

Parents' experiences and nurses' perceptions of  
decision making about childhood immunization

by

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## **Abstract**

The uptake of immunization against infectious childhood diseases such as mumps, measles, rubella, diphtheria, tetanus, and pertussis has resulted in positive global health outcomes. The estimated vaccine coverage for these diseases, however, falls below targets recently set by the World Health Organization. The reviewed literature demonstrated that parents have an active role in making decisions about their children's immunization status informed by contextual, individual, and vaccine-specific influences. Few studies addressed nurses' involvement in parental immunization decisions. No qualitative studies could be found that explored Canadian parents' and nurses' perspectives into this complex, contextually-bound phenomenon. The aim of this qualitative study is to understand parents' and nurses' experiences of decision making about childhood immunization, specifically measles-mumps-rubella and/or diphtheria-tetanus-acellular pertussis.

Thorne's interpretative description approach was used to facilitate parents' and nurses' sharing of their experiences and perspectives about childhood immunization to capture the relevancy for nursing practice. Results demonstrate that protection was the unifying goal across all parents and nurses. Motivated by protection of their child, parents searched for information about immunization, deliberated the information and sources to determine the relative benefits and risks of immunization, and assumed responsibility for their decision to accept, delay or decline immunization, and accepted responsibility for the consequences of their decision. Nurses described their role as protectors of child safety and population health. Findings of this study suggested that a tension that exists between nurses' professional obligation to protect the public against vaccine preventable diseases, promote immunization update, yet, respect individual parental choice. Parents desired encounters with health care providers that were open to acknowledging and addressing their concerns in order to protect the health of their child. Future

nursing approaches recommended by this study included nurse-led education sessions within a community environment, nurse-led forums that outreach to the public regarding fears and concerns about childhood immunizations, connecting with parents in the community could facilitate better access and improved engagement with health team members, forming partnerships with existing groups, and adding health literacy to the education curriculum could positively impact individual and community health.

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## **Chapter 1**

### **Introduction**

In the past century, the development and promotion of vaccinations against infectious childhood diseases such as mumps, measles, rubella, diphtheria, and pertussis has resulted in global declines in disability and death. Organizations such as the World Health Organization (WHO), the European Centre for Disease Prevention and Control, and the Centers for Disease Control and Prevention express concern regarding population health, particularly in regions where immunization uptake is limited. At the World Health Assembly in 2012, Canada was one of 194 participant states that contributed to and endorsed the Global Vaccine Action Plan: 2011-2020 (WHO, 2013). This global plan endeavours to improve health by extending the benefits of immunization to all people, regardless of their place of birth or residence. By 2020, the stated vaccination target is 90% national and 80% regional coverage.

The most recent National Immunization Coverage Survey, conducted in 2013, estimates vaccination coverage for Canadian two-year olds as follows: 77% for tetanus; 77.4% for diphtheria; 77% for pertussis; 89.6% for measles; 89.2% for mumps; and 89.2% for rubella (Public Health Agency of Canada, 2016a). The estimates for national vaccination coverage are lower for each of the identified diseases among seven-year olds (Public Health Agency of Canada, 2016a). This survey includes regional Ontario-specific data, which like the national vaccination estimates, fall short of the WHO vaccination targets for tetanus, diphtheria, and pertussis among two-year olds. The estimates for vaccine coverage for the same population against measles, mumps, and rubella exceed the WHO vaccination target. The Canadian national target for measles, mumps, and rubella coverage at two-years of age is 97% (Public Health Agency of Canada, 2016a), which was not met in Ontario.

In Canada, the National Advisory Committee on Immunization (NACI) provides the Public Health Agency of Canada with recommendations based on scientific evidence regarding the use of vaccines that are current or newly authorized for use among groups at risk for vaccine-preventable disease (Ismail et al., 2010). NACI recommendations are included in the Canadian Immunization Guide, which includes information about vaccines, vaccine safety and recommended immunization schedules (Public Health Agency of Canada, 2016b). The funding and delivery of immunization programs fall within the jurisdiction of each Canadian province and territory, thus resulting in variability. Regional scheduling of vaccines is reviewed and updated regularly in collaboration with the Canadian Nursing Coalition for Immunization and the Canadian Immunization Committee (Public Health Agency of Canada, 2016b).

Canadian health professionals responsible for childhood immunization are guided by the Canadian Immunization Competencies for Health Professionals (Public Health Agency of Canada, 2008). The competencies encompass scientific knowledge, immunization practices, and awareness of issues relevant to immunization. MacDonald, McIntyre, and Barry (2014) recognize that the complexity of immunizing children requires health professionals to understand global contexts, local programs, and scientific evidence. The immunization competencies emphasized by these authors include communication with parents, safe administration of vaccines and documentation of immunization. An indicator of competence in these areas is success in achieving the priority of immunization uptake.

To address the community health threat of vaccine-preventable diseases (VPD), the Day Nurseries Act and the Immunization of School Pupils Act were established to ensure universal immunization of children in Ontario (Government of Ontario, 1990a, 1990b). Not only are children protected against VPDs resulting from these acts, but as fewer transmissions occur in a

community, there is less infiltration of the virus, which protects the community including individuals who do not obtain vaccines for various reasons (Malone & Hinman, 2009; Powell et al., 2016). Within the Canadian and provincial contexts, it is important to note that immunization is recommended, not mandated. Parents, therefore, have discretionary decision making power regarding their child's immunization status. They may decide to accept, delay or decline recommended immunizations for their children. Those who elect to delay or decline immunization, may have the option to submit documentation and follow protocols that allow immunization exemption and social inclusion in institutions such as licenced day cares and the school system. Larson and colleagues (2014) found that parental decisions to delay or decline immunization are contextually-based and may vary with time, location, and individual vaccines.

With successful vaccination programs, current generations of parents may have limited exposure to the negative impact of VPDs on individuals and communities. For example, Casey and colleagues (2016) report that the incidence of measles, diphtheria, and tetanus have decreased globally since routine immunization has been made available. As the perceived threat of debilitating and life-threatening VPDs decrease, there is a trend for discussions to shift from the threat of disease to the adverse effects of the vaccines themselves (Corben & Leask, 2016). In this virtual era, with almost every household having access to the internet and social media, there are more platforms for discussion and debate about the risks associated with childhood immunization. Concerns include adverse reactions ranging from mild symptoms, such as fever and malaise, to anaphylaxis and chronic debility (Blendell & Fehr, 2012; WHO, 2014). In addition, past negative immunization experiences can be readily shared with others and influence future under-utilization of immunization (Stockwell, Irigoyen, Martinez, & Findley, 2011). Healthcare providers may better understand parental immunization beliefs and decisions through

awareness of past personal immunization experiences and access to information shared by others (Powell et al., 2016).

Safety concerns about the contents of vaccines and perceived associations with autism and learning disabilities have generated dissonance between parents and healthcare providers who espouse scientific evidence that contradicts that which is shared within a colloquial arena (Brunson, 2013; Hobson-West, 2007; Seethaler, 2016). Other influencing factors that impact decision making with regards to immunization may also include information endorsed by well-respected community members and celebrities (Freed, Clark, Butchart, Singer, & Davis, 2011). A recent study reports that parents who seek health care from practitioners who advocate for complementary and alternative medicine are more likely to decline immunizations (Corben & Leask, 2016).

Astbury, Shepherd, and Cheyne (2017) explored decision making regarding immunization within the context of healthcare provider-parent partnerships. They report that parents made decisions through multiple consultations beyond their healthcare provider. Gesser-Edelsburg, Walter, Shir-Raz, Sassoni, and Rosenblat (2017) report that substantive intra-family discourse can happen behind the scenes. This discourse has the potential to influence immunization decision making. More specifically, parents who were hesitant about vaccinations were four times more likely to involve family in their deliberations as opposed to parents who were accepting of immunization for their children.

Noone (2002) authored a concept analysis on client decision making based on a decade of published evidence. This author concludes that the four key defining attributes of decision making are: an intentional choice between options; recognition of a stimulus for action; commitment to a path of action; and expectation to accomplish a specific goal(s). The five

antecedents for decision making include: a stimulus for action; evaluation of the stimulus and appraisal of risk; awareness of choice and available options; gathering of information; and, evaluating alternatives, risks, and benefits based on contextual factors. The consequences include acceptance of one's decision and reappraisal of the choice. Though this facilitates a lens through which to consider decision making, it does not delve into the emotive component that may be involved when parents are making decisions for their children's health.

Emotion has been reported to have an impact on decision making. Halpern (2012), for example, found that personal beliefs and catastrophic thinking can impede informed decision making. Sax (2017) recently addressed the public's decision making in the realm of biotechnology, such as vaccines. This author emphasizes that ambiguity theory impacts the confidence of the decision maker in terms of the anticipated outcome of their health decision. Further, Sax identifies that affect theory describes how emotions can have an impact on the direction of a decision. Discussions about vaccines, for example, may elicit emotive responses that affect some individuals more than others, thus influencing the risk perceptions association with immunization.

Other researchers address parental decision making about health issues beyond childhood immunization such cancer treatment and acceptance of Human Papillomavirus immunization (Stewart, Pyke-Grimm, & Kelly, 2012; Todorova, Alexandrova-Karamanova, Panayotova, Dimitrova, & Kotzeva, 2014). Common features of parental decision making in this body of evidence are uncertainty, difficulty in rendering a decision, consideration of health risks, and overall anticipated well-being. Although there is some literature that specifically addresses the complexity of parental decision making about immunization, the emphasis is on the promotion of population health through strategies to enhance immunization uptake (Corben & Leask, 2016).

## **Purpose**

The reviewed evidence demonstrates that parents make decisions about their children's immunization status informed by multiple influences. Nurses may have an opportunity within the clinical environment to interact with parents as they deliberate their decision regarding immunization. As such, they are in a privileged position to bear witness to patterns and variations in parental decision making experiences, beliefs, attitudes, and opinions. No qualitative studies could be found that explored Canadian parents' and nurses' perspectives into this complex, contextually-bound phenomenon. Thus, the purpose of this qualitative study is to understand parents' and nurses' experiences of decision making about childhood immunization, specifically measles-mumps-rubella (MMR) and/or diphtheria-tetanus-acellular pertussis (Tdap).

The two core research questions posed in response to the stated purpose are:

1. What are the particular features inherent in decision making about childhood immunizations as experienced by parents?
2. How do nurses characterize their perceptions of parental decision making about childhood immunization?

## **Introduction to the Researcher**

In the search for an appropriate research focus, I was drawn to immunization in the wake of some measles outbreaks that were becoming more frequent. I was sent a link to a video by a colleague who thought it would be interesting to watch. Initially, I enjoyed the video. When it stopped, so did I. It was a video that supported my personal thinking as a parent, even as a nurse, since I used to administer immunizations in my previous position as public health nurse. After a moment, however, the video did not sit right with me. Ethically, a dilemma arose, not in my actions, but in recognizing my initial response to the video. In the past, what if someone had sat

with me who did not agree with the immunization message? What if they had other knowledge or experience, or even unexpressed fears? In retrospect, I may not have facilitated a very safe environment where further discussion about immunizations could occur. This is not who I am as person. This is not who I am as a nurse.

I value each person equally, and recognize that everyone has their own experiences and their own path, complete with varying strengths and challenges during this complex and dynamic lifetime we are given. I was confident in my knowledge regarding the benefits of immunization and shared this information enthusiastically. I realize, however, that I did not put much thought or consideration into parent experiences of decision making when I discussed immunization. This was partially biased by my past positive experiences, personal immunization status as a child, my role as a parent who accepted childhood immunization, and my professional knowledge. Perhaps I limited parents' willingness to express their unanswered questions, especially if in relation to concerns about the recommended vaccines.

Reflecting on previous discussions I had with other nurses during immunization seasons, it dawned on me that the pattern of discussions were in line with the benefits of immunization, the scientific facts, and our role in promoting immunization uptake. I realized that the approaches and philosophy demonstrated consistently were very beneficial to parents in favour of immunization. I recognized that any parents outside of that group were not well supported. I did not have information for them. I did not have a protocol to support them in their decision. If I were to encounter a parent questioning immunization, I would initiate strategies, such as education, to change their minds and accept immunization in compliance with local public health policy. I now acknowledge that service provision to parents hesitant to vaccinate their children may be different if informed by evidence.

In my current role as an educator, I realize that my previous approach and the role I had assumed during that time, was not congruent with my ethics and awareness of the value I placed on individuals and their rights as an autonomous decision-maker for their children. My motivation for selecting immunization as a research topic was set. I wanted to embark on an exploration of what is experienced from the position of parent and other nurses, in order to better understand particular experiences while making immunization decisions. Being an empathic practitioner, my goal is to develop an understanding of various parental experiences for professional development and to guide future clinicians as they promote efficacious clinical encounters with parents regarding childhood immunization.



## **Chapter 2 Literature Review**

### **Introduction**

The purpose of this chapter is to describe the qualitatively derived empirical knowledge about parental decision making regarding childhood vaccinations. This chapter begins with an overview of the process undertaken to gather relevant reports. The individual study purposes, designs, and methods are presented in both tabular and narrative form to represent the heterogeneity of this body of evidence. This is followed by a descriptive summary of study findings addressing parents' experiences with decision making about childhood immunization. This chapter concludes with recent theoretical representations of parental decision making for early childhood vaccinations.

### **Selected Qualitative Studies**

An electronic search was completed in the following databases: Cumulative Index to Nursing and Allied Health Literature; ProQuest Nursing and Allied Health; and PubMed. The search parameters were: peer-reviewed reports, available electronically; and full-text reports, published in English. Initially, all articles that focused on immunization were accepted for review. It soon became apparent that there were distinct groups of reports relative to types of immunization and population groups. Guided by this study's purpose, it was decided that a focus on qualitative literature that specifically address childhood MMR and Tdap immunization was most suitable. Literature that focuses on other immunizations, such as Human Papillomavirus, were not reviewed due to the population focus on teens; and these are more specifically gender-related, which differ greatly from childhood immunizations and the varied challenges surrounding immunization of young children.

