system.

I’m just like, “If I go over to that system they’re probably just going to just give a lot of stuff,” and I just don’t always want to jump to that approach right away.

**Ongoing Information Seeking.** Findings from qualitative research demonstrated that people’s decisions about their children’s vaccines are not static and unyielding. People who have initially made the decision to forgo vaccines continued to question their rationale and search for information that may either confirm their initial choice or lead them to vaccinate their children. Participants divulged that if circumstances changed in their community, due to an elevated risk of a VPD, a change in a family member’s health, or a decline in access to nutritious food or community sanitation, they would contemplate vaccinating (Helps et al., 2019; Ward et al., 2018). They also spoke about doing continuous risk assessments to evaluate the health of the greater community and calculate how this may impact their own household (Ward et al., 2017):

I’m always doing more research, I never am settling for what I’ve decided upon thus far.... It’s not a decision that it’s just very black and white once it’s made, it’s very fluid and definitely the hardest decision I’ve ever made, and is—yeah, it’s just always being researched, it’s always in—something in the back of my mind that I’m thinking of at all times [laughs] (Sobo et al., 2016c, p. 537).

I’ve kind of gone through each one and eliminated them in my mind. “Yeah, we don’t want this. Yeah, we don’t need this.” But that tetanus one keeps popping up in my head. It doesn't necessarily make me feel like I need to give it to her, but I’m still learning more.

All the other ones I'm pretty much like [no] but that one I'm still learning more about (Brunson, 2013, p. 5469).

Amy initially shared that she did not often re-think or question her decision about vaccinating. Nor did she discuss worrying excessively about whooping cough or measles. She had given her eldest child a tetanus shot because her children had been to the hospital several times for cuts, and this vaccine “just makes sense.” However, when we spoke about her kids growing older and having different health needs, Amy shared that she did have an ongoing concern about her children contracting chicken pox as they grow older. She was seeking information and was considering whether they might still receive this vaccine if they don't catch the virus:

The only thing I thought about was the fact that my kids don't have chicken pox. And they don't have the chicken pox vaccination. And I would say that's probably the only one that really, I think about, because I'm worried for their health in the future, 'cause, chicken pox could be something that they could get as they age. And so I do wonder, I just ... I feel annoyed about it, if anything.

I'm like: “Chicken pox is something we all got and we all survived it, and it's fine.” I don't want to vaccinate my children against it. I just want them to get the chicken pox and I can't find anyone that has chicken pox to give it to them. So I say that's the only one that has me kind of thinking about it, the only one that I'm worried about.

This finding in Amy's descriptions, in conjunction with those in the systematic review, strongly signal that health care providers should not consider a family's choice to not vaccinate a final decision. Most of the review participants reported giving their children some vaccines, akin

to Amy's decision, and remained open to changing their mind should circumstances or evidence compel them to do so.

### *Managing Social Interactions and Community Networks*

**Managing Risks and Relationships with Healthcare Providers.** Qualitative research participants shared how they actively and passively managed relationships with health care providers as part of the health work that's related to their vaccine decisions for their children. They anticipated unwelcome responses from healthcare providers who did not agree with their choices (Deml et al., 2022; Sythes & Bedford, 2022; Tombs-Heirman, 2009). Participants described screening potential healthcare providers, looking for those who may share similar views about vaccines or those who may disagree with them (Carrion, 2014; Tomljenovic et al., 2022). They managed and handled healthcare provider attempts to persuade them to vaccinate (Tombs-Heirman, 2009). Some participants discussed avoiding healthcare providers altogether, or not disclosing information about their children's vaccine status (Carrion, 2014; Tomljenovic et al., 2022; Ward et al., 2018):

I put off going to the doctor whenever the kids are sick because I know the few times I've been in, it's quite a negative reaction. So unless the kids are really sick, I don't tend to take them to the doctor. Which I, like—I need to find a doctor that is open to people who don't vaccinate (Ward et al., 2018, p. 1126).

I took him to the doctor, and she just absolutely laid into me about what a terrible mother I was, how irresponsible I was ... and that ... made me see, in my eyes anyway, that they were more interested in getting my child vaccinated than my child himself, in his wellbeing (Sythes & Bedford, 2022, p. 4).

I actually have not told them the truth, I told them I'd got them all done privately and that continues now if I ever pop in, I say, "... She's had the boosters so if you can just log her in as having the boosters." I sometimes even research what would she have had ... I lie about it so that they have not got me on a list (Sythes & Bedford, 2022, p. 5).

Though Amy reported having a good relationship with her family doctor who was accepting of her family's vaccine choices, she remarked that having to enter healthcare milieus with unfamiliar healthcare providers made her feel nervous. Namely, she reported that having to explain the rationale for her decisions made her feel apprehensive about accessing care:

I don't want to have to be put in a corner to be like: "Tell me the reasons. Your reasons aren't good enough. You clearly haven't read. You're harming your children. You don't know what you're talking about." I'm just avoiding that, you know? Being like ... academically bullied, I guess.

I'm just saying I can feel it right now. I hate the feeling of the judgments or the potential judgments. Or I think actually it's not even that.... I can hold the judgment and stuff. I just don't wanna have to prove myself.

**Managing Stigma, Confronting Critics and Staying Silent.** The health work enacted by people with unvaccinated children was demonstrated in their descriptions about how they managed relationships with family and friends. Participants discussed staying silent about their choices when conversations about vaccines came up with friends (Reich, 2020b; Wiley et al., 2021). They also anticipated and rehearsed their responses to being confronted by someone who disagreed with their perspectives and choices (Reich, 2020b; Wiley et al., 2021). Participants

managed, avoided, and prepared for stigmatizing statements through their awareness of negative media and online discourses about non-vaccinating people:

I'm actually having a hard time too, especially with sharing our choice if anyone asks, most of my really close friends and family just respect it and leave it alone (maybe secretly think we are nuts, but I'll take that) ... I'm tired of feeling nervous or anxious about this conversation coming up with play groups or new friends, parents who may be uncomfortable, or attack me because "their kid is in danger"(Reich, 2020b).

The mothers in our street had a meeting and they decided that they didn't want their kids to play with him because he wasn't vaccinated.... I wasn't really prepared for them all to come to my doorstep, so I was upset ... My kid could still play in the street, but what would happen is that they would bring their kids in when he went out" (Wiley et al., 2021, p. 4).

During our interview conversation, Amy mentioned a "web of connections" she had within her community that supported her family's health and recommended places for her to source fermented foods. At her children's school, "like-minded" people shared homeopathic remedies for illnesses. However, once when Amy's youngest child had a high fever, she called a parent from her children's school, who is a doctor, for advice. This experience showed her that not all parents in her school community agreed with her choices:

[Child's name], one time, had a high fever for quite a few days. And before taking them to emerg, I just called, and I said to this woman, I was like: "Could you just walk me through this? Should I be taking them in? What should I be doing?" And she asked me: "Is [child's name] vaccinated?" and I said: "They're not," and she said: "Ohhhhh." Like,

I could just hear like: “Ohhhh.” It was like a disappointment. She was like: “Okaaaay, right, okaaaay.”

Like that was the only time that I was like, oh man ... I don't like ... I don't love going to the hospital and then them asking me like: “Are they vaccinated?” Me having to say: “No.” You know, it's not like my favorite thing. Like I'm ... I don't love the judgment. I don't ... not that I've ever felt feel publicly judged about it. I just, this is not my favorite thing because it's kind of taboo. It's like the thing you don't do. Like, I'm doing the thing you don't do.

Amy also kept her vaccine choices to herself and did not share this information with some of her family members. Like the participant's illustration from the Wiley et al. (2020) study above, about a child not being included because they are unvaccinated, Amy feared that she and/or her children would be “othered” or not belong with their peers due to their decisions. Throughout our discussion, she mentioned that this was a topic that she would only address if directly asked by another person; otherwise she made a concerted effort to keep her viewpoints to herself:

You know, you vaccinate your children, like our culture's like: “You [must] vaccinate your children!” So I don't really tell people about it. My inlaws don't know. My grandmother doesn't know, nobody—unless they're asking me questions—knows that my kids are not vaccinated.

And so I always like ... feel that I'm left in this position of judgment because I can't back it up. But it's not that I haven't done my due diligence. Like I've read the books, I've had many conversations with ... people that chose not to vaccinate, and I read as much

information as I possibly can about this topic, I just can't regurgitate ... all of the ... And so I find that I avoid putting myself in a position ... where I will have to back it up. Out of fear of not belonging. Like ... that's my biggest fear. I don't want to not belong and I don't want my children to feel that they don't belong either. So we just don't talk about it if we don't have to.

**Forming Social Networks with Like-Minded People.** Despite the negative interactions that participants reported experiencing, managing, and anticipating in their communities, they also described their efforts to form social networks with other vaccine-hesitant people with children (Attwell, Meyer, et al., 2018; Duchsherer et al., 2020; Helps et al., 2019; Reich, 2020b; Sythes & Bedford, 2022; Wiley et al., 2021). Qualitative research participants reported health work that involved engaging with like-minded peers in-person and within online platforms to receive support and to inform their alternative health related practices (Helps et al., 2019; Sythes & Bedford, 2022; Wiley et al., 2021). They also engaged with anti-vaccination groups so that they could gain access to informational articles about vaccination (Helps et al., 2019). Other participants discussed the health choices and social networks they formed prior to making their vaccine decisions that continue to inform the health work they do for their children (Reich, 2020b).

I joined an anti-vaccination group purely so that when they come up with articles, I have that information. I don't actually like the people, the way they're posting on there.... But there isn't another option at the moment for people who really do not want to vaccinate (Helps, 2019, p. 8).

I actually ended up living close to kind of a small mommy group, like walking group ... [one woman in it] didn't vaccinate her baby and he was 24 months old when I first met

her. And what she did was she had these, I guess it was like some kind of drops, like vitamin drops or whatever, and something else ... And then she also took him to the chiropractor once a month, which I think is crazy. Like taking a baby to the chiropractor? Like do they really need—like they have such flexible joints anyway but she’s like, “No, it really helps and, you know, that affects everything in their body.” So yeah, I definitely listened to what she had to say ... (Reich, 2020b, p. 4).

Amy also discussed the support and advice she received from her children’s Waldorf School community. A recent systematic review that investigated the links between vaccine hesitancy and anthroposophy (the spiritual movement that guides the educational approach at Waldorf Schools), found that there was a consistent narrative about problems or concerns with vaccines, including toxicity and lack of trust in the system within anthroposophic communities (Herzig van Wees et al., 2023). Amy described the cohesiveness of her community, as a place she could obtain information pertaining to her children’s health.

I have a very well-connected community. Like as you know, I’m very well connected to the Waldorf community. So, there’s a lot of like-minded people there. I would say I connect to my community and ask questions and then I go to the places that feel best.” I’m just so connected to my community. So I go to the market and I chit chat with this person, who talked about that person, talks about this person ... It’s just like, the web of connections.

When asked about the ways she cared for her children’s health, Amy connected their health to the Waldorf School she sends her children to as a positive contributing factor:

Like ... a lot of time outside and good air, and a lot of time in their bodies, and I send them to a school that I really believe in. I do a lot of things to care for my children. I

spend a lot of time and I maintain them in a private school that cares for their mind, body, and soul.

### *Challenging Societal Discourse and Institutional Work Processes*

**Managing Punitive Measures at the Systems Level.** An interesting group of findings in our systematic review was how people described managing perceived and real threats from government agencies that determined their access to public schools, childcare, financial assistance, and nutritional programs based on their children’s immunization status (Ejuma, 2019; Helps et al., 2018; Reich, 2018; Thornton & Reich, 2022; Tomljenovic et al., 2022; Wiley et al., 2021). Participants discussed exerting a tremendous amount of thought and effort into filing exemptions, managing household finances due to loss of government tax benefits, navigating loss of childcare options, and handling financial and disciplinary penalties (Helps et al., 2018; Thornton & Reich, 2022; Wiley et al., 2021).

Participants completed health work to manage institutional work processes and avoid vaccinating their children, which they had determined to be an essential component of protecting their health:

The first report was at the hospital, I had to sign a paper which said I refuse to vaccinate and that I am informed about the benefits of vaccines (...) after a few weeks, I got a call to go to an informative talk with the epidemiologist, so the doctor can talk to me “about vaccines” and that I get better acquainted. She turned us in to the sanitary inspector, who is by duty obligated to file a court lawsuit, by which we get a fine, and you can get a fine for every vaccine you decline (Tomljenovic et al., 2022, p. 6217).

I work at my son’s [Waldorf] school, and we are legally not allowed to discuss the exemption forms if people don’t ask for them ... I still remember the panic I felt when I

got the letter (before I started working there) stating that he would not be admitted if his vaccines weren't up to date. I called, saying, "Isn't there an exemption?" And of course there is, but the thing that pisses me off is that we're not allowed to say it! I mean, we can say it after they ask, but not technically before (Reich, 2018, p. 229).

The top illustration originated from a study that explored underlying decision-making processes for avoiding mandatory child vaccination in Croatia (Tomljenovic et al., 2022). The study details a series of processing interchanges<sup>15</sup> that a participant encountered as steps of a governmental disciplinary process for avoiding childhood vaccines (Tomljenovic et al., 2022). In this study, the processing interchanges are demonstrated through multiple meetings and filing reports. These included visiting a hospital, a talk with an epidemiologist, getting "turned in" to a sanitary inspector and finally, with a potential lawsuit and paying fines.

Amy detailed her own efforts to secure two vaccine exemptions so her children could attend daycare and school. Though she did not have to pay fines for the vaccines her family had declined, she had to take a day to go through the process twice and incur the fees from having the exemption forms notarized:

The only thing I've had to do is go to public health and do a whole session on learning about the importance of vaccinating my children and I had to go through a course. This is Ontario, in order to send them to the school or into daycare, I had to sign a letter saying that I've done this course, I understand the risk that I'm taking, and then I had to get the letter notarized, and then I had to submit it to public health and then that's the way that

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<sup>15</sup> In IE, processing interchange identifies a work process that's characteristic of an institution. A text enters an individual's work setting and is processed or incorporated into a new text that becomes the focus of more or other's work (Smith, 2005).

I've been able to have my unvaccinated children at school. Yeah, you have to do it in Ontario for both children.

It's before they go into childcare situation, so any public childcare situation. You have to show your vaccinations or if you're not vaccinating you have to, there's a term for it ... it's religious or unconfirming. Essentially and you have to go to public health watch a bunch of videos. It's like a three-hour session. Get to talk to public health nurse and just let them know, and they make sure that you understood the risk that you're taking. Sign, notarized, deliver back to public health.

We were interested in how Amy experienced gaining vaccine exemptions for her children. Namely, how did she feel about the conversations she had with others involved in the processing interchanges? Her response shed light on how completing a vaccine exemption in Ontario ultimately led to a favorable outcome, allowing her to maintain autonomy over her children's health while still having access to public daycare and schools:

How did I feel about it? I was annoyed I had to do it, but I was grateful. I think there was part of me that experienced gratitude, that I wasn't being forced to vaccinate my children.

I'll do whatever. Fine. I'll watch your videos. I'll take them into consideration. I'll listen to them. I'll go do all the work. I'll sign the forms. I'll take it to a notary. I'll pay for the notary. I'll go back to public health. I'll do the things. I'm just grateful that they're letting me ... I'm still sending my kids to school.

At the end of our conversation, we asked Amy what she thought would be important for healthcare providers, like nurses, to know about the health work she does to care for her children's health. This question was asked in the spirit of trying to build a bridge between us, and

between her and health care providers who read her descriptions, and potentially between other people who decline their children's vaccines and the healthcare providers that work with them:

Not that I don't care for my children because I don't vaccinate them. Like it's quite the opposite, you know? I care a lot about their whole being. Being looked after ... so me not vaccinating them doesn't have anything to do with ... I don't feel like I'm being irresponsible. I feel like I've just made a decision. You know? That worked for our family, and that helps me sleep at night. I would not sleep at night knowing if I had vaccinated my child....

It's like there's a safety thing that has to be built because I'm very vulnerable. Not only just giving you my child, but even for me when I am a patient that has to come to ask for a physical. It's a vulnerable position that I am in ... and I'm putting myself in it ... and I'm coming to you and I'm telling you honestly that I've made this decision and what I need from you is to just be like: "Okay, I heard you made this decision and I'm not judging you for this and this is still a safe relationship."

## **Discussion**

Descriptions gleaned from a systematic review of qualitative research and an interview with a key informant (Amy) were combined in this exploratory synthesis to shed light on people's health work for their children after declining all or some routine scheduled vaccines. We linked the studies together based on the population of interest they investigated and extracted illustrations that participants shared about health work. To demonstrate our exploratory synthesis, we framed the empirical illustrations of health work within the three meta-aggregative findings from our systematic review that reflect the context in which participant's health work takes place (Huel et al., in press). Our meta-syntheses were generated to frame understandings about

people's every-day, every-night efforts after making a controversial health decision for their children.

### ***Repeating Discourses within Descriptions about Health Work***

Upon completion of our exploratory meta-ethnographic synthesis, we were surprised by the marked similarities in language contained within the illustrations from a very diverse group of participants across countries and continents. We noticed similar discourses surrounding people's health work for their children were repeated in multiple studies regardless of the context. Therefore, we paid particular attention to how participants' health work was described in their direct quotes, rather than the way the researchers explained or categorized their narratives.

**Natural Immunity.** Discourses surrounding 'natural,' 'nature,' and 'immunity' were repeated in participants' illustrations about natural living, natural ways, being close to nature, nature's side, natural measles, natural methods, natural infection, natural health, and natural healing. The discourses repeated about 'natural' and 'nature' came from qualitative research studies that took place in the United States (Ejuma, 2019; Fallet, 2017; Reich, 2016; Thornton & Reich, 2022), Australia (Attwell, Meyer, et al., 2018; Ward et al., 2018), Finland (Nurmi & Harman, 2022), Taiwan (Kuan, 2022), Spain (Martinez-Diz et al., 2014), Switzerland (Gross et al., 2015a), the Netherlands (Ten Kate et al., 2021), and Malaysia (Zin et al., 2022). The exact phrase 'natural immunity,' which refers to people gaining immunity to VPDs by first contracting them, rather than getting vaccinated was repeated by participants in The Netherlands (Harmsen et al., 2013; Ten Kate et al., 2021), Switzerland (Gross et al., 2015a), Finland (Nurmi & Harman, 2022), and the United States (Reich, 2016). During our analysis of Amy's interview transcript, we noted that she too had said that: "We typically solve the issues more naturally if possible."

**Homeopathy.** Similar to discourses about ‘natural,’ participants discussed using homeopathy as part of the health work they did for their children. This included a participant from Switzerland who had a homeopathic pediatrician (Deml et al., 2022). Participants in the United States discussed their use of homeopathic medicine for their family’s health (Haarstick, 2021a), and qualitative research participants from Malaysia and Spain discussed using homeopathic vaccines for their children (Martinez-Diz et al., 2014; Zin et al., 2022). Finally, participants in the United Kingdom shared discourses about homeopath and homeopathy during their research interview (Tombs-Heirman, 2009). Amy also discussed ‘turning to homeopathics’ and having a ‘homeopathic doctor’ as part of the ‘blended approach’ that she used for caring for her family’s health.

**Waldorf-Steiner Communities.** Finally, we took note from Amy’s descriptions and the illustrations from two of the studies that there was mention of Waldorf-Steiner Schools and the anthroposophic community<sup>16</sup> (Byström et al., 2014; Reich, 2018). There is evidence that anthroposophic communities have a substantial presence of vaccine hesitant people as evidenced by measles outbreaks within this population, particularly at Waldorf Schools (Herzig van Wees et al., 2023). We considered that engagement with this community could influence discourses and the social organization of people’s health work for their children because health-related information that reflects an alternative slant is commonly shared at schools and biomedical information, particularly that provided by pharmaceutical companies, is not widely considered trustworthy (Sobo, 2015). In addition, Sobo (2015) found that social mechanisms within Waldorf Schools sustained cultural norms, including a: “...school philosophy that actually embraces

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<sup>16</sup> A formal educational, therapeutic, and creative system established by Rudolph Steiner that seeks to primarily use natural means to optimise physical and mental health, along with well-being (Oxford, 2024).

illness because they believe that when your body has a strong illness, particularly a fever, it precedes a developmental leap in the child” (Sobo, 2015, p. 392). We noted that discourses around fever and embracing illness were also present in Amy’s descriptions of how she cares for her children when they are sick using a “wait and see” and “less is more” approach to determining if they seek allopathic treatment and the length of their convalescence. This opens another avenue for IE investigation in understanding how health work is socially organized for people who belong to a Waldorf Community and decline vaccines for their children.

### *Discourses from an IE Approach*

While the similarities in discourses have been highlighted in the exploratory synthesis, an IE approach also raises awareness about how or why people from different countries speak about their health work in such similar ways. In IE, discourses are considered to be ‘systematically produced,’ meaning that they are controlled and ordered; the concept of discourse is used as a tool to recognize the social relations in which work is coordinated by texts (Smith, 2005; Smith & Griffith, 2022; Stanley, 2018). Many qualitative research participants who chose not to vaccinate their children, and partake in work to enhance their health, participate in sharing a discourse around natural living, homeopathy, or natural immunity. They have also learned from others about how to do so. Our synthesis demonstrated that the discourses about people doing health work after declining infant and childhood vaccines are being shared and propagated on an international scale. As discourse is an organization of relations among actual people engaged and active in actual local settings, including homes, schools, and health clinics, their activities (as work) are coordinated textually (Smith & Griffith, 2022).

The illustrations shared by participants about the practices surrounding their health work are reflective of information that is being talked about, read, written about, and watched in

particular local places, at particular times (Smith & Griffith, 2022). People create texts for other people to read; they read what others have written about children's health, natural living, and immunity, and they may take them up and enact them in their own work (Smith, 2005; Smith & Griffith, 2022). They are active in participating in a discourse about what they do for their children's health, and their participation reproduces it and changes it.

In a full Institutional Ethnography, a researcher would seek to understand the social organization of people's health work by mapping<sup>17</sup> the texts, people, and experiences that have guided how they engage in their efforts. Their efforts may reflect institutional priorities that they may not be aware of. In our qualitative systematic review, it was impossible to find out which textual resources participants activated to inform the health work they do for their children. However, we can surmise from the remarkably similar discourses used to describe people's health work that a process of mapping their accounts, regardless of their geographic location, would include texts that replicate similar discourses of nature, natural, homeopathy, and immunity. We can also contemplate that the remarkable similarities found in participants' discourses about health work could be textually mediated through their use of the internet. As a number of participants discussed their ongoing efforts to search for information on the internet about vaccine safety, this could contribute to the proliferation of repeated, shared, and adapted discourses (Brunson, 2013; Sobo et al., 2016c; Ward et al., 2017). Pervasive discourses about not vaccinating that people access on the internet and use to inform their decisions and health work are not restricted to local settings. Therefore, people's health work could be socially organized on

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<sup>17</sup> Mapping is looking for sequences of action where work knowledge is embedded and implicate other people, other experience, and other work; it includes an informant's accounts of the texts that coordinate their work (Smith, 2005).

a broader, more international scale as a shared textual community active in social relations online, and the discourse is apparent right there in what they are doing (Smith & Griffith, 2022).

### **Considering People's "Health Work"**

Findings from our exploratory synthesis suggest that 'health work' occurs both inside and outside of the home. Amy responded early in our interview to clarify that her choice not to vaccinate her children had never increased the amount of work she had to do in caring for them. She also confirmed that her efforts in enhancing her children's health through nutrition and complementary and alternative medicine (CAM) were *not* related to her vaccine choices. Not vaccinating was "never a decision-maker for how I parent, or choose to feed, tend to, or look after my children." Although Amy began her interview with this statement, our conversation did produce examples of textually mediated work that was directly related to her vaccine choices. Obtaining the vaccine exemptions, staying home from work for an extended amount of time to care for sick children (who are required to stay out of school for longer periods because they are unvaccinated), and dealing with stigma from community members and healthcare providers were uniquely related to Amy's vaccine choices and wouldn't be experienced by a person who had vaccinated their child.

Qualitative research participants also discussed some elements of the health work they did to enhance their children's health in a positive light. Many people reported quitting their work outside of the home, cooking, growing their own vegetables, and tuning into their children's health, as a welcomed change to their lives (Byström et al., 2014; Carrion, 2014; Reich, 2014; Ward et al., 2017). We found that the emotional and financial stresses related to health work and not vaccinating were situated in the broader contexts outside of the home. They were reported by both Amy and qualitative research participants when they described the work of

managing stigma, anticipating and experiencing negative interactions with healthcare providers, and when dealing with punitive governmental penalties (Reich, 2018, 2020b; Thornton & Reich, 2022; Tomljenovic et al., 2022; Wiley et al., 2021).

Researchers have reported that the work of caring for children and their health has become substantially more burdensome for parents, regardless of the technological and healthcare advances gained in recent times. Individualist approaches to both healthcare and childrearing that are indicative of a neoliberal fixation on personal responsibility are well documented in research that explores the lofty expectations of modern-day caregiving (Avishai, 2007; MacKendrick, 2014; McCabe, 2016; Minnotte, 2023; Reich, 2020a).

Research has also indicated that people who care for children, particularly those who identify as mothers, regardless of choice surrounding vaccines, are challenged to take up responsibility for reducing their exposure to chemicals and toxins found commercially in food, consumer products, and in the home (MacKendrick, 2014). In tandem with mediating potential harmful exposures for their children, people are also faced with the shift from the traditional healthcare patient role to becoming a healthcare consumer. Amy's discussion of her "blended approach" to health work is echoed in literature that details the neo-liberal "responsibilization" of modern-day health services (Ward et al., 2018), whereby healthcare "consumers" demonstrate a high level of agency and empowerment to direct their own care and choose/decline treatments (Hamilton, 2016; Steiner & Bronstein, 2017).

Literature also indicates that healthcare providers who are part of the "western medical system" have voiced their concern that people who don't vaccinate their children have turned their back on the notion of community health and the *entire* allopathic approach to health, not just vaccines (Bryden et al., 2018; Edge, 2009). In contrast, our findings support a different view.

Many qualitative research participants, including Amy, who do not fully vaccinate, still trust other aspects of allopathic healthcare and want to maintain their relationships with those working within it (Blaisdell et al., 2016; Haarstick, 2021a; Tomljenovic et al., 2022).

Our exploratory synthesis, with an IE approach, contributes clear descriptions of health work, along with identifying traces of how health work related to vaccine hesitancy is socially organized. However, it also indicates that with elevated expectations for children's health and wellness, along with health work related to declining vaccines, *and* a myriad of choices to make in the healthcare consumer marketplace, there are multiple ways to consider the social organization of people's health work. Perhaps some people may not be aware of the similarities in ruling relations that underpin the production, marketing and sale of both vaccines and homeopathic medicines. Profit motives and neoliberal discourses may also be reflected in both allopathic and alternative health services today. However, on a positive note, our exploratory synthesis has indicated that people do not always make a definitive choice *not* to vaccinate. This was shown in their descriptions of ongoing information seeking about vaccines to re-affirm their initial choice to decline. In addition, people who do not vaccinate have voiced their intention to keep relationships with allopathic healthcare providers, blending their healthcare approach with CAM modalities. Both findings indicate an inroad for nurses to provide support and information, even if a difference of opinion exists, over the topic of infant and childhood vaccines.

## **Conclusion**

Our meta-ethnographic exploratory synthesis took enriching descriptions from a key informant interview and compared them to informants' illustrations from an extensive qualitative systematic review. Our goal was to combine both studies' empirical research illustrations of people's "health work" through an exploratory synthesis and consider our findings using IE

approach. Our synthesis revealed that people who decline all or some routine vaccinations for their children engage in health work that is meant to enhance their health, protect their right to choose or decline vaccinations, and address punitive measures from governmental agencies. People may not associate their “health work” as being a substantial effort, particularly within the home. Despite this, their efforts to manage stigma, advocate for their rights, and face penalties for their vaccine decisions can result in an emotional and financial toll on their families.

Health work connected to the choice not to vaccinate occurs in the home and community. People’s efforts also extend to the institutional level, where they work to respond to penalties they may encounter and maintain their rights as health decision makers for their children. Their vaccine decisions could be linked to their perceptions surrounding personal responsibility for health, independence, and empowerment to choose healthcare approaches as consumers. However, marked similarities in participants’ discourses surrounding natural, immunity, and homeopathy indicate that their health work is socially organized by a ruling relation that may be invisible to them.

People’s decision to not vaccinate does not signal an intention to turn away from all conventional healthcare providers, clinics, and hospitals. Our findings indicated that their choice is to engage in multiple health modalities and determine which ones best meet their needs at that moment in their children’s health. Their decision to not fully vaccinate itself might shift, leaving inroads for healthcare providers to look for opportunities to provide support. Within a neoliberal political and economic landscape that may seek to subjugate people who refuse childhood vaccines, engaging in this exploration provides an opportunity for nurses to recognize people’s intensive health contributions and identify possibilities for change at the institutional or ruling level.

## Chapter 5: Afterword

The purpose of this Afterword is to consider what I have learned along the way and reflect on what this means within the contexts that invariably impact how people's health work after declining vaccines is enacted. I will also identify a couple of potential areas for exploration based on pertinent reflections that I have contemplated and journaled about over the past several years. Using an IE approach to research doesn't yield suggestions about what should be done to fix the problem of vaccine hesitancy. The purpose of the research was to describe what is happening and to contemplate how it happens through textually mediated discourses with the aim of identifying opportunities within institutional work processes where change might be possible.

### Summary and Reflection

This Ph.D. dissertation described an IE approach to qualitative research within three manuscripts that seeks to form a better understanding about people's health work to enhance their family's health after declining routine childhood vaccinations. Examples of "health work" were identified in the qualitative systematic review and by a key informant, indicating commonalities between what people are doing for their children in different families and communities, at different times. To the best of my knowledge, an IE approach has not been previously used to understand people's "health work" after declining vaccines. My dissertation research presented a nuanced way to explore this topic using two diverse approaches to help form a better understanding of people's workful activities.

Chapters Two and Three, a JBI protocol and full JBI qualitative systematic review, were completed to answer the question of how parents experience the specific activities involved in caring for their under-vaccinated or unvaccinated young children after refusing routine scheduled

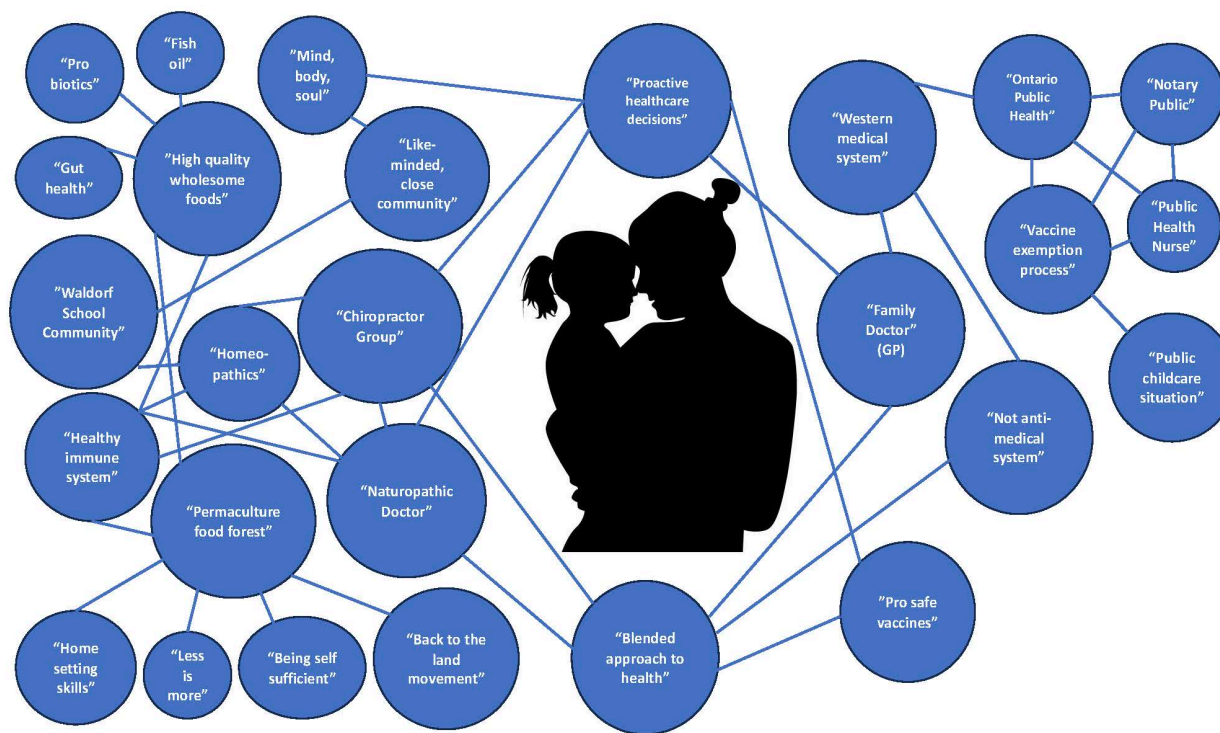
vaccines due to concerns about safety and efficacy. Our review team maintained an IE approach during the process of the systematic review by extracting findings about the care activities people described to enhance their children's health. We found that people were actively working within their family to enhance and protect their children's health after declining vaccines. In the community, people were managing difficult relationships with healthcare providers and peers, and cultivating new ones with like-minded parents. Our review also found that people were working at the societal level to protect their right to make vaccine decisions, and some people were also anticipating and planning for how they would respond to punitive measures by government agencies that penalize them for their decisions.

The second part of the dissertation included a key informant interview with 'Amy' (a pseudonym) using an IE approach to investigating people's experiences of health work after declining vaccines for their children. It began from Amy's standpoint as an informant who had declined vaccines for her children. Together, we explored her family "health work" to enhance her children's health. This included efforts to grow and provide a healthy diet for her family and navigating difficult relationships with people who disagreed with her choices, including peers and healthcare providers. Amy also worked to maintain her children's access to daycare and schools through a provincial vaccine exemption process. The discourses identified as potential threads for further investigation in the interview with Amy are illustrated in Figure 2.

In Chapter Four, Amy's descriptions of her health work were combined with participants' illustrations from the qualitative systematic review in a meta-ethnographic exploratory synthesis that provided rich and remarkably similar accounts of health work from two empirical studies. Discourses surrounding natural, immunity, homeopathy, and Waldorf education were explored through illustrations from studies that originated from multiple, diverse contexts.

**Figure 2**

*Key Informant Amy's Discourses*



*Note.* The lines connecting Amy's discourses reflect how they were related to other discourses within her descriptions of the family "health work" she does for her children. Amy's discourses provide further threads for IE investigation.

Our exploratory synthesis demonstrated that people's efforts to enhance their children's health and their experiences of providing health work are made visible through the verbatim descriptions of what they do. Before discussing our higher-level analysis of some of the institutional and societal discourses that influenced the health work of people who decline vaccines for their children, I first want to share some of my reflections about the research processes I have experienced. I will begin this section with a discussion about the limitations of my dissertation research and aspects of my investigation that I found challenging.

### **Research Limitations & Challenges**

#### ***Limitations***

Despite the recruitment challenges described in Chapter One, my dissertation has greatly benefited from a fulsome key informant interview with Amy. However, the research would have also been strengthened through the addition of more informants who experienced their health work from differing social locations, such as single or lone parents and people and families experiencing economic challenges. After completing such an extensive qualitative systematic review and feeling like I had a great foundation to begin interviews on this topic, recruitment challenges became a substantial limitation to my dissertation which I had not envisioned. Trying to recruit informants in a polarized, post-Covid context, where mistrust had grown amongst the people that I wanted to interview, was incredibly disheartening. Yet, it also offered me the chance to take stock of the situation and utilise an emergent design approach to qualitative research (Bruce et al., 2016). My evolving ability to collect data from informants led me to shift gears and look for other opportunities where knowledge could be generated.

It is also important to note that an IE approach has research limitations connected to the focus of the inquiry. An IE approach is concentrated on what is happening, not what should be

happening (Smith, 2005). Therefore, my topic and inquiry were not meant to solve the issue of people not fully vaccinating their children. However, by focusing on their health work, my aim was to provide awareness to health care providers, like nurses, about how people experience “authorized” vaccine discourses. Also, with further inquiry, I can aim to empower people who decline vaccines and may be stigmatized for their choices by showing them how things work in settings beyond their direct experience. Doing this involves being able to make connections with health care providers and community workers who also work within the health care system enacting power (ruling) relations embedded within. These are the textually mediated discourses and institutional work processes that socially organize people’s experiences of doing health work for their children. The end of this chapter provides suggestions for further research that could help to illuminate institutional organization within people’s direct experiences.

### *Challenges*

A challenge I experienced early on in my dissertation arose from discussions with other members of my Ph.D. cohort who are also family nurse practitioners. I was aware of the challenges of shedding a clinically focused primary care mind-set for a research lens, specifically with an IE approach (Harding, personal communication, May 9, 2023). Despite my intent to remain open to the descriptions provided by my informant, I still engaged in my research as a nurse, firmly footed in clinical practice, with relationships with families who choose not to vaccinate, and as a novice qualitative researcher.

IE researchers have discussed the challenge of engaging in topics that have personal meaning and how this can make the interviewing process emotionally difficult (Griffith & Smith, 1987). Though I did not find the interview process to be difficult, I felt uncomfortable with the discussions that situated health as an individual pursuit, devoid of implications for other people.

Smith and Griffith (1987) analysed the “unnoticed matrix of social organization that constructs both the interview talk and their emotional reaction to it” (p. 94) in their study of mothering. This analysis, in recognizing their own emotion within their research, led them to recognize how *their own experiences* helped them to find clues to the social organization of mothering (DeVault, 1990; Griffith & Smith, 1987). I have wondered if my own experiences of being a mother, a nurse, and a researcher have converged to provide further clues to the social organization of people’s “health work.”

### **Reflections on Learning from the Findings of this Investigation**

In the following section, I will discuss how vaccine hesitant people enact health work activities that are encouraged by allopathic healthcare providers, while their decisions about vaccines are simultaneously criticized. Further on, I will briefly examine some contextual factors that explain how choice in healthcare and mistrust of institutions can be linked to the added responsibility people experience that compels them to enact health work for their children after declining vaccines. The challenges of choices within healthcare will also be discussed from the standpoint of healthcare providers, like nurses, in caring for people and their families.

Next, I will present ideas for further research in relation to the institutional traces and work processes shared during the key informant interview and identified by study participants in our systematic review. Engaging in a dissertation research topic that explores the everyday experiences of people enhancing their children’s health after declining vaccines left me with several options for consideration. Specifically, what does an investigation of people’s health work tell us about how it is accomplished through textually mediated social organization? Findings from the qualitative systematic review and my key informant interview with Amy

provided some direction about how people's work processes are textually mediated in different ways.

I also reflected on how the predominant discourses about complementary and alternative medicine (CAM) and homeopathy in our data might mean that this form of health care is becoming more widely accepted and supported as a form of healthcare in Canada and what this means for issues like vaccine hesitancy. Concerns may arise when there are differing perspectives on the safety and necessity of vaccines being communicated to people by some CAM practitioners. What was missing in these discourses will be developed more fully in the pages that follow, where I build on my experiences to identify some problematics to guide further IE research.

### ***Institutional and Societal Discourses***

My supervisor and I examined the institutional and societal discourses identified by Amy and the study participants by drawing on our own knowledge of the health care system and the world we are currently enmeshed within. Within health care, we identified lifestyle discourses grounded in natural living, and discourses that reflected a profound sense of responsibility for making informed decisions about the health of their family, including the decision to decline some or all vaccines for their children. The study participants and our research informant framed these choices in terms of being an informed consumer of health products and services (Reich, 2014; 2016). Some people mentioned grounding their decision-making in their personal experiences and body knowledge, which is congruent with a feminist approach to knowledge construction (DeVault, 1999).

We also noted biomedical discourses that grounded health choices on rational processes of "informed" decision-making, meaning that these decisions were grounded in hierarchical,

more objective, and authorized research methods (Carrion, 2014; Reich, 2020b). Epidemiologic discourses were present in terms of promoting health and preventing illness in various ways (ten Kate et al., 2021; Tombs-Heirman, 2009; Vandenberg, 2013). Herd immunity was also mentioned by some people as a negative discourse, implying that their health care decisions reflected unquestioning acceptance of professional healthcare recommendations making explicit links to sheep and other herded animals (Reich, 2020b).

