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A Qualitative Examination of Vaccine Hesitancy Among Mothers

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A QUALITATIVE EXAMINATION OF VACCINE HESITANCY AMONG MOTHERS

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ABSTRACT

Vaccine hesitancy describes the reluctance to vaccinate or the delay of vaccines (World Health Organization [WHO], 2017a). Various factors contribute to vaccine hesitancy for patients (Salmon, Dudley, Glanz, & Somer, 2015), and multiple sources are used by patients to gain vaccine information (Salmon et al., 2015), making it difficult for healthcare providers to address vaccine hesitancy. This research was conducted to identify factors that cause mothers to be vaccine hesitant and information sources used to support the mothers' vaccination beliefs.

Phone interviews were conducted with twelve vaccine hesitant mothers. Participants were asked if the following factors contributed to their vaccine hesitancy: religion, media, fear of side effects/vaccine injury, autism, government distrust, pharmaceutical distrust, healthcare provider influence, complementary and alternative medicine (CAM), and additional factors. Participants were also asked about information sources relating to each factor.

All factors were identified by participants as a reason for their vaccine hesitancy. The three most common factors identified included fear of vaccine injury/side effects, government distrust, and the fear of autism. Information sources reported were widely variable.

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Chapter 1: Introduction

Introduction

This chapter discusses the concept of vaccine hesitancy and will introduce the qualitative study conducted. Vaccine hesitancy is a phrase used to describe the reluctance to vaccinate or the delay in acceptance of vaccines regardless of the accessibility of vaccines (WHO, 2017a). This introduction will include the background of the problem associated with vaccine hesitancy, the problem statement, the purpose of the study, the significance of the problem, the research question, and definitions of terms used within the study.

Background to the Problem

A 2014 report from the Centers for Disease Control and Prevention (CDC) estimated that between 1994-2013, the vaccine schedule that children were administered "will prevent 322 million illnesses, 21 million hospitalizations, and 732,000 deaths over the course of their lifetimes" (Whitney, Zhou, Singleton & Shuchat, 2014, p. 1). Currently, 17 diseases have vaccines available to prevent their occurrence (Cohn, Rodewald, Orenstein & Schuchat, 2018). The infectious organisms that are preventable by vaccines and are recommended for children between birth and six years of age include varicella, diphtheria, *Haemophilus influenzae* type b (Hib), hepatitis A and B, influenza, measles, mumps, pertussis, polio, pneumococcus, rotavirus, rubella, and tetanus (Centers for Disease Control and Prevention [CDC], 2017c). Additional vaccines recommended for adolescents include meningococcal B, and human papillomavirus (CDC, 2017c). Vaccines available for adults include herpes zoster as well as various boosters for childhood vaccines (CDC, 2017b).

Vaccines that are available reduce mortality and infectious disease occurrence (Dube, Laberge, Guay, Bramadat, Roy, & Bettinger, 2013). Measles, a disease caused by a virus, has been documented for 2,000 years (Stratton, et al., 2011). Prior to the measles vaccine,

nearly 100 percent of the United States population had experienced an outbreak in measles at some point in their childhood (Watson, Hadler, Dykewicz, Reef, & Phillips, 1998). Following the implementation of the measles, mumps, and rubella (MMR) vaccine, the amount of measles outbreaks has been reduced by 99% in the United States (Stratton, et al., 2011). Before the MMR vaccine, regional outbreaks of mumps occurred every two to five years; from 1968-1995 mumps outbreaks decreased 99% due to the MMR vaccine recommended for children (Stratton et al., 2011). Every year about 31,500 cervical cancers are attributed to human papilloma virus (HPV), of which 90% could be prevented by the HPV vaccine series (Walker et al., 2017). The average mortality rate for deaths primarily caused by varicella dropped 66% from 1990-2001 (Nguyen, Jumaan & Seward, 2005). These statistics are evidence towards the benefit of the CDC publishing vaccine schedules, recommending vaccines, and administering vaccines at different stages in life.

The government has created the Vaccine for Children (VFC) program to encourage impoverished parents with financial instability to be able to receive vaccines for their children at no cost (CDC, 2014). The VFC was initiated in 1994 after an outbreak of 55,000 measles cases from 1989-1991 that was a result of uninsured children in high density, low income areas who did not receive their recommended vaccines (Whitney et al., 2014). Initiatives like VFC have increased vaccine administration rates at an average of 11.8 % per year from 2009 to 2012 (Johnson, Hayes, Brown, Hoo, & Ethier, 2014). The rate of children 19-35 months of age that received the recommended childhood vaccines increased from 44.3% in 2009, 68.5% in 2011, 68.4% in 2012, and 70.4% in 2013 (Elam-Evans, Yankey, Singleton, & Kolasa, 2014). The 2016 rate of MMR vaccine coverage among kindergarteners' averages 94.5%, but the average ranges from 82.2% to 99.6% between states (Seither et al., 2017). The tetanus, diphtheria, and

pertussis vaccine coverage ranged from 77.5% to 96.7%, and the meningococcal vaccine coverage ranged from 54.2% to 96.7% in 2016 (Walker et al., 2017). Healthy People 2020 is a government initiative to reduce preventable disease, and their goal is to get vaccine administration rates to 95% or higher for kindergartners nationwide (Seither et al., 2017).

Even though the national average is as high and improving, geographic areas throughout the country have significantly lower vaccine administration rates and contributes to outbreaks of diseases as unvaccinated people tend to cluster in certain communities (CDC, 2015). In a study by Omer et al. (2008), geographic areas of reduced vaccine administration rates were found to be associated with an increase in pertussis outbreaks. In a 2015 measles outbreak, 68 unvaccinated individuals were diagnosed and 43% of these individuals reported personal opposition to vaccines (Clemmons, Gastanaduy, Fiebelkorn, Redd, & Wallace, 2015). Although the vaccine administration rate for MMR in 2013 was 91.9%, one in twelve children did not receive their recommended vaccines on time causing a possibility for measles susceptibility prior to their receipt of the vaccine (Elam-Evans et al., 2014). Vaccine preventable outbreaks could be reduced if more data were collected at the local level to identify regions susceptible to vaccine preventable diseases because of lowered vaccine administration rates, as well as to be able to address the risks to the community of low vaccine administration rates (Seither et al., 2017).

The Problem Statement

Some mothers are vaccine hesitant causing them to forgo childhood vaccines for their children. Refusal of childhood vaccines has been associated with outbreaks of infectious diseases and an increase in emergency department visits, morbidity, and death (McClure, Cataldi, & O'Leary, 2017). Vaccine hesitancy is complex and context specific varying across time, place, and vaccines (WHO, 2017a). Numerous factors cause parents to be vaccine hesitant

and each individual may have a variety of different factors that cause them to be hesitant towards vaccines (Salmon, Dudley, Glanz, & Somer, 2015). Additionally, parents use multiple sources to gain information regarding vaccines (Salmon et al., 2015). Due to the complexity of vaccine hesitancy, health care providers have a difficult time addressing vaccine hesitancy because they may not fully understand the factors that are contributing to vaccine hesitancy.

Purpose of the Study

The purpose of this study was to gain a deeper understanding of the factors that contribute to vaccine hesitancy as well as the sources from which these factors come. The outcome of the study allows health care providers to better understand vaccine hesitant mothers' concerns, allowing for providers to more effectively address these concerns. Additionally, identification of the information sources that vaccine hesitant mothers use allows healthcare providers to become familiar with the sources allowing providers to address the credibility of the sources with vaccine hesitant mothers. If healthcare providers take the time to understand vaccine hesitancy and adequately address the hesitancy, mothers may better understand vaccines which may alleviate their hesitancy.

Significance

For the past century, vaccines have been thought to be one of the most important improvements to public health (McClure et al., 2017). Many serious diseases have been eradicated from this country due to vaccines, many of which used to haunt the childhood of our elderly (McClure et al., 2017). In the past decade many people have become vaccine-hesitant, which has resulted in many unvaccinated children (McClure et al., 2017). Parents do not realize the detrimental effects of the diseases that are protected against by vaccines and that the benefits of vaccines greatly outweigh the dangers of them (McClure et al., 2017). Vaccine refusal has led

to a rise in children under the age of two that are under-vaccinated and the increase in the number of exemptions based on personal beliefs of vaccines (McClure et al., 2017).

Vaccines are important in that they create herd-immunity. If most of the community gets vaccinated, the chances of an outbreak decreases. Herd immunity helps to protect not only the people who get the vaccine, but also the vulnerable population who is unable to receive vaccines. With the decrease in vaccine administration rates, pregnant women, infants, and immunocompromised are becoming vulnerable to the diseases of the past since they are unable to receive vaccines (CDC, 2017e). Those who are too vulnerable to get vaccines are also vulnerable in the fact that they will have a hard time recovering if they were to contract the disease (McClure et al., 2017). Vaccines help to prevent people from becoming vectors of a disease that then can continue to spread. Research has found that refusal of childhood vaccines has been associated with outbreaks and an increase in emergency department visits, morbidity, and death (McClure, et al., 2017).

Before the implementation of vaccine programs, in the mid-1900s, diseases like polio, measles, rubella, and whooping cough infected hundreds of thousands of children and adults (CDC, 2017e). Thousands of these children would die each year due to the effects of these diseases (CDC, 2017e). Due to vaccines, only two cases of diphtheria have been reported to the CDC since 2004, 15 cases of rubella have been reported since 2012, and most doctors in the United States have never seen a case of measles (CDC, 2017e). Some people question the importance of continual vaccines for diseases that they never encounter and are eradicated from this county (Pierik, 2017). Some of these diseases are becoming a problem again (CDC, 2017e). One or two cases of a disease is all that is needed to produce an outbreak in a community where most of the people are unvaccinated (CDC, 2017e). In 2011, more than 350,000 cases of

measles were reported around the world and during that year 90% of the cases reported in the United States were brought into the country by someone traveling from another country (CDC, 2017e). Only one infected person is needed to create an outbreak in community of unvaccinated people (CDC, 2017e). Many of these diseases, such as whooping cough and measles, first present with mild cold like symptoms (CDC, 2016; CDC, 2017a). By the time the disease is diagnosed the infected individual has exposed many other people to it, which leads to outbreaks such as the ones that occurred in Minnesota and Disneyland. Many providers are faced with vaccine hesitant parents that have many different factors contributing to their desire to not vaccinate their children (Pierik, 2017). Provider awareness and understanding of how to address the different factors contributing to vaccine hesitancy may help to decrease the number of children that are unvaccinated.

The Research Question

The following research questions were addressed in this study:

1) What are the factors that cause mothers to be vaccine hesitant?

2) What are the information sources that contribute to these factors?

Definition of Terms

The following terms are used in the study, and will be defined as the following:

Autism: "a complex developmental disorder that can cause problems with thinking, feeling, language and the ability to relate to others. It is a neurological disorder, which means it affects the functioning of the brain. The effects of autism and the severity of symptoms are different in each person" (American Psychiatric Association, 2017, p. 1).

Complementary and alternative medicine (CAM): "The popular term for health and wellness therapies that have typically not been part of conventional Western medicine. Complementary

means treatments that are used along with conventional medicine. Alternative means treatments used in place of conventional medicine" (Mayo Clinic, 2014, p. 1).

Herd Immunity: "When a critical portion of a community is immunized against a contagious disease, most members of the community are protected against that disease because there is little opportunity for an outbreak. Even those who are not eligible for certain vaccines—such as infants, pregnant women, or immunocompromised individuals—get some protection because the spread of contagious disease is contained" (U.S. Department of Health and Human Services, 2017, p. 2).

Vaccine: "A biological preparation that improves immunity to a particular disease. A vaccine typically contains an agent that resembles a disease-causing microorganism and is often made from weakened or killed forms of the microbe, its toxins or one of its surface proteins. The agent stimulates the body's immune system to recognize the agent as foreign, destroy it, and "remember" it, so that the immune system can more easily recognize and destroy any of these microorganisms that it later encounters" (WHO, 2017b, p.1).

Vaccine Hesitancy: "Vaccine hesitancy refers to delay in acceptance or refusal of vaccines despite availability of vaccination services. Vaccine hesitancy is complex and context specific varying across time, place and vaccines. It includes factors such as complacency, convenience and confidence" (WHO, 2017a, p.1).

Conclusion

Vaccines are thought to be one of the most important improvements to public health of the past century (McClure et al., 2017). A 2014 report from the CDC estimated that between 1994-2013 the vaccine schedule that children were administered “will prevent 322 million illness, 21 million hospitalizations, and 732,000 deaths over the course of their lifetimes”

(Whitney et al., 2014, p. 1). Vaccines that are available reduce mortality and infectious disease occurrence (Dube et al., 2013). In addition to protecting the individual who is vaccinated, vaccines create herd immunity. Herd immunity helps to protect not only those who get the vaccine, but also the vulnerable population who is unable to receive vaccines (CDC, March 2017).

Chapter two is a literature review focusing on the background of vaccines, the historical perspective of vaccine hesitancy, public health concerns due to lowered vaccine administration rates, and factors contributing to vaccine hesitancy.

Chapter 2: Literature Review

Introduction

This literature review focuses on studies and facts that answer the following questions: What are the factors that cause mothers to be vaccine hesitant, and what are the information sources that contribute to these factors? Various search engines were utilized to find relevant studies, articles, books and government websites regarding vaccine hesitancy worldwide. This review will discuss the background of vaccines, the historical perspective of vaccine hesitancy, public health concerns due to lowered vaccine administration rates, and factors contributing to why people do not vaccinate: religion, fear of autism and the role of media, government and pharmaceutical distrust, general practitioner hesitancy, complementary and alternative medicine (CAM) beliefs, and vaccine injuries.

Background of Vaccines

Vaccines are one of the most important mechanisms that our world has to promote public health (Stratton, et al., 2011). Vaccines work by stimulating the body's natural defense mechanisms to reduce the risk and occurrence of dangerous diseases caused by infectious organisms. On its own, the body takes several days to recognize and attack an infectious organism, all the while the organism is attacking and multiplying (CDC, 2013). The body's natural immune system may be enough to fight off any disease on its own, but many infectious diseases have serious complications that cannot be predicted for each individual. Vaccines help to reduce the risk of developing complications from infectious diseases that are dangerous and potentially deadly (CDC, 2013). The theory behind vaccines is to imitate an infection to get the body to recognize what the disease looks like and to produce mechanisms to defend against this invader earlier than the body naturally would be able to. Depending on the type of vaccine,

sometimes more than one dose is necessary to build up the immune response against the infection that the vaccine is for (CDC, 2013). After a certain amount of time, the body may have some response to fight off the infection, but if the actual invader came along, the reaction wouldn't be strong enough to prevent the disease from taking over. Therefore, boosters are required for several different vaccines to make sure that the body is fully equipped to handle the infection should an individual be exposed to the disease (CDC, 2013).

The development of vaccines has changed dramatically throughout history (Rappuoli & Medaglini, 2014). The first vaccine was developed in 1796 in England for the prevention of small pox (Stern & Markel, 2005). Development of vaccines has gone from a single scientist to a team of experts in the fields of DNA technology, genomics, immunology, and business. Vaccines are no longer able to be developed in the academic setting, but in government regulated facilities with financial resources to invest in development (Rappuoli & Medaglini, 2014). To make a vaccine, scientists consider the infection's specific mechanism of attack as well as the human body's response to the specific invader (CDC, 2013).

To ensure that everyone, even the uninsured, have access to vaccines, the VFC program was initiated in 1994. It is estimated that between 1994-2013, vaccines saved $295 billion in medical costs and $1.38 trillion in societal costs by preventing disease, hospitalizations, and death (Whitney et al., 2014). Although the public health benefits far outweigh the risks of vaccines, it is important to acknowledge that there are side effects such as fever, seizures, and on rare occasions severe reactions such as anaphylaxis (Stratton, et al., 2011). The CDC studied immunization rates among kindergarteners in 2013-2014 and found that more than 5% of the children in several states were not immunized, leading to a higher occurrence of diseases that

should be mostly eliminated if the entire population were to contribute to the herd immunity by getting vaccinated (Offit, 2015).

Vaccine Hesitancy- A Historical Perspective

Vaccine hesitancy is not a new phenomenon. Vaccine hesitancy has occurred throughout history, and at the core of the mistrust is a multiplex conflict between science, citizens, and public health policy (Schwartz, 2012). Two main reasons have been proposed as a drive of vaccine hesitancy. The first is a view that the risks of vaccines are more dangerous than the diseases they prevent, and the second is a feeling of an infringement of freedom due to mandatory vaccine administration policies (Schwartz, 2012).

