Comprehensive Child and Adolescent Nursing





ISSN: (Print) (Online) Journal homepage: informahealthcare.com/journals/icpn21

Pushed to the Fringe – The Impact of Vaccine Hesitancy on Children and Families

Susan E. Smith, Nina Sivertsen, Lauren Lines & Anita De Bellis

To cite this article: Susan E. Smith, Nina Sivertsen, Lauren Lines & Anita De Bellis (2023) Pushed to the Fringe – The Impact of Vaccine Hesitancy on Children and Families, Comprehensive Child and Adolescent Nursing, 46:4, 262-276, DOI: 10.1080/24694193.2023.2222815

To link to this article: https://doi.org/10.1080/24694193.2023.2222815

9	© 2023 The Author(s). Published with license by Taylor & Francis Group, LLC.
	Published online: 15 Jun 2023.
	Submit your article to this journal 🗷
ılıl	Article views: 814
Q ^L	View related articles ☑
CrossMark	View Crossmark data ☑
4	Citing articles: 1 View citing articles 🗗







Pushed to the Fringe – The Impact of Vaccine Hesitancy on Children and Families

Susan E. Smith, RN, RM, PhD o, Nina Sivertsen, RN, PhD, Lauren Lines, RN, PhD, and Anita De Bellis, RN, PhD

^aCollege of Nursing and Health Science, Flinders University, Adelaide, South Australia; ^bRural and Remote Arctic Health, Campus Hammersfest, Flinders University and Arctic University of Norway, Adelaide, South Australia; ^cFlinders University, Bedford Park, South Australia

ABSTRACT

Vaccine hesitancy has been described as any delay or refusal of vaccines despite their availability and is increasing in Australia and other middle to high-income countries. The aim of this study is to gain a deep understanding of the experiences and influences on vaccine hesitant children and their families. A qualitative interview approach was undertaken with vaccine hesitant parents and pregnant women (n = 12). Semi-structured interviews were conducted by telephone. Inductive thematic analysis was undertaken on data obtained using the guidelines of Braun and Clarke. Three main themes were identified in this study, including Pushed to the fringe; A culture of Distrust; and Coerced choices. The study revealed that vaccine hesitant parents felt isolated and pushed to the fringe of society. They also expressed dissatisfaction with the Australian "No Jab - No Pay" and "No Jab -No Play" legislation. This contributed to feelings of marginalization. Participants also cited a breakdown in the therapeutic relationships, which impacted their child's health. Additionally, a lack of sufficient information was received to achieve informed consent. These results suggest that there is a need for enhanced education for some healthcare professionals, many of whom have reported being confronted by conversations with vaccine hesitant parents.

ARTICLE HISTORY

Received 6 March 2023 Accepted 19 May 2023

KEYWORDS

Children; families; vaccine hesitancy; nursing

Introduction

Immunization is universally accepted as one of the most significant health initiatives of recent times and has been described as any delay or refusal of vaccines despite their availability by the World Health Organization (WHO, 2019). Vaccine hesitancy persists in Australia and other middle to high-income countries including the USA, Canada, and the United Kingdom (Clarke, Sirota, et al., 2019; Dube et al., 2018; Rumetta et al., 2020; Saada et al., 2015; Syiroj et al., 2019). Many of these countries have a significant uptake shortfall (WHO, 2019). Pregnant women and children are some of the most severely affected by vaccine-preventable diseases including COVID–19 (Arthurs et al., 2021; Villar et al., 2021). There is evidence that nearly half of Australian parents have expressed concerns about childhood immunization (Danchin et al., 2018). Whilst many aspects of vaccine hesitancy

CONTACT Susan E. Smith Susan.smith@flinders.edu.au College of Nursing and Health Science, Flinders University, Sturt Road, Bedford Park 5042, South Australia.

 $[\]ensuremath{\texttt{©}}$ 2023 The Author(s). Published with license by Taylor & Francis Group, LLC.



have been extensively researched, more recently with a focus on COVID-19, few studies have investigated the impact of vaccine hesitancy on children and their families (Green et al., 2021, 2022). Similarly, few have explored the experiences of being a vaccine hesitant parent nor developed an understanding of their experiences.

Background

In Australia, parents and pregnant women have displayed high levels of anxiety associated with vaccine decision-making with children most likely to remain under-immunized when vaccines are refused (Danchin et al., 2018; Glanz et al., 2013). Pregnancy and the early postpartum period are times of high information needs and a time when attitudes to immunization are forming (Clarke, Paterson, et al., 2019; Danchin et al., 2018; Gencer et al., 2021; Smith et al., 2021, 2022a). Health-care professionals' role of educating and providing immunization is vital at this time; however, health-care professionals have been subject to some criticism and have reported feeling challenged by vaccine hesitant parents (Green et al., 2022; Smith et al., 2021). An integrative review of the literature was conducted to ascertain the knowledge gaps that would drive this research (Smith et al., 2022a). The review found multiple factors were influential in the decision to accept or reject immunization. These ranged from vaccine safety concerns to receiving inadequate information from a health-care professional. Additionally, local legislative incentives such as the Australian "No Jab - No Pay" and "No Jab - No Play" legislation, can have a negative impact on families and children (Smith et al., 2022b). The review of the literature also identified parental concerns about the safety of vaccines and distrust in the pharmaceutical industry along with distrust and dissatisfaction in the role of health-care professionals as influential factors in vaccine refusal.