In consultation with an academic librarian, refined search terms, including: parents, child immunization, vaccination, decision making, confidence, vaccine refusal, vaccine delay, concern, perception, and attitude, were used in varied combinations to locate published reports in the selected databases. These narrowed search parameters yielded nearly 200 potentially appropriate empirical articles once duplicates were removed. All titles and abstracts were read, with a removal of those reports deemed not relevant to the purpose of this study. Articles were excluded from this review for the following reasons. First, the type of immunization was not specific to MMR or Tdap. Second, parental decision making about immunization was not the focus of the study. Third, the purpose of the article emphasized immunization as a healthcare intervention. Finally, the immunization protocol or policy of the study's location markedly differed from that within a Canadian context.

Table 1 outlines features of the reviewed primary studies published during the past two decades. The majority of these studies originated from the United Kingdom. No Canadian literature, meeting the search criteria, was located. The stated purposes were mostly exploratory descriptive in nature with an emphasis on parental decision making about childhood vaccination, seven of which explicitly identified MMR in their study aims.

Across the studies, the researchers took unique approaches to achieve their aims. Some authors investigated elements and contexts that influence decision making exclusively for parents who accepted immunization for their children (Hill & Cox, 2013; Johnson & Capdevila, 2014; McMurray et al., 2004; Tickner, Leman & Woodcock, 2009; Wang, Baras & Bittenheim, 2015). Other researchers focused solely on the decision making of parents who delayed or declined immunization for their child (Blaisdell, Gutheil, Hootsmans & Han, 2016; Fadda, Galimberti, Carraro, & Schulz, 2016; Smartt Gullion & Gullion, 2008; Harmsen et al., 2013;

Luthy, Beckstrand, Callister & Cahoon, 2012; Whyte, Whyte, Cormier & Eccles, 2011). Nine additional studies, included or compared decision making for parents who accepted childhood immunization and parents who delayed or declined immunization (Austin, Camplon-Smith, Thomas & Ward, 2008; Benin, Wisler-Scher, Colson, Shapiro & Holmboe, 2006; Bond, Nolan, Pattison & Carlin, 1998; Brown et al., 2012; Byström, Lindstrand, Likhite, Butler & Emmelin, 2014; Brunson, 2013; Downs, Bruine de Bruin & Fischhoff, 2008; Poltorak, Leach, Fairhead & Cassell, 2005; Saada, Lieu, Morain, Zikmund-Fisher & Wittenberg, 2015). A smaller group of researchers examined the topic of parental decision making from the perspective of healthcare providers (Austvoll-Dahlgren & Helseth, 2010; Berry, Henry, Danchin, Trevena, Willaby & Leask, 2017; McMurray et al., 2004).

In nearly three-quarters of the papers ( $n = 17$ ) a research design was not identified. Some authors, however, did identify the use of a specific design. These included grounded theory ( $n = 3$ ), descriptive ( $n = 2$ ), and ethnography ( $n = 1$ ). Across the studies, there were similarities and variances in the manner in which researchers referred to their samples, which ranged in size from five to 287 participants. Parents who immunized according to the recommended schedule were variably described as: parents who reported following the nationally recommended vaccines (Saada, Lieu, Morain, Zikmund-Fisher & Wittenberg, 2015); parents of children who had received the MMR (Hill & Cox, 2013); MMR acceptors (Brown et al., 2012); mothers of children who had completed the primary immunization course (Tickner, Leman & Woodcock, 2009); parents of completely immunized children (Austin, Camplon-Smith, Thomas & Ward, 2008); parents who were favourable to vaccines (Downs, Bruine de Bruin, & Fischhoff, 2008); vaccinators who agreed and were acceptors or vaccine-hesitant (Benin, Wisler-Scher, Colson, Shapiro & Holmboe, 2006); parents who claimed their children to be fully vaccinated for their

age (Leask, Chapman, Hawe & Burgess, 2006). Parents were distinguished based on various preferences of the MMR vaccine, such as MMR all children, MMR all children, but delayed, one child but not all (Poltorak, Leach, Fairhead & Cassell, 2005); parents who agreed to vaccinate (McMurray et al., 2004); and complete immunizers (Bond, Nolan, Pattison & Carlin, 1998).

Alternately, parents who declined immunization for their children were described by the researchers as: vaccine objecting or non-vaccinating parents; MMR rejecters (Brown et al., 2012); parents who exempt vaccinations (Luthy, Beckstrand, Callister & Cahoon, 2012); parents who had chosen to refrain from involving at least one of their children in the standardized immunization regime (Whyte, Whyte, Cormier & Eccles, 2011); non-vaccinators who rejected immunizations (Benin, Wisler-Scher, Colson, Shapiro & Holmboe, 2006); no MMR nor DTP or other vaccines for all children (Poltorak, Leach, Fairhead & Cassell, 2005); parents to declined vaccination (McMurray et al., 2004).

In addition, there were parents who were described alternatively from accepting or declining immunization, such as: vaccine-hesitant parents (Blaisdell, Gutheil, Hootsmans & Han, 2016); parents who reported following an alternative vaccination schedule (Saada et al., 2015); parents who partially vaccinate their children (Harmsen et al., 2013); parents of incompletely immunized children (Austin, Champion-smith, Thomas & Ward, 2008); late-vaccinators who purposely delayed immunization (Benin, Wisler-Scher, Colson, Shapiro & Holmboe, 2006); reluctant vaccinators (McMurray et al., 2004); and incomplete immunizers (Bond, Nolan, Pattison & Carlin, 1998). A common data collection approach, with the exception of two studies which used questionnaires, was interviewing. Individual and focus group interviews occurred either face-to-face or were technologically mediated. A modified grounded theory approach to data analysis was used in almost 40% of the studies (n = 9).

Table 1

*Primary Qualitative Studies (n=23) examining decision making about childhood immunization*

Primary author (Publication year), Location	Purpose/Aim	Methods			
		Study design	Sample	Data collection	Analysis
Berry (2017), Australia	Understand health care providers' perspectives of challenges and strategies used when encountering parents who decline some or all childhood vaccinations	Not specified	General practitioners, community nurses, practice nurses (N = 26)	Audio-recorded in-depth interviews	Grounded theory
Blaisdell (2016), USA	Explore vaccine hesitant parents thought processes and perceived risks about vaccination and non-vaccination	Not specified	Parents (N = 42) of children ages < 8 years	Eight audio-recorded focus groups	Constant comparative method
Fadda (2016), Italy	Explore parents' perspectives on empowerment when MMR vaccination decision was pending	Not specified	Mothers (n=24)  Fathers (n=4)	Two audio-recorded focus groups	Inductive thematic analysis; themes compared to a conceptualization of psychological empowerment
Saada (2015), USA	Describe parents' rationale and motivations underlying chosen alternative vaccination schedules	Not specified	Parents (N = 24) of children aged 12 to 36 months	Audio-recorded, semi-structured telephone interviews	Inductive thematic analysis
Wang (2015), USA	Examine attitudes and beliefs of parents who are pro-vaccine	Not specified	Parent (N = 23) of young children	Semi-structured interviews	Modified grounded theory approach

Byström (2014), Sweden	Explore parents attitudes and decision making about MMR vaccination in an anthroposophic community	Not specified	Parents deciding on MMR vaccination (N = 20)	Digitally recorded semi-structured interviews	Content analysis
Johnson (2014), UK	Explore the ways in which mothers process advice and information about MMR and vaccinations from professional and non-professional sources	Not specified	Mothers (N = 5) of preschool children aged 12 to 18 months	Audio-recorded focus group	Thematic analysis
Brunson (2013), USA	Understand parental decision making about their children's vaccinations	Grounded theory	Mothers (n=15) of children aged ≤18 months  Couples (n=3) of children aged ≤18 months	Audio-recorded interviews	Inductive analysis
Harmsen (2013), Nether-lands	Explore factors regarding parental refusal of childhood vaccinations	Not specified	Parents who completely refused immunization (n = 39) of children aged < 4 years  Parents who partially refused immunization (n = 21) of children aged < 4 years	Eight online, semi-structured focus groups	Thematic analysis
Hill (2013), UK	Explore factors influencing parental decision making regarding childhood MMR vaccination	Pilot, modified grounded theory	Parents whose children had received MMR vaccination (N = 5)	Digitally recorded, semi-structured interviews	Thematic analysis

Brown (2012), UK	Understand factors underlying parents' decision making about the first dose of MMR	Not specified	Parents considering acceptance, postponement or decline of first MMR dose (N = 24) of their children aged 11–36 months	Audio recorded, semi-structured interviews	Modified grounded theory approach
Luthy (2012), USA	Describe parents' rationale and personal beliefs when exempting their children from receiving vaccinations.	Descriptive design	Parents (N = 287) who exempted their children from receiving at least one vaccination (n=287)	Narrative data elicited using Utah State parent-tested questionnaire	Thematic analysis of open-texted items
Whyte (2011), USA	Identify experiences of factors influencing parental decision to refrain from immunizing their children according to a standardized regimen	Descriptive design	Parents (N = 143)	Narrative data elicited using open-ended questionnaire	Content analysis
Austvoll-Dahlgren (2010), Norway	Identify parents' decision making processes about childhood vaccinations	Grounded theory	Public health nurses (n=16)  Parents who immunized their children (n=10)	Three semi-structured interviews with parents  Three focus groups	Constant comparative analysis
Tickner (2009), UK	Identify reasons for low uptake of pre-school immunizations	Not specified	Parents (N = 21) of children aged 2 to 5 years	Audio-recorded semi-structured interviews	Modified grounded theory approach
Austin (2008), UK	Understand parental decision making about childhood immunizations	Not specified	Parents (n = 15) of immunized children  Parents (n = 10) of incompletely immunized children	Four audio-recorded focus groups	Cresswell's spiral analysis

Downs (2008), USA	Identify parents' beliefs about vaccinations and understand parental response to new information	Not specified	Parents (N = 30) of children aged 18 to 23 months	Semi-structured telephone interviews	Content analysis
Smartt Gullion (2008), USA	Explore attitudes, beliefs, and information processing of parents who choose not to vaccinate their children	Not specified	Parents (N = 25) who have decided to forgo or delay childhood vaccination	Audio-recorded, in-depth, semi-structured interviews	Thematic analysis
Benin (2006), USA	Explore mothers' decision-making about vaccinations for infants	Not specified	Postpartum mothers (N = 33) with infants	Initial face-to-face open-ended interview followed by telephone interviews when child was aged 3 and 6 months	Grounded theory approach
Leask (2006), Australia	Explore how parents respond to competing media messages about vaccine safety	Not specified	Mothers (N = 37) of infants	Six tape-recorded focus groups  Individual follow-up telephone interviews	Thematic analysis
Poltorak (2005), UK	Examine parents' personal experiences and thinking about MMR vaccination for their own children	Ethnography	Mothers (N = 23) who attend parent-toddler groups	Participant observations  23 in-depth narrative interviews	Thematic analysis
McMurray (2004), UK	Explore parents' accounts of decision making relating to the MMR vaccine	Not specified	Parents (n = 69) of children aged between 4 and 5 years  Primary care practitioners, managers and immunization coordinators (n=12)	Semi-structured interviews	Continuous comparison



<p>Bond (1998), Australia</p>	<p>Explore mothers' health beliefs and decisions about vaccine-preventable diseases and associated childhood immunizations</p>	<p>Not specified</p>	<p>Mothers (N = 16) of children aged 3 to 30 months with complete immunization  Mothers (N = 7) of children aged 3 to 30 months with partial immunization  Mothers (N = 12) of children aged 3 to 30 months with incomplete immunization  Mothers (N = 10) of children aged 3 to 30 months with no immunization</p>	<p>Semi-structured interviews</p>	<p>Thematic analysis</p>
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Table 2

*Systematic Reviews (n=3) examining decision making about childhood immunization*

Primary author (Year)	Primary purpose	Design	Number of included studies	Key meta-findings
Corbin (2016)	Identify a spectrum of parent attitudes of childhood vaccination with estimates of the proportion of each group based on populations. Development of a framework related to each parental position with determination of key indicators, goals and strategies based on communication science, motivational interviewing and valid consent principles.	Literature review and development of a framework	12	Five distinct parental groups were identified: the 'unquestioning acceptor' (30–40%), the 'cautious acceptor' (25–35%); the 'hesitant' (20–30%); the 'late or selective vaccinator' (2–27%); and the 'refuser' of all vaccines (<2%). The goals of the encounter with each group will vary, depending on the parents' readiness to vaccinate. In all encounters, health professionals should build rapport, accept questions and concerns, and facilitate valid consent. For the hesitant, late or selective vaccinators, or refusers, strategies should include use of a guiding style and eliciting the parent's own motivations to vaccinate while, avoiding excessive persuasion and adversarial debates. It may be necessary to book another appointment or offer attendance at a specialised adverse events clinic. Good information resources should also be used.
Allan (2015)	Identify and evaluate research on the subject, with a view to present the reasons behind, and influences on parental decision making in relation to MMR.	Systematic review of qualitative studies with thematic analysis	14	Themes identified were categorized as follows: perceptions of risk; roles and responsibility; experience and knowledge. There were limited changes in parental decision making factors over the time period despite an increase in uptake. Many studies fail to differentiate between accepters and rejecters, making it difficult to draw out clear conclusions.
Forster (2015)	Understand the factors influencing parental decisions to vaccinate a child.	Systematic review of qualitative studies with thematic analysis	38	Two types of decision making had been adopted: non-deliberative and deliberative. With non-deliberative decisions parents felt they had no choice to make since they were happy to comply and/or relied on social norms. Deliberative decisions involved weighing up the risks and benefits, considering others' advice/experiences and social judgement. Emotions affected deliberative decision making. Trust in information and vaccine stakeholders was integral to all decision making. Practical issues affected those who intended to vaccinate.