Vaccines have caused a significant decline in mortality and morbidity from numerous infectious diseases (Dube et al., 2013), which has resulted in individuals focusing their fears on vaccines rather than on the diseases. Berezin and Eads (2016) examined newspaper articles from 1/1/1955- 12/31/2012 to examine the public view of vaccines and how they change over a time span. The polio vaccine was made available in 1955, and the public received it as a lifesaving advancement, as polio was the worst disease affecting baby boomers. The polio vaccine was followed by the MMR vaccine in 1971, the Hepatitis B vaccine in 1982, the pertussis vaccine, which was combined with Hepatitis B, and the varicella vaccine both in the 1990s. Due to the success of these childhood vaccines the generation following the baby boomers experienced very few childhood diseases. The newspaper data reviewed throughout these years show a change in attitude towards vaccines from a source of protection to a source of possible danger. In 1955 more articles discussed the benefits of vaccines while acknowledging possible risks. From 1955 to 1990 this theme decreased, and articles discussing the risks of vaccines as outweighing the risks of disease increased. By 1990 a greater percent of articles displayed vaccines as more

dangerous than the diseases they protected against, and after 2000, newspaper articles were dominated by a theme of the risks of vaccines only and not the risks of disease (Berezin & Eads, 2016).

Presently, the number of individuals exempting from mandatory vaccines in the United States is increasing (Dube et al., 2013). However, individuals exempting from vaccines is not a new occurrence (Schwartz, 2012). The first mandatory vaccine for school attendance in the United States was the smallpox vaccine in Boston in 1827. By the end of the 1800s most of the U.S. required the smallpox vaccine for school attendance. Groups began to form that opposed vaccines in 1879. One of the more notable groups was the Anti-Vaccination Society of America. As smallpox became less common the vaccine was no longer required. By 1970 most schools in the U.S. again required childhood vaccines for school attendance due to measles outbreaks and the development of new vaccines (Schwartz, 2012). In 1969 the three main factors that were identified as causes for objections towards mandatory vaccines were "government intrusion on religious beliefs, general distrust of medical science, and infringement of personal liberty" (Schwartz, 2012, p. 52).

Today vaccine hesitant parents operate together in organized networks at the national level. An important event that fueled the modern vaccine controversy was the *DPT: Vaccine Roulette,* television documentary of 1982 that showcased stirring stories of children whose parents thought they were harmed from the diphtheria-pertussis-tetanus vaccine (Schwartz, 2012). This documentary was the beginning of a time when public figures began speaking out against vaccines beginning with Barbara Loe Fisher who formed the Dissatisfied Parents Together group and co-founded the National Vaccine Information Center. There were also numerous publicized court cases regarding vaccine injuries (Berezin & Eads, 2016). In response

to the momentum of vaccine hesitancy in the 1980s congress passed the National Childhood Vaccine Injury Act protecting drug companies from lawsuits (Berezin & Eads, 2016). The Vaccine Adverse Events Reporting System (VAERS) allowing for vaccine injuries to be monitored at the federal level was also created (Berezin & Eads, 2016). Celebrities who believe that their children have been negatively affected by vaccines have an almost equal platform in the media as the medical and scientific community does advocating for the safety and importance of vaccines (Schwartz, 2012).

The Internet has further changed the landscape of vaccine hesitancy as vaccine hesitant parents form groups, blogs, and make use of social media platforms to share their beliefs and experiences. The Internet also allows individuals to explore medical and scientific research, however there are little to no regulations regarding what can be posted online (Schwartz, 2012). Information claiming to be research may have faulty methods, ulterior motives, or limited peer review. Quality research is difficult for the general public to distinguish from faulty research (Schwartz, 2012).

Importance to Public Health

In February of 2009, there was an outbreak of meningitis in Minnesota, killing one child (Offitt, 2011). In 2009, 1200 children were infected with mumps, which was found to have caused other manifestations amongst the body such as pancreatitis, meningitis, facial paralysis, and infertility in many of the people (Offitt, 2015). In 2015, there as a large measles epidemic originating at Disneyland in California, infecting 125 children (Offitt, 2015). The one thing these outbreaks have in common is that most of the kids involved had not been vaccinated against these diseases (Offitt, 2011). The overall goal of vaccines is to increase herd immunity to infectious diseases, many of which do not have cures and can lead to serious health

complications. By the implementation of mandatory vaccines, infectious diseases that used to kill many people had been eradicated from the United States. Infectious diseases such as small pox and polio no longer infect U.S. children, because of the high vaccine administration rates for these diseases. More recently, there have been some diseases that are coming back to the U.S. Measles, for example, has been out breaking across the country, because there are a large number of people that have not been receiving the MMR vaccine (Pierik, 2017). Many parents believe that vaccines are more harmful than the diseases they protect against (Offitt, 2015). Due to vaccines, parents and children that live today, have never experienced the effects of certain infectious diseases like measles and do not understand the implications of being infected. In the 19th century, measles would kill 1 in 1000 infected children and would sometimes cause fatal subacute sclerosing panencephalitis, but this is an infection that many today believe causes a severe rash. Whooping cough would cause pneumonia as the bacteria moved to the lungs as well as seizures due to the lack of oxygen to the brain, but again many people think it causes a bad cough (Offit, 2015).

When considering vaccines, many mothers are thinking about the well-being of themselves and their own children, not realizing how they can protect other children as well by getting their own children vaccinated. They do not understand the full effects of herd immunity for public health. The benefits of vaccines expand beyond just those that get the vaccine (Pierik, 2017). Many people are unable to be vaccinated such as infants, immunocompromised, and those with an allergy to the vaccine (Pierik, 2017). Vaccines prevent people from becoming a vector that further spreads the disease to others that may be affected more severely (Pierik, 2017). This protection for the vulnerable is the reason why the government has mandated vaccines. Measles is a highly contagious disease, in which an unvaccinated person has a 90%

chance of acquiring the infection if they are exposed (Pierik, 2017). For herd immunity to be achieved against measles, 92-94% of the population needs to be vaccinated to prevent an outbreak of the disease (Pierik, 2017). Herd immunity allows for 6-8% of the population to have exemptions from vaccines, which would account for the vulnerable population that is unable to receive vaccines. Although, most states also except many religious and secular exemptions that are separate from any medical reasons as to why someone cannot get vaccinated (Pierik, 2017).

Religion

Since the development of the first smallpox vaccines, certain religious groups have encouraged vaccine refusal. The Dutch Protestant-Christians and several other religions believe that vaccines change the fate of all humans in a way that God did not intend and that it messes with the work of his hands. Also, if a child were to get a vaccine and had a side-effect, it is thought that God is sending a sign that the parent made a wrong decision in giving their child the vaccine (Pierik, 2017). Other religious groups that refuse vaccines are Christian Scientists, Mennonites, and the Amish (Pierik, 2017). The Christian Scientists believe that illnesses are an illusion of the human body and that only prayer can relieve the body of the false beliefs that cause the illness, and thus vaccines are just adding to these false beliefs (Pierik, 2017). Many religions, such as Catholicism and other branches of Christianity do not agree with the use of an aborted fetus in the development of some vaccines. The MMR, varicella, and adenovirus vaccines all have components of the WI-38 cell line, which are cells from a 3-month Caucasian female fetus (Pelcic et al., 2016). Many religions believe in the right to life, and thus they do not want to support the use of vaccines that may contain cells from an aborted fetus (Pelcic et al., 2016). In our democratic country, mandated interventions that go against religious beliefs is

unattainable, which is why there have been religious exemptions allowed since the beginning of mandatory vaccines in 1872 (Pelcic et al., 2016, Schwartz, 2012).

Currently, children are required by law to have their vaccines up to date before they begin school, but many parents are still able to choose to not vaccinate their children. When mandatory vaccines were first enacted, the government allowed exemptions from vaccines due to distinct religious reasons from recognized religious groups (Pierik, 2017). However, there was argument as to why the government got to choose which religions were valid to refuse vaccines. Many people believed that it was their right to refuse vaccines, because vaccinations go against their beliefs and their right to the first amendment (Pierik, 2017). In 1971, several states decided to expand exemptions to include "everyone and anyone who claims a sincerely held religious belief opposed to vaccination" (Pierik, 2017, p. 11). Eight years later this was disputed in court to include secular exemptions, because it was discriminatory to those that are not a part of a religion (Pierik, 2017). Since then, the exemptions have continued to expand to many different religious and secular reasons, which has led to more and more unvaccinated children. As of today, there are three states that only accept medical exemptions from vaccines, 28 states also accept religious and medical exemptions, and 19 states accept religious, medical, and various other secular exemptions (Pierik, 2017).

Fear of Autism and the Role of Media

Parents commonly report being fearful of vaccines, because they believe that vaccines are linked to the development of autism in children (Dube et al., 2013). This fear has been traced to research performed by Andrew Wakefield, who released his findings in 1998 in London. Wakefield studied twelve children and found that eight of them developed severe intestinal inflammation six days after receiving the MMR vaccine, and nine of the children were diagnosed

with autism within two weeks of receiving the MMR vaccine. Therefore, Wakefield suggested that the MMR vaccine causes harmful proteins to leak out of the gut and cause autism after reaching the brain (Begley & Interlandi, 2009). These findings were quickly advertised to the public through media sources causing panic in many. British newspapers released a story titled "Doctors link autism to MMR vaccine and ban three-in-one jab, urge doctors after new fears" even though the research text explicitly said, "We did not prove an association between the MMR and autism" (Begley & Interlandi, 2009, p. 1.)

The results of Wakefield's study spread to the U.S. and caused vaccine hesitancy to increase. Parents were especially uneasy as autism rates were unexplainably rising (Begley et al., 2009) at the same time that the number of recommended vaccines were increasing for children under two years of age. From 1995 to 2015 the number of vaccines recommended increased from fifteen to twenty-four (Salmon et al., 2015). Additionally, in 1999 The American Academy of Pediatrics and the CDC required that thimerosal, a vaccine preservative, be removed from all vaccines because it contains ethyl mercury (Weber, 2008). Methyl mercury had been shown to have neurotoxicity side effects in large amounts, which caused public concern of ethyl mercury due to the name similarity with methyl mercury. In reality ethyl mercury and methyl mercury are very different chemically (Weber, 2008). In the same year, 1999, the California Department of Developmental Services released a report saying that autism had increased 273% percent in California in the past ten years. These two correlated events birthed the idea that thimerosal is a causative agent of autism (Weber, 2009). Individuals still believe that thimerosal causes autism even though there are no scientific studies that support this theory and autism has been continuing to increase even after thimerosal was removed from childhood vaccines in 2001 (Weber, 2008).

Following the release of Wakefield's study and the public perception of thimerosal as a causative agent for autism, the media played a large role in propagating vaccine hesitancy. In November of 2000, a story of children who seemed to develop autism after the MMR vaccine was aired on "60 Minutes," and in 2002 the New York Times Magazine released an article that supported the thimerosal and autism theory (Begley et al., 2009). Entertainers and politicians, such as Jenny McCarthy and Robert Kennedy Jr., began to publicly display their doubt of vaccine safety (Berezin & Eads, 2016). The nation had moved from trusting evidence-based medicine to trusting media and celebrities (Poland & Spier, 2010). The Internet provided and continues to provide another source of media to disseminate doubts concerning vaccines and autism. Individuals use the Internet as a source of information and as a way to share their personal stories related to vaccines. Researchers have examined the information on the internet regarding vaccines and have found that "information is of variable quality and that inexact or negative content is predominant" (Dube et al., 2013, p. 1766).

In 2004, the theory that the MMR vaccine causes autism fell under fire, as it was discovered that five of the children Wakefield studied were clients of an attorney who was working on a case against the MMR vaccine. Wakefield received 55,000 euros from a British group that supported lawsuit related research. Additionally, the children in the study displayed symptoms of intestinal inflammation and autism before the study began (Begley et al., 2009). These findings resulted in the *Lancet* retracting Wakefield's paper on February 2, 2010. The UK General Medical Council stated that "Wakefield had shown "callous disregard", "abused his position of trust," and acted in dishonest, misleading, and irresponsible ways in the conduct and report of this study." (Poland & Spier, 2010, p. 2361).

In addition to the charges against Wakefield and the removal of his article from the *Lancet* in the early 2000s many large-scale studies that examined millions of children concluded that there was no link between the MMR vaccine and autism (Begley, et al., 2009). In 2004 the Institute of Medicine (IOM) in the U.S. examined 200 studies and found no support for the vaccine-autism theory. The IOM concluded that autism typically manifests at the same age as when the MMR vaccine is administered, meaning that some children will show symptoms of autism shortly after being vaccinated, but this correlation does not indicate causation (Begley et al., 2009). However, the removal of Wakefield's study from the *Lancet* and the large body of evidence showing no link between the MMR vaccine and autism have not extinguished the fear of the MMR vaccine (Begley et al., 2009). The residual fear of the MMR vaccine may be due to individuals trusting emotions and anecdotal stories over scientific data (Poland & Spier, 2010).

Government and Pharmaceutical Distrust

In 2014-2015 the U.S. average of nonmedical exemptions for school immunization requirements among kindergarteners was 1.5% and reached above 5% in some states (Lee, Whetten, Omer, Pan, & Salmon, 2016). A 2016 case-control study looked at factors of vaccine hesitancy regarding distrust of the government and of healthcare providers (Lee et al., 2016). The populations who reported distrust of the government were more likely to report the government agencies such as the CDC, Food and Drug Administration (FDA), and local and state health departments were unreliable sources of information. The distrustful populations were more likely to think government laws regarding immunization requirements for schools were impeding their parental ability to make an educated decision for their child (Lee, et al., 2016). With the development of new vaccines, the recommended vaccine schedule is becoming more complicated; the increasing number of vaccines that the government is requiring for

children is one of the reasons that parents do not want to vaccinate their children (Lee et al., 2016). The amount of vaccines that are recommended and funded within the public health system tripled from 1990 to 2012 (Dube et al., 2013). The Pew Research Center found in 2013 only 19% of the U.S population trusts the government, as compared to 73% of the population in 1958 (Lee et al., 2016). Part of this government distrust may be attributed to the history of vaccines and parents not staying up to date on information regarding the current content of vaccines (Obaro & Palmer, 2003). For example, thimerosal is a compound derived from mercury that used to be used as a preservative in some vaccines but was associated with neurological disorders in children. Thimerosal has since been taken out of vaccines. This information and other examples like it may be a factor in a parent's choice to not trust the government's approval of vaccines and recommendations that children should be vaccinated (Obaro & Palmer, 2003). An amount of the population does not want to vaccinate their children for the sole fact that they feel as though the government is trying to force them to do so (Gostin, 2015). Every vaccine controversy that is communicated with the public, true or not, fuels even more distrust for the government and assumptions that the government is intentionally lying to the public (Fairhead & Leach, 2012).

In addition to government distrust impacting parental decisions to not vaccinate children, politics also influences the public's perception of vaccines (Sharfstein, 2017). When vaccine hesitant politicians are representing the population in lawmaking, it can create a rising concern in the nation. The public perception can be greatly impacted by those that are in the public sphere and are able to draw greater attention to conspiracies that might not necessarily be true. Government endorsement of science and policies that promote public health is important (Sharfstein, 2017). On the other side of the political arguments, people can be hesitant about

vaccinating their children because of their lack of confidence in the motives of policy makers who decide when a vaccine is required for someone (MacDonald, 2015).

The business aspect of vaccine development is another obstacle in the public's perception of vaccines. It is expensive to fund the research and only large companies with the financial resources can invest in vaccine development (Rappuoli & Medaglini, 2014). These companies that can afford to develop vaccines are profit driven which can create a skepticism to the public as they may believe these companies are only developing and promoting vaccines for their own financial gain (Obaro & Palmer, 2003). Trust is an integral factor in parents deciding to vaccinate their children. Parents tend not to trust pharmaceutical companies and the government because they are an isolated institution that have not established a relationship with the community (Dube et al., 2013). A vaccine program that is not driven by profits nor politically motivated is necessary to increase societal trust in vaccinations (Obaro & Palmer, 2003).

