

ABSTRACT

UNDER WHAT BELIEFS AND KNOWLEDGE DO PARENTS ANSWER THE QUESTION NOT TO VACCINATE?

By Lindsey E. Baade

Many misconceptions are publicized about immunizations. The factors and influences that parents cite for not immunizing their children are important to know and understand as family practice providers in order to provide education on credible sources of benefits and risks of immunization. The purpose of this study was aimed at identifying parental beliefs and understanding toward immunization. Further, this study anticipated to identify immunization implications and practice guidelines for the advanced practice nurse (APN).

This phenomenological qualitative study used semi-structured interview questions through snowball sampling to delve into the reasons parents oppose immunization. While parents affirmed several reasons for not vaccinating their children, the three major congruent themes were *the body knows best*, *toxic consequences*, and *balancing act*. The conclusions drawn from this study indicate that parents who do not vaccinate their children believe that a healthy body, free of toxins, will build natural immunity to fight off disease. Implications for APNs include providing parents with credible information, as well as providing parents with information on vaccine preventable diseases. Implications for future research include re-interviewing these parents to see if they were at all affected by their decision not immunize.

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QUESTION NOT TO VACCINATE?

by

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I would like to dedicate this project to my family. To my husband, whose love and support through thick and thin have kept me balanced and grounded. To our boys, Maximus and Cooper, your love, smiles, giggles, and silliness have kept a smile on my face and brought me relief when I really needed it. Thank you for all the sacrifices you have made while I was in school. I look forward to putting the books back on the shelf and you back in my arms. And to the rest of my family, my parents, siblings, and in-laws, for believing in me and being there for last minute help and support when it was really needed.

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TABLE OF CONTENTS

	Page
LIST OF TABLES	vii
LIST OF FIGURES	viii
CHAPTER I – INTRODUCTION	1
Significance to Nursing	4
Problem Statement	5
Purpose	5
Research Question	6
Definition of Terms.....	6
Conceptual Definitions	6
Operational Definitions	6
Assumptions	7
Summary	7
 CHAPTER II – THEORETICAL FRAMEWORK AND REVIEW OF LITERATURE	 9
Theoretical Framework	9
Health Belief Model	9
Perceived Susceptibility.....	12
Perceived Severity	12
Perceived Benefits	12
Perceived Barriers	13
Cues to Action	13
Application of Theory to this Study	14
A Case Study	15
Individual Perceptions	15
Modifying Factors	15
Review of Literature	16
Immunization History	16
Anti-Vaccination Movement	17
Anti-Vaccinations on the World Wide Web	18
Autism and Vaccination	19
Parental Beliefs	21
Parental Influences	23
Social Influences, Media and Government	23
Provider Beliefs	23
Summary	24

TABLE OF CONTENTS (Continued)

	Page
CHAPTER III – METHODOLOGY	26
Research Design	26
Population, Sample and Setting	26
Data Collection Instruments	27
Procedures for Data Collection	27
Procedure for Data Analysis	28
Anticipated Limitations	28
Summary	29
CHAPTER IV – RESEARCH FINDINGS AND DISCUSSION	30
Demographic Data	30
Process	31
Results and Discussion	32
Patient Themes	33
Theme One: Body Knows Best	33
Natural Immunity and Breastfeeding	33
Food is Your Medicine	35
Theme Two: Toxic Consequences	36
Contents	36
Risks versus Benefits and Backup Plans.....	37
Theme Three: Balancing Act	40
Mistrust	40
Balanced Interactions	42
Current Influences	43
Relation of Study Findings to Previous Studies	44
Mistrust	44
Consequences of Vaccination	44
Summary	45
CHAPTER V – SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS	46
Summary of Study Findings	46
Relevance to Health Belief Model	48
Conclusions	49
Limitations	50
Implications for Nursing Practice and Education	50
Recommendations for Research	51
Summary	52

TABLE OF CONTENTS (Continued)

	Page
APPENDICES	
Appendix A. Interview Questions	53
Appendix B. Demographic Questionnaire	55
Appendix C. Participant Consent	57
Appendix D. UW Oshkosh IRB Approval	59
REFERENCES	61

LIST OF TABLES

	Page
Table 1. Themes and Subthemes	33

LIST OF FIGURES

	Page
Figure 1. Health Belief Model	11

Chapter I

Introduction

Vaccination against childhood diseases is one of the greatest medical success stories of the last half century. In the United States (U.S.), immunization rates are at all-time high levels and vaccine-preventable diseases (VPD) are at all-time lows (Cooper, Larson, & Katz, 2008, p. 149). Nonetheless, the allegations of harmful side effects from vaccines has been so widespread that they pose a threat to immunization programs and erode the trust in primary care providers (PCP) and public health organizations. The tremendous success of immunization is evidenced by the control of VPD and that the benefits of immunization outweigh the risks (Salmon et al., 2009). There are also a plethora of subjective reports suggesting that immunizations can cause great harm in some instances (Friedlander, 2001). Parental decision to forego immunization is very anxiety ridden. For PCPs and other individuals of the community, such as public health organizations, members of society, and government, immunizations are so successful in health promotion and disease prevention that it is inconceivable that parents do not understand the threat of many communicable diseases.

For some, the strong belief of action versus inaction may be reason enough to opt out of immunization. In omission bias, harm resulting from action (immunizing a child) is considered less acceptable than harm resulting from inaction (not immunizing a child) (Wroe, Turner, & Salkovskis, 2004). The adverse publicity of vaccinations, such as the suspension of the rotavirus vaccine (Lyren & Leonard, 2006) and the discontinuation of thimerosal-containing vaccines, and continuing reports linking autism with the measles-mumps-rubella (MMR) vaccination, albeit unproven, (Luthy,

Beckstrand, & Callister, 2010), has caused parents to be concerned about vaccinating their children. The rapid spread of information and misinformation by internet technology and mass media has created an environment where parents have a high likelihood of encountering anti-vaccination material (Wu et al., 2007). "Vaccines are victims of their own success," is the reality now that reflects in the absence of VPD, many parents fear the vaccines more than the diseases (Cooper et al., 2008, p. 149).

Many research studies have unveiled parallel results on parental beliefs toward immunization in relation to perceived severity and susceptibility of VPD. Perceived susceptibility and severity of VPD is low (Bennett & Smith, 1992; Bond, Nolan, Pattison, & Carlin, 1998; Kennedy, Brown, & Gust, 2005; Wroe et al., 2004). However, there have been recent outbreaks of VPD, given the increasing numbers of unimmunized individuals. In 2005, Indiana confirmed 34 cases of measles, which the time, made it the largest U.S. outbreak since 1996 (Parker et al., 2006). Between January 1, 2008 and April 25, 2008, there were five measles outbreaks and 64 reported cases; all but one of the persons with measles reported that they were unvaccinated (Omar, Salmon, Orentstein, DeHart, & Halsey, 2009). One hundred and thirty-one cases of measles were reported to the Centers of Disease Control (CDC) during the first 7 months of 2008, which now represents the largest number of measles cases since 1996 (De los Reyes, 2010). As evident by the above noted research studies, VPD are on the rise.

Lyren and Leonard's investigative report (2006) revealed parents' common objection to vaccination was that they didn't believe in putting their child at risk for diseases that do not exist in the community. When, in fact, these diseases do still exist in communities and are on the rise again because of parental refusal to immunize

against VPD, as evidenced by a measles outbreak in 2005 and pertussis outbreaks in Wisconsin (Omer et al., 2009).

Further probing into parental beliefs and influences regarding vaccine safety and efficacy has been highlighted by the literature. As reported in the study by Salmon et al, (2009), "... further studies to explore vaccine safety concerns among parents are needed" (p. 22). Examining how to improve parental understanding of vaccine safety is noted by Salmon et al. (2009). Cullen's study (2005) supports the need for further research, as evidenced by the lack of understanding about diseases that vaccines prevent. The study by Luthy et al. (2010) also supports the need for vaccine safety understanding, given that despite eight different review panels from the Institute of Medicine (IOM) reassuring there is no causal link between immunization and autism, parents still were uncertain regarding vaccine safety. Luthy et al. (2010) further stated that a current need to assess parental understanding regarding childhood immunizations is important. Generalizability and homogeneity were limitations noted in previous studies (Gullion, Henry, & Gullion, 2008; Smailbegovic, Laing, & Bedford, 2003), and therefore, a broader spectrum of vaccine objectors could be studied.

Studies of parents' comfort with new vaccines repeatedly document the importance of provider attitudes (Sturm, Mays, & Zimet, 2005). As stated in Sturm et al. (2005), Freeman and Freed surveyed parents of 2-year-old children. Sixty percent of parents who obtained or intended to obtain a new varicella vaccine reported the doctor's recommendation as influential. Research suggested that greater outreach by providers to offer recommendations to obtain vaccination may improve parental acceptance of vaccination.

Throughout the persistent debate on immunization, it is important to note that the American Academy of Pediatrics (AAP) fully support vaccination for health care, along with many other professional organizations, including the American Association of Family Physicians (AAFP) and the Centers for Disease Control and Prevention (CDC) (AAP, 2008; CDC, n.d.). Vaccines save lives and protect against the spread of disease. It is because of vaccinations that our children are safe from diseases with high morbidity and mortality rates. This study will give further insight into parental concerns, beliefs toward immunization, as well as knowledge and understanding of VPD.