Despite the variability in the study aims and methods, the findings of the reviewed studies indicate that there are multiple influences that can be involved in parental decision making regarding childhood vaccination. To organize the collective findings, the influences are grouped as follows: contextual, individual, and vaccine-specific influences. Although the presentation of the reported decisional influences is organized in these three groups, the groups are not mutually exclusive.

### **Contextual Influences**

Within the reviewed literature, contextual influences included media messages and socio-political culture. Each of these will be addressed separately.

#### **Media messages**

Leask and colleagues (2006) used television vignettes to explore mothers' response to competing messages about vaccinations. Most mothers had a positive attitude toward immunization and expressed fear of disease. These parents perceived that vaccination provides a "blanket of protection" against measles and pertussis. Other parents were skeptical about the vaccination information presented by authorities, such as the government, as they are "telling you what they WANT you to know." Faced with both pro- and anti-vaccination messages, parents described using a risk/benefit analysis approach to make their decision about immunization. For most, factual rather than emotive messages had the greatest impact on their decision. In addition, parents reported that doing something about their perceived risks was better than doing nothing at all.

#### **Socio-political culture**

Several studies described parents' perception of their social obligation to immunize their children in accordance with recommended schedules. Their choice to

immunize their child was considered as contributing to the greater societal good in protection of others (Bond, Nolan, Pattison & Carlin, 1998; Benin, Wisler-Scher, Colson, Shapiro & Holmboe, 2010; Brunson, 2013; Saada et al., 2015; Tickner, Leman & Woodcock, 2009).

Byström and colleagues (2014) examined the decision making regarding MMR of 20 parents living in an anthroposophic community in Europe. A defining characteristic of the community was low vaccine uptake rates. The researchers report that a cultural orientation towards natural immunity existed within the mixed sample of parents who accepted, declined or delayed immunization. Those who postponed or refused childhood immunization were aligned with this orientation. Disease risk was perceived as minimal, and if contracted, could be treated with home remedies.

Johnson and Capdevila (2014) explored five mothers' engagement with others to make sense of advice and information about immunization for their children under 24 months of age. Amid multiple sources of professional and non-professional advice, mothers described the context of decision making about immunization. According to the mothers, compliance with immunization was constructed as a societal expectation, and simply part of having a child. "It's one of the things you're just expected to do isn't it?" (p. 871).

Austvoll-Dahlgren and Helseth's (2010) study exploring decision making processes identified the parents' right to choose which was emphasized by healthcare providers. They experienced, however, that the health system had a powerful voice about what was "the right choice to make." Parents in this study were challenged to balance their right to decide with what is officially communicated as the best decision to make as

determined by the health system. Some parents expressed concern that if they decided to delay or decline immunization, there would be negative social consequences for themselves and their children. Similarly Brown and colleagues (2012) reported that parents who chose to delay or decline immunization experienced negative judgment regarding their parenting, morals and even intellect (Brown et al., 2012).

### **Individual influences**

Individual influences were most often reported in the reviewed literature. These will be presented as follows: parents' experiences with past vaccination, their trust in healthcare professionals and health system, their awareness of information about vaccines, and their attitudes and beliefs about immunization.

#### **Past experiences with vaccination**

Several authors have reported previous experiences with vaccination as an influence in parental decision making regarding childhood immunization. Tickner and colleagues (2009) aimed to identify possible reasons for uptake of pre-school immunization among a group of 19 families. They report that parents' past positive personal or vicarious experience, through family and friends, dissipated their worry about second vaccinations and; they were more likely to proceed with further vaccinations. A similar finding was reported subsequently in Benin and colleagues' (2009) investigation of parental decision making about vaccinations for infants with 23 mothers, of whom 76 % chose vaccination. In contrast, past negative personal experiences associated with vaccination, such as diagnosis with severe acute or complex chronic illnesses subsequent to immunization, influenced the decision to refuse additional childhood vaccination

(Austin, Champion-Smith, Thomas & Ward, 2008; Harmsen et al., 2013; McMurray et al., 2004).

Poltorak, Leach, Fairhead, and Cassell (2005) report that mothers told about the importance of considering their personal and familial vaccination decisions and disease experiences. Some mothers, for example, decided to continue their longstanding family history of being unvaccinated. They regard the MMR as not right for their children. Brown et al. (2012) aimed to explore 24 mothers' decision making influences regarding a first MMR vaccination. Some parents, regardless of their decision to accept an initial MMR vaccination, reported past personal experience with vaccine failure and mild adverse events. Further, they heard about a possible MMR-autism link, not through personal experience, but through second- and third-hand experiences. For those parents who accepted vaccination, these negative consequences were attributed to 'flukes' or unsubstantiated claims of 'cause and effect'. In contrast, parents who declined immunization viewed these negative experiences as supportive evidence for problems with vaccination.

### **Trust in healthcare professionals and health system**

Healthcare professionals are referred to throughout the literature about parental decision making and childhood immunization, often relative to their perceived trustworthiness. Fadda and colleagues (2016) describe parents' experience of empowerment when they are able to freely exercise their parental responsibility to make decisions regarding MMR vaccination in a partnership with a trusted healthcare provider. The healthcare provider either communicates their competent knowledge regarding vaccination, or assists the parent to locate, assess, and understand immunization

information. This finding is supported by Benin and colleagues' (2006) study involving 33 mothers with varying decisional outcomes regarding vaccination. They report that knowledgeable healthcare providers who spent long periods of time with parents, presented large amounts of scientific information, answered all of their questions, and treated them in a non-patronizing manner as unique individuals were deemed trustworthy. Alternately, parents who choose not to vaccinate their children expressed having previous negative experiences with healthcare providers resulting in distrust.

Saada and colleagues' (2015) examination of parents' rationale for choosing alternate vaccination schedules describe that in addition to lack of trust in their healthcare providers, parents experienced being 'pressured' and 'bullied' to comply with recommended schedules, and felt judged by the healthcare provider when they did not comply. Parents expressed being inhibited to ask questions, because of lack of time and anticipating that they would be told that the pros outweigh the cons and to just do it (Saada et al., 2015). Parents expressed a preference for dialogue with their providers about both sides of thinking that would assist in their decision making about vaccinations. Berry and colleagues (2017) studied healthcare providers' experiences of interacting with parents who did not chose to vaccinate their children. These researchers report that healthcare providers perceived that their expert scientific knowledge and trustworthiness as patient advocates was disregarded by this group of parents. Most providers described that it was challenging to address all of the parents' questions in a standard time-limited appointment. The authors of both studies acknowledge the unwelcome tension associated with divergent views on childhood immunization and recommend that therapeutic communication must be prioritized in such circumstances. For some parents, healthcare

providers may be positively biased toward vaccination, and thus have a limited role in their decision making deliberations regarding childhood immunization (Smartt Gullion, Henry & Gullion, 2008; McMurray et al., 2004).

### **Awareness of information about vaccines**

Across the selected studies, most researchers address vaccine knowledge as an aspect of parental-decision making about childhood immunization. Benin et al. (2006) report that knowledge deficits about vaccine scheduling exist among parents who decide to accept, delay or decline immunization. Parents who were aware of their information needs sought vaccine information from at least one source prior to making a decision. Some authors identify that multiple sources of information were used to build knowledge prior to deciding how to proceed in the interest of their child. Family, friends, acquaintances, medical professionals, and the internet were identified as common sources of information (Austvoll-Dahlgren & Helseth, 2010; Brown et al., 2012; Brunson, 2013; Harmsen et al., 2013; Hill & Cox, 2013). The availability of diverse sources of information complicated decision making for some parents, particularly if information was contradictory, incomplete, or perceived as biased. Johnson and Capdevila (2014) report that within this ambiguity, mothers are most often left to make decisions for their child based on their instincts, following the mantra "Mother knows best" (p. 868). Wang, Bara, and Buttenheim (2015) report that having to make a judgement about what is best for one's child when confronted with volumes of conflictual information contributed to parents' decision to delay or refuse vaccinations despite being initially 'pro-vaccine.' Further, parents who chose to follow an alternative vaccination schedule expressed an affinity for like-minded parents, potentiating a culture of 'vaccine hesitancy.' In an earlier



study, Austin and colleagues (2008) found that information overload was associated with multiple negative emotions and likely to influence parental decision to not vaccinate their child.

### **Attitudes and beliefs about immunization**

Bond and associates (1998) investigated perceptions of vaccine preventable diseases and associated vaccines in terms of susceptibility, severity, benefits, and barriers. The sample included a mix of parents whose children were immunized, partially immunized, or not immunized. Parents who accepted immunization believed that vaccine side effects were less of a concern than the risk of disease. Some described that they had no decision to make; that they always planned to immunize. Alternately, parents who declined immunization were more concerned about the unknown and long-term side effects of vaccines than disease. All parents in the study acknowledged the phenomenon of herd immunity. Those children who were immunized were believed to help protect others. If immunization uptake was minimal, however, they acknowledged the increased risk of contracting vaccine preventable diseases.

Downs and colleagues (2008) report that parents construct mental models to render a decision regarding childhood immunizations. Findings reveal that parents held either a health or risk-orientation regarding vaccination. Parents who focused on a risk orientation were most reliant on internet narratives about how vaccines have hurt children in making their own decision. Further, parents with a naïve, as opposed to a focused understanding of vaccine mechanisms, were most vulnerable to non-factual information.

Smartt Gullion, Henry and Gullion (2008) explored the attitudes and beliefs of 25 parents who delayed or declined immunization. Prior to making their decision, all parents

collected and considered information about immunization. Most of the parents sought out biases in the scientific evidence to align with their self-declared natural living philosophy. In doing so, they concluded that vaccines posed a risk to their child's health and, thus, consciously objected to proceeding with immunization of their child.

More recently, two teams of researchers examined beliefs of parents who choose not to vaccinate their children. Luthy, Beckstrand, Callister and Cahoon (2012) report that such parents are most concerned about vaccinations' threat to the immune system of young children. Some parents believed that naturally healing methods were superior to immunization, while others expressed that their young children were not at risk of being exposed to VPDs, which were perceived as mild diseases. Harmsen and colleagues (2013), examined factors that influenced 60 Dutch parents' decision not to vaccinate their children. They report that parents attributed their healthy life style as a protective factor in promoting their child's health and decreasing the risk of disease. In contrast, they believed their child's health was threatened by vaccine side effects, questionable vaccine efficacy, and vaccine scheduling that did not coincide with immune system maturity. Further support for the deliberate decision to refuse immunization, for some parents, was prior negative experiences, social environment, and perceived advantage regarding experiencing childhood diseases.

Most recently, Blasidell and colleagues (2016) elicited the thought processes regarding perceived risks associated with vaccination and non-vaccination among 42 vaccine-hesitant parents. In response to multiple sources of ambiguity, including: unknowable, missing, conflicting, changing, and non-credible information, parents concluded that the risks of vaccination and non-vaccination are unknown to some extent.

In response to such ambiguity, vaccine hesitant parents in the study constructed subjective risk judgements that maximize the risk of vaccination, affirm their sense of control of future outcomes, and minimize the risk of vaccine preventable disease. The authors recommended that mitigating vaccine hesitancy may require healthcare providers to acknowledge ambiguities about vaccine related risk and assist parents to cope with their uncertainty whenever unavoidable.

### **Vaccine and vaccination-specific issues**

This final group of influences was constituted by customizing vaccine schedules to meet individual needs, and the role of healthcare professionals.

#### **Customizing vaccines and vaccination schedule to individual needs**

Poltorak, Leask and colleagues (2006) describe parental perceptions about how their child's risk differed from those of the average population. As a result, parents choose to follow an alternate vaccine schedule or decline all vaccinations. The vulnerability of children was attributed to factors such as pre-existing allergies, digestive disorders, a premature birth, or being generally considered unwell.

Saada and colleagues (2015) report that 20 of the 24 parents in their study deliberately chose not to accept the recommended vaccination schedule. Five alternate schedules were described. These included: delayed, spaced out, and withheld vaccines; shot-limiting approach; selective delay or decline; visit by visit decision; and refusal of all vaccines. The rationale provided for these alterations was variable. Reasons provided by parents in support of their choice to customize their child's vaccination and scheduling included: controlled exposure to vaccine ingredients, questionable vaccine safety, immune system burden, and perceived disease risk. The authors concluded that health

care providers must address and acknowledge parental rationale for alternative schedules in order to increase vaccine uptake.

Whyte, Whyte, Cormier and Eccles (2011) examine the basis of parental decisions for declining adherence to a standardized immunization schedule. Parents in this study commonly made adjustments to standard immunization schedules for at least one of their children based on their concerns about association with autism, inadequate vaccine research, and exposure to toxins. The main benefit of altering the recommended schedule was to have a healthy child.

Byström and colleagues (2014) identify two groups of parents, conformers and pragmatists. Conformers were parents who followed recommended vaccine immunization schedules and had their children immunized at 18 months. This group of parents were primarily motivated by a will to avoid disease. Parents who they describe as pragmatists preferred to delay immunization as late as 3-4 years of age. In the event of disease such as measles, which they perceive as a serious disease, they ultimately decide to immunize their children. Concurrently, outbreaks of measles facilitated the parents in another study to opt to immunize against that VPD (Hill & Cox, 2013). Parents in Tickner et al's., (2009) study revealed that they believed that pre-school doses were just a repeat of something experienced previously whereas others thought them safer because they were not as strong as primary immunizations.