General Practitioner Hesitancy

When it comes to medical decisions, mothers are influenced by the advice they get from medical professionals. In 2007, an influential doctor, Robert Sears MD, published a book on an alternative schedule to the recommended vaccine regimen, because he believes that a child's immune system is not strong enough to handle receiving more than one vaccine at a time (Offitt, 2015). Due to Dr. Sears's credentials, mothers automatically trusted his book and believed that there was something wrong with the recommended vaccine schedule. Mothers were frightened into thinking that children were not able to receive many vaccines at one time, and this opened the door for mothers to believe they could adjust the recommended vaccine schedule. Along with Dr. Sears, another influential figure that has spoken out against vaccines is Dr. Mehmet Oz, who is widely known from his T.V. show. Not only has Dr. Oz supported Dr. Sears's statements,

but he has openly refused to vaccinate his children against influenza. Dr. Oz has also advised against receiving the polio and rotavirus vaccines due to their side effects (Offitt, 2011).

In addition to the above-mentioned doctors, there are other healthcare providers that are just as hesitant about recommended vaccines. A survey in 2015, showed that 43% of general practitioners were not recommending vaccines to their patients due to their own hesitancy of the vaccines (MacDonald, 2014). These providers also will likely not have as much information on the benefit of the vaccine and thus patients will not be convinced as to why they should get the vaccine (Paterson, 2016). How general practitioners approach the topic of vaccines also effect parents' decision on whether to vaccinate or not (Paterson, 2016). For example, parents were more likely to vaccinate their children if providers said, "Today we are vaccinating your child with …" versus "how do you feel about the vaccines?" The latter sets a more negative tone, giving the parent reason to believe that there may be bad feelings about vaccines and that there would be an option for their child to not get them (Paterson, 2016). These general practitioners contribute to the amount of kids that do not get vaccinated every year. Parents look to their general practitioner for advice on medical decisions such as vaccines, but if the practitioner themselves do not believe in the vaccines they are not going to take the time to explain the benefit of vaccines to parents that have questions (MacDonald, 2014).

Complementary and Alternative Medicine Beliefs

CAM refers to health therapies that are not traditionally included in Western medicine. The term complementary in the phrase indicated that often these therapies are used in conjunction conventional medicine. The term alternative refers to therapies that are used instead of conventional medicine (Mayo Clinic, 2014). Popular CAM therapies include, but are not limited to, treatment such as acupuncture, chiropractic manipulation, massage therapy, energy

healing, homeopathic treatment, naturopathy, natural products, tai chi, yoga, and meditation (Barnes, Bloom & Nahin, 2008).

Individuals that visited a CAM provider have been strongly associated with choosing not to vaccinate their children (Dube et al., 2013). Parents who have taken their children to see a CAM provider before the age of two years old are less likely to be up to date with the recommended vaccines (Downey, Tyree, Huebner, & Lafferty, 2010). It is supported that naturopathic medicine profoundly impacts patient's belief that vaccines create harm to the natural immunity that each person has innately (Cassell et al., 2006). Parents' inclination towards CAM has also been linked to parent's heightened concern for side effects of vaccines (Gellin, Maibach, & Marcuse, 2000). A 2003 survey of Canadian CAM students found that 74.4% of participants would advise patients towards partial vaccines, and only 12.8% would advise the full government recommended vaccine schedule (Wilson, Mills, Boon, Tomlinson, & Ritvo, 2003). Ernst (2001) found that CAM providers tend to steer their patients away from vaccines and have been an integral support to the anti-vaccine movement. Ernst quotes several passages from chiropractic literature that deem vaccinology unsafe and ineffective (Ernst, 2001). One chiropractic literature source quoted in Ernst's article is a Fundamentals of Chiropractic and Management textbook stating, "it cannot be said that the…program has been proven successful…and the complication rates for the vaccines continues to claim the lives of children via disability and/or death" (Ernst, 2001, p. S92).

In a 2006 study, Cassell et al. determined that 87% of mothers that chose not to vaccinate their children were also inclined towards natural diets, determined by the mothers claim that they do not purchase food with certain genetic modifications listed in the ingredients. Within this same pool of mothers that did not vaccinate their children, 43% reported that they believe it is

better for their child to acquire natural immunity than to receive a vaccine (Cassell et al., 2006). Those that wish to lead their family in an all-natural lifestyle, avoiding added chemicals and preservatives, will also tend to avoid vaccines (Pierik, 2017). Naturopaths that were interviewed in Washington in 1983 claimed that they opposed vaccines because they viewed the process as unnatural and unnecessary. In 2001, twice as many naturopaths at the conference of the British Naturopathic Association reported that they did not support vaccines as those that favored vaccines (Ernst, 2001).

Individuals often use CAM as a replacement for conventional medicine and prefer natural products and supplements such as fish oil, flaxseed, ginseng, ginkgo, and garlic (Barnes et al., 2008). Naturopathy, a CAM system, suggests that there is an innate healing power in the body that needs to be accessed to establish and maintain health (Barnes et al., 2008). Naturopathic providers work with patients to find non-medicinal solutions via lifestyle changes, dietary supplements, and medicinal plants (Barnes et al., 2008). A portion of the public believes that vaccines are too strong for children and the vaccine overwhelms their immune system (Pierik, 2017). The parent without formal immunology training may make decisions about vaccines based on depictions of the immune system and the immunity that is initiated by vaccines as portrayed in popular literature. (Cassell et al., 2006). A 2012 study in Oregon found that 61.6% of parents that chose to exempt their children from vaccines believed that it is better for immunity if children are allowed to acquire a disease naturally than to receive a vaccine (Guadino & Robinson, 2012). In a 2000 national telephone survey, 25% of participants believed that too many childhood vaccines could damage the immune system (Gellin et al., 2000). Another related misconception that propagates vaccine refusal includes the theory that vaccines

do not induce immunity, and instead actually causes disease in those that are vaccinated (Downey et al., 2010).

Vaccine Injuries and Misinformation

Vaccine injury or adverse effects, other than autism, also contribute to vaccine hesitancy (Salmon et al., 2015). These adverse effects include anaphylaxis, febrile seizures, encephalopathy, encephalitis, and minor adverse effects like local reactions and fever (Miller, Haber, Hibbs, & Broder, 2014). Many of the childhood health problems that vaccine hesitant mothers believe vaccines cause are health problems that usually manifest themselves at the same age as when children receive their childhood vaccines. Therefore, mothers tend to believe that correlation is causation, leading mothers to attribute the adverse health event to vaccines (Salmon et al., 2015).

The Internet allows for stories of vaccine injury to be widely disseminated (Salmon et al., 2015). The stories that parents share are rarely challenged with medical facts as this type of response can be viewed as insensitive in the face of a health tragedy that is being attributed to vaccines (Shelby & Ernst, 2013). There are numerous anti-vaccine pages and groups on the Internet where parents share their stories of vaccine injuries. Any comments challenging the connection of the condition to the vaccine may be responded to as being insensitive and may even be deleted from the post (Shelby & Ernst, 2013). According to Shelby & Ernst (2013), anti-vaccine groups on the Internet are driven by emotion without any validity or credibility checks occurring, meaning the information shared tends to exacerbate the misunderstanding of the science behind vaccines. Thus, parents may be led to form vaccine hesitant beliefs (Shelby & Ernst, 2013). The National Childhood Vaccine Injury Act of 1986 was passed mandating that providers report adverse events that occur after giving a vaccine (Miller et al., 2014). A part of

the National Childhood Vaccine Injury Act was to establish the Vaccine Injury Compensation Program, which is meant to resolve vaccine injury claims (CDC, 2017d). Claims of believed vaccine injury or death are reviewed by the Court to determine if compensation should be given (CDC, 2017d). Additionally, VAERS was established in 1990 by the Department of Health and Human Services and is sponsored by the CDC and FDA. It serves to collect and analyze vaccine injury cases. Although vaccines are held to a higher standard of safety than any other type of medicine, vaccines can still cause common effects like fever, local reactions, and anaphylaxis or febrile seizures, which are rare (Miller et al., 2014). Individuals other than health care providers can report incidents to VAERS (Miller et al., 2014).

Data collected by VAERS shows that vaccine injuries happen infrequently. Annually 220 million vaccines are given in the U.S., and only 28,000 events are reported to VAERS per year. Reports from 2006-2010 showed that 0.6% reported death, 7.7% reported a serious non-fatal event, while 91.7% reported non-serious events (Miller et al., 2014). Furthermore, a meta-analysis examining the administration of 25 million vaccine doses found only 33 cases of anaphylaxis caused by vaccines (McNeil et al., 2016).

A lack of knowledge of vaccines is not directly tied to vaccine hesitancy. On the contrary, studies have shown that parents who vaccinate their children typically have less knowledge of vaccines than vaccine hesitant parents. Studies show that vaccine hesitant parents have usually explored much information regarding vaccines and are interested in health-related topics (Dube et al., 2013). Berezin and Eads (2016) found that parents who were vaccine hesitant were of high income and education, whereas individuals of low income and education were not vaccinating their children due to a lack of access. The question then becomes where are these educated vaccine hesitant parents receiving their information about vaccines. The Internet

allows individuals to research vaccines; however, individuals may be ill-equipped at recognizing a credible source from source that is not credible. Studies supporting vaccine hesitant beliefs are most often in publications that are considered unsound by the scientific community (Schwartz, 2012).

Conclusion

Vaccine hesitancy is a complicated phenomenon with many different contributing factors. The available literature suggests the key factors are religion, fear of autism and the role of media, government and pharmaceutical distrust, naturopathic beliefs, and vaccine injury. Chapter three will describe the methods employed to gain a deeper understanding of the factors that contribute to vaccine hesitancy as well as the information sources that vaccine hesitant mothers use.

Chapter 3: Methods

Introduction

The purpose of this study was to gain a deeper understanding of the factors that contribute to vaccine hesitancy in mothers who have a child or children ages 0-18 and to identify the sources from which these factors come. The research questions that were addressed include:

- What are the factors that cause mothers to be vaccine hesitant?
- What are the information sources that contribute to these factors?

This chapter will discuss the study design, study population, experimental protocol, data collection, and limitations and delimitations of the study.

Study Design

This study was a qualitative design. Highly structured interviews were conducted over the phone with vaccine hesitant mothers who met pre-determined criteria and volunteered their participation. The survey questions were based off factors for vaccine hesitancy found in available literature. The interview responses are summarized in the results section. This type of design allowed the purpose of the study to be attained, which is to gain a deeper understanding of the questions "What are the factors that cause mothers to be vaccine hesitant?" and "What are the information sources that contribute to these factors?" Demographic statistics such as ages of children, extent of education of the participants, annual household income, and the number of their children that received some, none, or all vaccines are included in the analysis of the data as well.

Study Population

The population that participated in this study were mothers that are vaccine hesitant and that have at least one child between the ages of 0 and 18. Each mother is a citizen of the United States. Participants were attempted to be found via posts within Facebook groups that are exclusively for mothers and/or healthy living. However, the Facebook groups did not yield any participants, so an addendum was made to the data collection of the study (Appendix G). Participants were found via word of mouth by friends, family, and classmates of the researchers.

Data Collection/ Experimental Procedure

The researchers contacted administrators of Facebook groups that are for mothers and/or healthy living asking for permission to recruit participants from the group. The Facebook groups were found by either contacting acquaintances that were known members of a group or by simply searching for groups that fit the criteria. After a population agreement with the group administrator had been established (Appendix C), the researchers or the Facebook group administrator posted a message that was pre-written by the researchers in the Facebook group. The post described the research and contained the researchers' emails and instructions to email the researchers if individuals were willing to participate (Appendix D). The participants were asked to not comment or react to the Facebook post to ensure confidentiality, but instead to email the researchers. The researchers or the Facebook administrator monitored the post for any participants who directly replied to the post. Through private message, the participants were asked to delete their comment or reaction to the post to ensure confidentiality, and they were asked for an email to be contacted by. The Facebook post was made every two weeks.

The posts on Facebook pages did not yield any participants, so permission was obtained from the Bethel IRB to locate participants alternatively by word of mouth (Appendix G).

Family, friends, and classmates of the researchers contacted individuals they believed would qualify for the study. The volunteers were provided the researchers' contact information, and participants voluntarily sent an email to the researchers for more information about the study. The researchers then emailed participants according to the order of participant response with an informed consent form (Appendix A), inclusion criteria questions, and demographic questions (Appendix B). Participants' confidentiality was maintained as they voluntarily contacted the researchers. Contact information of participants were deleted to ensure confidentiality after the interview was completed. Individuals that family, friends, and classmates reached out to were under no obligation to email the researchers and could choose not to participate in the study. If the individual met the inclusion criteria, a phone interview time was established with the participant. The specific number of interviews conducted was determined by when the saturation of results was attained. Twelve interviews were conducted. All participants' contact information was kept on a password protected computer owned by the researcher.

The data was collected through a highly structured interview that was conducted over the phone. The phone conversation was conducted in a private room and was recorded with a recording software on a password protected computer that belonged to the researcher. The conversation was then transcribed, and the audio file and the participants' contact information was destroyed upon completion. The research tool included a script of questions to ask each participant. The study data will be kept on an external storage device locked in the PA program office for a minimum of five years, per securing requirements for Bethel University's Physician Assistant program.

Before the actual interviews were conducted, there were pilot interviews done with each researcher interviewing at least one mother that does not fit the inclusion criteria. The pilot interviews were conducted using the same script of questions. The pilot interviewees provided helpful feedback to make sure the questions were easily understood and to help the interviewer better connect with the participants of the study.

Each interview was conducted with the same script of questions that was based on the literature review found in chapter two (Appendix C). At the beginning of the conversation, participants were informed they are being recorded on a password protected computer owned by the researcher, that they may discontinue participation at any time without consequences from Bethel University, and asked if they have any follow up questions regarding the informed consent. The participants were also told that by answering the following questions, they indicate that they have read and agree to the informed consent. The participants were then asked to share how many children they have, the ages of their children, and how many children have received some, none, or all vaccines. Participants were then asked how they understand a vaccine works in the body. Then participants were asked about a series of factors that may have influenced their vaccine hesitancy. These factors were: religion, media, fear of side effects/vaccine injury, autism, government distrust, pharmaceutical distrust, healthcare provider influence, and CAM. If the participant expressed that one of the factors did influence their vaccine hesitancy, they were then asked to further explain how it was influential. At the end of the conversation, each participant was asked if there were any other factors that have contributed to their vaccine hesitancy that was not already discussed, and the participants were asked where they acquired the information that influenced their vaccine hesitancy. The

researchers kept a neutral voice throughout the interview to prevent any expression of emotion or personal bias regarding vaccinations.

In order to ensure validity and reliability, the research was conducted using the same questions and script for each interview so that each interview was consistent to provide the most valid results. If the research would be duplicated using the same questions and procedure, the results should be similar and reliable. The interview questions were based from the literature review, and the responses contributed to the answers of the research questions.

Data was analyzed qualitatively by summarizing how the participants answered questions regarding the factors that contribute to their vaccine hesitancy. Demographic statistics such as ages of children, extent of education of the mother, annual household income, and how many children have received some, none, or all vaccines were included in the analysis of the data as well. All data was kept electronically on a password protected computer owned by the researcher.

The independent variable are mothers with children age 0-18 that are vaccine hesitant. The dependent variable are the factors that contribute to the vaccine hesitancy of mothers with children 0-18.

The study was reviewed by Bethel University Institutional Review Board level 3 for ethical approval of conducting research involving human beings, prior to collecting data.

Limitations/Delimitations

A limitation of the study was researcher personal bias during the interview. The researchers understood the benefits of vaccinations, and this may have interfered with interviews leading to inaccurate results. In an effort to control this bias, the interviewers kept a neutral voice to encourage the participants to give the most accurate responses. Another limitation may

have been participants refusing to answer certain questions or not giving truthful answers. In an effort to control for this bias, participants were ensured that the interviews were solely for the purpose of gaining a deeper understanding of vaccine hesitancy and researchers would not be attempting to share their opinions about vaccines. Furthermore, interviews were conducted until saturation of data was attained in an effort for all factors of vaccine hesitancy to be accurately represented in this study. The delimitation of the study was the sample population that was interviewed. Only vaccine hesitant mothers of children 0-18 years old who are US citizens were interviewed.

Conclusion

In conclusion, this study was conducted in order to gain a deeper understanding of the factors that contribute to vaccine hesitancy in mothers of a child or children of 0-18 years and to identify the information sources that contribute to these factors. The outcome of the study will allow healthcare providers to better understand vaccine hesitant mothers' concerns, allowing for providers to more effectively address these concerns. Additionally, identification of the information sources that vaccine hesitant mothers use will allow healthcare providers to become familiar with the sources allowing providers to address the credibility of the sources with vaccine hesitant mothers.