In 2016, the Australian government introduced the 'No Jab - No Pay and "No Jab - No Play" legislation as an incentive for parents to immunize children (SA Health, 2019). This legislation has both financial and social implications for families who are not compliant with the Australian Immunization schedule, resulting in exclusion from early education and loss of taxation benefits. Whilst this legislation resulted in increased uptake of vaccines, considerable resistance to the legislation persists (Beard et al., 2017). Similarly, legislation exists in the United States of America where state vaccination laws exist, which include vaccination requirements for children in public and private schools and day-care settings, college/university students, health-care workers and patients in certain facilities (Centers for Disease Control, 2022). The review by Smith et al. (2022a) identified that vaccine hesitant parents felt that the Australian legislation created a sense of hardship among the vaccine hesitant. The aim of this study was to gain a deep understanding of the influences and experiences of vaccine hesitant families, which are rarely reported in academic literature.

Method

This study is part of a larger body of research that was underpinned by an ethnographic/ netnographic methodology. This study included an exploratory online survey and a netnographic study of Facebook discussion threads, which is currently under peer review (Smith et al., 2022b). Netnography adopts the principles of ethnography, whilst using online interactions and textual discourses as fieldwork (Kozinets, 2015). This study adopted a qualitative approach whilst recruiting vaccine hesitant parents and pregnant women via the purpose-designed Facebook page. Researcher reflexivity is vital in an ethnographic methodology. Through reflexivity, personal biases are identified, and rigor is enhanced. The primary author addressed reflexivity throughout this research by initial reflection on personal beliefs and biases and through the taking of field notes. These recorded key insights and reflected on issues raised in the interviews. Additionally, to limit interviewer bias, open-ended questions were employed which ensured that participants could express their feelings about their lives as vaccine hesitant parents. Ethics approval was obtained through Flinders University HREC Project No. 2464.

A Business Facebook page "Vaccine hesitancy in pregnancy and early childhood" was developed to recruit participants (Smith et al., 2022b, 2023). This was required due to COVID19, the researchers were unable to access preexisting groups as they had been forced to shut down. Some rebirthed on different social media platforms under different names but remained impossible to access. Dissemination of the Facebook page was not limited geographically; however, participants were all from Australia (Demographic data -Table 1). The primary author acted as the site administrator. No gatekeepers were employed for this project. Participants were invited to volunteer for the study via the final question of the online survey, which was accessible via the Facebook page. This recruitment method was chosen as vaccine hesitant parents have been shown to prefer the online environment where they feel safe and can elect to participate or not (Tustin et al., 2017). Convenience sampling was used to recruit pregnant women and parents (n = 12) who self-identified as vaccine hesitant. Data were collected between June and August 2021, when data saturation was achieved, and recruitment ceased. Data saturation was identified when no new information was received, and sufficient data was obtained to replicate the study (Fusch & Ness, 2015). The participants of this study provided rich information and added a deep understanding of what it is like to be vaccine hesitant. An interview guide was developed in consultation with all authors and informed by the results of a literature review and is available on request (Smith et al., 2022a) (Appendix 1). Parents who volunteered for this study via the final question of the online survey were contacted by the primary author to confirm consent. Semi-structured interviews (n = 12) were conducted via telephone due to the social distancing

Table 1. Demographic data.

Name (pseudonym)	No. of Children	Immunisation Status of children	Pregnancy status
Al	2	Partially	Not pregnant
Annie	5	Partially	Not pregnant
Arlene	1	Unimmunised	Not pregnant
Emma	0	N/A	Pregnant
Jane	1	Unimmunised	Not pregnant
Jessica	3	Partially	Pregnant
Maree	6	Partially	Not pregnant
Persephone	2	Unimmunised	Not pregnant
Rachel	5	Unimmunised	Not pregnant
Rebecca	2	Partially	Not pregnant
Sarah	2	Unimmunised	Not Pregnant
Shan	1	Unimmunised	Pregnant

Table 2. Themes and sub-themes.

Theme 1	Theme 2	Theme 3
Pushed to the fringe	Culture of distrust	Coerced choices
Isolated, ostracised and labeled	Big pharma and vaccine safety concerns	Informed consent
Healthcare professional's role and critical points	Decision-making, beliefs, and influences	Legislative issues

requirements during the global COVID-19 pandemic. Participants were encouraged to describe their experiences of being vaccine hesitant, with the interview questions providing a framework for discussions. The interviews were audio-recorded and transcribed verbatim. Participants adopted a pseudonym that was used throughout the interview and no identifying features were attached to the data.