### **Role of healthcare professionals**

The role of the nurses in parental decision making is variable across the reviewed literature. For example, Austvoll-Dahlgren and Helseth (2010) identify that nurses were described as counsellors and mediators of information even when parents had made a

decision about immunization that may be contrary to their professional guidance. In Berry and colleagues' (2017) examination of healthcare providers' challenging interaction with parents who did not choose to vaccinate their children, a number of key strategies to manage the encounters were identified. These include exploring and informing, mobilizing clinical rapport, and keeping the parent engaged. Underlying each strategy was the need to develop resources to support healthcare providers' therapeutic communication skills within challenging encounters about childhood immunization. McMurray et al. (2004) determine that though nurses and healthcare providers were considered the most reliable and trustworthy with regards to MMR information, they were not generally an influence in parents' immunization decision making. The authors also highlight concerns iterated by a few parents who did not immunize; that they perceived some healthcare providers to be biased toward immunization due to supplementary payments they were believed to receive for reaching immunization uptake targets. A few parents expressed reluctance to discuss concerns since they felt time was limited for discussion, and some emphasized that they felt practitioners were not approachable to discuss concerns due to experiences of the practitioner to be dismissive, condescending, or coercive.

A literature review by Corbin and Leask (2016) led to the development of a framework to guide healthcare providers' discussions with parents about vaccination. More specifically, this framework addressed what can be said and how it should be said. They identify six helpful and six unhelpful strategies for addressing parental concerns about vaccination with all parents. For example, within this framework it was considered helpful to address parental information needs using a chunking and checking approach.

This involved strategic delivery of small amounts of similar information labelled chunking, followed by verification of parental understanding labelled checking.

### **Theoretical representations of parental decision making**

The reviewed literature demonstrates that multiple influences have the potential to impact parental decision making about childhood immunization. Two papers, in particular, presented unique theoretical representations to illustrate the interplay of influences on decision making. Brunson (2013) developed a model of parents' decision making process from a grounded theory study of 21 U.S.-born parents with children 18 months of age or younger. The three stages in the process of how parents make a final decision about childhood immunization include awareness of vaccination as a relevant issue for their child; assessing and examining issues relative to vaccination for their child; and choosing to accept, delay or reject vaccination for their child. Once a decision is made, parents either remain steadfast in their choice or continue to reassess vaccine related issues. Over time, parents may transition between periods of stasis or ongoing assessment. More recently, Corben and Leask (2016) undertook a review of literature to explore parent decision making about vaccination. They organized the selected literature using a behavioral-ecological model of vaccination decision making that include five levels of environmental influence on health behaviors. These include intrapersonal, interpersonal, institutional, community, and public policy influences. This schematic offers healthcare providers with insight into the interplay of multiple influences on parental decision- making as they tailor interventions for hesitant parents with the goal to enhancing vaccination coverage.

### **Chapter 3**

#### **Methodology and Methods**

This study uses the qualitative research approach known as interpretative description. This approach is amenable to building knowledge to meet the practice mandate of the nursing discipline (Thorne, 2008, 2016; Thorne, Reimer-Kirkham, Macdonald-Emes, 1997). Interpretive description yields evidence through the application of rigorous research techniques with the goal of generating practical knowledge for disciplinary members. Generating nursing knowledge, through this approach, is not intended “to control, or to claim truths” (Thorne, 2013, p.296), but rather, to inform professional practice through understanding of health-related experiences. Underpinned by a logic model, the researcher has flexibility when "discerning and making sense of patterns and variations across the beliefs, attitudes and opinions that persons... bring to a particular care situation" (Thorne, 2013, p. 297). Given that interpretative description is selected to address clinically-generated questions, it is expected that the findings will yield practical knowledge to address the "so what?" in the real world of nursing (Thorne, 2008, 2016; Munhall, 2012; Hunt, 2011).

Using interpretative description was conducive to addressing the purpose of this study, to understand parents' and nurses' experiences of decision making about childhood immunization, specifically MMR and/or Tdap. Driving this inquiry were the following clinical questions: What are the particular features inherent in decision making about childhood immunizations as experienced by parents? How do nurses characterize their perceptions of parental decision making about childhood immunization?

Assumptions are not made to determine parents' explanations of their decision making experience, nor are they made regarding clinical encounters. The inductive nature

of interpretative description facilitates parents' and nurses' articulation of their experiences from their unique contexts, to inform the researcher's interpretations to capture the relevancy for nursing practice. This chapter provides details regarding the methodological components of the study.

### **Methodology**

A core tenet of interpretative description is recognition that experiences are socially constructed. Thereby, human experiences are subject to multiple meanings and interpretations. In the absence of a singular human truth (Thorne, 2013), interpretative description allows for a "rigorously derived, elegantly explained, logically argued, and intelligently ordered" (p. 303) depiction of complex, constructed health-related experiences. The interpretive possibilities generated not only make meaning of present-day realities, but serve as a guide to inform understanding of future realities (Thorne, 2014). This approach is appropriate for nursing inquiry when the researcher aims to "grasp and sense the lived experience of their clients, to enter into the life world that these people inhabit, and to understand the basic social processes that illuminate human health and illness events" (Thorne, 1997, p. 288). Interpretive description has been recently used by health disciplines to examine perception about telehealth use in diabetes foot care (Kolltveit et al., 2017), patient experience of radiation treatment (McQuestion & Fitch, 2016), exercise and fatigue in people with multiple sclerosis (Smith, Hale, Olson, Baxter & Schneiders, 2013), and communication challenges for persons with chronic cancer (Thorne, Oliffe, Oglov, & Gelmon, 2013). Particular to this study, interpretative description reveals participants' shared patterns of perspectives, experiences, and concerns related to acceptance, delay, or decline of childhood immunization.



Interpretative description was developed by nurse researchers as a result of their identification that existing constructivist research approaches, predominantly from the social science discipline, such as phenomenology, grounded theory, and ethnography, did not fully capture the uniqueness of nursing inquiry (Thorne et al., 1997). This new 'non-categorical' approach (Thorne, Reimer Kirkham, and MacDonald-Emes, 1997) responds to the knowledge needs of nurses by describing and exploring the meaning of events or experiences relevant to clinical practice. Interpretative description is constituted by the naturalistic, constructed and contextual elements of human experiences.

## **Methods**

### **Design**

To understand clinically relevant human experiences, the study design is interpretative description. This approach allows the researcher to acknowledge: multiple, complex, subjective realities that only can be examined holistically; a priori theory is not available to capture the multiple realm that is likely to be encountered; and, the knower and known are inseparable (Thorne, Reimer Kirkham, & O’Flynn-Magee, 2004). To clarify, the relationship between “the inquirer and the ‘object’ of inquiry interact to influence one another” (Thorne et al., 2004, p. 5).

### **Setting**

The location of this study was a small urban center in northeast Ontario, with a population of approximately 42,000 residents. According to the most recent census of population in this community (Statistics Canada, 2016) the number of children under the age of five is estimated to be 2,285. Within this community, residents have choices regarding the services they select for information about and administration of childhood

immunization. These include, individual practitioners, a multi-site family health team, a health clinical associated with an educational institution, and the local health unit.

Further, residents within this community have internet access to global health information through independent or publically funded resources.

### **Sample**

The population of interest was parents of children, under the age of five, and nurses involved in childhood immunization education and/or administration. To obtain the goal of identifying 'key informants' willing to describe their experiences with the topical focus of the study, a variety of sampling methods may be used within Interpretative Description (Thorne, 2008, 2016). Typically, at the onset, convenience sampling circumscribes the population. Nurses at each of the settings, who interact with parents for childhood immunization education and/or administration, were invited to participate in this study. Upon meeting with management of the clinics included in this study, the researcher obtained approval from management to contact nurses through email or by telephone in order to request participation. Posters were also approved and the respective clinics permitted posters with study information to be made available throughout the waiting rooms and clinic assessment rooms requesting parent and nurse participants. Participation was left to the discretion of the nurse.

The parent participants were initially sought through convenience sampling at each of the three study settings. The rationale for this technique was the wide use of primary health care access, through the study setting, by parents of young children. Once convenience sampling was underway, the researcher employed purposive sampling to focus the recruiting process for identification of "key informants." Purposive sampling is

particularly suitable to seeking unique participant experiences to best illuminate the research phenomenon (Thorne, 2008, 2016). Study posters (Appendix A) were made visible in the settings' waiting areas, and clinic rooms.

Recruitment of parents occurred in collaboration with designated healthcare providers at each of the settings. Clinicians at the study settings identified potential participants during routine appointments. The clinicians introduced the study, provided a study information letter (Appendix B), and sought verbal consent to provide contact information to the researcher; or if preferred, the potential participant could make contact directly with the researcher. The initial contact between the potential participants and the researcher involved four key foci: (1) to introduce the researcher as nurse and student; (2) to explain the purpose of the study; and (3) to explain the participant's role in the study; and (4) answer any questions raised by the potential participant.

The researcher, in an effort to represent a diverse experiential scope within the sample, recognized that the initial pool of parent participants did not capture all types of decisions relative to childhood immunization. This judgement is what Thorne (2014) refers to as "making sense of what you have and don't have in the study sample" (p. 108). Therefore, the study's sampling was expanded to include snowball sampling, another non-probability technique, to identify parents from the population of interest that were not immediately accessible through the study settings. Snowball sampling is particularly conducive to obtaining hard-to-reach marginalized participants, particularly when the topic of inquiry is perceived to be sensitive (Sadler, Lee, Lim, & Fullerton, 2010). Parent participants who were identified through purposive sampling, were asked to identify their parental peers who may be interested in study involvement. Rationale for this approach,

was that parents interact within a social network, outside of the healthcare setting. The snowball approach is particularly suitable given that parents who decline or delay childhood immunization may have established informal networks of individuals who share health beliefs about MMR and/or Tdap immunization.

Study inclusion criteria specific to nurse participants were: self-declared registration as a registered nurse or nurse practitioner; ability to understand and speak English; self-identify as responsible for childhood immunization including education and administration; and past encounters with parents who accepted, declined, or delayed immunization for their children within the past six years. Inclusion criteria for the parent participants were: ability to understand and speak English; aged 18 years or older; male or female; self-identify as a legal guardian of a child; and acceptance, decline, or delay of immunization for their children within the past 6 years. Exclusion criteria was demonstrated distress regarding the sensitive topic of inquiry during introduction of the study to prospective participants.

Thorne (2008, 2016) suggests that sample size for an interpretive descriptive study is dependent on the nature of the study phenomenon and the state of the science rather than a prescriptive number. At the onset of the study, to solicit multiple and diverse perspectives, the anticipated sample size was 10 nurses and 15 parents. Six nurses provided written consent (Appendix C) and participated in the study. A total of 15 parents participated in the study. Nine parents had chosen to immunize their children according to the recommended immunization schedule. Six parents had chosen to decline or delay immunization for their children. This subset of parents were grouped to protect anonymity.

## **Ethical approval**

Approval from the Laurentian University Research Ethics Board (REB) was obtained (Appendix D), given that the study is conducted in partial fulfilment of a Master of Science in Nursing degree through this educational institution. Approval was also obtained from each of the study settings.

## **Data Collection**

Socio-demographic data was not collected to promote the anonymity of participants in the small urban centre in which the study was conducted. Data was collected using semi-structured interviews. The use of semi-structured interviews allows the researcher, in interpretive descriptive, to extend the dialogue beyond what is already known, based on a preliminary examination of the literature and their own experiential professional knowledge (Thorne, 2013). An inherent feature of semi-structured interviews is its flexibility, such that participants can share diverse experiences unique to, meaningful, and valued by them (Austvoll-Dahlgren & Helseth, 2010; Barriball & While, 1994). Through the interview process, participants become expert informants as opposed to research respondents. This process facilitated the researcher's quest for structuring new knowledge that may support or challenge prior knowledge about childhood immunization.

To conduct the interviews, the researcher used a general interview guide about the topic of inquiry to provide an intentional focus for the researcher/participant interaction. The questions and probes in the interview guide (Appendix E) were intended to elicit beliefs, values, emotions, perspectives, actions, and behaviours related to accepting, declining or delaying childhood immunizations. The guide assisted me to align with the

study purpose while examining meaningful experiences unique to each participant. In interpretive description, the researcher must be cognizant of their own perceptions, beliefs, and knowledge that could influence not only what they would say and how they would behave, but also what they may see, hear, and interpret. This was important for me to consider given my personal choices and experiences with immunization and my professional background as a public health nurse, as described in Chapter 1. Thorne (2013) clarifies that a nurse researcher is "never pretending not to be a nurse, but is positioning that nursing expertise in suspension for the purpose of inquiry" (p. 301). As the interviews progressed, I began interpreting preliminary patterns across and within the interview data. Thorne (2008, 2016) emphasizes that with time in the field, researchers will begin to identify, confirm, question, and evaluate information which participants reveal.

Over a six month period of time, each participant completed a minimum of one interview that lasted between 45 to 60 minutes. Thorne (2013) recommends serial interviews to clarify constructed interpretations. I approached one participant, who re-consented, and was interviewed a second time. The second interview allowed the participant to follow up on and clarify ideas experienced in their first interview and clarify their ideas. If parents expressed interest in being interviewed as a couple, both were required to provide written consent. All interviews were conducted in a location determined to be safe by both the participant and the researcher.

Each semi-structured interview was recorded on a handheld password protected device. Upon completion of each interview, the researcher downloaded its corresponding audio-recording to a password protected electronic audio file which was assigned an

identity code and organized in a password protected network. Recordings were immediately deleted off of the handheld device. Each electronic audio file of raw data was transcribed verbatim to record and represent nuances of the interview. Undertaking verbatim transcription brings the researcher closer to the data, increasing familiarity with and knowledge of each interview (Halcomb, & Davidson, 2006; Thorne, 2008). Each transcribed electronic file was also assigned an identity code and stored in the password protected network. Hardcopies of all transcriptions were securely stored in a locked filing cabinet belonging to the researcher.