Following this chapter is the results section where the interview responses are summarized, and demographic statistics are displayed. The final chapter is the discussion in which the results are discussed and related to the review of literature. Limitations and delimitations of this study may have affected the results and are discussed in the discussion section, as well as how the results of this study may be utilized by healthcare providers.

Chapter 4: Results

Introduction

This chapter exhibits and reviews the results of the qualitative data that was collected during the interview process of 12 participating mothers. The interview tool (see Appendix C) was used in an attempt to identify factors that contribute to vaccine hesitancy in mothers with children ages 0-18. The interviews were completed between the months of May-December 2018. The purpose of this chapter is to analyze and compare individual answers to identify common themes as well as independent themes that aid in answering the questions:

- What are the factors that cause mothers to be vaccine hesitant?
- What are the information sources that contribute to these factors?

The purpose of the study is to identify factors that cause mothers to be vaccine hesitant in order to better understand and address these concerns as a healthcare provider. Participants were interviewed over the phone, with the interview recorded on a password protected computer owned by the researcher, and then the interview responses were transcribed. The participants were asked to identify factors that have contributed to the hesitancy towards vaccines, and to identify any sources of the information that they could recall (see interview tool appendix C). The data collected was then reviewed by the researchers to identify common themes and thoughts of the participants. The data presented in this chapter reflects the participant's opinions and include the most prominent motifs found during data review. The following material and data presented is exclusive to the participants' responses to interview questions.

Demographics

All of the participants were found via word of mouth by the researchers or members of the Bethel PA program. There was a total of twelve participants that volunteered to be

interviewed. All of the participants were US citizens and mothers with at least one child between the ages of 0-18. The number of children the participants had ranged from one to six children. Two of the participants had never had any of their children vaccinated. Two participants' children were all up to date with vaccines, but they were hesitant about vaccines and the recommended schedule. Finally, the other eight participants had given their children a mixture of some of the recommended vaccines. Three of the participants noted that they had started vaccinating their first child/children as recommended, but then stopped vaccinating later children due to concerns about vaccines.

The participants were also asked to fill out a survey on their highest level of education (Figure 1) and annual income (Figure 2), because it was found in the literature review that vaccine hesitancy correlated with higher income and education levels. Ten participants had education past high school. Two participants had some college education, four had a Bachelor's degree, and three had a Master's degree (Figure 1).

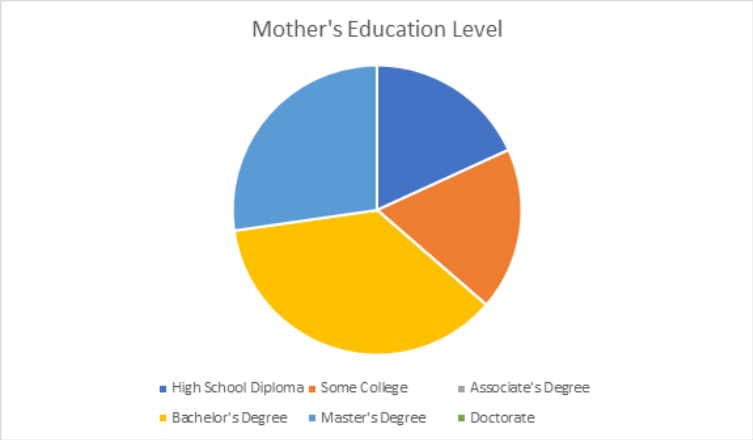

Figure 1. Education level of participants interviewed.

All of the participants had an annual household income of over $25,000. One participant had an income between $25,000-$34,999, two participants had an income between $35,000-$49,999, four had an income between $50,000-$99,999, two had an income between $100,000-

$149,999, and two had an income of more than $150,000. The income ranges chosen for the survey were based off of the literature review (Figure 2).

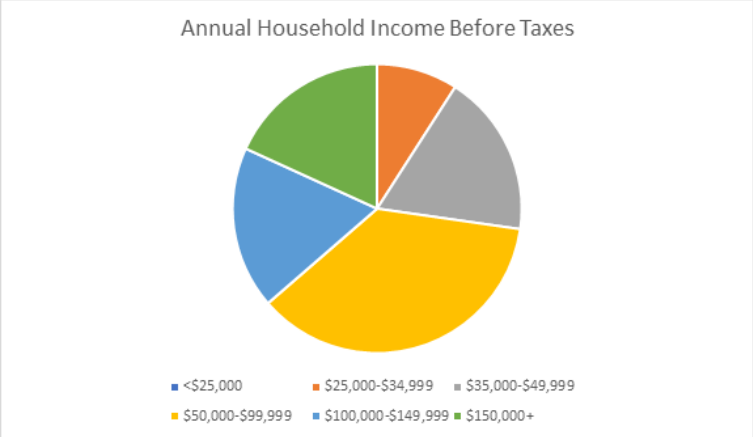

Figure 2. Participants' annual household income before taxes.

Data analysis

The data was obtained until there was saturation of the results. The twelfth interview was analyzed and provided no original data that was relevant to the research. Data collection was then stopped, as the saturation theory was met. For more details on methodology, data collection is described in Chapter 3.

After each interview, the data was transcribed and organized by different categories. The categories were broken down first by how the participants perceived that a vaccine works in the body and then the main factors that contribute to vaccine hesitancy as found in Chapter 2. The data was analyzed in each of the categories, making it more efficient to assess all the responses for each question.

The purpose of this research was to understand the factors leading to vaccine hesitancy in mothers. The first section describes the results of how the interviewees believe vaccines work in the body. The subsequent sections are broken into the different factors contributing to vaccine hesitancy.

How a Vaccine Works

The participants were asked to describe how a vaccine works in the body. This was asked to gain a better perspective of the overall knowledge the participants had on vaccines. Eight of the participants understood that a vaccine is used to build up the body's immune system to a specific disease by introducing a "small amount" or an "inactive form" of the disease, as two of the participants described. Five of the participants discussed the forming of antibodies as an immune response to vaccines. One such participant stated:

> It triggers an immune response by injecting a small amount of the virus, or the pathogen, in order to trigger an immune response to provide antibodies against that, so that if they were exposed to it in the future their body would be able to fight it off.

All participants understood the intended purpose of vaccines is to prevent disease. As one mother responded, "When a vaccine is given, it protects the child from the certain disease or illness. It is used as a preventative measure."

One mother discussed that she did not think that this type of immunity worked and that natural immunity by getting the actual disease was better. She stated:

> The problem is that instead of getting the disease itself, vaccines do not produce lifetime protection. There are boosters, because vaccines don't fully protect the body from the disease, and in many cases, it just causes a weaker reaction to the infection.

This participant went on to discuss how children continue to get chicken pox even after getting the vaccine, but just a milder form, and that the incidence of shingles is increasing because vaccines do not allow the body to fully fight off the infection naturally. As a group, the participants seemed to understand that vaccines initiate an immune response by introducing the pathogen to the body, thus attempting to protect the individual from the disease.

Research Question One: Factors Contributing to Vaccine Hesitancy

The factors contributing to vaccine hesitancy identified in the literature review found in chapter 2 are the following: religion, media, fear of side effects or vaccine injury, fear of autism, government distrust, pharmaceutical distrust, experience with healthcare providers, and contact with CAM. These are the factors that participants were asked about during the interview. A summary of participants' responses regarding vaccine hesitancy factors is found in table 1.

Participant	Religion	Media	Fear of Vaccine Injury/ Side Effects	Autism	Government Distrust	Pharmaceutical Distrust	Healthcare Provider	CAM	Other
1			x	x	x	x	x		x
2					x	x		x	x
3	x		x		x		x	x	
4		x	x	x	x	x	x	x	
5		x	x	x			x		x
6	x	x	x		x	x			x
7	x	x	x	x	x	x	x	x	x
8			x	x	x	x			x
9	x	x	x	x	x	x	x	x	
10		x	x	x			x	x	
11	x		x	x	x	x			x
12			x	x	x			x	x
Total	5	6	11	9	10	8	7	7	8

Table 1. Contributing factors of vaccine hesitancy for each participant

Five of the twelve participants stated that religion is a factor contributing to their vaccine hesitancy. Six of the twelve participants stated that media is a factor. Eleven of the twelve participants stated that fear of side effects or vaccine injury is a factor. Nine of the twelve participants stated that the fear of autism is a factor. Ten of the twelve participants stated that government distrust is a factor. Eight of the twelve participants stated that pharmaceutical distrust is a factor. Seven of the twelve participants stated that their experience with their healthcare providers and their views towards vaccines are factors. Seven of the twelve participants stated that their exposure to CAM has been a factor. Eight of the twelve participants

identified additional factors of their vaccine hesitancy when asked if there were other factors that we had not discussed (Figure 3).

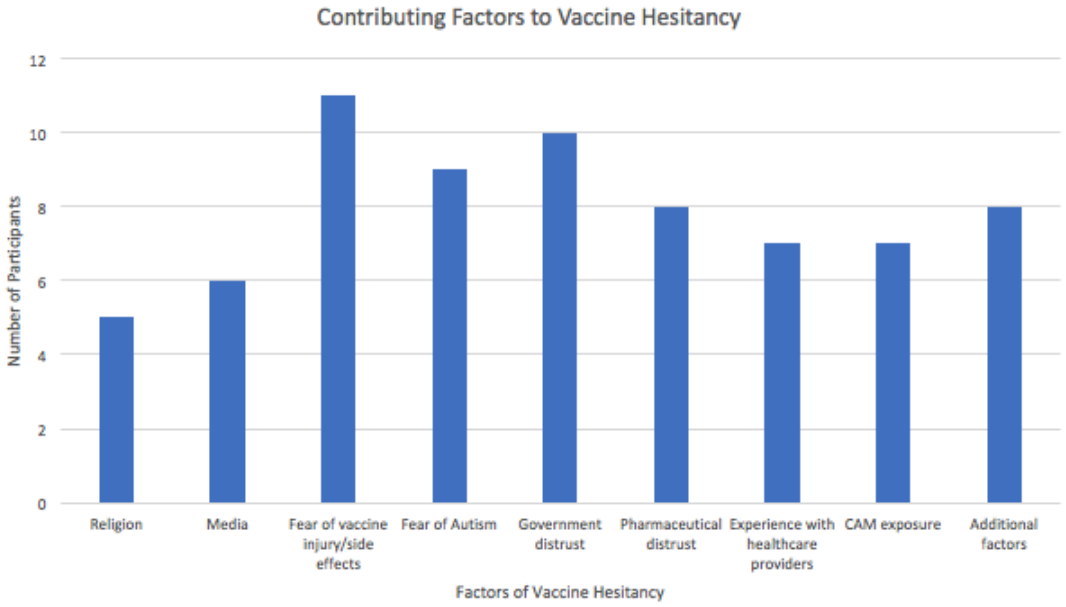

Figure 3. Factors Contributing to Vaccine Hesitancy

Religion

The first factor relating to vaccine hesitancy that was identified in Chapter 2 Literature Review is religion. Participants were asked to answer whether religion is a factor that contributes to their vaccine hesitancy. If the participants answered yes, they were then asked how this has been influential to their vaccine hesitancy and where they feel that they have received this information from. 41.6% participants claimed that religion is a factor in their vaccine hesitancy. Five out of twelve of the participants stated that their religion and their religious beliefs play a role in their concern towards vaccines. Seven of the twelve participants stated that religion does not play a role in their vaccine hesitancy. The specific religion that each participant believes in was not confirmed.

Among the explanations of how religion impacts their vaccine hesitancy, several participants stated that humans have a natural immunity and thus do not need the human-made immunity via vaccinations. One participant stated:

> God made us with natural immunity, even one-day old babies have immunity, so why would they need vaccines? God gave us the immunity that we need. The diseases that we are vaccinated against are good, they help to keep our immune system strong to keep away worse diseases such as cancer.

This notion is reciprocated in one participant's statement, "God gave us an immune system […] I don't think that God created us faulty." Another participant identified that she believes the God-given natural immunity lasts a lot longer than immunity provided by vaccines. Of the five participants that stated religion is a factor in their vaccine hesitancy, three of these participants cited that they believe God has made the human body to be able to fight off infection as a reason for their vaccine hesitancy.

Additionally, two of the five participants that confirmed religion as a factor in their vaccine hesitancy explained that they do not believe that vaccinations are God's will. One participant stated, "vaccines are human made and I believe that they are going against God's will. They are going against fate." Another participant said:

> If you look in the Bible, there is a verse that talks about vaccines […] it talks about how vaccines are from Satan and that they are made to kill children of God. I honestly believe that this is witch craft and that there is nothing more Satanic than immunizations.

When describing which of her children had been vaccinated, the previously quoted participant stated, "I do not allow my children to be vaccinated. It goes against my religion, because I believe that vaccines are from Satan since they contain aborted fetuses." Relating to this

quotation, all of the participants that cited religion as a factor for their hesitancy mentioned that vaccines are made using human DNA, and in four of five cases, they refer to the DNA contained within vaccines as aborted fetal cells, tissue, or matter.

Referring to fetal matter contents of vaccines, many of the participants claimed that this goes against their beliefs and in one participant's opinion is "morally wrong." One participant stated that "There have been many fetuses aborted to make these vaccines." Several participants detailed that they discovered that there is fetal DNA in vaccines from either the CDC website or from vaccine inserts themselves. In one case, a participant stated:

> Vaccines are made with human DNA. God did not intend for us to have other people's DNA in our body. I think this is why we are having so many homosexuals and transgenders now. They have been injected with the DNA of the opposite sex, and this has led to a confusion of who they are.

The topic of sexuality was not a repetitive theme between multiple participants; however, three participants did mention that it is unknown what the DNA that is used in vaccinations may do in the body. These participants spoke about DNA fragmentations inserting into the DNA of the recipient of the vaccinations. A participant stated, "God made us all unique with our own DNA, so why would I want fetal tissue that has its own DNA injected into my children?" Another participant expressed concerns that the DNA used in vaccinations is not tested for the potential to cause cancer, and the associated fear of her child developing cancer caused her to defer vaccinations.

Relating to the DNA topic, another common theme between participants responding in the religion category, as well as several other factor categories, cite that there are ingredients in the vaccines that they don't approve of because of religious reasons or other beliefs. One

participant stated, “overall, just injecting a lot of the nasty ingredients I don’t think is Biblical,” while another said:

There are lots of toxins and proteins and fetal human DNA and all kinds of other weird DNA in there that hasn’t been studied for very long and it’s not really considered safe, so I don’t want to be injecting those into my babies without really good evidence that it’s safe.

In several different categories in addition to religion, participants discuss the potential for ingredients to cause harmful physical and behavioral effects. Participant’s fear of side effects or vaccine injury as well as behavioral effects including autism will be discussed at length below.

Media

Six of the participants that were interviewed claimed that media does have an impact on their hesitancy towards vaccines. Six participants stated that media does not have an impact on their vaccine hesitancy. Among those that responded that media does not have an impact on their vaccine hesitancy, 83.3% of these participants cited media outlets such as websites/internet, books, and social media sites throughout their interview. One participant reported that she first started researching vaccinations because of a post regarding vaccine ingredients that a member of a Facebook group had posted on the page, and she has since become hesitant towards vaccinations. 91.7% of participants described their information sources throughout the interviews or specifically in the media section of the interview and indicated that media plays a role in obtaining information both in favor of vaccinations and in opposition of vaccinations. One participant stated, “pharmaceutical companies basically own the advertisements on TV and it’s flooded with [..] vaccine type stuff or pharmaceutical stuff, and the news even appears to be slanted in that direction too.” This participant continued to discuss that the bias she has observed in the media towards promoting vaccinations has made her wariness of vaccinations increase.

A participant claimed, “No, I do not think that media has influenced my hesitancy, because they all tell you to vaccinate. They are just puppets for the pharmaceuticals.” She continued on, “I would say that the media used to be more split and that they use to support both sides, but in the last 10 years they have only supported vaccines.” Another participant described:

> I think media influences me in both positive and negative ways. There is so much out there about this topic on media. You can find anything on the internet, but the problem is shifting through to what is truth and reliable sources.

This participant went on to describe that she has learned to navigate media outlets as to which ones to avoid and which sources are reliable.