Some societal discourses shared were about the need to grow their own organic, healthy foods as protection from industrial farming practices that result in environmental contamination (Carrion, 2014; Tombs-Heirman, 2009). Similar concerns were raised about the profit motives of pharmaceutical companies, and decreased or inadequate monitoring of health risks related to vaccines (Crescitelli et al., 2020). As a result, some people turned more toward CAM for treatment of health conditions while still relying on the Western medical system for diagnosis and care when these less dangerous homeopathic therapies were ineffective or inappropriate for their children (Atasever et al., 2021; Fallet, 2017; Martinez-Diz et al., 2014). Most of the high-level societal discourses were firmly grounded in overarching neoliberal economic discourses that support free markets and competition, investors and corporations, consumer choices and freedom from governmental regulations and control<sup>18</sup> (Hamilton, 2016; McCabe, 2016, Minnotte, 2023).

Ultimately, we identified two institutional circuits that appear to be exerting a profound impact on the standpoint of people's health work, these included:

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<sup>18</sup> An introduction and discussion of neoliberal discourses is present in the discussion section of Chapter Three: JBI qualitative systematic review.

- 1) Consumer choice discourses that resulted in a profound sense of responsibility for health work being located almost exclusively within families; and
- 2) Freedom discourses that champion for less government and decrease funding for health and social services, and are also linked to subsequent mistrust of government programs and institutions.

The need for further study in relation to these two institutional circuits arose from deep reflection on my findings and will be introduced and discussed in more depth in the pages that follow. Both will require further IE investigation grounded in the developing problematics that I will later articulate.

There were moments in this research exploration that bothered me as a nurse. For example, there were times when my focus wavered from the standpoint of the key informant to the standpoint of the healthcare provider. This mostly occurred in the descriptions my key informant provided about negative interactions she had had with nurses and doctors due to her vaccine choices. It also occurred during her discussions about where she would access support and care if her children became ill. Amy detailed that if her children contracted a VPD, she would approach her physician (GP) for assistance.

I did not expect people to avoid accessing healthcare if their unvaccinated child contracted a VPD and required support, but rather, I was curious to see if my key informant would mention the risk of her children spreading the disease to other people in these healthcare settings. My informant did not mention this, and some qualitative research participants stated that their children, due to their superior health status and natural immunity, did not pose a health risk to other children.

**Individualized Responsibility for Health Work.** The primary focus for both my key informant and for qualitative research participants was on the individual health needs of their own children and family. Researchers have indicated that the denial of a social contract inherent in accepting vaccines in favour of individual pursuits directly rejects public health as a worthwhile endeavour (Sanders & Burnett, 2019). Vaccine critics have rejected the argument that immunizations foster community welfare, and instead stipulate that their responsibility resides in assuring the health of their own children (Sanders & Burnett, 2019). The community-wide considerations, ingrained in my own standpoint, rang alarm bells in my mind as I considered the young immunocompromised patients who may be exposed to a VPD in a primary care, emergency room, or hospital setting. I re-read my interview notes frequently to contemplate the reaction I had to these responses and what it meant to the approach I was trying to take in my research.

My interest in how people care for their children's health is undoubtedly driven by my personal and professional experiences. However, deeper exploration has also led me to understand that individualist approaches to health work that veer strongly from notions of community health are not exclusive to people who don't fully vaccinate their children (Hamilton, 2016; Hays, 1996; Steiner & Bronstein, 2017). Individualist approaches to both health and childrearing are indicative of a neoliberal discourse of personal responsibility for health outcomes that are well documented in research that explores the high expectations of modern-day caregiving (Avishai, 2007; MacKendrick, 2014; McCabe, 2016; Minnotte, 2023; Reich, 2020a). Attending to my emotional "knee-jerk" reactions involved cultivating my own awareness of how my informant (like many parents) were accepting high levels of responsibility for their children's health. I could see how this would leave little space to contemplate on the health of the

entire community, or even seeing their children's health as being connected to the broader population.

The knowledge generated from writing this dissertation provided awareness about the heightened responsibility of people's "health work" after declining childhood vaccines. Much of what was described in Chapters Three and Four about "health work" or "care activities" are taken for granted, embodied experiences of people who are laboriously trying to enhance their children's health, while managing the stigma related to their vaccine choices (Huel et al., in press). The remaining parts of this Chapter offer perspectives from research on how vaccine hesitant people are perceived as "anti-vaxxers," discuss discourses reflected in their talk about "health work," and explore some contextual factors that may have led people to take up an individualist approach to their children's health. It reflects my own push-back to the discomfort I experienced, and my effort to contemplate why people may approach health this way, rather than as a community or collective venture. The first part focuses on consumer choice discourses that resulted in a profound sense of responsibility for health work being located almost exclusively with families.

### ***Being Called an "Anti-Vaxxer"***

The IE approach to my dissertation was a reflection of my intention to align this topic with a method of inquiry that could provide a nuanced understanding about people's "health work" after choosing not to vaccinate their children. IE as a critical approach to qualitative research seemed particularly fitting, because it addresses power and ruling relations along with taken-for-granted assumptions about what people are doing (Campbell & Gregor, 2004). It seemed that regardless of how people responded to feeling hesitant about vaccines (e.g. refusing all or some vaccines or agreeing to vaccines, but feeling unsure about their decision), they were

being grouped into one category. The term “anti-vaxxer” has a strong negative connotation and continues to be used in health care contexts. It goes beyond feeling hesitant about vaccines or not fully vaccinating your children. Being called an “anti-vaxxer” also extends to assumptions about people taking strong positions on other social, political, and moral issues (White & O'Doherty, 2023). Recent discursive analysis research found that the term “anti-vaxxer” is broadly applied to people whose attributes are overgeneralized, and unlikely to represent all individuals who choose not to vaccinate (White & O'Doherty, 2023).

An IE approach avoids the objectification of research informants by producing knowledge for people, instead of knowledge of people, in which the direction of looking is reversed by taking up the standpoint of the people whose work or problems you seek to understand (DeVault, 1999). My research explored this topic out of the pervasive concern that the label of “anti-vaxxer” was demonstrative of an ideological circle, or circuit, that seeks to control ideas within public textually mediated discourse, as part of ruling relations, and dominate the terms of the debate on the topic of people choosing not to vaccinate (Stanley, 2018). Ultimately, this discursive practice disciplines the people who decline vaccines for their children for not conforming to medically sanctioned recommendations.

White and O’Doherty (2023) remarked on how dismaying it was that so many health professionals and scholars use terms like “anti-vaxxer” in professional and public settings, either disregarding or perhaps even taking populist pleasure in the inflammatory nature of its use. Smith (1990) notes that an ideological circuit is produced in hierarchal organizations and enacted by people, like health professionals and scholars, with the aim of accounting for courses of action as appropriate ones: “There is a process of practical interchange between an inexhaustibly messy, different, and indefinite real world and the bureaucratic and professional system that

controls and acts upon it. Professionals are trained to produce out of this an order, which they believe they discover in it” (Smith, 1990, p. 126). My dissertation research demonstrated a component of the inexhaustibly messy, different, and indefinite real world of people’s embodied health work. I wanted to offer a divergent perspective from the professional systems that may seek to simplify the issue of vaccine hesitancy, label it a product of “anti-vaxxers,” and ostracize people for their choices (White & O’Doherty, 2023). This view is a reductionist approach that ignores how societal discourses responsabilize parents to focus exclusively on their own children and family. It provides another illustration of how people’s health work for their children is socially organized by institutions that are outside of their realm of control. The following section discusses vaccine hesitant people’s sanctioned health work processes for their children and provides perspectives on how this health work has evolved with the introduction of consumer-like choices in healthcare.

### **Sanctioned Family Health Work Processes**

It’s important to note that in people’s descriptions of health work for their children, there are examples of workful activities that would be considered beneficial for children’s health, regardless of vaccine choices. An example of this would be Amy’s descriptions of feeding her children a healthy diet with fresh, homegrown produce and probiotic foods. Healthy eating, breastfeeding, exercise, and avoiding unnecessary antibiotics would be considered sanctioned by the healthcare system, as this “health work” is not fundamentally different to the health advice that most people who care for children would receive from healthcare providers.

### ***Gaining Vaccine Exemptions: An Accommodation***

The other textually mediated work process that was “allowed” was Amy’s work to gain the preschool/school vaccine exemptions for her children. Though this process is sanctioned by

the Ministry of Health in Ontario, it does not have the same association with being a health benefit as the work described above. This process of exemption is part of the Ontario Immunization of School Pupils Act (2021) that stipulates that all children who attend primary or secondary school must be immunized against diphtheria, tetanus, polio, measles, mumps, rubella, meningitis, pertussis, and varicella. Parents are required to provide proof of their child's immunization at their local public health unit and keep their immunization information up to date to attend school. If a parent declines vaccines for conscience or religious belief, their children can still attend school, but they need to complete an exemption process (Ontario Ministry of Health, 2024). The work done by this process is to provide an accommodation for people who decline vaccines, as this decision is not sanctioned or authorized by public health.

This process begins with a local public health unit organizing the exemption, which includes watching a vaccine education video, discussing vaccines and the exemption process with public health unit staff, and obtaining a *Vaccine Education Certificate* (Ontario Ministry of Health, 2024). Afterwards, people complete a *Statement of Conscience or Religious Belief* form and have it signed by a commissioner for taking affidavits in Ontario. People are required to make copies of these documents for their own records, as the original copies of the *Vaccine Education Certificate* and notarized *Statement of Conscience or Religious Belief* form are submitted at the local public health unit (Ontario Ministry of Health, 2024). The Ministry of Health advises parents to make and keep copies of these documents, because the ministry and local public health unit do not keep records of the exemption documents (Ontario Ministry of Health, 2024).

Regardless of the punitive nature of this sanctioned work process, or how “annoying” it was, Amy relayed to me that she felt grateful after the experience. She expressed gratitude that

she wasn't being forced to vaccinate her children and was given the choice to complete this process so that her children could attend daycare and school. This statement led me to consider what it is to have "authorized" choices (or expectations) in many facets of our health and well-being? How do choices related to vaccines, schooling, healthy diets, probiotic foods, breastfeeding, and exercise fit into how people care for their children along with the issue of vaccine hesitancy? Are these choices in healthcare sanctioned by ruling regimes, or labeled as being resistant or non-compliant, and by which institution? This question is particularly pertinent when you consider the prevalence of complementary and alternative healthcare practitioners and the divergent viewpoints that some may share with people regarding health work and vaccines (Caulfield et al., 2017). Finally, I ask the question, do the litany of healthcare choices that we are presented with reflect what is best for our health, or do they accomplish a goal or priority that's more aligned with institutional power relations and financial interests that supersede people's well-being? The following section looks at sanctioned choices, and their impact on people and healthcare providers.

### ***Choosing Health: Challenges for People***

A common thread in the descriptions of people's sanctioned "health work" in both the qualitative systematic review and in informants' descriptions was the prevalent discourse of seemingly limitless *consumer choices* in healthcare. People discussed choosing the best healthcare for their family (Haarstick, 2021), choosing to breastfeed (Harmsen et al., 2013; Wiley et al., 2022), choosing natural lifestyles (Thornton & Reich, 2022), choosing to minimise sugar and processed foods (Wiley et al., 2022), choosing to home birth (Attwell et al., 2018b), and choosing to keep their kids: "as healthy as they can" (Wiley et al., 2022, p. 1683).

During the interview, Amy discussed her choice to decline her doctor's recommendations to vaccinate her children. However, she also explained that if her children became ill from a VPD, she would *choose* to seek help, treatment, and support from her physician. This was echoed by qualitative research informants who also reported their confidence in allopathic physicians' abilities to care for their children's VPD symptoms if they required care outside of the home (Blaisdell et al., 2016; Haarstick, 2021; Tomljenovic et al., 2022). The common thread in this finding is how people are independently determining under which conditions they would choose to access allopathic health care for their children. Throughout the course of both studies, I was struck by the level of responsibility that people shouldered in making choices in their children's health. This wasn't done in isolation of other forms of advice from healthcare providers, peers, or CAM practitioners, but the final decision was located with people caring for children to make these determinations.

**Logic of Choice.** In 2008, Dutch philosophy professor Annemarie Mol wrote a short book that both theorized and provided examples about how the prevailing shift from a "logic of care" to a "logic of patient choice" in healthcare systems was negatively impacting the way people deal with disease (Mol, 2008). Mol argued that a healthcare preoccupation with our patients becoming our "customers" had not intrinsically improved how care is provided. This is despite having access to limitless consumer choices, and the responsibility (both independently and in collaboration) for choosing the correct assortment of health options. Specifically, the fallacy of "choice" in healthcare could be observed in situations where patients, regardless of their health status, make incorrect assessments about risks that inadvertently lead them to poorer health outcomes regardless of their ability to choose their course of treatment (Mol, 2008). This

could be seen when people lack material resources or when a sense of fear compounds the level of responsibility that is built into their choice.

Essentially, Amy's vaccine choices had some element of trepidation built into them, both in the potential for her children to contract a VPD, and in her fears about vaccines negatively impacting her children's health. My practice experiences providing vaccines to young children have taught me that people are often fearful about providing vaccines to young infants and children. However, once the children are closer to school age, much of this fear dissipates. I noted that Amy's fears could be more persistent, more grounded in a potential that is impossible to predict.

**Fear and Vigilant Consumption.** Fear related to making decisions about children's health has been detailed in research that explored mothers' health work to mediate exposure to environmental chemicals. MacKendrick (2014) explored how mothers employed precautionary consumption choices for their children to reduce their exposure to chemicals found in food, consumer products, and in the home. This research study detailed that the concept of *vigilant consumption* was representative of an ever-expanding sphere of responsible motherhood whereby, in the absence of a government's commitment to legislate protective frameworks surrounding environmental toxins, responsibility for avoiding harmful chemical/toxins is placed on women; namely, those who are contemplating pregnancy, are pregnant, or caring for children (MacKendrick, 2014). This research provided awareness about how people's health work to be vigilant about toxins their children may be exposed to are working from a frame of reference that puts them at odds with institutional authorities, like governments, who may play a role in environmental contamination.

People are taking their own initiative, within their families, to make informed health care choices and avoid toxin exposure in response to what they perceive as governmental inaction to protect them as citizens and consumers (Cairns & Johnston, 2018; Reich, 2016). Logic of choice in healthcare and vigilant consumption, in combination with people's concern for their children's health and mistrust of governmental regulation, provide perspectives about societal discourses that may influence people's experiences of health work for their family. Namely, these are deliberations that people may be considering when making decisions about vaccinating and determining which health work activities they do to enhance their children's health.

### ***Responsibility and Choosing Vaccination***

Beck (1992) argued that a recalibration of risk has shifted from the institutional to the individual level. As people began to realize that health was as much a product of lifestyle as it was of science, they began to view risk as a choice, subject to individual control (Beck, 1992).

The responsibility for "health work" that people do for their families, regardless of the vaccine decisions, is under the auspices of having "choices" in their care. I would argue that the consumeristic allure of authorized health choices is actually concealing a moral obligation and expectation for people to independently make health decisions and promote a healthy lifestyle for their children (McCabe, 2016; Pozniak, 2017; Trnka & Trundle, 2014). "Health work" is a significant burden of responsibility and is done in tandem with other family obligations, household work, occupational duties, studies, community commitments, and leisure time. In addition, the expectations to enact this work is evenly distributed amongst all people with children, regardless of the personal, social, and financial resources they may have (or not have) at their disposal (Thornton & Reich, 2022).

### ***Talking about Complementary, Alternative and Integrative Medicine***

The final area discussed in this chapter discusses an emerging second problematic related to neoliberal freedom discourses that champion less government, decreased funding for health and social services, and are linked to mistrust of government programs and institutions (McCabe, 2016). Although CAM is currently located outside of publicly funding health services, recent inroads by private companies into health services suggest that things are shifting toward more acceptance of profit-driven health care services receiving part of the funding envelope currently allocated for public health care. The use of CAM was also mentioned as part of the “health work” people described doing for their children’s health.

### ***Examples of Health Work and CAM in the Studies***

Health work that included using CAM was discussed by many of the informants from the included systematic review studies as well as my key informant. Amy provided descriptions about accessing CAM providers along with providing some of her own modalities to her children (probiotics). Similarly, qualitative review informants accessed CAM providers for healthcare (Haarstick, 2021; Tombs-Heirman, 2009; Zin et al., 2022), and they independently learned and administered CAM-related health products for their children (Attwell et al., 2018; Haarstick, 2021).

While looking at the findings from both studies, I was interested in understanding how workful activities related to using CAM for family health are socially organized. This could be followed up through analyzing the book Amy mentioned: *Raising a Vaccine-Free Child* (Lydall, 2005) to look for traces of CAM discourses in the instructions the author provides to people about how to care for their children’s health. Alternatively, Amy’s chiropractor provided her with information about caring for her children and how to take care of a child who has the measles. If

Amy's chiropractor was willing to speak with me, this would be another way to trace the information she has been provided about caring for her children's health if they contract a VPD or about how to enhance their general health. These are two avenues to continue an IE exploration of my topic based on the textual resources mentioned during our conversation. I now feel strongly that CAM needs to be considered a burgeoning institution in Canadian health care and investigated to bring awareness about the textually mediated ruling relations and social processes being distributed to local settings of health working, particularly when this alternate health-related institution may have hidden profit motives and appeal to people with a holistic, individualized approach to health.

### ***What is CAM/CAIM?***

According to the National Centre for Complementary and Integrative Health, 'CAM' is better described as complementary, alternative and integrative medicine (CAIM), because it involves two separate approaches to healthcare (NCCIH, 2021). CAIM includes "non-mainstream" health approaches used together with conventional medicine and therefore considered "complementary." If a non-mainstream approach is used *in place* of conventional medicine, it's considered "alternative." "Integrative health" involves bringing conventional and complementary approaches together with "multimodal interventions" (NCCIH, 2021). These are two or more interventions originating from conventional health care approaches (medication, physical rehabilitation, psychotherapy), in combination with complementary health approaches (like acupuncture, yoga, and probiotics) in various combinations (NCCIH, 2021). It's not easy to identify an overall definition for what "CAIM" includes. Instead, The Cochrane Collaboration has developed an operational definition of CAIM that can be accessed on the internet and includes all interventions that are considered to be under the CAIM umbrella (Ng et al., 2022).

### ***The Relationship between CAIM and Vaccine Hesitancy***

The relationship between people using CAIM and feeling hesitant about, or refusing, all or some vaccines has been explored in research. Ward et al. (2023) investigated the relationship between attitudes to CAIM and attitudes towards vaccines, and found that among vaccine-hesitant people, pro-CAIM attitudes are often combined with other traits, like distrust of health agencies, radical political preferences, and low income. The researchers found that pro-CAIM attitudes were not directly related to people feeling hesitant about vaccines (Ward et al., 2023). Other researchers have reported that CAIM is a weak predictor of vaccine hesitancy; however, vaccine hesitancy is strongly associated with distrust of conventional medicine, and *this* relationship was particularly strong among CAIM users (Hornsey et al., 2020). Therefore, CAIM isn't reported as a major obstacle to people's willingness to vaccinate; the more relevant obstacle appears to be people's mistrust of conventional medical treatments (Hornsey et al., 2020). Though refusal of vaccination could be higher amongst CAIM users than non-users, the use of CAIM and not vaccinating are considered to have overlapping reasoning rather than a causative relationship in that both are more strongly linked to a critical attitude and distrust of conventional/allopathic medicine.

### ***Combining Health Care Modalities and Services: Consumer Choices***

In Canada, approximately 20% of households with children under the age of 18 have used CAM/CAIM for their children (Esmail, 2017). While contemplating the relationships between health work, choices, trust/mistrust, healthcare provider practice, institutions, CAIM, and childhood vaccines, I was interested to think about this web of connections, particularly when it seems that use of CAIM doesn't necessarily cause someone to eschew vaccines.

However, my research demonstrated that CAIM does play a role in people's choices about where they go first when they require healthcare.

Amy discussed receiving a diagnosis from her family doctor, but then going to a naturopathic physician or homeopath for treatment options. She supported this choice because she felt that if she went to the allopathic system, they would give her children "a lot of stuff" and she did not want to jump to that approach right away. Amy explained that she wasn't "anti-medical system," but she had faith that her children's bodies were smart and intuitive and could heal themselves. She was comfortable with her children having a "super-high fever" for a short period of time and would see her GP only if her children had been sick with a fever over an extended time with no improvement. Some informants from the systematic review accessed CAM practitioners as their first choice for treatment, while others reported seeing a CAM provider as an alternative if their allopathic provider was not providing "treatment options" that were amenable or agreeable to them (Attwell et al., 2018; Tombs-Heirman, 2009).

In IE "ruling relations" communicates the expectation that institutional practices will be shaped by the logics of a capitalist patriarchy (DeVault, 1999). However, within these institutional practices shaped by a capitalist lens, contradictions, slippages, openings, and windows of possibility remain in waiting. Regimes transform over time and accommodate new forms of accumulation and resistance (DeVault, 1999). Throughout my dissertation research, I have considered if CAIM's resistance to sanctioned allopathic health work processes are actually part of a bigger move to play a more substantial (and profitable) role in healthcare. An example of this pervasive resistance to vaccine recommendations and VPD care was described by Amy when she discussed how she tried to get information about caring for a child who has contracted a VPD:

*Amy:* I also want to add one piece, is that our Chiropractor group ... probably shouldn't name who it is, umm, she, is also very helpful with us around ... you know, she's like, "Call me if the measles or the whooping cough come, like I can support you in this."

*Christine:* Got it. Got it. And your chiropractor and your naturopathic, doctor, have they ever given you any specific resources or information? And you mentioned your doctor didn't, but they did?

*Amy:* Yeah.

*Christine:* What did they give you to help you in terms of your information needs?

*Amy:* Okay. Yeah, they gave me ... just like: "Check out these links. These are the links to go to." They gave me a curio link. All of them ... it was like covert, they're like: "I'm going to lose my license...."

*Christine:* Yeah. Yeah.

*Amy:* "...like, you can't use my name. This is very risky for me right now. We're off record. I'm not doing this on Zoom because you could be recording." It's all very hush-hush. "I'll meet you in person, but I'm not going to do it over a phone call."

Devault (1999) explains that an institutional ethnographer contributes a map, not a definitive account of this continually transforming terrain to chart the specific practices that operate systems of oppression, and thus are useful for activist groups deciding on strategies for change. I have continued to ask myself if the Canadian healthcare system, chronically underfunded, understaffed, over-managed, and struggling to meet people's health needs, has

provided the slippage, the opening, the window of opportunity that has allowed for widespread CAIM use to enter healthcare, as a competing capitalist discourse, and accommodating new forms of resistance through contradicting narratives about the necessity of vaccines?

At the time of writing, I have followed news reporting that Alberta Health Services may consider providing provincial monies towards alternative forms of healthcare including naturopathic physicians (Bruch, 2023). While examining 330 naturopath websites in British Columbia and Alberta, researchers found that 40 included “vaccine hesitancy” discourses and 26 offered vaccine or flu shot alternatives (Caulfield et al., 2017). Providing government funding for health services that may fuel vaccine hesitancy would be very confusing for the public. There would be competing and contradictory discourses from ruling institutions that would call into question the governmental stance on the necessity, safety, and efficacy of vaccines. Or perhaps it would present childhood vaccines as optional, another choice for people to make, rather than a strongly recommended preventative health measure supported by the Ministry of Health. This signals a move towards a type of healthcare that is highly individualized, holistic, and offers even more choices to people. However, many of the modalities under the CAM/CAIM umbrella lack scientific evidence of efficacy (Caulfield et al., 2017).

Amy’s descriptions demonstrated resistance when her CAIM providers presented information about vaccines as covert, undercover, or something that they could lose their license over. This is a compelling discourse from a trusted healthcare provider that could lead a person to decline vaccines for their children and take up their recommendations for “health work” sanctioned by CAIM, yet unsanctioned by the allopathic healthcare system. However, I am concerned that we are on course to formally introduce (and fund) CAIM to healthcare, without adequately addressing underlying problems, like access, in our healthcare system. When there

are fundamental disagreements between the two systems on something as important as vaccines, can there be a middle ground?

### **Future Directions for Research: Building Bridges**

I engaged in my dissertation in a way that's akin to the way I prefer to engage as a nurse practitioner; by building bridges to people and populations whose decisions don't always align with my own. Several years ago, I attended the Nurse Practitioner's Association of British Columbia Conference and heard a Family Medicine Professor (David Kuhl) from the University of British Columbia speak about the problems with *patient-centred care*. His criticism, which was mildly controversial for a crowd of nurse practitioners who had likely had their entire nursing education grounded in family/patient-centred care discourses resonated with me. David Kuhl surmised that leaving healthcare providers out of patient-centred care was going to make us resent our patients (Kuhl, 2017). Instead, he recommended that we focus on relationship-centred caring, with healthcare providers and patients, working together in a way that fosters everyone's health and understanding.

I took this with me into my practice, and have thought a great deal about how I would provide relationship-centred care to the families I worked with who decided not to vaccinate their children. It led me to this dissertation, as I determined that providing relationship-centered care to people you disagree with, is through maintaining a bridge between you. One where you feel comfortable to inquire about their children's vaccines and they feel comfortable to approach you in return. However, it also involved trying to understand people who make this choice, as people, not as anti-vaxxers. I also wanted to build a bridge through my research to explore topics with them that wouldn't further marginalize them for their perspectives.

I saw that within a contestable vaccine decision, people had inner and outer strengths that contributed positively to their children's health (Gottlieb, 2014). People were working hard to try and continue to understand information about vaccines that would either reaffirm their choice or cause them to re-evaluate it. Exploring people's "health work" was a way for me to try and shift the prevailing negative narrative on people who don't vaccinate, while still trying to understand a facet of vaccine refusal that could provide healthcare providers and researchers with a different awareness surrounding their workful activities for their children's health. It has also given me ideas or avenues on where to take the studies I have just completed to follow some of the institutional threads to different levels of IE mapping or inquiry.

### **Areas for Further IE Investigation**

The social organization of consumer choice discourses resulting in a profound sense of responsibility for health work being located almost exclusively with families could be further explicated as an institutional circuit<sup>19</sup> that is firmly grounded in neoliberal economic discourses. We also identified in Amy's interview a segment on an institutional work process that could be explicated more fully, namely the Ontario vaccine exemption process addressed below. The final area for further development reflects neoliberal economic "freedom" discourses that champion for less government and decreased funding for health and social services. Are these textually mediated discourses linked to mistrust of government programs and institutions? Could these discourses also be operating as institutional circuits? I will introduce how my concerns arose in the following section as an example of a developing problematic for further research.

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<sup>19</sup> The displacing of what is actually going on in people's lives when they are caught up in the textual representations of institutional order; shown through standardized representations that conform to language and framing of governing or boss texts (e.g. theories, laws, procedures, policies, rules, regulations) (Smith & Griffith, 2022).

### *Public Health Exemption and Accommodation Work Processes*

Amy shared details about her process for receiving a conscience exemption for her children's vaccines so they can attend school. This could be a possible thread to follow in future IE inquiry. After Amy's interview, I searched and found an example of an Ontario Vaccine Exemption Form, I also looked for prior research to see if or how the vaccine exemption process had been studied. A presentation by the Associate Medical Officer of Toronto Public Health, reported that the exemption process had undergone a survey study of the people who attended a public health unit for the video and discussion (Dubey, March 3, 2020). I was not able to find research that explored the public health perspective on the exemption process. A potential research avenue would be to interview nurses or managers from Ontario Public Health Units to see how vaccination and the vaccine exemption process are undertaken as an institutional chain of action. The possibility of observing a person working with the public health staff to complete the exemption would also be an insightful option. This could provide more awareness about the processing interchanges people experience as they navigate the exemption paperwork and the visits to different institutional actors involved.

A notable conclusion of the JBI qualitative systematic review was that gender-based, economic, and racially marginalized people experienced health work differently. Their illustrations were more focused on the health work needed to thwart governmental punitive measures, rather than that related to natural lifestyles. Future research with public health nurses involved in the exemption process could also explore how parents who struggle financially manage to complete the accommodation process. As the process requires taking time away from work (both inside and outside of the home), going to different locations, and paying a fee to a notary, understanding nurse's experiences of helping (or not) people who may find this

challenging, could be another possible way to understand and map health work with respect to their experiences.

### ***Tensions between CAM and our Publicly Funded Allopathic Health Care System***

The prior section detailed how CAM is becoming more present in health care and may be related to the health work and healthcare people provided to their children. Originally, I would have assumed that the medical system, as part of a ruling relation, would not want to lose primary care patients to CAM practitioners. Recent events may be indicating that naturopathic physicians may begin to play a government-funded role in primary care provision. It would be interesting to interview primary care physicians or family nurse practitioners, or someone in a leadership position with the Canadian Paediatric Society, to inquire about their thoughts about this potential influx of CAM into primary care and how (or if) they are seeing it successfully partnering with an allopathic system. Also, interviewing primary care providers to understand the texts that guide their vaccine recommendations and their understandings of VPDs could provide understandings about how their practice is organized with consideration to families who are vaccine hesitant and their approach to caring for them.

### **Summary and Conclusion**

This Ph.D. dissertation described an IE approach to qualitative research within three manuscripts to better understand people's health work to enhance their family's health after declining routine childhood vaccinations. A JBI protocol and qualitative systematic review were completed, and we found that people enacted laborious care strategies for their children after declining vaccines in three contexts. People's health work happened within the home to enhance and protect children's health. They also engaged in health work in the community, by handling schooling responsibilities, managing difficult relationships with healthcare providers and peers,

and cultivating new ones with like-minded parents. People also worked at the systems level to protect their right to make vaccine decisions. They anticipated and planned for how they would respond to punitive measures by government agencies that penalize them for their decisions.

The second part of my dissertation was a key informant interview using an IE approach to investigating people's experiences of health work after declining vaccines for their children. It began from the key informant's (Amy's) standpoint as a person who had declined vaccines for her children. Together, we explored her family "health work" to enhance their children's health. Amy's descriptions of her health work were combined with participant's illustrations from the qualitative systematic review in a meta-ethnographic exploratory synthesis that provided rich and remarkably similar accounts of health work from two empirical studies. Discourses surrounding natural, immunity, homeopathy, and Waldorf education were explored through illustrations from studies that originated from multiple, diverse contexts. Our exploratory synthesis demonstrated that people's efforts to enhance their children's health are made visible through the verbatim descriptions of what they do.

My dissertation research has offered an entry point into bringing awareness about how institutions within ruling relations influence the social organization of people's health work activities. My goal in this research was to produce an understanding that assists people and healthcare providers to recognize societal discourses and identify potential influencing factors of vaccine hesitancy that can increase awareness of their health work that may have gone unnoticed. From this understanding, I hope that healthcare providers and researchers recognize that respect for people's "health work" can exist in tandem with a difference in viewpoints about the safety, necessity, and efficacy of vaccines.



## References

- Allan, N., & Harden, J. (2015). Parental decision-making in uptake of the MMR vaccination: A systematic review of qualitative literature. *Journal of Public Health, 37*(4), 678–687.  
<http://doi.org/10.1093/pubmed/fdu075>
- Ames, H. M., Glenton, C., & Lewin, S. (2017). Parents' and informal caregivers' views and experiences of routine early childhood vaccination communication: Qualitative evidence synthesis. *Cochrane Database of Systematic Reviews, 2*(2), CD011787.  
<http://doi.org/10.1002/14651858.CD011787.pub2>
- Aromataris, E., & Munn, Z. (2017). *Joanna Briggs Institute Reviewer's Manual* (Joanna Briggs Institute Reviewer's Manual).  
<https://synthesismanual.jbi.global>. <https://doi.org/10.46658/JBIMES-20-01>
- Aromataris, E., & Riitano, D. (2014). Constructing a search strategy and searching for evidence. *American Journal of Nursing, 114*(5), 49–56.
- Atasever, B. N., Sayar, S., Sabancı, M., Gür, A. B., & Karakoç, H. (2021). Vaccine rejection for parents with babies of 0–24 months: Solution recommendations for causes and reduction. *Journal of Pediatric Infection / Çocuk Enfeksiyon Dergisi, 15*(2), e97–e102.  
<http://doi.org/10.5578/ced.202119817>
- Attwell, K., Meyer, S. B., & Ward, P. R. (2018). The social basis of vaccine questioning and refusal: A qualitative study employing Bourdieu's concepts of 'capitals' and 'habitus'. *International Journal of Environmental Research and Public Health, 15*(5), 1044.

Attwell, K., Smith, D. T., & Ward, P. R. (2018). 'The unhealthy other:' How vaccine rejecting parents construct the vaccinating mainstream. *Vaccine*, 36(12), 1621–1626.

<http://doi.org/10.1016/j.vaccine.2018.01.076>

Attwell, K., Ward, P. R., Meyer, S. B., Rokkas, P. J., & Leask, J. (2018). "Do-it-yourself:" Vaccine rejection and complementary and alternative medicine (CAM). *Social Science & Medicine*, 196, 106–114. <http://doi.org/10.1016/j.socscimed.2017.11.022>

<http://doi.org/10.1016/j.socscimed.2017.11.022>

Avishai, O. (2007). Managing the lactating body: The breast-feeding project and privileged motherhood. *Qualitative Sociology*, 30, 135–152.

<http://doi.org/10.1007/s11133-006-9054-5>

Austin, H., Champion-Smith, C., Thomas, S., & Ward, W. (2008). Parents' difficulties with decisions about childhood immunization. *Community Practitioner*, 81(10), 32–36.

Austvoll-Dahlgren, A., & Helseth, S. (2010). What informs parents' decision-making about childhood vaccinations? *Journal of Advanced Nursing*, 66(11), 2421–2430.

<http://doi.org/10.1111/j.1365-2648.2010.05403.x>

Backman, F. (2019). *Us against you: A novel*. Simon and Schuster.

Baskett, W.I., Qureshi, A.I., Shyu, D., Armer, J.M., Shyu, C-R., & editors (2023). COVID-specific long-term sequelae in comparison to common viral respiratory infections: an analysis of 17 487 infected adult patients. *Open Forum Infectious Diseases*, Oxford University Press US. <http://doi.org/10.1093/ofid/ofac683>

Bedford, H., Attwell, K., Danchin, M., Marshall, H., Corben, P., & Leask, J. (2018). Vaccine hesitancy, refusal and access barriers: The need for clarity in terminology. *Vaccine*, 36(44), 6556–6558.

- Beck, U. (1992). *Risk society: Towards a new modernity* (Vol. 17). Sage Publications.
- Bisaillon, L. (2012). An analytic glossary to social inquiry using institutional and political activist ethnography. *International Journal of Qualitative Methods*, 11(5), 607-627.
- Blaisdell, L. L., Gutheil, C., Hootsmans, N. A., & Han, P. K. (2016). Unknown risks: parental hesitation about vaccination. *Medical Decision Making*, 36(4), 479-489.  
<http://doi.org/10.1177/0272989X15607855>
- Blume, S. (2017). *Immunization: How vaccines became controversial*. Reaktion Books Ltd.
- Brezis, M. (2008). Big pharma and health care: unsolvable conflict of interests between private enterprise and public health. *Israel Journal of Psychiatry and Related Sciences*, 45(2), 83.
- British Columbia Centre for Disease Control (2020). *Communicable disease control manual chapter 2: Immunization part 1 – immunizations schedules*. British Columbia Centre for Disease Control. [http://www.bccdc.ca/resource-gallery/Documents/Guidelines%20and%20Forms/Guidelines%20and%20Manuals/Epid/CD%20Manual/Chapter%202%20-%20Imms/Part\\_1\\_Schedules.pdf](http://www.bccdc.ca/resource-gallery/Documents/Guidelines%20and%20Forms/Guidelines%20and%20Manuals/Epid/CD%20Manual/Chapter%202%20-%20Imms/Part_1_Schedules.pdf)
- British Columbia Centre for Disease Control (2021). *Immunization coverage in children by the second birthday 2011-2020*. British Columbia Centre for Disease Control.  
<http://www.bccdc.ca/resource-gallery/Documents/Statistics%20and%20Research/Statistics%20and%20Reports/Immunization/Coverage/2yo%20Coverage%20Birth%20Cohort.pdf>
- Britten, N., Campbell, R., Pope, C., Donovan, J., Morgan, M., & Pill, R. (2002). Using meta ethnography to synthesise qualitative research: a worked example. *Journal of Health Services Research & Policy*, 7(4), 209-215.

- Brody, D. S., Miller, S. M., Lerman, C. E., Smith, D. G., & Caputo, G. C. (1989). Patient perception of involvement in medical care: relationship to illness attitudes and outcomes. *Journal of General Internal Medicine, 4*, 506–511.
- Browning, M. E., Satterfield, S. L., & Lloyd-Richardson, E. E. (2023). Mischievous responders: data quality lessons learned in mental health research. *Ethics & Behavior*, 1–11.  
<https://doi.org/10.1080/10508422.2023.2239398>
- Bruce, A., Beuthin, R., Shields, L., Molzahn, A., & Schick-Makaroff, K. (2016). Narrative research evolving: Evolving through narrative research. *International Journal of Qualitative Methods, 15*(1). <https://doi.org/10.1177/1609406916659292>
- Bruch, T. (2023, December 7, 2023). “Pseudoscience:” Alberta’s health minister under fire for naturopathic medicine meeting [Video Journalism].  
<https://calgary.ctvnews.ca/pseudoscience-alberta-s-health-minister-under-fire-for-naturopathic-medicine-meeting-1.6678219#:~:text='Pseudoscience'%3A%20Alberta's%20health%20minister%20under%20fire%20for%20naturopathic%20medicine%20meeting&text=Alberta's%20health%20minister%20is%20facing,in%20the%20province's%20primary%20care>
- Brunson, E. K. (2010). *The Point of the Needle: An Anthropological Study of Childhood Vaccination in the United States* (Publication No. 3431516) [Doctoral dissertation, University of Washington]. Ann Arbor.  
<http://search.proquest.com.ezproxy.library.uvic.ca/dissertations-theses/point-needle-anthropological-study-childhood/docview/807446307/se-2?accountid=14846>

- Brunson, E. K. (2013). How parents make decisions about their children's vaccinations. *Vaccine*, *31*(46), 5466–5470. <http://doi.org/10.1016/j.vaccine.2013.08.104>
- Bryden, G. M., Browne, M., Rockloff, M., & Unsworth, C. (2018). Anti-vaccination and pro-CAM attitudes both reflect magical beliefs about health. *Vaccine*, *36*(9), 1227–1234.
- Byström, E., Lindstrand, A., Likhite, N., Butler, R., & Emmelin, M. (2014). Parental attitudes and decision-making regarding MMR vaccination in an anthroposophic community in Sweden—a qualitative study. *Vaccine*, *32*(50), 6752–6757.  
<http://doi.org/10.1016/j.vaccine.2014.10.011>
- Cairns, K., & Johnston, J. (2018). On (not) knowing where your food comes from: meat, mothering and ethical eating. *Agriculture and Human Values*, *35*, 569–580.
- Campbell, M., & Gregor, F. (2002). *Mapping social relations: A primer in doing institutional ethnography*. University of Toronto Press.
- Carrion, M. L. (2014). Risk, expertise, and the good mother: A qualitative examination of maternal vaccine refusal [Unpublished doctoral dissertation]. Purdue University.
- Carrion, M. L. (2018). “You need to do your research:” Vaccines, contestable science, and maternal epistemology. *Public Understanding of Science*, *27*(3), 310–324.  
<http://doi.org/10.1177/0963662517728024>
- Cascalheira, C. J. (2023). Yes stormtrooper, these are the droids you're looking for: A method paper evaluating bot detection strategies in online psychological research. Advance online publication. <https://doi.org/10.31234/osf.io/gtp6z>

- Caulfield, T., Marcon, A. R., & Murdoch, B. (2017). Injecting doubt: responding to the naturopathic anti-vaccination rhetoric. *Journal of Law and the Biosciences*, 4(2), 229–249. <https://doi.org/10.1093/jlb/lxx017>
- Cooper, S., Schmidt, B. M., Sambala, E. Z., Swartz, A., Colvin, C. J., Leon, N., & Wiysonge, C. S. (2021). Factors that influence parents' and informal caregivers' views and practices regarding routine childhood vaccination: a qualitative evidence synthesis. *Cochrane Database of Systematic Reviews*, (10). <http://doi.org/10.1002/14651858.CD013265.pub2>
- Corben, P., & Leask, J. (2016). To close the childhood immunization gap, we need a richer understanding of parents' decision-making. *Human Vaccines & Immunotherapeutics*, 12(12), 3168–3176. <http://doi.org/10.1080/21645515.2016.1221553>
- Coronado-Vázquez, V., Canet-Fajas, C., Delgado-Marroquín, M. T., Magallón-Botaya, R., Romero-Martín, M., & Gómez-Salgado, J. (2020). Interventions to facilitate shared decision-making using decision aids with patients in Primary Health Care: A systematic review. *Medicine*, 99(32).
- Crescitelli, M. D., Ghirotto, L., Sisson, H., Sarli, L., Artioli, G., Bassi, M. C., ... & Hayter, M. (2020). A meta-synthesis study of the key elements involved in childhood vaccine hesitancy. *Public Health*, 180, 38–45. <http://doi.org/10.1016/j.puhe.2019.10.027>
- Crotty, M. J. (1998). *The foundations of social research: Meaning and perspective in the research process*. Sage Publications.
- Dalmer, N. K. (2020a). 'Add info and stir': an institutional ethnographic scoping review of family care-givers' information work. *Ageing & Society*, 40(3), 663–689.