Thematic analysis was employed using the framework of Braun and Clarke (2006). This form of analysis is flexible and suitable for the research question. It is a widely used method for identifying, classifying, and interpreting data. The analysis was supported by a computer assisted qualitative data analysis software (CAQDAS), NVivo (Version 12). Additionally, an inductive approach was chosen to code data without trying to fit the data into a preexisting pattern. This decision was made based on a strong desire to accurately reflect the intent of participants, as opposed to fitting it into a preexisting coding framework. Therefore, thematic analysis was driven by the data and attempted to faithfully reproduce the intentions of each participant in line with the analytical framework of Braun and Clarke (2006). Initial analyses were performed by the primary author (SS) and investigator triangulation took place between all authors (SS, NS, LL, and AD). All authors were actively involved in verification of the themes, and consensus was achieved in the development of themes and sub themes through regular meetings and ongoing discussions.

Results

Data were obtained from all female participants (n = 12), despite gender not being a requirement for this research. Eleven were parents of at least one child, one participant was pregnant with her first child, and two others were currently pregnant but had other children. All had stated that they were vaccine hesitant, with their children ranging from unimmunized to partially immunized. The study participants were all from Australia and ranged in age from 30 to 45 years (Table 1).

Three major themes were identified (Table 2).

Pushed to the fringe

The theme "Pushed to the fringe" included two sub-themes including "Isolated, ostracized, and labeled" as well as "Health-care professionals' role and the critical timing of immunization education. This theme emerged as one of the most significant concerns that vaccine hesitant parents expressed. Participants stated that they felt "Pushed to the fringe" by society, sometimes their friends and families, and by some health-care professionals. Participants also expressed feelings of being labeled and stated that the resulting social isolation had a devastating effect on their mental health and wellbeing.

People get labeled and demonized as anti-vaxxer, when really, there is no such thing. There are people who are scared, there are people that have questions but are shouted down and demonized. (Annie)

Participants (n = 8) reported avoiding immunization discussions and lied about their vaccine choices to retain the support they had in place. One participant stated "... because I'm sure you can appreciate how important the first months after having the baby is, and you need that network around you to keep you sane" (Emma). Whilst other participants (n = 5) lied about their immunization decision or avoided the discussion altogether. Participants (n = 6) also discussed the difficulties associated with social isolation. One participant (Rebecca) stated that" being ostracized is really difficult" and it " ... makes life really hard." Similarly, parents felt that the social isolation was not restricted to their peer support networks. Several participants (n = 4) suggested that their decision had also impacted their relationships with their parents and extended family, whilst another participant (Al) cited incidences of losing friendships and being "unfriended" on Facebook.

Parents also expressed feelings of being verbally attacked and incidences of name-calling, aggression and have been called a "threat to society." They also reported feeling marginalized politically and argued that the Australian government's "No Jab - No Pay" and "No Jab - No Play" legislation had exacerbated their feelings of social isolation within their own community.

This study identified that one of the impacts of being labeled as an "antivaxxer" was the effect this has on gaining information from a health-care professional. One participant (Maree) stated that being labeled had made communication with health-care professionals more difficult. Another participant (Arlene) expressed feelings of being bullied and judged by her doctor because of her antivaccination stance. As a result of the perceived "judgment" at her medical appointments, she stopped attending her general practitioner, thereby, placing both herself and her infant at risk.

Similarly, parents felt that the social isolation was not restricted to their peer support networks. Participants (n = 3) also discussed the feeling of being labeled, as well as experiencing a feeling of being bullied by health-care professionals. They believed that the information they were receiving from health-care professionals was inadequate to reach the threshold for informed consent. Some (n = 3) expressed concerns about personal rights and access to medical treatment, among other services. One participant (Arlene) stated that accessing a medical professional during the Global COVID-19 pandemic was becoming increasingly more difficult for the unimmunized. Sarah, on the other hand, felt that she was subject to bullying by medical professionals for giving her newborn infant a Hepatitis B immunization against her will. One participant stated:

- - - it actually was harder to get information second time round being labelled an 'anti-vaxxer.' II am not, I am trying to find valid, scientific information here. (Maree)

One participant (Arlene) explained it was like having to "go into battle." She also stated that the attitudes of some health-care professionals resulted in avoidance and expressed concerns that this was, "... putting children's lives at risks because mums that don't vaccinate don't want to go to the doctor because every time they do they are bullied and intimidated



and belittled." Whereas Emma stated that there is a lack of good-quality information, but also asked " ... why aren't I allowed to ask questions?." Emma was also critical of the knowledge of general practitioners by stating:

So, I think doctors don't get a lot of information about vaccinations, how vaccines work and how different vaccines may react to each other. They get a lot of information about the vaccine schedules and when babies and children should be vaccinated. But not necessarily actual information about production and reaction. (Emma)

These findings are consistent with those of Wiley et al. (2021) who reported incidences of being stigmatized due to vaccine hesitancy (Wiley et al., 2021).

Several participants (n = 3) lied about their child's vaccination status to avoid confrontation. The medical system was referred to as a "sickness industry." One participant (Emma) stated that there is a lack of good-quality information but also asked " ... why aren't I allowed to ask questions?." One participant (Annie) reported encountering general practitioners who refused to treat their unvaccinated child for unrelated medical issues:

In the circumstances where they've been refused treatment, it's directly impacted the wellbeing of the children. It makes you reluctant to go and see a GP or disclose fully. There have been incidences where we've said to people, "Oh yeah, they're fully vaccinated," because we're fearful of their response, which can potentially jeopardize their health. You have to be very aware though, if you're going to start lying because you're putting them at risk. (Arlene)

One participant reported a general practitioner's resistance to report an adverse reaction and general unwillingness to discuss the possibility that her sons Kawasaki disease may have been the result of a vaccine (Rebecca). Another participant (Sarah) reported a general reluctance among health-care practitioners to discuss any aspect of her vaccine hesitancy. Shan shared her experience as a health-care professional giving a vaccine to her child against her express wishes and without consent. These results expand on findings by Helps et al. (2019) which found that parents experience systematic stigmatization and experienced health-care professionals who were dismissive and unhelpful when faced with vaccine hesitancy.