Additionally, another participant described her experience coming across stories in the media that involve vaccinations. She stated, “I am interested in other people’s stories […], it’s not like someone told me a horror story and I freaked out. I try to see both sides of it.” She described further, “media hasn’t influenced my decision, but I do see it and read it and hear about it and try to listen to other peoples’ stories.” Another participant articulated that opinions about vaccinations are “inundated everywhere, like on the news, like on social media” and continued to say that:

> A lot of people have [..] made assumptions about vaccines, but I think even those assumptions scare people and then make you worry about if it will happen to your kid, whether or not it actually happened or not.

This participant summarized that whether stories and opinions are founded with research or not, they are out there for the public to see, hear, and read about through media outlets. She described a worry and fear that developed from hearing these stories that has ultimately led to her hesitancy towards vaccines.

Throughout the various interviews, eleven of the twelve participant shared media resources that they have used find and support concerns about vaccinations. One participant described:

> We watched the anti-vax documentary, which increased our hesitancy about vaccines. It is hard because there are so many things out in the media that supports both sides, that vaccines are harmful or that they are good. I would say that we have mostly gotten our information from the documentary and other media articles though.

Another participant promoted the documentary *Anti-vax*, as well as "books called the *Truth about Vaccines* and *Dissolving Illusions*, which talk about how vaccines are not good." Additionally, a participant cited, "here is another great book I read called, *Disconnected Kids*. It talks about how the brain develops and how anything foreign, like vaccines, can affect the brain."

Overall, 50% of the participants stated that media is a factor in their vaccine hesitancy. Although six participants claimed that media is not a factor in their hesitancy, five of these participants quoted some form of media elsewhere in their interview. Media impacted eleven of twelve of the participants in that it acts as an avenue for obtaining information and sharing information between vaccine hesitant people. Two participants also cited media sources that are pro-vaccine that appear to be biased towards pharmaceutical companies, which has made them more skeptical about vaccines.

Fear of side effects or vaccine injury

All but one participant said that vaccine injury or side effects from vaccines was one of the reasons they were hesitant about vaccines. One participant stated, "The side effects seen with vaccines is probably the biggest reason as to why I am vaccine hesitant." Another said the fear of vaccine injury was her "second biggest reason why I do not vaccine after religion."

Seven of the participants expressed their fear of their child having an immediate reaction to vaccines such as fever, swelling at the site of injection, and seizures. One such participant stated, "Every time my son had a vaccine, he had a very high fever, and we had to rush him to the emergency room." Another participant described the experience of her child having a reaction to the DPT vaccine:

> The vaccination site on her leg swelled up and was bright red. She had a high temp and the spot on her leg had an even higher temp. Then she developed a hard spot under where the vaccine was injected and she still has it to this day. I was actually told by the doctor that she is lucky to be alive!

This experience led her to not vaccinate anymore of her children.

Eight of the participants went on to express their concerns of long-term side effects from vaccines as well, which seemed to be what they feared the most. Three of the participants mentioned concerns of their child developing autism from vaccines. Four stated that vaccines were to blame for an increase of allergies, asthma, and ADHD. One such participant stated, "There is an increase of many things such as allergies and asthma, and I believe that it is due to the chemicals in vaccines." Another participant stated, "I think mainstream children who are vaccinated, because that's what people think is right to do, they're sick a lot. They have respiratory issues, they have allergies, and they have ADHD."

Three of the participants discussed concern that the additives in vaccines were causing the long-term side effects. One participant stated, "Even all the heavy metals that are used in vaccines can possibly contribute to Alzheimer's and seizures, and just different chronic issues, maybe that don't even manifest until later in life." Another participant discussed that she was

happy her child developed a hard lump at the injection site, because then the additives were stuck in his leg and did not spread to the rest of his body. She stated:

> Many vaccines have aluminum in them, which is really bad for you. The ethyl aluminum goes straight to brain, and the body's immune system sends out macrophages to attack it. All of this causes damage to the cells in the brain, which can cause harmful side effects.

Another participant also expressed concern of aluminum in vaccines, stating:

> There are so many harmful things that make up vaccines that people don't even realize. Aluminum is a big one! I have training in nutrition, and I have learned about the harmful effects aluminum can have on the GI tract.

She also went on to say that aluminum along with thimerosal in the vaccines causes autism.

Overall, vaccine injury was one of the main factors stated as to why the participants were hesitant about vaccines. 92% of the participants discussed their fear of vaccines harming their children leading to their vaccine hesitancy.

Fear of autism

Nine of the participants stated that autism was a factor that has contributed to their vaccine hesitancy. Three of the participants described stories they have heard in which the child was talking and acting normal, but then after receiving vaccines at one of their childhood visits they developed autism. One participant stated, "The kid knew colors, he knew numbers, had three to five words, went in and got his one-year-old shots, couple days later completely regressed, nonverbal, and now is severely autistic." She went on to say that her sole purpose as a mother is to protect her child, so why would she give her child a vaccine if it could harm them. Another participant relayed information that she had heard from many mothers on a Facebook group, "Their child gets a vaccine and goes to bed normal, and then after 24 hours they are never

the same again. They are unable to talk or do the things that they use to be able to. They have autism!"

Three participants expressed their concern of specifically the MMR vaccine causing autism. One participant stated, "I would say that the vaccine we were the most worried about was the MMR due to the fear that it causes autism." Another participant discussed how many of the Somali people do not want their children to get the MMR vaccine, because they are afraid of autism. She stated, "the Somali people call autism the American disease, because they do not have children with autism in their country. They have realized that after their children receive the MMR vaccine they stop talking and they act differently." The participant reported that all the parents say the same thing about when their child developed autism, "their children were able to talk until they received vaccines and then they were unable to talk."

Again, four of the participants expressed their concern of the harmful effects from the additives in vaccines. They were all concerned about the heavy metals, aluminum and mercury contained in vaccines. Two of the participants mentioned their concern of the use of thimerosal, which is a mercury-based preservative. One participant described a study she read, "There was a study done recently in China and Great Britain both stating that vaccines cause autism. In one of the studies, they found that there is double the amount of aluminum in autism as there is in Alzheimer's." She stated that the aluminum was from vaccines. Three of the participants described a "gut-brain reaction" that occurs after the metals are injected, which causes autism. One participant described it as:

> There is a gut-brain reaction from the mercury that can cause autism. If the body can't get rid of the mercury then it attacks the brain, so children with a disturbance in their GI tract may have a higher chance of getting Autism.

She went on to say that this also is the cause for ADD, dyslexia, ODD, and Asperger's. Another mother also described this reaction stating, "a lot of the ingredients would have the potential to cause gut issues. […] [The aluminum] has to go out somewhere though, and it's able to cross the blood brain barrier and it can go into your brain." The participant explained that everyone has a unique gut flora which is the reason why not every vaccinated child develops autism.

Three of the participants discussed their distrust in the government and CDC surrounding the information about vaccines causing autism. One participant stated that there are many cases of children developing autism after receiving vaccines, but the government does not want the community to know about. She described one case of a child developing autism from a vaccine, "One example is the case of Porter Bridges. The courts now pay for his medical bills and have reimbursed his parents because it was proven that vaccines gave him autism." She went on to say that the media and government are trying to hide the autism epidemic. She also discussed another case, "Another case is Hannah Polling, she is one of the first people to win government compensation for the bad effects of vaccines." Another participant discussed how the CDC has not conducted reliable studies on whether vaccines cause autism. She stated, "the studies, they are not a full vaccinated vs. unvaccinated for a long period of time. […] then they say that doesn't cause autism, when they can't really prove it from that tiny little window." She also expressed her concern that the CDC has only studied the effects of thimerosal and not the other additives in vaccines.

Overall, even though autism was not a concern for all of the participants, it was the third most common factor leading to the participants' factors. They feared that vaccines were the cause of the increase in autism and that the government is trying to cover it up.

Government distrust

Ten of the twelve participants stated that government distrust is a factor contributing to their vaccine hesitancy. Three of these participants stated that government distrust was a small factor to their hesitancy, while the other seven stated that it was a big factor. One participant stated, "I would have to say yes, but it is super low on the scale... I think we as a society just kind of float through life and do things because that's what we think we are supposed to do." Another participant stated that "everything the government does is based on the pharmaceuticals." One participant stated:

> Probably, I don't, like it's not on the forefront of my mind, but pretty much since I am anti-government, as far as it being involved in my life. When they mass produce things... you can question exactly what the agendas are.

The most stated reason that government distrust was a factor for vaccine hesitancy was that vaccine manufacturers cannot be sued over vaccine injuries and that the vaccine injury compensation program is not sufficient. One participant stated:

> Vaccines are completely exempt from liability which to me is very upsetting, because they don't have any liability. So there is no incentive for them to make a safer vaccine. So because of that, the government made the vaccine court, which is hard to get your case through there and get all your evidence seen. I feel like it's not a legitimate court, and it doesn't make sense to me that it should have ever been that way in the first place, like the vaccine manufacturers should have liability, so I don't know why the government are allowing them to have exemption from liability. And then the court is not really very helpful.

In regards to the vaccine manufacturers being protected from lawsuits, one participant stated, "I think it's really evil to not have checks and balances for something that is potentially life-endangering." Another participant stated, "I don't believe that the vaccine injury compensation program and the vaccine adverse reporting system is made public enough to parents."

Two participants stated the fact that the CDC owns patents to various vaccines plays into their distrust of the government. One participant stated, "Of course they are going to endorse their own product and tell us that we need vaccines. It is all for the almighty buck! All the government and pharmaceuticals care about is money." Another participant stated:

> The CDC owns the patents to the vaccines. They are the ones that are supposed to do the safety tests on the vaccines, but they have never tested them like they should. Merck is run by the pharmaceuticals, and everything the government does is based on the pharmaceuticals. They support vaccines and will make sure that the pharmaceuticals don't get sued. I do think that President Trump will help with this though, because he believes that vaccines are bad too. Honestly that is why a lot of people voted for him, and I think that is why he won.

Four participants stated that they had a general distrust in all things related to the government rather than only being distrustful of the government when it comes to vaccines. One participant stated:

> I do not believe that it is actually true what the government says vaccines are. I think they do not tell the whole truth of what is actually in vaccines. I think they are just government mandated for control over us, and I do believe there is a conspiracy. I don't trust the government, but I still live under their rules. But that doesn't mean I have to listen to everything that they tell me.

One participant discussed her distrust in the FDA specifically as contributing to her distrust of the government. She discussed how she believes the FDA buys out natural options to artificial sugars, their support of fluoride in the drinking water when "Harvard says that it's a neurotoxin," and she continued to say, "When you say that frosted flakes are healthier than avocados because of the fat content per the FDA, like who are you?" Overall, government distrust was a large factor of vaccine hesitancy for most of the participants.

Pharmaceutical distrust

Eight of the twelve participants stated that pharmaceutical distrust is a factor of their vaccine hesitancy. The most cited reason for the distrust in pharmaceutical companies was that the companies are solely after making a profit. Five of the eight participants who said pharmaceutical distrust was a factor for their vaccine hesitancy attributed their distrust of the companies to their pursuit of a profit. One participant stated:

> I think that vaccines and a lot of other pharmaceuticals are just a big ploy to make money. They just want to make money off people even when they are healthy. If people are healthy, there is no reason to go to the doctor or get vaccines.

Another participant stated:

> They're making all the money for the vaccines, and they don't have liability. So they can do whatever they want basically, and they're going to get paid either way especially if the vaccines get mandated. Then they are automatically making all this money with no liability.

Yet another participant stated, "It's not about helping people, it's about making money."

Other reasons for pharmaceutical distrust include the fact that pharmaceutical companies pay the cost of the research for vaccines and that the companies do not make vaccine inserts accessible enough to healthcare providers or to patients. One participant stated:

> There is all of this research studies out there, but you know, who funds them and how are they being paid for? And often times the pharmaceutical companies are footing the bill to pay that. And you know, that kind of leads me to be a little leery.

In regards to the vaccine inserts not being accessible enough, one participant stated:

> They [pharmaceuticals] don't make the vaccine inserts as readily available to the health care providers or to the patient. And I think, I feel that if some parents read the ingredients and the lists of potential side effects, not just the information sheet that they give out, the actual insert from the package, I think that it may make parents think twice.

A final reason for pharmaceutical distrust is a concern about the production of vaccines from one participant. She believes there is a "high, high breeding ground for things to go wrong" with the development of vaccines that are then dispersed to medical facilities. She reports that this concern has come from working in healthcare and witnessing medications be recalled or the side effects of medications. One participant said that pharmaceutical distrust was not a factor because, "They [pharmaceuticals] don't have a choice in the matter. I think they are just controlled by the government and have to do whatever they tell them."

Overall, pharmaceutical distrust seemed to be a common factor for vaccine hesitancy, and specifically the belief that the companies are only after making a profit.

Experience with healthcare providers and their views

Five of the twelve participants stated that healthcare providers did not have an influence on their views of vaccines, whether they decided to vaccinate their child or not. Four

participants stated that healthcare providers had influenced the participants to vaccinate their child at some point. Two participants stated that healthcare providers have influenced their vaccine hesitancy because they did not seem honest or because they pushed the vaccines too much. One participant stated that a pediatrician she used to see did not discuss vaccines with her, and any time she had questions he would "Beat around it and every time I asked about schedules and alternatives he would just redirect." One participant stated that she has seen many providers who do not vaccinate and have provided her with resources about the dangers of vaccines. Three of the five participants who stated that healthcare providers did not influence their views on vaccines stated that their providers did not spend much time discussing vaccines with them. One participant stated:

> I do not think they had much influence on my decision to vaccinate. They did not give very much information on vaccines, they would just give them. There just wasn't much discussion about it back when we had our first child.

Another participant said:

> I don't really think that my provider has any influence on my decision. My children used to see a provider that wanted me to vaccinate, so I stopped seeing that provider. I have noticed that many providers don't seem to want to discuss vaccines with parents because they know that the parents are right, that they are bad. Instead they just show up with the vaccines and say, 'here are the vaccines that your child is getting.' They don't really give parents the choice, because then they will refuse the vaccines. I realize that it is hard for providers because they feel forced to give vaccines; I know there are incentives put in place by the pharmaceuticals to encourage all providers to vaccinate their children. And they only teach providers one side of the story in medical school, that vaccines are good...

> I guess I just don't look to my doctors on advice about vaccines, because I know that they have not done all the research on vaccines like I have.

One participant who stated that her healthcare provider influenced her to vaccinate her child stated:

> I had some good discussions prior to my daughter being born. And I told her straight up that I had some serious questions about vaccines, we had some really educational conversations about it, she sent me a variety of articles, I read the articles...so I think she's influenced me in a positive way towards her belief system.

Another participant who stated that her healthcare provider influenced her to vaccinate said that she and her husband were considering doing an alternative vaccine schedule for their child, but her provider said "there has been a lot of research done on the best way to give children vaccines and so that this why the vaccine schedule is the way that it is. So, we just decided to stick with the typical vaccine schedule."

The participant who said that she thought that healthcare providers are not honest about vaccines stated:

> I feel like they [healthcare providers] weren't really honest. So, when I had my first daughter, they said that they wanted her to get the Hepatitis B vaccine when she was a day old, and we were questioning that. Then they said that it would be for life. So, we were like, 'oh well maybe if she goes on mission trips or goes overseas, then later she won't need to get the vaccine because she already has it.' Well it doesn't last for life, and no vaccine really lasts for life, you're going to need to get a booster and it's like 10-20 years with hepatitis B, so by the time she would be going overseas, it wouldn't really be

effective anyways, so I feel like that was not really honest to say it lasts forever or for life.

Two participants mentioned that they quit seeing a healthcare provider that wanted them to vaccinate their children, and one of them said that she no longer takes her children to a pediatrician, but rather she takes them to a homeopathic provider.

Overall, participants have quite variable experiences with their healthcare providers in regards to vaccines, and whether or not their healthcare provider influenced their views of vaccines. Interestingly, the four of the five participants who said that their healthcare provider did not influence their view of vaccines stated that their provider did not discuss vaccines with them very much, whereas the four participants who were influenced by a provider to vaccinate their child at some point relayed times that their provider took time to answer their questions about vaccines.

One of the questions asked was whether the participants felt comfortable discussing vaccines with their provider. Of the twelve participants, three participants said that they would not be comfortable talking to their provider about vaccines. One participant stated, "I don't initiate conversation on [vaccines], because it becomes sensitive and is a hot topic, and then people become judgey." Another participant said that she picks providers based on other parents' experiences, because she would not feel comfortable having a conversation about vaccines with all healthcare providers. She stated, "I know plenty of people who have had hostile and condescending [providers], and I just stick to the ones that I either know are supportive of not vaccinating or are neutral."