- Dalmer, N. K. (2020b). Unsettling knowledge synthesis methods using institutional ethnography: Reflections on the scoping review as a critical knowledge synthesis tool. *Qualitative Health Research, 30*(14), 2361–2373.
- Damnjanović, K., Graeber, J., Ilić, S., Lam, W. Y., Lep, Ž., Morales, S., ... & Vingerhoets, L. (2018). Parental decision-making on childhood vaccination. *Frontiers in psychology, 9*, 735. <http://doi.org/10.3389/fpsyg.2018.00735>
- Danchin, M. H., Costa-Pinto, J., Attwell, K., Willaby, H., Wiley, K., Hoq, M., ... & Marshall, H. (2018). Vaccine decision-making begins in pregnancy: Correlation between vaccine concerns, intentions and maternal vaccination with subsequent childhood vaccine uptake. *Vaccine, 36*(44), 6473–6479. <http://doi.org/10.1016/j.vaccine.2017.08.003>
- Deml, M. J., Buhl, A., Huber, B. M., Burton-Jeangros, C., & Tarr, P. E. (2022). Trust, affect, and choice in parents' vaccination decision-making and health-care provider selection in Switzerland. *Sociology of Health & Illness, 44*(1), 41–58. <http://doi.org/10.1111/1467-9566.13388>
- DeVault, M. L. (1990). Talking and listening from women's standpoint: Feminist strategies for interviewing and analysis. *Social problems, 37*(1), 96–116.
- DeVault, M. L. (1991). *Feeding the family: The social organization of caring as gendered work*. University of Chicago Press.
- DeVault, M. L. (1999). *Liberating method: Feminism and social research*. Temple University Press.
- DeVault, M. L., & McCoy, L. (2012). Investigating ruling relations: Dynamics of interviewing in institutional ethnography. In J. Gubrium, J. A. Holstein, A. B. Marvasti, & K. D.

- McKinney (Eds.), *The SAGE handbook of interview research: The complexity of the craft* (Vol. 2, pp. 381–396). SAGE Publications Inc.
- Dixon-Woods, M., Bonas, S., Booth, A., Jones, D. R., Miller, T., Sutton, A. J., Shaw, R. L., Smith, J. A., & Young, B. (2006). How can systematic reviews incorporate qualitative research? A critical perspective. *Qualitative research*, 6(1), 27–44.
- Dolin, N. (2022). *Alternative Diet Practices as Predictors for Vaccine Confidence*. Publication No. 12327 [Doctoral dissertation, Walden University]. Walden U ScholarWorks. <https://scholarworks.waldenu.edu/dissertations/12327>
- Dubé, E., Gagnon, D., MacDonald, N., Bocquier, A., Peretti-Watel, P., & Verger, P. (2018). Underlying factors impacting vaccine hesitancy in high income countries: a review of qualitative studies. *Expert Review of Vaccines*, 17(11), 989–1004.
- Dubé, E., & MacDonald, N. E. (2020). How can a global pandemic affect vaccine hesitancy? *Expert Review of Vaccines*, 19(10), 899–901. <http://doi.org/10.1080/14760584.2020.1825944>
- Dubé, E., Vivion, M., Sauvageau, C., Gagneur, A., Gagnon, R., & Guay, M. (2016). “Nature does things well, why should we interfere?:” Vaccine hesitancy among mothers. *Qualitative Health Research*, 26(3), 411–425. <http://doi.org/10.1177/1049732315573207>
- Duchsherer, A., Jason, M., Platt, C. A., & Majdik, Z. P. (2020). Immunized against science: Narrative community building among vaccine refusing/hesitant parents. *Public Understanding of Science*, 29(4), 419–435. <http://doi.org/10.1177/0963662520921537>
- Edge, L. (2009). Vaccine safety: informing the misinformed. *The Lancet Infectious Diseases*, 9(12), 719.

- Ejuma, N. (2019). Decision-making & beliefs of vaccine-hesitant & parents in the United States and Jamaica: A cross-cultural study [Unpublished doctoral dissertation]. The Chicago School of Professional Psychology. APA PsychInfo.
- Enkel, S. L., Attwell, K., Snelling, T. L., & Christian, H. E. (2018). 'Hesitant compliers:' qualitative analysis of concerned fully-vaccinating parents. *Vaccine*, *36*(44), 6459–6463. <http://doi.org/10.1016/j.vaccine.2017.09.088>
- Esmail, N. (2017). *Complementary and alternative medicine: Use and public attitudes 1997, 2006, and 2016*. Fraser Institute. <https://www.fraserinstitute.org/sites/default/files/complementary-and-alternative-medicine-2017.pdf>
- Fallet, K. I. (2017). *Understanding parents' vaccination choices: a qualitative study of parents living in eastern Norway*. [Master's thesis, Inland Norway University of Applied Sciences]. <https://brage.inn.no/inn-xmlui/handle/11250/2450455>
- Forster, A. S., Rockliffe, L., Chorley, A. J., Marlow, L. A., Bedford, H., Smith, S. G., & Waller, J. (2016). A qualitative systematic review of factors influencing parents' vaccination decision-making in the United Kingdom. *SSM-Population Health*, *2*, 603–612. <http://doi.org/10.1016/j.ssmph.2016.07.005>
- García-Escamilla, E. (2017). *Qualitative systematic reviews: Contextualizing a study and sensitizing researchers in important issues regarding the research question*. SAGE Publications Ltd.

- Gidengil, C., Chen, C., Parker, A. M., Nowak, S., & Matthews, L. (2019). Beliefs around childhood vaccines in the United States: a systematic review. *Vaccine*, *37*(45), 6793–6802. <http://doi.org/10.1016/j.vaccine.2019.08.068>
- Glanz, J. M., Wagner, N. M., Narwaney, K. J., Shoup, J. A., McClure, D. L., McCormick, E. V., & Daley, M. F. (2013). A mixed methods study of parental vaccine decision making and parent–provider trust. *Academic pediatrics*, *13*(5), 481–488. <http://doi.org/10.1016/j.acap.2013.05.030>
- Glassman, L. W., & Szymczak, J. E. (2022). The influence of social class and institutional relationships on the experiences of vaccine-hesitant mothers: a qualitative study. *BMC Public Health*, *22*(1), 2309. <http://doi.org/10.1186/s12889-022-14420-1>
- Gottlieb, L. N. (2014). Strengths-based nursing. *American Journal of Nursing*, *114*(8), 24–32.
- Government of Canada. (2023, June 16). *Radon: About*. <https://www.canada.ca/en/health-canada/services/health-risks-safety/radiation/radon.html>
- Griffith, A. I., & Smith, D. E. (1987). Constructing cultural knowledge: Mothering as discourse. *Women and Education: A Canadian Perspective*, *3*(1), 87–103.
- Greyson, D. (2019). The activated patient paradox. *Health Promotion International*, *34*(3), 376–377. <http://doi.org/10.1093/heapro/daz058>
- Gross, K., Hartmann, K., Zemp, E., & Merten, S. (2015). ‘I know it has worked for millions of years’: The role of the ‘natural’ in parental reasoning against child immunization in a qualitative study in Switzerland. *BMC Public Health*, *15*, 1–7. <http://doi.org/10.1186/s12889-015-1716-3>

- Haarstick, K. A. (2021). *Vaccine skeptical mothers in the upper Midwest and their kitchen-based care practices* [Unpublished master's thesis]. North Dakota State University.
- Hamilton, P. (2016). The 'good' attached mother: An analysis of postmaternal and postracial thinking in birth and breastfeeding policy in neoliberal Britain. *Australian Feminist Studies*, 31(90), 410–431.
- Harmsen, I. A., Mollema, L., Ruiter, R. A., Paulussen, T. G., de Melker, H. E., & Kok, G. (2013). Why parents refuse childhood vaccination: A qualitative study using online focus groups. *BMC Public Health*, 13(1), 1–8. <http://doi.org/10.1186/1471-2458-13-1183>
- Hays, S. (1996). *The cultural contradictions of motherhood*. Yale University Press.
- Helps, C., Leask, J., & Barclay, L. (2018). "It just forces hardship": Impacts of government financial penalties on non-vaccinating parents. *Journal of Public Health Policy*, 39(2):156–169. <http://doi.org/10.1057/s41271-017-0116-6>
- Helps, C., Leask, J., Barclay, L., & Carter, S. (2019). Understanding non-vaccinating parents' views to inform and improve clinical encounters: a qualitative study in an Australian community. *BMJ Open*, 9(5). <http://doi.org/10.1136/bmjopen-2018-026299>
- Herzig van Wees, S., Abunnaja, K., & Mounier-Jack, S. (2023). Understanding and explaining the link between anthroposophy and vaccine hesitancy: a systematic review. *BMC Public Health*, 23(1), 2238.
- Hilton, S., Petticrew, M., & Hunt, K. (2006). Combined vaccines are like a sudden onslaught to the body's immune system': Parental concerns about vaccine 'overload' and 'immune-vulnerability. *Vaccine*, 24(20), 4321–4327.

Hornsey, M. J., Lobera, J., & Díaz-Catalán, C. (2020). Vaccine hesitancy is strongly associated with distrust of conventional medicine, and only weakly associated with trust in alternative medicine. *Social Science & Medicine*, 255, 113019.

Huel, C. (2015). A review of the evidence surrounding interventions for vaccine hesitancy in primary care [Unpublished master's thesis]. University of Northern British Columbia.

Huel, C., Harding, J., MacKinnon, K., Gordon, C., & MacDonald, S. E. (2022). Parental experiences of caring for their preschool children after declining vaccines: A qualitative systematic review protocol. *JBIC Evidence Synthesis*, 20(1), 196–203.

<http://doi.org/10.11124/JBIES-21-00116>

Huel, C., MacKinnon, K., Harding, J., Haghiri-Vijeh, R., Gordon, C., & MacDonald, S. E. (in press). Parental experiences of caring for their preschool children after declining vaccines: A qualitative systematic review. *JBIC Evidence Synthesis*.

Hsu, C., Evers, S., Ibrahim, A., Patricia, M., Throne, P., Melton, M., ... & Hofstetter, A. M. (2023). Sometimes your heart says 'I don't know': Insights from parents of undervaccinated children. *Academic Pediatrics*, 23(1), 57–67.

<http://doi.org/10.1016/j.acap.2022.10.002>

Immunization of School Pupils Act, R. S. O. 1990, c. I.1 (2021).

<https://www.ontario.ca/laws/statute/90i01>

JBIC. (2014). *JBIC Grades of Recommendation* [Internet]. Adelaide, Australia. Available from:

[https://jbi.global/sites/default/files/2019-05/JBI-grades-of-recommendation\\_2014.pdf](https://jbi.global/sites/default/files/2019-05/JBI-grades-of-recommendation_2014.pdf)

- Jordan, Z., Munn, Z., Aromataris, E., & Lockwood, C. (2015). Now that we're here, where are we? The JBI approach to evidence-based healthcare 20 years on. *JBI Evidence Implementation, 13*(3), 117–120.
- Kempe, A., Daley, M. F., McCauley, M. M., Crane, L. A., Suh, C. A., Kennedy, A. M., Basket, M. M., Stokley, S. K., Dong, F., & Babbel, C. I. (2011). Prevalence of parental concerns about childhood vaccines: The experience of primary care physicians. *American Journal of Preventive Medicine, 40*(5), 548–555.
- Kuan, C. I. (2022). Vaccine hesitancy and emerging parental norms: A qualitative study in Taiwan. *Sociology of Health & Illness, 44*(3), 692–709. <http://doi.org/10.1111/1467-9566.13446>
- Kuhl, D., Appleby, A., Pearson, H., MacNutt, L., & Lotherington, K. (2017). What we know, cures; Who we are, heals. *Transplantation, 101*, S77.
- Lawrence, P. R., Osborne, M. C., Sharma, D., Spratling, R., & Calamaro, C. J. (2023). Methodological Challenge: Addressing Bots in Online Research. *Journal of Pediatric Health Care, 37*(3), 328–332.
- Lehmann, B. A., de Melker, H. E., Timmermans, D. R., & Mollema, L. (2017). Informed decision making in the context of childhood immunization. *Patient Education and Counseling, 100*(12), 2339–2345.
- Li, A., Toll, M. (2021). Removing conscientious objection: The impact of 'No Jab No Pay' and 'No Jab No Play' vaccine policies in Australia. *Preventive Medicine, 145*, 106406. <http://doi.org/10.1016/j.ypmed.2020.106406>

- Lockwood, C., Porritt, K., Munn, Z., Rittenmeyer, L., Salmond, S., Bjerrum, M., ... & Stannard, D. (2020). *Chapter 2: Systematic reviews of qualitative evidence*. In Aromataris, E., Munn, Z. (Eds.), *JBI Manual for Evidence Synthesis* [cited 2021 Jul 6].  
<https://synthesismanual.jbi.global>
- Luken, P. C. (2008). Institutional Ethnography. In V. N. Parrillo (Ed.), *Encyclopedia of Social Problems* (pp. 409–411). Sage Publications. <https://doi.org/10.4135/9781412963930>
- Lupton, D. A. (2012). ‘Precious cargo’: Foetal subjects, risk and reproductive citizenship. *Critical Public Health*, 22(3), 329–340.
- Lupton, D. A. (2011). ‘The best thing for the baby’: Mothers’ concepts and experiences related to promoting their infants’ health and development. *Health, Risk & Society*, 13(7–8), 637–651.
- Lydall, W. (2005). *Raising a Vaccine Free Child*. AuthorHouse.  
<https://books.google.ca/books?id=ecsyMDv4KrMC>
- Lyren, A., & Leonard, E. (2006). Vaccine refusal: issues for the primary care physician. *Clinical Pediatrics*, 45(5), 399–404. <http://doi.org/10.1177/0009922806289581>
- MacDonald, N. E. (2015). Vaccine hesitancy: Definition, scope and determinants. *Vaccine*, 33(34), 4161–4164. <http://doi.org/10.1016/j.vaccine.2015.04.036>
- MacKendrick, N. (2014). More work for mother: Chemical body burdens as a maternal responsibility. *Gender & Society*, 28(5), 705–728.  
<http://doi.org/10.1177/0891243214529842>

- MacKinnon, K. (2006). Living with the threat of preterm labor: women's work of keeping the baby in. *Journal of Obstetric, Gynecologic & Neonatal Nursing*, 35(6), 700–708. <http://doi.org/10.1111/j.1552-6909.2006.00097.x>
- MacKinnon, K., & McCoy, L. (2006). The very LOUD discourses of risk in pregnancy! In P. Godin (Ed.), *Risk and Nursing Practice* (pp. 98–120). Palgrave Macmillan Hampshire.
- Martinez-Diz, S., Martinez Romero, M., Fernandez-Prada, M., Cruz Piqueras, M., Molina Ruano, R., & Fernandez Sierra, M. A. (2014) Demands and expectations of parents who refuse vaccinations and perspective of health professional on the refusal to vaccinate— Demandas y expectativas de padres y madres que rechazan la vacunación y perspectiva de los profesionales sanitarios sobre la negativa a vacunar. *Anales de Pediatría (Barcelona)*, 80(6), 370–378. <http://doi.org/10.1016/j.anpedi.2013.08.009>
- McCabe, K. (2016). Mothercraft: Birth work and the making of neoliberal mothers. *Social Science & Medicine*, 162, 177–184. <http://doi.org/10.1016/j.socscimed.2016.06.021>
- McCoy, L. (2008). Institutional ethnography and constructionism. In J. A. Holstein & J. F. Gubrium (Eds.), *Handbook of constructionist research* (pp. 701–714). The Guilford Press.
- McGregor, S., & Goldman, R. D. (2021). Determinants of parental vaccine hesitancy. *Canadian Family Physician*, 67(5), 339–341. <https://doi.org/10.46747/cfp.6705339>
- Mendel-Van Alstyne, J. A., Nowak, G. J., & Aikin, A. L. (2018). What is 'confidence' and what could affect it?: A qualitative study of mothers who are hesitant about vaccines. *Vaccine*, 36(44), 6464–6472. <http://doi.org/10.1016/j.vaccine.2017.09.007>

Minnotte, K. L. (2023). Decentering intensive mothering: More fully accounting for race and class in motherhood norms. *Sociology Compass*, e13095.

<http://doi.org/10.1111/soc4.13095>

Ontario Ministry of Health (2024). *Vaccines for children at school*.

<https://www.ontario.ca/page/vaccines-children-school>

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & PRISMA Group\* (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *Annals of Internal Medicine*, 151(4), 264–269. <http://doi.org/10.7326/0003-4819-151-4-200908180-00135>

Mol, A. (2008). *The logic of care: Health and the problem of patient choice*. Routledge.

Mosby, I., & Swidrovich, J. (2021). Medical experimentation and the roots of COVID-19 vaccine hesitancy among Indigenous Peoples in Canada. *Canadian Medical Association Journal*, 193(11), E381–E383.

Munn, Z., Aromataris, E., Tufanaru, C., Stern, C., Porritt, K., & Farrow, J. (2019). The development of software to support multiple systematic review types: The Joanna Briggs Institute System for the Unified Management, Assessment and Review of Information (JBI SUMARI). *International Journal of Evidence-Based Healthcare*, 17(1), 36–43.

<http://doi.org/10.1097/XEB.0000000000000152>

Munn, Z., Porritt K., Lockwood, C., Aromataris, E., & Pearson, A. (2014). Establishing confidence in the output of qualitative research synthesis: The ConQual approach. *BMC Medical Research Methodology*, 14(1), 1–7. <http://doi.org/10.1186/1471-2288-14-108>

- Mykhalovskiy, E., & McCoy, L. (2002). Troubling ruling discourses of health: Using institutional ethnography in community-based research. *Critical Public Health, 12*(1), 17–37.
- National Center for Complementary and Integrative Health. (2021). *Complementary, alternative, or integrative health: What's in a name?*  
<https://www.nccih.nih.gov/health/complementary-alternative-or-integrative-health-whats-in-a-name>
- Ng, J. Y., Dhawan, T., Dogadova, E., Taghi-Zada, Z., Vacca, A., Wieland, L. S., & Moher, D. (2022). Operational definition of complementary, alternative, and integrative medicine derived from a systematic search. *BMC complementary medicine and therapies, 22*(1), 104.
- Nield, L. S., & Kamat, D. M. (2008). Anti-vaccine media: its impact—and strategies to combat it. *Consultant360, 7*(9 suppl): S4–7.
- Noblit, G. W., & Hare, R. D. (1988). *Meta-ethnography: Synthesizing qualitative studies* (Vol. 11). Sage.
- Nurmi, J. (2021). Building ‘Natural’ immunities: Cultivation of human-microbe relations in vaccine-refusing families. In Brives, C., Rest, M., Sariola, S. (Eds.), *With Microbes* (pp. 104–121). Mattering Press.
- Nurmi, J., & Harman, B. (2022). Why do parents refuse childhood vaccination? Reasons reported in Finland. *Scandinavian Journal of Public Health, 50*(4), 490–496.  
<http://doi.org/10.1177/14034948211004323>

- O'Donnell, N., Satherley, R.-M., Davey, E., & Bryan, G. (in press). Fraudulent participants in qualitative child health research: identifying and reducing bot activity. *Archives of Disease in Childhood*.
- Opel, D. J., Lo, B., & Peek, M.E. (2021). Addressing mistrust about COVID-19 vaccines among patients of color. *Annals of Internal Medicine*, 174(5), 698–700.  
<http://doi.org/10.7326/M21-0055>
- Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., ... & Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *International Journal of Surgery*, 88, 105906.  
<http://doi.org/10.1016/j.ijisu.2021.105906>
- Peretti-Watel, P., Ward, J. K., Vergelys, C., Bocquier, A., Raude, J., & Verger, P. (2019). ‘I Think I Made the Right Decision ... I hope I’m Not Wrong’. Vaccine hesitancy, commitment and trust among parents of young children. *Sociology of Health & Illness*, 41(6), 1192–1206.  
<http://doi.org/10.1111/1467-9566.12902>
- Piltch-Loeb, R., DiClemente, R. (2020). The vaccine uptake continuum: Applying social science theory to shift vaccine hesitancy. *Vaccines*, 8(1), 76.  
<http://doi.org/10.3390/vaccines8010076>
- Poltorak, M., Leach, M., Fairhead, J., & Cassell, J. (2005). ‘MMR talk’ and vaccination choices: An ethnographic study in Brighton. *Social Science & Medicine*, 61(3), 709–719.  
<https://doi.org/10.1016/j.socscimed.2004.12.014>

- Pozniak, K. (2017). Neoliberal pedagogies of motherhood at an Ontario Early Years Centre. *Journal of the Motherhood Initiative for Research and Community Involvement*, 8(1,2), 30–45.
- Rankin, J. M. (2013). Institutional Ethnography. In C. T. Beck (Ed.), *Routledge International Handbook of Qualitative Nursing Research* (pp. 244–255). Routledge.
- Rankin, J. M. (2017). Conducting analysis in institutional ethnography: Analytical work prior to commencing data collection. *International Journal of Qualitative Methods*, 16, 1–9.
- Reich, J. A. (2014). Neoliberal mothering and vaccine refusal: Imagined gated communities and the privilege of choice. *Gender & Society*, 28(5), 679–704.  
<http://doi.org/10.1177/0891243214532711>
- Reich, J. A. (2016). Of natural bodies and antibodies: Parents' vaccine refusal and the dichotomies of natural and artificial. *Social Science & Medicine*, 157, 103–110.  
<http://doi.org/10.1016/j.socscimed.2016.04.001>
- Reich, J. A. (2018). “I Have to Write a Statement of Moral Conviction. Can Anyone Help?": Parents' strategies for managing compulsory vaccination laws. *Sociological Perspectives*, 61(2), 222–239. <http://doi.org/10.1177/0731121418755113>
- Reich, J. A. (2020a). Teaching women to question and control: Public pedagogies of birth and vaccine refusal. *BioSocieties*, 15(4), 580–600.  
<http://doi.org/10.1057/s41292-019-00168-2>
- Reich, J. A. (2020b). Vaccine refusal and pharmaceutical acquiescence: parental control and ambivalence in managing children's health. *American Sociological Review*, 85(1), 106–127. <http://doi.org/10.1177/0003122419899604>

- Reich, J. A. (2020c). “We are fierce, independent thinkers and intelligent”: Social capital and stigma management among mothers who refuse vaccines. *Social Science & Medicine*, 257, 112015. <http://doi.org/10.1016/j.socscimed.2018.10.027>
- Ridge, D., Bullock, L., Causer, H., Fisher, T., Hider, S., Kingstone, T., Gray, L., Riley, R., Smyth, N., & Silverwood, V. (2023). ‘Imposter participants’ in online qualitative research, a new and increasing threat to data integrity? *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*, 26(3), 941.
- Rhodes, M. E., Sundstrom, B., Ritter, E., McKeever, B.W., & McKeever, R. (2020). Preparing for a COVID-19 vaccine: A mixed methods study of vaccine hesitant parents. *Journal of Health Communication*, 25(10), 831–837.  
<http://doi.org/10.1080/10810730.2021.1871986>
- Ridge, D., Bullock, L., Causer, H., Fisher, T., Hider, S., Kingstone, T., Gray, L., Riley, R., Smyth, N., & Silverwood, V. (2023). ‘Imposter participants’ in online qualitative research, a new and increasing threat to data integrity? *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*, 26(3), 941.
- Roth, P. H., & Bruni, T. (2022). Participation, Empowerment, and Evidence in the Current Discourse on Personalized Medicine: A Critique of “Democratizing Healthcare”. *Science, Technology, & Human Values*, 47(5), 1033–1056.
- Sanders, C., & Burnett, K. (2019). The neoliberal roots of modern vaccine hesitancy. *Journal of Health and Social Sciences*, 4(2), 149–156.

- Seiter, H. (2023). Factors impacting vaccine hesitant parents of young children in Northern British Columbia: A qualitative study from a health care communicator's lens [Unpublished master's thesis]. Royal Roads University.
- Smith, D. E. (1987). *The everyday world as problematic: A feminist sociology*. University of Toronto Press.
- Smith, D. E. (1990). *The conceptual practices of power: A feminist sociology of knowledge*. University of Toronto Press.
- Smith, D. E. (2005). *Institutional ethnography: A sociology for people*. AltaMira Press.
- Smith, D. E., & Griffith, A. I. (2022). *Simply institutional ethnography: Creating a sociology for people*. University of Toronto Press.
- Sobo, E. J. (2015). Social cultivation of vaccine refusal and delay among Waldorf (Steiner) school parents. *Medical anthropology quarterly*, 29(3), 381–399.
- Sobo, E. J. (2016a). Theorizing (vaccine) refusal: Through the looking glass. *Cultural Anthropology*, 31(3), 342–350. <http://doi.org/10.14506/ca31.3.04>
- Sobo, E. J. (2016b). What is herd immunity, and how does it relate to pediatric vaccination uptake? US parent perspectives. *Social Science & Medicine*, 165, 187–195. <http://doi.org/10.1016/j.socscimed.2016.06.015>
- Sobo, E. J., Huhn, A., Sannwald, A., & Thurman, L. (2016c). Information curation among vaccine cautious parents: Web 2.0, Pinterest thinking, and pediatric vaccination choice. *Medical Anthropology*, 35(6), 529–546. <http://doi.org/10.1080/01459740.2016.1145219>
- Stanley, L. (2018). *Dorothy E. Smith, feminist sociology & institutional ethnography: A short introduction*. X Press Edinburgh.

- Steiner, L., & Bronstein, C. (2017). Leave a comment: Mommyblogs and the everyday struggle to reclaim parenthood. *Feminist Media Studies*, 17(1), 59–76.  
<http://doi.org/10.1080/14680777.2017.1261840>
- Suk, J. E. (2010). Vaccine safety: Misinformed about the misinformed. *The Lancet Infectious Diseases*, 10(3), 144.
- Sumengen, A. A., Ozcevik, D., Kursun, H. Y., & Ocakci, A. F. (2021). Vaccine-hesitant parents' reasons for choosing alternative protection methods in Turkey. *Journal of Research in Nursing*, 26(6), 540-553. <http://doi.org/10.1177/1744987120970635>
- Sythes, L., & Bedford, H. (2022). Motherhood and vaccine refusal in the United Kingdom: A new examination of gender, identity and the journey to contemporary non-vaccination. *Child: Care, Health and Development*, 48(6), 979–89. <http://doi.org/10.1111/cch.12976>
- Tarrant, M., & Gregory, D. (2003). Exploring childhood immunization uptake with First Nations mothers in north-western Ontario, Canada. *Journal of Advanced Nursing* (Wiley-Blackwell), 41(1), 63–72. <http://doi.org/10.1046/j.1365-2648.2003.02507.x>
- Tarrant, M., & Gregory, D. (2001). Mothers' perceptions of childhood immunizations in First Nations communities of the Sioux Lookout Zone. *Canadian Journal of Public Health*, 92(1), 42–45. <http://doi.org/10.1007/BF03404842>
- ten Kate, J., Koster, W. D., & Van der Waal, J. (2021). “Following your gut” or “questioning the scientific evidence:” Understanding vaccine skepticism among more-educated Dutch parents. *Journal of Health and Social Behavior*, 62(1), 85–99.  
<http://doi.org/10.1177/0022146520986118>

- Thornton, C., & Reich, J. A. (2022). Black mothers and vaccine refusal: Gendered racism, healthcare, and the state. *Gender & Society*, 36(4), 525–551.  
<http://doi.org/10.1177/08912432221102150>
- Tombs-Heirman, E. (2009). *Understanding vaccination refusal: A qualitative study of parents' health beliefs and practices* [Master's thesis, University of Edinburgh].  
<https://era.ed.ac.uk/bitstream/handle/1842/9819/Tombs-Heirman2009.pdf?sequence=1>
- Trnka, S., & Trundle, C. (2014, April). Competing responsibilities: Moving beyond neoliberal responsabilisation. In *Anthropological Forum* (Vol. 24, No. 2, pp. 136-153). Routledge.
- Tomljenovic, H., Bubic, A., & Hren, D. (2022). Decision making processes underlying avoidance of mandatory child vaccination in Croatia—A qualitative study. *Current Psychology: A Journal for Diverse Perspectives on Diverse Psychological Issues*, 41(9), 6210–6224. <http://doi.org/10.1007/s12144-020-01110-7>
- Uher, I., Cholewa, J., Kunicki, M., Švedová, M., Cimbolakova, I., Kůchelová, Z., ... & Jusková, M. (2020). Allopathic and naturopathic medicine and their objective consideration of congruent pursuit. *Evidence-Based Complementary and Alternative Medicine eCAM*, 2020, 7525713. <https://doi.org/10.1155/2020/7525713>
- Vandenberg, S. Y. (2013). Saying no to childhood immunization: Perceptions of mothers and health care professionals in southern Alberta [Unpublished master's thesis]. University of Lethbridge.
- Wang, E., Baras, Y., & Buttenheim, A. M. (2015). “Everybody just wants to do what's best for their child”: Understanding how pro-vaccine parents can support a culture of vaccine hesitancy. *Vaccine*, 33(48), 6703–6709.

- Ward, P. R., Attwell, K., Meyer, S. B., Rokkas, P., & Leask, J. (2017). Understanding the perceived logic of care by vaccine-hesitant and vaccine-refusing parents: A qualitative study in Australia. *PLOS ONE*, *12*(10), e0185955.  
<http://doi.org/10.1371/journal.pone.0185955>
- Ward, P. R., Attwell, K., Meyer, S. B., Rokkas, P., & Leask, J. (2018). Risk, responsibility and negative responses: A qualitative study of parental trust in childhood vaccinations. *Journal of Risk Research*, *21*(9), 1117–1130.  
<http://doi.org/10.1080/13669877.2017.1391318>
- White, J. B., & O'Doherty, K. C. (2023). Constructing the Anti-Vaxxer: Discursive analysis of public deliberations on childhood vaccination. *Journal for the Theory of Social Behaviour*, *53*, 471–487.
- World Health Organization (2022). Understanding the behavioural and social drivers of vaccine uptake WHO position paper—May 2022. *Weekly Epidemiological Record*, *97*, 209–224.
- Whyte, M. D., Whyte IV, J., Cormier, E., & Eccles, D. W. (2011). Factors influencing parental decision making when parents choose to deviate from the standard pediatric immunization schedule. *Journal of Community Health Nursing*, *28*(4), 204–214.
- Wiley, K. E., Leask, J., Attwell, K., Helps, C., Degeling, C., Ward, P., & Carter, S. M. (2020). Parenting and the vaccine refusal process: A new explanation of the relationship between lifestyle and vaccination trajectories. *Social Science & Medicine*, *263*, 113259.  
<http://doi.org/10.1016/j.socscimed.2020.113259>
- Wiley, K. E., Leask, J., Attwell, K., Helps, C., Barclay, L., Ward, P. R., & Carter, S. M. (2021). Stigmatized for standing up for my child: A qualitative study of non-vaccinating parents

in Australia. *SSM-Population Health*, 16, 100926.

<http://doi.org/10.1016/j.ssmph.2021.100926>

Wiley, K. E., Robinson, P., Degeling, C., Ward, P. R., Leask, J., & Carter, S. M. (2022). ‘Get your own house in order’: Qualitative dialogue groups with nonvaccinating parents on how measles outbreaks in their community should be managed. *Health Expectations*, 25(4), 1678–1690. <http://doi.org/10.1111/hex.13511>

World Health Organization (2020). COVID-19 Dashboard. Retrieved June 21, 2023, from <https://covid19.who.int/>

Wu, A. C., Wisler-Sher, D. J., Griswold, K., Colson, E., Shapiro, E. D., Holmboe, E. S., & Benin, A. L. (2008). Postpartum mothers’ attitudes, knowledge, and trust regarding vaccination. *Maternal and Child Health Journal*, 12, 766–773.

Xu, Y., Pace, S., Kim, J., Iachini, A., King, L. B., Harrison, T., DeHart, D., Levkoff, S. E., Browne, T. A., & Lewis, A. A. (2022). Threats to online surveys: recognizing, detecting, and preventing survey bots. *Social Work Research*, 46(4), 343–350.

Zin, Z. M., Krishnan, M., Iman, S. S. S., Jaafar, N., Zulkepli, M. Z., Kadir, K. A., & Ahmad, N. (2022). Exploring parental refusal of vaccine in Selangor. *SEARCH: Journal of Media and Communication Research*, 14(2), 105–118. <https://fslmjournals.taylors.edu.my/wp-content/uploads/SEARCH/SEARCH-2022-14-2/SEARCH-2022-P8-14-2.pdf>

### Appendix A: Search Strategy

CINAHL (EBSCO)

*Search conducted on June 29, 2021*

#	Query	Limiters/expanders	Last run via	Records retrieved
S1	(“Immunization In Infancy and Childhood” or MH “Attitude to Vaccines” or MH “Anti-Vaccination Movement” or vaccin* refusal or anti vaccin* or vaccin* choice or vaccin* hesitancy or immuni* or vaccin* decision-making OR vaccin* uptake or vaccin* choice)	Expanders - Apply equivalent subjects Search modes - Find all my search terms	Interface – EBSCO. Research Databases Search Screen - Advanced Search Database - CINAHL Complete	69,875
S2	(parent or mother or father or MH “Mothers” or MH “Fathers or MH “Parents”) AND (infan* or child* or toddler* or MW “Infant” OR MH “Child, Preschool”)	Expanders - Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCO Research Databases Search Screen - Advanced Search Database - CINAHL Complete	381,100
S3	(qualitative or experienc* or perception or interview* or ethnograph* or phenomenol* or narrat* OR MH “Qualitative Studies+”)	Expanders - Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCO Research Databases Search Screen - Advanced Search Database - CINAHL Complete	923,512
S4	(attitude* or decision-making or strateg* or promot* or prevent* behavio* or optimiz* OR MH “Decision-making, Family”)	Expanders - Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCO Research Databases Search Screen - Advanced Search Database - CINAHL Complete	1,037,733
S5	S1 AND S2 AND S3 AND S4	Expanders - Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCO Research Databases Search Screen - Advanced Search Database	972

#	Query	Limiters/expanders	Last run via	Records retrieved
			- CINAHL Complete	
S6	S1 AND S2 AND S3 AND S4	Limiters - Published date: 19800101- Expanders - Apply equivalent subjects  Search modes - Find all my search terms	Interface - EBSCO Research Databases Search Screen - Advanced Search Database - CINAHL Complete	972
S7	S1 AND S2 AND S3 AND S4	Limiters - Published date: 19980101-20211231 Expanders - Apply equivalent subjects  Search modes - Find all my search terms	Interface - EBSCO Research Databases Search Screen - Advanced Search Database - CINAHL Complete	932

CINAHL Complete (EBSCO)

*February 1, 2022–January 31, 2023*

*Search conducted on January 31, 2023*

Search	Query	Limiters/Expanders	Records retrieved
1	("Immunization In Infancy and Childhood" or MH "Attitude to Vaccines" or MH "Anti-Vaccination Movement" or vaccin* refusal or anti vaccin* or vaccin* choice* or vaccin* hesitancy or immuni* or vaccin* decision-making) OR (vaccin* uptake or vaccin* choice*)	Limiters - Published Date: 20220201-20230131 Expanders – Apply equivalent subjects Search modes - Find all my search terms	5,725
2	(parent* or mother* or father* or MH "Mothers" or MH "Fathers or MH "Parents") AND (infan* or child* or toddler* or MW "Infant" OR MH "Child, Preschool")	Limiters - Published Date: 20220201-20230131 Expanders – Apply equivalent subjects Search modes - Find all my search terms	15,930
3	((qualitative or experienc* or perception* or interview* or ethnograph* or phenomenol* or narrat*) OR MH "Qualitative Studies+")	Limiters - Published Date: 20220201-20230131 Expanders – Apply equivalent subjects Search modes - Find all my search terms	67,972

Search	Query	Limiters/Expanders	Records retrieved
4	(attitude* or decision making or strateg* or promot* or prevent* behavio* or optimiz*) OR MH “Decision Making, Family”	Limiters - Published Date: 20220201-20230131 Expanders – Apply equivalent subjects Search modes - Find all my search terms	75,708
5	((attitude* or decision making or strateg* or promot* or prevent* behavio* or optimiz*) OR MH “Decision Making, Family”) AND (S1 AND S2 AND S3 AND S4)	Search modes - Boolean/Phrase	88
Interface – EBSCOhost Research Databases Search Screen – Advanced Search Database – CINAHL Complete			

*PsychInfo (EBSCO)*

*January 1, 1998-February 18, 2022*

*Search conducted on February 18, 2022*

Search	Query	Limiters/Expanders	Records retrieved
1	(DE “Vaccination Attitudes” or DE “Immunization” or DE “Conspiracy Beliefs” or DE “Misinformation” or vaccin* refusal or anti vaccin* or vaccin* choice* or vaccin* hesitancy or immuni* or vaccin* decision-making) OR (vaccin* uptake or vaccin* choice* )	Expanders – Apply equivalent subjects Search modes - Find all my search terms	75,047
2	(parent* or mother* or father* or DE “Mothers” or DE “Parents” or DE “Fathers”) AND (infan* or child* or toddler* OR DE “Preschool Students”)	Expanders – Apply equivalent subjects Search modes - Find all my search terms	233,105
3	(qualitative or experienc* or perception* or interview* or ethnograph* or phenomenol* or narrat*) OR DE “Qualitative Methods”	Expanders – Apply equivalent subjects Search modes - Find all my search terms	1,648,302
4	(attitude* or decision making or strateg* or promot* or prevent* behavio* or optimiz*) OR (DE “Health Attitudes” or DE “Childrearing Attitudes” or DE “Childrearing Practices” or DE “Child Health” or DE “Parental Attitudes” or DE “Parenting”)	Expanders – Apply equivalent subjects Search modes - Find all my search terms	1,425,491
5	((attitude* or decision making or strateg* or promot* or prevent* behavio* or optimiz*) OR (DE “Health Attitudes” or DE “Childrearing Attitudes” or DE “Childrearing Practices” or DE “Child Health” or DE “Parental Attitudes” or DE “Parenting”)) AND (S1 AND S2 AND S3 AND S4)	Expanders – Apply equivalent subjects Search modes - Find all my search terms	532

6	((attitude* or decision making or strateg* or promot* or prevent* behavio* or optimiz*) OR (DE "Health Attitudes" or DE "Childrearing Attitudes" or DE "Childrearing Practices" or DE "Child Health" or DE "Parental Attitudes" or DE "Parenting")) AND (S1 AND S2 AND S3 AND S4)	Limiters – Publication Year: 1998-2022 Expanders – Apply equivalent subjects Search modes - Find all my search terms	498
Interface – EBSCOhost Research Databases Search Screen – Advanced Search Database - APA PsychInfo			

## PsychInfo (EBSCO)

February 1, 2022–January 31, 2023

Search conducted on January 31, 2023

Search	Query	Limiters/Expanders	Records retrieved
1	(DE "Vaccination Attitudes" or DE "Immunization" or DE "Conspiracy Beliefs" or DE "Misinformation" or vaccin* refusal or anti vaccin* or vaccin* choice* or vaccin* hesitancy or immuni* or vaccin* decision-making) OR (vaccin* uptake or vaccin* choice*)	Limiters - Published Date: 20220201-20230131 Expanders – Apply equivalent subjects Search modes - Find all my search terms	1,225
2	(parent* or mother* or father* or DE "Mothers" or DE "Parents" or DE "Fathers") AND (infan* or child* or toddler* OR DE "Preschool Students")	Limiters - Published Date: 20220201-20230131 Expanders – Apply equivalent subjects Search modes - Find all my search terms	13,794
3	(qualitative or experienc* or perception* or interview* or ethnograph* or phenomenol* or narrat*) OR DE "Qualitative Methods"	Limiters - Published Date: 20220201-20230131 Expanders – Apply equivalent subjects Search modes - Find all my search terms	42,938
4	(attitude* or decision making or strateg* or promot* or prevent* behavio* or optimiz*) OR (DE "Health Attitudes" or DE "Childrearing Attitudes" or DE "Childrearing Practices" or DE "Child Health" or DE "Parental Attitudes" or DE "Parenting")	Limiters - Published Date: 20220201-20230131 Expanders – Apply equivalent subjects Search modes - Find all my search terms	37,022
5	((attitude* or decision making or strateg* or promot* or prevent* behavio* or optimiz*) OR (DE "Health Attitudes" or DE "Childrearing Attitudes" or DE "Childrearing Practices" or DE "Child Health" or DE "Parental Attitudes" or DE "Parenting")) AND (S1 AND S2 AND S3 AND S4)	Search modes - Boolean/Phrase	28
Interface – EBSCOhost Research Databases			

