

# BEST PRACTICE

Evidence-based information sheets for health professionals

## Parental experiences of caring for their preschool children after declining vaccines

#### Recommendations\*

- · Health care providers should maintain relationships with parents who decline all or some vaccines for their children. Parents rarely refuse all vaccines but actively seek information about vaccine safety, vaccine preventable disease outbreaks in their community, and the health of their family to determine if they should vaccinate. (Grade A)
- To foster a relationship with parents who decline vaccines, health care providers should inquire about what they do to enhance their children's health. Ask about what informs their care activities and what information sources they deem trustworthy. Provide positive attention and acknowledgment for the work they do for their children's health. (Grade A)
- · Health care providers should recognize that parents who decline vaccines are anxious and fearful when they approach health care providers with questions about immunizations and when their children are ill. Some parents avoid health care encounters due to fears of being called negligent or unfit. Parents are mentally preparing themselves for encounters that health care providers may not consider overly important or memorable. A negative experience can leave a lasting impression that puts a child's health at risk if parents avoid seeking medical attention. (Grade A)
- Please refer to: JBI's Grades of Recommendation

#### Information source

This Best Practice Information Sheet is a summary of evidence derived from a systematic review published in 2025 in JBI Evidence Synthesis.1

#### **Background**

The World Health Organization has defined vaccine hesitancy as a motivational state of being conflicted about, or opposed to, getting vaccinated. This definition emphasizes people's intentions or willingness to get vaccinated rather than the choice they ultimately make about immunizations. Parents who feel hesitant about childhood immunizations may have a wide range of fears, opinions, and perspectives that impact how they choose to prevent vaccine preventable diseases (VPDs) in their family. In response to vaccine hesitancy, they may delay their acceptance or refuse all or some vaccines for their children, regardless of access to immunization services. Parents who decline routine childhood vaccines weigh the perceived benefits and risks of vaccinating to make a decision that reflects their intention to protect their children's health and well-being based on their beliefs.

Vaccine hesitancy research has detailed how parents who choose to decline all or some routine childhood vaccines continue activities to prevent VPDs, re-evaluate their decisions, and enhance their young children's health after their initial decision has been made. Parents have reported making natural living lifestyle choices such as breastfeeding, eating organic and/ or homegrown food, and reducing exposure to toxins, due to beliefs that this may minimize the risk of critical VPD illnesses. Care activities to enhance children's health and prevent VPDs are seen as a significant burden of responsibility for parents; however, previous research on vaccine hesitancy tends to focus

on parents' viewpoints and opinions rather than the descriptions of what they do for their children's health following their decision. The findings of our review provide a comprehensive understanding of what parents are doing for their children's health, as an alternative to immunizations, to inform health care providers about the care activities that parents value and the information about VPDs they deem important.

### **Objective**

The purpose is to present the best available evidence about the experiences of parental caregivers in caring for their preschool children's health after deciding not to vaccinate them. The aim is to help health care providers better understand the parental work involved in caring for under-vaccinated or unvaccinated children by presenting a different facet of vaccine hesitancy, one that shifts from contested opinions about the safety and necessity of immunizations to what parents are doing in the absence of vaccination. This will help to inform health care providers' approaches when working with vaccine-hesitant families.

#### Phenomena of interest

The phenomena of interest are the experiences and care activities that vaccine-hesitant parents reported doing for their unvaccinated or under-vaccinated preschool children after declining all or some routine childhood vaccines due to concerns about safety and efficacy. "Care activities" are all the everyday activities that parents do for their children's health and safety after their initial decision to forgo immunizations. These include providing hands-on care in the home to enhance children's health, obtaining access to community schooling, and advocating for parents' rights to decline routine childhood vaccines.

## **Quality of the research**

Forty qualitative studies were included. Fifteen studies were companion studies that shared an overlapping dataset with one or more of the included studies. The companion studies were closely compared to ensure that extracted findings and informants' illustrations were unique to each included report. Study designs included phenomenology, grounded theory, ethnography, action research, and feminist research. The studies were described in 33 journal articles, 4 master's theses, 2 doctoral dissertations, and 1 book chapter. The reports were published over a 14-year period spanning 2009-2023. Methodological quality of included studies was assessed by 4 reviewers using the JBI critical appraisal tool for qualitative research; all reports were deemed to be of high methodological quality.

#### **Findings**

The included studies were conducted in 14 countries across 4 continents and included approximately 676 participants, with sample sizes ranging from 4 to 60. Of the studies that reported on the genders of non-vaccinating parents, 324 identified as female, 56 identified as male, and 1 participant asked that their gender not be divulged. Most studies were from the United States (n=14) and Australia (n=9), and the remaining studies were from Turkey (n=2), Switzerland (n=2), The Netherlands (n=2), United Kingdon (n=2), Finland (n=2), Canada (n=1), Croatia (n=1), Malaysia (n=1), Norway (n=1), Spain (n=1), Sweden (n=1), and Taiwan (n=1). Parental care strategies included activities that took place in the home, the community, and at the systemslevel. From the included studies, a total of 115 findings were extracted and grouped into 12 categories based on similarity of meaning. These categories were aggregated into 3 synthesized findings using the process of meta-aggregation. The synthesized findings are presented below.