The rest of the participants said that they did feel comfortable talking to their healthcare provider about vaccines. Two of the participants stated that they felt comfortable talking about

vaccines now that they have done research on it. One participant described, "I feel comfortable talking to them, because I feel like I have done the research and I am not going to be swayed in a direction that I don't believe in." Another participant stated that she felt comfortable talking to her provider because the provider was transparent on their stance, and another participant stated she was comfortable because the provider was "easy to talk to."

Complementary and alternative medicine

The last factor that the participants were asked about was CAM. Participants were first asked whether they have had any contact with CAM, in which they were given examples of popular CAM modalities such as acupuncture, chiropractic manipulation, massage therapy, energy healing, homeopathic treatment, naturopathy, natural products, tai chi, yoga, and meditation. Every participant stated that they had in some way participated in CAM therapy. The participants were then asked if the CAM therapies or relationships they have experienced have influenced their hesitancy towards vaccines. Seven of the twelve participants confirmed that CAM had played a role in their vaccine hesitancy.

57.1% of the participants that acknowledged that CAM played a role in their hesitancy claimed that CAM practices promote a healthy lifestyle. Two participants that stated that CAM has not played a role in their vaccine hesitancy went on to describe that CAM has contributed to their healthy lifestyle choices (including not vaccinating) and were subsequently included in the group of participants that stated CAM impacted their vaccine hesitancy. Of these two participants, one stated, "just the fact that people around me are just more health conscious." The other participant described her healthy lifestyle by saying:

> I have been trying to live a natural life. So, I wouldn't use deodorant that has aluminum in it, because I don't want to rub aluminum in my armpits because it's been linked to

> things like breast cancer and whatever else. So, if I'm not willing to rub aluminum in my armpits, I'm not going to be willing to inject it into my babies that have a developing immune system.

This participant went on to say:

> There are lots of toxins and proteins and fetal human DNA and all kinds of other weird DNA in there that hasn't been studied for very long and it's not really considered safe, so I don't want to be injecting those into my babies without really good evidence that it's safe.

Another participant stated that, "I am a firm believer in healthy eating and home remedies instead of vaccines and treating everything with drugs," while another stated "if you have an overall understanding of health and how your body works […] it makes me less afraid to not vaccinate."

Additional to living healthy lifestyles, 51.7% of participants that claimed CAM has impacted their vaccine hesitancy noted that professionals that work in the CAM industry have specifically impacted their hesitancy. A participant stated that "I would say they have encouraged me to do my own research regarding vaccines," and another said, "Our chiropractor has helped us to stay strong in what we believe. They have taught us a lot." One participant is a CAM provider and she said, "I definitely believe that my training has led to many of the thoughts that I have about vaccines." She explained further:

> I started to be exposed to talks and literature on the effects of vaccines. After coming home from some talks, I told my husband that I do not want to give our children anymore vaccines, and since then they have not received a single vaccine.

Another participant has a husband that is a CAM provider. She stated:

> Since my husband is a [CAM provider], he is exposed to more medical articles and was really the one that was hesitant about vaccines when we had our son. So, I mainly just discuss it with him, and he is the reason that I became vaccine hesitant.

Whether CAM providers encouraged research regarding the safety of vaccinations, or provided patients with research results themselves, they have impacted families and their thoughts on vaccinations.

Of the seven participants that claimed that CAM did have an impact on their vaccine hesitancy, four concluded that CAM impacted them in that they try to live a more natural and health-conscious lifestyle. Four of the seven participants also expressed that their CAM provider(s) had directly or indirectly impacted their vaccine hesitancy.

Additional factors

To conclude the interview, the participants were asked if there were any other factors that contribute to their hesitancy to vaccinate that were not already discussed. Eight of the participants responded that they had additional concerns. Of the eight participants that responded, six identified additional factors that had not been discussed throughout the interview, while two of the participants reiterated points that have been previously discussed. Two of these participants mentioned that they feel there is a lack of safety studies, especially ones that compare vaccinated children to unvaccinated. One of these two participants specifically stated "I think they're afraid to do those kinds of studies. I don't think we have adequate safety studies at the all." One participant mentioned that not enough Vaccine Injury Reports (VIR) are published each year. Another participant stated, "we all have this right to refuse vaccines for our children." One participant identified that peer pressure and mom shaming has heightened her vaccine hesitancy. She said: "I think that sometimes just like family and peer pressure [from] friends,

family, coworkers […] I mean it's a little different than social media because they're right there." She continues to describe:

> "It's just judgment, and their opinions can make me a little more hesitant and then a little bit of mom shaming whether you do [vaccinate] or whether you don't [vaccinate] and why."

Additionally, a participant expressed concerns that "doctors get paid for vaccines." Furthermore, one participant presented a new idea; "a lot of these diseases have been cleared up by proper sanitation." This was an original idea that the evolution of sanitation and proper cleaning techniques have perhaps been even more effective for disease control and prevention than the initiation of vaccinations.

One participant introduced several additional ideas to conclude her interview. One of these ideas is that vaccines may actually be causing more of the disease that they are meant to prevent. Referring to statistics presented in a book she read, *Dissolving Illusions*, she said "you see things like the measles and polio are almost down to zero and then the vaccine is introduced and then it actually spikes again." She continued on to say:

> Did you know we have the bubonic plague here still? But people aren't dying from it here, but we still have cases of it. But we don't have a vaccine for it, so […]
>
> why aren't people dying from the bubonic plague then?

Another concern that this participant identified was concerning vaccine failure rates. She stated, "there's a […] vaccination failure rate, so in highly vaccinated populations there are still outbreaks of things like measles, or pertussis." She goes on to talk about mutant strains of diseases and states:

> For example, [we] are seeing this a lot with measles. You could have a 100% vaccinated population, and if somebody brought in a wild strain of measles you would still probably get measles, and they were seeing that a lot.

The last concern that this participant acknowledged was that vaccines continue to need booster shots throughout a lifetime. She said, "a lot of adults are actually unvaccinated, and they don't realize it, because if you're not continuing to get your booster shots you don't have that immunity." These various ideas, and more, have all contributed to this participant's hesitancy to vaccinate her children. One participant concluded her interview by stating that she has a gut feeling that in the future, science will find new evidence that vaccinations were not necessary and that they have caused more damage than they have prevented.

Eight participants identified additional factors for their vaccine hesitancy that had not been discussed elsewhere in the interview. These additional factors included notions such as lack of safety studies and vaccine injury reports, peer pressure, "mom shaming," rights of individuals, diseases potentially caused by vaccines, vaccine failure rates, and mutant strains of diseases that can cause outbreaks. By the conclusion of the interview, the participants confirmed that they had no other additional concerns about vaccinations to share.

Research Question Two: Information Sources

Throughout the interviews, the following information sources were identified: CDC website; VAERS; vaccine inserts; websites; books, specifically *The Truth About Vaccines, Dissolving Illusions, DPT a Shot in the Dark,* and *Disconnected Kids;* CAM providers, such as chiropractors; social media, with Facebook being sited multiple times; documentaries; articles; speakers; T. V., studies; well-known doctors, such as Dr. Mercola and Dr. Del Vidree who is the producer of the show, *Doctors*; friends; and life experiences.

Information sources identified with specific factors were the following:

Religion: CDC and vaccine inserts. These sources were used for information regarding DNA ingredients in vaccines.

Media: Websites, books, social media sites, Facebook posts about vaccine ingredients, T.V. advertisements, the internet, a documentary, and books. One participant expressed that it is difficult to shift through internet resources regarding vaccines and distinguish reliable vs. unreliable sources. Social media was indicated to be used to hear others' stories about vaccines and adverse reactions. A specific documentary named was, *Anti-vax.* Three books were named, being *Truth About Vaccines, Dissolving Illusions,* and *Disconnected Kids.*

Side effects/vaccine injury: Facebook, chiropractors, speakers, online research, books, VAERS, and stories from friends. One participant reported that her nutrition training provided her with information about the harmful effects of aluminum on the GI tract. *DPT, a Shot in the Dark* was a specifically named book providing information about vaccine injuries.

Autism: Other's stories, word of mouth, posts on Facebook groups, studies, websites, peer reviewed articles, CDC, the book *Disconnected Kids,* and Dr. Del Vidree, producer of the show, *Doctors.*

Government distrust: Most participants did not have any sources contributing to their distrust of the government. Although, one participant stated that Dr. Mercola has influenced her government distrust.

Pharmaceutical distrust: Articles, doctors, books, and life experiences. One participant reported that her experience working in healthcare is a source of her distrust of pharmaceuticals, because she has seen medications get recalled and has seen patients deal with side effects of certain medications.

Experience with healthcare providers: No specific sources were listed.

CAM: CAM providers. One participant is a CAM provider herself, so she reported that her CAM education was an information source for her vaccine hesitancy.

Additional Factors: The book, *Dissolving Illusions,* was again stated as a resource for vaccine hesitancy, as it discussed that vaccines may be causing the disease they are meant to prevent.

Conclusion

In conclusion, twelve participants were interviewed regarding their vaccine hesitancy. The participants were asked about eight specific factors that contribute to vaccine hesitancy that were identified in the literature review (chapter 2). Participants were also asked about any additional factors to their vaccine hesitancy as well as how they understood a vaccine works in the body. Additionally, participants were asked to identify sources that they obtained information from about the various factors for their vaccine hesitancy. The data was then analyzed by the factors contributing to vaccine hesitancy in order to identify which factors were most cited as contributing to vaccine hesitancy and to identify common themes and thoughts of the participants. These steps were carried out to answer our two research questions, which are the following:

- What are the factors that cause mothers to be vaccine hesitant?
- What are the information sources that contribute to these factors?

The purpose of answering the above research questions is to identify factors that cause mothers to be vaccine hesitant in order to better understand and address these concerns as a health care provider.

The factors contributing to vaccine hesitancy identified in the literature review are the following: religion, media, fear of side effects or vaccine injury, fear of autism, government

distrust, pharmaceutical distrust, experience with healthcare providers, and contact with CAM. Five of the twelve participants stated that religion is a factor contributing to their vaccine hesitancy. Six of the twelve participants stated that media is a factor. Eleven of the twelve participants stated that fear of side effects or vaccine injury is a factor. Nine of the twelve participants stated that the fear of autism is a factor. Ten of the twelve participants stated that government distrust is a factor. Eight of the twelve participants stated that pharmaceutical distrust is a factor. Seven of the twelve participants stated that their experience with their healthcare providers and their views towards vaccines are factors. Seven of the twelve participants stated that their exposure to CAM has been a factor. Eight of the twelve participants identified additional factors of their vaccine hesitancy when asked if there were other factors that we had not discussed. The order of factors that were most identified as contributing to vaccine hesitancy is the following: fear of side effects or vaccine injury (11), government distrust (10), fear of autism (9), pharmaceutical distrust (8), additional factors (8), exposure to CAM (7), experience with healthcare providers (7), media (6), and then religion (5).

Various information sources regarding vaccine hesitancy were identified. They are the following: the CDC website; VAERS; vaccine inserts; websites; books, specifically *The Truth About Vaccines, Dissolving Illusions, DPT a Shot in the Dark,* and *Disconnected Kids;* CAM providers, such as chiropractors; social media, with Facebook being sited multiple times; documentaries; articles; speakers; studies; well-known doctors, such as Dr. Mercola and Dr. Del Vidree who is the producer of the show, *Doctors*; friends; and life experiences.

The results found in this chapter were analyzed and compared to existing literature as outlined in Chapter 2. The comparison is written about in Chapter 5.

Chapter 5: Discussion

Introduction

This chapter discusses the results found in chapter 4. The results will be compared to the existing literature found in chapter 2 in order to identify similarities, differences, and new findings. The findings that will be investigated relate to our two research questions, which are the following:

- What are the factors that cause mothers to be vaccine hesitant?
- What are the information sources that contribute to these factors?

The following sections will be divided by the factors found in Chapter 2 that relate to vaccine hesitancy. The information sources contributing to those factors will also be discussed in each of the sections. Then there will be further discussion on the information sources as a whole. Opportunities for application of the findings by healthcare professionals will be discussed as well as opportunities for further research. Additionally, the limitations and delimitations of this research will be examined.

Demographics

As noted in the literature review (Chapter 2), vaccine hesitant parents tend to be of high income and education, while parents of lower income and education do not vaccinate their children due to lack of access to a medical system (Berezin and Eads, 2016). The demographic data collected agreed with this finding, as the majority of the participants have had post-secondary education, and all of the participants reported an income that is greater than $25,000. The poverty line of a family of four in Minnesota is $25,750 (Federal poverty thresholds and guidelines, 2019).

Research Question One: Factors contributing to vaccine hesitancy

The first research question addressed in the study was: What are the factors that cause mothers to be vaccine hesitant? During the interview, participants were asked whether a series of factors identified in the literature review had an impact on their own vaccine hesitancy including: religion, media, fear of side effects or vaccine injury, fear of autism, government distrust, pharmaceutical distrust, experience with healthcare providers, and CAM. Factors additional to those that were identified in the literature review were also discovered with our final interview question "Are there any other factors that contribute to your hesitancy to vaccinate that we have not discussed?" These new ideas and thoughts that participants expressed are the driving force of this research in that the opinions of mothers who do not want to vaccinate are being uncovered. This will allow healthcare providers who will need to have discussions with mothers about vaccinations better understand where vaccine hesitant mothers are coming from.

The research completed indicates that each participant had a combination of multiple factors that influenced their vaccine hesitancy. The results of this research question will be broken down into the nine categories of factors to compare the participants' answers outlined in chapter 4 with published literature that was discussed in chapter 2. Several ideas presented in chapter 2 were reflected in the interview responses of the participants.

Religion

Religion was cited as a factor in participants' vaccine hesitancy in five out of the twelve total participants. All of the participants that cited religion as a factor talked about human DNA being used in the process of vaccination production, and how this does not coincide with their beliefs. Four of the five participants mentioned that that they were uncomfortable with aborted

fetuses being used in vaccinations. Four participants suggested that the use of human DNA and fetal cells is morally wrong according to their beliefs. Existing literature confirmed that many religions, such as various branches of Christianity disagree with the use of an aborted fetus in the development of various vaccines (Pelcic et al., 2016). The MMR, varicella, and adenovirus vaccines all have components of the WI-38 cell line, which are cells from a 3-month Caucasian female fetus (Pelcic et al., 2016). One of the participants did specifically mention the WI-38 cell line in regards to using aborted fetal cell lines to make vaccines. Two of the participants that expressed concerns with the human DNA used to make vaccinations cited the CDC website or vaccine inserts themselves as a source of their information. A new idea was introduced by one mother stating that human DNA of the opposite gender has the potential to affect the sexuality of the child receiving the vaccination. This thought had not been previously reflected in existing literature.

One idea that participants cited as a factor for their hesitancy relating to their religious principles, is that vaccinations are going against fate and God's will. This is reflected in existing literature that Dutch Protestant-Christians and several other religions believe that vaccines change the fate of all humans in a way that God did not intend and that it messes with the work of His hands (Pierik, 2017). Two of the five participants that stated religion was a factor in their vaccine hesitancy, confirmed that they believe vaccines go against God's intentions. One of these participants introduced a new idea, one that is not reflected in existing literature, that vaccinations are the work of Satan and intended to harm God's children. Participants discussed the topic of natural immunity as a subfactor to their religious beliefs. Several participants cited that they believed natural immunity is stronger than immunity provided to children by vaccinations. They also cited that God made humans in his image and that he created humans

with the ability to fight off infections on their own without the help of human-made products like vaccinations. This is reflected in existing literature in that a 2006 study showed 43% of mothers that chose not to vaccinate their children believe that it is better for their child to acquire natural immunity than to receive a vaccine (Cassell et al., 2006). One participant expanded on this notion, claiming diseases that humans are vaccinated against are good to acquire, because they naturally strengthen the immune system and keep away diseases that are worse and more deadly than the current vaccine preventable diseases.

Lastly, several participants expressed concerns regarding the ingredients used to make vaccinations. One participant stated that she does not believe the various harmful ingredients that are used in vaccines and to make vaccines are biblical. Although existing literature has not explored the relationship between the bible and vaccine ingredients, the notion of not wanting to expose a child to chemicals in vaccines is certainly reflected in existing literature. One source noted that those who wish to lead their family in an all-natural lifestyle, avoiding added chemicals and preservatives, will also tend to avoid vaccines (Pierik, 2017).