Search	Query	Limiters/Expanders	Records retrieved
Search Screen – Advanced Search Database - APA PsychInfo			

## Web of Science

*January 1, 1998-February 28, 2022*

*Search conducted on February 28, 2022*

Search	Query	Records retrieved
1	vaccin* refusal or anti vaccin* or vaccin* choice* or vaccin* hesitancy or immuni* or vaccin* decision-making or vaccin* uptake or vaccin* choice* (Topic)	467,653
2	parent* or mother* or father* (Topic) and infan* or child* or toddler* (Topic)	400,777
3	qualitative or experienc* or perception* or interview* or ethnograph* or phenomenol* or narrat* (Topic)	3,810,219
4	attitude* or decision making or strateg* or promot* or prevent* or behavio* or optimiz* (Topic)	12,042,147
5	#1 AND #2 AND #3 AND #4	1,661
6	#1 AND #2 AND #3 AND #4 and 1998 or 1999 or 2000 or 2001 or 2002 or 2003 or 2004 or 2005 or 2006 or 2007 or 2008 or 2009 or 2010 or 2022 or 2021 or 2020 or 2019 or 2018 or 2017 or 2016 or 2015 or 2014 or 2013 or 2012 or 2011	1,597
7	vaccin* refusal or anti vaccin* or vaccin* choice* or vaccin* hesitancy or immuni* or vaccin* decision- making or vaccin* uptake or vaccin* choice* (Topic)	467,653
8	parent* or mother* or father* (Topic) and infan* or child* or toddler* (Topic)	400,777
9	qualitative or experienc* or perception* or interview* or ethnograph* or phenomenol* or narrat* (Topic)	3,810,219
10	attitude* or decision making or strateg* or promot* or prevent* or behavio* or optimiz* (Topic)	12,042,147
11	#8 AND #9 AND #10 AND #11	1,661
<b>Database – Web of Science Core Collection</b>		

## Web of Science

*February 28, 2022-February 7, 2023*

*Search conducted on February 07, 2023*

Search	Query	Limiters/Expanders	Records retrieved
1	TS = (vaccin* refusal or anti vaccin* or vaccin* choice* or vaccin* hesitancy or immuni* or vaccin* decision-making or vaccin* uptake or vaccin* choice*)		505,384

Search	Query	Limiters/Expanders	Records retrieved
2	TS = (parent* or mother* or father* (Topic) and infan* or child* or toddler*)		425,800
3	TS = (qualitative or experienc* or perception* or interview* or ethnograph* or phenomenol* or narrat*)		4,085,391
4	TS = (attitude* or decision making or strateg* or promot* or prevent* or behavio* or optimiz*)		12,982,303
5	#4 AND #3 AND #2 AND #1		1,860
6	#4 AND #3 AND #2 AND #1	28/02/2022-to 07/02/2023	182
<b>Database – Web of Science Core Collection</b>			

### ProQuest

*Search conducted on February 15, 2022*

Search	Query	Records retrieved
1	su("Immunization") OR su("Vaccines") OR su("Treatment Refusal")	2,670
2	noft(vaccin* refusal or anti vaccin* or vaccin* choice* or vaccin* hesitancy or immuni* or vaccin* decision- making ) OR noft(vaccin* uptake or vaccin* choice*)	23,874
3	(su("Immunization") OR su("Vaccines") OR su("Treatment Refusal")) OR (noft(vaccin* refusal OR anti vaccin* OR vaccin* choice* OR vaccin* hesitancy OR immuni* OR vaccin* decision-making) OR noft(vaccin* uptake OR vaccin* choice*))	25,216
4	su(Mothers or fathers or parents)	21,254
5	noft(Mother* OR father* OR parent*)	200,588
6	su(Mothers OR fathers OR parents) OR noft(Mother* OR father* OR parent*)	200,588
7	su((Children OR youth OR toddlers OR Babies OR Preschool children)) OR noft((Infan* OR child* OR toddler*))	271,473
8	((su("Immunization") OR su("Vaccines") OR su("Treatment Refusal")) OR (noft(vaccin* refusal OR anti vaccin* OR vaccin* choice* OR vaccin* hesitancy OR immuni* OR vaccin* decision- making) OR noft(vaccin* uptake OR vaccin* choice*))) AND (su(Mothers OR fathers OR parents) OR noft(Mother* OR father* OR parent*)) AND (su((Children OR youth OR toddlers OR Babies OR Preschool children)) OR noft((Infan* OR child* OR toddler*)))	483
9	su("Qualitative research" OR "Grounded theory" OR "Action research" OR "Phenomenological research" )	12,048
10	noft(qualitative or experienc* or perception* or interview* or ethnograph* or phenomenol* or narrat* )	978,423
11	su("Qualitative research" OR "Grounded theory" OR "Action research" OR "Phenomenological research") OR noft(qualitative OR experienc* OR perception* OR interview* OR ethnograph* OR phenomenol* OR narrat*)	979,028

Search	Query	Records retrieved
12	((su("Immunization") OR su("Vaccines") OR su("Treatment Refusal")) OR (noft(vaccin* refusal OR anti vaccin* OR vaccin* choice* OR vaccin* hesitancy OR immuni* OR vaccin* decision- making) OR noft(vaccin*uptake OR vaccin* choice*))) AND (su(Mothers OR fathers OR parents) OR noft(Mother* OR father* OR parent*)) AND (su((Children OR youth OR toddlers OR Babies OR Preschool children)) OR noft((Infan* OR child* OR toddler*))) AND (su("Qualitative research" OR "Grounded theory" OR "Action research" OR "Phenomenological research") OR noft(qualitative OR experienc* OR perception* OR interview* OR ethnograph* OR phenomenol* OR narrat*))	190
13	su("Decision making" OR "Prevention" OR "Health promotion" OR "Parent attitudes" OR "Families & family life")	66,406
14	noft(attitude* or decision making strateg* or promot* or prevent* or behavio* or optimiz* )	1,186,509
15	su("Decision making" OR "Prevention" OR "Health promotion" OR "Parent attitudes" OR "Families & family life") OR noft(attitude* OR decision making strateg* OR promot* OR prevent* OR behavio* OR optimiz*)	1,216,534
16	(((((su("Immunization") OR su("Vaccines") OR su("Treatment Refusal")) OR (noft(vaccin* refusal OR anti vaccin* OR vaccin* choice* OR vaccin* hesitancy OR immuni* OR vaccin* decision-making) OR noft(vaccin* uptake OR vaccin* choice*))) AND (su(Mothers OR fathers OR parents) OR noft(Mother* OR father* OR parent*)) AND (su((Children OR youth OR toddlers OR Babies OR Preschool children)) OR noft((Infan* OR child* OR toddler*))) AND (su("Qualitative research" OR "Grounded theory" OR "Action research" OR "Phenomenological research") OR noft(qualitative OR experienc* OR perception* OR interview* OR ethnograph* OR phenomenol* OR narrat*))) AND (su("Decision making" OR "Prevention" OR "Health promotion" OR "Parent attitudes" OR "Families & family life") OR noft(attitude* OR decision making strateg* OR promot* OR prevent* OR behavio* OR optimiz*))	145
Database – ProQuest Dissertations & Theses A&I		

## ProQuest

*Search conducted on January 30, 2023*

Search	Query	Records retrieved
1	((SUBJECT(Immunization) OR SUBJECT(Vaccines) OR SUBJECT(Treatment Refusal)) AND stype.exact("Dissertations & Theses")) AND at.exact("Dissertation/Thesis") AND pd(>20220215)	5
2	((NOFT(vaccin* refusal OR anti vaccin* OR vaccin* choice* OR vaccin* hesitancy OR immuni* OR vaccin* decision- making) OR NOFT(vaccin* uptake OR vaccin* choice*)) AND stype.exact("Dissertations &Theses")) AND at.exact("Dissertation/Thesis") AND pd(>20220215)	19
3	((SUBJECT(Immunization) OR SUBJECT(Vaccines) OR SUBJECT(Treatment Refusal)) AND stype.exact("Dissertations & Theses")) AND at.exact("Dissertation/Thesis") AND pd(>20220215)) OR	21

Search	Query	Records retrieved
	(((NOFT(vaccin* refusal OR anti vaccin* OR vaccin* choice* OR vaccin* hesitancy OR immuni* OR vaccin* decision- making) OR NOFT(vaccin* uptake OR vaccin* choice*)) AND stype.exact("Dissertations & Theses")) AND at.exact("Dissertation/Thesis") AND pd(>20220215))	
4	SUBJECT(mothers OR fathers OR parents) AND stype.exact("Dissertations & Theses") AND at.exact("Dissertation/Thesis") AND pd(>20220215)	35
5	NOFT(Mother* OR father* OR parent*) AND stype.exact("Dissertations & Theses") AND at.exact("Dissertation/Thesis") AND pd(>20220215)	147
6	(SUBJECT(mothers OR fathers OR parents) AND stype.exact("Dissertations & Theses") AND at.exact("Dissertation/Thesis") AND pd(>20220215)) OR (NOFT(Mother* OR father* OR parent*) AND stype.exact("Dissertations & Theses") AND at.exact("Dissertation/Thesis") AND pd(>20220215))	147
7	((SUBJECT(Children OR youth OR toddlers OR Babies OR Preschool children) OR NOFT(Infan* OR child* OR toddler*)) AND stype.exact("Dissertations & Theses")) AND at.exact("Dissertation/Thesis") AND pd(>20220215)	239
8	(((SUBJECT(Immunization) OR SUBJECT(Vaccines) OR SUBJECT(Treatment Refusal)) AND stype.exact("Dissertations & Theses")) AND at.exact("Dissertation/Thesis") AND pd(>20220215)) OR (((NOFT(vaccin* refusal OR anti vaccin* OR vaccin* choice* OR vaccin* hesitancy OR immuni* OR vaccin* decision- making) OR NOFT(vaccin* uptake OR vaccin* choice*)) AND stype.exact("Dissertations & Theses")) AND at.exact("Dissertation/Thesis") AND pd(>20220215))) AND ((SUBJECT(mothers OR fathers OR parents) AND stype.exact("Dissertations & Theses") AND at.exact("Dissertation/Thesis") AND pd(>20220215)) OR (NOFT(Mother* OR father* OR parent*) AND stype.exact("Dissertations & Theses") AND at.exact("Dissertation/Thesis") AND pd(>20220215))) AND (((SUBJECT(Children OR youth OR toddlers OR Babies OR Preschool children) OR NOFT(Infan* OR child* OR toddler*)) AND stype.exact("Dissertations & Theses")) AND at.exact("Dissertation/Thesis") AND pd(>20220215))	2
9	SUBJECT(Qualitative research OR Grounded theory OR Action research OR Phenomenological research) AND stype.exact("Dissertations & Theses") AND at.exact("Dissertation/Thesis") AND pd(>20220215)	4
10	NOFT(qualitative OR experienc* OR perception* OR interview* OR ethnograph* OR phenomenol* OR narrat*) AND stype.exact("Dissertations & Theses") AND at.exact("Dissertation/Thesis") AND pd(>20220215)	700
11	(SUBJECT(Qualitative research OR Grounded theory OR Action research OR Phenomenological research) AND stype.exact("Dissertations & Theses") AND at.exact("Dissertation/Thesis") AND pd(>20220215)) OR (NOFT(qualitative OR experienc* OR perception* OR interview* OR ethnograph* OR phenomenol* OR narrat*) AND stype.exact("Dissertations & Theses") AND at.exact("Dissertation/Thesis") AND pd(>20220215))	700
12	(((SUBJECT(Immunization) OR SUBJECT(Vaccines) OR SUBJECT(Treatment Refusal)) AND stype.exact("Dissertations & Theses")) AND at.exact("Dissertation/Thesis") AND pd(>20220215)) OR (((NOFT(vaccin* refusal OR anti vaccin* OR vaccin* choice* OR vaccin*	1

Search	Query	Records retrieved
	hesitancy OR immuni* OR vaccin* decision- making) OR NOFT(vaccin* uptake OR vaccin* choice*)) AND stype.exact("Dissertations & Theses")) AND at.exact("Dissertation/Thesis") AND pd(>20220215))) AND ((SUBJECT(mothers OR fathers OR parents) AND stype.exact("Dissertations & Theses") AND at.exact("Dissertation/Thesis") AND pd(>20220215)) OR (NOFT(Mother* OR father* OR parent*) AND stype.exact("Dissertations & Theses") AND at.exact("Dissertation/Thesis") AND pd(>20220215))) AND (((SUBJECT(Children OR youth OR toddlers OR Babies OR Preschool children) OR NOFT(Infan* OR child* OR toddler*)) AND stype.exact("Dissertations & Theses")) AND at.exact("Dissertation/Thesis") AND pd(>20220215))) AND ((SUBJECT(Qualitative research OR Grounded theory OR Action research OR Phenomenological research) AND stype.exact("Dissertations & Theses") AND at.exact("Dissertation/Thesis") AND pd(>20220215)) OR (NOFT(qualitative OR experienc* OR perception* OR interview* OR ethnograph* OR phenomenol* OR narrat*) AND stype.exact("Dissertations & Theses") AND at.exact("Dissertation/Thesis") AND pd(>20220215)))	
13	SUBJECT(Decision making OR Prevention OR Health promotion OR Parent attitudes OR Families family life) AND stype.exact("Dissertations & Theses") AND at.exact("Dissertation/Thesis") AND pd(>20220215)	61
14	noft(attitude* OR decision making strateg* OR promot* OR prevent* OR behavio* OR optimiz*) AND stype.exact("Dissertations & Theses") AND at.exact("Dissertation/Thesis") AND pd(>20220215)	867
15	(SUBJECT(Decision making OR Prevention OR Health promotion OR Parent attitudes OR Families family life) AND stype.exact("Dissertations & Theses") AND at.exact("Dissertation/Thesis") AND pd(>20220215)) OR (noft(attitude* OR decision making strateg* OR promot* OR prevent* OR behavio* OR optimiz*) AND stype.exact("Dissertations & Theses") AND at.exact("Dissertation/Thesis") AND pd(>20220215))	873
16	((((SUBJECT(Immunization) OR SUBJECT(Vaccines) OR SUBJECT(Treatment Refusal)) AND stype.exact("Dissertations & Theses")) AND at.exact("Dissertation/Thesis") AND pd(>20220215)) OR (((NOFT(vaccin* refusal OR anti vaccin* OR vaccin* choice* OR vaccin* hesitancy OR immuni* OR vaccin* decision- making) OR NOFT(vaccin* uptake OR vaccin* choice*)) AND Theses")) AND at.exact("Dissertation/Thesis") AND pd(>20220215))) AND ((SUBJECT(mothers OR fathers OR parents) AND stype.exact("Dissertations & Theses") AND at.exact("Dissertation/Thesis") AND pd(>20220215)) OR (NOFT(Mother* OR father* OR parent*) AND stype.exact("Dissertations & Theses") AND at.exact("Dissertation/Thesis") AND pd(>20220215))) AND (((SUBJECT(Children OR youth OR toddlers OR Babies OR Preschool children) OR OFT(Infan* OR child* OR toddler*)) AND stype.exact("Dissertations & Theses")) AND at.exact("Dissertation/Thesis") AND pd(>20220215))) AND ((SUBJECT(Qualitative research OR Grounded theory OR Action research OR Phenomenological research) AND stype.exact("Dissertations & Theses") AND at.exact("Dissertation/Thesis") AND pd(>20220215)) OR (NOFT(qualitative OR experienc* OR perception* OR interview* OR	0

Search	Query	Records retrieved
	ethnograph* OR phenomenol* OR narrat*) AND stype.exact("Dissertations & Theses") AND at.exact("Dissertation/Thesis") AND pd(>20220215))) AND ((SUBJECT(Decision making OR Prevention OR Health promotion OR Parent attitudes OR Families family life) AND stype.exact("Dissertations & Theses") AND at.exact("Dissertation/Thesis") AND pd(>20220215)) OR (noft(attitude* OR decision stype.exact("Dissertations & Theses")) AND making strateg* OR promot* OR prevent* OR behavio* OR optimiz*) AND stype.exact("Dissertations & Theses") AND at.exact("Dissertation/Thesis") AND pd(>20220215)))	
<b>Database – ProQuest Dissertations &amp; Theses A&amp;I</b>		

*Ovid MEDLINE(R) ALL*

Search conducted on February 01, 2022

Search	Query	Records retrieved
1	exp Vaccination/ or exp Vaccination Refusal/ or vaccination.mp.	194,718
2	exp Anti-Vaccination Movement/ or anti-vaccin*.mp.	785
3	exp Vaccines/	253,457
4	Vaccin* hesitancy.mp.	2,863
5	Vaccination Refusal/ or vaccin* refusal.mp.	1,140
6	vaccin* choice*.mp.	133
7	vaccin* decision making.mp.	294
8	vaccin* uptake.mp.	4,004
9	Immunization/ or Immunization.mp.	163,040
10	(Anti vaccin* or anti vax*).mp.	836
11	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10	413,635
12	father*.mp. or exp Fathers/	50,299
13	exp Mothers/ or mother*.mp.	262,213
14	parent*.mp. or exp Parents/	563,402
15	12 or 13 or 14	750,198
16	infan*.mp. or exp Infant/	1,365,911
17	exp Child, Preschool/ or exp Child/ or exp Infant/ or child*.mp.	3,098,463
18	toddler*.mp.	13,006
19	16 or 17 or 18	3,196,221
20	exp Qualitative Research/ or Qualitative.mp.	297,100
21	Grounded Theory.mp. or exp Grounded Theory/	13,631
22	Hermeneutics.mp. or exp Hermeneutics/	1,259
23	experienc*.mp.	1,273,306
24	exp Perception/ or perception*.mp.	676,633
25	interview*.mp. or exp Interview/	441,545
26	ethnograph*.mp.	12,586
27	phenomenol*.mp.	30,409
28	narrat*.mp.	71,082
29	20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28	2,371,007
30	attitude*.mp. or exp Attitude/	698,923

Search	Query	Records retrieved
31	decision Making.mp. or exp Decision Making/	362,053
32	patient acceptance of health care.mp. or exp "Patient Acceptance of Health Care"/	167,348
33	strateg*.mp.	1,311,769
34	promot*.mp.	1,247,100
35	exp Health Knowledge, Attitudes, Practice/ or Health Knowledge.mp.	125,109
36	behavio*.mp.	1,851,414
37	optimiz*.mp.	447,991
38	30 or 31 or 32 or 33 or 34 or 35 or 36 or 37	5,072,556
39	11 and 15 and 19 and 29 and 38	1,992
Limiter – 1946 to February 01, 2022		

*Ovid MEDLINE(R) ALL*

Search conducted on February 03, 2023

Search	Query	Records retrieved
1	exp Vaccination/ or exp Vaccination Refusal/ or vaccination.mp.	217,736
2	exp Anti-Vaccination Movement/ or anti-vaccin*.mp.	925
3	exp Vaccines/	271,419
4	Vaccin* hesitancy.mp.	5,056
5	Vaccination Refusal/ or vaccin* refusal.mp.	1,305
6	vaccin* choice*.mp.	172
7	vaccin* decision making.mp.	370
8	vaccin* uptake.mp.	5,372
9	Immunization/ or Immunization.mp.	168,667
10	(Anti vaccin* or anti vax*).mp.	1,004
11	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10	444,788
12	father*.mp. or exp Fathers/	52,957
13	exp Mothers/ or mother*.mp.	276,734
14	parent*.mp. or exp Parents/	592,835
15	12 or 13 or 14	788,946
16	infan*.mp. or exp Infant/	1,404,971
17	exp Child, Preschool/ or exp Child/ or exp Infant/ or child*.mp.	3,214,972
18	toddler*.mp.	14,084
19	16 or 17 or 18	3,317,882
20	exp Qualitative Research/ or Qualitative.mp.	330,518
21	Grounded Theory.mp. or exp Grounded Theory/	14,829
22	Hermeneutics.mp. or exp Hermeneutics/	1,382
23	experienc*.mp.	1,374,110
24	exp Perception/ or perception*.mp.	710,850
25	interview*.mp. or exp Interview/	475,179
26	ethnograph*.mp.	13,577
27	phenomenol*.mp.	32,989
28	narrat*.mp.	83,511
29	20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28	2,537,800

Search	Query	Records retrieved
30	attitude*.mp. or exp Attitude/	722,657
31	decision Making.mp. or exp Decision Making/	387,142
32	patient acceptance of health care.mp. or exp "Patient Acceptance of Health Care"/	171,342
33	strateg*.mp.	1,456,639
34	promot*.mp.	1,360,590
35	exp Health Knowledge, Attitudes, Practice/ or Health Knowledge.mp.	128,616
36	behavio*.mp.	1,962,837
37	optimiz*.mp.	501,630
38	30 or 31 or 32 or 33 or 34 or 35 or 36 or 37	5,470,242
39	11 and 15 and 19 and 29 and 38	2,206
40	11 and 15 and 19 and 29 and 38 (2022-2023)	260
<b>Limiters</b> – 1946 to February 02, 2023		

*Google Scholar*

1998–2022

Search conducted on February 16, 2022

Search	Query	Records Retrieved
1	("anti-vaccination" OR "vaccination refusal" OR "vaccine hesitancy") "decision making" ("preschool children" OR infants OR children) (parents OR mothers OR fathers) (qualitative) (prevention OR promotion) Only the first 150 results were looked at.	3300

*Google Scholar*

2022–2023

Search conducted on January 31, 2023

Search	Query	Records Retrieved
1	("anti-vaccination" OR "vaccination refusal" OR "vaccine hesitancy") "decision making" ("preschool children" OR infants OR children) (parents OR mothers OR fathers) (qualitative) (prevention OR promotion) Only the first 150 results were looked at.	1380

## Appendix B: Studies Ineligible Following Full Text Review

1. Abakar, M. F., Seli, D., Lechthaler, F., Schelling, E., Tran, N., Zinsstag, J., & Muñoz, D. C. (2018). Vaccine hesitancy among mobile pastoralists in Chad: A qualitative study. *International Journal for Equity in Health*, 17, 1–10.

*Reason for exclusion:* Wrong phenomena of interest

2. Abebe, A. M., Wudu Kassaw, M., Zemariam, A. B., & Estifanos Shewangashaw, N. (2019). Coverage, opportunity, and challenges of expanded program on immunization among 12–23-month-old children in Woldia town, northeast Ethiopia, 2018. *BioMed Research International*, 2019.

*Reason for exclusion:* Wrong population

3. Aharon, A. A., Nehama, H., Rishpon, S., & Bron-Epel, O. (2017). Autonomy and control among parents who do not comply with recommended pediatric vaccinations: A qualitative case study. *Journal of Community and Public Health Nursing*, 3(1), 1–6.

*Reason for exclusion:* Wrong phenomena of interest

4. Alabadi, M. & Aldawood, Z. (2020). Parents' knowledge, attitudes and perceptions on childhood vaccination in Saudi Arabia: A systematic literature review. *Vaccines*, 8(4), 750.

*Reason for exclusion:* Wrong method

5. Albrecht, C. & Fomby-White, B. (2012). A qualitative analysis of increasing adherence to the Centers for Disease Control and Prevention Recommended Guidelines for Childhood Immunization (1509561), 66.

*Reason for exclusion:* Wrong phenomena of interest

6. Allan, N. & Harden, J. (2015). Parental decision-making in uptake of the MMR vaccination: A systematic review of qualitative literature. *Journal of Public Health*, 37(4), 678–687.

*Reason for exclusion:* Wrong method

7. Ames, H. M., Glenton, C., & Lewin, S. (2017). Parents' and informal caregivers' views and experiences of communication about routine childhood vaccination: A synthesis of qualitative evidence. *The Cochrane Database of Systematic Reviews*, (2).

*Reason for exclusion:* Wrong method

8. Ask, L. S. (2019). *The introduction of rotavirus vaccine in Sweden: Setting the scene and short term outcomes* [Doctoral dissertation, Karolinska Institutet]. ProQuest Dissertations and Theses.

*Reason for exclusion:* No relevant findings

9. Attwell, K., Leask, J., Meyer, S. B., Rokkas, P., & Ward, P. (2017). Vaccine rejecting parents' engagement with expert systems that inform vaccination programs. *Journal of Bioethical Inquiry*, 14(1), 65–76.

*Reason for exclusion:* Wrong phenomena of interest

10. Attwell, K., Smith, D. T., & Ward, P. R. (2021). “If your child’s vaccinated, why do you care about mine?” Rhetoric, responsibility, power and vaccine rejection. *Journal of Sociology*, 57(2), 268–285.

*Reason for exclusion:* Wrong phenomena of interest

11. Attwell, K., Smith, D. T., & Ward, P. R. (2018). “The unhealthy other”: How vaccine rejecting parents construct the vaccinating mainstream. *Vaccine*, 36(12), 1621–1626.

*Reason for exclusion:* No relevant findings

12. Attwell, K. (2019). The politics of picking: Selective vaccinators and population-level policy. *SSM-Population Health*, 7.

*Reason for exclusion:* Wrong phenomena of interest

13. Austvoll-Dahlgren, A. & Helseth, S. (2010). What informs parents' decision-making about childhood vaccinations? *Journal of Advanced Nursing*, 66(11), 2421–2430.

*Reason for exclusion:* Wrong population

14. Aygün, E. & Tortop, H. S. (2020). Ebeveynlerin Aşı Tereddüt Düzeylerinin ve Karşıtlık Nedenlerinin İncelenmesi. *Journal of Current Pediatrics / Güncel Pediatri*, 18(3), 300–316.

*Reason for exclusion:* Full-text not available

15. Barbacariu, C. L. (2014). Parents' refusal to vaccinate their children: An increasing social phenomenon which threatens public health. *Procedia-Social and Behavioral Sciences*, 149, 84–91.

*Reason for exclusion:* No relevant findings

16. Barbieri, C. L. A., Couto, M. T., & Aith, F. M. A. (2017). Culture versus the law in the decision not to vaccinate children: Meanings assigned by middle-class couples in Sao Paulo, Brazil. A (nao) vacinaçao infantil entre a cultura e a lei: os significados atribuidos por casais de camadas medias de Sao Paulo, Brasil. *Cadernos de Saúde Pública*, 33(2), e00173315.

*Reason for exclusion:* Wrong phenomena of interest

17. Barbieri, C. L. A. & Couto, M. T. (2015). Decision-making on childhood vaccination by highly educated parents. *Revista de Saude Publica*, 49, 18.

*Reason for exclusion:* Wrong phenomena of interest

18. Barnard, M. (2011). Trust in health system influences childhood vaccination primarily. *Nursing Children & Young People*, 23(9), 8.

*Reason for exclusion:* Wrong method

19. Bell, J., Lartey, B., Spickernell, G., Darrell, N., Salt, F., Gardner, C., ... & Sharma, S. (2022). Applying a social-ecological model to understand factors impacting demand for childhood vaccinations in Nigeria, Uganda, and Guinea. *SSM-Qualitative Research in Health*, 2, 100180.

*Reason for exclusion:* Wrong phenomena of interest

20. Benin, A. L., Wisler-Scher, D. J., Colson, E., Shapiro, E. D., & Holmboe, E. S. (2006). Qualitative analysis of mothers' decision-making about vaccines for infants: the importance of trust. *Pediatrics*, 117(5), 1532–1541.

*Reason for exclusion:* Wrong phenomena of interest

21. Berreth, T. (2011). *Reasons behind immunization exemptions at school entry in Idaho: Parents' attitudes and beliefs* [Unpublished Doctoral dissertation]. University of Idaho.

*Reason for exclusion:* Wrong population

22. Blair, A., & Davies, E. (2003). Parental reasons for discontinuing the Australian vaccination schedule. *Neonatal, Paediatric & Child Health Nursing*, 6(1), 6–12.

*Reason for exclusion:* Wrong method

23. Bond, L., Nolan, T., Pattison, P., & Carlin, J. (1998). Vaccine preventable diseases and immunisations: A qualitative study of mothers' perceptions of severity, susceptibility, benefits and barriers. *Australian & New Zealand Journal of Public Health*, 22(4), 441–446.

*Reason for exclusion:* No relevant findings

24. Bond, L. & Nolan, T. (2011). Making sense of perceptions of risk of diseases and vaccinations: A qualitative study combining models of health beliefs, decision-making and risk perception. *BMC Public Health*, 11(1), 943–943.

*Reason for exclusion:* No relevant findings

25. Bradshaw, A. S., Shelton, S. S., Wollney, E., Treise, D., & Auguste, K. (2021). Pro-vaxxers get out: Anti-vaccination advocates influence undecided first-time, pregnant, and new mothers on Facebook. *Health Communication*, 36(6), 693–702.

*Reason for exclusion:* Wrong phenomena of interest

26. Braka, F., Asimwe, D., Soud, F., Lewis, R. F., Makumbi, I., & Gust D. (2012). A qualitative analysis of vaccine safety perceptions and concerns among caretakers in Uganda. *Maternal and Child Health Journal*, 16(5), 1045–1052.

*Reason for exclusion:* Wrong population

27. Brown, K. F., Long, S. J., Ramsay, M., Hudson, M. J., Green, J., Vincent, C. A., ... & Sevdalis, N. (2012). UK parents' decision-making about measles–mumps–rubella (MMR) vaccine 10 years after the MMR-autism controversy: A qualitative analysis. *Vaccine*, *30*(10), 1855–1864.

*Reason for exclusion:* No relevant findings

28. Brunson, E. K. (2010). *The point of the needle: An anthropological study of childhood vaccination in the United States* (Publication No. UMI3431516) [Doctoral dissertation, University of Washington]. ProQuest Dissertations and Theses.

*Reason for exclusion:* Wrong phenomena of interest

29. Burghouts, J., Del Nogal, B., Uriepero, A., Hermans, P. W. M., de Waard, J. H., & Verhagen, L. M. (2017). Childhood vaccine acceptance and refusal among Warao Amerindian caregivers in Venezuela; a qualitative approach. *PloS One*, *12*(1), e0170227.

*Reason for exclusion:* Wrong phenomena of interest

30. Campeau, K. L. (2019). Vaccine barriers, vaccine refusals: Situated vaccine decision-making in the wake of the 2017 Minnesota measles outbreak. *Rhetoric of Health & Medicine*, *2*(2), 176–207.

*Reason for exclusion:* Wrong phenomena of interest

31. Carrion, M. L. (2018). An ounce of prevention: Identifying cues to (In)action for maternal vaccine refusal. *Qualitative Health Research*, *28*(14), 2183–2194.

*Reason for exclusion:* Wrong phenomena of interest

32. Carrion, M. L. (2018). “You need to do your research”: Vaccines, contestable science, and maternal epistemology. *Public Understanding of Science*, *27*(3), 310–324.

*Reason for exclusion:* Wrong phenomena of interest

33. Casiday, R. (2006). Uncertainty, decision-making and trust: Lessons from the MMR controversy. *Community Practitioner*, *79*(11), 354–357.

*Reason for exclusion:* Wrong phenomena of interest

34. Casiday, R. E. (2007). Children's health and the social theory of risk: Insights from the British measles, mumps and rubella (MMR) controversy. *Social Science & Medicine*, *65*(5), 1059–1070.

*Reason for exclusion:* No relevant findings

35. Çelik, K., Turan, S., & Üner, S. (2021). I'm a mother, therefore I question”: Parents' legitimation sources of and hesitancy towards early childhood vaccination. *Social Science & Medicine*, *282*, 114132.

*Reason for exclusion:* Wrong phenomena of interest

36. Chang, K. & Lee, S. Y. (2019). Why do some Korean parents hesitate to vaccinate their children? *Epidemiology and Health*, 41, e2019031.

*Reason for exclusion:* Wrong method

37. Chantler, T., Newton, S., Lees, A., & Diggle, L. (2006). Parental views on the introduction of an infant pneumococcal vaccine. *Community Practitioner*, 79(7), 213.

*Reason for exclusion:* Wrong population

38. Charles, K. (2017). *Parental perspectives on vaccinating children against preventable childhood diseases* (Publication No. 10271230) [Doctoral dissertation, Walden University]. ProQuest: Ann Arbor.

*Reason for exclusion:* Wrong population

39. Cheater, F. M. (2006). Mothers' decisions about MMR vaccination were framed by their children's vulnerabilities and wider social trends. *Evidence-Based Nursing*, 9(1), 27.

*Reason for exclusion:* Wrong phenomena of interest

40. Cooper, S., Schmidt, B. M., Sambala, E. Z., Swartz, A., Colvin, C. J., Leon, N., ... & Wiysonge, C. S. (2019). Factors that influence parents' and informal caregivers' acceptance of routine childhood vaccination: A qualitative evidence synthesis. *The Cochrane Database of Systematic Reviews*, 2019(2).

*Reason for exclusion:* Wrong method

41. Cooper, S., Schmidt, B. M., Sambala, E. Z., Swartz, A., Colvin, C. J., Leon, N., & Wiysonge, C. S. (2021). Factors that influence parents' and informal caregivers' views and practices regarding routine childhood vaccination: A qualitative evidence synthesis. *Cochrane Database of Systematic Reviews*, (10).

*Reason for exclusion:* Wrong method

42. Couto, M. T. & Barbieri, C. L. A. (2015). Care and (non)-vaccination in the context of high-income and well-schooled families in Sao Paulo in the state of Sao Paulo, Brazil. Cuidar e (nao) vacinar no contexto de familias de alta renda e escolaridade em Sao Paulo, SP, Brasil. *Ciência & Saúde Coletiva*, 20(1), 105–114.

*Reason for exclusion:* Full text not available

43. Crescitelli, M. D., Ghirrotto, L., Sisson, H., Sarli, L., Artioli, G., Bassi, M. C., ... & Hayter, M. (2020). A meta-synthesis study of the key elements involved in childhood vaccine hesitancy. *Public Health*, 180, 38–45.

*Reason for exclusion:* Wrong method

44. Cruz Piqueras, M., Rodriguez Garcia de Cortazar, A., Hortal Carmona, J., & Padilla Bernaldez, J. (2019). Vaccine hesitancy: Discourse analysis of parents who have not fully or partially vaccinated their children. Reticencia vacunal: Analisis del discurso de madres y padres con rechazo total o parcial a las vacunas. *Gaceta Sanitaria*, 33(1), 53–59.

*Reason for exclusion:* Wrong phenomena of interest

45. Cullen, J. (2005). Why parents choose not to vaccinate their children against childhood diseases. *Professional Nurse*, 20(5), 31–33.

*Reason for exclusion:* Full text not available

46. Danso-Odei, L. (2017). *Addressing immunization challenges in rural Florida: A qualitative case study research* (Publication No. 10260256) [Doctoral dissertation, Capella University]. ProQuest: Ann Arbor.

*Reason for exclusion:* Wrong population

47. David, A. E., Enache, C. R., Hasmațuchi, G., & Stanciu, R. (2022). No need for the needle. A qualitative analysis of the antivax movement in Romania. *Profesional de la información*, 31(1).

*Reason for exclusion:* Wrong phenomena of interest

48. Deas, J., Bean, S. J., Sokolovska, I., & Fautin, C. (2019). Childhood vaccine attitudes and information sources among Oregon parents and guardians. *Health Promotion Practice*, 20(4), 529–538.

*Reason for exclusion:* Wrong phenomena of interest

49. Downs, J. S., de Bruin, W. B., & Fischhoff, B. (2008). Parents' vaccination comprehension and decisions. *Vaccine*, 26(12), 1595–1607.

*Reason for exclusion:* Wrong phenomena of interest

50. Dubé, E., Vivion, M., Sauvageau, C., Gagneur, A., Gagnon, R., & Guay, M. (2016). “Nature does things well, why should we interfere?” Vaccine hesitancy among mothers. *Qualitative Health Research*, 26(3), 411–425.

*Reason for exclusion:* No relevant findings

51. Dugas, M., Dubé, E., Kouyate, B., Sanou, A., & Bibeau, G. (2009). Portrait of a lengthy vaccination trajectory in Burkina Faso: From cultural acceptance of vaccines to actual immunization. *BMC International Health and Human Rights*, 9, 1–11.

*Reason for exclusion:* Wrong phenomena of interest

52. Ebi, S. J., Deml, M. J., Jafflin, K., Buhl, A., Engel, R., Picker, J., ... & Tarr, P. E. (2022). Parents' vaccination information seeking, satisfaction with and trust in medical providers in Switzerland: A mixed-methods study. *BMJ Open*, 12(2), e053267.

*Reason for exclusion:* Wrong phenomena of interest

53. Ellis, N., Walker-Todd, E., & Heffernan, C. (2020). Influences on childhood immunisation decision-making in London's Gypsy and Traveller communities. *British Journal of Nursing*, 29(14), 822–826.

*Reason for exclusion:* Wrong phenomena of interest

54. Evans, M., Stoddart, H., Condon, L., Freeman, E., Grizzell, M., & Mullen, R. (2001). Parents' perspectives on the MMR immunisation: A focus group study. *British Journal of General Practice*, 51(472), 904–910.

*Reason for exclusion:* Wrong phenomena of interest

55. Faasse, K., Chatman, C. J., & Martin, L. R. (2016). A comparison of language use in pro- and anti-vaccination comments in response to a high profile Facebook post. *Vaccine*, 34(47), 5808–5814.

*Reason for exclusion:* Wrong method

56. Fadda, M., Depping, M. K., & Schulz, P. J. (2015). Addressing issues of vaccination literacy and psychological empowerment in the measles-mumps-rubella (MMR) vaccination decision-making: A qualitative study. *BMC Public Health*, 15(1), 1–13.

*Reason for exclusion:* No relevant findings

57. Fadda, M., Galimberti, E., Carraro, V., & Schulz, P. J. (2016). What are parents' perspectives on psychological empowerment in the MMR vaccination decision? A focus group study. *BMJ Open*, 6(4), e010773.

*Reason for exclusion:* Wrong phenomena of interest

58. Fonseca, I. C., Pereira, A. I., & Barros L. (2021). Portuguese parental beliefs and attitudes towards vaccination. *Health Psychology and Behavioral Medicine*, 9(1), 422–435.

*Reason for exclusion:* Wrong method

59. Forster, A. S., Rockliffe, L., Chorley, A. J., Marlow, L. A., Bedford, H., Smith, S. G., & Waller, J. (2016). A qualitative systematic review of factors influencing parents' vaccination decision-making in the United Kingdom. *SSM-Population Health*, 2, 603–612.

*Reason for exclusion:* Wrong method

60. Fredrickson, D. D., Davis, T. C., Arnould, C. L., Kennen, E. M., Humiston, S. G., Cross, J. T., & Bocchini, J. A. (2004). Childhood immunization refusal: Provider and parent perceptions. *Family Medicine-Kansas City*, 36, 431–439.

*Reason for exclusion:* Wrong phenomena of interest

61. Fredrickson, D. D., Davis, T. C., Arnould, C. L., Kennen, E. M., Humiston, S. G., Cross, J. T., & Bocchini, J. A. (2004). Childhood immunization refusal: Provider and parent perceptions. *Family Medicine*, *36*, 431–439.

*Reason for exclusion:* Wrong phenomena of interest

62. Fryer, M. M. (2016). *Influence of the internet on children's vaccination: Applying intercultural theories to analyze parental decision-making* [Master's thesis, Royal Roads University]. ProQuest: Ann Arbor.

*Reason for exclusion:* Wrong phenomena of interest

63. Gardner, B., Davies, A., McAteer, J., & Michie, S. (2010). Beliefs underlying UK parents' views towards MMR promotion interventions: A qualitative study. *Psychology, Health & Medicine*, *15*(2), 220–230.

*Reason for exclusion:* Wrong phenomena of interest

64. Gerdes, J. & Thorsen, T. (2006). So dangerous are not measles, mumps and rubella ... A qualitative survey of causes of MMR vaccination refusal in the county of Vejle. *Ugeskrift for Laeger*, *168*(33), 2670–2674.

*Reason for exclusion:* Full-text not available

65. Gesser-Edelsburg, A., Shir-Raz, Y., & Green, M. S. (2016). Why do parents who usually vaccinate their children hesitate or refuse? General good vs. individual risk. *Journal of Risk Research*, *19*(4), 405–424.

*Reason for exclusion:* No relevant findings

66. Glanz, J. M., Wagner, N. M., Narwaney, K. J., Shoup, J. A., McClure, D. L., McCormick, E. V., & Daley, M. F. (2013). A mixed methods study of parental vaccine decision making and parent–provider trust. *Academic Pediatrics*, *13*(5), 481–488.