Health-care professionals have a vital role to play in providing information, correcting misinformation often found on social media, and educating vaccine hesitant parents (Clark et al., 2022; National Health and Medical Research Council, 2013). Previous research has highlighted the important role of nurses and midwives in immunization education (Green et al., 2022). However, criticisms were made by some participants (n = 10) about health professionals knowledge levels and attitudes displayed to vaccine hesitant parents and pregnant women. Whilst some participants in this research reported positive and respectful relationships with their health-care professionals, others experienced the breakdown of the therapeutic relationship. One of the most prevalent criticisms of health-care professionals by (n = 8) participants in this study was their perceived reluctance to answer questions and address the concerns of vaccine hesitant parents. Annie stated that "I think when you roll up to the general practitioner, if you don't ask questions, you don't get any information." Several participants (n = 4) also believed that general practitioners were not very well educated or informed whilst another participant (Arlene) stated that her general practitioner had refused to treat her unvaccinated child for an unrelated medical issue.

This study has confirmed that many participants (n = 8 of 12) began investigating immunization during their pregnancy. Several participants (n = 5) expressed how difficult it was getting answers to their questions. Parents who did not make childhood vaccine decisions in pregnancy stated that they were confronted by the first vaccine on the Australian Immunization Schedule (Hepatitis B). This vaccine is given in the first week of a child's life (National Health and Medical Research Council, 2013). One participant stated that "... it just really didn't make sense to me anyway, that you would vaccinate a tiny baby against something that they are unlikely to catch" (Jessica), whilst another focused on how to keep her child healthy without vaccinating them (Rachel).

A culture of distrust

The theme "A culture of distrust" had two sub-themes, "Big pharma and vaccine safety concerns" as well as "Decision-making, beliefs, and influences." All participants involved in this research demonstrated varying degrees of distrust in the pharmaceutical industry and dissatisfaction with vaccines in general. Some expressed minimal concern about the risks associated with vaccine-preventable diseases whilst others saw disease as beneficial and "instructive to the body in ways we cannot fully understand" (Rebecca). However, distrust and anxiety were evident among the participants in this research. This distrust was multifactorial and included both a general distrust of the pharmaceutical industry and its perceived influence on health-care professionals. There was also evidence of anxiety and distrust in vaccine safety testing as well as the safety of vaccines in general, including misguided concerns about vaccine contents like aluminum, which is only present in Australian vaccines in small amounts or not at all. Misguided concerns were also raised about the potential for short- and long-term side effects including adverse reactions and long-term conditions such as autism and auto-immune conditions. Vaccine safety studies, including the lack of placebos conducted by the pharmaceutical industry prior to releasing new vaccines to the public were also brought into question. Several participants (n = 5)criticized the use of a control group containing another vaccine as opposed to a saline placebo. One participant (Shan) discussing the testing process stated:

- - I'm putting it out there, we actually don't know, and if the proper studies were done, the proper research, um, I acknowledge that I could be proven wrong. Like, maybe they are safe, but all of what I'm seeing, and investigating is they're not doing the proper studies and I'm fearful of cover-ups. (Shan)

Vaccine safety concerns were raised by most (n = 10 of 12) of the participants. Whilst some of these were based on misinformation and conspiracy theories. These concerns largely followed the risk associated with the disease versus the benefits of the vaccine debate. Concerns were expressed about the number of vaccines in the current Australian vaccine schedule, although this was based on inaccurate data whilst others were falsely concerned about long-term health implications and potential chronic health conditions like asthma, allergies, and autoimmune deficiencies resulting from childhood immunization. Jessica expressed her concern by stating:

My concern with vaccines in general is not the immediate adverse outcomes, it's all the insidious stuff, um, and we know that auto immune diseases and things like that have increased in lockstep, really, with our vaccination schedule and I think this is one of those things, you know, you can have the vaccine and you feel fine the next day and you feel fine even a month from now and maybe down the track, that you just don't know. (Jessica)

The decision to reject vaccines was a simple one for some participants and subject to ongoing review by others. Several participants (n = 4) constantly reassessed their decision to refuse vaccines. "So, it's not like we decided, you know, eighteen years ago, when the first kid was born, yep, that's it, we've made our decision and we're going to stand by it, no matter what changes in the future (Rebecca). Another participant stated that she was constantly "checking and rechecking" her choice (Jessica), whilst Shan expressed concern in vaccine testing:

Until there's new science to come out to show me that they are safe, and I'm talking like quality science, like independent studies, looking at vaccine safety with proper control groups, standardised control trials, I will continue to review the literature and I'll make my decision based on that. But in the near future, I don't think my stance on vaccines will change. (Shan)

Several participants (n = 5) discussed their experience of prior adverse events, which subsequently affected their vaccine decision-making. Arlene reported a personal adverse event connected to the Hepatitis B vaccine whilst Emma, Maree, and Rebecca discussed events connected to people close to them including siblings and children. Additionally, Arlene also discussed vaccine reactions such as fever and site pain, which she considered to be child abuse.