Significance to Nursing

The significance of a study on primary childhood immunizations for advanced practice nurses (APN) can be summed up by a statement made by Searson and Smith (1997),

The nurse practitioner as a primary care provider is on the front line to obtain parent cooperation and ensure timely and appropriate immunizations. Further, improving primary immunization rates requires a better understanding of the interplay of reasons for immunization delay (p.21).

As APNs, dealing with parental concerns in regards to vaccine safety will become a daily occurrence. It is necessary to understand why parents refuse vaccination and whether the parents understand the severe sequelae associated with VPD. As stated in Omer et al (2009), parents of both vaccinated and unvaccinated children refer to their health care providers as their most frequent source of information on vaccination. Understanding the parental beliefs is beneficial to APNs in order to better target education and resources to those parents.

Problem Statement

Vaccines are among the most effective prevention tools available to APNs. High immunization coverage has decreased VPD. A reduction in the incidence of VPD has led to the public perception that the disease severity and susceptibility has decreased (Omar et al., 2009). For many parents, immunizations have become the risk, not the benefit. Perceived vaccine safety issues remain at the forefront of parental concerns. According to the study done by Luthy et al (2010), the development of autism remained a major concern of parents despite past research evidence and education to relieve this concern. The problem with parents opting out of childhood immunization is the risk it poses not only to their own children, but the community. Herd immunity is immunity incurred by having those around oneself immunized and thereby protecting oneself from VPD, instead of the vaccination itself (Omer et al., 2009). Herd immunity is thought to protect unimmunized children; however, as evidenced by recent research on outbreaks of measles and pertussis, the numbers of unimmunized children are counteracting the effect of herd immunity (Salmon et al., 2009). Unfortunately, the success of immunizations in controlling VPD has resulted in diminishing parental fear of these illnesses, and increasing fear in immunizations themselves.

Purpose

The purposes of this study include further delving into parental understanding and beliefs regarding immunization of their children against VPD. Secondly, to identify parental knowledge of immunizations, so APNs in a primary care setting are able to tailor education to parents questioning the safety and efficacy of vaccination based on their beliefs and knowledge.

Research Question

The research question will be: What beliefs and understanding do parents have of vaccines and vaccine-preventable diseases that guide their decision to opt out on childhood immunizations?

Definitions of Terms

Conceptual definitions.

Parents: For purposes of this study are defined as a mother or father of a child.

Beliefs: Convictions without necessary supporting evidence.

Vaccine-preventable diseases: Are deadly diseases that have been decades gone because of immunization and are now on the rise again because of refusal to vaccinate.

Immunizations: Is actively protecting one's child through utilization of a vaccine to introduce an antigen for one's body to develop antibodies against that disease.

Operational definitions.

Parents: For purposes of this study are defined as a biological mother or father, at least 18 years of age, having one or more children aged 0 to 6 years, who do not receive any of the compulsory childhood immunizations within 1 year based on the recommendations from the CDC, AAP, and AAFP.

Beliefs: Beliefs will be defined by the participants of this study using open-ended questions, asking them to describe their beliefs and influences toward immunization of their child and perceived susceptibility of VPD for their children, as well as their knowledge and understanding of immunizations and their importance for disease prevention.

Vaccine-preventable diseases: Will be defined by participants' descriptions as perceived susceptibility and severity of contracting the diseases, as well as what parents consider VPD.

Not immunizing: As defined for purposes of this study will be measured as vaccinations not received within 1 year of the recommended timetable, as defined by the CDC per parental report. The primary vaccinations for children ages 0 to 6 are the following: Hepatitis B (Hep B), Rotavirus (RV), Diphtheria, Tetanus, Pertussis (DTaP), Haemophilus Influenzae (Hib), Pneumococcal (PCV), Inactivated Polio (IPV), MMR, Varicella, and Hepatitis A (Hep A) (CDC, n.d.).

Assumptions

1. Parental knowledge of immunization stems from family members and friends whom have had a bad experience with immunization and therefore cluster all immunization to be harmful rather than beneficial.
2. A parental decision to refuse immunization is influenced by media coverage and past research linking immunization to autism.
3. Parental understanding and knowledge of immunization leans more toward the fact that VPD are no longer a dangerous threat to children today.
4. Parents make decisions about vaccinations with their child's best interest in mind.

Summary

In this chapter, an overview of the impact of immunization to VPD was presented. Past research has focused on parental attitudes, social influences, and beliefs; however,

many of the studies were limited by the homogeneity of their studies. The significance of the problem to APNs has been provided, and thus a rationale for this study. Conceptual and operational definitions were provided, as well as assumptions of this study. Chapter II follows with the theoretical framework of this study, a case presentation, and the review of literature.

Chapter II

Theoretical Framework and Review of Literature

This chapter presents information on the theoretical framework. A case study will be utilized to expand the theory and concepts within and how they fit into this descriptive phenomenological qualitative study. A review of the literature will include a critical, concise discussion to synthesize the research already available on immunizations, parental beliefs, and social influences on childhood vaccination. as well as vaccine history; to include the anti-vaccination movement, misconceptions about vaccination and autism, and provider beliefs as influencing parental decisions.

Theoretical Framework

The Health Belief Model (HBM) (Figure 1) provides the framework for this research study. The HBM attempts to explain participation in health-related behaviors. Individual perceptions, modifying factors, and likelihood of action play a role in the HBM. Perceived vulnerability and severity of the disease plays a factor in health behavior decisions, and the benefits of the action have to outweigh the inaction.

Health Belief Model

The HBM is a theory of preventative health behavior and has been used extensively in preventative health practices. Developed by Hochbaum in 1958, the HBM explains why and under what conditions people will take preventative actions. Hochbaum revealed that individuals engage in preventative health behavior based on three factors: (a) perceived vulnerability, (b) perceived severity, and (c) perceived benefits (Rosenblum, Stone, & Skipper, 1981, p. 337). Further development of the HBM

by Rosenstock unveiled five dimensions of decision making within the HBM: (a) perceived susceptibility to the disease, (b) perceived severity of the disease, (c) perceived benefits of health-related behavior, (d) perceived barriers/cost of the health-related behavior, and (e) a cue to action that initiates the behavior (Searson & Smith, 1997). Rosenstock's HBM model will be used for this study.

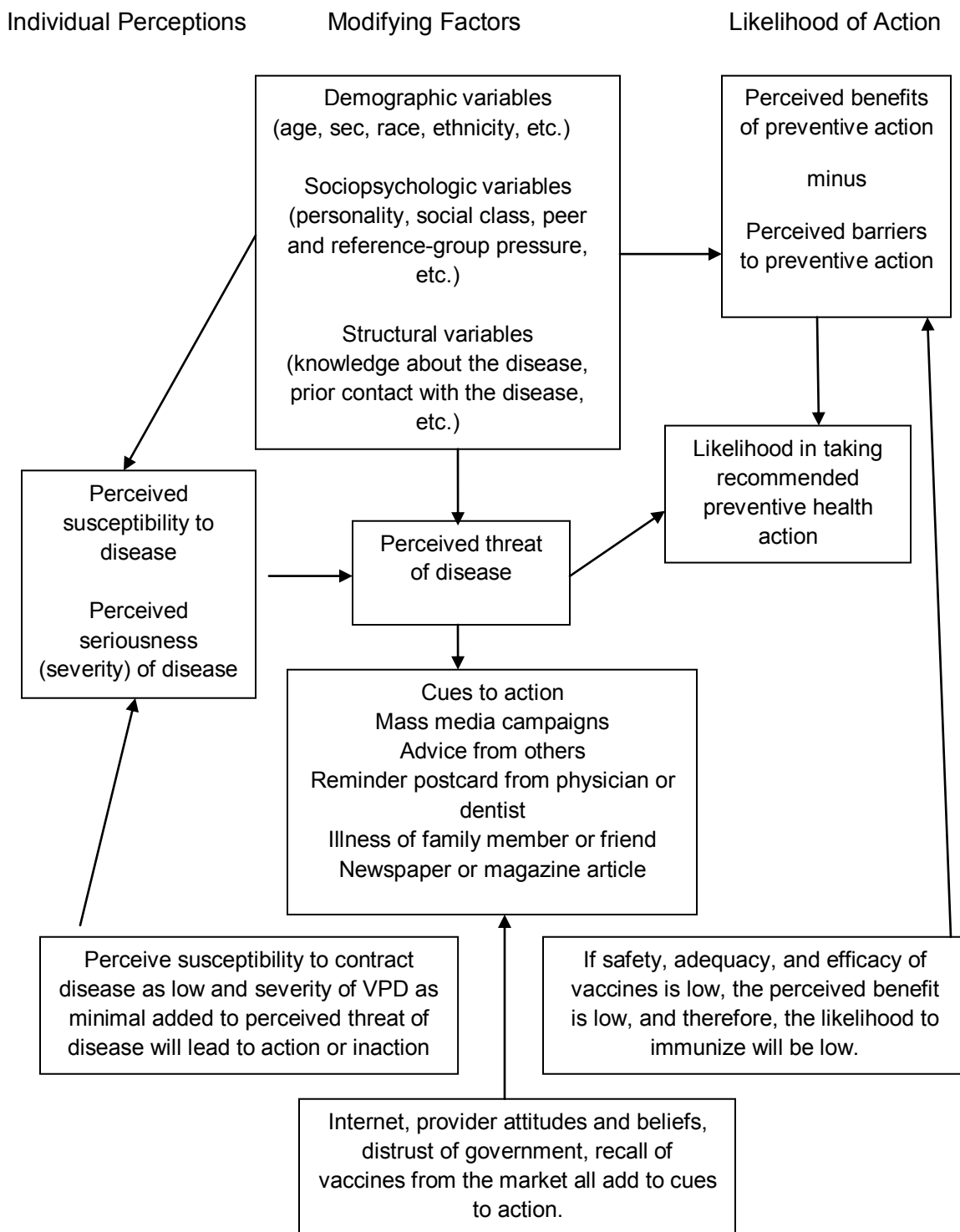


Figure 1. Health Belief Model (National Institute of Health [NIH], 2008).