*Reason for exclusion:* No relevant findings

67. Glassman, L. W. & Szymczak, J. E. (2022). The influence of social class and institutional relationships on the experiences of vaccine-hesitant mothers: A qualitative study. *BMC Public Health*, *22*(1), 1–9.

*Reason for exclusion:* No relevant findings

68. Greyson, D., & Bettinger, J.A. (2022). How do mothers' vaccine attitudes change over time? *SSM-Qualitative Research in Health*, *2*, 100060.

*Reason for exclusion:* Wrong population

69. Gullion, J. S., Henry, L., & Gullion, G. (2008). Deciding to opt out of childhood vaccination mandates. *Public Health Nursing*, *25*(5), 401–408.

*Reason for exclusion:* No relevant findings

70. Hal, L. A. (2022). *Using social perspectives on vaccination to build public trust in pro-vaccine communication* [Doctoral dissertation, Walden University]. ProQuest: Ann Arbor.

*Reason for exclusion:* No relevant findings

71. Harmsen, I. A., Ruiters, R. A. C., Paulussen, T. G. W., Mollema, L., Kok, G., & de Melker, H. E. (2012). Factors that influence vaccination decision-making by parents who visit an anthroposophical child welfare center: A focus group study. *Advances in Preventive Medicine*, 175694.

*Reason for exclusion:* Wrong population

72. Harris, P. F. B. (2020). *Parents' perceptions of healthcare influences on their decisions to vaccinate their children* [Doctoral dissertation, Walden University] ProQuest: Ann Arbor.

*Reason for exclusion:* Wrong phenomena of interest

73. Helps, C., Barclay, L., Carter, S. M., & Leask, J. (2021). Midwifery care of non-vaccinating families—Insights from the Byron Shire. *Women & Birth*, 34(4), e416–425.

*Reason for exclusion:* No relevant findings

74. Henderson, L., Millett, C., Thorogood, N., Henderson, L., Millett, C., & Thorogood, N. (2008). Perceptions of childhood immunization in a minority community: Qualitative study. *Journal of the Royal Society of Medicine*, 101(5), 244–251.

*Reason for exclusion:* Wrong phenomena of interest

75. Hijazi, R., Gesser-Edelsburg, A., Feder-Bubis, P., & Mesch, G. S. (2022). Hesitant and anti-vaccination groups: A qualitative study on their perceptions and attitudes regarding vaccinations and their reluctance to participate in academic research—an example during a measles outbreak among a group of Jewish parents in Israel. *Frontiers in Public Health*, 10, 1012822.

*Reason for exclusion:* Wrong phenomena of interest

76. Hobson-West, P. (2007). “Trusting blindly can be the biggest risk of all”: Organised resistance to childhood vaccination in the UK. *Sociology of Health & Illness*, 29(2), 198–215.

*Reason for exclusion:* Wrong population

77. Jalloh, M. F., Bennett, S. D., Alam, D., Kouta, P., Lourenço, D., Alamgir, M., ... & Wolff, B. (2019). Rapid behavioral assessment of barriers and opportunities to improve vaccination coverage among displaced Rohingyas in Bangladesh, January 2018. *Vaccine*, 37(6), 833–838.

*Reason for exclusion:* Wrong population

78. Jama, A., Ali, M., Lindstrand, A., Butler, R., & Kulane, A. (2018). Perspectives on the measles, mumps and rubella vaccination among Somali mothers in Stockholm. *International Journal of Environmental Research and Public Health*, 15(11), 2428.

*Reason for exclusion:* No relevant findings

79. Johnson, S. & Capdevila, R. (2014). “That’s just what’s expected of you ... so you do it’: Mothers discussions around choice and the MMR vaccination. *Psychology & Health*, 29(8), 861–876.

*Reason for exclusion:* Wrong phenomena of interest

80. Kaplan, S. J. (2018). *The everyday life and information practices of a natural immunity advocate*. The University of North Carolina at Chapel Hill.

*Reason for exclusion:* No relevant findings

81. Kaur, B. (2011). *Attitudes, risks and norms: Understanding parents’ measles-mumps-rubella (MMR) immunisation decision-making* (Publication No. U614834). [Doctoral dissertation, University of Stirling].

*Reason for exclusion:* No relevant findings

82. King, C. L. & Leask, J. (2018). Parental disease prevention health beliefs and triggers for keeping children home from childcare—A qualitative study in Sydney, Australia. *Child: Care, Health and Development*, 44(2), 326–331.

*Reason for exclusion:* Wrong phenomena of interest

83. Koski, K. & Holst, J. (2017). Exploring vaccine hesitancy through an artist-scientist collaboration: Visualizing vaccine-critical parents’ health beliefs. *Journal of Bioethical Inquiry*, 14(3), 411–426.

*Reason for exclusion:* Wrong phenomena of interest

84. Kowal, S. P. (2014). *Risk communication and vaccination decision-making by recent immigrant mothers* (Publication No.10100165) [Master’s thesis, University of Alberta]. ProQuest: Ann Arbor.

*Reason for exclusion:* Wrong population

85. Kulig, J. C., Meyer, C. J., Hill, S. A., Handley, C. E., Lichtenberger, S. M., & Myck, S. L. (2002). Refusals and delay of immunization within Southwest Alberta: understanding alternative beliefs and religious perspectives. *Canadian Journal of Public Health*, 93, 109–112.

*Reason for exclusion:* No relevant findings

86. Kurup, L., He, H. G., Wang, X., Wang, W., & Shorey, S. (2017). A descriptive qualitative study of perceptions of parents on their child's vaccination. *Journal of Clinical Nursing*, 26(23–24), 4857–4867.

*Reason for exclusion:* Wrong population

87. Leader, A. E., Burke-Garcia, A., Massey, P. M., & Roark, J. B. (2021). Understanding the messages and motivation of vaccine hesitant or refusing social media influencers. *Vaccine*, 39(2), 350–356.

*Reason for exclusion:* No relevant findings

88. Limaye, R. J., Malik, F., Frew, P. M., Randall, L. A., Ellingson, M. K., O'Leary, S. T., ... & Omer, S. B. (2020). Patient decision making related to maternal and childhood vaccines: Exploring the role of trust in providers through a relational theory of power approach. *Health Education & Behavior*, 47(3), 449–456.

*Reason for exclusion:* Wrong population

89. Loyal, J., Weiss, T. R., Cheng, J. H., Kair, L. R., & Colson, E. (2019). Refusal of vitamin K by parents of newborns: A qualitative study. *Academic Pediatrics*, 19(7), 793–800.

*Reason for exclusion:* Wrong phenomena of interest

90. Luthy, K. E., Beckstrand, R. L., Callister, L. C., & Cahoon, S. (2012). Reasons parents exempt children from receiving immunizations. *The Journal of School Nursing*, 28(2), 153–160.

*Reason for exclusion:* Wrong phenomena of interest

91. Luthy, K. E., Beckstrand, R. L., & Callister LC. (2010). Parental hesitation in immunizing children in Utah. *Public Health Nursing*, 27(1), 25–31.

*Reason for exclusion:* No relevant findings

92. MacDonald, M. (2005). Parents' decisions on MMR vaccination for their children were based on personal experience rather than scientific evidence. *Evidence Based Nursing*, 8(2), 60.

*Reason for exclusion:* Wrong method

93. Mack, R. W. & Darden, P. M. (1999). Children's immunizations: The gap between parents and providers. *Health Marketing Quarterly*, 16(4), 7–14.

*Reason for exclusion:* Wrong population

94. Marshall, S. & Swerissen, H. (1999). A qualitative analysis of parental decision making for childhood immunisation. *Australian & New Zealand Journal of Public Health*, 23(5), 543–545.

*Reason for exclusion:* Wrong phenomena of interest

95. McCoy, J. D., Painter, J. E., & Jacobsen, K. H. (2019). Perceptions of vaccination within a Christian homeschooling community in Pennsylvania. *Vaccine*, 37(38), 5770–5776.

*Reason for exclusion:* Wrong population

96. McDonald, P., Limaye, R. J., Omer, S. B., Bottenheim, A. M., Mohanty, S., Klein, N. P., & Salmon, D. A. (2019). Exploring California's new law eliminating personal belief exemptions to childhood vaccines and vaccine decision-making among homeschooling mothers in California. *Vaccine*, 37(5), 742–750.

*Reason for exclusion:* No relevant findings

97. McHale, P., Keenan, A., & Ghebrehewet, S. (2016). Reasons for measles cases not being vaccinated with MMR: Investigation into parents' and carers' views following a large measles outbreak. *Epidemiology & Infection*, 144(4), 870–875.

*Reason for exclusion:* Wrong phenomena of interest

98. McKeever, B. W., McKeever, R., Holton, A. E., & Li, J.-Y. (2016). Silent majority: Childhood vaccinations and antecedents to communicative action. *Mass Communication & Society*, 19(4), 476–498.

*Reason for exclusion:* No relevant findings

99. McMurray, R., Cheater, F. M., Weighall, A., Nelson, C., Schweiger, M., & Mukherjee, S. (2004). Managing controversy through consultation: A qualitative study of communication and trust around MMR vaccination decisions. *British Journal of General Practice*, 54(504), 520–525.

*Reason for exclusion:* No relevant findings

100. McNeil, D. A., Mueller, M., MacDonald, S., McDonald, S., Saini, V., Kellner, J. D., & Tough, S. (2019). Maternal perceptions of childhood vaccination: Explanations of reasons for and against vaccination. *BMC Public Health*, 19, 1–12.

*Reason for exclusion:* Wrong phenomena of interest

101. Meleo-Erwin, Z., Basch, C., MacLean, S. A., Scheibner, C., & Cadoret, V. (2017). "To each his own": Discussions of vaccine decision-making in top parenting blogs. *Human Vaccines & Immunotherapeutics*, 13(8), 1895–1901.

*Reason for exclusion:* Wrong phenomena of interest

102. Mendel-Van Alstyne, J. A., Nowak, G. J., & Aikin, A. L. (2018). What is "confidence" and what could affect it?: A qualitative study of mothers who are hesitant about vaccines. *Vaccine*, 36(44), 6464–6472.

*Reason for exclusion:* Wrong phenomena of interest

103. Miller, N. K., Verhoef, M., & Cardwell, K. (2008). Rural parents' perspectives about information on child immunization. *Rural & Remote Health*, 8(2), 863–863.

*Reason for exclusion:* Wrong phenomena of interest

104. Moran, C. L. (2004). *Needling Doubts: A Sociological Examination of Parental Resistance to Childhood Immunizations* (Publication No. 3158679) [Doctoral dissertation, University of New Hampshire]. ProQuest: Ann Arbor.

*Reason for exclusion:* No relevant findings

105. Moran, N., Shickle, D., & Richardson, E. (2008). European citizens' opinions on immunisation. *Vaccine*, 26(3), 411–418.

*Reason for exclusion:* Wrong phenomena of interest

106. Mossey, S., Hosman, S., Montgomery, P., & McCauley, K. (2020). Parents' experiences and nurses' perceptions of decision-making about childhood immunization. *Canadian Journal of Nursing Research*, 52(4), 255–267.

*Reason for exclusion:* Wrong phenomena of interest

107. Mourão S & Bernardes, S. F. (2019). What determines immigrant caregivers' adherence to health recommendations from child primary care services? A grounded theory approach. *Primary Health Care Research & Development*, 20, e31.

*Reason for exclusion:* Wrong phenomena of interest

108. Muhati, J. P. (2023). *Attitudes and the lived experiences of vaccine hesitant parents: A mixed-methods study*. [Doctoral dissertation, Wilkes University]. ProQuest dissertations and Theses.

*Reason for exclusion:* No relevant findings

109. Murele, B., Vaz, R., Gasasira, A., Mkanda, P., Erbetto, T., & Okeibunor, J. (2014). Vaccine perception among acceptors and non-acceptors in Sokoto State, Nigeria. *Vaccine*, 32(26), 3323–3327.

*Reason for exclusion:* Wrong phenomena of interest

110. Musa, S., Kulo, A., Bach Habersaat, K., Skrijelj, V., Smjecanin, M., & Jackson, C. (2021). A qualitative interview study with parents to identify barriers and drivers to childhood vaccination and inform public health interventions. *Human Vaccines & Immunotherapeutics*, 17(9), 3023–3033.

*Reason for exclusion:* Wrong phenomena of interest

111. Nair, A. T., Nayar, K. R., Koya, S. F., Abraham, M., Lordson, J., Grace, C., ... & Pandey, A. K. (2021). Social media, vaccine hesitancy and trust deficit in immunization programs: a

qualitative enquiry in Malappuram District of Kerala, India. *Health Research Policy and Systems*, 19, 1–8.

*Reason for exclusion:* Wrong phenomena of interest

112. Newton, P. & Smith, D. M. (2017). Factors influencing uptake of measles, mumps and rubella (MMR) immunization in site-dwelling Gypsy, Roma and Traveller (G&T) communities: A qualitative study of G&T parents' beliefs and experiences. *Child: Care, Health and Development*, 43(4), 504–510.

*Reason for exclusion:* Wrong phenomena of interest

113. Niederhauser, V. P., & Markowitz, M. (2007). Barriers to immunizations: Multiethnic parents of under- and unimmunized children speak. *Journal of the American Academy of Nurse Practitioners*, 19(1), 15–23.

*Reason for exclusion:* Wrong phenomena of interest

114. Ojaka, D. I., Ofware, P., Machira, Y. W., Yamo, E., Collymore, Y., Ba-Nguz, A., ... & Bingham, A. (2011). Community perceptions of malaria and vaccines in the South Coast and Busia regions of Kenya. *Malaria Journal*, 10, 1–11.

*Reason for exclusion:* Wrong population

115. Engberink, A. O., Carbonnel, F., Lognos, B., Million, E., Vallart, M., Gagnon, S., & Bourrel, G. (2015). Comprendre la décision vaccinale des parents pour mieux accompagner leurs choix: Étude qualitative phénoménologique auprès des parents français. *Canadian Journal of Public Health*, 106, e527–e532.

*Reason for exclusion:* Full-text not available

116. Peden, J. K. (2005). *An investigation into the factors influencing the parental decision to have MMR*. [Doctoral dissertation, University of London, London School of Hygiene and Tropical Medicine]. ProQuest: Ann Arbor.

*Reason for exclusion:* Full-text not available

117. Peretti-Watel, P., Ward, J. K., Vergelys, C., Bocquier, A., Raude, J., & Verger, P. (2019). “I think I made the right decision ... I hope I’m not wrong”. Vaccine hesitancy, commitment and trust among parents of young children. *Sociology of Health & Illness*, 41(6), 1192–1206.

*Reason for exclusion:* No relevant findings

118. Pihl, G. T., Johannessen, H., Ammentorp, J., Jensen, J. S., & Kofoed, P.-E. (2017). “Lay epidemiology”: An important factor in Danish parents' decision of whether to allow their child to receive a BCG vaccination. A qualitative exploration of parental perspective. *BMC Pediatrics*, 17, 1–8.

*Reason for exclusion:* Wrong population

119. Poltorak, M., Leach, M., Fairhead, J., & Cassell, J. (2005). “MMR talk” and vaccination choices: An ethnographic study in Brighton. *Social Science & Medicine*, *61*(3), 709–719.

*Reason for exclusion:* Wrong phenomena of interest

120. Powelson, J. A. (2021). *Determinants of immunization dropout among children under the age of two in Zambézia Province, Mozambique: A community-based participatory research study using photovoice*. [University of Washington]. ProQuest: Ann Arbor.

*Reason for exclusion:* No relevant findings

121. Reading, R. (2007). Review of Children’s health and the social theory of risk: Insights from the British measles, mumps and rubella (MMR) controversy. *Child: Care, Health and Development*, *33*(6), 805–806.

*Reason for exclusion:* Wrong method

122. Roberts, K. A., Dixon-Woods, M., Fitzpatrick, R., Abrams, K. R., & Jones, D. R. (2002). Factors affecting uptake of childhood immunisation: A Bayesian synthesis of qualitative and quantitative evidence. *Lancet*, *360*(9345), 1596–1599.

*Reason for exclusion:* Wrong method

123. Robson, J. (2000). Mothers’ attitudes to vaccination. *AIMS Journal*, *12*(1), 17–17.

*Reason for exclusion:* Wrong phenomena of interest

124. Rodrigues de Souza Andrade, D., Lorenzini, E., & Franco da Silva, E. (2014). Conhecimento de maes sobre o calendario de vacinacao e fatores que levam ao atraso vacinal infantil. *Cogitare Enfermagem*, *19*(1), 179–192.

*Reason for exclusion:* Full-text not available

125. Romijnders, K. A. G. J., van Seventer, S. L., Scheltema, M., van Osch, L., de Vries, H., & Mollema, L. (2019). A deliberate choice? Exploring factors related to informed decision-making about childhood vaccination among acceptors, refusers, and partial acceptors. *Vaccine*, *37*(37), 5637–5644.

*Reason for exclusion:* Wrong phenomena of interest

126. Rozbroj, T., Lyons, A., & Lucke, J. (2020). Vaccine-hesitant and vaccine-refusing parents’ reflections on the way parenthood changed their attitudes to vaccination. *Journal of Community Health*, *45*(1), 63–72.

*Reason for exclusion:* Wrong phenomena of interest

127. Rumetta, J., Abdul-Hadi, H., & Lee, Y. K. (2020). A qualitative study on parents' reasons and recommendations for childhood vaccination refusal in Malaysia. *Journal of Infection and Public Health*, 13(2), 199–203.

*Reason for exclusion:* No relevant findings

128. Saada, A., Lieu, T. A., Morain, S. R., Zikmund-Fisher, B. J., & Wittenberg, E. (2015). Parents' choices and rationales for alternative vaccination schedules: A qualitative study. *Clinical Pediatrics*, 54(3), 236–243.

*Reason for exclusion:* No relevant findings

129. Senier, L. (2008). "It's your most precious thing": Worst-case thinking, trust, and parental decision making about vaccinations. *Sociological Inquiry*, 78(2), 207–229.

*Reason for exclusion:* Wrong phenomena of interest

130. Smith, D. & Newton, P. (2017). Structural barriers to measles, mumps and rubella (MMR) immunisation uptake in Gypsy, Roma and Traveller communities in the United Kingdom. *Critical Public Health*, 27(2), 238–247.

*Reason for exclusion:* Wrong phenomena of interest

131. Smith, S. E., Sivertsen, N., Lines, L., & De Bellis, A. (2022). Decision making in vaccine hesitant parents and pregnant women—An integrative review. *International Journal of Nursing Studies Advances*, 15, 100062.

*Reason for exclusion:* Wrong method

132. Sobo, E. J. (2015). Social cultivation of vaccine refusal and delay among Waldorf (Steiner) School parents. *Medical Anthropology Quarterly*, 29(3), 381–399.

*Reason for exclusion:* Wrong phenomena of interest

133. Sobo, E. J. (2016b). What is herd immunity, and how does it relate to pediatric vaccination uptake? US parent perspectives. *Social Science & Medicine*, 165, 187–195.

*Reason for exclusion:* No relevant findings

134. Song, G. (2012). *The strain of the herd: Risk perceptions, policy preferences, and parental decision-making for childhood vaccination*. [Doctoral dissertation, The University of Oklahoma]. ProQuest: Ann Arbor.  
[https://shareok.org/bitstream/handle/11244/318606/Song\\_ou\\_0169D\\_10816.pdf?sequence=1](https://shareok.org/bitstream/handle/11244/318606/Song_ou_0169D_10816.pdf?sequence=1)

*Reason for exclusion:* Wrong method

135. Sporton, R. K., & Francis, S. A. (2001). Choosing not to immunize: Are parents making informed decisions? *Family Practice*, 18(2), 181–188.

*Reason for exclusion:* No relevant findings

136. Stefanoff, P., Mamelund, S. E., Robinson, M., Netterlid, E., Tuells, J., Bergsaker, M. A. R., ... & VACSATC Working Group on Standardization of Attitudinal Studies in Europe. (2010). Tracking parental attitudes on vaccination across European countries: the Vaccine Safety, Attitudes, Training and Communication Project (VACSATC). *Vaccine*, 28(35), 5731–5737.

*Reason for exclusion:* Wrong method

137. Stewart, J., & Sayer, L. (2021). What factors influence measles, mumps and rubella vaccine hesitancy among parents? A systematic review. *British Journal of Child Health*, 2(3), 143–152.

*Reason for exclusion:* Wrong method

138. Sun, X., Huang, Z., Wagner, A. L., Prosser, L. A., Xu, E., Ren, J., ... & Zikmund-Fisher, B. J. (2018). The role of severity perceptions and beliefs in natural infections in Shanghai parents' vaccine decision-making: A qualitative study. *BMC Public Health*, 18, 1–9.

*Reason for exclusion:* Wrong population

139. Swaney, S. E. & Burns, S. (2019). Exploring reasons for vaccine-hesitancy among higher-SES parents in Perth, Western Australia. *Health Promotion Journal of Australia*, 30(2), 143–152.

*Reason for exclusion:* No relevant findings

140. Syiroj, A. T. R., Pardosi, J. F., & Heywood, A. E. (2019). Exploring parents' reasons for incomplete childhood immunisation in Indonesia. *Vaccine*, 37(43), 6486–6493.

*Reason for exclusion:* Wrong population

141. Tandy, C. B. & Jabson Tree, J. M. (2021). Attitudes of East Tennessee residents towards general and pertussis vaccination: A qualitative study. *BMC Public Health*, 21(1), 1–11.

*Reason for exclusion:* Wrong phenomena of interest

142. Tangherlini, T. R., Roychowdhury, V., Glenn, B., Crespi, C. M., Bandari, R., Wadia, A., ... & Bastani, R. (2016). “Mommy blogs” and the vaccination exemption narrative: Results from a machine-learning approach for story aggregation on parenting social media sites. *JMIR Public Health and Surveillance*, 2(2), e6586.

*Reason for exclusion:* Wrong method

143. Tarrant, M. & Gregory, D. (2001). Mothers' perceptions of childhood immunizations in First Nations communities of the Sioux Lookout Zone. *Canadian Journal of Public Health*, 92(1), 42–45.

*Reason for exclusion:* Wrong phenomena of interest

144. Tarrant M & Gregory D. (2003). Exploring childhood immunization uptake with First Nations mothers in north-western Ontario, Canada. *Journal of Advanced Nursing* (Wiley-Blackwell), 41(1), 63–72.

*Reason for exclusion:* Wrong phenomena of interest

145. ten Kate J, de Koster W, & van der Waal J. (2022). Becoming skeptical towards vaccines: How health views shape the trajectories following health-related events. *Social Science & Medicine*, 293, 114668.

*Reason for exclusion:* No relevant findings

146. Thornock, B. S. O. (2016). *A new strategy for persuading vaccine hesitant parents of children with autism to immunize: A grounded theory study and metarhetorical approach*. [Doctoral dissertation, Saint Louis University]. ProQuest-Ann Arbor.

*Reason for exclusion:* Wrong phenomena of interest

147. Tickner, S., Leman, P. J., & Woodcock, A. (2007). “It’s just the normal thing to do:” Exploring parental decision-making about the “five-in-one” vaccine. *Vaccine*, 25(42), 7399–7409.

*Reason for exclusion:* Wrong phenomena of interest

148. Timmermans, D. R. M., Henneman, L., Hirasings, R. A., & van der Wal, G. (2005). Attitudes and risk perception of parents of different ethnic backgrounds regarding meningococcal C vaccination. *Vaccine*, 23(25), 3329–3335.

*Reason for exclusion:* Wrong method

149. Timmermans, D. R. M., Henneman, L., Hirasings, R. A., & van der Wal, G. (2008). Parents’ perceived vulnerability and perceived control in preventing Meningococcal C infection: A large-scale interview study about vaccination. *BMC Public Health*, 8, 1–7.

*Reason for exclusion:* Wrong population

150. Tomljenovic, H., Bubic, A., & Hren, D. (2022.) Decision making processes underlying avoidance of mandatory child vaccination in Croatia—a qualitative study. *Current Psychology*, 41(9), 6210–6224.

*Reason for exclusion:* No relevant findings

151. Topçu, S., Almış, H., Başkan, S., Turgut, M., Orhon, F. Ş., & Ulukol, B. (2019). Evaluation of childhood vaccine refusal and hesitancy intentions in Turkey. *Indian Journal of Pediatrics*, 86(1), 38–43.

*Reason for exclusion:* Wrong method

152. Vaccine hesitancy among parents—A study in Thiruvananthapuram. Chennai, India: Loyola College of Social Sciences.

*Reason for exclusion:* Full-text not available

153. Vandenberg, S. Y., & Kulig, J. C. (2015). Immunization rejection in Southern Alberta: A comparison of the perspectives of mothers and health professionals. *CJNR: Canadian Journal of Nursing Research*, 47(2), 81–96.

*Reason for exclusion:* No relevant findings

154. Vieira de Lima, C. R., de Sousa Bispo, B. K., Nonobe de Araujo, E. A., Leite Meirelles Monteiro, E. M., & Low, S. T. (2012). Difficulties reported by parents/guardians for the fulfillment of the basic immunization of children from a nursery. *Journal of Nursing UFPE / Revista de Enfermagem UFPE*, 6(10), 2404–2410.

*Reason for exclusion:* Wrong phenomena of interest

155. Wachinger, J., Reñosa, M. D. C., Endoma, V., Aligato, M. F., Landicho-Guevarra, J., Landicho, J., ... & McMahon, S. A. (2022). Bargaining and gendered authority: A framework to understand household decision-making about childhood vaccines in the Philippines. *BMJ Global Health*, 7(9), e009781.

*Reason for exclusion:* Wrong phenomena of interest

156. Wang, L. D., Lam, W. W., Wu, J. T., Liao, Q., & Fielding, R. (2014). Chinese immigrant parents' vaccination decision making for children: A qualitative analysis. *BMC Public Health*, 14(1), 1–13.

*Reason for exclusion:* Wrong population

157. Watson, P. B., Yarwood, J., & Chenery, K. (2007). Meningococcal B: Tell me everything you know and everything you don't know. New Zealanders' decision-making regarding an immunisation programme. *The New Zealand Medical Journal*, 120(1263), U2751.

*Reason for exclusion:* Wrong phenomena of interest

158. Weiner, J. L., Fisher, A. M., Nowak, G. J., Basket, M. M., & Gellin, B. G. (2015). Childhood immunizations: First-time expectant mothers' knowledge, beliefs, intentions, and behaviors. *Vaccine*, 33(Suppl 4), D92–8.

*Reason for exclusion:* Wrong population

159. Wilson, K., Barakat, M., Vohra, S., Ritvo, P., & Boon, H. (2008). Parental views on pediatric vaccination: The impact of competing advocacy coalitions. *Public Understanding of Science*, 17(2), 231–243.

*Reason for exclusion:* Wrong phenomena of interest

160. Wilson, K, Barakat, M, Vohra, S, Ritvo, P, & Boon, H. (2008). Parental views on pediatric vaccination: The impact of competing advocacy coalitions. *Public Understanding of Science*, 17(2), 231–243.

*Reason for exclusion:* Wrong phenomena of interest

161. Woo, E. J., Ball, R., Bostrom, A., Shadomy, S. V., Ball, L. K., Evans, G., & Braun, M. (2004). Vaccine risk perception among reporters of autism after vaccination: Vaccine Adverse Event Reporting System 1990–2001. *American Journal of Public Health*, 94(6), 990–995.

*Reason for exclusion:* Wrong method

162. Yates, J. F. (2015). *MMR Uptake in Somerset following the 2009 National Catch-up Campaign: Factors affecting parents' decisions to accept or decline immunisation*. Stirling, United Kingdom: University of Stirling.

*Reason for exclusion:* No relevant findings

### Appendix C: Characteristics of Included Studies

Author/Year/Country	Methods for data collection and analysis	Phenomena of interest	Setting/context /culture	Informant characteristics and sample size	Description of main results
Atasever et al., 2021 Turkey	(Article) Qualitative research method using both semi-structured and open-ended questions with in-person, in-depth interviews. Interview notes and voice records were transcribed and studied with content analysis and interpreted by evaluating in terms of research problems. Thematic framework was determined using the answers of the informants. Research data was coded and organized.	Mothers' attitudes towards vaccines and their reasons to reject vaccination.	Two family healthcare centres and one private hospital in Konya, Turkey between November 2019 and May 2020.	<b>20 mothers</b> who rejected vaccination. Eight had secondary school education. Seven were university graduates. Five were high school graduates.	Breast milk and propolis are among the traditional/alternative treatment methods used to strengthen immunity and protect against diseases, herbal products and spiritual practices were also included.
*Attwell et al., 2018 Australia companion paper to Attwell, Meyer, & Ward, 2018, Ward 2017 & Ward 2018)	(1 of 4 Articles) Qualitative research study using in-person, in-depth, semi-structured interviews with qualitative analysis. Interviews were transcribed verbatim, coded, and analyzed in Nvivo 10 (QSR International).	The relationship between vaccine rejection or hesitancy and complementary and alternative medicine (CAM).	Fremantle, Western Australia, and Adelaide, South Australia, from September 2013–December 2015.	<b>29 parents.</b> 9 from Fremantle and 20 from Adelaide. <b>26 identified as women. 3 identified as men.</b> The age range was 25–50 years; 19 were between 36 and 42. Over half of the parents were university graduates. 13 parents had never vaccinated their children, 5 had started vaccinating but stopped, 7 had delayed or partially vaccinated, 4 parents had delayed but were now up to	Parent's do-it-yourself ethic and personal agency was enhanced by self-directed CAM use, alongside (sometimes informal) CAM practitioner instruction. Reifying 'the natural,' parents eschewed vaccines as toxic and adulterating, and embraced CAM as a protective strategy for immune systems before, during and after illness. Users saw CAM as harm-free, and when it came to experiences that non-users might interpret as demonstrating CAM's ineffectiveness, parents rationalised to the contrary. Parents also generally

Author/Year/Country	Methods for data collection and analysis	Phenomena of interest	Setting/context /culture	Informant characteristics and sample size	Description of main results
				date. 3 informants were qualified or student CAM practitioners, 17 used or referred positively to CAM, 8 did not mention CAM, 6 said they did not use or trust particular CAM modalities.	glossed over its profit motive. CAM emerged as part of an expert system countering Western medicine.
*Attwell, Meyer, & Ward, 2018 Australia	(2 of 4 Articles) Qualitative study with in-person, in-depth, semi-structured interviews. Interviews were transcribed verbatim and coded and analyzed in NVivo 10 (QSR International). Analysis used sociological theory of Bourdieu and Ingram, and the work of philosopher Mark Navin.	How parents experience non-vaccination as a valued form of capital in specific communities, and how this can affect their decision-making.	Fremantle, Western Australia and Adelaide, South Australia	32 parents. 12 from Fremantle and 20 from Adelaide. 28 identified as women. 4 identified as men. The age range of parents was 24–50 years, 19 parents aged between 36 and 42. Two thirds of the parents were university graduates. 12 parents had never vaccinated their child(ren), 5 had started vaccinating but stopped, 7 had delayed or partially vaccinated, and 5 parents had previously delayed but were now up to date. <b>(3 parents [2 mothers, 1 father] added to SR total, as per Attwell 2018)</b>	Parents experienced disjuncture and tugs towards ‘appropriate’ forms of vaccination behaviour in their social networks, as these link to broader behaviours around food, school choices and birth practices.
Blaisdell et al., 2016 USA	(Article) Qualitative study using in-person, semi-structured, focus group interviews with exploratory aims. Interviews were audio-recorded and transcribed verbatim. Analysis	Perceived risk and constructed personal judgments about the risks and uncertainties associated with	Portland, Maine	<b>42 vaccine hesitant parents (VHPs)</b> of children aged 0 to 8 years. 14 refused vaccines. 28 were hesitant. 1 parent was under 25 years, 1 parent was over 45 years. 21 were between the ages of 26-34.	Vaccine hesitant parents (VHPs) engaged in various reasoning processes and tend to perceive risks of vaccination as greater than the risks of vaccine preventable diseases. VHPs engage in other reasoning processes that lead them to perceive

Author/Year/Country	Methods for data collection and analysis	Phenomena of interest	Setting/context /culture	Informant characteristics and sample size	Description of main results
	completed via NVivo9 (QSR International) using coding and constant comparative methods (inductive grounded theory). Informants' statements were categorized by thematic content.	vaccines and vaccine preventable diseases (VPDs) and how these subjective risk judgements influence parents' decisions about childhood vaccination.		19 were between 35-44. 1 parent had some high school education, 3 had some college, 25 were college graduates, 2 had an associate degree, 11 had postgraduate education.	ambiguity in information about the harms of vaccination—citing concerns about the missing, conflicting, changing, or otherwise unreliable nature of information.
Brunson, 2013 USA	(Article) Qualitative study using in-person interviews, Interviews were transcribed verbatim. Data collection and analysis was guided by grounded theory (Charmaz); involving coding, and model development of the decision-making process.	How parents make decisions about their children's vaccines	King County Washington (Western State), an area with lower-than-average vaccination rates.	21 parents "15 mothers and three couples," aged 18-40 years (29 median). 5.5% had some high school, 5.5% had completed high school, 11.1% had some college, 77.8% had at least a college education. Children were aged 3-18 months of age or less. 38.9% were completely vaccinated, 38.9% were partially vaccinated, 22.2% were completely unvaccinated. <b>(12 informants added to SR total)</b>	Through grounded theory, a general vaccine decision-making process was identified. Stages included: ongoing assessment. This research suggests that three general assessment groups exist, it includes searchers, who seek for information on their own, primarily from published sources.
Byström et al., 2014 Sweden	(Article) Qualitative study using in-depth, in-person, semi-structured interviews. Interviews were digitally recorded and transcribed. Used qualitative content analysis (meaning unit	Explore facilitators and barriers to MMR vaccination among parents living in anthroposophic	Parents in an anthroposophic community near Stockholm. Data collected between Feb—May 2013.	20 parents. 13 identified as mothers. 2 identified as fathers. 9 parents vaccinated their children. 11 parents were non-vaccinating. Of the non-vaccinating parents, 1 was aged 25-30, 4 were aged	Two overarching views of health emerged that differentiated the parents who vaccinated vs. parents who did not vaccinate. The last theme, promoters of natural immunity, represented the attitude of

Author/Year/Country	Methods for data collection and analysis	Phenomena of interest	Setting/context /culture	Informant characteristics and sample size	Description of main results
	[quote], coding, sub-category, category)	communities in Sweden.		30-40, 6 were aged 40-50. <b>(11 informants added to SR total)</b>	parents postponing or refusing vaccination beyond childhood.
Carrion, 2014 USA	(Doctoral dissertation) Qualitative methodology using semi-structured, in-depth, telephone interviews. Study was guided by a model of patient-centred health communication research. Interviews were audio recorded and transcribed verbatim. Data analysis guided by constant comparison (Corbin & Strauss)	To examine how mothers' accounts of vaccine refusal reflect and construct ideas about health, risk, motherhood, and the relationship between maternal experience and medical authority.	Data collected in 2013, from Babycenter online forum.	<b>50 mothers</b> aged 21-41 years (29.84 median). 4 had completed high school, 17 had some college, 4 had associate degrees, 18 had completed a bachelor's degree, 7 had completed graduate degree(s). 9 selectively vaccinated, 3 were unsure and delaying vaccines, 26 had vaccinated previous children but stopped vaccinating a child born in the last 2 years or had begun vaccinating their youngest (or only) child and then stopped then stopped. Informants had 1-6 children.	Informants perceived vaccine injury as a greater threat than vaccine preventable disease. This perception was shaped by an intuitive and highly individualized sense of risk, as well as communication with and from expert sources.
Deml et al. 2022 Switzerland	(Article) Qualitative study with in-person, semi-structured, qualitative interviews with parents; and observations of vaccination consultations between parents and practitioners of CAM and biomedicine. Interviews were audio-recorded and transcribed verbatim. Framework method, and thematic	How parents make vaccination decisions and investigating relationships between parents' use of CAM and vaccine attitudes. The researchers switched the phenomena of interest to parents	French and German-speaking regions of Switzerland between August 2017 and August 2018. Observations of vaccination consultations between parents and	30 parents (French-speaking region: N = 13, German speaking region: N = 17) from 26 families. Eight parents were interviewed as couples. The researchers interviewed mothers (N = 24) and fathers (N = 6). Parents' ages ranged from 26 to 55 years (average ~37 years). The number of children per family ranged from one to five (average ~2	There was not always a clear-cut, direct relationship between (non)vaccination and parents' use of CAM and/or biomedicine. The researchers described and analysed the underdiscussed provider-switching phenomenon.

Author/Year/Country	Methods for data collection and analysis	Phenomena of interest	Setting/context /culture	Informant characteristics and sample size	Description of main results
	analysis for guiding analysis of interview transcripts and clinic observations. Conceptually borrowed from Hirschman ( <i>Exit, Voice, and Loyalty</i> ) to inform analysis. Researchers used MAXQDA software to code segments of text from the transcripts and narrative accounts of observations.	switching providers or seeking services from another doctor around the issue of vaccination.	practitioners of CAM and biomedicine took place in clinic setting.	children). Most parents had attained education at a bachelor's degree level or higher. Researchers observed 34 vaccination consultations (N = 18 CAM consultations with five providers, N = 16 biomedical consultations with six providers). In seven families, at least one child had received none of the recommended vaccines. In 11 families, children had been partially vaccinated or in an individualized/delayed fashion. <b>In eight families, the children had been vaccinated according to official recommendations (18 added to SR total)</b>	
Duchsherer et al., 2020 USA	(Article) Qualitative online content analysis of a pre-existing sample of discourse testimonials on YouTube from the vaccine refusing/hesitant community given to the creators of the anti-vaccination documentary VaxXed. The researchers used a two-cycle coding process to analyse	How the individualist epistemologies are externalized and validated in communication with others, focusing on how the narrative strategies used to do so contribute to community	States with the lowest vaccination rates were targeted to ensure that narratives aligned closely with themes related to vaccine refusing or hesitant	Vaccine refusing and hesitant parents who resided in Virginia, West Virginia, Florida, Oregon, and Michigan and had provided video testimonials to the VaxXed producers. The researchers used the VaxXed website, which lists testimonial videos by state, to assign a state/number identification code to each video, using an	Testimonials of vaccine refusing, and hesitant parents (VR/H) provided insight to several aspects of the VR/H community building and advocacy process. The five most prominent themes in this dataset were: distrust of doctors, self-diagnosis, building credibility, advocacy, and community building.

Author/Year/Country	Methods for data collection and analysis	Phenomena of interest	Setting/context /culture	Informant characteristics and sample size	Description of main results
	the transcripts from the videos.	building among vaccine refusing and hesitant parents.	parents. The states represented in the dataset are Virginia, West Virginia, Florida, Oregon, and Michigan.	online randomizer. The researchers selected the first five videos on the list (n=25) for analysis. <b>(5 informants added to SR total)</b>	
Ejuma, 2020 USA	(Doctoral dissertation) Qualitative cross-cultural and phenomenological study using in-depth phone interviews (via Skype), interpretative phenomenological analysis (IPA).	Investigate parental beliefs and decision-making processes regarding childhood immunizations among vaccine-hesitant parents/caretakers of zero to five-year-olds in Washington DC, United States and Kingston, Jamaica.	Washington DC and Kingston Jamaica	<b>15 informants</b> (parents of young children) from each community. In Jamaica parents had complied with their jurisdiction's vaccine requirements. In Washington, DC, 9 parents had delayed vaccines, 2 had substituted vaccines, and 4 had refused vaccines. Informant's children were aged 0-5 years	The study results demonstrate that the decisions parents ultimately made regarding vaccinations their children was heavily influenced by the options they had available to them. Parental choice was a major contributing factor in the decision to vaccinate.
Fallet, 2017 Norway	(Master's thesis) Qualitative study, informed by constructivist grounded theory principles, in-person, semi-structured interviews. Analysis was guided by a "modified" grounded theory	This project aimed to explore and understand parents' vaccination choices in Eastern Norway.	Hedmark County, Eastern Norway	8 parents. 7 identified as women, 1 identified as a man. One of the female informants was under 30 years old, and the rest were between 30-45 years old. All but one (who was a student) of the informants had a bachelor's	Three categories emerged from the data and came together in one core category 'parenting as managing health risk to protect their child'. Those who chose to delay or refuse evaluate risks of vaccine preventable diseases (VPDs) and the vaccine based on their subjective views.