## Synthesized finding 1: Parental care strategies in the home - focusing on the individual and family

The first synthesized finding is from 6 categories based on 64 findings. Parents enacted specific care strategies in the home that were intended to protect their children from VPDs, enhance their health, strengthen their immunity, and inform their ongoing decision-making about vaccinating. To enhance their children's health, parents used complementary and alternative health modalities. They also willingly exposed their children to VPDs, due to beliefs that this provides superior, longer-lasting immunity over vaccines and the convalescence was beneficial for growth and development. Parents reported living natural lifestyles and provided a healthy environment in their home, away from social contacts, so that their children would have stronger immunity to suppress VPD symptoms, decrease the severity of symptoms, or avoid contracting a VPD altogether. Parents reported their experiences and their intentions to care for children who become ill with a VPD based on their perception that the severity of these illnesses is negligible. Importantly, parents conveyed that their vaccine decisions were not a final choice; they described an intensive, ongoing search process for information that would either confirm their suspicions or disprove them, leaving the door open for reconsideration.

. . . 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.

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

#### Synthesized finding 2: Parental care strategies in the community - managing social interactions and community networks

The second synthesized finding was formed from 4 categories and 32 findings. Parents' care activities expanded from the hands-on care they provide in the home and into the greater community. Their vaccine decisions led them to anticipate and plan for difficult relationships with members of their community who disagree with their choices. Parents discussed how they actively and passively responded to criticism and managed relationships with health care providers, teachers/schools, friends, and family members. They also reached out to likeminded peers for support and information to guide the care they provided to their children and to gain knowledge about vaccines.

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.'

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.

## Synthesized finding 3: Parental care strategies at the systems-level - challenging societal discourse and institutional work processes

This synthesized finding was created from 2 categories and 19 findings. Parents worked to protect their vaccine choices and their family's overall well-being from perceived and real punitive measures imposed by governmental agencies. They planned next steps by describing what their family would do if penalties became too overwhelming. Parents reported their efforts to stand their ground and challenge societal discourses about "anti-vaxxers" that undermined their rights as parents to exert ownership of their children's health. They also discussed ways to push back against systems-level penalties.

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.

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.

#### **Conclusions**

This review found that after declining routine childhood vaccines for their young children, parents engaged in intensive care activities for their children's health that were related to their decision to withhold all or some immunizations. Parents' care activities extended from the household and into the community, and represented multiple anticipatory and reactive measures. Parents reported being strongly committed to their family's health and well-being, and their care activities were as intensive as they were invisible to health care providers, who often placed their focus on the vaccine choices they were not pursuing.

### Implications for practice

Based on review findings, health care providers should maintain relationships with parents who decline vaccines for their children because their decision is rarely final. Ostracizing parents pushes them toward like-minded communities that confirm their fears, rather than offering balanced support on this topic. To foster a relationship with parents who disagree with health care providers' advice about routine childhood vaccines, do not focus solely on their refusal. Ask parents about what they do for their children's health, what informs their care activities, and what makes these information sources trustworthy for them. Health care providers should recognize that parents may be apprehensive to ask questions about vaccines and may have had negative interactions with health care providers due to their vaccine decisions. Parents spend time and effort mentally preparing themselves for health care encounters or may avoid them altogether, which can be risky for their children's health. Despite differences of opinion, health care providers should maintain a bridge to families.



#### **POPULATION**

Parents and caregivers of children aged 0 to 6 years who declined routine childhood vaccines for their children

#### **PHENOMENA OF INTEREST**

Experiences and care activities that vaccine-hesitant parents reported doing for their unvaccinated or under-vaccinated preschool children after declining all or some routine childhood vaccines due to concerns about safety and efficacy

#### CONTEXT

Studies from any context

#### SYNTHESIZED FINDINGS





Protecting from VPDs



Enhancing health

Parental care strategies in the home

focusing on the individual and family





Support from like-minded peers



Responding to criticism



Community relationships

Parental care strategies at the systems-level

challenging societal discourse and institutional work processes





#### RECOMMENDATIONS FOR PRACTICE

Maintain relationships with parents who decline vaccines for their children:

Parents rarely refuse all vaccines. They continue to seek information about safety, VPD outbreaks in their community, and health of their family. (Grade A) ▶ Inquire about what parents are doing for their children's health:

To foster a relationship with parents who decline vaccines, ask the parent about their care activities, what informs this care, and what information they trust. Acknowledge the work they do for their children's health. (Grade A)

Recognize that parents who decline vaccines are anxious or fearful to ask about immunizations and when their child is ill:

Parents may be fearful about asking vaccine questions or accessing health care due to their vaccine decisions. A negative interaction could lead to avoidance of health care providers, which increases the child's health risks. (Grade A)

#### References

1. Huel C, MacKinnon K, Harding J, Haghiri-Vijeh R, Gordon C, MacDonald SE. Parental experiences of caring for their preschool children after declining vaccines: a qualitative systematic review. JBI Evid Synth. 2025;23(2): 244-332.

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