Perceived susceptibility.

Perceived susceptibility according to the HBM is the degree to which a parent perceives their child's likelihood of contracting the VPD. Perceived susceptibility, severity and threat of a disease, and individual perceptions guide parental decisions (Figure 1). Parents who choose not to immunize believe that their child is less susceptible to contracting the disease. Another parental belief evidenced in research is that the body can protect itself without vaccines (Kennedy et al., 2005). Due to successful immunization efforts, few parents have had any experience with VPD; and because of the rarity of these diseases due to vaccines, parents unrealistically view their child's susceptibility and prevalence in the community to be minimal, if any, risk at all.

Perceived severity.

Severity according to the HBM is the degree of seriousness of the disease as perceived by the parents, again, individual perception (Figure 1). If parents do not perceive VPD as severe enough to warrant preventative action, they will be more likely to oppose vaccination policy (Kennedy et al., 2005). Parents believe that VPD no longer pose a threat to their children (Searson & Smith, 1997), and this belief is still evident in research today (De los Reyes, 2010). It appears evident in the research (Cullen, 2005; Luthy et al., 2010; Omer et al., 2009; Salmon et al., 2009) that parents perceive VPD as lacking in severity in the present day; furthermore, evidence is lacking in whether or not parents truly understand the VPD well enough and the potentially life-threatening aspects of the diseases.

Perceived benefits.

According to the HBM, perceived benefits of the health behavior must outweigh the risks of inaction and lead to likelihood of action. If parents believe that vaccine

safety, efficacy, and adequacy are low, then the perceived benefit is low and the likelihood to immunize is also low (Figure 1). Parents who refuse vaccination primarily fear the side effects of the vaccine itself over the benefit of immunizing their child from VPD. Not immunizing is perceived as acceptable because the benefit is keeping their child protected from potential side effects of the vaccine.

Perceived barriers.

Barriers are the tangible and psychological costs that stand in the way of a person from acting out the health behavior. Barriers may be lack of health insurance, cost, adequacy, and safety of vaccines (Searson & Smith, 1997). The perception of barriers by parents is influential in their decision to carry out immunization or not. If the adequacy, safety, and efficacy of vaccines are low, parents' likelihood of action is low (Figure 1).

Cues to action.

Cues to action are occurrences or events that encourage the parent to seek out the health behavior. Misinformed parents are more likely to receive their cues from family and friends (Searson & Smith, 1997, p. 24). The media coverage of adverse vaccination events provides cues to action. The widespread anti-vaccination proclamation on the internet is adding to the number of individuals that are still opposing vaccination (Bennett & Smith, 1992; Cooper et al., 2008). These cues to action (mass media, internet, advice, illness of a family member or friend) are all considered modifying factors, and parents use these cues to make their decision on immunization of their child (Figure 1).

Application of Theory to This Study

As stated by Searson and Smith (1997), other research suggests that parents perceive immunizations to be only partly or never effective. The perceived severity of the VPD is severely reduced as related to the huge success of immunization efforts. Unfortunately, due to the colossal success of immunizations in controlling VPD, parents consequently have a diminished fear of the illnesses and instead have an increasing fear of the immunizations themselves (Salmon et al., 2009). Therefore, parents perceive the susceptibility and severity of their children contracting the disease as minimal because the U.S. has not seen outbreaks of the diseases over the past 30 years.

Following the HBM, perceived benefits of immunization are minimized and barriers to immunization relate to trust of the adequacy, efficacy, and safety of vaccines; therefore, the likelihood to immunize is low. Parents take their cues to action from their own individual experiences, family members' experiences, friends' experiences, and the media and internet coverage of adverse events, and do the best to protect their child.

The goal of the HBM as a framework for health education is to provide incentive to take action. When the components of the HBM are understood, the APN can address each individual's perceptions of susceptibility and severity, focus on modifying factors and benefits of taking action to immunize, and acknowledge when an individual is likely to change their behavior. Advance practice nurses can promote immunization, and in receiving repeated and consistent health education, parents will be prepared to recognize that benefits of immunization outweigh the risks (Searson & Smith, 1997).

A Case Study

The following provides a brief case study application, depicting how a parent may use the HBM to make the decision to opt out of immunizing their child.

Individual perceptions.

Faith is a mother of three, a 4-year-old, a 2-year-old, and a 2-week-old. She has always believed in naturalistic methods and alternative therapies of medical care. Faith has always opted out of immunization related to her own personal health beliefs and that the risks to her children of contracting any VPD are minimal (perceived susceptibility). Influences from media coverage from the MMR and autism link have led Faith to not immunize her children. She does take her children to play dates at a local café, as well as enlist them in activity classes at the local YMCA. She also plans to enroll her 4-year-old into public kindergarten this fall.

Faith perceives that her children's susceptibility to contacting any VPD is minimal compared with the potential side effects and long term effects of the vaccination itself (perceived threat). She does not feel that the severity of VPD is serious and no longer poses a threat in today's society (perceived threat and seriousness). Faith perceives benefits of protecting her children from potential neurological disorders and learning disabilities, such as autism. A few friends and family of Faith's had immunized their first born children.

Modifying factors.

Faith has several modifying factors and cues to action that have encouraged her decision. Faith's family member's son developed Cerebral Palsy (CP) after an administration of the MMR vaccination. Faith's friend has firm belief that her autistic son had developed the disorder from the MMR vaccination. Faith had read several websites

on the internet claiming of the risk of autism and other neurological disorders, as well as learning disabilities, and the potential risk of having doses of metal in her children's bodies from the vaccines. These cues to action lead Faith to opt out of immunizing her children all together (Likelihood of Action).

Review of the Literature

The review of literature for this research study focused on what evidence is available on parental beliefs and influences toward vaccination and the HBM as it applies to primary immunizations, as well as the influence of provider beliefs, the anti-vaccination movement, anti-vaccinationists on the worldwide web (WWW), and vaccination linked with autism.

Immunization history.

The first compulsory vaccination law came about in the United Kingdom (UK), namely the Vaccination Acts of 1853 and 1867. These acts granted the government jurisdiction over civil liberties related to public health (Sturm et al., 2005). Pasteur's first rabies vaccination in the 1880s sparked division within the medical community over the perception of purposeful introduction of a medical agent into the body. In like fashion, current-day debate amongst the medical community reveals opposing viewpoints.

Vaccines have long been blamed for causes of medical conditions, as seen with the small-pox vaccine in the 19th century, as it was falsely linked to leprosy and syphilis, and again in the 1980s and 1990s, as vaccines were put forth as possible causes of autism and sudden infant death syndrome (SIDS) (Sturm et al., 2005, p. 444).

Anti-vaccination movement.

Alfred Russell Wallace led the anti-vaccination movement in Victorian England in the 1860s (Weber, 2010, p. 666). His voice created anti-vaccination groups to act with a prompt response, hence the Vaccination Act of 1898. The act provided a “conscientious objector” clause for parents to request exemption on behalf of their children (Sturm et al., 2005). Many of the anti-vaccinationists agree with Wallace that susceptibility to the disease may not have been distributed equally among social classes. Wallace and his followers felt that only specific social classes were at risk for contracting VPD, and therefore, individuals who were not at risk of contracting VPD did not require immunization, as it was an imposition on their rights.

In 1867, Great Britain implemented compulsory vaccinations in an order to control smallpox. Soon thereafter, anti-vaccination groups formed to protest. According to Swales (1992), forced vaccination was an impingement by the government on an individual’s right to liberty and anti-vaccinationists opposed vaccination on religious grounds (as cited in Gullion et al., 2008, p. 402). Therefore, in 1898, the first conscientious objection law was passed allowing parents the right to exempt their children from vaccination. This paved the way for vaccine objectors worldwide.

Early in U.S. history, compulsory vaccination was linked to school attendance, and parents protested. The 1905 U.S. Supreme Court Case, *Jacobson v. Massachusetts*, the Court upheld the right of the state to use penalties from the past, such as exclusion from school, to pressure vaccination of children (Gullion et al., 2008). Today, all 50 states allow for medical exemptions from childhood vaccinations, 48 states allow for religious exemptions, and 19 states allow for philosophical exemptions. Wisconsin (WI) is one of the 48 states allowing for religious exemption and one of the 19

states allowing for philosophical exemptions (Salmon et al., 2009). That is concerning to APNs in WI, therefore making it more central to address why parents of exempt children are opting out of immunization.

In the 1980s and 1990s the MMR vaccine and autism controversies arouse, causing more parental fear of the vaccine itself rather than the morbidity and mortality of MMR. Then, in 1999, the Rotavirus (RV) oral vaccine, related to a temporal relationship between vaccination and intussusception, was removed from the market (Lyren & Leonard, 2006). It is such events that led to parental fear of vaccination and distrust for the government agencies telling parents to do so.

Anti-vaccinationists on the World Wide Web (WWW).