Author/Year/Country	Methods for data collection and analysis	Phenomena of interest	Setting/context /culture	Informant characteristics and sample size	Description of main results
	approach outlined by Charmaz.			degree or higher. 4 informants had fully vaccinated their children. 4 had delayed or declined some or all vaccinations. All the parents with unvaccinated children had two or more children, but only one child in the age group between 5-24 months. <b>(4 informants added to SR total)</b>	There was also seen a preference for the 'natural immunity' gained by diseases and vaccines were seen as an 'unnatural' way to acquire immunity.
Gross et al., 2015 Switzerland	(Article) Qualitative study using in-person, semi-structured interviews. Interviews were audio-recorded and transcribed verbatim. Transcripts were analyzed with Atlas.ti using qualitative latent content analysis, coding, and an interpretative approach.	How Swiss parents argued along the lines of a natural development of the child to explain their critical attitudes towards immunization against measles and other childhood diseases.	Two cantons with high immunization coverage: Aargau and Fribourg; and two cantons with low immunization coverage Lucerne and Vaud in the German and French speaking part of Switzerland.	<b>35 parents. 28 mothers, 1 father, 3 couples (mother &amp; father)</b> Mean age mothers: 37 Mean age fathers: 40 Highest education of mothers (22 secondary school, 10 university degree) Highest education of fathers (6 obligatory education, 14 secondary school, 12 university degree) Number of children (9 informants had 1 child, 14 had 2, 7 had 3, and 2 had 4+) 7 informants had children who were not yet vaccinated. 16 informants had children who were partially immunized. 9 informants had children who were not immunized Parents had a mixed socio-economic status,	Parents built their arguments against immunization on a strong faith in the strength of the naturally acquired immune system. Childhood diseases were not perceived as a threat but as part of the natural way to reinforce the body and to acquire a "natural" and thus strong immunity.

Author/Year/Country	Methods for data collection and analysis	Phenomena of interest	Setting/context /culture	Informant characteristics and sample size	Description of main results
				<p>but the majority could be characterized as middle class with many parents working in the field of medical care (N = 19) or education (N = 9) None of the interviewed parents had fully immunized their lastborn child. Nine parents had not immunized their lastborn child at all. Another 23 parents had only partially immunized their children or not yet immunized their lastborn child.</p>	
Haarstick, 2021 USA	<p>(Master's thesis) In-person and virtual ethnographic research. In-person, informant observation with semi-structured and open-ended interview time, five informants also engaged in "virtual hangouts." Virtual hangouts, or virtual informant observations with semi-structured and open-ended interviews with two informants (due to COVID-19). Data collection through fieldnotes, audio recordings and photographs of health items. Data analysis was guided by</p>	<p>To gather in-depth health and life narratives of vaccine skeptical mothers' decision making about vaccination and biomedical interactions. Observing their home health and care practices to determine if there are consistent themes in home-based healthcare provided in lieu of vaccination and</p>	<p>Research took place from October 2019 through April 2021 in a mid-size city in the Upper Midwest of the United States</p>	<p><b>7 vaccine skeptical mothers</b> from the upper Midwest of the United States. Informants 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 2 children (2-5) 3 children 18mo- 6 years 1 child (6-10) 1 child (3-5) 3 child 11-15 3 child 6-10 bachelor's degrees: 1 high school: 5 master's degree: 1</p>	<p>Mothers took an expansive approach to health and wellness that included alternative interventions that existed alongside biomedical options. Vaccine skeptical mothers focused on daily care practices centred around a healthy diet and eating whole foods. 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.</p>

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	"immersion/crystallization" process.	biomedical interactions.			
Harmsen et al., 2013 Netherlands	(Article) Qualitative research method using online focus groups. The researchers used a semi-structured format, opened ended questions, with minimal control. A thematic analysis and an inductive process was used to code and analyse the data for the sub-themes from these main themes. Using software program NVivo 9 (QSR International), separate analyses were conducted for partially vaccinating parents and non-vaccinating parents.	To attain more insight into the factors that lead parents to refuse vaccines to design public information and interventions that will help parents make decisions that best serve their children and the wider community.	Informants were randomly selected from Praeventis, the vaccination database in The Netherlands. Informants were selected based on the vaccination status of their children (0–4 years old).	<b>60 parents</b> who had refused all or some vaccinations on non-religious grounds. Of the 8 groups, 5 included parents who completely refused vaccinations (n = 39, 7–9 parents each), and 3 included parents who partially refused vaccinations (n = 21, 7 parents each). Informant's children were 0-4 years old. Five parents had one child; most parents had two (n = 34) or three children (n = 14); 6 parents had four children, and one parent had five children. Because of the anonymity of the informants, no other demographic variables (like gender) were available.	Refusal of vaccination was found to reflect multiple factors including family lifestyle; perceptions about the child's body and immune system; perceived risks of disease, vaccine efficacy, and side effects; perceived advantages of experiencing the disease; prior negative experience with vaccination; and social environment.
*Helps, Leask & Barclay, 2018 Australia (companion to Helps, et al., 2019)	(1 of 2 Articles) Community-based study using semi-structured, in-person interviews. The authors identified and analysed all quotes pertaining to the government policy in the interviews. The primary researcher undertook initial	To better understand the impact of financial penalties from the "No Jab, No Pay" policy on parents' attitudes and behaviours.	Northern NSW coastal area of Byron Shire, an area which has recorded low rates of vaccination uptake for more than 20 years.	32 non- vaccinating parents: <b>9 fathers, 22 mothers and 1 pregnant woman</b> with at least one unvaccinated child under 11 years. <b>(31 added to SR total)</b>	Three key themes: 'questioning policy integrity', 'minimising impact' and 'holding my ground'. Affected parents offset reduced income by removing children from early childhood learning, reducing work commitments, moving residence to reduce living costs, and accessing informal childcare arrangements.

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	inductive thematic analysis which was cross-checked by the authors. The authors achieved consensus of themes through a collaborative iterative process.				Parents reported a greater commitment to their decision not to vaccinate and an increased desire to maintain control over health choices for their children including an unprecedented willingness to become involved in protest action.
*Helps, et al., 2019 Australia	(2 of 2 Articles) Qualitative design using semi-structured, in-person interviews. Initial inductive analysis guided by Charmaz (2014). Included early analysis in parallel with ongoing data collection; line by line coding; refining, combining and contrasting codes to explore emerging concepts; memo writing and making field notes. Early analysis was cross checked and interpretive consensus was achieved through a collaborative iterative process.	To explain vaccination refusal in a sample of Australian parents by exploring what they value.	Parents were recruited from the Byron Shire Local Government Area of New South Wales, Australia.	32 non- vaccinating parents: 9 fathers, 22 mothers and 1 pregnant woman with at least one unvaccinated child under 11 years. <b>(0 added as per Helps 2018)</b>	Common patterns in parents' accounts included: perceived deterioration in health in Western societies; a personal experience introducing doubt about vaccine safety; concerns regarding consent; varied encounters with health professionals (dismissive, hindering, and helpful); a quest for 'the real truth'; reactance to system inflexibilities and ongoing risk assessment.
Hsu et al., 2023 USA	(Article) Qualitative study using in-person focus groups. Transcripts were analyzed using template analysis with deductive and inductive approaches to	To explore drivers of suboptimal vaccination rates by understanding why parents without strong antivaccine beliefs	Washington State. Distinct geographic regions: 1 rural and 2 urban. Three focus groups had	<b>41 parents of children</b> aged 24 to 48 months who delayed, declined, or missed some but not all vaccines. Informants were diverse in race, number of children, income, education, and	Focus groups identified multiple reasons for parents deciding to delay or decline vaccines for their children, including issues of individualism and control.

Author/Year/Country	Methods for data collection and analysis	Phenomena of interest	Setting/context /culture	Informant characteristics and sample size	Description of main results
	code development and analysis.	do not fully vaccinate their children.	parents of children who were patients at 1 of 3 large healthcare organizations and 1 group had parents from the Somali community.	health insurance type. Most informants were married, but over one quarter (27%) were single, separated or divorced. While a range of incomes were represented, 54% of informants reported annual income under \$45,000.	
Kuan, 2022 Taiwan	(Article) Qualitative study using fieldwork observations of lectures and activities concerning childhood vaccination organised by parental groups and open-ended, (19 in-person, 5 online) interviews. Field notes were taken at the observed events and coded to the interview transcripts. Fieldwork was triangulated to the interview data. Thematic analysis of main and final themes by researcher and research assistant.	How do parents understand their roles and responsibilities regarding childhood vaccination under new parental norms? How do new parental norms interweave with other social contexts to shape parental practices of childhood vaccination?	19 interviewees lived in northern Taiwan (Taipei, Taoyuan and Hsinchu), 1 lived in central Taiwan (Taichung), 2 lived in southern Taiwan (Kaohsiung), and 2 lived in eastern Taiwan (Yilan). Fieldwork observations took place in conferences, maternal classes, parental group meetings in Taiwan.	24 parents, 17 vaccine-hesitant parents and 7 vaccine policy compliers, were interviewed. The interviewees comprised 22 mothers and 2 fathers who were the main decision-makers regarding their children's vaccination. The majority of the informants were well educated and middle class in terms of occupation. The average number of children for each parent was 1.79. 83.7% of informants' children were in the preschool age range (under 6 years old). Regarding vaccination status, 11 children were fully vaccinated, 20 were partially vaccinated, and 12 were unvaccinated. Most	Results show that 'uniqueness of every child', 'informed decision-making' and 'intensive parenthood' are three essential elements in contemporary parental norms that significantly influence parents' experiences regarding childhood vaccination.

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				of the vaccine-hesitant parents in this study were users of CAM (N = 7) and belonged to alternative parenting communities (N = 10). <b>(17 informants added to SR total)</b>	
Martinez-Diz et al., 2014 Spain	(Article) Qualitative research using grounded theory, focal-groups, and semi-structured, in-person interviews with healthcare providers and parents. Researchers used field notes, recorded our observations, and documented how the research was carried out. Using the verbatim transcription of interviews, they performed a semantical analysis to classify the content into categories, examining the data and assigning the answers to thematic units to draw conclusions.	To examine the opinions, beliefs and attitudes about vaccination, of parents who decide not to vaccinate their children. To determine the opinions and attitudes of the health professionals on the behaviour towards childhood vaccination.	Granada, Spain, April—September 2011	17 informants. 10 healthcare providers. 7 parents with children whose children's vaccines were incomplete. <b>4 identified as mothers, 3 identified as fathers.</b> 3 mothers had children with incomplete vaccination. 1 father had children with incomplete vaccination. 1 mother had completely unvaccinated children. 2 fathers had completely unvaccinated. <b>(7 informants added to SR total)</b>	Parents argued on the benefits of suffering vaccine-preventable diseases in a natural way, without non-natural, aggressive, or toxic products. Vaccinations was considered unnecessary, if given adequate hygienic-sanitary conditions, effectiveness unproven and more dangerous than the disease they prevent, especially the polyvalent vaccines.
*Nurmi, 2021 Finland (companion: Nurmi, 2022)	(Book chapter, 1 of 2 Records) Ethnographic in-depth, in-person interviews. The interviews were analyzed using qualitative content analysis. Used lay-	1) what led informants to refuse childhood vaccinations, 2) which health-promoting and	Interviews occurred between 2016 and 2019 with informants living in southern,	<b>34 parents. 32 identified as women, 2 identified as men.</b> All had opted out of vaccinating at least one of their children. Informant's children were 2 months to 22	Many informants in the study aimed to co-produce 'natural' immunities, avoid autoimmunity and possible adverse effects from vaccines, and live in a symbiotic relationship with

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	immunologies lens for analysis.	illness-preventing practices informants used, and 3) informants' experiences in the healthcare system. 4) The perceptions of and practices related to 'natural' immunity and illness prevention without vaccines, 5) examining their diverse and even contradictory manifestations.	western, and central Finland.	years old. There was a total of 78 children, of whom 35 were non-vaccinated, 30 partially vaccinated and 12 fully vaccinated until at least the age of six.	their environment and the non-human actors in it.
*Nurmi & Harman, 2022 Finland	(Article 2 of 2 Records) In-depth interviews (36 in-person, 2 over the phone) with Finnish parents who have refused all or several vaccines for their children. The interviews were analyzed using qualitative content analysis.	The reasons for partial and complete refusal of childhood vaccination. To analyze perceptions and experiences central in vaccination decisions.	Informants lived in southern, western, and central Finland. Interviews took place between 2016-2019.	38 parents. 35 identified as women, 3 identified as men. All parents who had refused all or several vaccines for their children. Informants' children were between the ages of two months and 30 years, but most of the children were minors. The informants had a total of 106 children, of which 45 were non-vaccinated, 37 were partially vaccinated, and 24 were fully vaccinated until at least the age of six. Some continued to give their	Health perceptions and practices – parents supported their vaccination choices with complementary and alternative medicine treatments and alternative health understandings. Many stated that contracting vaccine-preventable illnesses would provide longer lasting and more 'natural' immunity than vaccination, and possibly other health benefits.

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				<p>children certain recommended vaccines. Six informants had never vaccinated any of their children. Some considered their vaccination decisions to be fairly permanent, while others stated that they might reconsider vaccination later.</p> <p><b>(4 informants [3 women, 1 man] added to SR total as per Nurmi 2021)</b></p>	
<p>*Reich, 2014 USA (companions: Reich 2016, Reich 2018, Reich 2020b, Reich 2020c)</p>	<p>(Article 1 of 5) In-depth, semi-structured, in-person, interviews and ethnographic observations at community events, listservs, and meetings with national organizations that oppose vaccine mandates. Interviews were recorded and transcribed verbatim. Data were coded and analyzed thematically as per constructivist grounded theory (Charmaz). Where data are collected and analyzed "to learn informants' implicit meanings of their experiences to build a</p>	<p>How do women advocate for their children by challenging state control of their bodies? How do mothers through their vaccine choices, embrace and replicate privilege?</p>	<p>Colorado, USA. Lowest rates of vaccination in the country and one of the states with the highest use of personal belief exemptions. Interviews held from 2007 to 2013.</p>	<p><b>25 informants who identify as mothers</b> who have either chosen to refuse all recommended vaccines or allow some vaccines on a schedule of their own devising. 12 had at least one child without any vaccines. 8 chose select vaccines for their children, opting out of a significant portion. 5 gave all vaccines but on a schedule of their own devising. 9 mothers had bachelor's degrees, 8 had graduate degrees, 6 had some college education, 2 had completed high school. 9 parents had 1 child, 8 have 2 children, 3 have 3 children, 4 have 4 children, and 1 had 8</p>	<p>Mothers, see themselves as experts on their children and weigh perceived risks of infection against those of vaccines and dismiss claims that vaccines are necessary. Mothers see their own intensive mothering practices—particularly around feeding, nutrition, and natural living—as an alternate and superior means of supporting their children's immunity. Mothers attempt to control risk through management of social exposure.</p>

Author/Year/Country	Methods for data collection and analysis	Phenomena of interest	Setting/context /culture	Informant characteristics and sample size	Description of main results
	conceptual analysis of them."			children. The mothers are aged 35-55 years. All but one mother had a minor child at home.	
*Reich, 2016 USA	(Article 2 of 5) In-depth interviews with three groups: parents, paediatricians, and complementary healthcare providers who oppose vaccines; through ethnographic observations at national conferences of organizations that oppose vaccine mandates or support natural living; and from analysis of online parenting forums for parents throughout the country. Data were coded and analyzed thematically as per constructivist grounded theory (Charmaz). Where data are collected and analyzed "to learn informants' implicit meanings of their experiences to build a conceptual analysis of them."	To understand the perspectives, reasons and conceptual resources that parents draw on when they decline mandated vaccines for their children.	Colorado, USA.	34 parents. (29 identify as mothers & 5 identify as fathers). All rejected vaccines completely or devised their own vaccine schedule. All but one identifies as heterosexual; all but 1 identify with being white. 29 are married and five are divorced or separated. Among the parents were 4 informants who also identified as providers (two paediatricians and two chiropractors). 10 parents had bachelor's degrees, 11 had graduate degrees, 8 had some college and 5 were high school educated. Ten parents stay home full-time, 11 work full-time for wages, 13 work part-time, help run family-owned businesses, or are professionals with limited work hours and great autonomy, including massage therapist, yoga instructor, birth coach, and writer. 10	Parents perceive immunity occurring from illness to be natural and superior and immunity derived from vaccines as inferior and potentially dangerous. Parents highlight the ways their own natural living serves to enhance their children's immunity rendering vaccines unnecessary.

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				<p>parents have 1 child, 12 have 2 children, 6 have 3, 5 have 4 children, and 1 has eight children. Parents were between 26 and 60 years old. All but two parents had at least one minor child at home. <b>(5 fathers and 4 mothers [9 informants] added to SR total as per Reich 2014)</b></p>	
<p>*Reich, 2018 USA</p>	<p>(Article 3 of 5) In-depth, in-person interviews, ethnographic observations with parents, paediatricians, vaccine researchers and attorneys who represent claims in the federal Vaccine Injury Compensation Program. Interviews were recorded and transcribed verbatim. Transcripts were coded and analyzed thematically, and then themes were developed into theoretical frames to build constructivist grounded theory (Charmaz), where data are collected and analyzed "to learn informants' implicit meanings of their</p>	<p>How parents who opt out of vaccines for their own children understand mandates for and exemptions to vaccines in law, craft claims to use exemptions, and articulate their perception of the state as curtailing their individual freedoms in efforts to promote public health.</p>	<p>Colorado, USA.</p>	<p>54 informants. 9 paediatricians. 11 attorneys. 34 parents (29 identify as mothers and 5 identify as fathers) —demographics of parents identical to Reich 2016. <b>(0 added as per Reich 2014, 2016)</b></p>	<p>Parents laboriously manage information about their children's care to protect access to exemptions, and how they strategize how to use exemptions in ways they see as in their children's best interests, but not necessarily as the laws were intended. The results show how these efforts represent a way to challenge state power, which parents see as limiting individual freedoms.</p>

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	experiences to build conceptual analysis of them."				
*Reich, 2020b USA	(Article 4 of 5) In-person, in-depth interviews. Secondary analysis of interviews conducted between 2007 and 2014. Transcripts were initially coded and analyzed thematically, and then as patterns were identified. Used constructivist grounded theory (Charmaz), in which data are collected and analyzed "to learn informants' implicit meanings of their experiences to build a conceptual analysis of them."	The strategies parents use to pharmaceutically manage their children's health, even when espousing a larger rejection of pharmaceutical interventions like childhood vaccines.	Colorado, USA	34 parents (29 mothers and 5 fathers). See Reich, 2016, Reich 2018, for informant characteristics. <b>(0 added as per Reich 2014, 2016)</b>	Parents managed ambivalence, which allowed them to accept medication for their children as a tool to be deployed as deemed necessary in some contexts, while at the same time communicating their rejection of it.
*Reich, 2020c USA	(Article 5 of 5) Secondary analysis of in-depth interview with 28 mothers (data collected between 2007 and 2014). This analysis focuses on social capital and stigma management among mothers who refuse vaccines.	How mothers provide each other information critical of vaccines, encourage a sense of oneself as empowered to question social expectations around vaccination, provide strategies	Colorado, USA	28 informants who all identify as mothers who either opted out completely from vaccines or consented to a schedule of their own devising. This is a companion study to Reich 2014, 2016, 2018, 2020. All but one identified as being white. All but one identified as heterosexual; 24 were married; and four were divorced or separated from	Vaccine-refusing mothers face disapproval for breaking social norms and rejecting consensus that supports community standards for disease prevention. Women who are disproportionately white, college educated, and wealthy, bring cultural capital into their networks of like-minded mothers. Yet, they face stigma in their social interactions outside of those networks, with those who insist vaccines are a public good,

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		for managing stigma that results from refusing vaccines, and define a sense of obligation to extend social capital to other mothers.		their child's other parent. 9 mothers had bachelor's degrees, 8 had graduate degrees, 7 had some college and 4 were high school educated. 9 mothers stayed home full-time; 7 worked full-time for wages; 12 worked part-time. <b>(0 added as per Reich 2014, 2016)</b>	illustrating the limits of their access to social capital in these mixed interactions. As mothers build networks with other sympathetic mothers, they gain information, alternative ways of understanding illness and health, and support for vaccine refusal. As both audience and expert, they share strategies for navigating mixed interactions. These networks may be local or they may be virtual, spanning huge distances, and may result from daily interaction, or contact that is more sporadic.
Sobo et al., 2016c USA	(Article) Secondary analysis of "rapid assessment techniques to facilitate data collection from busy parents, who completed a few short surveys (including a demographic survey) and a quick or 'five minute' in-person interview involving a single, highly focused question. Analyzed transcribed interviews using anthropologically informed qualitative content analysis.	How parents deploy the vaccine-related information they have procured, filtered, and made sense of, and to illuminate how parents experience their role in vaccine decision-making.	California, USA. Study undertaken in 2014. Informants were recruited from State University campus daycare centre and community locations known to attract vaccine-cautious individuals.	53 parents with at least one child kindergarten age or younger. 49 identified as being female. 4 identified as being male. 100% had a high school education. 33% had completed a bachelor's degree, 33% had a master's degree. ~10% had a PhD or MD. The children were aged 2.71 years on average. 33 parents fully vaccinated their children. <b>13 selectively vaccinated. 7 refused all vaccines. (20 added to SR total)</b>	Selective and nonvaccinating parents exhibited the type of self-informed engagement that the healthcare system recommends. Selective vaccinators also expressed multiple, sometimes contradictory positions on vaccination that were keyed to individual children's biologies, child size, environmental hazards, specific diseases, and discrete vaccines.
Sumengen et al., 2021	(Article) Qualitative research design using	To examine the reasons parents	Turkey, informants had	<b>22 parents. 21 identified as female, 1 identified as male.</b>	Parents resorted to natural nutrition, vitamin support and some other

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Turkey	phenomenological, semi-structured, online interviews. Thematic analysis: formed subheadings to code and categorise the collected data. The data collection process was carried out simultaneously with the analysis. The data collected from the informants were continuously compared. Categories were created from the raw data. When analysing the data, the correspondence and analysis on the social media platforms were documented verbatim.	shared for choosing alternative protection methods over vaccines to strengthen their child's immune system.	posted anti-vaccination comments on anti-vaccine groups on Facebook.	Age: 28–38. All had refused one or more childhood vaccination. Nationality: 20 Republic of Turkey & 1 Ukraine. Ages of children: 10 months to 12 years. Education: 14 bachelor's degree; 6 high school; 1 secondary school; 1 master's degree.	precautions, such as avoiding takeaway food or preparing homemade food, rather than having their children vaccinated.
Sythes & Bedford, 2022 United Kingdom	(Article) Qualitative approach using semi-structured, phone interviews. Interviews were audio-recorded and transcribed verbatim. Coding in Nvivo 12. Codes were grouped, analyzed, and synthesized to look for patterns and theoretical insights (thematic analysis).	To understand the origin of non-vaccination beliefs, exploring themes such as maternal health responsibility, relationships, and interactions with healthcare professionals	England. Personal contact of primary researcher posted written invitations to UK online parenting forums, and online groups. Mothers recruited across the country.	<b>10 mothers</b> who have rejected some or all of their child's routine vaccinations in the last 5-10 years. Age range 30-43 years. 5 married, 1 co-habiting, 4 single. 3 mothers had 1 child, 5 mothers had 2 children, 1 mother had 3 children, 1 mother had 6 children. Children's age range 6 months-16 years. 8 mothers had at least one child 5 years	The mothers all wanted the same thing: to have happy and healthy children, a goal which they saw as their responsibility and within their control and did not include vaccination.

Author/Year/Country	Methods for data collection and analysis	Phenomena of interest	Setting/context /culture	Informant characteristics and sample size	Description of main results
				<p>or younger, 2 mothers had children aged 7-13. 3 mothers lived in the city, 1 lived in the suburbs, 5 lived in a town or village, 1 lived in a rural area. 6 identified as White British, 1 identified as White European, 1 identified as Black Caribbean, 1 identified as Mixed Ethnicity (did not specify), 1 identified as both White British and Black Afro-Caribbean.</p>	
<p>ten Kate et al., 2021 Netherlands</p>	<p>(Article) Qualitative study using in-depth, in-person, inductive, open-ended interviews. Interviews analyzed using ATLAS.ti., transcribed verbatim, coded, and compared iteratively with relevant theories (Glaser and Strauss). The transcripts were first coded openly, then narrowed down through constant comparison, then further categorized into groups corresponding to the overarching themes. Axial coding as per Charmaz. Notes on the interactions</p>	<p>To develop a sociological understanding of vaccine skepticism among more-educated Dutch parents by exploring how they view vaccinations and how their actions can be understood in the light of this perspective.</p>	<p>More-educated Dutch parents. Interviews conducted from March 2019-February 2020.</p>	<p><b>31 parents (8 identified as male, and 23 identified as female).</b> Vaccine uptake: 8 none; 6 full; 5 partial; 2 partial and delayed; 1 delayed (full); 1 full + additional vaccines; 1 plans to fully vaccinate; 1 eldest full, youngest none; 1 eldest 2 full, youngest 2 partial and delayed. 20 had completed a program at a higher vocational school, 11 had completed a university degree. Parents were aged 28-60. No ages of children provided.</p>	<p>All respondents ascribed a central role to the individual in obtaining knowledge, this is expressed in two repertoires. A neoromantic one focuses on deriving truth through intuition and following a “natural” path and informs a risk typology: embracing (refusing) “natural” (“unnatural”) risks such as “childhood diseases” (“pharmaceutical substances”).</p>

Author/Year/Country	Methods for data collection and analysis	Phenomena of interest	Setting/context /culture	Informant characteristics and sample size	Description of main results
	during the interviews were coded interpretatively.				
Thornton and Reich, 2022 USA	(Article) Qualitative online analysis of websites, blogs, social media posts, and comments that reflected vaccine-critical sentiment among Black mothers. Most posts were from Twitter and Facebook, which provided some profile information. Authors thematically coded each post and resulting comment. They generated themes through an iterative process of first creating descriptive codes and then identifying conceptual similarities between codes. Consistent with the goals of constructivist grounded theory, they identified patterns that illustrated larger concepts in the data to represent social experiences.	To better understand Black mothers' concerns about vaccines and the role of the state in their lives.	Black mothers in the United States using Facebook and Twitter between October 2019 and February 2020.	In total, the researchers analyzed 249 threads with 311 posts. Of those, approximately 250 (about 80 percent) were from Facebook groups; the remainder were from Twitter. Tweets came from users who identified as Black in their profile, image, or tweet. Throughout the research process, the researchers viewed the Facebook and Twitter profiles of posters to identify those who present themselves as Black <b>women</b> and to verify that the profiles were still active, rather than from defunct accounts. <b>(unable to add number to SR total, all women)</b>	Unlike white women who reject vaccines as a personal choice, Black mothers express unique concerns about the role of the state in their lives. They describe efforts to strategize interactions with paediatricians and other healthcare providers who can report them to social service agencies or block access to welfare and nutritional benefits for their families if they refuse vaccines. Black women's experiences with structural gendered racism in interactions with healthcare and education systems shape vaccine decisions and should be taken seriously.
Tombs-Heirman, 2009 United Kingdom (Scotland)	(Master's thesis) Qualitative study using in depth, open-ended, (5) in-person, and (10) phone interviews and fieldwork; qualitative constructivist grounded	The health beliefs of parents who make active decisions not to vaccinate in the context of those	Informants were recruited through the networks of homeopathic practitioners in	15 informants who had not vaccinated their children for common childhood illnesses and travel vaccinations. <b>12 identified as female, 2 identified as male. 1 was not</b>	Parents' experiences with healthcare practitioners varied enormously; from support and encouragement for their stance on vaccination to accusations of being a 'bad parent'. Some parents would never have any vaccination for

Author/Year/Country	Methods for data collection and analysis	Phenomena of interest	Setting/context /culture	Informant characteristics and sample size	Description of main results
	theory guided analysis (Charmaz)	beliefs and health related practices.	Scotland, England, and one informant lived in Africa (researcher also a homeopathic practitioner).	<b>a parent.</b> Age range was 20-50 years. 7 parents had 1 child, 5 parents had 2 children, 1 parent had 3 children, 1 parent had 4 children. <b>(14 informants added to SR total)</b>	themselves or their children in any circumstances as they did not agree with the principle at the outset. Others did not rule out all vaccinations in all circumstances but kept an open mind.
Tomljenovic et al., 2022 Croatia	(Article) Qualitative study using a pragmatist, epistemological approach following the principle [sic] of basing the enquiry in human experience. 23 phone interviews and 2 in-person (pilot interviews). Semi-structured interviews. Interviews were audio-recorded and transcribed verbatim. Data analysis using the framework of thematic analyses. It included developing a preliminary coding framework based on the initial analysis of important themes on the first six interviews.	Perceptions and reasoning of vaccine hesitant parents from Croatia where child vaccination is mandatory. To reveal different strategies by which they avoid mandatory vaccination schedules and hypothetical situations in which they would reconsider vaccinating, as well as to identify features of related decision-making.	Croatian parents or caregivers recruited through social media or <a href="http://www.roda.hr">www.roda.hr</a>	<b>25 parents/caregivers</b> who were vaccine-hesitant. <b>4 identified as males and 21 identified as females;</b> of average age 37 years (total range 27–50). Two informants were married to each other, while others were not members of the same family. Children were aged 3 months to 15 years. 3 informants refused all vaccines for their children. 6 informants had given one vaccine (in the maternity ward) and none later. 6 parents had a high school education. 19 had a university education. 22 were employed, 1 was unemployed, and 2 were on parental leave. 21 were married, 2 were in a relationship, 1 was divorced, and 1 was single. 11 had 1 child, 9 had 2 children, and 4	The identified themes were related to the parents' avoidance behaviour of mandatory vaccination schedules and related consequences, dealing with outcomes of the decision and reconsidering vaccinating.

Author/Year/Country	Methods for data collection and analysis	Phenomena of interest	Setting/context /culture	Informant characteristics and sample size	Description of main results
				had 3+ children. 3 parents had experience with measles and whopping cough.	
Vandenberg, 2013 Canada	(Master's thesis) Qualitative study using grounded theory (Strauss), open-ended, in-person interviews. Data analysis through constant comparison, coding and theory generation.	To explore how mothers develop an understanding of childhood immunization which contributes to the decision-making process resulting in a decision not to participate in immunization. Second, the perceptions of childhood immunization of healthcare professionals were also examined.	Southern Alberta (included religious groups: Dutch Reform & Mormon). Rural setting with low vaccination rates.	20 informants. Eight mothers who did not immunize their children as per the routine childhood immunization schedule and 12 healthcare professionals. Mothers had children aged 0–6 years. <b>(8 informants added to SR total)</b>	A grounded theory was developed which emphasizes the importance of collaboration between non-immunizing mothers and healthcare professionals to promote positive health outcomes in children.
*Ward et al., 2017 Australia	(3 of 4 Articles) Qualitative study using interpretive, in-person, in-depth, semi-structured interviews with qualitative thematic analysis. Open and non-judgmental manner, akin to empathetic neutrality. Interviews were transcribed verbatim, coded, and analyzed in Nvivo 10	To shed a light on the narratives of parents, from their perspectives, as opposed to advocating for or against their vaccination decisions.	Fremantle, Western Australia, and Adelaide, South Australia, from 2013–2016. Two studies with the same aim were combined for analysis.	29 parents. 9 from Fremantle and 20 from Adelaide. 25 identified as women. The age range was 25–50 years; 19 were between 36 and 42. Over half of the parents were university graduates. 13 parents had never vaccinated their children, 5 had started	The main themes focus on parental perceptions of 1. their capacity to reason; 2. their rejection of Western medical epistemology; and 3. their participation in labour intensive parenting practices (termed salutogenic parenting).

Author/Year/Country	Methods for data collection and analysis	Phenomena of interest	Setting/context /culture	Informant characteristics and sample size	Description of main results
	(QSR International). All interviews were analysed using both inductive and deductive processes, and logic of care. This paper focused on "parents talking about the factors that shaped their decisions not to (or partially) vaccinate their children."			vaccinating but stopped, 7 had delayed or partially vaccinated, 4 parents had delayed but were now up to date. <b>(0 added as per Attwell 2018)</b>	
*Ward et al., 2018 Australia	(4 of 4 Articles) Qualitative study, in-depth, semi-structured interviews, interviews were transcribed and analysed using both inductive and deductive processes (coding, conceptual & theoretical categorisation). This paper focuses on "the chronological process through which parents navigate risk." See companion papers for more details: (Ward et al. 2017; Attwell et al. 2017).	Exploring the ways in which such parents talk about the perceived risks and benefits incurred by vaccinating (or not vaccinating) their children.	Fremantle, Western Australia and Adelaide, South Australia, from 2013–2016. Two studies with the same aim were combined for analysis.	See Ward et al. 2017. <b>(0 added as per Attwell 2018)</b>	Parents attempted to navigate multiple and conflicting 'risks': the risk of vaccine-preventable diseases, risks associated with vaccination and risks associated with their own perceived lack of understanding. They construct these risks with reference to particular discourses, engagement with expert opinion and lifestyle choices emblematic of late modernity. The risks they are willing to accept and the subsequent responsibility and blame they assume when choosing to abstain, or partially abstain, from vaccinating their children are, to the parents, coherent with their interpretation of best parenting practice.
*Wiley et al., 2020 Australia	(Article 1 of 2) Qualitative research using constructivist grounded theory, semi-structured telephone,	To elicit and explain patterns and variation in the social	Informants were from in or around the cities of (1)	<b>21 parents. 19 identified as mothers, 1 identifies as a father, and one parent did not want their gender</b>	Parents all spoke of wanting happy, healthy, robust children. All endorsed parenting values and approaches aligned with modern societal

Author/Year/Country	Methods for data collection and analysis	Phenomena of interest	Setting/context /culture	Informant characteristics and sample size	Description of main results
(companion: Wiley 2021)	online, and on-person interviews. Grounded Theory methodology guided data collection and analysis.	processes of parental refusal of childhood vaccines.	Perth, (5) Adelaide, (4) Melbourne, (1) Canberra, (6) Sydney, and (5) Brisbane. Interviews took place between September 11th, 2017— February 20th, 2019.	<b>recorded</b> who had intentionally delayed or refused some or all of the vaccines under the National Immunisation Programme. Parents' ages ranged from mid- 30s to mid-50s, and they had between one and six children, ranging from 9 months to 33 years old. All had at least one child 18 years old or younger at the time of interview.	expectations of taking responsibility for their child's health. They varied, however, in their lifestyle and vaccination trajectories. Informants self-identified as situated along an 'alternative' to 'mainstream' lifestyle spectrum and had moved both away from and toward vaccination over time.
*Wiley et al., 2021 Australia	(Article 2 of 2) Qualitative study using constructivist Grounded Theory, semi-structured interviews were conducted via telephone, zoom, or in-person. Interviews were audio-recorded, transcribed and de-identified using pseudonyms. Inductive analysis identified stigmatization as a central concept; stigma theory was adopted as an analytical lens.	To understand the lived experience of non-vaccinating parents in contemporary Australia. Three key lines of inquiry: 'Tell me what's important to you as a parent', 'Tell me how you got here' (with respect to vaccine refusal), and 'What was influential in helping you come to your current	Parents were from five of Australia's eight states and territories between September 11th, 2017, and February 20th, 2019.	21 parents who had intentionally delayed or refused some or all of the vaccines under the National Immunisation Programme. 19 identified as mothers, one identified as a father, one parent did not want their gender recorded. Parents' ages ranged from mid- 30s to mid-50s, and they had between one and six children, ranging from 9 months to 33 years old. All had at least one child 18 years old or younger at the time of interview. <b>(0 added as per Wiley 2020)</b>	Parents experienced (1) labelling and (2) stereotyping, with many not identifying with the "anti-vaxxers" portrayed in the media and describing frustration at being labelled as such, believing they were defending their child from harm. Informants described (3) social "othering", leading to relationship loss and social isolation, and (4) status loss and discrimination, feeling "brushed off" as incompetent parents and discriminated against by medical professionals and other parents. Finally, (5) legislative changes exerted power over their circumstances, rendering them unable to provide their children with the same financial and educational opportunities as



Author/Year/Country	Methods for data collection and analysis	Phenomena of interest	Setting/context /culture	Informant characteristics and sample size	Description of main results
	transcribed and analysed thematically.		2017-November 2017.	old., 1 parent was >40 years old. 3: primary school education, 7: secondary school education, 10: certificate/diploma, 7: degree/master's/PhD. 21 were working, Six were not working.	external forces that drive parental refusal of vaccination.

### Appendix D: Study Findings and Illustrations

Study: Atasever, 2021	
Finding	Conventional/Alternative Treatment Modalities: "When conventional/alternative treatment modalities practiced to boost immunity and be protected from diseases were questioned, breastmilk and propolis ranked first, followed by herbal products and spiritual endeavors" (p. e100) (U)
Illustration	"I use chamomile water, carob molasses, celery, honey, sage, and antibiotics. I buy propolis from herbalists. I care about hygiene" (P11, p. e99).
Study: Attwell et al., 2018	
Finding	Self-directed and practitioner led use: "CAM use went beyond simply visiting and trusting a practitioner. It involved CAM providers being information sources, applying friends' CAM advice, or personal study. In these ways, parents came to see themselves as proficient in navigating the right path to ensure the health of their children, including the selection of treatment as well as sources of information. Reliance upon friends fit with what we identified as a DIY (do-it-yourself) ethic of the informants, whereby they invested time and energy into learning how to manage life and health choices themselves, including learning from others who were already doing so" (p. 109). (U)
Illustration	"I would go to the naturopath a whole lot more if it wasn't so expensive. So I end up doing lots of research on my own, or talking with friends, or trying out this or that. I've got a few friends that have been doing it longer than me, so I'll call them and say, 'Okay what would you do?'" (Anna, p. 109).
Finding	Engagement with CAM: "Utilising CAM—whilst not directing it towards prevention of specific infectious disease—enabled parents to feel that they were managing risks by taking responsibility for them. This did not necessarily mean avoiding infection, but rather being able to manage it" (p. 108). (C)
Illustration	Questioned whether she would be worried during an outbreak of measles or diphtheria, Kavita (SA/CV) would trust in her son's "body to be strong enough to fight that" and "probably just do some probiotics and some colostrums and some bone broth and a bit of Reiki and some hippie stuff, apple cider vinegar in the bath" (Kavita, p. 108)
Study: Attwell, Meyer, & Ward, 2018	
Finding	Habitus Tug (pull toward an alternative social group with different caregiving practices): "For some informants, pregnancy and birth experiences were a pivotal point that made them question their previous/current practices and consider new/alternative ones. These experiences moved them

	from a 'mainstream' to an 'alternative/natural' social group, which included vaccine questioning" (p. 7). (U)
Illustration	"Another example of 'habitus tug' was described by Pippa in Adelaide, who started vaccinating according to the schedule but then became a selective vaccinator. Pippa attributed this to a shift in her approach to the birthing model between her two children. "[I]n the intervening time, between [first child]'s birth and my second pregnancy, I had begun to question a lot more the medical model about how we approach pregnancy and birth. That sort of flowed out fairly naturally then into other mainstream medical decision making.... [B]y the time I was pregnant for the second time...I chose to have a home birth, and that led me to sort of question a lot of the standard antenatal care. That led me to question a lot of aspects of standard medical ways of handling birth, obviously choosing to home birth, and then also I had a lot of questioning then about our approach to healthcare, I suppose, for children, after..." "I joined up with a couple of consumer groups around maternity care and I met midwives, I met women who'd home birthed and that really helped—and I read a lot of research papers about the safety of home birth so that helped me to feel that I could make an informed decision....Just because I'm pregnant, it doesn't have to mean that I have the glucose tolerance test, you know, there are other ways I can sort of measure my—what's happening with me in the pregnancy. I don't necessarily have to have the GBS [Group B streptococcus] swab, there are other things that we can do, or I can sort of weigh up the risks. So that's what led me then when I had [younger child] to think maybe I want to reconsider the vaccine stuff."(Pippa, p. 8)
Finding	Disjunctive Habitus: "Not all parents who found themselves participating in social groups via other high capital practices expected or were comfortable with the idea of rejecting vaccines, as Fremantle informant Marianne revealed. Her 'habitus tug' was home birth, but she found vaccine rejection to be a jarring fit within the social network she entered—a form of 'disjunctive habitus'" (p. 9). (U)
Illustration	"It surprised me, when my husband and I decided to have our child at home and started exploring attitudes around parenting and pregnancy and health, and that sort of stuff... that people were anti-vaccination....That really came out of left field. I guess I had perceived [that] it was something that was more associated with, perhaps, poorly educated people, rather than the highly educated people that were certainly engaged and around us with the home birthing practices" (Marianne, p. 9)
Finding	Destabilized Habitus: "Almost all parents had experienced a shift in parenting practices, dispositions and worldviews, often as a result of pregnancy and childbirth, but sometimes due to

	<p>an illness of their child or perceived reaction to vaccinations. This shift started with a questioning of their current parenting practices (which were similar to other parents in their social group at the time) and a quest for new practices, which were more similar to those in a different social group. This process may be understood in terms of a destabilization of habitus—an initial questioning of why they did the things they did followed by a search for new and improved ways of doing things” (p. 7). (U)</p>
Illustration	<p>Kavita’s destabilized habitus and habitus tug from and entry into a “resistant epistemic community” [30] coincided with her son being an undiagnosed celiac, and her development of distrust when her child health nurse suggested to a group of mothers that infant formula might help their babies sleep better—a practice Kavita afforded low symbolic capital. Kavita ultimately went on to become an important actor within her (new) social group: “I think it’s sort of a journey that you start on, and you think, ‘Okay, what do I want my child to eat? Yes, I want him to eat organically.’ You do a bit of research, and you say, ‘Yeah, it does seem that it is a better way to go and, hey, the food tastes better as well.’ And you sort of start an organic market because you think that seems like a nice hobby to get involved in. Then it becomes a fulltime job and you have to call it business after three and a half years . . .”(p. 7)</p>
Study: Blaisdell et al., 2016	
Finding	<p>Living in a low-risk environment: "Parents in the groups also minimized the subjective harms from vaccine preventable diseases by citing various factors that they believed reduced these risks. Low-risk environment was commonly cited risk modifier. Vaccine hesitant parents believed that their children were protected from vaccine preventable diseases by low exposure to other children, isolation from geographic areas of disease, and avoidance of traveling" (p. 482). (U)</p>
Illustration	<p>"We don't send them to daycare. I felt like they weren't exposed to a lot of different kids all day long, or for long periods of time without me around watching and keeping them safe. It doesn't mean that they are not gonna get a disease, it also means that they have a less chance" (p. 484).</p>
Finding	<p>Treatment is available: "Some parents expressed confidence that they could treat measles by themselves. More commonly, parents expressed that the symptoms, side effects, and treatment of vaccine preventable diseases were known quantities and that key information about these issues was readily accessible should the need arise" (p. 483). (C)</p>
Illustration	<p>"It stinks because back when this used to be a regular childhood illness that everyone got, like chicken pox was for us, people would pass down remedies. But now, we don't know</p>

	them anymore so we have to go online. I'd probably go online and look up a home remedy for measles" (p. 484).
Finding	Parental control over risk: "When probed about how they would respond if their unvaccinated child were exposed to a vaccine preventable disease such as measles, parents expressed confidence that they could promptly detect symptoms of the disease and obtain clear and accurate information about further treatment" (p. 483). (C)
Illustration	"[I'm] a parent who is very in tune with their child, you know, I'm gonna know that something is wrong. I feel like if they're coming down with an illness, I have that mother's instinct. I'm so in tune with my kids I can tell they're sick, before they show any symptoms. So, you can jump on that, you can be on top of that and then get them treatment and get them well before—" (p. 484).
Finding	Treatability of VPDs: "Other vaccine hesitant parents minimized the potential harms of vaccine preventable diseases, citing consistent themes such as the treatability of vaccine preventable diseases and the low severity of vaccine preventable diseases" (p. 482). (C)
Illustration	"If she gets diphtheria, that's fine, she's going to throw up, she will just drink water. If she doesn't drink water, we will take her to the hospital, they will give her an IV, so we didn't (vaccinate), we based our rationale on risk" (p. 484).
Finding	Current health and healthy lifestyle: "Other parents perceived their children as having healthy lifestyles and strong immune systems that reduced their risk of vaccine preventable diseases and need for vaccination" (p. 482). (U)
Illustration	"I agree that a healthy immune system can often take care of a healthy body and so we put the emphasis on making really healthy choices for her to have a strong immune system. We have exposed my daughter four times to chicken pox! She won't get it!" (p. 484)
Study: Brunson, 2013	
Finding	Stasis, reassessment and ongoing assessment: "Parents in the ongoing assessment phase continue to assess issues related to vaccination, although the particular issues vary. While some continue to assess vaccination generally, others only continue to consider vaccinations as they are offered to their children, and yet others only continue to assess specific topics such as a particular vaccine or additive" (p. 5469). (U)
Illustration	"I've kind of gone through each one and eliminated them in my mind. 'Yeah we don't want this. Yeah we don't need this.' But that tetanus one keeps popping up in my head. It doesn't necessarily make me feel like I need to give it to her, but I'm still learning more. All the other ones I'm pretty much like [no] but that one I'm still learning more about" (p. 5469).