Religion is certainly a factor for vaccine hesitancy that mothers will present to their health care providers. Participants have various different reasons as to how religion plays a role in their hesitancy including vaccinations are against God's will and fate, children have an adequate natural immunity, diseases strengthen immunity against more deadly diseases, vaccinations contain fetal cells, human DNA of the opposite gender may affect children's sexuality, and ingredients in vaccinations are not biblical. Religion is a difficult subject to navigate in the health community, as many of the beliefs are not evidential, but are based on opinions or principles. However, it is important that healthcare providers open up a conversation

about religion and vaccines in order to better understand where patients' concerns about vaccines lie.

Media

50% of the participants stated that media is a factor in their vaccine hesitancy, but 91.7% of the participants referenced one or several media outlets throughout their interview. The majority of participants acknowledged that the media has an impact on their vaccine hesitancy by providing information regarding vaccinations and by allowing information to be shared between vaccine hesitant people. Several participants cited that there is information both for and in opposition of vaccinations, and it is hard to stifle through what is legitimate information. Other participants stated that they think media is slanted and biased towards vaccinations, and that television and media sources are puppets for pharmaceutical companies. This reported bias has impacted these participants in that they have become increasingly wary towards vaccinations. However, the existing literature contradicts these notions in that researchers in 2013 found that information on the internet regarding vaccinations is predominantly inexact or negative in content (Dube et al., 2013).

Another aspect of the media that has impacted the participants' vaccine hesitancy is the avenue for information sharing and story-telling that is readily accessible. One participant stated that she didn't start researching about vaccinations until she saw a post on Facebook regarding ingredients in vaccinations. Another stated that the worry and fear that resulted from seeing a story about a vaccine injury in a child has made her vaccine hesitant. Stories that may not be scientifically founded are being shared on all kinds of media outlets including social media, news, documentaries, books, magazines, websites, etc. Stories about vaccines causing Autism were spread through media via sources that are generally thought to be trustworthy such as *60*

Minutes and *New York Times Magazine* (Begley et al., 2009). The existing literature reports that the internet continues to provide sources of media to disseminate doubts concerning vaccines (Dube et al., 2013). Poland and Spier claim that the nation has moved from trusting evidence-based medicine to trusting media and celebrities (2010). Celebrities and politicians perpetuate misinformation via media by publicly displaying their doubt of vaccine safety (Berezin & Eads, 2016).

Participants reported obtaining vaccine information from television, the internet, social media, movies, books, magazines, documentaries, etc. Participants reported hearing of personal stories on media outlets, which increase their fear and cause them to worry about the safety of vaccinating their children. Healthcare providers need to be aware that media has a profound impact on their patients. Although only six of twelve participants claimed that media impacts their vaccine hesitancy, eleven of the twelve participants mentioned a media outlet as a source of their information within their interview. Providers must learn to navigate the education of their patients regarding reliable information sources and the necessity of communicating scientific research as a cornerstone of reliable information.

Fear of side effects or vaccine injury

Fear of vaccine injury was the factor that contributed the most to the participants' vaccine hesitancy. 92% of the participants responded that fear of injury was one of the reasons they did not like vaccines. There were many different injuries and side effects that the participants were concerned about. 58% of the participants described fear of immediate reactions to vaccines, such as fevers or seizures. Often these immediate reactions are non-serious events, such as fever or a reaction at the site of injection. More serious events such as seizures, death, and anaphylaxis are

rare. Between 2006-2010, only 8.3% of the reports of vaccine injury were serious events; the other 91.7% were non-serious (Miller et al., 2014).

The participants also discussed the fear of the more long-term effects of vaccines, such as causing autism. Four of the participants were concerned about the use of some additives in vaccines, such as thimerosal, causing these long-term disorders. Even though two of the participants expressed their concern about this additive, thimerosal has been removed from vaccines since 2001 (Weber, 2008). Yet, 67% of the participants believe that vaccines are the current cause of autism, ODD, ADD, and Asperger's. 83% of the participants stated that they obtained this information from websites and social media pages. The media has allowed for stories of vaccine injury to be spread, but often these stories are opinion based. Two of the participants stated that the stories they have read about vaccine injury must be true, because they have seen many of the same stories told about vaccine injury by different mothers on anti-vaccine pages and groups. However, there are no medical facts that support the stories that are told on these numerous online anti-vaccine groups, and comments that do not support the anti-vaccine comments may be deleted from the page (Shelby & Ernst, 2013).

Five of the participants stated they had read several peer reviewed articles or books on vaccines. As discussed in chapter 2, parents that are vaccine hesitant are educated and often research vaccines (Dube et al., 2013). As seen in the demographics section of chapter 4, all but two of the participants had education past high school and most of them had either a bachelors or master's degree. One of the participants stated that the reason they felt so comfortable talking to providers about vaccines was because of the research they have done. The participants interviewed were well educated on the topic of vaccines, but the information they are getting

could be inaccurate. This is where medical providers need to provide parents with resources that show how side effects from vaccines are rare.

Fear of autism

Nine of the participants expressed their fear of vaccines causing autism. Three of the participants believed that the MMR vaccine is to blame for the increase of autism. This could be due to the results of Andrew Wakefield's study completed in 1998 which stated that the MMR vaccine was causing children to develop autism. The results of his study quickly spread across the world, instilling the fear into parents that their children would develop autism if they gave them the MMR vaccine (Begley et al., 2009). Even though this study was revoked in the early 2000s, parents continue to fear the MMR vaccine (Begley et al., 2009). As mentioned above, the media has done a good job of spreading the information from Andrew Wakefield's study and continues to release stories on children developing autism after receiving the MMR vaccine (Begley et al., 2009).

The rest of the participants did not specifically blame the MMR vaccine for their fear of autism. They were afraid of their children developing autism after any of the vaccines, which led to their hesitancy of vaccines in general. Six of the participants stated that additives and heavy metals in vaccines caused autism. 25% of the participants specifically discussed the use of thimerosal in vaccines, a mercury-based preservative, as the link between vaccines and autism. The public has become concerned because methyl mercury can cause neurotoxicity, but thimerosal is actually made with ethyl mercury which does not have the same effects (Weber, 2008). Either way, thimerosal was removed from vaccines in 2001 due to the public's fear of mercury in vaccines (Weber, 2008). Even though there are articles stating that thimerosal is no

longer used, these participants are still finding information somewhere that is leading them to believe that there are additives, such as thimerosal, in vaccines that is causing autism.

25% of the participants also discussed a "gut-brain reaction" as the reason vaccines cause autism. They explained that the additives cause the gut to not be able to have its normal immune response, so the additives build up in the body and get deposited in the brain. This idea was also discussed in the Wakefield study. In his article, Wakefield thought that the MMR vaccine caused harmful proteins to leak out of the gut, and once they traveled to the brain the child would develop autism (Begley et al., 2009). Even though the Wakefield study was proven to be wrong, mothers continue to believe in the gut-brain reaction.

Overall, 75% of the participants stated that autism is a factor contributing to their vaccine hesitant, as all parents want their children to be healthy. Even with current research showing no link between vaccines and autism, these mothers continue to get information somewhere that vaccines do cause autism (Begley et al., 2009). One reason for the continued fear of vaccines and autism is the timing of the vaccine. Autism is usually first discovered when a child is supposed to start talking and walking, around the age of one. At the age of one, is also when children receive their first MMR and varicella vaccines according to the vaccine schedule recommended by the CDC (CDC, 2018). Therefore, many parents do not realize that there is a developmental delay until their child is behind their peers, and it has been attributed to the vaccines given around the child's first birthday (Begley et al., 2009).

Government distrust

Ten of the twelve participants stated that government distrust is a factor of their vaccine hesitancy, meaning only 17% of the participants trust the government. According to a study by Lee et al. (2016), only 19% of the population trusted the government in 2013. Our population

reflects a similar percentage of individuals who trust the government. The most stated reason that government distrust is a factor to our participants' vaccine hesitancy was the fact that vaccine manufacturers cannot be sued for vaccine injuries and that the vaccine injury compensation program is viewed as faulty. Interestingly, this reason was not found in the available literature regarding vaccine hesitancy. However, a study by Lee et al. (2016), found that those who were vaccine hesitant often report believing that the CDC and FDA are unreliable information sources. Two participants reported that they do not trust the fact that the CDC owns vaccine patents, because they feel like money is more important than the safety of the vaccines. One participant discussed her distrust of the FDA specifically by covering various things that the FDA supports that she does not trust such as fluoride and artificial sugars.

Four participants reported that they have a general distrust of the government, and this contributes to their vaccine hesitancy. Two studies from the literature review report similar findings. A study by Gostin (2015) states, "An amount of the population does not want to vaccinate their children for the sole fact that they feel as though the government is trying to force them to do so." Another study by MacDonald (2015) found that people can have a "lack of confidence in the motives of the policy makers."

One participant discussed President Trump's vaccine hesitancy, and that he will help correct the government when it comes to vaccines. Interestingly, it has been found that:

> When vaccine hesitant politicians are representing the population in lawmaking, it can create a rising concern in the nation. The public perception can be greatly impacted by those that are in the public sphere and are able to draw greater attention to conspiracies that might not necessarily be true (Sharfstein, 2017).

Government distrust is a common factor contributing to vaccine hesitancy. People have different reasons that they do not trust the government including the law protecting vaccine manufacturers from law suit, a belief that the vaccine injury reporting system is faulty, distrust of the CDC and FDA, a general mistrust of all government entities, and politicians who express vaccine hesitancy. The fact that 83.3% participants stated government distrust is part of their vaccine hesitancy and the varied reasons they cited for causing their distrust of the government indicates that work at the government level is needed to educate the public about the reasoning and importance of the law protecting vaccine manufacturers and the process of vaccine development and testing. In regards to the reported general distrust of the government, government entities and politicians should strive to be transparent with the public and work on assuring people that they function for the good of the citizens, because as Dube et al. (2013) discovered, parents often do not trust the government in regards to vaccines because of the lack of relationship the government has with the community.

Pharmaceutical distrust

Pharmaceutical distrust was a common factor of the participants' vaccine hesitancy, as eight of the twelve participants indicated that it is a factor for them. Five of the eight participants who said they do not trust pharmaceutical companies reported the distrust stems from their impression that the pharmaceuticals are pursuing monetary profit through vaccines. This aligns with a study by Obaro & Palmer (2003), who found that the companies who develop vaccines are profit driven, causing the public to believe that vaccine development is solely for a financial gain. Obaro & Palmer (2003) believe that in order to decrease vaccine hesitancy, there needs to be a vaccine program that is not seeking a profit. However, according to Rappuoli & Medaglini (2014), large companies with financial resources are needed to develop vaccines because of the

cost of vaccine research. It seems that a vaccine company that does not pursue monetary profit would certainly help decrease vaccine hesitancy based off of how many of the participants hold this as a concern. If this is not possible due to the expenses of vaccine research and development, then great effort should be taken to educate the public about the process of vaccine research and development, so that they may understand why the companies are profit driven.

Three novel reasons for pharmaceutical distrust were shared from the participants, as they were not found in the literature review. They are the fact that pharmaceutical companies fund the research of vaccines, pharmaceutical companies do not make vaccine inserts available enough to providers and the public so that informed decisions about the vaccines can be made, and finally a concern about the quality and safety of the production and disbursement of vaccines. These concerns may be addressed by open communication with the public from the pharmaceutical companies, as people tend to trust entities who have established relationships with the public (Dube et al., 2013).

Overall, pharmaceutical distrust is a factor for over half of the participants' vaccine hesitancy. This distrust centers around the profit-driven pharmaceutical companies mostly, but there is also concern that the companies fund the research, that vaccine inserts are not readily available, and that things may go wrong during development of the vaccine. These are concerns that pharmaceutical companies should take steps to address.

Experience with healthcare providers and their views

The participants have quite variable experiences with healthcare providers in regards to vaccines and how they have influenced their vaccine hesitancy. Five participants reported their healthcare providers did not influence their view of vaccines at all. These five participants reported that their healthcare providers did not spend much time discussing vaccines with them.

Four participants reported that their healthcare providers did influence them to vaccinate their children at some point, and all four of these participants reported that their healthcare provider took time to understand their concerns and discuss vaccines with them. This trend seems to be contrary to Paterson (2016), who found that parents were more likely to vaccinate if providers did not open up discussion about vaccines and rather just told parents what vaccines they were going to give their child. He found that asking parents how they feel about vaccines caused parents to believe there may be negative feelings about vaccines and that they had the option to not vaccinate their children (Patterson, 2016). However, in our interview with participants those who reported discussions with their healthcare providers about vaccines indicated that they were influenced to vaccinate at some point. Also, one participant shared that her healthcare provider influenced her vaccine hesitancy, because he pushed vaccines too much. This may be the perception if a provider does not open up discussion about vaccines, but rather just states that a vaccine will be given as Patterson (2016) suggests is the optimal way for healthcare providers to approach vaccines.

One participant shared that she has seen many healthcare providers who do not vaccinate and share their concerns about vaccine safety as well as provide her with resources about the dangers of vaccines, and in doing so have contributed to her vaccine hesitancy. In 2015, a survey by MacDonald (2015) found that 43% of general healthcare providers are vaccine hesitant, and they do not recommend vaccines to their patients or provide resources about the benefits of vaccination (Paterson, 2016). It is important to educate general healthcare providers about vaccines and the effect that their attitudes towards vaccines have on patients.

One participant shared that she felt that her healthcare provider was not honest about vaccines because he told her that the hepatitis B shot lasts for life, but she learned that boosters

are needed for most shots. Now, she does not trust his opinion on vaccines, because she thinks he is not being truthful. Feeling that healthcare providers are not truthful about vaccines was not a factor that was identified in the literature review. This participant's story highlights the importance of choosing words carefully as a healthcare provider and ensuring that patients correctly understand what is being said.

In the literature review there was mention of famous medical professionals and how they influence vaccine hesitancy in the public. Famous healthcare professionals discussed were Dr. Sears who recommended an alternative vaccine schedule and Dr. Oz, who has spoken out against vaccines on his T. V. show (Offit, 2015). None of the participants mentioned famous healthcare professionals when asked about experience with healthcare providers. Finally, two participants stated that they no longer see certain healthcare providers, because they had recommended vaccinations for their child. The literature review did not discuss the phenomenon of parents leaving healthcare providers due to their pro-vaccine views.

Participants reported various experiences with healthcare providers in regards to vaccines. Four participants reported that healthcare providers influenced them to vaccinate their children at some point, five reported healthcare providers had no effect on their vaccine hesitancy, and three reported that healthcare providers encouraged their vaccine hesitancy. The four participants who stated that their healthcare provider influenced them to vaccinate at some point shared that their healthcare provider took time to discuss vaccines with them. Whereas the fiver participants who stated that healthcare providers have had no influence on their vaccine hesitancy all stated that they had providers who did not discuss vaccines with them. This implies that it is important for healthcare professionals to discuss the benefits of vaccines with patients and address patients' concerns, as healthcare providers may be able to influence vaccine hesitant

individuals to vaccinate their child. Healthcare providers do need to be careful in their word choice and ensure patients understand what is being said so that patients do not feel lied to as one of our participants shared. Two of the participants left certain healthcare providers who wanted them to vaccinate their children. This may be unavoidable with some patients; however, healthcare providers should strive to treat their patients with respect while discussing vaccines in order to prevent patients from leaving their care.

Overall, a quarter of the participants stated that they were not comfortable with talking to their healthcare provider about vaccines. The main point of this study was to help providers understand how to better address the topic of vaccines with their patients. First, it is important that the patients feel comfortable talking to their providers on the subject. If patients do not feel comfortable with their provider, they will not visit the clinic or they will not listen to what their provider has to say about vaccines. One participant felt comfortable talking to her healthcare provider because they were transparent about the topic and told her the facts. Another participant stated that her healthcare provider was easy to talk to, which made it more comfortable for her. As this research aims to help healthcare providers better understand why mothers are hesitant about vaccines, it should also remind providers that approach to conversating with parents will determine how well the conversation goes.