Anti-vaccinationists on the WWW have a great advantage. A study done by Davies, Chapman, and Leask (2002) examining the words “vaccination” and “immunization” on 10 search engines, reported that 55% of U.S. adults were using the internet to seek health-related information. Forty four sites contained content encouraging parents to refuse vaccines and emphasized the dangers of vaccines. The anti-vaccination groups on the WWW sought to present themselves as legitimate authorities with scientific credibility. Allegedly damning research was often quoted without citation of its source. Sites frequently targeted audiences with emotive appeals and tried to provide evidence for conspiracy, and sites referred to their anti-vaccination struggle as a search for the truth as covered up by government organizations (Davies et al., 2002).

Another study done in 2005 looked at the terms “vaccine,” “vaccination,” “vaccinate,” and “anti-vaccination” that produced 78 cites for the study that provided anti-vaccine information (Zimmerman et al., 2005). Sixty seven percent of U.S. adults use

the internet to find health-related information according to their study. Thirty seven percent of the websites shared personal stories of children allegedly injured by vaccines. Zimmerman et al. (2005) highlighted that anti-vaccination web sites report of conspiracy, cover-up, and civil liberty violations.

Friedlander (2001) also reported of the opposition to vaccination on the WWW. His report confirmed that many of the anti-vaccinationist web sites do not have cited sources of their information nor do they dispel any true myths of vaccines. Reports of specific studies identifying vaccines as unsafe and ineffective, took a statement from another study to support their claims, but failed to include the information that it was in cases of severely immunocompromised individuals and not of healthy children.

Autism and vaccination.

The immunization-autism controversy in America continues to date, albeit the numerous research studies providing no causal link between autism and immunization (Lyren & Leonard, 2006; Wroe et al., 2004; Wu et al., 2007). The common belief in the anti-vaccination community is that the preservative, thimerosal, previously used in vaccines, is a neurotoxin that affects brain development and that any mercury-based preservative in small amounts can cause a detriment in brain development (Luthy et al., 2010). Factually, thimerosal is an organic compound of ethyl-mercury, which is a nephrotoxin not a neurotoxin (De los Reyes, 2010, p. 490).

The removal of thimerosal in 2002 from vaccines by the vaccine manufacturers further fueled parents to oppose vaccination and the vaccine community. Both the CDC and AAP had recommended the removal of thimerosal from vaccines in hopes to reduce children's exposure to mercury and reduce parental hesitation to immunize their children. While not the intent of the CDC and AAP recommendation, the autism

community misinterpreted the statement and began questioning the overall safety of immunizations. Furthermore, parents opposing vaccines today still question the safety of immunizations and maintain that statements from government agencies cannot be trusted as viable sources of information. Concerns of “heavy metals,” thimerosal and mercury specifically, were reported by parents on the effect of brain development (Luthy et al., 2010).

As stated by Lyren and Leonard (2006), the MMR vaccine has been the most frequently implicated vaccine to the development of autism, as well as other developmental disabilities. Dr. Andrew Wakefield, a British gastroenterologist, loudly championed that MMR was linked with autism. Wakefield’s study vaguely reported a link between MMR and autism, but additional research could not confirm this. Ten of the 13 authors who participated in his original study have retracted their endorsement. In 2003, the CDC published the results of the Vaccine Safety Data Link Project that reviewed over 100,000 medical records and found no causal link between thimerosal-containing vaccines and autism and any other language or emotional disorders. In May of 2004, the IOM published their results of an independent study that again found no link between thimerosal-containing vaccines and autism (Lyren & Leonard, 2006).

Moreover, Smailbegovic et al.(2003) conducted a study in London of children born from January 1999 to February 15, 1999 who had received one or more immunizations by 18 months of age. One hundred and twenty nine questionnaires were mailed to parents and 68 return questionnaires were collected for quantitative and qualitative analysis. The results of the study were long term concerns by parents that were related to MMR and autism (Smailbegovic et al, 2003). One parent was quoted as saying, “From what I understand from the media, MMR vaccination is more risky than

actual diseases,” (Smailbegovic et al., 2003, p. 307). All mothers in their study had concerns related to MMR vaccine. Half of the families interviewed had personal contact with the parents of children who were autistic and suspected a link between MMR and autism (Smailbegovic et al., 2003). This study was limited to a population in London, and therefore, homogeneity of the study resulted, as well as immunization standards of Europe differ from the recommendations by the CDC in the U.S. The Wakefield study on MMR and autism was published in 1998. These children were born in early 1999, and therefore, parent’s cues to action were from the Wakefield paper and presumably outweighed the recommendations from PCPs. Participants of that study were generally aware of the 1998 Wakefield et al. (in Luthy et al., 2010) paper that proposed the link between MMR vaccine and autism, but reported not being familiar with the studies that followed refuting the evidence provided in the 1998 Wakefield et al. study. According to Margaret Spoelstra, as stated on the Canadian Medical Association Journal website, the conspiracy theory that vaccine manufacturers are hiding the truth about MMR and autism is what fuels parents’ need to know what is causing autism, despite the fact that no large study has replicated Wakefield’s work (Canadian Medical Association, 2010). In January 2010, Britain’s General Medical Council ruled that the children of Wakefield’s study were carefully selected and that some of Wakefield’s research was funded by lawyers acting for parents who were involved in lawsuits against vaccine manufacturers (Canadian Medical Association, 2010). As a result, The Lancet, which published Wakefield’s work in 1998, retracted his paper.

Parental beliefs.

A descriptive comparative study using the HBM was carried out by Pielak and Hilton (2003) on university students and measles immunization status. A self-

administered questionnaire was mailed to a stratified random sample of 400 immunized students and 400 unimmunized students from Simon Fraser University (SFU) in British Columbia. The results of the study concluded that students were more likely to be immunized if they believed that they were highly susceptible to contracting measles. The students perceived susceptibility to contracting measles was low even though a 1997 measles outbreak began among students who were attending SFU (Pielak & Hilton, 2003).

Kennedy et al. (2005) mailed a panel survey of the Consumer Styles Survey of 2002 using a stratified random sample of participants from May 2002 to June 2002 to form the 2002 Health Data Health Styles Survey. The survey was mailed to 10,000 participants with a response rate of 73%. Parental beliefs were on the safety and utility of vaccines, and parents indicated a low level of perceived susceptibility to contracting VPD. It is concerning to have parents believe that susceptibility of contracting VPD is low given that there are more and more outbreaks of VPD in relation to the number of individuals not immunized. As an example, there were 131 cases of pertussis reported to the CDC in 2008 in the U.S., representing the highest outbreak to date (De los Reyes, 2010). Further investigation of parental understanding of VPD and risks associated with VPD compared to immunization is necessary.

Cullen's (2005) qualitative phenomenological study revealed that parents have a fear of the unknown and would rather opt out of immunizations than take action and have their child suffer a serious side effect or neurologic disease. Parents who did not vaccinate their children were anxious about the risks associated with the safety of vaccines.

Parental influences.

The media and press covering adverse reactions of vaccination, as well as social influences and provider interactions, have greatly influenced parents despite the evidence that vaccination protects our children from VPD.

Social influences, media and government.

A cohort study of parents with children aged 2 to 2.5 years was conducted in 1991. Of the 228 respondents, 18% had at least one member of their family advised them against one or more vaccination. Eighty-six percent of those participants had been advised against the pertussis vaccination, and 19% against MMR vaccine (Bennett & Smith, 1992, p. 344). While this study is almost 20 years old, it is important to know if the same reasons and cues to action that affected parents' likelihood of action back then still plague parental decision making today. Cues to action reported in the study done by Bennett & Smith (1992), included family social influences, vaccine safety, and perceived severity and susceptibility of VPD to be low, while risk associated with immunization were high (p. 343-344).

Distrust in government agencies also provides an influence in parents' decisions. Removal of thimerosal in vaccines was the start, and then recall of the RV vaccine in 1999 and again 2 years ago has prompted this distrust once again. Distrust also stems from the social networking which has empowered and reinforced the zeal of even relatively small numbers of people with similar views (Cooper et al., 2008). Even cell phones are rapidly spreading vaccination news in record time.

Provider beliefs.

Humiston et al. (2009) conducted a study in 2005 of 18 physicians and six registered nurses by purposive sampling to achieve representation from primary care

physicians (pediatrics or family practice) or nursing licensure (registered nurse or pediatric nurse practitioner). These practitioners reported that parents rely heavily on their opinion of “what they would do if it were their own child” (p. 123). The health care provider’s perception of the disease and vaccine greatly influence parental perceptions, as reported in the Humiston et al study (2009).

As reported by Diekema and the Committee on Bioethics (2005), it is the role of the physician to provide parents with risk and benefit information necessary for parents to make an informed decision and to attempt to correct any misinformation or misperceptions that may exist.

An anonymous questionnaire consisting of open-ended and closed-ended questions was mailed to 129 parents in the London Borough of Hackney for children who had defaulted for one or more primary immunizations between January 1999 and February 15, 1999 (Smailbegovic et al., 2003). Parents believed that the information given to them by health professionals was biased and that information on vaccine safety was withheld. Of 68 returned questionnaires, 30% considered the information given to them by health professionals as unsatisfactory and requested more detailed discussion.