### **Data Analysis**

Once transcripts were received, open coding was conducted to initially categorize the data. Constant comparative analysis was consistently undertaken to ensure traceability by clarifying the variety of data that arose and by considering commonalities and differences in expressed attitudes and beliefs about vaccines, immunization decisions, and experiences described. This iterative process also impacted external validity through the comparison of parent participants, as well as comparisons made between parents and nurses. Selective coding and axial coding, systematically guided the analysis to facilitate the process to evolve where themes and ideas were highlighted and distinguished particulars emerged (Thorne, Reimer Kirkham, O'Flynn-Magee, 2004).

Table 3  
*Inductive Analytic Process*

Steps	Description	Example
Data preparation	Data transcribed verbatim within 15 days of interview	<p>Respondent We've actually decided to delay the immunizations for—it was a very difficult decision to make, because it is a very difficult decision whether or not we're going to vaccinate our child.</p> <p>And, we've decided just to postpone this a little bit because—because of what other countries are doing. A lot of the research we did has conflicting results—the information—and it's—it's really hard to pick and choose what you think is the best for your child.</p> <p>Interviewer Right.</p>
Reacting to data	Re-read transcription, underlining and circling key words, making margin notes to get a feel of the initial data and hunches	<p>Respondent: We've actually decided to delay the immunizations for—it was a very difficult <u>decision</u> to make, because it is a very difficult decision whether or not we're going to vaccinate your child. <i>(delay) difficult decision</i></p> <p>35 And, we've decided just to postpone this a little bit because—because of what <u>other countries</u> are doing. A lot of the <u>research</u> we did has <u>conflicting results</u>—the information—and it's—it's really hard to pick and choose what you think is the best for your child. <i>resource: other countries. own research. conflicting.</i></p> <p>Interviewer: Right. <i>well-being of child</i></p>



<p>Dividing the data</p>	<p>Difficult 31 31 We've actually decided to delay the immunizations for—it was a very difficult decision to make, because it is a very difficult decision whether or not we're going to vaccinate our child</p> <p>36 conflicting results—the information—and it's—it's really hard to pick and choose what you think is the best for your child.</p> <p>78 It's—I mean, it wasn't an easy decision to make and, I think, just looking at the research across the world with the tool we have—the wonderful tool we have—the internet—I feel like we made the best decision that we could for our child right now.</p> <p>Protection 36 conflicting results—the information—and it's—it's really hard to pick and choose what you think is the best for your child.</p> <p>80 I feel like we made the best decision that we could for our child right now.</p> <p>195 And I know that there's no solid proof, it's all hearsay and—but, in all, I think I looked at a lot of different research and we tried to make the best decision.</p> <p>240 I don't know where I found this [unintelligible00:14:28], it's been a while since I've looked at it, so I—I heard there were—there were concerns about giving three at the same time, and that it's probably better to give one at a time and then wait a little bit before you give the next one.</p> <p>267 Well, you do worry your child could get ill. You wouldn't want him to lose limbs or, you know, he can die from these terrible diseases that we probably do have vaccinations against. Like, that would make me feel like I made a terrible mistake if that happened, obviously.</p> <p>271 But, at the same time, if I did give him the vaccine and he did have an adverse reaction and it did affect his health in some way, I would feel terrible the same. So, it's, you know, it's a hard decision either way.</p>
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## **Rigor**

The credibility of this interpretive description study moves beyond the trustworthiness and transferability of data as supported by Thorne (2014). Four key evaluative criteria can be applied to judge the credibility in interpretive description studies (Thorne, 2008, 2016). These include epistemological integrity, analytic logic, representative credibility, and interpretive authority. Each criterion will be further examined below.

### **Epistemological integrity**

Thorne (2008) describes epistemological integrity as the demonstration of a defensible line of reasoning “from the assumptions made about the nature of knowledge through to the methodological rules by which decisions about the research process are explained” (p. 224). In interpretive description studies the research question should not only describe a phenomenon of interest but should also interpret the phenomenon. Specific to this study, the review of the literature sensitized the researcher to previously identified influences on parental decision making regarding childhood immunization. Exposure to empirical knowledge regarding contextual, individual, and vaccine-specific influences presented in the literature review informed my purposeful engagement with participants. I was attentive to their accounts, and willing to discover what is not yet known about the phenomenon of study. Discussion with the thesis committee members required me to articulate and further investigate identified patterns within and across the data. Thinking-out-loud about the data and its meaning was particularly helpful to discover, deconstruct, and reconstruct patterns related to parental decision making.

### **Analytic logic**

Analytic logic is an indication that the researcher followed an inductive manner for the analysis of the data (Thorne, 2008, 2016). An audit trail of the themes and categories is a

principle used to ensure analytic logic is maintained. An audit trail allows for an outside researcher to follow the reasoning pathway. For this study, the researcher maintained an audit trail throughout the analytic process. Each transcript was individually scrutinized, allowing for the inductive development of codes particular and relevant for that particular interview. Clusters of particular codes and data were grouped, and themes emerged, and were recorded in additional documents in order to facilitate the inductive development of clarifying the data to make sense of the emergent themes.

### **Representative credibility**

Thorne (2008, 2016) indicates that representative credibility is the demonstration that the selected study sample is well positioned to elaborate on the topic of inquiry. The phenomenon of interest for this study is decision making about childhood immunizations. The study participants were varied in that parents were not selected according to a particular immunization decision, rather, parents deciding or having recently made a decision were the primary focus. These varying perspectives provide the opportunity for depth and breadth of data, and offer emphasis that regardless of the decision, certain patterns and commonalities do emerge. Nurses were also included as participants in this study as they are an accessible professional resource for parents during their decision making about immunization for their children.

### **Interpretive authority**

Thorne indicates that interpretive authority requires the researcher to assure that they are cognizant of his/her bias in the interpretation and analysis of the data (Thorne, 2008, 2016). Positioning of the researcher was purposeful and guided by the ethically approved plan. Though I had immunized my own children, I acknowledge that other social and familial contexts may impact the decision making of other parents. Further, I am cognizant that my professional

judgement about the scientific evidence and merit of immunization and contextual influences impacted my personal experience of decision making regarding immunization. At the outset of the study, I was aware that variable experiences would arise within the study. Assumptions were not made regarding the decision making of childhood immunization. As such, the utmost regard was upheld for all participants, regardless of their decision, such that individualized experiences could be disclosed. In turn, the inductive process inherent in interpretative description further facilitated a progressive understanding of some patterns in decision making despite variability in the choice to immunize.

## **Chapter 4**

### **Results**

In this chapter, the parental experiences specific to decisions about childhood immunizations are described. The majority of parents made the decision to proceed with the recommended immunization schedule. Fewer parents decided to decline immunization against vaccine-preventable diseases (VPD). Fewer still chose to proceed with immunization on an altered schedule. Delayed immunization was attributed to their need for additional time to consider the safety of scheduling the vaccination for their child. In addition, the role, influence, and perceptions of nurses will be detailed. The results will demonstrate that protection was the unifying goal across all parents and nurses regardless of decisional outcomes. All parents were motivated to protect their child, while nurses communicated their obligation to uphold client safety. The three common actions undertaken to actualize the goal of child protection were searching for information about immunization, deliberating prior to deciding, and bearing responsibility for their immunization decision. Each of these actions, particularly for those parents who delayed or declined childhood immunizations, were described as "hard," "difficult," "time intensive," and carried out under public and familial scrutiny. Further, this group of parents often described feeling pressured to make a decision by family members, friends, schools, and healthcare providers. The interrelated activities, undertaken to make a decision for child protection will be described sequentially.

### **Protection**

All parents, regardless of their decision whether or not to immunize, described their ultimate goal as protecting their child. For those who selected to immunize their child, their goal was to safeguard from vaccine preventable diseases (VPD). The decision to follow recommended immunization schedules offered these parents assurance that their child would be

protected against VPD. For parents who delayed or declined immunization, their goal was to protect their child from vaccine-associated injury. The potential negative consequences of exposure to vaccine, even if only “one in a million,” was not worth the risk of vaccinating their child. These parents were vigilant in protecting against such risks as anaphylactic shock, permanent brain damage, or death. As summarized by one parent, “delaying immunization is the right decision for her child.”

Nurses recognized the role of individual immunization as a public health issue. Although the parents generally considered their protection of their own child as their central focus, one parent acknowledged her role in public health through vaccination.

I strongly believe in immunization. It was never a question for me not to do it... it is the responsibility of the masses to immunize... to protect those who cannot... to eradicate those diseases we do immunize for. We don't want to be the cause of them coming back.

So everybody, the general population as a whole, should be immunized.

### **Searching for information about immunization**

At a minimum, all participants sought or were provided with the recommended scheduling of childhood immunization, in accordance with provincial public health standards. There was variability, however, in the energy and effort directed toward searching for additional information about immunization to support their ultimate decision. Motivated by protection, parents described independent browsing for relevant information, interacting with others to obtain information, verification of their findings, and further exploring monitoring for supplementary information. During the search for information, parents described affective experiences including “confidence”, “doubt”, “fear”, “pressure”, “surprise”, “confusion”, and “relief”. The actions of searching for information was characterized by two subcomponents:

accessing sources of information and deliberation about believability and trustworthiness. Each of these components will be described below.

### **Accessing sources of information**

In their search for information, participants accessed a range of information sources including formal healthcare providers, health promotion campaigns, online websites, media, research reports, expert opinions, past personal experiences, and family and friends.

Parents who chose to immunize relied predominantly on a single source of evidence: that which was provided by their formal health care provider. One parent shared that she "did not need to have to delve into any other type of, you know, reading up on stuff." Parents who immunized their children, perceived that their health care providers, including nurses, family physicians, pediatricians, and employees at the local public health unit, were an accessible source of information. Nurse participants described their efforts to be content experts and have current information available to disseminate to their clients, in particular, related to the differences between adverse reactions and anticipated side effects from vaccinations. One nurse stated that being accurately and confidently informed supported consistency in messaging between health care providers.

Nurses were generally perceived by parents who chose to immunize their children as "really good at providing information." The role of nurse in providing information was validated by the nurses. As stated by one nurse, "...my job is not just to immunize. My job is to educate, so that either way, [parents] are making an informed decision...and when [parents] are educated, [they] lose their fear." For some parents, the availability of take-home printed packages provided them with information to answer their questions and clarify their concerns following interactions with the healthcare provider. Most parents did not deem it necessary to invest substantive effort

to seek additional information. As explained by one parent "I didn't really do too much more research, but did look some things up online, and just checked the sources." When parents expressed the desire to access additional information on their own, nurses guided their search: "Well, I try and talk with them upfront and direct them to appropriate sources of information. I let them know about Public Health Canada and caution them about some websites. I try to get them to go to evidence-based sources."

Parents who chose to delay or decline immunization tended to seek additional information beyond what was provided through discussion with or documentation received from their formal healthcare providers. Content sought through independent searching included vaccine adverse effects and ingredients. In an effort to answer these questions, they used the internet as a primary source information. One parent described the searching for specific answers as a challenging undertaking. "Online searching may begin with what appears to be a simple question, such as what are the ingredients of a vaccine, but then I'm stuck researching and it's hard. I didn't know how to research and I didn't know which papers were good. I didn't know what everything meant. ... it should be clearer.... every ingredient should be listed and backed up."

Online searching was complicated given the plethora of available information sources, questionable clarity of the information, and incongruencies in messaging. As described by a parent, "a lot of the research we did showed conflicting results. It's really hard to pick and choose what you think is the best for your child." In addition, some parents discovered variability in immunization schedules and adverse effects based on geography. As described by one parent, "I don't exactly remember where, but they delay immunization schedules in their countries. And they had reasons for this." This rendered decision making regarding



immunization for their child a challenge, despite efforts to be evidence-informed. At times, information obtained from the internet stimulated further information seeking and clarification from their healthcare provider.

In an effort to seek online information to validate their understanding of immunization risks, parents targeted a number of organizational websites. Commonly identified sites included the international World Health Organization; the American Center for Disease Control and Prevention, and BabyCenter Canada (2012), whose mission is to "provide high-quality, medically reviewed information." Here they described uncovering information about the merits of vaccination and alterations in health status such as neurological, gastrointestinal, and developmental concerns. In addition, the WebMD online resource was accessed by some parents in follow-up to recommendations from their healthcare providers.

Parents who chose to delay or decline immunization spoke of their efforts to seek out information through online platforms, blogs, and videos. These venues offered personal experiences regarding vaccinations from parents perceived to be just like them. In addition, celebrity endorsements found in these sources were considered when making a decision regarding immunization. As described by one parent: "I did look at the Vaccination Awareness Network. It includes some testimonies of people who have children who appear completely normal...healthy...and intelligent [after being vaccinated.] And then there are cases where the vaccination has caused some sort of brain injury... and the child is very low functioning for the rest of their lives."

The information discovered through social media often prompted active searches for additional information online. As described by an inquisitive parent, "I don't always believe everything I read. People on social media share their own opinions. Whatever words they would

use that I did know... I would do my own search to look those terms up and see what it was. I just kind of need to find out... I'm nosey.”

A small group of parents indicated that they accessed primary and secondary research findings in order to explore the health controversies associated with vaccines that they found in the media. This quest for research evidence was undertaken to elicit "proof" that their personal convictions, to either immunize or not immunize their child, were well supported. These parents recognized that there are multiple perspectives regarding immunization, and they were cautious to ensure that their search included research findings.