The influences and philosophies impacting vaccine decision-making included the number of vaccines and the predominance of multi-valent vaccines included on the current Australian schedule. Several participants (n = 5) stated that the prevalence of these types of vaccines, rather than single antigens, influenced their decision-making. They believed that if single antigen vaccines were an option in Australia, they may have chosen an alternative immunization path for their children. Annie was particularly concerned about the lack of single antigen vaccines, whilst Sarah believed that it was unnecessary to vaccinate against most diseases, which she mistakenly believed were either not in existence in Australia or mild and not an issue for her children.

One belief system that was adopted by many vaccine hesitant parents (n = 10) was the use of salutogenic parenting. This finding is consistent with results of previous studies, which found that labor-intensive parenting practices were often adopted by vaccine hesitant parents (P. R. Ward et al., 2017). Whilst salutogenic parenting often accompanied vaccine hesitancy, there was no evidence to suggest that the adoption of this parenting style influenced the decision to reject vaccines; rather, this practice seemed to accompany the lifestyle choice. Salutogenic parenting is a labor-intensive parenting style, which focuses on healthy food, fresh air, and low toxin lifestyle and long-term breastfeeding (Salutogenesis (n.d) In Merriam-Webster's Collegiate Dictionary, 1999).

Belief systems that accompanied vaccine decision-making included the apparent opposite approaches of the "wellness" and the "sickness" industry. Several participants (n = 5)believed in the benefits of preventative health. Arlene stated:

... and the fact that people can't even see that preventative health is just so important, um you know, obviously you are what you eat, and yet doctors will say, no, like that has no relevance and I just sit there, and my brain explodes. I go "really, how can that not be? (Arlene)

Additionally, the use of alternative therapies featured prominently in the health practices of most of the participants (n = 10 of 12). Those who did not use alternative therapies did so based largely on the prohibitive cost of these therapies. A large variety of alternative practices and allied therapies were in use in this population, including naturopathy, chiropractic, meditation, yoga, homeopathy, Chinese medicine, essential oils, kinesiology, remedial massage, and bio resonance. Diet and lifestyle factors were also present in the philosophies of most of the participants (n = 10). These ranged from healthy eating and/or organic food to vitamin supplements, sunshine, exercise, and long-term breastfeeding. Throughout this study, it became evident that the use of alternative therapies accompanied the decision to refuse vaccines and was complementary to their lifestyle choices when finances allowed. Jessica expanded on this by stating:

... I use complementary therapies myself and I find them helpful, but I don't use them with a mind for immunising in any way. It's just about those pillars of health really, for me. (Jessica)

Whilst most participants had rejected all vaccines, one participant (Annie) chose an alternative schedule and followed a plan from her naturopath on how best to support their child during immunization. She stated that she regularly visited her naturopath to "prepare her child for a vaccine and support her with supplements afterward, to avoid "damage or negative interactions."

Coerced choices

The third theme "Coerced choices" is made up of two sub-themes, "informed consent" and "legislative issues." Issues associated with informed consent, as well as access to medical treatment and the coercive nature of the No Jab - No Pay legislation were prevalent in this research. Concerns were also raised regarding the Australian Immunisation Schedule. Participants in this research, who had rejected immunization at the time of the interview, firmly believed that they were subject to bullying and coercion at a governmental level and rejected any form of "mandated" health practices. "I am definitely not in favor of any kind of mandated schedule, I believe that a coerced choice is not free choice" (Sarah). Persephone and Jessica agreed and stated:

I feel that I have been forced into a corner by the mandatory vaccine lobby, and that I have been forced into a corner that I don't fit into, but I am antivax, because I feel influenced by the mandatory vaccination lobby - and we effectively do have mandatory vaccination." (Persephone)

Several participants (n = 6) raised concerns about the perceived absence of informed consent, which is a legal requirement for immunization and other medical procedures (National Health and Medical Research Council, 2013). Annie expressed concerns about accepting medical procedures (immunization) with no possible support in the event of an adverse event, whilst another felt she was unable to give legal informed consent without access to sufficient information. Other participants (n = 3) felt that they were financially coerced into immunizing their children by the existing government legislation.

One participant (Persephone) stated that she had received forced medical treatment against her will as a child, resulting in a doctor and needle phobia as an adult. Maree was also concerned about informed consent and stated:

I spent a fair bit of time re-evaluating it when I had my next three children, um, just to see what had changed. I was actually really surprised in that the situation had gone backwards. It was harder to get information, and you were more stigmatised if you asked questions, so - - -(Maree).