Summary

The purpose of this study was to further explore why there is parental opposition and hesitation to immunize their children, as well as provide an understanding of parental knowledge about immunization that influences the decision to opt out of immunization. A review of the HBM supports use of the model for the preventative health behavior, immunization. The HBM is especially important for the APN who manages care of pediatric clients and will be educating parents who are making the

decision to opt out of vaccinating their children from VPD. The literature review identified common themes as parental beliefs and influences toward vaccination. The literature unveiled a need for more research to be done, as immunization rates are still not 100%. Furthermore, three past studies have reported on the number of adults using the internet to find health-related information, as well as to share personal stories of alleged injuries from vaccines (Bennett & Smith, 1992; Davies et al., 2002; Friedlander, 2001). One study on parental concerns with immunizations noted limitations in generalizability and homogeneity of the sample population (Smailbegovic et al., 2003). Another three studies evaluated parental beliefs on immunizations (Cullen, 2005; Diekema & the Committee on Bioethics, 2005; Kennedy et al., 2005). One study utilized mailed out consumer surveys (Kennedy et al., 2005), another used a comparative study of self-administered questionnaires to evaluate students' perception of likelihood to contract measles (Pielak & Hilton, 2003), as well as a qualitative study on parental fear of the unknown (Cullen, 2005; Gullion et al., 2008; Sturm et al., 2005). Given the limited number of qualitative studies done with parents to explore their beliefs about immunization and understanding of VPD, this study has potential to provide implications of great value to APNs.

Chapter III

Methodology

The purpose of this study was to explore the parental beliefs and influences that factor into the decision to opt out of childhood immunizations. In this chapter, the study design, setting, sample, procedures for data collection, including instruments to be used, and data analysis are presented. Protection of human participants and the anticipated limitations to the study will be described.

Research Design

A descriptive, phenomenological qualitative study design was used in this study. This is appropriate for use in this study because it allows for direct exploration, analysis, and description of the phenomena toward opting out of immunization. Furthermore, the study design allowed for participants to freely answer open-ended questions for full disclosure of parental beliefs, attitudes and influences toward immunization, as well as parental knowledge and understanding of VPD (Speziale & Carpenter, 2007).

Population, Sample and Setting

The target population in this study was biological mothers or fathers from separate families in WI who will be interviewed separately. The accessible population was parents living in northeastern WI and voluntarily agreeing to participate in this research study. Inclusion criteria required that participants be at least 18 years of age and have at least one child aged 0 to 6 years who has not received any one of the

recommended vaccinations in the last year, as per CDC guidelines. The participants had to be able to read and write English.

Snowball sampling was used in this study. The anticipated sample size was between 10 and 20 participants. Data saturation was achieved at 9 participants. The setting for interviews was at the participants' discretion, which included home, restaurant, and café.

Data Collection Instruments

Data was collected via face-to-face, semi-structured, open-ended interview questions to explore parental beliefs and influences when opting out of childhood vaccinations. Questions focused on parental beliefs and influences, as well as their sources of information and how their provider plays a role. Further, questions focused on parental understanding of VPD susceptibility and severity (Appendix A). The researcher engaged in reflexivity in order to enhance the quality of this research study. The use of open-ended interviewing techniques, tape recordings, and verbatim transcriptions increased the accuracy of data collection, as well as eliminated biases. Bracketing of the researcher's prior knowledge helped to ensure trustworthiness and authenticity of the descriptions of the phenomenon by the participant.

Procedures for Data Collection

Permission for this research study was obtained from the University of Wisconsin Oshkosh Institutional Review Board (UWO-IRB) (Appendix D). Upon obtaining approval from the UWO-IRB, snowball sampling method was used to assemble volunteer participants. The participants were asked to complete a demographic questionnaire

(Appendix B). The full nature of the research study was explained to the participants, as well as goals, procedures, risks, and benefits. Full disclosure of the study was included, and the participants were told that participation was voluntary and anonymous, the right to privacy was granted, and participants could opt out at any time. In this way, informed, implied consent was obtained from all those who participated.

Procedure for Data Analysis

The researcher became immersed in the data in order to preserve the uniqueness of the lived experience of the participants describing this phenomenon. The interviews were tape recorded, transcribed verbatim, and the content was analyzed for emergent themes. Data analysis for this research study utilized Giorgi's 1985 Methodological Interpretations of qualitative data (Speziale & Carpenter, 2007).

Anticipated Limitations

1. Use of snowball sampling could yield participants of the same socioeconomic background.
2. Study was done in a northeastern city in Wisconsin. Therefore, generalizability of the study findings may be limited.
3. Individuals volunteering for this kind of study may be more passionate about their values and beliefs toward immunization.
4. Researcher bias was anticipated and eliminated by having an experienced researcher faculty advisor validate themes.

Summary

This descriptive phenomenological qualitative study explored in depth the attitudes, beliefs, and influences amongst parents who opt out of immunization. This chapter presented the design of the research study, the population, sample size, and setting, as well as data collection instruments and procedures. Data analysis and anticipated limitations of this research study were explained and highlighted.

Chapter IV

Research Findings and Discussion

The purpose of this study was to explore parental understanding and beliefs towards vaccinations with parents who do not vaccinate their children. A phenomenological qualitative study was conducted utilizing snowball sampling method and semi-structured interviews. The findings and discussion are presented in this chapter.

Demographic Data

Nine participants were recruited for face-to-face semi-structured interviews to assess parental understanding and beliefs toward vaccination. Participants were from the Midwest, and included both males and females between the ages of 26 and 36 years. All were married and had opted not to vaccinate their children with the routine recommended immunizations by the AAP. Participants were recruited via snowball sampling and were given a demographic questionnaire and consent for participation in the study. The demographic questionnaire consisted of 10 items regarding each participant's year of birth, gender, ethnicity, marital status, family size, gross yearly income, use of natural alternative complimentary (NAC) medicine, and breastfeeding status (Appendix B). Semi-structured interviews were conducted at a mutually agreed upon time and place. The interviews were audio-recorded and transcribed verbatim for theme development and analysis. Data saturation was felt to be reached at nine participant interviews.

Each interview ranged in time from 20 to 60 minutes. Ten questions were asked in the semi-structured interviews, with 100% response rate. The participants were both male and female. The sample comprised of three males and six females, all of whom were married. One participant was Asian American, while the remaining eight participants were White. Family size of seven participants ranged from one to four people, while the remaining two had family size of greater than five people. Three participants had doctorate degrees, three had baccalaureate degrees, and two had associates or technical degrees, while the remaining one participant had a master's degree. Five participants reported use of chiropractic NAC medicine, three participants reported use of homeopathy along with vitamins and supplements. Almost all participants reported exclusivity of breastfeeding. Four participants reported living in a suburban area, three reported living in rural communities, while two participants reported living in the city.

Process

Each participant was contacted either by phone or email by the researcher to discuss the study and ascertain interest in participating. Face-to-face interviews took place in a secluded, private, quiet area that was mutually agreeable to participants and the researcher. Two participants preferred a phone interview due the distance they lived from the researcher and the participants availability to travel to meet the researcher. All interviews were audio-taped after a written consent was obtained. With exception to occasional probing questions, the researcher followed the following script of questions (Appendix A):

1. Please describe your beliefs and opinions about vaccinations?
2. When did you first start thinking about vaccination of your child (ren)?
3. Please describe events that led to your decision not to immunize.
4. Who or what influenced your decision the most?
5. During the decision making process, who was involved?
6. What comes to mind when I say “MMR?” “Hib?” “Varicella?” Tetanus and Pertussis?
7. Can you describe what a bad reaction would be to immunizations?
8. Please tell me about your interactions with your Primary Care Physician?
9. Where do you obtain current knowledge about vaccination?
10. How do you feel your child is protected from Vaccine Preventable Diseases?

Results and Discussion

The verbatim transcriptions of the interviews were analyzed using a Giorgi's 1985 Method for Phenomenological Analysis. Three major themes were identified from the study. These included *body knows best*, *toxic consequences* and *balancing act*. All of the major themes led to the decision not to immunize. From the transcripts, three major themes were identified (Table 1) with numerous subthemes.

Table 1.

Themes and Subthemes

Major Theme	Subthemes
Body Knows Best	<ul style="list-style-type: none"> • Natural immunity and breastfeeding • Food is your medicine
Toxic Consequences	<ul style="list-style-type: none"> • Contents of vaccines • Risks vs. benefits and back up plans
Balancing Act	<ul style="list-style-type: none"> • Mistrust • Balanced process • Current influences

Patient Themes**Theme One: Body knows best.**

In this theme, the recurring response of the concept that the body knows best was used when participants would describe their beliefs about immunizations.

Comments included, “I feel it is a disservice to my child’s body to not allow her immune system to strengthen itself by reacting to actual illnesses,” “God didn’t make junk and he intended us to fight off...,” “I just think we don’t trust our bodies enough to, um do what it’s supposed to do,” “I think the good Lord has made our bodies to heal ourselves and um, I think, we can do that without the immunizations,” and “The body knows what it is doing.”

Natural immunity and breastfeeding.

Within *body knows best*, participants identified that natural immunity and breastfeeding were components of *body knows best* and seemed to go hand in hand. The participants highlighted natural immunity and more times than not, associated it with breastfeeding. One participant described her own belief of natural immunity.

(F)irst of all I practice extended breastfeeding. Research has shown that as you get into the second year of life and beyond, the immunities that the mother has ah, are stronger in the breast milk...I also believe based upon research that I've done, that the immune system functions better when it is exposed to disease in a natural setting because that is what strengthens you, ... that allows your immune system to work the way it's designed to do.

Another participant described his beliefs on building the immune system with natural immunity from the common cold because his child did not receive vaccines.