Those who chose to delay or decline immunizations identified that the expert opinions of members of the health disciplines were sought in their deliberation about consenting or refusing to immunize their child. Specific professionals identified included cardiologists, health researchers, healthcare students, and homeopathic practitioners. Their opinions were accessible through direct conversations or indirectly through written material such as books and articles. One parent identified that their social relationship with a healthcare professional led to discussion about her personal choice to delay of vaccination for her child. "I consider this person pretty-well educated [about vaccines]... it helped us make our decision to delay as well."

An immediate source of information, considered by all parents, were their own past experiences. One parent who consented to the immunization of her eldest child readily shared that "she became very ill and started having a febrile seizure" following vaccination. This experience was considered during deliberation regarding immunization for all younger children. Another parent remarked that her first child experienced a serious health challenge early in her young life: "I started reading, and reading and researching, and researching, and then it just kind of all fell into vaccine reaction. And I brought it up with the doctor, and he said, oh, vaccines

don't do that. And I was like, but it does say on the CDC website that vaccines can cause permanent brain damage... So from that point on, none of my children got any more vaccines.”

Further, experiential knowledge of family and friends regarding vaccine side effects and reactions were commonly sought or openly disclosed without solicitation. This exchange of personal knowledge often impacted decision making and for some, motivated searching additional sources for information to confirm or refute that which was shared. In some circumstances, parents perceived "a lot of stress and pressure from the people around" them to comply with their opinions regarding immunization. Comments such as "you should really do that;" "you haven't done that yet;" and, "it is silly that you would not do it" factored into parental decision making regarding immunization of their one child.

### **Deliberating prior to deciding**

Beyond seeking information, parents and nurses shared stories about the deliberations that occurred prior to rendering a final decision regarding immunization of their child. Thoughtful consideration of the collected information allowed parents to make judgements for or against vaccination based on its perceived believability. In addition, intentional assessments were made regarding the trustworthiness of the source of information. All parents considered the information and the information sources to determine the best way for them to protect their child.

Once again, the three final decisions determined by parents in this study were to immunize, decline, or delay immunization.

### **Believability of information**

During interactions with parents, nurses shared their perceptions of parental deliberations regarding immunization. Minimal to no uncertainty was witnessed when parents were confident that their decision regarding immunization would protect their child against VPD. Most parents

were certain that, as described by one parent, “so much medical research and innovation over time,” has rendered immunization safe. Further, “for decades and decades and decades we’ve been immunizing people. And these people are healthy ...from immunization”.

In addition, parents expressed belief that the immunization schedule put forth by Health Canada "makes sense" and “modern medicine has really ...hit the nail on the head.” Another parent addressed the veracity of the information shared by nurses indicating that “I know that when she gives me information it is based on research.” Another parent who considered the available research concurred that it demonstrates that vaccines prevent "children from various outbreaks." Yet, she questioned whether all of the research evidence is disclosed to parents. She was "sure [vaccines] save the government a lot of money because they are not hospitalizing children" from VPDs. She doubts, however, that the risk of serious complications from vaccines are fully disclosed in the healthcare information that is provided to parents. Another parent indicated that “the science behind immunization” is ongoing and that there are “things that science doesn’t know yet.” Some parents believed that "information was withheld," and therefore "felt compelled to do further research in order to feel more informed."

A few parents who believed in the protective benefit of immunization and proceeded with the initial vaccination of their children, described witnessing “life threatening symptoms” soon thereafter. As described by one parent, this occurrence led her to doubt whether the vaccine was actually protecting or threatening her children: “I would like to have them immunized now, but I’m too scared. No one knows what happened ... odds are that they are going to get sick from them again. I’m on the fence. It’s hard because I’m scared even though they are bigger now. How bad is it going to be if we do it? Are they going to have this reaction again? Is it going to be bad enough that they’re not going to be okay? I’m stuck.”

Some parents believed that there was an association between immunization and harm to their child. They feared that too many vaccines at once were thought to overwhelm the child's immune system. Much attention was focused on the controversy regarding vaccines and negative health outcomes, such as autism. One parent shared her deliberations about this issue as follows: "I started looking into the MMR and autism link when I was pregnant... obviously it's the main issue that people are confused about. Is there any link between neurological dysfunction injuries and vaccines? I did have some doubts. Instead of giving the MMR at 12 months, can it be given at two years? I don't know. I came to the conclusion that I would immunize."

Some parents expressed doubt regarding the safety of vaccine ingredients. As stated by one parent, "I understand that there are ingredients added to trigger your immune response. I believe it's not best to do that so early on... most of my concerns are around the use of heavy metals. It would be awesome if vaccines could be made without them... but I know it would be a lot more expensive."

For some parents, having a list of "every single ingredient" would increase the credibility of the information they receive about the safety of vaccines. One parent calls in to question the composition of vaccines simply asking "Is there mercury? Is there anything else?" Unanswered question raised doubts about the believability of the information parents accessed.

Nurses shared that their role in patient education includes efforts to make sense of the information they had collected. One nurse commented that, "sometimes I can negotiate some of the vaccines, but not all of the vaccines. And then we have a conversation about it again depending on their fears." The nurses emphasized the need to present "the facts" regarding immunization in a respectful manner. This approach limits the parents' perception of "feeling attacked" and has the potential to increase the believability of the information shared.

Historical facts were challenged in terms of the believability in comparison to other sources of information. One parent expressed disbelief in the commonly accepted information provided regarding historical facts about immunization and disease. She denied the link between vaccine and the prevention of disease: “like the smallpox, it was in a small town and they were giving the vaccines for smallpox because they had an outbreak, but they discovered that once they stopped giving the vaccination for smallpox, it had actually started to go away on their own.” The variety of information made available from many perspectives fosters the interpretation and believability of an individual’s collection of selected pieces of information to their discretion.

### **Trustworthiness of sources of information**

Parents spoke about their deliberations regarding the trustworthiness of the sources from which they sought and received information. In particular, they spoke of the trustworthiness of health organization, health care providers, nurses, celebrity activists, and experts.

*Healthcare organizations.* Parents who consented to follow the recommended immunization protocol generally expressed "faith in the health care system." One parent elaborated that “Health Canada and our government protects us as a whole... and I understand that they continually research to try to improve. I believe that their goal is protecting the public.”

Mistrust was attributed to organizations, which in the assessment of the parent, were not child-centered, but rather driven by profit. One parent referred to a particular story describing a pharmaceutical company, “...not long ago, (company) had given children prescription drugs that had contained HIV in the prescriptions. So they took it off the shelf in the USA and sent it off to Japan. Is that fair?” The understanding of one event contributed to a general lack of trust in pharmaceutical companies.

Also in question is the Center for Disease Control (CDC) and the integrity of the immunization programs. One parent verbalized her understanding that the CDC is also a manufacturer of vaccines: “They’re [CDC] the ones that are making, manufacturing the product, and the product speaks for itself. Right? With the risks, I think that the child’s best interest is not at heart anymore, where it used to be. Like, they would try to make these vaccines to help prevent, but I think along the way, somewhere along the line, that got shuffled and turned into something else.”

*Healthcare providers.* Some parents who made the decision to immunize their child communicated trust in their healthcare providers as a source of credible information relative to their decision making about immunization. One parent indicated that she did not need to be informed on details that she found unnecessary: “...for the most part I don’t even know what vaccinations they’re getting until after and I look at their card...so I think that we’re maybe somewhat, naïve about them.” She specified that she trusts the expertise of health care providers: “someone who’s in that field, a doctor, a nurse, those are the people that I get my medical advice from.”

Some parents, particularly those who were considering delay or decline of immunization, were concerned that some health care providers are not sufficiently knowledgeable regarding immunizations, and the difference between anticipated side effect and adverse reaction are not fully known. One parent stated that, “it bothers me because healthcare providers have only been taught this much. I think that they are given a book in school, and told 'this is what it is.' That is it. They don't go beyond to dig deeper to see if there is any truth behind the possibility that vaccines cause injuries. They talk about 'one-in-a-million.' This is not true.”

The parents who chose to immunize rely on the expertise of health care providers, and the health care recommendations regarding childhood immunization. There is trustworthiness that supports this reliance on another, and facilitates parents to not feel the need to understand all of the aspects of immunization in order to agree to its administration to their children.

In addition, there was some concern regarding the overall trustworthiness of health care providers. This led parents to question their contribution in guiding decision making about protecting their children. As stated by one parent, “If you can’t really trust the person, then how can you trust them to help make decisions for your child?”

Parents who chose to delay or decline immunization experienced some challenges during their interactions with HCPs related to immunization. They described a lack of trust and/or respect in the interactions. Further, they perceived that their knowledge, opinions and views were “not acknowledged at all by health care professionals.” Some parents questioned if they were respected at all if their views differed from their provider.

Trustworthiness of the health care system was also expressed as a challenge for some parents. One parent highlighted a lack of clarity regarding immune-compromised individuals: “...people who are severely compromised, they’re at risk if other people aren’t immunized, right? So, it’s really tough you know, but um, yea, I mean. I think just not getting the answers, the answers to my questions made me very, you know, from the health unit.”

*Nurses.* Nurses commented that when parents were clearly resolved to proceed with recommended immunization schedules, there was limited necessity for sustained dialogue about the benefits of immunizations. The focus of these interactions with nurses, as described by one parent, was patient teaching as illustrated in the following quotation. “They would debrief before



giving the shots, what was being given, any side effects, and then we would just go from there and immunize.”

A positive relationship was noted by some parents to develop over time. One parent stated, “the nurses have been there for a while and they know who we are and I find them awesome nurses – really good.” The reciprocal relationship with the nurses facilitated a supportive approach that resulted in positive interactions during home visits, as one parent expressed, “As long as it was explained to us, we went ahead and we’ve done it.” Further to this, it was also highlighted how the familiar HCPs and office facilitated trust and comfort she had with the information provided, “I have that trust with the office that we’re with.” This familiarity demonstrated to be a positive contribution toward the trustworthiness of the nurses and HCPs.

*Celebrity activists.* Sources of information were perceived as trustworthy if the message was aligned with parents’ views about immunization and their motivation to protect children from the side effects of vaccines. Others called into question the authority of celebrity activists acknowledging that their viewpoints were largely based on personal experience. When parents “could not connect” with the celebrity’s personal experience, negatively appraised their social behaviours, or deemed their information sources unbelievable, activists were considered an untrustworthy source of information. Some parents who made decisions to both vaccinate and decline vaccination indicated that they were exposed to the “compelling arguments” against immunization by celebrity moms. Their personal stories made them think. Some valued these perspectives and considered them influential and trustworthy sources of information. Others discounted their views as part of sensationalized “pop culture... not a valid source of information.” Others, were motivated to “dig deeper.”

*Experts.* Parents who chose to delay or decline immunization considered information as more credible if it came from an expert who espoused messages consistent with their current immunization beliefs. Online media provided parents with access to the viewpoint of professionals who supported their perspectives regarding the risk of vaccines. Some of these experts, although initially discredited for their views regarding the risk of vaccines, were subsequently “exonerated,” and considered as trustworthy sources of information by multiple parents. For one parent, she describes that, “after researching and researching and listening online to a number of doctors [names specifically mentioned], they have so much evidence to prove that vaccines do cause harm.”

### **Benefits and risks of immunization**

Parents described that weighing the anticipated benefits and risks associated with immunization was an essential component of all parents’ decision making experiences. This benefit/risk analysis was driven by a need to determine the best course of action to uphold safety for their child. Parents verbalized a weighing of the relative risk of potential disease versus possible injury from vaccination. Nurses recognized that this harm-reduction approach was a serious undertaking for parents, often involving consultation with family and friends to make a final decision. As described by one parent, “...we’ve discussed it. And we’ve talked about it. And I’ll say, 'okay what about this?' And then we look at that new information, and then we weigh pros and cons, and then we decide.”

*Immunization benefits outweigh the risks.* Minimal to no uncertainty was witnessed when parents were confident that their decision regarding immunization would protect their child. Parents who elected to immunize their child declared a desire for protection against vaccine-preventable diseases. Their resolution to proceed with the recommended immunization schedule

resulted in limited necessity for dialogue between nurses and parents. As one parent recalled, “I got the information package. I understood what my child could get. I had no questions. I was there. I did not engage in a debate about it. It wasn’t an issue for me.”

For some parents, the threat of removal from the school system was too high a risk. Therefore they decided to accept vaccination for their child. This threat was communicated through receipt of recurring letters from the school, prompting parents to question, “What is going to happen? What are the repercussions if we don’t get it done? Will the Children's Protection Services be called?” These potential risks, and not the threat of disease, tipped the scales in favour of immunization for some parents.

*Immunization risks outweigh the benefits.* Parents who decided to delay or decline immunization were resolved that their decision would protect their child, not from vaccine-preventable diseases, but rather, the greater risk that "the vaccine is going to hurt their child." Parents verbalized a weighing of the relative risk of potential disease versus possible injury from vaccination. Judging that the risk of injury from vaccination was greater, their decision to delay or decline immunization was framed by a harm reduction orientation. For example, one parent verbalized that, "the risks of permanent brain damage or death does outweigh the benefits for me." From nurses' perspectives, parental conclusions that vaccines cause neurological impairments were "ingrained and hard to change."

Some parents expressed belief that vaccine preventable diseases were not life threatening, and therefore, did not warrant intervention such as immunization. Although healthcare providers relayed that "there are this many cases of deaths from vaccine preventable diseases every year, I feel that those cases happen when children are already immunocompromised in many other

ways." For "healthy" children, some parents determined that any exposure to vaccines to ward off non-life threatening illness was an unacceptable risk.

Parents held views and made decisions that were at times contrary to the views of the nurses. The nurses, however, spoke of their regard for parents' right to delay or refuse immunization. To support parental autonomy nurses accepted that "there is a point when we agree to disagree." This juncture, often following discussion of relative benefits and risks of immunization, was determined by the parents. As stated by one nurse, "I take my cues from them, and move on." Parents described their awareness that they were ultimately responsible for weighing the evidence and reaching a final decision. As illustrated by one parent, when she was confident that having "already done a lot of [her] own research" she was able to come to the best decision for her child, which was to decline immunization. She explained that she had come to the clinic and, "the nurse came in, who said, 'Can I discuss the vaccinations with you?' and I said, 'I'm not interested, I'm very sorry' and we moved on."