Several participants (n = 5) expressed dissatisfaction in the No Jab – No Play legislation. In addition to the financial and legislative coercion, they believed that the legislation had an impact on the early learning of their children, as well as having a considerable financial impact on their family. The legislation was discussed by Sarah who stated "... they say it's a choice, but it's a coerced choice, in my opinion." Participants also reported feeling bullied, victimized and intimidated by the legislation, which was also referred to as "financial bribery." This finding is consistent with those of Helps et al. (2018) which found that the "No Jab – No Pay" legislation forced hardship in vaccine hesitant families.

One participant (Arlene) stated that as a result, she had rejected the entire system by homeschooling her children. The lack of an Australian vaccine injury compensation scheme was also raised. Several participants (n = 3) believed that existing legislation, combined with inadequate support in the event of an adverse reaction, had led them to refuse all vaccines.

Discussion

Participants in this research have revealed their experiences of life as a vaccine-hesitant parent. They expressed feelings of being labeled, isolated, ostracized, and pushed to the fringe of society. These findings are consistent with findings obtained in other studies, which have investigated vaccine-hesitant parents (Attwell et al., 2018; Rudolfsson & Karlsson, 2020; J. K. Ward et al., 2017; Wiley et al., 2021). Pregnancy and early parenting have been shown to be a time when support networks are vital for emotional and mental health (Mcleish & Redshaw, 2017). It is also a time when vaccine decision-making begins and a time when information should be provided by health-care professionals (Danchin et al., 2018; Smith et al., 2022b; J. K. Ward et al., 2017). This research has shown that some health-care professionals have contributed to feelings of marginalization through bullying, refusing care and an anecdotal reluctance to respond appropriately to vaccine-hesitant parents, which extends the findings of Helps et al. (2019). Given the polarizing nature of vaccine hesitancy, it is important that health-care professionals are aware of the impact this may have on social isolation, mental health, and the marginalization of some people, whilst bearing in mind the potential negative impact vaccine hesitancy can have on the health and wellbeing of children (Green et al., 2021). This research expands on evidence from other studies, which suggests that some health-care professionals lack the knowledge and ability to communicate with vaccine hesitant parents (Giambi et al., 2018; Smith et al., 2021). If the public health impacts on vaccine hesitancy are to be minimized, and child and outcomes prioritized, it is vital that health-care professionals receive appropriate education and develop an understanding of the factors that influence vaccine decision-making.

Vaccine-hesitant parents have also reported feeling marginalized by government policy. Whilst the legislation was designed to promote immunization compliance, participants in this study believed that this legislation placed financial, social, emotional, and legislative pressures on them, which supports and extends the findings of Beard et al. (2017). These findings also suggest that more research is required to address the impact of this legislation on the wellbeing of families who are vaccine hesitant as well as the educational impacts on preschool-aged children. Expand discussion here, i.e., promoting the health and development of children from vaccine hesitant families, whilst minimizing risks to heard immunity and other children/ community members.

This study identified that the choice to refuse vaccines was rarely taken lightly and was often accompanied by a sense of anxiety. Parents reported frequently revisiting their decision-making to ensure the decision was taken with their child's best interest in mind. However, despite this, factors such as the perceived lack of informed consent and legislative issues such as the No Jab – No Pay and the No Jab – No Play legislation negatively impacted their decision-making. These findings confirm and extend contemporary knowledge by delving deeper into the lived experiences of vaccine hesitant families (Helps et al., 2018). Factors, including the educational impact on preschool children, go beyond the financial and affect the family socially and emotionally, contributing to their feelings of being driven to the fringe of society.

A strength of this study was the use of in-depth semi-structured interviews, which produced rich data. The voices of vaccine hesitant parents are rarely heard in academic literature, and this study explored their experiences without bias. The use of social media as a recruiting point provided some advantages, including the ability to access geographically diverse participants. The small number of participants and the lack of fathers recruited was a limitation and may have introduced bias due to the all-female participants (Lechuga, 2012). Similarly, conducting this research during a global pandemic could be seen as a limitation and as a result, the findings of this research cannot be extended to a non-pandemic environment. Finally, qualitative research is not without bias; however, the researcher used reflexivity to critique their own assumptions and interpretations to enhance rigor.

Conclusion

This study has deepened the understanding of impacts of vaccine hesitancy on children and their families. It has shown that they feel pushed to the fringes of society, experience bullying and can be ostracized for their choices. This study has also revealed that a culture of distrust exists surrounding vaccine safety and the pharmaceutical industry. Additionally, the therapeutic relationship between parents and some health-care professionals was shown to influence vaccine decision-making and contribute to the culture of distrust. Participants expressed concern about the perceived absence of sufficient information to achieve informed consent. This was accompanied by the belief that health-care professionals lacked education and the ability to discuss vaccine issues objectively. Participants also reported difficulty obtaining care due to their vaccine hesitant label. Through improved immunization education of health-care professionals and an enhanced understanding of vaccine hesitancy, health-care professionals may be better able to respond to vaccine hesitancy, promote vaccines, and maintain therapeutic relationships with families who might otherwise be marginalized.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

The author(s) reported that there is no funding associated with the work featured in this article.