Study: Byström et al., 2014	
Finding	Promoters of natural immunity: "Parents discussed their knowledge and ability to cope with measles in case their children fall ill. Parents perceived no serious complications due to measles in previous outbreaks. They expressed confidence in experienced physicians to give treatment. Parents expressed that having access to this knowledge is comforting and also strengthened their self-efficacy" (p. 6756). (C)
Illustration	"I know that there is a risk for complication but I personally believe that the risk for complications is very small, if you take care of the disease in a good way and make sure to gain that knowledge. I mean that it may be important not to give pyretic and to allow for rest and care" (Interview 8, mother, p. 6756).
Study: Carrion, 2014	
Finding	Resistance: "Overall, mothers in this sample were highly self-conscious of the public perception and discourse about non-vaccinating mothers. They acknowledged their role as an unpopular counter-public, and many mothers discussed the often vitriolic nature of media and online discourse about vaccine refusal" (p. 133). (U)
Illustration	"People are very, very hostile toward not vaccinating...They're pretty sure that you're, like, destroying the world by not vaccinating, you're the most ignorant and naïve person and you're irresponsible and whatever" (Diane, p. 133).
Finding	The costs of intensive mothering: "This is related to the paradigm of intensive mothering, which suggests that the healthy growth and development should be the central focus of the mother's identify. Nicole acknowledged that such diligence in diet might not be practically or financially feasible in the long term..." (p. 142). (U)
Illustration	<p>"If I can eliminate some of those outside influences [toxins] onto their little developing bodies for the time being I will definitely do that." (Nicole, p. 142).</p> <p>Nicole, like many other mothers I interviewed, acknowledged the economic costs that came with adopting the kind of healthy lifestyle that informants espoused. It is worth noting that such choices, including organic foods, are not available much less affordable in many communities (Nicole, p. 142).</p>
Finding	Resisting social opposition: "Many informants limited the social opposition they faced by simply not disclosing their choices with regard to vaccination. Relatedly, many informants discussed calling health care providers in advance in order to screen for potential disagreements about policy or choices. Likewise, informants actively sought health care providers who shared similar perspectives on health, especially those who

	were willing to take a more “holistic” or “homeopathic” approach to care” (p. 140). (U)
Illustration	"It's not really something that we talk about with other people because, you know, you don't want to invite other people's opinions or freak them out...So, I don't know, [I'd] just rather not open that can of worms [laughs]" (Mandy, p. 140) .
Finding	Research as Ongoing: "Research was framed by informants as not a one-shot deal but a constant and ongoing process. This speaks to the vast amount of research available, as well as its varied and mutable nature" (p. 128). (U)
Illustration	"I take it [research] very seriously...I read at least an hour a day on new information, vaccination studies, this or that. [I'm] just trying to get as much knowledge in my head as I can so that I feel more comfortable with my decision" (Jeanette, p. 129).
Finding	Controlling risk: "In addition to lowering children's susceptibility to vaccine preventable disease, mothers also suggested that efficacy to care for those diseases would be increased provided people could stay home to care for their sick kids" (p. 145). (U)
Illustration	Stacey, a 29-year-old mother of five, recalled reading a CDC document on ten reasons to vaccinate. These reasons, she argued, "were the most completely generalized, non-evidence-based reasons I have seen anywhere. They were saying things like, 'it will save you money,' and like, they were ridiculous and, you know, that was one of the things I was—A lot of the times, the reasons that people do vaccinate is because they don't want their kids to get sick so they don't miss time at work. It does save them money, but I'm with my kids, they're all at home anyway [so] that doesn't make sense whatsoever" (Stacey, p. 145).
Study: Deml et al., 2022	
Finding	Affect: Emotions and social proximity: "Parents commonly described experiences with health care providers in emotional terms. They cited affect or their general sense of comfort or discomfort, as important elements of clinical encounters...some parents discussed negative emotional and affect experienced in interactions with their children's doctors" (p. 49). (U)
Illustration	Ms. Besse decided to consult with a homeopathic paediatrician because her son's first biomedical paediatrician had referred to her as an 'unfit mother' and mentioned her son dying as a possible consequence of non-vaccination. At first, the original paediatrician was accepting of Ms. Besse's wishes to not vaccinate. However, the doctor changed her mind after talking to the son's father. Ms. Besse explained, "I switched paediatricians recently (...). [The first one] had been very open to my choice to not vaccinate, but then, the father talked to

	<p>her about it again. At our last check-up, she said to me, 'But you don't realize, he could die!' That really upset me because, while I accept that a paediatrician can disagree with me, she shouldn't make me feel guilty. It's not the role of a doctor. I need someone with whom I am comfortable."She elaborated on her decision to change doctors, "I don't want to have my stomach in knots every time I see her because I have certain ideals!' She considered sending the paediatrician a letter to explain her departure because, during their tense exchange, Ms. Besse was shocked, emotional, and 'did not have the guts' to say something. At the time of the interview, she had not sent the letter. She later found a new homeopathic paediatrician after perusing a Facebook group moderated by vaccine-sceptical mothers in Switzerland. She explained how group members circulated lists of doctors, commonly CAM providers, who were open to non-vaccination.</p>
<p>Study: Duchsherer et al., 2020</p>	
<p>Finding</p>	<p>Self diagnosis: "Data in transcripts were coded with self-diagnosing whenever a mother mentioned that they identified the origin of their child's illness without the help of a medical professional...Although mothers typically did not receive a formal diagnosis or explanation of the cause of their child's condition, many attributed their child's illness to vaccine injury. Instances of self-diagnosing reflected the privileging of maternal individualist knowledge over the opinion of medical professionals, a privileging that was reinforced by other stories of self-diagnosis found in online vaccine refusing and hesitant communities" (p. 426) (U)</p>
<p>Illustration</p>	<p>Other individuals described in greater detail their process of knowledge-gathering and diagnosis. Tara explains that after reading a book about vaccine injury, she began to review her son's medical record and concluded that his vaccination history caused his symptoms. Tara states, "I read [a book about vaccine injury] and I was horrified because here we were like, "I wonder if this happened to Isaac." And like the same day I was reading the book, I went back in his medical record and there was a shot, there he was sick. It was like a pattern of sickness after every shot and I told my husband...I'm like, "This is what happened to Isaac because all this time he was sick and we didn't know why." Tara later makes the connection that the times of illness her son experienced after vaccines ultimately led to his developmental delays when she states, "[Isaac] was always delayed because after every shot it did damage." That is, Tara diagnoses her son as being developmentally delayed because of his vaccine history" (p. 426)</p>
<p>Finding</p>	<p>Advocacy: "Mothers in this dataset seemed to feel a personal responsibility to spread the word about the dangers of</p>

	vaccination and suggested specific platforms for sharing this message" (p. 427). (U)
Illustration	<p>Some individuals, like Bethany, choose to fight vaccinations on the government level: "we have been fighting for more than a decade. Literally thousands and thousands and thousands of dollars we've raised trying to fight our corrupt government" (p. 427)</p> <p>Others, like JB, have chosen to advocate against vaccinations as a form of public service. JB noted that a group: "started Generation Rescue...we bought a bunch of ads in USA Today...our feeling then was that we weren't going to get any press so just go around the press and buy the ads and you know... starting a public dialogue about autism...before we knew it we were totally embroiled in the vaccine debate" (p. 427).</p>
Finding	Building credibility: "This theme was present when mothers sought to establish themselves as a trustworthy source of information related to vaccine injury...Mothers in this study contrasted their own commitment to wanting what was best for their child with what they saw as a medical community uninterested in responding to their individual questions or needs. Many of the mothers who shared that they conducted research on vaccinations and vaccine injury indicated that main sources of information included those within the VR/ H community, namely other VR/H parents and advocacy groups. The strength of the VR/H community was cited at times to bolster individual mothers' claims of credibility" (p. 427) (U)
Illustration	JB engaged this tactic by explaining that "people who are telling you that we can't go back to the dark ages and this has been scientifically disproven are utterly wrong ... I have written extensively about the science." While JB discusses credibility from a position of authority (i.e. a well-known anti-vaccine advocate), others build credibility based on their own research about the subject. For example, Jayma builds her credibility when she states, "I started reading about the connection and I decided I'm going to stop vaccinating [my children] ... So, I do my research and...I took a class about diseases" (p. 426).
Study: Ejuma, 2020	
Finding	Ownership of child's health: "Having the ability to take ownership of their child's health emerged as a strongly communicated consideration among parents in both Informant pools" (p. 72). (U)
Illustration	For the parents in the Washington, DC, pool, that ownership manifested itself into the action of opting out of immunizations. Informant 4 (USA) said "I filed an exemption. Nobody can protect my child's interests like me, and it's wrong

	to bully parents into doing something harmful" (Informant 4 (USA), p. 72).
Finding	Should focus on natural interventions instead of chemical ones: "Informants reported a desire for alternative means to immunity. Some reasoned that natural interventions would be preferable and more effective in protecting their children against diseases" (p. 75). (U)
Illustration	"There are other ways to make sure your children have a strong immune system. We work hard to reduce our little one's toxic exposure and prepare their bodies to fight against any pathogens they might encounter naturally. This isn't just with the things that enter their body, this is with everything that comes into our home from floor cleaners to detergent and toothpaste. We eat an organic diet and limit things that might harm their immune systems in any way" (Informant 3 (USA), p. 75)
Study: Fallet, 2017	
Finding	Making choices to protect their child: "...health beliefs and the anxiety that those beliefs can provoke and influence how parents appraise the risk associated with vaccination, which gives rise to them making particular kinds of choices. This illustrates how a mother who has declined vaccination for her children continue to evaluate the risk of vaccine up against risk of disease, and if circumstances alters, possibly make a different choice to protect her children or family. " (p. 47). (C)
Illustration	However, strong beliefs regarding MMR, Liv said she would reconsider her choice about vaccination if someone in her near family or acquaintances got an illness that made them vulnerable to VDPs, "If I had someone in my family or acquaintance that couldn't handle the disease or vaccination, I would have reconsidered vaccinating my children that is how I feel".
Finding	Letting 'nature' run its course: "There was some consensus among the parents who delayed or refused vaccination that some of the diseases were named childhood diseases for a reason; that is to say, they believed that children were meant to have them as children...Some of the parents who delayed or rejected vaccination had either gone through or had close experience with someone who had gone through a childhood disease such as measles, mumps, rubella or whooping cough. They generally viewed these diseases as mild and not as a threat. They also shared the belief that children having a childhood infection could provide them with needed immunity, and that they would recover and be stronger both mentally and physically as a result" (p. 54). (U)
Illustration	For example, one mother argued that vaccines were unnecessary and that a healthy child with a normal immune

	system could overcome childhood diseases without the need for vaccines. Nina put it this way; "I think we're good enough from nature's side and I think we have to go other ways (than to vaccinate), thus nature can!" (p. 54).
Study: Gross et al., 2015	
Finding	Immunization as an intrusion into natural bodily orders: "Immunization was generally perceived as artificial and as an unnecessary intrusion into the development of a natural immune system and the healthy status of the child. Many parents, such as this mother working as a theater instructor, were convinced that the natural way of acquiring immunity through diseases should not be disturbed nor forestalled by a vaccine" (p. 4). (C)
Illustration	"I have the feeling that I don't want to meddle with it [natural immunity] and mess it up. Things exist and one has to handle them when they are there. But to treat an illness before it is there, ehm... that is something weird. It is like having a bypass operation while the heart is still strong" (LU02).
Finding	The strength of the naturally acquired immune system: "Many parents argued that the strength of the immune system can be built up by healthy food. Moreover, breastfeeding was often mentioned as a sufficient measure to protect infants particularly in the early phase." (p. 4) (C)
Illustration	"If one is really concerned with health, with food, with hygiene, with the whole life style, one has a natural immunity strong enough against so many things" (FR01).  "I think with breast milk a baby has already sufficient antibodies. Why inject then something else at such an early stage?" (FR05).
Study: Haarstick, 2021	
Finding	Using immune boosting herbs and tinctures: "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" (p. 63). (U)
Illustration	"Above Charlotte's stove is a cabinet which contains jars of dried herbs and spices. 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. Charlotte's typical treatment protocol includes elderberry, vitamin C, raw garlic with honey, and gingerroot. These are for 'pushing the cold out'" (p. 63).
Finding	Care through food: "Hannah sees providing nutrient dense foods to her family as a form of care, adding that this is her first line of health maintenance and illness defense" (p. 34). (U)

Illustration	Hannah spends “hundreds of dollars a week” on whole food groceries. 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” (Hanna, p. 34).
Finding	Parental activist blogging: "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" (p. 47). (U)
Illustration	"Writing about these topics has resulted in frequent written threats to her body and family, ‘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” (Layla, p. 48).
Finding	Using supplements to boost the immune system: "If one of her children have a cold or illness, she (Ursula) will 'boost their immune system' through doses of elderberry syrup, vitamin C and D, and liquid silver" (p. 54). (U)
Illustration	"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" (p. 55).
Finding	Healthy eating: "Although Kate stresses healthy eating, she also feels that to follow a strict healthy or organic foods diet is based on economic privilege" (p. 70). (U)
Illustration	"With six family members remaining in the house their grocery budget is tight, so Kate has to determine which food items to purchase organically. She tries to follow the list of the ‘dirty dozen and clean fifteen.’ 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" (p. 70).

Finding	Attending to diet and whole foods: "Janis strongly believes that the best way for her daughters to be and stay healthy is through diet and whole foods" (p. 40). (U)
Illustration	"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" (p. 41).
Finding	Simple clean diet: "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'" (p. 48). (U)
Illustration	"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" (p. 48).
Finding	Health maintenance and illness treatment supplements (p. 35) (U)
Illustration	"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. All homeopathics are kept separately behind a small narrow cabinet door. In the bathroom, Hannah has a "medicine" cabinet with essential oils and salves" (Observations, Hannah, p. 35).
Finding	Using CAM for health maintenance and illness treatment (p. 59) (U)
Illustration	"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, p. 59 - 60).
Finding	Natural at home: "Ursula uses a 'natural at home' approach for health care maintenance and illness prevention" (p. 53). (U)

Illustration	"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" (Ursula, p. 54)
Finding	Folk medicine: "Her (Layla's) 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" (p. 48). (U)
Illustration	"In the corner of her kitchen was a raised counter space shaped like a triangle. 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" (p. 48-49).
Finding	Home remedies: "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" (p. 72). (U)
Illustration	"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...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'" (p. 73).
Study: Harmsen, 2013	
Finding	Perceived advantages of having the disease (C)
Illustration	"Let the body itself go through the disease. This is good for building up the resistance by the body itself. Diseases often give life-long immunity, while vaccines often protect for only 15 years" (PV) (p. 4)
Finding	Lifestyle: "Informants mentioned that their healthy lifestyle promotes their children's health, and therefore the risk of getting an infectious disease is reduced" (p. 1473). (U)

Illustration	"All of my choices are currently aimed to give my children a peaceful basis for life: choose to breastfeed (about 1.5-2 years), raise children in a small-scale home, part-time work, first half-year no childcare, minimize shopping/traveling with young children, All kinds of things that do not overcharge the immune system" (NV) (p. 3).
Study: Helps, Leask & Barclay, 2018	
Finding	Minimising impact of the "No Jab; No Pay" policy: "Families who were currently, or expecting to be, affected by the inability to lodge exemptions and receive family tax benefits and child care subsidies had to re-evaluate how to manage financially without this assistance. Strategies included increasing extended family support, reducing work and study commitments, informal child care arrangements, house sharing, or relocating to reduce rental burden and withdrawal of children from child care, including before and after school care services" (p. 161). (U)
Illustration	<p>"The fact that I'm studying at Uni...it would make sense when he turns two to put him in daycare...But it's out of the question, it's just unaffordable. The amount of help that I have to ask of my mum and my ex, in order to be able to study. I've even thought, you know, maybe I should just give up the study" (Selina, p. 161).</p> <p>"I've seen people having to re-evaluate where they live, what they do, where their children are at school so yes it has impacted. But it's just forced people I think, the people that I know to have to work harder to sustain their point of view....I mean if you arrived at the point of view, \$700 a year doesn't really compensate for that...it forces hardship" (Mark, p. 162)</p>
Finding	Holding my ground: "Concerns were expressed about further punitive measures that may be imposed upon families who continued to decline vaccination. If additional penalties or restrictions were applied such as exclusion from public schooling, these parents would seek solutions such as home schooling or accessing education outside the mainstream system" (p. 163). (C)
Illustration	"if mandatory vaccinations became a thing we would relocate overseas...I really hope it doesn't come to that because that would really make me absolutely devastated for our democracy" (Emily, p. 163).
Finding	Underpinning beliefs—shared: "The suite of behaviours that accompanied non-vaccination such as eating organic food, breastfeeding, minimal screen time, using complementary medicines and cloth nappies appeared to be derived from this same understanding [11]. Informants avoided all things

	perceived to be unnecessary for the well-being of themselves and their child" (p. 160). (C)
Illustration	Layla was aware of the inevitable trade-off but articulated an approach she also believed to reduce risk: "...life is a risk. You know we can't just cotton wool ourselves. We can do whatever we can and if a person believes that vaccination is the way that they can be safe then they are doing that...and if I believe that by prolonged breastfeeding and feeding my child healthy food and making sure there is exercise and emotional stability, then that's what I do. And either way there is risk" (Layla, p. 160).
Study: Helps, et al., 2019	
Finding	Reactance to system inflexibilities: "Elements of psychological reactance were evident in these parents accounts when their desire to make the best decision for their child was met with inflexibility in the immunisation schedule or health system" (p. 9). (C)
Illustration	"I'll home school, move overseas...whatever...I feel so passionately about this, no one is going to force us to do something that we don't think is right for our child" (Melinda, p. 9).
Finding	Ongoing risk assessment: "Many parents in this study acknowledged that the choice not to vaccinate is one that makes sense only for those who living in ideal circumstances and that if access to fresh air, nutritious food and excellent hygiene was not available, they may need to and would indeed revisit this decision. Some described it as an evolving risk assessment" (p. 9). (U)
Illustration	"...saying about risks, that's a really interesting factor because as a (person working in a frontline emergency setting), we're always looking at what level of risk the current situation is under. So, to say that we are non-vaccinators isn't true, because there may be a situation that arises where we may" (Jacob, p. 9).
Finding	Quest for 'the real truth': "Most parents in the study mentioned Facebook groups as a source of sharing with other parents who choose not to vaccinate" (p. 8). (U)
Illustration	Lindy did not find the ideology nor the discussions in an anti-vaccination Facebook group to be appealing but maintained membership to gain access to a variety of informational sources about vaccination: "I joined an anti-vaccination group purely so that when they come up with articles, I have that information. I don't actually like the people, the way they're posting on there...But there isn't another option at the moment for people who really do not want to vaccinate" (Lindy, p. 8).
Study: Hsu, 2023	

Finding	Individualism and Control: "Many informants felt they could control their child's exposures and infection risk, and therefore, tailor their vaccination schedule according to their child's circumstances." (p. 58). (U)
Illustration	"I think comes down to, like—I feel like there should be more leeway for individual family's needs because for families like us where your kids are at home, they're not in daycare, you are breastfeeding, you know that you're low risk in all these areas, maybe a delayed schedule makes sense for that specific family if that's their preference" (Group 3, Informant 2, p. 61).  "The one of other things about postponing...what popped me up is postpone Hep B [sic], mostly because of the way of transmission, and my son was not gonna be cared for by anyone else, but our immediate family" (Group 4, Informant 8, p. 61).
Study: Kuan, 2022	
Finding	Intensive parenthood: "Informants who did not trust vaccines sought to improve their children's health through everyday practices" (p. 702). (U)
Illustration	"We have a few principles. We stay close to nature as much as possible. We prefer outdoor over indoor activities and whole foods over processed foods. We stay calm and happy. This is how my children grow up. They are free and healthy" (Su, p. 702).  "I am very close with my children. I monitor their health carefully. I have done everything I can to keep them healthy. If they contract a disease, it must be fate. Nothing will help, not even vaccines" (Yu, p. 703).
Study: Martinez-Diz et al., 2014	
Finding	Alternatives to vaccination (C)
Illustration	"There are more effective methods of preventing or treating disease. I would get vaccinated with (homeopathic) vaccines that were absolutely safe..." (p. 374).
Finding	It is beneficial to undergo the natural course of the disease, as part of a new way of life (C)
Illustration	"I would rather my children and I have measles or other diseases in a natural way, without putting their lives at risk with the MMR" (p. 374). "We should reconsider childhood diseases and not fear them, stand by our children as they develop their immune system" (p. 374).
Study: Nurmi, 2021	
Finding	Microbes as unpredictable agents: "...well-functioning immune systems were perceived as limiting the disease-inducing agency of microbes while simultaneously co-producing immunities with them. Humans could also be carriers of viruses that

	enable their spread without necessarily getting (very) sick. In this mutually beneficial process, both humans and viruses needed each other" (p. 117). (C)
Illustration	Some VPDs, such as chickenpox, mumps, and measles, were considered 'ordinary' or even beneficial diseases that had been rebranded as dangerous by health authorities and the pharmaceutical industry. Because of the health benefits assigned to these illnesses, some informants felt positively about their children contracting them. Nora explained: "I feel sad that [some VPDs] are not around because I'd like my son to catch chickenpox and measles. (...) In general, I'd like him to get certain illnesses as a child when they're usually [milder], especially when you use the right treatments" (Nora, p. 117).
Study: Nurmi & Harman, 2022	
Finding	Health perceptions and practices: "Informants also presented health-related perceptions and practices as reasons for vaccine refusal. They often stated views and attitudes alternative to the mainstream understanding of health and illness; for instance, they talked about VPDs serving a purpose in strengthening the immune system" (p. 493). (C)
Illustration	Many informants hoped that their children would get illnesses such as chickenpox or measles during childhood when the symptoms would allegedly be milder; contracting the illness would also provide longer lasting, more 'natural' immunity than vaccination, and could possibly provide other health benefits: "There's indications that having certain illnesses will protect you from others. I found a study that said that children who've had the rotavirus had significantly lower rates of severe respiratory illnesses and pneumonia. Then I've read about measles – that it has (...) a protective effect against certain types of cancer, same with mumps (...) It may be nature's way of strengthening your immunity so that you'll live longer and be healthier." (Irene, p. 494)
Study: Reich, 2014	
Finding	Managing the risk of travel: "Travel presents new challenges to mothers' abilities to manage social contact. Molly, for example, admits she would reconsider her decision to opt out of all vaccines, depending on what countries they visit" (p. 695). (U)
Illustration	"Well, because I'd probably have to do all new research....Where are we going? Are we being exposed to, you know, where are the outbreaks in that country and what are they of, and are they people that we'd be exposing ourselves to on a regular basis?" (Molly, p. 695-696).
Finding	Feeding as health promotion: "As mothers frame health as a state of being naturally immune to infection (and illness as being vulnerable), vaccines become unnecessary. This belief

	reflects their faith in their family's healthful living, particularly around food" (p. 692). (U)
Illustration	<p>"I think, just, you know, you have this tiny little infant that's just being born, I'm breastfeeding already which is providing the immunisation from my breast milk ... and she wasn't gonna be in any environments when she would potentially be exposed to any of these things, so why would we do that [vaccinate]?" (Astrid, p. 693).</p> <p>"We buy local as much as possible and organic. We don't do pre-made. We make our own rice milk. We make a lot of our own stuff. We don't do additives, food colorings. When we make Halloween cookies, we make food coloring out of beets and semolina and carrots" (Tara, p. 694).</p>
Finding	Managing risk from imagined gated communities: "These mothers see those they believe share their values and lifestyle choices as unlikely to present risk of infection, while evoking unsafe "outsiders" who carry disease as requiring them to create and laboriously maintain protective barriers" (p. 695). (U)
Illustration	<p>"I was at home with them; they didn't have to be in daycare. We were kinda attachment parenting-style where I really didn't separate from them at all...Because of our lifestyle environment, [they're] low-risk for some of these things" (Heather, p. 695).</p> <p>"Lauren, for example, felt confident in her ability to avoid illness for her daughter, explaining, "We are pretty careful about where she is and who she interacts with. I mean it's not—it's rare that she's ever in a place that we haven't preapproved or haven't been aware of."(Lauren, p. 695)</p>
Study: Reich, 2016	
Finding	Natural infection and the quest for varicella: "Parents—many of whom consent to other vaccines—broadly view the varicella (or chickenpox) vaccine to be inferior and unnecessary. Wanting their children to be immune to the disease, particularly because complications of infection increase as children age, parents often seek out wild virus varicella in hopes that their children will catch it and develop natural immunity" (p. 107). (U)
Illustration	"There are lots of non-vaccinated kids I believe at [this private school] and there was a huge outbreak—or not a huge, there was—a number of kids got chicken pox last winter and I was like 'Can I bring my kids over?'" Much to her chagrin, her children, she explains, "didn't get sick, which I was bummed out about" (Katie, p. 108)."I haven't vaccinated [my son] for the chickenpox and I'm not planning to, and I'm not planning to,

	and I'm really hoping that he can catch it soon because I want him to get natural immunity to it... I don't know how that works, but, [I'm] thinking maybe he would get natural immunity to chickenpox whereas [the vaccines] don't last very long—two years—and so they have to keep getting boosters" (Heather, p. 108). "A good rousing infectious disease—like what do we allow anymore? The common cold? Fevers of 102? No. That's not acceptable...Days lost from work is like the main reason for preventing chickenpox. Lifelong immunity from chickenpox is not" (Sarah, p. 108).
Finding	Rejecting vaccines as an unnatural mode of absorption: "Several parents complained that the process of injecting into the body viral or bacterial matter is unnatural and undesirable" (p. 106). (C)
Illustration	"If someone sneezes on me or I let my child get chickenpox by itself, or mumps, rubella, whatever these things are, even polio, now my body says, "Oh, that's already gone through the lymph channels. It's already gone through the mucus channels. It's already gone so by the time it hits the blood stream, the immune system says, "Hey, we've already weakened this germ to the point where now we can kick its butt...And now once your body defeats that bug naturally...anytime anything else comes at the immune system, that first string gets released immediately, and now you have lifetime immunity. You don't need boosters. You don't need anything, because you've got it" (Jake, p. 107).
Finding	Natural living as immune-promoting: "Parents identify caregiving practices as central to immune promotion or recovery from illness, rendering vaccines less necessary. Natural living—is key to this" (p. 108). (C)
Illustration	Weakness in immunity, which manifests by becoming sick, ties back to individual failures in natural living. Margaret elaborates: "We compromise ourselves through not eating correctly or taking care of ourselves, and that's a hard pill for a lot of people to swallow, because a lot of people don't want to give up their vices...so most people are gonna be prone to cancer and other problems" (Margaret, p. 108).
Study: Reich, 2018	
Finding	Crafting claims to exemptions: "Parents frequently describe the process of figuring out how to exercise an exemption as stressful, particularly in states that are more restrictive and only offer religious exemptions, rather than the broader personal or philosophical belief exemption. Some see these as laborious processes, often requiring them to challenge school experts or even seek legal advice from professionals. In crafting claims to exemptions based on religion, parents often find themselves challenged by the necessity of claiming a religious

	belief they do not actually hold. As a result, most advice offered identifies the importance of limiting detail about their claim, lest they undermine their own claims" (p. 232). (U)
Illustration	Many online community members offer her sympathy and advice. One mother explains that finding a pattern across the vaccines she rejects can be a strategy for claiming an objection. She notes, "Partial vax is a problem where there is no philos. exemp. You'll have to do your research on each vaccine you choose and decline and find the ingredients. If all the ones you decline have animal products or aborted fetal tissue, you can probably go with an 'ethical conviction against injecting animal or aborted human tissue into your body'—like a vegan, but if you do not eat vegan, that argument prob. won't work. Or if the vaccines you decline all have a known cancer ingredient, maybe that might work but prob most vaccines have them. Try to find a common denominator" (p. 233).
Finding	Challenging state power: "Parents frequently complain that vaccine exemptions are increasingly hard to get. This may reflect the handful of new regulations that went into effect in 2016 in response to a measles outbreak at Disneyland in 2014 that led to tightened enforcement of exemptions and removed personal belief exemptions from law in California and Vermont (Blank et al. 2013)" (p. 234). (U)
Illustration	Taking this on, one blogger addresses the challenges of exercising a religious exemption: "Okay guys, let's talk. Peeps be hittin' up my inbox because they can't get religious exemptions. Apparently, the religious exemptions we're entitled to by law are hard to come by. Paperwork, interrogations interviews, the third-degree...it's quite the process. Some lucky parents are getting called to the rug to defend their religious beliefs in front of a panel of people who have probably never even heard of Jesus and whose sole purpose in life is to trip them up with tricky questions designed by vaccine enthusiasts to rob people of their rights. Gone are the days where you could just Google, "vaccine religious exemption letter" and change the greeting at the top. Getting your school to serve a lunch that's fit for human consumption is easier than getting a vaccine exemption (Heimer, 2016)" (p. 234).
Finding	Strategizing interactions with the state: "Parents—both those who have permitted some and those who have rejected all vaccines—laboriously manage information about their children's care for fear of jeopardizing claims to an exemption. How to effectively do so is an ongoing discussion with parents seeking advice, reflections of others' experiences, and explanations of requirements" (p. 230). (U)

Illustration	<p>One mother's explanation of how she registered her son for kindergarten illustrates this. At that time, her son had had one vaccine, not the full required series. Yet she chose not to disclose this to school personnel. She explains her strategy: "According to them, he's had none...[be]cause in this state, you know, we have personal exemption, but the way it was explained to me was that you can't just list one vaccine, because if they've seen that he's had one vaccine [you cannot claim an exemption]. In support of this strategy, another mother in an interview describes how she manages information carefully. She explains, "Basically, I have an immunization card that I keep in my records at home, and my school has a different immunization record. Because if you have one vaccine, then they can make the case that, 'Oh, you don't really object to vaccines on principle, so you need to do it the way we tell you to do it.' And they take the choice away. So as far as they know, he hasn't had any" (p. 231).</p>
Finding	<p>Claiming a right to know: "... all states have some legal mechanism for opting out of vaccinations while maintaining access to schools or child care settings. Yet this information is not readily available or promoted. This is not particularly surprising, considering the strong preference that states have in limiting the size of their unvaccinated population. Lack of information about exemptions is a source of frustration for many parents who say the information can be hard to come by, even in states that permit a wide range of exemptions" (p. 229). (U)</p>
Illustration	<p>One mother describes online how this lack of information affects parents: "I work at my son's [Waldorf] school, and we are legally not allowed to discuss the exemption forms if people don't ask for them.... I still remember the panic I felt when I got the letter (before I started working there) stating that he would not be admitted if his vaccines weren't up to date. I called, saying, "Isn't there an exemption?" And of course there is, but the thing that pisses me off is that we're not allowed to say it! I mean, we can say it after they ask, but not technically before." (p. 229)</p>
Study: Reich, 2020b	
Finding	<p>Interactional negotiations: Negotiating Quarantine: "Carolyn's choice to reject vaccines became an issue at the school when an outbreak of rubella was reported. In collaboration with the county health department, the school arranged to vaccinate anyone missing the MMR vaccine against measles, mumps, and rubella. Carolyn refused the vaccine for her children and was quarantined in her home until the outbreak subsided. Carolyn recalled the teacher apologetically suggesting the quarantine was unnecessary, which emboldened Carolyn to show up with</p>

	her children at the planned school field trip that week” (p. 118). (U)
Illustration	“She recalled, “So I went to the field trip and there was two nurses that were mothers of the kids in the class and so they went and called the health department to send me home. And when they did, they tacked something on my door that said we're quarantined for a week.” Carolyn saw this gesture as an effort to humiliate her and force her to acquiesce to state agencies promoting vaccines. “They knew themselves that I was not any more contagious than anybody else. It just—we did not comply, so we got spanked” (Carolyn, p. 119)
Finding	Managing Institutional Insistence: “Much of the discourse of individualized management of health communicates that wellness is a moral imperative and that illness results from failures to make healthy lifestyle choices. Parents who aim to meticulously manage their children’s health are often baffled when their children become sick, despite good nutrition, healthful living, and good parenting. They face both an inability to control health and limits on their power to treat illness” (p. 120). (U)
Illustration	“Distrustful of chemotherapy, an indisputably toxic intervention, Bob [a chiropractor] remembers feeling unsure of what to do. Yet even with that sense of uncertainty, he recalls feeling confident that he was well equipped to determine the right outcome: ‘You feel sorry for the people who don’t know anything. Of course they’re gonna automatically do what the doctor or the social workers or the government tells them to do because they don’t have the knowledge base that they need to make an appropriate decision.’ ” (Bob, p. 121)
Finding	Interactional negotiations: “Some parents found themselves in negotiations with organizational actors, like school personnel and healthcare providers, who challenged their autonomy. These interactions often reflected competing and incongruous beliefs about risk, necessity, and expertise” (p.117). (U)
Illustration	Carolyn stays home full-time with her three children, homeschooling them until recently. She rejects all vaccines and virtually all medical interventions; she instead prioritizes individual efforts at healthy living. Drawing a contrast to her hard work, Carolyn disapproves of people who accept vaccines, which she believes remove personal responsibility for health: “If you think you've got a band aid called a vaccination, then you're going to live like the dickens and not worry about what you put in your mouth and how fat you are....So then you've got no responsibility. 'I can do whatever I want because I've been vaccinated,' so you think. You live this false premise of 'I don't have to take care of myself" (p. 118).