*Uncertainty about the risks and benefits.* Nurses described that some parents expressed uncertainty regarding weighing the relative risks and benefits of immunization. One parent, for example, questioned whether her healthy child was actually vulnerable to vaccine preventable diseases. She questioned whether the risk for measles was limited to "the kids who are severely compromised?" Nurses perceived that this uncertainty was a catalyst for patient education. It offered an opportunity for them to assess parents' informational needs. With this knowledge, nursing tailored educational sessions in an effort to alleviate parental uncertainty. A common topic of discussion during these interactions were clarifying the nature of distinguishing between anticipated side-effects of vaccines such as local discomfort, topical reactions, and adverse reactions such as anaphylaxis. The outcomes of educational sessions, however, were variable.

Although nurses recognized that they were responsible to inform, they acknowledged that any decision regarding immunization was ultimately the parents' choice. As stated by one nurse, "you don't want to force parents into something they don't want to do. You want to give them sound information, the real facts. It is our job. We can only advise and the choice is essentially left up to them."

Weighing the evidence was complicated when parents did not have a trusting relationship with their health care provider. One parent described that their ill child experienced many hospitalizations. As parents, they struggled to know whether their child was strong enough to be immunized, but did not trust that the health care team took the necessary time to adequately help examine and answer their questions. They perceived that they were abandoned by the healthcare team and therefore, unsure of the relative risks of immunization in their child's unique circumstances. They expressed concern about doing the right thing to protect their child.

### **Bearing Responsibility for Immunization Decision**

Three types of decisions were made across the participants: proceed with immunization, following the recommended schedule; delay immunization; and decline immunization. Nurses and parents were cognizant that there was variability within their communities regarding child immunization. Most participants spoke about the impact not only of individual parental decisions on the health and well-being of their child, but also the implications of the contrary decisions made by others. Protection extended beyond the immediate decision to immunize, delay or decline immunization for the health of a single child, to encompass living with the anticipated social implications for the parents and communities where they reside.

Some parents, especially those who chose to immunize their child, identified immunization as a parental and social responsibility to protect their child, other children, and

ultimately prevent the resurgence of vaccine-preventable illnesses. As described by one parent, “we know it’s our responsibility to take care of our own children, but at the same time, when it comes to pandemics and epidemics and communicable diseases, it is the responsibility of all parents together.”

Some of these parents described that it was frustrating when other parents “just choose not to immunize.” Concern regarding the ongoing well-being of their child in the midst of other children who were not vaccinated, elicited “anxiety,” “fear,” and animosity. For some parents, there was an internal struggle to not judge the decisions of others: “I hate to look at parents or children in a different way if I know that they haven’t been immunized. I have a hard time with it.” For others, their concern resulted in blatant expressions of “anger,” marginalizing their parental peers by labeling them as “anti-vaxers,” “ridiculous,” and “misinformed.”

Such labels were marginalizing for parents who were motivated to protect their child, through actively searching for information, weighing the relative risks, and coming to an informed decision that they would delay or decline immunization. As stated by parents, “I do have a brain” and “I am educated.” To avoid “being treated badly,” however, some parents who chose to delay or decline immunization for their children were reluctant to disclose or discuss their decision regarding immunization. As shared by one parent, “I was very nervous going in for a follow-up appointment because I didn’t want to be judged. I am very scared to bring it up with most people. It is something that I don’t want to bring up to everyone and have everyone, you know, judge me.” This example depicts ambivalence and avoidance of making a private parental decision public. Non-disclosure was commonly enacted as a protective strategy when negative judgements about one’s parental and social responsibility were anticipated. As further described, “It is awkward. Inside you definitely feel the pressure. You dread it. You feel the pressure. You

just feel disrespected as a whole. You try but you cannot even explain it.” This parent suggests that she shares a collective experience with other parents who live with the negative social consequences of delaying or declining immunization in the best interest of their child, yet being labelled as a "terrible parent."

Parents who chose to disclose their decision to delay or decline immunization for their child often experienced the need to provide rationale. As shared by one parent "I always, always feel like I have to explain myself," even if my ideas are dismissed as irrational. Faced with formal obligations to disclose the non-immunization status of their child, within the childcare or education systems, meant accepting limited access and/or the ongoing threat of removal. For example, as expressed by parents, "I've had to do a lot of special things because schools don't like that. They make you jump through hoops. Even daycares. They can choose whether or not to take you or keep you on as a client."

Parents were aware that the topic of immunization status may arise without warning during any familial, social, scholastic, or healthcare encounter. Parents lived in wait of "periodic debates" and sometimes "very, very, heated conversations." For some, this looming threat prompted some parents to make choices about with whom they associate, including changing healthcare service providers.

Not all interactions following the decision to delay or decline immunization were met with animosity. As described by one parent, "It is a hard decision to make. But after talking [to the nurse] I felt a lot better. Because she wasn't angry at us."

Within respectful relationships, parents' role as protector was validated, regardless of the decision made. It was described as comfort in associating with other adults who shared similar

viewpoints about immunization. Such associations could be direct social or professional interactions, or virtual connections through social media.

Overall, most parents remained steadfast in their decision and confident that their searching for information and weighing the risks/benefits regarding immunization led them to make the "right decision" for the "protection" of their child. All parents were able to articulate the rationale for their decision regarding immunization. Subsequent to rendering a decision, parents described living with the aftermath of their choice. Inherent in bearing responsibility for their decision about immunization, was ongoing protection from current and future negative health and social consequences of the immunization status of their child or other children.



## **Chapter 5 Discussion**

In this study, interpretative description was used to come to understand parents' and nurses' experiences of decision making about childhood immunization, specifically MMR and/or Tdap. In response to the guiding clinical questions, the findings identify the particular features inherent in decision making about childhood immunizations as experienced by parents and perceived by nurses. The findings indicate that there is variability in experiences across study participants. Protection, however, was identified as the shared feature across all parents and nurses.

Motivated by protection of their child, parents searched for information about immunization, deliberated the information and sources to determine the relative benefits and risks of immunization, and assumed responsibility for their decision to accept, delay or decline immunization. Elements of each of these components will be discussed relative to the implications for nursing practice. Though these are inter-related, there must be emphasis on the non-linear characteristic of this experience. Nurses also described their role in protection, communicating their obligation to uphold client safety. Protection is required where risk is identified, and interventions are feasible to address risk. Only in the wake of threat is protection determined to be needed (Shearer, 2002).

Parents who immunize their children according to the recommended schedule are motivated to protect their children from the potential threat of VPD. These parents consider immunization as a tool to assist them in safeguarding their children from illness. Immunization is not considered a significant risk from which their children require protection. It is the threat of disease that they perceive as the greatest threat to the well-being of their children. Some of these parents expressed interest in promoting protection of the larger community and other children

susceptible to VPDs, through immunization of their child. They perceived that acceptance of immunization actively minimizes their children's risk of contracting a VPD or the intensity of a VPD, if exposed.

Parents who delay immunization took time to determine the most protective action for the safety of their children. Delays were seen as a means to allow their children the time needed to develop, physiologically, in order to lessen the threat of harm from vaccines. Proceeding with immunization on an altered schedule allowed parents to provide vaccine coverage against VPDs, but within what was individually determined as an accepted timeframe to mitigate all perceived risks. This aligns with the earlier work of Shearer (2002). This author suggests that vigilant management includes perception of an imminent threat and actions taken that address this threat when deemed appropriate. More recently, Lorenz (2007) describe the importance of self-efficacy of the protector within Protection Motivation theory. The self-efficacious decision maker is able to undertake timely and appropriate action in the presence of a perceived threat.

Parents who declined immunization were motivated to protect their children from the threats that they understood to be greatest, that is risks posed by the vaccine itself. What is described by some nurses as refusal of immunizations was, for this group of parents, the most acceptable protective action they could undertake on behalf of their child's safety. Lorenz (2007) clarifies the concept of protection, emphasizing that actions for harm reduction are undertaken once a particular risk is appraised as a real threat. Strategies for protection are determined based on a quantification of acceptable and unacceptable levels of risk. The idea of immunizing their children was not considered by this group of parents as a protective strategy, but rather as real threat to their child. VPDs, in contrast, were not perceived as an imminent threat. Their ultimate goal as protectors of their children was to actively remove the threat of vaccines.

Nurses in this study described their role as protectors of child safety and population health. According to current evidence, a decrease in immunization increases the risk of contraction of disease, intensity of infection, and proliferation of the virus throughout the community (Bradford & Mandich, 2015; Omer, Salmon, Orenstein, deHart, & Halsey, 2009). Study nurses were aware of their mandate to communicate with parents, facilitate access to information and services that support the immunization program and the recommended immunization schedule. As described by Glanz, Kraus, and Daley (2015) healthcare providers prioritize the provision of health information when attempting to promote immunization uptake. This study's nurses were most influenced by their professional knowledge, grounded in scientific evidence. When evidence-informed recommendations regarding childhood immunizations purport significant health benefits in the face of VPDs, nurses perceive that their perceived role in protecting individuals and populations is reinforced. (Glanz, Kraus, & Daley, 2015).

In this study, nurses' descriptions of parental decision making regarding childhood immunization included a self-evaluative component regarding their capacity to fulfill their accepted mandate as protectors of the public through immunization uptake. Evidence of external validation of individual nurse's effort and achievements relative to immunization uptake is symbolized through awards and use of language such as “champions” (Swallow & Roberts, 2016; Thibodeaux & Nix, 2017). Uptake in such circumstances equates to successful nursing practice. This study's findings suggests that low immunization uptake may equate to perceived role failure. No published evidence, however, was found to explain the relationship between nurse-experienced success, failure and immunization uptake. Further inquiry into these relationships may yield insights into the professional practice of nurses involved in parent's decision making regarding childhood immunization.

Findings of this study suggest an undercurrent in the nurses' discourse around the tension that exists between their professional obligation to protect the public against VPDs, promote immunization uptake, yet respect individual parental choice. This conflict is situated within a healthcare system that recommends but does not mandate childhood immunization. As such, nurses are positioned to encourage immunization uptake yet parents are positioned to function as autonomous decision-makers over their child's immunization status. As indicated in this study, a contentious environment can be created during the decision making process. To minimize conflict, Jackson, Cheater, and Reid (2008) suggest that parents' decision making requires support that includes a thoughtful approach to information, astute understanding of the various interpersonal processes experienced by parents, and understanding parents' need for a sense of control.

When interacting with parents who have consciously and definitively made the decision to delay or decline, the nurse's initial focus on providing protection against the spread of VPDs, for any given family, may shift to health promotion. This shift may transform a contentious environment to one that supports a nurse-parent partnership while validating the individual parent's autonomy in decision making for their child, and assisting them to bear responsibility for their choice. Effective communication in challenging circumstances depends upon recognition of parents as the expert about their child, and the ultimate decision-maker for their health and well-being (Ruberton et al., 2016). There is a risk, as this study indicates that parents may negate the expertise of the healthcare system following negative encounters; thus, not only perpetuating parents' decline of immunization, but their avoidance of seeking information and services regarding a broader spectrum of protective and preventive healthcare.

Actively acknowledging and addressing parental concerns regarding immunization and vaccines may engender discourse regarding independently gathered information and negative experiences shared by others. In addressing non-scientifically generated information, nurses remain positioned to facilitate future clinical interactions that support parents' decisions to best meet their children's ongoing needs, and ultimately in protection of the well-being of their child. Through connectedness with parents, the nurse can facilitate a level of trust, demonstrate behaviours and approaches supporting respect, and participating in mutuality (College of Nurses of Ontario, 2009; Lane & Serafica, 2014). Immunization is one of the early protective decisions encountered in a parent's trajectory of decisions to be made for the health of their child. In recognition of this, the nurse who respects, although may not agree with, the parents' autonomous decision for their child's health opens the door to conciliatory interactions between healthcare providers and parents who endeavor to protect health - the common goal. Such encounters could integrate various topics that are foundational to child health that begin to establish points of common interest (McNeil & Arena, 2017).

Ongoing clinical encounters with healthcare providers that involved talking openly about common concerns were desired by parents. Parents wanted to be heard and understood. Being perceived as genuinely interested in the health of their child may render nurses as a trusted and believable source of information, a sounding board when weighing the benefits and risks of immunization, and a partner for navigating the consequences of their decision making. Further, trust in one's healthcare provider could mediate difficult discussions and enhance confidence in scientifically-generated health information (Yang, Chen & Muhamad, 2017). Given that clinic visits are time-limited, with little opportunity to discuss parents' concerns at any length (Davis,

et al., 2004), it may be reasonable to structure longer visits for parents likely to delay or decline immunization.

Dedicated time for nurse-led education sessions within a community environment could facilitate opportunities to address parents' questions, concerns, and even actively search for helpful information while in session. The nurses conducting these sessions would need preparation to competently address challenging questions, explore concerns, ask questions, and affirm parents' right to decide (Keyko, 2014; Moore, Engel & Prentice, 2014). Ongoing professional development is essential to facilitate a partnership approach to engaging positively with parents (Young, Stephens, & Goldsmith, 2017) in support of parental decision making about childhood immunization. Jones and Shah (2016) support the importance of nurses' role in building trust to create partnerships with parents for health.