I look at it as oh he's sick, he's got a cough, runny nose, but I look at it that you are vaccinating your children, but those vaccines weren't for the common cold...his body is getting rid of that stuff because his immune system is being built. It takes time to do that.

Another participant described his understanding of natural immunity versus acquired immunity through vaccination.

(B)ecause I think that once a child or person contracts the full disease, that, my understanding is that, they have immunity for life, uh from that disease versus receiving the vaccine and then they only have limited time which is completely unknown. Some vaccines only work for 10 years, some 20, and it's all, in there. He further went on to say in his interview "(W)e believe that the antigens are passed on through, uh, from the mother through the breast milk to the baby."

Other participants highlighted breastfeeding as their foremost support of the immune system. Comments included, "for one, he's still breastfed. I think breastfeeding is the biggest thing, I think it's underemphasized in this society" and "...I'm still

breastfeeding ... and I'm hoping my immune system is stronger and I'll help her out with that."

Food is your medicine.

Participants also expressed their beliefs that good nutrition will provide the body with what it needs to fight disease. Comments included: "food is your medicine and medicine is your food," "good health and nutrition are important as prevention," "I think nutrition is just...overlooked by medicine as a way to stay healthy," "I feed my children the best diet we can...more organic food," and "we feed him good food, when they start getting sick I take sugar out of their diet."

One participant expressed his beliefs of what good nutrition is for the body. "People eat a lot of soda, fast food and don't exercise. I mean I drink a lot of water, eat healthy foods and exercise and keep out toxins, you're going to be a lot better."

Another participant spoke of her beliefs towards good nutrition.

So, like, the nutrition and like health. I don't think you can just say that my kid's not going to get this disease, we'll just keep eating McDonald's and Doritos and we'll be fine. I don't think that...and what I make for my family is not processed. And what I mean by not processed is we don't eat cereal because that is processed. I don't drink pasteurized milk because that is processed.

Other participants' comments towards their beliefs of good nutrition included: "there's too much emphasis on quick fixes versus uh good nutrition...like the fat and protein in a good old fashion steak," "we rarely have packaged foods or processed foods. We try to eat local organic things as much as possible," and "we try to buy like organic or hormone free milk, some organic foods, we don't always buy all organic, that's expensive, but um, ya fruits, fresh vegetables, you know, whole grain instead of whites."

Theme Two: Toxic Consequences

Theme two evolved from participants' expression that the risks of vaccinating did not match up to the benefit of natural immunity. Safety and efficacy of vaccines brought doubt to a few of the participants' minds. The adverse effects, whether fever or autism, were too much for the participants to take the risk. Comments included: "they have preservatives that could effect, effect the blood..." and

I believe that there are lots of side effects of them, some minor, some very severe, um that the risk is not worth it to me and my family, um and effective as we see over and over and over they are wearing off.

Contents.

For participants of this study, it was clear that the decision to not vaccinate involved knowledge of vaccine manufacturing. A few participants acknowledged safety and efficacy of vaccines. Participants expressed their many concerns with the contents of vaccines as being a contributing factor to deciding not to immunize their child(ren). Remarks included: "...when we throw in heavy metals, toxins, preservatives, it's going to decrease our immune function," "I don't support repeatedly injecting foreign and KNOWN toxic substances (aluminum, mercury and formaldehyde for instance) into her rapidly developing body," and "(rubella) that one is grown through aborted fetal tissue, that has aluminum in it, it's not good for me, we all know that causes neurological problems."

One participant described her understanding of the contents of vaccines from research she had done on simian kidneys.

In fact, as I understand it with MMR in particular, it is still grown in simian kidneys, and we only know about 2% of simian diseases...SV40 was found to be

contaminating MMR's I think in the '60s or '70s-don't quote me on that time frame- and was found to be passed from mother to fetus. The significance is that they also found it in many tumors as cancer rates rose. Could be coincidence, but doesn't change the fact that we know relatively little about these SV's yet don't hesitate to use these organs which are sources of possible contamination. Safe? I think not.

Another participant described his understanding of what goes into manufacturing of vaccines.

(A)ctually, I think it was learning about um, thimerosal, that goes into vaccinations, specifically for me, and um knowing that it's link to mercury. Ah, with that, with that blood brain barrier not being developed in infants realizing that there is no way to protect chemicals from simply getting to the brain.

A different participant described his thoughts of vaccine safety testing.

(O)ne thing I don't like about vaccines is when they are testing them for safety, like, they aren't testing them against a benign placebo, they are testing them against other vaccines. So, if, you know, this vaccine is causing this much, you know, ah, a certain amount of destruction and, and um, so the new vaccine they produce is causing an equal amount of destruction with the same effect, you know they say it is perfectly safe because it is the same as the last vaccine.

That's, I think, that's just flaw of safety testing.

Risks versus benefits and back up plans.

Many of the participants expressed that they devoted time reviewing the risks and benefits of vaccination. Participants weighed risks based on contents of vaccines, side effects of vaccines, and that the United States was a developed country with good

sanitation and hygiene. Participants acknowledged that socioeconomic status also played an important role in their decision process. A few participants noted the role of history of vaccinations and how that played a part in their decision process. Participants further discussed measures they use to keep their children healthy. Rationalization included: "I don't think its necessarily, think that it's necessary for every child in the United States to be required to have a vaccination for diseases that are not as prevalent here," "you know, our economic status is good, we have good insurance if we do get sick we can be treated," and "I truly believe that the reason some of those disease are still going are because we still have the vaccine causing those."

Some participants focused heavily on side effects of vaccines as being too great a risk to vaccinate. Several participants noted that an adverse reaction to vaccines would be fevers and irritability; " I mean it can be fever, I don't think fever is bad," "I know kids can get fever, kids can get very lethargic," and "I think even a bad reaction would be you know fever, crying, crying a lot or um, you know." While others focused on the more serious neurological side effects, such as autism and seizures. "Oh goodness, I mean there's death, there's seizures, there's autism, there's hospitalizations, SIDS, asthma, everything out of the womb," commented a participant when asked to describe a bad reaction to immunizations. Another participant similarly commented, "a bad reaction is not soreness at the injection site, sorry. Um you know, like, neurological problems, death, paralysis."

One participant commented about his thoughts on MMR,

I've had a patient say that her 2 or 3 year old daughter was vaccinated and she was driving away from the hospital and looked in the rearview mirror and her daughter was having a seizure. So she pulled over and freaked out. Oh um,

Asperger's, and anything on the spectrum where autism is the nice warm fuzzy name, but the real name is nonfatal sclerosing of the brain. I think if people say autism, people say ah, that poor child, but you know if you say nonfatal sclerosing of the brain, people would say ah that's really bad.

One participant expanded upon her decision to not vaccinate related to the U.S. being a developed country.

This is just again my United States perspective, first world country, high levels of sanitation and disease control and there are camps that say, well the reason we have disease control is because we have this, this immunization herd here. And um, there are more and more families opting out of vaccines so that is kind of changing herd mentality ... so to say how is ___ protected because I feel the disease aren't rampant anymore, I don't know if I think it's protection or if it's just, or if it just is ... but I think if measles were running rampant, we probably would be a little more, we probably would have given her the immunization for that.

Another participant further described his belief that at the time vaccines were introduced, the diseases were on their way out:

When mass vaccination started 1965/1970, all diseases kind of go up, bell shape and fall down. Every disease, that, that is vaccinated for now, all pretty much died out by the time the vaccine was introduced. So I don't think you can correlate the vaccine did that ... I'll use, polio is probably is one of the big ones. Well you know what the other name of polio is? Aseptic meningitis. That exists today! That is polio! So how did polio stop, but aseptic meningitis go up? I don't think it really did.

Several participants stated measures they take to protect themselves. These back up plans were determined from participant remarks such as: “ we play in dirt, I don’t use antibacterial soap because our kids need to be in touch with bacteria,” “ when they do get sick I give them things to build their immune system, higher levels of vitamin C, other immune supporters, vitamin D,” “I adjust them once a week, once a month, whatever it takes...if need be, runny nose or cough/cold, I adjust them more,” and “being chiropractors we believe the body heals itself, so um, we keep them adjusted, we feed them well.”

Theme Three: Balancing Act

As APNs, it is important for us to provide accurate and adequate information to our patients from credible sources. It is important to keep a nonbiased persona and to encourage the patient to do what is best for them, but highlight the recommendations from credible governing bodies and why that is. Participants highlighted that much of their decision was from mistrust of governing bodies, pharmacy, and providers. A few participants highlighted that taking the information they would get and sieving out what was important information. Participants described where they keep current on their information and their interactions with their providers, good and bad. Within *balancing act*, three subcategories evolved; *mistrust*, *balanced interactions* and *current influences*.

Mistrust.

Participants varied on their provider interactions. More participants than not reported that their interactions with their providers were good. Participants who developed a mistrust of their provider tended to look elsewhere for care. A lot of frustration seemed to stem from the governing bodies and pharmacies’ perceived

influence on the providers giving the care and recommendations to vaccinate.

Comments included: “like the AAP, the fact that like you know, they’re given huge contributions by huge pharmaceutical companies,” and “conflict of interest, um that’s what I say about the AAP accepting money from pharmaceutical companies.” Further, a participant commented on media being influenced by pharmacy stating “if the news company says anything bad about it, what happens to their, their money from the commercials Merck is going to say, hey you ah aren’t talking about our flu vaccine in a very good way.” Another participant strongly noted:

If you can give somebody toxins, poisons, preservatives and whatever else they throw in there, heavy metals, sick at a young age, you have them for life. As a very, I hope, I truly hope that that is not their way (providers, government) but I really feel that. If we can compromise somebody’s immune system at birth, you have them for life. They are always going to rely on that cough drop we give them or whatever they are going to need.