Finding	Individual Strategies and selective use of medications/vaccines: "Like many parents who reject vaccines, she [Astrid] envisions individual parents as responsible for evaluating risk and making informed decisions, rather than following advice from providers that seems generic" (p. 116). (U)
Illustration	"Pointing to the behavioral nature of the risk, Astrid explained, "All of the ways that you get Hep B are risky behaviors, so the child who's gonna have risky behaviors, it seems like a good opportunity for the parents to say, "Okay here are your choices. You can—certainly you can you can have sex or whatever they, all the behaviors are. You can do drugs. Know that this is a risk and if you want to have that shot, we need to talk about that." (p. 117, Astrid, mother, selective use of medications and vaccines)
Study: Reich, 2020c	
Finding	Decentering medical care: "These networks extend social capital to members who aim to reconceptualise vaccine-preventable diseases in ways rejected by allopathic medicine. By providing information alongside affirmation. they reframe infection as a way of strengthening the body, rather than something to fear" (p. 5). (C)
Illustration	"Measles and mumps and chicken pox are necessary immune stimulants" (p. 5). "So the toxins that we can control, we control, even in our body products... So we set our bodies up to win ... And we're healthy" (p. 5).
Finding	Using social capital to support alternative ways of knowing: "Many of the mothers in this study referenced the importance of building a network of other mothers who share their experiences or views" (p. 3). (U)
Illustration	"I actually ended up living close to kind of a small mommy group, like walking group ... [One woman in it] didn't vaccinate her baby and he was 24 months old when I first met her. And what she did was she had these, I guess it was like some kind of drops, like vitamin drops or whatever, and something else... And then she also took him to the chiropractor once a month, which I think is crazy. Like taking a baby to the chiropractor? Like do they really need —like they have such flexible joints anyway but she's like, "No, it really helps and, you know, that affects everything in their body." So yeah, I definitely listened to what she had to say..." (p. 4)
Finding	Strategies for managing stigma: "As mothers share their sense of stigma because of their vaccine choices, social support from their network provides strategies with which to challenge or manage it. In addition to providing sympathy and understanding, their networks provide opportunities for "stigma management rehearsal..."(p.6). (U)

Illustration	"I think it's to the point where we need to keep quiet about our health choices if we are not within a like-minded community. I used to feel like I was a rebel and was educating people when the subject came up (not lecture-y or anything, just sharing in a simple way to show that "normal" people are thinking about these things), but now I just nod and smile if I am with a group that might not accept my views" (p. 6).
Finding	Social capital in the face of stigma: "The decision to reject some or all vaccines is often met with criticism from those outside of the mothers' sympathetic networks. Parents who reject recommended vaccines encounter negative feedback from peers, doctors, schools, or even their own family members" (p.5). (U)
Illustration	"I'm actually having a hard time too, especially with sharing our choice if anyone ever asks, most of my really close friends and family just respect it and leave it alone (maybe secretly think we are nuts, but i'll take that) ... I'm tired of feeling nervous or anxious about this conversation coming up with play groups or new friends, parents who may be uncomfortable, or attack me because "their kid is in danger" (p. 5).
Finding	Confronting critics: "In contrast to those who suggest smiling and keeping quiet, others insist mothers who reject vaccines need to speak out about their choices to educate others" (p. 6). (C)
Illustration	"I've decided that if anyone should outright attack me, I am going to 'baaaa' them. I'm going to just not bother w/justifying myself and just tag them for what they are: 'Oh, sheeepy, sheeepy, sheepole, so sad that you're a sheeepy. Baaaaa, baaaaa.'" (p. 6)
Study: Sobo et al., 2016c	
Finding	Standpoint mobility: "Rather than sticking to a single standpoint, informants moved from vista to vista.[...] Notably, selective vaccinators (those in the middle) spoke from the most standpoints (7.03) and shifted standpoints the most. They also exhibited the highest tendency toward indeterminacy. [...] Further, among selectively vaccinating parents indeterminacy seemed more deeply experienced" (p. 536-537). (U)
Illustration	"I'm always doing more research, I never am settling for what I've decided upon thus far...It's not a decision that it's just very black and white and once it's made, it's very fluid and definitely the hardest decision I've ever made, and is—yeah, it's just always being researched, it's always in—something in the back of my mind that I'm thinking of at all times [laughs]" (p. 537)
Study: Sumengen et al., 2021	

Finding	Natural methods/additive-free nourishment: "In our study, the majority of informants stated that they strengthened their children's immune systems by natural methods" (p. 547). (U)
Illustration	<p>"In the winter, I add bone broth to the food, once a week I provide kelle paca (soup made from sheep's head and feet), I give fish oil and royal jelly, I follow-up the status of vitamin D, I administer oral drops, I apply for vitamin D analysis..." (p. 547).</p> <p>"Takeaway foods never enter my house, which is a plus for me, we consume more vegetables and fruits, which is also a plus" (p. 547).</p>
Study: Sythes & Bedford, 2022	
Finding	Healthcare professionals: "Before, during and after the decision-making process, interactions with healthcare professionals and health institutions were important for non-vaccinating mothers. Negative experiences included being confronted publicly in the waiting room by a doctor, being called a 'disgusting parent,' not feeling able to receive appropriate medical care, switching GPs due to repeated challenges and their child potentially being removed from a hospital ward due to non-vaccination. The unpredictability of medical interactions adds a layer of anxiety, the uncertainty and possibility of a negative experience having the potential to push mothers even further from the medical establishment" (p. 5). (U)
Illustration	<p>For some mothers, their choice became a barrier to healthcare, describing experiences where they or their child were unable to get the medical attention they required due to vaccinations being brought up in what they perceived to be unrelated contexts."for us it's like if anything were to happen to a child who was unvaccinated ... that would be the first thing that they mention. We're all waiting for that y'know?" (Interviewee 3, p.5).</p> <p>"I took him to the doctor, and she just absolutely laid into me about what a terrible mother I was, how irresponsible I was ... and that ... made me see, in my eyes anyway, that they were more interested in getting my child vaccinated than my child himself, in his wellbeing" (Interviewee 9, p. 4).</p>
Finding	Trust: "Trust is an important component of relationships with healthcare professionals and more widely with institutions and government. For some mothers, a lack of trust manifests itself as lying or hiding their decision for fear of repercussions. Although this was not always expressed as distrust in establishments per se, the inability to be honest about their vaccine stance potentially suggests wider concerns about establishments and their power. Dishonesty was also seen as a

	way to avoid confrontation or having to justify their choice" (p. 5). (U)
Illustration	"I actually have not told them the truth, I told them I'd got them all done privately and that continues now if I ever pop in, I say '... she's had the boosters so if you can just log her in as having the boosters'. I sometimes even research what would she have had ... I lie about it so that they have not got me on a list" (Interviewee 2, p. 5)
Finding	Lifestyle: "For many of the mothers, non-vaccination is therefore not an isolated behaviour but reflects wider lifestyle and parenting choices. These lifestyle choices included long-term breastfeeding, avoiding formula milk, eating raw and/or organic food and following a vegan lifestyle. This often also included an avoidance of 'Western medicine' and medical intervention where possible, with many of the mothers emphasizing 'natural immunity' and lifestyle" (p. 6). (C)
Illustration	"I did not even let them give him Vitamin K shots ... I was so anti-intervention by the time [he] came that I did not even let them do that nor did I let them clamp his cord" (Interviewee 1, p. 6).
Finding	Changing their minds: "When looking to the future, mothers had mixed thoughts. Some were completely firm in their stance and said they would never change their minds, whereas others had a more nuanced approach, admitting that they would be open to new information and potentially accepting future vaccines depending on the context and the individual needs of their child" (p. 6). (C)
Illustration	"I do not think anything would change my mind, I think if I had to, I would go and live in the countryside and lead a completely alternative, self-sufficient lifestyle rather than comply with a government regulation" (Interviewee 7, p. 6)  "we were confident in the decision that we'd made— and are making ... it's not set in stone and we'll see, we can re-evaluate at any point" (Interviewee 10, p. 6).
Finding	Social networks: "Following, or sometimes during, their research many mothers sought social support through online groups, local groups or existing friends. Other mothers spoke of feeling isolated by their decision and unable to tell those around them, highlighting the differing experiences of non-vaccinating mothers: Some felt supported and able to build a network, whereas others were alone with their decision" (p. 3) (U)
Illustration	"I felt really, really uncomfortable telling people that I had not vaccinated because it wasn't a very common thing, and it did lead me to struggling to ... build relationships with other mums" (Interviewee 7, p. 4)

	"it's not socially acceptable to not vaccinate ... friends do not know about the decision that I've made because I do not want to become a social outcast." (Interviewee 8, p. 4)
Study: ten Kate, 2021	
Finding	Positioning in the health care field: "Parents often chose the option that they perceived to be the most natural or the measure that respected or supported a natural approach the most. In contrast, health care measures and practices that were seen as chemical, artificial, or polluting were avoided as much as possible" (p. 91). (C)
Illustration	<p>Mark and Eliza stressed that they only viewed immunity derived from "natural measles" (or other diseases) as natural immunity, which they considered to be lifelong. Sophie, Ray, and Annette like-wise preferred their children to experience a disease like the measles naturally rather than vaccinating against it (p. 92).</p> <p>More specifically, some parents argued that children should not be vaccinated against "childhood diseases" like measles or mumps because contracting them naturally is viewed as a vital element of child development. Childhood diseases were thought to "serve a certain purpose, children really experience growth because of them (Sophie); are "not called 'childhood diseases' for nothing" (Annie); and are essential for children to catch because "your immune system has to be trained" (Babette) (p. 92).</p>
Study: Thornton & Reich, 2022	
Finding	Refusal and the risk of state sanctions—Signing Exemptions: "Many suggested that Black families should exercise caution when opting out because the act of signing exemption forms could make a family visible to state agencies" (p. 541). (U)
Illustration	Noting the conflict between her right to use legal processes available and her co-parent's concerns about state surveillance, she asked, "Baby needs a physical and I would have to show them my exemption paperwork for vaccines. All this for me is not an issue. Here comes Dad telling me that the pediatrician that performs the physical could still call cps for our son being non vax...exemptions are still legal here. Is there something I'm missing?" (p. 540)
Finding	Refusal and the risk of state sanctions—Impact on social programs: "Mothers also warned that vaccine refusal could jeopardize public assistance eligibility. The Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) presented particular challenges to mothers who want to reject vaccines. Because WIC focuses on children's nutrition and health, having up-to-date vaccine records and

	regular well-child health visits are typically required for eligibility" (p. 542). (U)
Illustration	One woman shared her story: "Hey everyone. I really could use some advice. I'm in the WIC program, well kind of. I stopped going because my WIC worker keeps talking about my kids check-up appointments and vaccines. I told her several times I do not vaccinate. She says her supervisor keeps asking why my kids don't go to their check ups...her supervisor is under department of health and once department of health finds out they will contact cps" (p. 543)
Finding	The privilege of vaccine refusal— Homeschooling: "Identifying how white privilege facilitates vaccine choice, mothers weighed the risks of living in a predominantly white state that might be hostile to families of color against the benefits of having a legally permissive environment that promised them autonomy to exercise their choices for their families. Throughout, they identified the ways their options were limited by state-structured inequality" (p. 538). (U)
Illustration	Lacking documentation to access medical exemptions in states without other mechanisms to opt out, some mothers identified homeschooling as one of the few legally permitted ways to avoid vaccines and the associated surveillance from schools. One mother cited the inability to access exemptions as a reason to homeschool, explaining, "His father and I have to home school bc we live in California and exemption is no longer an option as of now. The things we do to protect our babies." (p. 538)
Finding	The privilege of vaccine refusal— Getting Childcare: "Even in states that allow nonmedical exemptions, childcare providers are not obligated to accommodate them, because infant care and preschool are not legally mandated in the ways that primary and secondary school are" (p. 539). (U)
Illustration	Costs of care and providers' freedom to accept or reject unvaccinated children presented challenges to mothers' abilities to realize their goals. One mother described her limited options: "Because of my financial and family situation, I don't make little enough for daycare vouchers but I definitely don't make enough [to pay] for daycare. He is also non vaccinated so the in home mommies won't take him!" (p. 539).
Finding	Refusal and the risk of state sanctions— Avoiding Child Protective Services (CPS): "Of all forms of state surveillance, CPS was mentioned with the most frequency. Because the CPS system, charged with identifying child maltreatment, is a civil system and not a criminal one, social workers make decisions based on subjective interpretations of risk that rely heavily on race and gender"(p. 540). (U)

Illustration	Many advised mothers to be aware of how scrutiny of their families' lifestyles could lead to state intervention. One mother explained, "I want to encourage those of you that choose any kind of natural lifestyle, to please, please know your state laws. Institutions bank on people's ignorance. Then they threaten with CPS. CPS has to comply with state laws and they also count on folks being ignorant. If you homeschool, homebirth, choose not to vax/delay vax, know your rights cuz they aren't going to tell you" (p. 540).
Finding	Refusal and the risk of state sanctions—Healthcare providers: "In these discussions of structural gendered racism, women offered advice on how to refuse vaccines while minimizing risk of state intervention. In particular, mothers identified healthcare providers who are mandated reporters as particularly high-risk encounters, and at times recommended avoiding them" (p. 542). (U)
Illustration	"Some people recommend taking the child for their well child visits at least. Just as precautions in case any funny business is conjured up in the medical practice. Then you are on file bringing your child in for those recommended visits. Some believe not attending these visits can help build a case against you" ( p. 542).
Study: Tombs-Heirman, 2009	
Finding	Removing children from school: "Keeping them off school for the duration of the vaccinations and perhaps for a short time after as well, in case the vaccinated children may be infectious, was the only option for many parents, if they are to protect their children from scrutiny, stigmatisation or perhaps even from disease" (p. 140). (U)
Illustration	Martha: "It is one of the reasons why we have decided to home educate." (p. 140). Melanie: "I would happily keep him off school for a week if I knew that this would prevent that happening." (p. 140).
Finding	Positive effects of illness and the purpose of illness: "That illnesses may serve a purpose was another concept which came up with some of the respondents. They believed that by allowing a child to experience a self limiting benign illness without medical intervention and by not suppressing the symptoms they were actually helping their child to become healthier" (p. 158). (C)
Illustration	"Well I see the childhood illnesses as having a purpose. I do appreciate that I live in a society where many of them, like polio, aren't a threat like they used to be, so I do have, I am lucky to be able to make that decision. Where something like chickenpox or measles or any of the others I feel it is beneficial for the children to experience it. Yes, there are risks with not having the vaccinations, but equally, there, it goes both ways. I

	would prefer to have that possibility of change for the child rather than prevent it." (Karen, p. 159).
Finding	Interactions with health professionals: "How the respondents handled their GP's, practice nurse's or health visitor's attempts to persuade them to vaccinate their children, varied enormously. The people I interviewed had good relationships with professionals on the whole, with a few exceptions" (p. 142). (U)
Illustration	"When he first became ill, we didn't worry so much at the start but then we did and we took him to the doctor. That was a horrendous experience with that doctor. He was absolutely terrible. He was blaming me; it was my fault that Billy was ill. He said, 'It's probably measles'. Well, he had no spots. He looked inside his mouth and his tongue was coated white. 'Are they Koplick spots then?' I asked. He said, 'Yes' (brusquely). They weren't. It wasn't measles. He listened to his chest and told me it was clear! He had Pneumonia! It was far from clear! This guy was basing it on pure prejudice. No science behind it all. He was very aggressive with me. He blamed me, for not having vaccinated my child! He wanted to have this long blaming conversation in front of my ill child when it had absolutely nothing to do with it. I mean even if I'd poured boiling water all over this child I wouldn't expect a doctor to stand there and blame me like that. It made me feel awful" (Pam, p. 144)
Finding	Positive health-care options/what they did to keep their child well: "All the respondents actively searched for and provided what they saw as positive health-care options in; childcare, nutrition and life style. What they saw as important varied" (p. 151). (U)
Illustration	"Good health is the only way to achieve anything. That is the reason why I only feed my children well. Go outside a lot, they get sunshine on their skin. They do what kids should be doing. So many kids just watch television all day. That is just rubbish. When people think it is normal, to feed a child chips and fish fingers, or chicken nuggets or burgers, because they wouldn't eat what the rest of the family are eating, they think that that is what the kids will eat. They don't give them water! 'Oh no', they say, 'My kids would never drink water; I have to give them squash'! If you would give them water in the first place! I breast fed both of mine till they were 18 months, one was 17 months and I believe I've done everything I possibly can. I feed them healthily; only on very rare occasions do they get rubbish. We never have crisps in the house. If anyone asks me, 'Oh, how do your children keep so healthy?' I tell ehm!" (p. 152).

Finding	Alternative medicine as complementary or as primary healthcare: "All of the respondents had used alternative health professionals for advice or treatment either for themselves or their children at some point. Some went to see a practitioner as their first port of call, where others used them when the bio-medical option wasn't desirable to them, or nothing else was available to them" (p. 161). (U)
Illustration	"Like I mean, since then we have all been ok and haven't been to a doctor. I go to the homeopath if something doesn't clear up by itself. My homeopath will also advise me over the phone. I don't panic a lot but I do like to talk to my homeopath. Like something like earache, I mean my oldest son had earache badly and it clears up very quickly with homeopathy" (Astrid, p. 161).
Finding	On vaccinations and schools: "Several parents who had school age children, or had spoken to people who had children in school, were upset about the social implications when vaccinations were introduced at school" (p. 138). (U)
Illustration	"When my son went away on a school trip in year 5, all his friends were standing in a long queue, giving them medicine, they all had inhalers they all had headache tablets, God knows what else. And Billy (son) had Arnica in case he hurt himself, the cream and the tablets. Also they were supposed to have an injection of Tetanus, which Billy didn't have. I was just about to go ahead with it when they were somehow referring to the notes and they said, 'Oh, this is Tetanus and something else'! I then talked to my homeopath about it. I then came back to the doctor and said that I did want him to have the Tetanus, but not the others. So they couldn't give him the Tetanus because they didn't have it on its own. I was very worried about it and sent away to several organisations for papers about Tetanus vaccinations and after reading them I was very glad that he hadn't had it." (p. 139, Astrid)
Study: Tomljenovic et al., 2022	
Finding	Vaccination avoidance behavior—Not being truthful (p. 6217). (U)
Illustration	One mentioned not being truthful and stalled claiming their child might suffer from allergies: "Actually, we said that we have allergies in our family and that we wanted to wait and see what happens when he starts eating food and he actually started getting these rashes, so the doctor said 'ok, let's wait for a year' but he still had those. When he was two years old, we made an allergy test, and nothing was found. The doctor said we can decide if we want to vaccinate" (Sara, 36, p. 6217).
Finding	Dealing with the outcome: "When asked how they cope with the risk of their child being infected with a disease, several informants seemed to lack any strategies of dealing with the

	risk and reported they have never so far considered it, therefore displaying only vague strategies related to this issue" (p. 6218). (C)
Illustration	<p>Next, some stated that they would rely on modern medicine, claiming it would be easy to find a way of successfully treating the infection if it emerged: "Well I think today's medicine has a solution for that" (Frank, 42, p. 6218).</p> <p>The informants most frequently stated that they relied on keeping the body and immune system strong and believed that their child could only be infected with a milder form of the disease: "Well then, he would probably get a milder type, because my child has recovered from all the usual childhood diseases, which were all in their mildest form (...) because of his good immune system and his health condition" (Sofia, 37, p. 6218).</p>
Finding	Vaccination avoidance behaviour—Avoiding school (p. 6217). (U)
Illustration	One mentioned giving instructions to the child about how to avoid the upcoming vaccination at school. Another did not send the child to school on those days and, instead, sent in an excuse notice: "When the vaccination was planned in school, I just would not send her to school that day" (Samantha, 46, p. 6217).
Finding	Vaccination avoidance behaviour—Stalling and avoiding contact with clinicians (p. 6217). (U)
Illustration	<p>The next strategy included stalling and avoiding contact with the clinicians, ignoring calls, going to a private clinic, or transferring to a less strict physician: "When I would go to the doctor, he said let's make a date. I said ok, when the child feels better. He would get better, and I did not show up." (Emma, 33, p. 6217)</p> <p>"I did not go to that doctor anymore and did the check-ups in a private polyclinic." (Jennifer, 41, p. 6217)</p>
Finding	Vaccination avoidance behavior— Informed consent: "In regard to the consequences of avoiding vaccination, some parents experienced being asked to sign an informed consent about the refusal, being referred to a talk with an epidemiologist, or being legally prosecuted, as well as receiving financial fines and not being able to enroll the child into kindergarten" (p. 6217). (U)
Illustration	"The first report was at the hospital, I had to sign a paper which said I refuse to vaccinate and that I am informed about the benefits of vaccines (...) after a few weeks, I got a call to go to an informative talk with the epidemiologist, so the doctor can talk to me 'about vaccines' and that I get better

	acquainted. She turned us in to the sanitary inspector, who is by duty obligated to file a court lawsuit, by which we get a fine, and you can get a fine for every vaccine you decline" (Julie, 38, p. 6217).
Finding	Vaccination avoidance behavior—Deceit (p. 6217). (U)
Illustration	Some also mentioned second-hand experience of malingering, bribery, deceptions or adulteration of medical records: "Most parents actually lie to their pediatrician and try to postpone vaccinating. (...) Some parents are desperate (...), desperate to such a degree they forge their vaccination medical documentation, just so their child could get into kindergarten" (Lisa, 27, p. 6217).  "You can go to a second pediatrician, pay her something, she gives you the certificate so you can get the children into kindergarten." (Tom, 37, p. 6217).
Finding	Vaccine avoidance behavior—Moving out (p. 6218). (C)
Illustration	Finally, two informants stated they knew people for whom mandatory vaccination was a motive for moving out of Croatia: "A lot of people leave here because of it. That is certainly not the only reason but those who are a bit more open or alternative; they just pack and move to a country where they won't have problems with it. (...). I know such people, who moved to Germany. They did not want to be bothered with it the whole time; they just did not want to. I know two families who moved." (Sara, 36, p. 6218)
Study: Vandenberg, 2013	
Finding	Natural health beliefs: "Study informants expressed strong beliefs in natural health, which include beliefs that the body was created to sustain itself and deal with diseases through its complex immune system, and vaccines and other unnatural substances interfere with the immune system. Preferences for natural healing remedies and therapies were also mentioned" (p. 123). (C)
Illustration	"I believe your body, for a lot of childhood diseases that we have around here, a healthy child should be able to fight it off, and that is the best way to do it, build up your own immune response to it" (p. 123).
Study: Ward et al., 2017	
Finding	Salutogenic parenting—Comprehensive health promoting and illness preventing activities: "Informants talked at length about the variety of health promoting and illness-preventing activities they engaged in, within which not vaccinating their children was contextualised and justified. Their praxis, eclectic yet often uniform, was held together by a milieu and identity that appeared utterly coherent to those within it. Parents' activities included managing nutritional intake during pregnancy,

	breastfeeding, feeding their children organic and/or home-grown food, cooking from scratch to reduce preservative consumption, reducing their children's exposure to chemicals and toxins and promoting physical activity and play-based learning" (p. 7-8). (U)
Illustration	<p>"I stepped back...I think it was great for me because it enabled me to achieve a certain lifestyle, creating my own food from scratch. I grow vegetables and I have chickens I mean, I feed my children organic food, I cook everything from scratch. I don't give them processed food. We have no chemicals in the house. We don't drink fluoridated water, we drink rainwater which has been filtered. So why would I then go and put all those chemicals in my child?" (Diane, p. 8)</p> <p>"I look at the whole picture of the organism, I guess. So my children eat the best quality food, whole food. Eat a rainbow, as I would say, in colour. Our water is—we've got a lovely filter on the outside of our house so we've got nice, fresh, clean water coming through. We get sunshine every day. Play outside every day. We eat organic" (Holly, p. 8).</p>
Finding	Questioning science/shifting evidence: "Parents who self-consciously value their capacity to reason also value their capacity to question and distrust traditional scientific evidence, and formulate alternative systems of parsing evidence.[...] parents in our study talked at length about not only the evidence underpinning vaccinations, but more broadly about the evidence underpinning numerous health-promoting and illness-preventing activities they undertook with and for their children. Their interrogation of, and engagement with, this evidence took the form of critiquing Western medical epistemology and making space for a different one" (p. 6). (U)
Illustration	Owen (SA) talked about the difficulties involved in searching for and synthesising evidence in order to make the best possible decisions for his children, and how he is open to new information, "to me it isn't a closed door...it's an enquiry about a lot of things, but that's kind of my life; it like takes up a lot of RAM, all this questioning...I'm grasping with it, you know, to make the best decision because all of my things are about making the best decision. You know, about the vaccinations...I haven't been able to let go totally of it and say `oh fuck that'. There's still a question...it's bloody challenging. I know it's a done deal for my wife but I'm not a closed—you know, I'm still wondering" (p. 7).
Study: Ward et al., 2018	
Finding	Risk assessments: "For parents assessing vaccine risk, the risk of disease was clearly waiting on the opposing arm of the scales, also demanding consideration" (p. 1123). (U)

Illustration	"[T]he decision was to do a delayed schedule with [child's name], and then to immunise him first with the things we felt were most threatening. And then with the least threatening at the end ... [F]irst was whooping cough, which ... as you know is epidemic around here. And then the least important at the time was hep B. So we still haven't completed hep B" (Tabitha, p. 1123).
Finding	Responsibility: "With every significant decision for a responsabilised parent, there may be unavoidable consequences. Parents in our study had to navigate through the frame of responsibility for their decision, particularly if anything was to go wrong either way" (p. 1123). (U)
Illustration	"... I am a better father in the sense, like, that I am more nurturing. I have had to put the work in ... I decided that the state wasn't going to be responsible for my child's health. I was going to be responsible ... [S]he has had whooping cough. And I took her out of school and took time off work and made sure I was with her that whole time she had it, to make sure she was going to be okay. She's had the measles and I spent, you know ... [A]nytime she has been sick, I just made sure that I took time off work and I spent the time she needed to actually recover from these things" (Evan, p. 1125).
Finding	Responses and reflexivity: "Despite the efforts to which the parents went in order to protect and promote the health of their children and the community, almost all experienced judgement by others, including friends and family, vaccinating parents and some healthcare professionals.[...], we widen the scope of parental risk engagement to consider risks to social relationships and medical care, considering that parents must also deal with the potential risk of unwelcome responses and problematic encounters" (p. 1125). (U)
Illustration	<p>"I put off going to the doctor whenever the kids are sick because I know the few times I've been in, it's been quite a negative reaction. So unless the kids are really sick, I don't tend to take them to the doctor. Which I, like – I need to find a doctor that is open to people who don't immunise" ( Angela, p. 1126).</p> <p>"She said that when she took him into hospital with chicken pox ... the looks she got from the nurses, she was basically judged and not helped as much as she could have been, and just ostracized ... That's really scary as a parent. Going into a hospital and say, 'Oh well, she is having a complication with chicken pox' and 'No, she is not vaccinated'. You know, I would try and keep her at home and treat her naturally ... I would be fearful of going to hospital. So that sets up maybe not giving her the best emergency care" (Cally, p. 1126).</p>

Finding	Responsibilisation: "Salutogenic parenting is an enactment of responsabilisation, with parents demonstrating a high level of agency in ensuring their child's development, well-being and health. Most parents in this study adhered to a salutogenic parenting pathway including eating organic food; reducing the ingestion of, and exposure to, chemicals in their environment; limiting children's time on 'screens'; and encouraging physical and emotional development through creative play" (p. 1121). (U)
Illustration	"[W]e use very minimal chemicals, the same as in our cooking. We have the organic fruit and vegetables wherever possible, drink filtered water, things like that. I guess our whole lifestyle, we make sure we're moving. We're not a sedentary family sitting in front of the TV, we're out in the garden, we're growing our own food ... I look at the whole picture of the organism" (Holly, p. 1121).
Study: Wiley et al., 2020	
Finding	Fulfilling the role of responsible parent: "Informants were highly attuned to their children's health, wellbeing and developmental needs, taking active responsibility for meeting those needs. Many invested significant time and resources into providing the best environment for their children" (p. 3). (U)
Illustration	For example, Jane had quit her successful business and moved out of the city to provide a 'slower paced' life, with access to fresh air and home-grown vegetables."[N]othing's more important. I have sacrificed so much for the child... My whole life has been coming up to this moment, I wanted to be a mother forever, and every decision that I make is with his best interests in mind" (Jane, p. 4).
Study: Wiley et al., 2021	
Finding	Finding new supportive social groups: "Relatedly, some informants described reacting to the more stringent government policies by doubling down on their resolve and becoming more vocal and engaged with like-minded people. In these instances, rather than seeking to 'pass' and avoid stigma, parents became more public about their vaccine rejection" (p. 5). (U)
Illustration	"After they [the government] came in and they were pushing No Jab No Play[sic] ....I've become a lot more active. I post stuff on Facebook and I try and convince people .... Before No Jab No Pay, I didn't know anyone else that chose not to vaccinate, not one person" (Jay, p. 5)
Finding	Status loss and discrimination at an interpersonal level: "For many, status loss and moral judgement extended beyond uncomfortable interactions, to outright ostracism. Parents described exclusion from parent and friend groups, as well as from family" (p. 4). (U)

Illustration	Emma and her son experienced social exclusion because of her decision: "The mothers in our street had a meeting and they decided that they didn't want their kids to play with him because he wasn't vaccinated.... I wasn't really prepared for them all to come to my doorstep, so I was upset ... My kid could still play in the street, but what would happen is that they would bring their kids in when he went out" (Emma, p. 4).
Finding	Finding new supportive social groups: "New peers who were supportive or accepting of their choices in a few cases helped activate and mobilise parents to be more proactive in their non-vaccinating stance" (p. 5) (U)
Illustration	Jane spoke of aligning herself with a new group of friends who "just have the same values" because she felt she was not accepted as part of mainstream society, "I feel that in all of the like-minded people that I associate with now, it feels as though we have to form our own little groups, because it feels like we're not even welcome in society." Jane then went on to say that she felt forcing people "underground into their own little communities" was "dangerous" because it meant they inhabited an "echo chamber," limiting exposure to perspectives different from their own (p. 5).
Finding	Status loss and discrimination at a systemic level: "In these parents' accounts, systemic status loss was experienced as differential treatment of their families, through policies excluding unvaccinated children from early childhood education and federal financial assistance. Some of the parents described suffering financially under the federal "No Job No Pay" policy, combined in some states with the loss of access to childcare services" (p. 4). (U)
Illustration	Some parents explicitly said they felt the policies are unethical and discriminatory, pointing to perceived social injustices. Sally said she: "would really like [her child] to be able to go to a childcare centre where she's with other children, but [she] can't do that .... It is discriminatory" (p. 4).  Eloise felt that the policies affected people with lower incomes differently: "if you're wealthy, you can make these decisions yourself, but if you're not wealthy, you have no choice" (p. 4).
Finding	Responding to stigmatization: doing what it takes to defend my child: "Having experienced judgement or discrimination, and/or fearing the ramifications of being "outed" as a non-vaccinator, parents spoke of adjusting their approach to interpersonal engagement about vaccination..."(p. 5). (U)
Illustration	"This is not a table conversation we have ... I'm much more careful about who I would talk to about things. I'm much more cautious about what I share" (Jessica, p. 5)

Finding	Reciprocal obligations fulfilled: "When specifically asked what they feel is reasonable for society to expect of nonvaccinating parents, the informants' response was generally that nonvaccinating parents do not owe society anything because of the lengths they already go to in raising healthy children who can withstand the diseases that vaccines are intended for" (p. 1683). (C)
Illustration	"The way I see it is that ... parents who choose not to vaccinate their children do actually offer quite a lot in return. They choose to breast feed their children longer, they choose to minimise sugar and processed foods and they choose to keep their kids as healthy as they can so that, when they do contract an infection, then obviously their symptoms are going to be less... they generally keep their kids home when they're sick... These decisions to not vaccinate are not made in a blasé way and they really work hard to keep their kids home, look after them properly and ensure that they're disease doesn't progress to something that's dangerous. And in doing so they're protecting the population" (Martina, Group 5, p. 1683).
Study: Zin et al., 2022	
Finding	Beliefs in alternative practices: "... some parents thought alternative methods were safer for their children's health than vaccination. They felt that over the years, dietary practices by Prophet Muhammad s.a.w and healthy food are more natural and nutritious for children's growth. Such a "superfood" was considered as good as vaccinating the children. Parents have also stated that as-sunnah food and homeopathy are other forms of vaccine, apart from the conventional vaccines in Malaysia" (p. 109). (U)
Illustration	<p>"For me, I am more about taking care of health through natural ways, meaning that eating healthy food, reduce sugar intake, like myself and wife, we drink goats' milk, eat Habbatus Sauda, honey, raisins" (Informant 5, p. 109).</p> <p>"I have my ways; I practice my vaccine (referring to as-sunnah food)" (Informant 2, p. 109).</p> <p>"I practice homoeopathy, that is a vaccine (homoeopathy vaccine)" (Informant 11, p. 109).</p>

## Appendix E: Certificate of Approval



Office of Research Services | Human Research Ethics Board  
 Michael Williams Building Rm B202 PO Box 1700 STN CSC Victoria BC V8W 2Y2 Canada  
 T 250-472-4545 | F 250-721-8960 | uvic.ca/research | ethics@uvic.ca

### Certificate of Approval - Amendments

PRINCIPAL INVESTIGATOR:	<b>Karen MacKinnon</b> (Supervisor)	<b>ETHICS PROTOCOL NUMBER</b>	<b>22-0252</b>
PRINCIPAL APPLICANT:	<b>Christine Huel</b> PhD student	Expedited review - delegated	
UVIC DEPARTMENT:	<b>Nursing NURS</b>	ORIGINAL APPROVAL DATE:	13-Mar-2023
		APPROVED ON:	28-Sep-2023
		APPROVAL EXPIRY DATE:	12-Mar-2024

**PROJECT TITLE: The Everyday Experiences of Family Caregivers Enhancing Health for their Young Children after Declining Vaccines**

**RESEARCH TEAM MEMBERS:**

Anne Bruce - PhD Committee / Research team member, University of Victoria  
 Shannon E. MacDonald - PhD Committee member / Research team member, University of Alberta

**DECLARED PROJECT FUNDING:**

University of Victoria (UVIC), Faculty of Human and Social Development

**DOCUMENTS INCLUDED IN THIS APPROVAL:**

CHUEL\_tcps2\_core\_certificate.pdf - 15-Dec-2022  
 Eligibility Email Response\_CHUEL\_Final3.docx - 22-Feb-2023  
 Demographic Questionnaire\_CHUEL\_Final3.docx - 22-Feb-2023  
 Data Collection Methods- Interview Questions-CHUEL\_Final3.docx - 22-Feb-2023  
 Verbal\_Consent\_Script\_CHUEL\_Final3.docx - 22-Feb-2023  
 Recruitment Approval Letter\_CHUEL\_Final3.doc - 22-Feb-2023  
 Poster for Social Media Recruitment\_CHUEL\_Final4.doc - 20-Sep-2023  
 Consent\_Form\_CHUEL\_Final5.doc - 20-Sep-2023

### Conditions of approval

This Certificate of Approval is valid for the above term provided there is no change in the protocol.

**Amendments**

To make changes to the approved research procedure in your study, please submit "Amendments" or "Annual renewal with amendments" form. You must receive research ethics approval before proceeding with your amended protocol.

**Renewals**

Your ethics approval must be current for the period during which you are recruiting participants or collecting data. To renew your protocol, please submit a "Request for Renewal" form before the expiry date on your certificate. You will be sent an emailed reminder prompting you to renew your protocol about six weeks before your expiry date.

**Project Closures**

When you have completed all data collection activities and will have no further contact with participants, please notify the Human Research Ethics Board by submitting a "Notice of Project Completion" form.

### Certification

This certifies that the UVic Human Research Ethics Board has examined this research protocol and concluded that, in all respects, the proposed research meets the appropriate standards of ethics as outlined by the University of Victoria's policies for research involving human participants.

Dr. Sandra Gibbons  
 Chair, Human Research Ethics Board

Dr. Matthew Murphy  
 Vice-chair, Human Research Ethics Board

## Appendix F: Poster for Social Media Recruitment




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### Invitation to participate in the research study: “The Everyday Experiences of Family Caregivers Enhancing Health for their Young Children after Declining Vaccines”

**Principal investigator:** Christine Huel, Ph.D. Candidate, School of Nursing, University of Victoria and family nurse practitioner in British Columbia, Alberta, and Ontario. I am conducting this research for my Ph.D. dissertation, as part of my doctoral degree in the School of Nursing at the University of Victoria.

**Email:** [chuel@uvic.ca](mailto:chuel@uvic.ca)

**If you are a parent or family caregiver to an infant, toddler, or preschool child, and have chosen to decline some or all of the infant and childhood vaccines from your provincial or territorial routine immunization schedule, this study might be of interest to you!**

#### Purpose and Objectives

The purpose of this study is to form a better understanding of the experiences of family caregivers and parents who have declined some or all routine schedule vaccines for their infant or preschool child through exploring the activities they do to enhance health for their children. The objective of this study is to inform healthcare provider practice, education, research, and policy.

You will have an opportunity to share your experiences of enhancing health for your children after choosing to decline immunizations. This part of parent’s and caregiver’s work is not widely understood in research to date. You will assist in forming new understandings about what people do for their children’s health, rather than focusing on perspectives and opinions about vaccines.

#### What is Involved?

An individual interview will be conducted virtually through Zoom. You will have the choice to have the camera on or off during the interview. This interview may take 1-2 hours.

#### Compensation

**As a sign of thanks for your time we would like to offer you either 1) a \$60.00 e-transfer to your chosen email, or 2) a \$60.00 gift card mailed to your chosen address.**

#### Contacts

If you have any questions about the research and would like to participate in this study please contact the principal investigator, Christine Huel at [chuel@uvic.ca](mailto:chuel@uvic.ca) directly. You are welcome to contact her Ph.D. supervisor Dr. Karen MacKinnon at [kamackin@uvic.ca](mailto:kamackin@uvic.ca) for further information.

**\*If you are reading this poster online and are interested in participating in this research study, please respond privately, and not post publicly, as this is best practice for maintaining confidentiality.**

**Appendix G: Recruitment Approval Letter****University  
of Victoria***Recruitment Letter*

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**The Everyday Experiences of Family Caregivers Enhancing Health for their Young Children after Declining Vaccines**

Hello,

I am sharing this letter with you to ask you for help with the study I'm conducting for my Ph.D. dissertation. It's a part of my doctoral degree in the School of Nursing at the University of Victoria.

The purpose of this study is to form a better understanding of the experiences of family caregivers and parents who have declined some or all routine schedule vaccines for their child(ren) through exploring the activities they do to enhance health for their children.

I feel that researchers and healthcare providers have not engaged with family caregivers in a way that fully illuminates the work they do to enhance their children's health after declining vaccines. Research of this type is important because few studies have sought to understand family caregiver's work, rather than focusing on vaccine decision-making or perspectives about vaccine safety and necessity.

I would like to request your assistance in bringing this study to the attention of family caregivers and parents to infants, toddlers, and preschool children who have declined all or some of the routine schedule immunizations for their children by sharing the study's recruitment poster in your online community. Parents and caregivers who are interested in participating in the study can contact me at [chuel@uvic.ca](mailto:chuel@uvic.ca). If you have any questions about my dissertation research, please do not hesitate to contact me via my email at [chuel@uvic.ca](mailto:chuel@uvic.ca). You are also welcome to contact my Ph.D. supervisor Dr. Karen MacKinnon at [kamackin@uvic.ca](mailto:kamackin@uvic.ca)

Sincerely,

Christine

## Appendix H: Eligibility Email Response

### Pre-screening Eligibility Checklist Email Response

Subject line: The Everyday Experiences of Enhancing Health

Hi,

I would like to thank you for expressing your interest in participating in my research study titled: **“The Everyday Experiences of Family Caregivers Enhancing Health for their Young Children after Declining Vaccines.”**

My name is Christine Huel, I’m a Ph.D. candidate at the University of Victoria and a family nurse practitioner. To complete my doctoral degree in nursing, I’m working on a new research study and need your help.

The purpose of this new study is to form a better understanding of the experiences of family caregivers and parents who have declined some or all routinely scheduled vaccines for their infant or preschool child through exploring the activities they do to enhance health for their children.

Would you like to help? To see if you are eligible, please read the requirements below.

Who Can Participate?

1. People over 19 years of age
2. People who feel comfortable communicating in English
3. A family caregiver or a parent to an infant, toddler, or preschool child (under 5 years of age), who has declined **some or all vaccines** from a provincial/territorial infant and/or early childhood schedule for their child(ren)
4. Have access to an electronic device and internet that can support an online Zoom meeting
5. Willing to be audio or video-recorded for the purpose of research
6. People who have **not** been a former patient of mine, I currently and/or previously practiced at GOeVisit virtual clinic, Parhar Adult ADHD Clinic, Castlegar TMVC Clinic, Waneta Primary Care Clinic, and Ktunaxa Nation Health Clinic.

If you fit these requirements and are interested in participating, please reply to this email as soon as possible. I’m happy to answer any questions you have and send you more information at any point. Thanks so much for your interest!

Take care, Christine



## Appendix J: Interview Questions

### The Everyday Experiences of Family Caregivers Enhancing Health for their Young Children after Declining Vaccines

#### Data Collection Methods: Interview Questions

The principal applicant will use open-ended questions to understand informants' everyday experiences, activities, and the texts they engage to enhance the health of their children after declining vaccines.

In Institutional Ethnography (IE)-oriented studies, the researcher(s) do not prepare a set list of interview questions. Using an IE lens involves an iterative approach to research that takes into account each informant's interview and its contribution to a developing understanding of the coordination of activity in multiple sites and how things work (Campbell and Gregor, 2002). Therefore, standardized interviews do not fit with this evolving picture about what is taking place and how to shape questions in response to the information that informants share.

However, the principal applicant/student researcher will begin the interviews with a few opening questions. These are based on McCoy's (2006) suggestions on how to identify family caregiver work and link it to institutional order:

1) *"I am interested in the work that family caregivers do every day to care for the health of their children and family members. Could you please think back to a fairly recent day when some of your work was amplified/increased or more difficult because your children had not been fully vaccinated? [pause]. If possible, could you please tell me about this particular day in as much detail as you can remember?"*

The following sample questions then become probes for further information:

- 2) After you decided to not fully vaccinate your child(ren) what do you do to help make and keep your children healthy? What do you do to build their immunity to illnesses?
- 3) What does it feel like to do this work? Who do you turn to for help or support?
- 4) When did you first become aware of the need to protect your children from becoming sick from illnesses like whooping cough or measles? Did you feel the need to protect them?
- 5) What kinds of things did you do to protect them? Did you notice other people in your community trying to protect their children the same way?
- 6) What information did you need to help you?
- 7) Who do you turn to for help or support?
- 8) What does it feel like to try and protect your children from these illnesses?

The plan is to transcribe and analyze interviews before engaging in another interview, in order to listen and reflect on changing or adapting questions based on informants' responses. It is important to note that the questions listed above may change after the first interview to a different set of opening questions that better reflect the responses from earlier informants. Sometimes an IE researcher will share what a previous informant has told them about their experiences to explore what this person thinks about these ideas.

Campbell, M. L., & Gregor, F. M. (2002). *Mapping Social Relations: A Primer in Doing Institutional Ethnography*. Aurora, ON: Garamond Press.

McCoy, L. (2006). Keeping the institution in view: Working with interview accounts of everyday experience. In D. E. Smith (ed.), *Institutional Ethnography as Practice* (pp. 109–125). Lanham, MD: Rowman & Littlefield.