ORCID

Susan E. Smith RN, RM, PhD (b) http://orcid.org/0000-0002-4469-3959

References

- Arthurs, A. L., Jankovic-Karasoulos, T., & Roberts, C. T. (2021). COVID-19 in pregnancy: What we know from the first year of the pandemic. *Biochimica et Biophysica Acta Molecular Basis of Disease*, 1867(12), 166248–166248. https://doi.org/10.1016/j.bbadis.2021.166248
- 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. https://doi.org/10.3390/ijerph15051044
- Beard, F. H., Leask, J., & Mcintyre, P. B. (2017). No jab, no pay and vaccine refusal in Australia: The jury is out. *The Medical Journal of Australia*, 206(9), 381–383. https://doi.org/10.5694/mja16.00944
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. https://doi.org/10.1191/1478088706qp063oa
- Centers for Disease Control. 2022. *Vaccination Laws* [Online]. Retrieved 2023, from. https://www.cdc.gov/phlp/publications/topic/vaccinationlaws.html
- Clark, S. E., Bledsoe, M. C., & Harrison, C. J. (2022). The role of social media in promoting vaccine hesitancy. *Current Opinion in Pediatrics*, 34(2), 156–162. https://doi.org/10.1097/MOP. 000000000001111
- Clarke, R. M., Paterson, P., & Sirota, M. (2019). Determinants of satisfaction with information and additional information-seeking behaviour for the pertussis vaccination given during pregnancy. *Vaccine*, 37(20), 2712–2720. https://doi.org/10.1016/j.vaccine.2019.04.008
- Clarke, R. M., Sirota, M., & Paterson, P. (2019). Do previously held vaccine attitudes dictate the extent and influence of vaccine information-seeking behavior during pregnancy? *Human Vaccines & Immunotherapeutics*, 15(9), 2081–2089. https://doi.org/10.1080/21645515.2019.1638203
- Danchin, M. H., Costa-Pinto, J., Attwell, K., Willaby, H., Wiley, K., Hoq, M., Leask, J., Perrett, K. P., O'keefe, J., Giles, M. L., & 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. https://doi.org/10.1016/j.vaccine.2017.08. 003
- Dube, 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. https://doi.org/10.1080/14760584.2018. 1541406
- Fusch, P. I., & Ness, L. R. (2015). Are we there yet? Data saturation in qualitative research. *The Qualitative Report*, 20, 1408–1416. https://doi.org/10.46743/2160-3715/2015.2281
- Gencer, H., Özkan, S., Vardar, O., & Serçekuş, P. (2021). The effects of the COVID-19 pandemic on vaccine decisions in pregnant women. *Women and Birth: Journal of the Australian College of Midwives*, 35(3), 317–323. https://doi.org/10.1016/j.wombi.2021.05.003
- Giambi, C., Fabiani, M., D'ancona, F., Ferrara, L., Fiacchini, D., Gallo, T., Martinelli, D., Pascucci, M. G., Prato, R., Filia, A., Bella, A., Del Manso, M., Rizzo, C., & Rota, M. C. (2018). Parental vaccine hesitancy in Italy results from a national survey. *Vaccine*, *36*(6), 779–787. https://doi.org/10.1016/j.vaccine.2017.12.074
- 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. https://doi.org/10.1016/j.acap.2013.05.030
- Green, J., Petty, J., Whiting, L., Orr, F., Smart, L., Brown, A.-M., & Jones, L. (2022). 'Blurred boundaries': When nurses and midwives give anti-vaccination advice on Facebook. *Nursing Ethics*, 29(3), 552–568. https://doi.org/10.1177/09697330211041749