One participant felt much pressure to vaccinate at each visit and commented the following,

The pressure was always on. Even before I was pregnant, to get the HPV shot, and the doctor was like “well I even gave it to my 13 year old daughter and I just was like, in 20 years when these girls cannot even have babies. Even with the swine flu, it was like one outbreak, the media blows it up and then there are not even enough vaccinations. People were freaking out about it. It’s scary how much people depend on vaccinations and medicine.

Another participant further identified his mistrust,

I think vaccination is designed to protect, but um I don't feel like the doctors do a good job of informing of the risks of vaccinations as well. Uh, that to me is also frustrating, it seems that is such a part of our inherent culture; that the babies are born and then get vaccinated. I counted up the number of shots they wanted to give our daughter under 2, and it was over 50 shots. That's, that's too high, that's just too high. So I think there should be more research done on the benefits with breastfeeding at the early age.

Other comments from participants included "I don't want to be pegged as one of those moms who's just mistrustful of the medical community in general, but I feel like the more I learn about them, the less I trust," "I am very skeptical of that, like you know, I feel doctors and nurses generally have ... have our best interests at heart," and "I felt like I should be signing a consent to have them do it (vaccinate), not to not do it. You know?"

Balanced interactions.

Participants expressed that they generally had good interactions with their providers. Comments included: "he made me feel legitimate with my concerns, um, made me feel really good and comfortable," "I'm not opposed to the guy, he's very open, very nice. He, in no way has ever pushed," and

(S)he asked about vaccinations and I said we weren't going to be doing vaccinations and she said I assume you've researched and ah come to that decision for a reason and I said yes we have and that was the end of it.

One participant described her experience with her provider,

We enjoy our primary care physician, who is also our family doctor so he seems ... and myself and he delivered ... so he kind of has been with us the whole, whole way. We like him because he, he is who we described. Who I described at the beginning. Who allows us to make an informed decision, who even though

he may disagree, he shares his opinion, he shares his suggestion and in the end he'll say, well this is your child, your body, I trust that you've done your research and you know, we'll go with you, we'll go with your decision.

Current influences.

Participants emphasized that while making their decision to not vaccinate, they remained educated on both sides of the argument. Participants' comments included: "I read bloggers. There's a really good blog, it's on the New England Skeptical Society, about the neurological blog...it's really good," "I read a lot of books, um journals, uh and sometimes it's the books and even the internet will be a huge source of journal articles and things like that where they found information," "newsletters," "Bradley method teacher," "we went to a, ah, session at our chiropractor," "I do get updates from our chiropractor," and "NDIC and then Wisconsin citizens for immunizations, 909 shot.com." One participant elaborated on his sources of influence on vaccinations,

(I)ts mercola.com, he's an osteopath, and I get newsletters from him every day, sometimes I read them, sometimes I don't. He covers the whole gamut. He's got a ah, different, every once in a while, there's different things on there ...um there is kind of the group of doctors I work with down in Chicago, Myer Epstein,... big pediatrician. I may be mixing it up, but I know it's either him or another doctor, that they have been treating for 30, 40, 50 years, treating tens of thousands of different kids, and none of the children in their office have ever been vaccinated. He runs one of the best clinics in the world...Tim Wakefield puts out some good stuff... Blaylock is a medical doctor...he's the guy on mercola when they tend to interview people.

Relation of Study Findings to Previous Studies

The findings of this study are congruent with prior studies done on parental opposition to vaccination and add implications for APNs. As stated previously in this paper, Cullen's (2005) qualitative phenomenological study revealed that parents have a fear of the unknown and would rather opt out of immunizations than take action and have their child suffer a serious side effect or neurologic disease. The results of this study confirm that parents fear the unknown, but believe that the serious side effects of vaccinations do not outweigh the benefits.

Mistrust.

It is the role of the provider to provide parents with risk and benefit information necessary for parents to make an informed decision and to attempt to correct any misinformation or misperceptions that may exist (Diekema & the Committee on Bioethics, 2005). Participants of this study emphasized their mistrust of governing bodies and pharmaceutical companies and then, therefore, their providers. Implications for future APNs would be full disclosure of vaccine benefits and risks and to promote informed decisions in regards to vaccination.

Consequences of vaccination.

Previous studies implicated parental belief of the link of autism and the MMR vaccine (Kennedy et al., 2005; Lyren & Leonard, 2006). As stated in the literature review, the study done by Andrew Wakefield, created the stir of an autism - MMR link. However, in 2010, Andrew Wakefield had to revoke that study given accusations of tampering with data, and his study was retracted. Even so, this study still concluded parental hesitation with immunization and a fear of MMR linked with autism, among other neurological risks associated with vaccination.

In general, the findings of this study have confirmed the findings of previous studies. Implications for APNs include better education in the office to give parents a greater understanding of vaccine safety and manufacturing. Another implication includes reinforcement of good health and good nutrition. This study indicates that immunization may not be the right choice for everyone; however, it is the job of the APN to reinforce vaccination, as well as good health, in order to give the body full benefit against VPD.

Summary

The findings of this study provide a better understanding of why parents opt out of childhood immunizations. The analysis of nine participant interviews revealed three major themes. Subthemes were noted within each major theme. The major themes were *body knows best*, *toxic consequences* and *balancing act*. Participants ultimately emphasized that the body knows best given the opportunity for natural immunity to VPD. If we give our bodies the fuel, good nutrition and breastfeeding, and avoid the toxic consequences, the benefits of natural immunity will outweigh immunizations.

Chapter V

Summary, Conclusions, and Recommendations

The purpose of this study was to examine the parental understanding and beliefs towards vaccination that opt out of immunizing their children. It was hoped that a better understanding of why parents select not to immunize their children would lead to an increased awareness for APNs and assist in tailoring further education on vaccine safety. In this chapter, the summary of the results, conclusions and implications for nursing practice, and recommendations for further study are provided.

Summary of Study Findings

In this study, nine participants were interviewed and asked the following ten questions:

1. Please describe your beliefs and opinions about vaccinations?
2. When did you first start thinking about vaccination of your child (ren)?
3. Please describe events that led to your decision not to immunize.
4. Who or what influenced your decision the most?
5. During the decision making process, who was involved?
6. What comes to mind when I say “MMR?” “Hib?” “Varicella?” “Tetanus and Pertussis?”
7. Can you describe what a bad reaction would be to immunizations?
8. Please tell me about your interactions with your Primary Care Physician?
9. Where do you obtain current knowledge about vaccination?

10. How do you feel your child is protected from Vaccine Preventable Diseases?

Nine participants were recruited via snowball sampling method to participate in this study. Face to face interviews were held at the choice of the interviewee, and two interviews were conducted over the phone for convenience of the interviewee. The interviews were audio-taped and lasted approximately 20 minutes to 1 hour. The tapes were then transcribed verbatim and analyzed using the Giorgi's 1985 Method of Phenomenological Analysis (Speziale & Carpenter, 2007).

The analysis of the transcripts revealed three major themes that ultimately led to the decision not to immunize. The theme of *body knows best* was the first major theme, which was then broken down into two subthemes: *natural immunity* and *breastfeeding and food is your medicine*. Participants described that the body knows what it's doing and if given the proper nutrition, it can provide one with permanent immunity that is stronger than the immunity acquired from vaccinations.

The second major theme was *toxic consequences*. This theme was further broken down into *risks vs. benefits and back-up plans* and *contents of vaccines*. All of the participants noted similar feelings of weighing the risks and benefits of vaccinations. For these participants, the risks of vaccinations outweighed the benefits. The participants had several back-up plans to assist their children in natural immunity. Some participants noted utilizing chiropractic care and homeopathy, while others noted supplementation with vitamins and minerals.

The third and last theme that evolved from this study was *balancing act*. This theme was further broken down into three subthemes: *mistrust*, *balanced interactions* and *current influences*. Parents ultimately struggle with deciding what is best for their children and look to educated individuals to provide them with answers. These

participants had a great deal of mistrust for providers given support from governing bodies, such as the AAP and pharmaceutical companies that manufacture the vaccines.

Relevance to Health Belief Model

The HBM was chosen for this research undertaking. The theory was developed by Hochbaum in 1958 and explains why and under what conditions people will take preventative actions. Rosenstock's HBM model was used and adapted for this study (Figure 1) (Rosenblum et al., 1981).

Other research suggests that parents perceive immunizations to be only partly or never effective. The perceived severity of the VPD is severely reduced as related to the huge success of immunization efforts. Unfortunately, due to the colossal success of immunizations in controlling VPD, parents consequently have a diminished fear of the illnesses and instead have an increasing fear of the immunizations themselves (Salmon et al., 2009). Parents perceive the susceptibility and severity of their children contracting the disease as minimal because the U.S. has not seen outbreaks of the many of the diseases over the past 30 years. Following the HBM, perceived benefits of immunization are minimized and barriers to immunization related to trust of the adequacy, efficacy, and safety of vaccines. Parents take their cues to action from their own individual experiences, family members' experiences, friends' experiences, and the media and internet coverage of adverse events, and do the best to protect their child (Searson & Smith, 1997).