Regardless of the decision made regarding childhood immunization, parents received or searched for information as an early aspect of protecting their child. In this study, parents who physically attended health care environments that offered immunization programs had access to written literature and staff for information. Protection of child, for this group, was facilitated through perceived believability of the information shared, trust in the source of information, perception of vaccine safety, belief that VPDs were a threat, and ultimate acceptance of immunization. Other parents expanded their search beyond what is provided by healthcare providers to meet their self-identified need for information (Davis et. al., 2004; Dwivedi & Sagar, 2017; Yang, Chen, & Muhamad, 2017). Although this study was not designed to analyze the content and relative influence of information sources that parents used in decision making, parents did describe a range of informational sources that they accessed including family, friends, other healthcare providers, and celebrity activists. Hobson-West (2007) report that on-

line resources provided parents with access to information that meets their particular information needs in real-time. Further, parents find confidence in their decision through connections with like-minded people through social media. A future study can be designed to conduct an environmental scan on the availability of historical and contemporary information sources for parental decision making about childhood immunization. A type of question could be "what do celebrity blogs tell parents about vaccines for VPDs?"

There is emerging evidence regarding the use of social media by healthcare professionals to engage members of the public (Welch, Petkovic, Pardo, Rader, & Tugwell, 2016). Nurse-led forums could reach out to the public regarding fears and concerns about childhood immunizations. Professional hosts could hear the voice of the parental community, offer immediate responses, and prepare more comprehensive information in posted blogs in response to particular concerns. In addition, other authors have indicated that the sharing of stories could generate interest and tap into the emotive component of immunization (Jha, Lin, & Savoia, 2016; McNeil & Arena, 2017; Rathert, Mittler, Baneerjee, & McDaniel, 2017). The believability of stories is enhanced through the emotional expression of human experiences (Hobson-West, 2007). They are a way of transmitting others' lived experiences of bearing the responsibility of their decisions. Such stories could complement more traditional health information provided by the health care providers (Davis et al., 2004; Dwivedi & Sagar, 2017; Jha, Lin & Savoia, 2016; Jiang & Street, 2017). An online presence and time-sensitive dialogue with community members could engage the parental audience who is comfortable seeking information using the online environment.

Fundamental to integrating information as a source of influence in decision making about childhood vaccination is parents' health literacy skills. Although data regarding health literacy

skills was not collected in this study, some parents spoke of the difficulty locating and interpreting the information that they found. Previous researchers have described that health information literacy varies amongst individuals, with low literacy levels shown to be associated with negative health outcomes (McNeil & Arena, 2017; Sand-Jecklin, Daniels, & Lucke-Wold, 2017; Takashi Yamashita & Brown, 2017). A future study can be designed to explore the relationship between health literacy and autonomous decision making for health.

When sought, nurses provide information required that is focused on immunization and answering questions. When sought, nurses clarify concerns in order to contribute to the parents' weighing of the information. Nurses provide input in order to inform parents. The believability of the information provided by nurses is relative to the trustworthiness that the parents have of the nurses. Parents will assign greater credibility to the information provided by a more trusted source, than a lesser source (Jones & Shah, 2016). In this study, nurses are a means through whom information is sought, and a resource with whom parents may consult in their deliberations regarding protection of their child through acceptance, delay or decline of immunization. Similarly, Moore, Engel, and Prentice (2014) advocate for the provision of tailored information within a supportive nurse-client partnership.

Connecting with parents in the community, at the grass roots level, could facilitate better access and improved engagement with health team members. Nurses could tap into already existing groups. Partnerships could be formed with these groups. As Dwivedi and Sagar (2017) express, customizing the approach and initiating intentional partnerships relevant to that group or locality would properly position interactions conducive to a relational approach to engaging parents. Immunization goals for these partnerships could aim to facilitate informed and autonomous immunization decision-makers as opposed to the traditional immunization goal to



ultimately increase immunization uptake. If interactions are consistent and effective, and information is current and relevant, engaged parents will be better informed, and more confident in making the most correct decision for the well-being of their children. This would confirm that the utmost was done in the protection of their children, lessening the feeling that they are bearing the responsibility of their final immunization decision in isolation.

There is also opportunity for nursing and public health to influence school curriculum. Health literacy could be addressed through amendments in health and life skills education courses (Bruselius-Jensen, Bonde, & Christensen, 2017). With the explosion of health information, conflicting messages, and confusing information, there is rationale to add health literacy to the education agenda in order to positively impact individual and community health. Not only would this empower young individuals to be better prepared to manage information about their own health, but these skills could follow them throughout their lives and optimize their own and their future children's health.

In summary, past research has emphasized strategies to increase immunization uptake as a strategy for improving population health. Given the global mandate to increase immunization uptake, the findings of this study offer one interpretation of parents' and nurses' experiences relative to the contentious and highly debated issue of childhood immunization. Despite individual parental variations in immunization decisions, and nurses' variable perspectives regarding parents' decision making experiences, this study illuminated protection as the core motivator across participants. This study adds to the body of evidence by illuminating the value of acknowledging parents' will to protect their children, and their right to make an informed and independent decision within the Canadian healthcare system. The findings from this study support healthcare providers situating themselves as trusted and accessible resources such that

they connect with individual parents to hear their concerns, support their search for information, participate in their deliberation of information and sources to determine the relative benefits and risks of immunization for their child, and be available as they live with the consequences of their decision to either accept, delay or decline immunization. To this end, nurses' effort to protect public health incorporates health promotion beyond the act of educating for and administering childhood immunizations, to respecting autonomous parental decisions.

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Appendix A  
Study Poster



Study Poster

# Childhood Immunization

**Parents and Nurses  
are invited to  
participate in a research study  
about decision-making concerning  
childhood immunizations**

**For more information about this study, please  
contact:**

**Shelly  
Laurentian University School of Nursing  
[sm\\_hosman@laurentian.ca](mailto:sm_hosman@laurentian.ca)  
1-705-235-3211 extension 7289**

## **Appendix B Study Information Letter**



### Information for Potential Study Participants

Study Title: Childhood Immunization: Parents' and Nurses' Perspectives

Investigator: Shelly Hosman, R.N., B.Sc. N. (705-235-3211 ext. 7289)

I am a registered nurse and a student in the Masters of Science in Nursing program at Laurentian University. As part of my education, I am interviewing nurses and parents for my research study about consenting, delaying or refusing childhood immunizations. Based on your health beliefs and experience with childhood immunizations, I am inviting you to take part in this study.

Although there are no immediate benefits to participating in the study, the results may help nurses and other health care providers to better understand the challenges experienced by parents as they make decisions about immunizing their children.

You are not required to take part in this study. Your decision is completely voluntary, and whether you participate or not, your involvement in the clinic will not be affected. There are no known risks for study participants.

If you decide to participate, you will be asked to sign a consent form before your interview. During the interview, which will take 45 to 60 minutes, I will be asking you to share some personal experiences about childhood immunizations to understand more about the decision making of parents regarding immunization for their children. You do not have to answer all of the questions that I will ask you. You do not have to give any reasons for not answering any question, or for deciding not to complete the entire interview. There will be no consequences to not answering a question or not completing the entire interview.

Together we can decide on the location of the interview, possibly at the clinic, your home or a friend's home. The entire interview will be audiotape recorded and the information will be kept confidential. All information collected will be kept in locked files for a period of seven years after which it will be destroyed. Individual information will be grouped with other participants' information to preserve your identity. At no time will your name or information that can identify you be released. The results of the study may be published in a professional journal, presented at conferences or at presentations in the community, such as the clinic. You may also request a summary of results from me or my research supervisor.

Please accept my sincere thank you in advance for taking time to consider participating in my study. Should you have any questions or concerns about the study or about being a participant, please feel free to contact either me (705-235-3211 ext. 7289), my research supervisor, Sharolyn Mossey R.N., M.Sc.N. (705-675-1151, ext. 3813). You may also contact a Research Ethics

Office at Laurentian University Research Office, not attached to the research study regarding possible research ethical issues at 705-675-1151, ext. 2436 or toll free at 1-800-461-4030 or by email at [ethics@laurentian.ca](mailto:ethics@laurentian.ca)

Sincerely,

Shelly Hosman, R.N., B.ScN, Student in the MScN program at Laurentian University

Please keep this information sheet for your records.



**Appendix C  
Consent Form**



Childhood Immunization: Parents` and Nurses` Perspectives

I have read the Letter of Study Information and have had any questions answered to my satisfaction. I understand that I am consenting to participate in the study called; Childhood Immunization: Parents` and Nurses` Perspectives. I understand that this involves completing a one-hour audiotape recorded interview.

I understand that my participation in this study is voluntary and I may withdraw at any time. I understand that every effort will be made to maintain the confidentiality of the data now and in the future. My confidentiality and anonymity is assured and my identity will not be revealed. My individual responses will be grouped with other participants to preserve anonymity.

If I am uncomfortable with any interview questions, I can choose not to answer.

I also understand that the discussion about childhood immunization may generate some uncomfortable feelings. If desired, Shelly will assist me in getting in touch with a support person to address my concerns regarding childhood immunizations.

I understand that results may be published in professional journals or presented at conferences, or at community presentations, such as the health clinics.

I understand the information collected during the study will be stored in a locked cabinet by Shelly in her workplace office for a period of seven years.

I can access a one-page summary of the findings directly from Shelly or her research supervisor. Check here if I would like a summary of the study results provided to you.

I am aware that if I have any questions, concerns, or complaints, I can contact the principle researcher, Shelly Hosman (705-235-3211 ext. 7289) a M.Sc.N. student, or her research supervisor, Sharolyn Mossey R.N., M.Sc.N., at Laurentian University (705-675-1151, ext. 3813).

I am also aware that I may contact a Research Ethics Office at Laurentian University Research Office, not attached to the research study regarding possible research ethical issues at 705-675-1151, ext. 2436 or toll free at 1-800-461-4030 or by email at [ethics@laurentian.ca](mailto:ethics@laurentian.ca)

I have read the above statements and freely consent to participate in this research:

Name (please print clearly): \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix D Ethical Approval Letters



### APPROVAL FOR CONDUCTING RESEARCH INVOLVING HUMAN SUBJECTS Research Ethics Board – Laurentian University

This letter confirms that the research project identified below has successfully passed the ethics review by the Laurentian University Research Ethics Board (REB). Your ethics approval date, other milestone dates, and any special conditions for your project are indicated below.

TYPE OF APPROVAL / <u>New</u> <u>X</u> / Modifications to project / Time extension	
<b>Name of Principal Investigator and school/department</b>	Shelly Hosman (Nursing) Sharolyn Mossey, Phyllis Montgomery (supervisors, Nursing)
<b>Title of Project</b>	Childhood Immunizations: Parents' and Nurses' Perspectives
<b>REB file number</b>	2014-04-09
<b>Date of original approval of project</b>	June 2, 2014
<b>Date of approval of project modifications or extension (if applicable)</b>	
<b>Final/Interim report due on</b>	June 2, 2015
<b>Conditions placed on project</b>	Final report due on September 30, 2015

During the course of your research, no deviations from, or changes to, the protocol, recruitment or consent forms may be initiated without prior written approval from the REB. If you wish to modify your research project, please refer to the Research Ethics website to complete the appropriate [REB form](#).

All projects must submit a report to REB at least once per year. If involvement with human participants continues for longer than one year (e.g. you have not completed the objectives of the study and have not yet terminated contact with the participants, except for feedback of final results to participants), you must request an extension using the appropriate [REB form](#).

In all cases, please ensure that your research complies with [Tri-Council Policy Statement \(TCPS\)](#). Also please quote your REB file number on all future correspondence with the REB office.

Congratulations and best of luck in conducting your research.

Susan James, Chair  
Laurentian University Research Ethics Board

**Porcupine Campus**

Mail:  
P.O. Box 3211  
Timmins, ON  
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September 25, 2014

Shelly Hosman  
91 Sterling Avenue West,  
Timmins ON  
P4N 3K4

Re: Ethics Review Application – File #14-09R

Dear Shelly,

Thank you for applying to the Research Ethics Board (REB). I am pleased to inform you that the Northern College Research Ethics Board has now approved your application to conduct the following study at Northern College:

**“Childhood Immunizations: Parents’ and Nurses’ Perspectives”**

You may now begin your research.

Please note that your REB approval is contingent upon your adherence to the exact procedures and documents as described in the final version of the application documents that you have submitted to the REB as of this date. Should you make any substantive changes to your research processes from what has been described in these application documents, or should you wish to do any research beyond what was described in the application in the future, you will need to re-apply for REB review and approval. You are not permitted to implement any changes until you have received the written approval of the REB.

Researchers are expected to keep detailed records of their research activities (i.e., interview log sheets, signed consent forms etc.) in a secure place along with the data collected and destroyed when the data is destroyed in accordance with the REB approved application. Please notify me when your research has been completed.

All the best with your study.

Sincerely,



Aaron Klooster, Chair  
Northern College Research Ethics Board

C: Tori Hanson, Director Trades and Technology

## **Appendix E**

### **Interview Guide**

#### For Interviews with Parents

Looking back at your decision regarding immunization and your child, what stands out in your mind? (Probe: What/who influenced you? Family, friends, neighbours, media, school, regulations, pamphlets...)

What kinds of experiences did you have with nurses or health care providers to discuss immunization before and after you made your decision? What stands out in these particular experiences? (Probe: approachable/not approachable; helpful/not helpful; knowledgeable/not knowledgeable; positive/not positive)

Now that some time has passed since you made the decision with regards to immunization, would you now make the same decision? (Probe: Why or why not?)

How does the news of outbreaks, such as the current measles outbreaks, affect you? (Probe: impact your decision?)

What particular sources of information did you refer to or rely on?

#### For Interviews with Nurses

What experiences have you had with parents and their decision to immunize? (Probe: Specific and general)

What information do you provide? Is there certain information or formats of information that you prefer? (Probe: Rationale? Anything specific to the immunization itself, such as ingredients?)

Does it include both pros and cons to immunization?)