- Green, J., Petty, J., Whiting, L., Orr, F., Walker, K., Brown, A. M., Crisp, E. P., Fowler, C., & Jones, L. K. (2021). The impact of the anti-vaccination movement and vaccine hesitancy on the health of the child. *Pediatric Nursing*, 47, 216–243.
- 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. https://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. British Medical Journal Open, 9(5), e026299. https://doi.org/10.1136/bmjopen-2018-026299
- Kozinets, R. V. (2015). Netnography: Redefined. SAGE. https://doi.org/10.1002/9781118767771. wbiedcs067
- Lechuga, V. M. (2012). Exploring culture from a distance: The utility of telephone interviews in qualitative research. International Journal of Qualitative Studies in Education, 25(3), 251-268. https://doi.org/10.1080/09518398.2010.529853
- Mcleish, J., & Redshaw, M. (2017). Mothers' accounts of the impact on emotional wellbeing of organised peer support in pregnancy and early parenthood: A qualitative study. BMC Pregnancy and Childbirth, 17(1), 28-28. https://doi.org/10.1186/s12884-017-1220-0
- National Health and Medical Research Council. (2013). The Australian immunisation handbook. Commonwealth of Australia.
- Rudolfsson, G., & Karlsson, V. (2020). Interacting with parents in Sweden who hesitate or refrain from vaccinating their child. Journal of Child Health Care: For Professionals Working with Children in the Hospital and Community, 24(3), 432-443. https://doi.org/10.1177/1367493519867170
- 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. https://doi.org/10.1016/j.jiph.2019.07.027
- SA Health. (2019). Understanding vaccines and the National Immunization Program [Online]. https:// www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/clinical +resources/professional+development/immunisation+provider+training+and+education/under standing+vaccines+and+the+national+immunisation+program
- 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. https://doi.org/10.1177/0009922814548838
- Salutogenesis (n.d) in Merriam-Webster's Collegiate Dictionary. 1999. https://www.merriamwebster.com/dictionary/salutogenesis
- Smith, S. E., Gum, L., & Thornton, C. (2021). An exploration of midwives' role in the promotion and provision of antenatal influenza immunisation: A mixed methods inquiry. Women & Birth, 34(1), e7-e13. https://doi.org/10.1016/j.wombi.2020.04.009
- Smith, S. E., Sivertsen, N., Lines, L., & De Bellis, A. (2022a). Decision making in vaccine hesitant parents and pregnant women - an integrative review. International Journal of Nursing Studies Advances, 4, 100062. https://doi.org/10.1016/j.ijnsa.2022.100062
- Smith, S. E., Sivertsen, N., Lines, L., & De Bellis, A. (2022b). Weighing up the risks Vaccine decision-making in pregnancy and parenting. Women and Birth: Journal of the Australian College of Midwives, 35(6), 547-552. https://doi.org/10.1016/j.wombi.2022.02.007
- Smith, S. E., Sivertsen, N., Lines, L., & De Bellis, A. (2023). Vaccine hesitancy and cyberculture a study of the influences on parents and pregnant women [Unpublished manuscript].
- 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. https://doi.org/10.1016/j.vac cine.2019.08.081
- Tustin, J. L., Crowcroft, N. S., Gesink, D., Johnson, I., Keelan, J., & Lachapelle, B. (2017). Facebook recruitment of vaccine-hesitant Canadian parents: Cross-sectional study. JMIR Public Health and Surveillance, 3(3), e47. https://doi.org/10.2196/publichealth.6870
- Villar, J., Ariff, S., Gunier, R. B., Thiruvengadam, R., Rauch, S., Kholin, A., Roggero, P., Prefumo, F., Do Vale, M. S., Cardona-Perez, J. A., Maiz, N., Cetin, I., Savasi, V., Deruelle, P., Easter, S. R., Sichitiu, J., Soto Conti, C. P., Ernawati, E., & Papageorghiou, A. T. (2021). Maternal and neonatal



morbidity and mortality among pregnant women with and without COVID-19 Infection: The INTERCOVID multinational cohort study. JAMA Pediatrics, 175(8), 817-826. https://doi.org/10. 1001/jamapediatrics.2021.1050

Ward, J. K., Crépin, L., Bauquier, C., Vergelys, C., Bocquier, A., Verger, P., & Peretti-Watel, P. (2017). 'I don't know if I'm making the right decision': French mothers and HPV vaccination in a context of controversy. Health, Risk & Society, 19(1-2), 38-57. https://doi.org/10.1080/13698575.2017. 1299856

Ward, P. R., Attwell, K., Meyer, S. B., Rokkas, P., Leask, J., & Lee, A. (2017). Understanding the perceived logic of care by vaccine-hesitant and vaccine-refusing parents: A qualitative study in Australia. PLoS One, 12(10), e0185955. https://doi.org/10.1371/journal.pone.0185955

WHO. 2019. Ten threats to global Health [Online]. Retrieved May 29, 2020, from https://www.who. int/news-room/spotlight/ten-threats-to-global-health-in-2019

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, 100926-100926. https://doi.org/10.1016/j.ssmph.2021. 100926

Appendix Interview Questions

Gender: Male/Female Age in years:
Marital Status: Married/Single/Partner
Employment: Employed as/Unemployed/Home Duties
Currently pregnant: Yes No
Number of children and ages:
Number of Children not vaccinated:
Are any of your children vaccinated?
Number of children partially vaccinated.
Describe vaccination history for each child:
Postcode of home address:

OUESTIONS

- (1) Can we start by you telling me about your child/children/pregnancy?
- (2) Can you describe your personal beliefs about immunization?
- (3) Does the father/mother of your children have similar views? If not, what are their views?
- (4) Can you tell me when you began to think about immunization?
- (5) What was your main source of immunization information?
- (6) Did you discuss your choice with anyone else, e.g., family, friends, partner? And what sort of reaction did you get and from whom?
- (7) How did you feel about the information given? Were all your questions answered?
- (8) What if you have any unanswered questions?
- (9) What was important to you in making this choice not to vaccinate your child or children?
- (10) Can you tell me which childhood vaccines concern you the most? Why?
- (11) What was helpful and what was not helpful for you in making the decision not to vaccinate your child?
- (12) Can you tell me which childhood vaccines concern you the most? Why?
- (13) How do you feel about that decision and is it likely to change in the future?
- (14) If your child or children are partially vaccinated, what was the reason for this?
- (15) What are your thoughts on complementary therapies such as naturopathy, chiropractic, natural medicines, and/or herbs as far as immunization is concerned?
- (16) What are your thoughts about COVID-19 and any vaccinations that may become available for your children?

- (17) Do you have any other comments you would like to make?
- (18) Would you like a transcript of this interview sent to you? If so, can you give me your e-mail address (recognizing that this is not a secure medium) or home address.

Thank you for your time. Here is your voucher/your voucher that will be sent to you by e-mail or post.

Extra Questions

Can you give me more details? Could you describe that more? Can you give me an example? When, where, how, why, and what?