The HBM provides an appropriate and relevant framework for this study. Individual perceptions of perceived susceptibility to contract the disease is low and perceived severity of disease is low. Taken into consideration with the modifying factors

plus the cues to action, participants make a decision to act. Likelihood of action is determined by perceived benefits minus perceived barriers. If safety, adequacy, and efficacy of vaccines are low, the perceived benefit is low. Therefore, the likelihood to immunize will be low (Figure 1).

Conclusions

The findings of this study only begin to touch the surface of the enormous topic of why parents decide not to immunize their children. Following are some study conclusions:

1. Participants believed that natural immunity and allowing the body to work as it was designed to do will conquer diseases and illnesses as a person acquires them.
2. The perceived threat of VPD is low, and the perceived benefits of vaccinations are low and do not outweigh the risks. and therefore. participants make the decision to not immunize their children.
3. The perception of disease severity is low. The participants see that these VPD are not deadly.
4. Participants make the decision to not vaccinate their child with their best interests in mind.
5. The risks associated with vaccination are perceived as high to participants. Participants would rather acquire the VPD than suffer the neurological side effects that are perceived to be linked with vaccines.

6. Participants have a genuine mistrust of the governing bodies and manufactures of vaccines and, therefore, tend to use natural alternative complimentary measures of healthcare to keep their bodies in a good health status.
7. Married, White, highly educated participants, with good socioeconomic status believe in good health, nutrition, and NAC for protection against VPD.

Limitations

Potential problems of working with phenomenological research can include errors in data collection and analysis. The researcher minimized the potential for such errors by working with an experienced qualitative research advisor. The small homogeneous sample size also limits the generalizability of this study.

The demographic population could also be a limitation for this study. All of the participants of this study were White, except for one participant. All participants had good socioeconomic status with sufficient gross yearly income (Appendix B). Participants were educated, with a minimum of an associate's degree for education. The findings may not be applicable to others outside this sample.

Another limitation of this study is researcher bias. The researcher minimized this bias by working with an experienced researcher to validate themes.

Implications for Nursing Practice and Education

The implications of this study for APNs include providing accurate data on vaccine safety to parents. Providing parents with accredited resources and tailoring

education to each parent will help to decrease the mistrust of providers, governing bodies like the AAP, and pharmaceutical companies. Education regarding childhood immunizations is necessary in order for parents to make informed decisions regarding their child's immunizations (Luthy et al., 2010). Understanding where parents are coming from when they decide not to immunize their children and being able to assess how parents came to that conclusion is important for APNs. The significance of implications for APNs can be summed up by a statement made by Searson and Smith (1997), "(T)he nurse practitioner as a primary care provider is on the front line to obtain parent cooperation and ensure timely and appropriate immunizations" (p. 21).

Implications for nursing education include better preparation of APNs in school to handle immunization questions and concerns of parents. This would provide the APN with better understanding of vaccine safety and manufacturing efforts in order to better answer parental concerns and help to give parents trust in their medical provider. Advanced practice nurses need to foster clear and open communication with parents regarding childhood immunizations, while providing honest and direct communication of risks and benefits of immunizations (Luthy et al., 2010). The AAP Committee on Bioethics recommends that "providers share honestly what is and is not known about the risks and benefits of the vaccine in question" (Omer et al., 2009, p. 1986).

Recommendations for Research

Recommendations for further research would be to replicate this study in a different setting in the U.S. in a different demographic population within a larger, more diverse population to analyze the research to date about parental beliefs of immunizations holds true for everyone. Further researchers may also consider returning

to these participants and conducting a qualitative phenomenological study exploring if their child had any health problems related to acquiring VPD. If problems did occur, would their decision have been different.

Another important recommendation for future research would be to survey APNs to assess their comfort level with addressing the concerns and questions parents have in regards to immunizations and their safety.

Summary

The purposes of this study were to delve into parental understanding and beliefs regarding immunization of their children against VPD and identify parental knowledge of immunizations, so APNs in a primary care setting are able to tailor education to parents questioning the safety and efficacy of vaccination based on their beliefs and knowledge. In this chapter, the summary of findings, conclusions, implications for nursing practice, and recommendations for future research were provided.

APPENDIX A
INTERVIEW QUESTIONS

Interview Questions

1. Please describe your beliefs and opinions about vaccinations?
2. When did you first start thinking about vaccination of your child (ren)?
3. Please describe events that led to your decision not to immunize.
4. Who or what influenced your decision the most?
5. During the decision making process, who was involved?
6. What comes to mind when I say “MMR?” “Hib?” “Varicella?” Tetanus and Pertussis?
7. Can you describe what a bad reaction would be to immunizations?
8. Please tell me about your interactions with your Primary Care Physician?
9. Where do you obtain current knowledge about vaccination?
10. How do you feel your child is protected from Vaccine Preventable Diseases?

APPENDIX B
DEMOGRAPHIC QUESTIONNAIRE

Demographic Questionnaire

1. What year were you born? _____
2. What race do you classify yourself?
 - a. White/Caucasian
 - b. Hispanic
 - c. African American
 - d. Asian American
 - e. Pacific Islander
 - f. Other
3. What is your gender? Male/Female (circle one)
4. What is your marital status?
 - a. Single
 - b. Married
 - c. Separated
 - d. Divorced
5. What is your household size?
 - a. 1-4
 - b. 5 or greater
6. What is your highest level of education?
 - a. High school Diploma/GED
 - b. Associate's Degree/Technical Degree
 - c. Baccalaureate Degree
 - d. Master's Degree
 - e. Doctorate
7. What is your family gross yearly income?
 - a. < 24,999
 - b. 25,000-49,999
 - c. 50,000-74,999
 - d. 75,000-99,999
 - e. >100,000
8. How many children do you have? _____ Placing of the unimmunized child (ren) in the family _____
9. What method of feeding did you use for your child (ren)?
 - a. Exclusively breastfed/given exclusively breastmilk
 - b. Mostly breastmilk with few formula bottles
 - c. 50% formula and 50% breastmilk
 - d. Exclusively Formula Bottlefed
10. Do you use any forms of natural alternative complementary forms of medicine?
Y/N If so what are
they _____
11. What type of community do you consider yourself to live in?
 - a. Rural
 - b. Suburban
 - c. City

APPENDIX C
PARTICIPANT CONSENT

Participant Consent

Dear Participant,

My name is Lindsey Baade and I am a registered nurse working towards my master's degree in nursing at the University of Wisconsin Oshkosh. I am working on my clinical paper research project for completion of my degree. I am interested in the beliefs of parents in the decision to opt out of childhood immunizations. I hope to find out what understanding parents have about vaccine-preventable diseases as well as the beliefs and influences toward the vaccines themselves.

You are invited to participate in my research study, which investigates your beliefs in your decision to choose to not vaccinate your child (ren). Your participation in this study may help health care providers to provide complete, reliable information that is trustworthy to parents.

Participation in this study is completely voluntary, and you may decide to stop your participation at any point. If you choose to participate, you will complete a demographic questionnaire and will take part in a face-to-face interview, that will be tape recorded, conducted by myself. This will take approximately 30 minutes of your time. Your name will not be included or any other identifying factors. This is to protect your identity and keep all information confidential.

Participating in this study will not present any medical or social risk to you, and you will not incur any costs. You will only be inconvenienced by the time it takes to complete the questionnaire and interview. Although this study may not benefit you directly, you will provide valuable data, which will be beneficial in understanding your experience and your perceptions of immunization and vaccine-preventable diseases. You will help health care providers continue to provide reliable, accurate, trustworthy information.

I feel that obtaining information directly from you is the best way to understand your beliefs and influences in this decision. Please know that I greatly appreciate your time and effort. I am excited by this opportunity to gather your very important thoughts.

This study has been approved by the University of Wisconsin Oshkosh Institutional Review Board for the Protection of Human Participants. If you have any questions about this study, or your rights, you may call or write:

Lindsey Baade
187 Villa Dr
Neenah, WI 54956
920-385-8298 or baadel45@uwosh.edu

Chair, Institutional Review Board for
Protection of Human Participants
Grants Office
UW Oshkosh
Oshkosh, WI 54901
920-424-1415

Signature

X _____

Thank you,
Lindsey Baade, RN, BSN
University of Wisconsin Oshkosh

APPENDIX D
UW OSHKOSH IRB APPROVAL



Ms. Lindsey Baade
187 Villa Dr.
Neenah, WI 54956

Dear Ms. Baade

On behalf of the UW Oshkosh Institutional Review Board for Protection of Human Participants (IRB), I am pleased to inform you that your application has been approved for the following research: Under What Beliefs & Knowledge do Parents Answer the Question: To Vaccinate or Note to Vaccinate?

Your research has been categorized as NON-EXEMPT, which means it is subject to compliance with federal regulations and University policy regarding the use of human participants as described in the IRB application material. Your protocol is approved for a period of 12 months from the date of this letter. A new application must be submitted to continue this research beyond the period of approval. In addition, you must retain all records relating to this research for at least three years after the project's completion.

Please note that it is the principal investigator's responsibility to promptly report to the IRB Committee any changes in the research project, whether these changes occur prior to undertaking, or during the research. In addition, if harm or discomfort to anyone becomes apparent during the research, the principal investigator must contact the IRB Committee Chairperson. Harm or discomfort includes, but is not limited to, adverse reactions to psychology experiments, biologics, radioisotopes, labeled drugs, or to medical or other devices used. Please contact me if you have any questions (PH# 920/424-7172 or e-mail:rauscher@uwosh.edu).

Sincerely,



Dr. Frances Rauscher
IRB Chair

cc: Dr. Judith Westphal
1885

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