Complementary and alternative medicine

All twelve participants that were interviewed stated they had previously had some contact with CAM. Many of the participants reported having interactions with CAM providers themselves as well as having exposed their children and family to CAM. The participants conveyed that they have used chiropractors, homeopathy, essential oils, massage, yoga, and acupuncture. Seven of the twelve participants confirmed that CAM has played some role in their

vaccine hesitancy. Existing literature has stated that individuals that have visited a CAM provider have been strongly associated with choosing not to vaccinate their children (Dube et al., 2013). Another research article published in 2001 stated that CAM providers are likely to encourage patients to be hesitant towards vaccinations. This article deciphers several quotes from chiropractic literature that suggests vaccines are unsafe and ineffective (Ernst, 2001). One participant is a CAM provider herself and confirmed that the literature that was presented to her throughout their education was not in favor of vaccinations. Another participant's husband is a CAM provider, and she reported the same concern towards vaccinations stemming from his education. Besides these examples of participants that have been primarily affected by CAM, 100% of the mothers have been exposed to the CAM industry in some way.

Another idea that was uncovered is that CAM has affected participants in that they try to lead a more natural and health conscious lifestyle. Several participants stated that they try to eat healthy and live a life without exposing their children to unnecessary chemicals and toxins. One participant said that CAM has encouraged her to understand more deeply how the human body works, and that this had made her less inclined to vaccinate. This same lifestyle is reflected in existing literature in that 87% of mothers that chose not to vaccinate their children were also inclined towards natural diets (Cassell et al., 2006). Also, it has been concluded that those who wish to lead their family in an all-natural lifestyle, avoiding added chemicals and preservatives, will also tend to avoid vaccines (Pierik, 2017). CAM providers interviewed in 1983 reported that they did not support vaccinations because they viewed them as unnatural and unnecessary (Ernst, 2001). Another participant expanded on her lifestyle choices by stating she supports home remedies and healthy eating instead of depending on vaccines and medications. Seven participants expressed concerns with the ingredients in vaccinations throughout the course of

their interviews, because the ingredients do not align with their desire to avoid unnecessary chemicals and toxins. One participant stated that there are toxins and proteins that are present in vaccinations and have not been adequately studied to indicate that they are completely safe for children.

The last topic that is revisited in the CAM portion of the interview was the subject of natural immunity. Throughout the interviews, many participants expressed concerns with vaccinations overloading the immune system of a child. Participants also stated that humans are born with a natural immunity that has the ability to fight off disease and that the natural immunity of a baby is better than anything that can be injected into them via vaccinations. This thought process is repeatedly expressed in existing literature. It was discussed that 43% of mothers who chose not to vaccinate their children believe that it is better for their child to acquire natural immunity than to receive a vaccine (Cassell et al., 2006). Cassell et al. (2006), also found that CAM profoundly impacts their patient's belief that vaccines create harm to the natural immunity that each person has innately. Another research article stated that the vaccine hesitant public believes that vaccines are too strong for children and the vaccine overwhelms their immune system (Pierik, 2017). In Oregon, Guadino and Robinson (2012) found that 61.6% of parents that chose not to vaccinate their children believed that it is better for immunity if children are allowed to acquire a disease naturally than to receive a vaccine. Lastly, in a 2000 telephone survey, 25% of participants believed that too many childhood vaccines could damage the immune system (Gellin et al., 2000).

58.3% of the participants reported that CAM has had an effect on their vaccine hesitancy in some way or another. 100% of the participants have come into contact with CAM or CAM providers. Whether participants were directly or indirectly impacted by CAM, this research

study and existing literature align in that CAM overwhelmingly promotes vaccine hesitancy. CAM providers are educated that vaccines are unnecessary and have passed this information on to their patients. Participants have reported that CAM has encouraged them to live a natural lifestyle and has encouraged them that a child's developing immunity does not need vaccinations. Healthcare providers must be aware that families are increasingly being exposed to CAM, and that this may be participating in their hesitancy towards vaccines. It is important to relay the mechanisms in which vaccinations work and to have an open and honest discussion with parents about their concerns regarding healthy lifestyles and children's immunity.

Additional factors

The twelve interviews conducted were concluded by asking each participant if she had any other concerns regarding vaccinations that had not already been discussed. Six of the participants identified additional factors that had not been discussed throughout the interview. This category is extremely important to this study, because participants brought up thoughts and opinions that were not discovered as a pattern in the existing literature review that was conducted. The participants expressed concerns that did not necessarily fit in one of the categories that had been presented to them throughout the interviews. Participants also used this time to reiterate points and talk about issues at greater length than they perhaps spoke about previously in the interview. This is the location of the interview that participants spoke most in depth about the concern regarding inadequate safety studies of vaccinations. One participant stated that safety studies cited in vaccine inserts had been conducted over the span of a small amount of days and that no long-term or substantial length studies were cited in vaccine inserts. Two participants also expressed concerns that vaccine studies have never compared

unvaccinated children against vaccinated children but have only studied children with varying numbers of vaccinations given to them.

The participants also expressed concerns that there is an inadequate amount of vaccine injury reports (VIR) that are published each year, and that there need to be more studies surrounding the injuries caused by vaccinations. Another idea that was presented was that judgement from fellow mothers had created an insecurity about vaccinating. Along the same lines, peer pressure from other vaccine hesitant mothers seems to be an increasingly common theme encouraging mothers not to vaccinate their children. Another participant indicated that proper sanitation techniques that have been developed are adequate enough to prevent disease from spreading. Additionally, the idea that vaccines may be causing more disease than they are preventing was presented. Vaccine failure rates as well as mutant strains of diseases that vaccines are unable to prevent were presented as further concerns. Booster shots were another concern that one participant spoke about. She stated that she believes a lot of adults are actually unvaccinated because vaccines require booster shots to continue to promote immunity, and many adults do not obtain scheduled booster shots.

Lastly, participants expressed concerns that their rights as a human should allow them to refuse vaccinations for their children should they think this is the safest option. One participant expressed that she was uncomfortable with the government trying to mandate vaccinations as a dictation of what U.S citizens can and cannot do, which is a violation of human rights. This idea of mandated vaccinations violating human rights is an idea that was reflected in existing literature as well. Pierik (2017) stated that many people believed that it was their right to refuse vaccines, because vaccinations go against their beliefs and their right to the first amendment.

Another participant expressed that she believes medical providers get paid for each vaccination that they administer, giving them an incentive that may not be entirely ethical.

The factors contributing to vaccine hesitancy that were found in existing literature and presented to participants were: religion, media, fear of side effects or vaccine injury, fear of autism, government distrust, pharmaceutical distrust, experience with healthcare providers, and CAM. In addition to these factors, notions such as lack of safety studies and vaccine injury reports, vaccine ingredients, peer pressure, "mom shaming", rights of individuals, government control, diseases potentially caused by vaccines, vaccine failure rates, mutant strains of diseases that can cause outbreaks, and gut feelings that vaccinations are unnecessary were identified. Throughout the interviews, there were many individual thoughts and beliefs that didn't necessarily follow a pattern between participants. Although participants responded "yes" to many of the categories, their reasons that the category has been a factor in their vaccine hesitancy varied significantly. This goes to show that patients are truly individuals and must be engaged in discussion about vaccinations as an individual. As a healthcare provider, it is impossible to discuss every concern with each and every patient within a 20-minute appointment, but it is necessary to get to the root of patients' concerns regarding vaccinations and to be able to educate them effectively regarding the concerns that they have. Each mother may have different concerns that stand out to them. It is important to be aware of and educate about all of the concerns that vaccine hesitant parents have, in order to address the specific concerns that individuals have.

Research Question Two: Information Sources

The second research question addressed in this study was: What are the information sources that contribute to the factors of vaccine hesitancy? The purpose of identifying

information sources that contribute to vaccine hesitancy is to allow healthcare providers to become familiar with these resources in order that they may better address vaccine hesitancy. A variety of sources were identified during the interviews. However, it was difficult to obtain specific titles of resources that participants used. Most resources were stated in general terms, such as, "books." Although, some resources were provided by name.

It is obvious that information sources about vaccine hesitancy factors are widely variable. Some individuals get their information from word of mouth, while others take time to read articles and watch documentaries. It is important for healthcare providers to understand the wide array of information sources that exist about vaccine hesitancy factors. It may be worthwhile for healthcare providers to take time to ask their patients what sources they are using for their information regarding vaccines in order that they may facilitate a better discussion about the patient's concerns. Additionally, healthcare providers may benefit from researching the various resources that were specifically named, such the documentary, *Anti-Vax* and the books, *Truth About Vaccines, Dissolving Illusions, Disconnected Kids,* and *DPT, a Shot in the Dark.* The well-known doctors that were mentioned may also be researched, such as Dr. Del Vidree and Dr. Mercola. Researching these information sources may better prepare and equip healthcare providers to address vaccination concerns, because they will better know the information that patients have been getting.

Limitations/Delimitations

As mentioned in chapter 3, a limitation to the study was researcher bias, as the researchers understand the benefits of vaccines. In order to control this bias, the researchers kept a neutral voice and informed the participants that the interviews were conducted to solely hear their answers to the questions. The interviewers did not debate or discuss their view of the topic.

Another limitation to the study was participants not fully answering the question due to fear of what the researchers might say. The participants knew that the researchers were all in the medical field, so they may have not been completely truthful or expressed everything due to concern about the researchers' opinions. Lastly, another limitation was the sample size. There were only twelve participants interviewed, but the data reached saturation which was the goal of this study.

The delimitation of the study was the sample population that was interviewed. Only vaccine hesitant mothers of children 0-18 were interviewed. There was a survey that the participants had to fill out before the interview to ensure that they fit the sample.

Further Research

The purpose of this study was to gain a deeper understanding of the factors that contribute to vaccine hesitancy as well as the information sources from which these factors come. Through conducting twelve interviews, many different factors contributing to vaccine hesitancy have been divulged. Asking participants about factors, and how these factors have impacted their hesitancy opened the door to uncover a multitude of explanations of the concerns regarding vaccines. A handful of specific information sources that these concerns have stemmed from have also been identified. As a result of this research, healthcare providers can become more familiar with the multitude of concerns that parents may have regarding vaccines and may also be able to address the credibility of information sources with their patients.

Through this research, it has been established that healthcare providers must take the time to understand their patients' vaccine hesitancy and adequately address their concerns in order to alleviate their hesitancy. This research has been crucial to gaining a deeper understanding regarding concerns that mothers may have about vaccines, but another area of research that is

essential is how healthcare providers can most efficiently and effectively communicate the necessity of vaccinating children. It would be very helpful for healthcare providers if there was a follow-up study performed to specifically address each concern that parents may present with. In the heat of the moment during a 20-minute visit, it is difficult to have an educated and meaningful discussion with parents who are adamantly vaccine hesitant. If there was a credible research study compiling scientific evidence as rebuttals to these concerns that have been uncovered, it would be an invaluable resource for healthcare providers. Stemming from this proposed research, a patient handout could be composed with reliable sources and explanations regarding the proposed contradictions that science is able to make towards the factors that contribute to vaccine hesitancy.

Conclusion

For many years, vaccines had been thought of as one of the most important improvements to public health (McClure et a., 2017). They have eradicated diseases, formed herd-immunity, and decreased disease outbreaks. In the past decade, parents have become vaccine hesitant, deciding to not vaccinate their children (McClure et al., 2017). This has led to the increase in under vaccinated children, which causes more outbreaks of preventable diseases.

The purpose of this study was to determine the factors that contribute to vaccine hesitancy in mothers. There were several factors found in the literature review that seemed to be common reasons as to why mothers did not want to vaccinate their children. The order of factors that were found to contribute the most to the participants' vaccine hesitancy is fear of vaccine side effect/injury (11), government distrust (10), fear of autism (9), pharmaceutical distrust (8), additional factors (8), experience with CAM (7), views of healthcare providers (7), media (6), and religion (5). All of the participants said that at least one of the main factors found through

the literature review contributed to their vaccine hesitancy. But when answering each of the questions, the participants all had their own unique experiences or insights as to why that specific factor has affected them. The participants were also asked about the sources they used to find information about vaccines. There was a wide variety of sources, such as from acquaintances, social media, and websites. The goal of this research was to better help providers understand the reasons why their patients were vaccine hesitant so that they could have better conversations addressing the parents' concerns, and the providers could give their patients more reliable sources of information on vaccines. Increased time discussing vaccinations with providers and available vaccination information through video clips or pamphlets at clinics have correlated with increased vaccination rates (Stinchdfield, 2008). Unfortunately, only 32% of providers spend 10-15 minutes discussing vaccines with hesitant parents (Stinchdfield, 2008). More exposure to correct information about vaccines through discussions with providers, pamphlets, or video clips may help to close the gap in non-vaccinated children. Healthcare providers play a crucial part in their patients' medical decision making, including whether they should get their children vaccinated. These important discussions can make a difference in public health by increasing the rate of vaccinated children and thus decreasing the incidence of disease outbreak.

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Appendix A

Informed Consent

Informed Consent

Dear Participant:

We are physician assistant students from Bethel University's Physician Assistant Program, conducting research in partial fulfillment of the requirements for a Master's Degree in Physician Assistant Studies. Our study investigates vaccine hesitancy. We hope to learn the factors behind vaccine hesitancy to facilitate more productive conversations between healthcare providers and vaccine hesitant individuals.

You were selected as a possible participant in this study because you are a vaccine hesitant mother that is a United States citizen and have a child/children between the ages of 0-18. This research is being conducted to fulfill our Evidence Based Medicine and Research class, and we are not getting any funding for our research.

If you decide to participate, we will contact you with demographic questions via email and set up an interview time to discuss 14 pre-determined questions. The length of the interview will be 10-30 minutes depending on your responses. Questions that are asked may be personal or cause emotional responses for participants, as vaccine hesitancy factors asked about will include vaccine injuries and autism. If a participant has a personal experience with one of these factors it may be emotional and difficult to discuss that factor. You may choose to not answer any question at any point during the interview. By answering the interview questions, you are indicating that you have read and agreed to the informed consent.

Any information obtained in connection with this study that can be identified with you will remain confidential and will be disclosed only with your permission. In any written reports or publications, no one will be identified or identifiable and only aggregate data will be presented. Interviews will be conducted over the phone. The conversation will be recorded on the researcher's computer. The conversation will then be electronically transcribed by the researcher. The audio file will be destroyed after transcription of the conversation. The audio and electronic transcribed data will be kept on a password-protected computer owned by the researcher. Upon completion of the study all files will be destroyed from the password-protected computer owned by the researcher. All data will be kept on an external storage device locked in the PA program office for a minimum of five years, per securing requirements for Bethel University's Physician Assistant Program.

Your decision whether or not to participate will not affect your future relations with Bethel University in any way. If you decide to participate, you are free to discontinue participation at any time without affecting such relationships.

This research project has been reviewed and approved in accordance with Bethel University's Levels of Review for Research with Humans. If you have any questions about the research and/or research participants' rights or wish to report a research related injury, please call Teia

Koopmeiners, PA-S: 320-333-4919, Alicia Benner, PA-S: 715-271-4839, Annie Vasterling, PA-S: 651-787-0878:, or Lisa Naser, PA-C: 651-635-8679.

You will be offered a copy of this form to keep.

We understand that you have an extremely busy schedule and your time is limited. Please realize that your participation is vital to the success of this research. The information that you provide is essential to the validity of this study. Thank you in advance for your prompt response to this study. Please email us with your responses to the demographic questions and available time to be interviewed by (Insert date). If you have any questions, please contact Teia Koopmeiners, PA-S: 320-333-4919, Alicia Benner, PA-S: 715-271-4839, Annie Vasterling, PA-S: 651-787-0878, or Lisa Naser, PA-C: 651-635-8679.

Thank you again for your help.

Sincerely,

Alicia Benner, Annie Vasterling, and Teia Koopmeiners

Appendix B

Inclusion Criteria/ Demographic Questions

Inclusion Criteria/ Demographic Questions

Inclusion Criteria:

Are you a U.S. citizen? Yes or No

What are the ages of your children?

Are you vaccine hesitant?

Demographic Questions:

Mother's education level: High school diploma, some college, associate's degree, bachelor's degree, master's degree, or doctorate

Annual household income before taxes:

Less than $25,000

$25,000-$34,999

$35,000-$49,999

$50,000-$74,999

$75,000-$99,999

$100,000-$149,999

$150,000 +

Appendix C

Research Tool

Research Script

Hi I am, (insert interviewer name), Physician Assistant student at Bethel University. Thank you for taking the time to talk to me. Before we begin I want to inform you that this conversation is being audio recorded on a password protected computer that is owned by the researcher. The audio file will be destroyed after transcription of the interview. No identifying information regarding you will be recorded, and you will be kept anonymous. I would like to remind you that if you feel uncomfortable, you may decide to not answer any question or you may end the conversation at any time without any consequences from Bethel University or the Facebook group you are affiliated with. By responding to these questions, you are indicating that you have read and agree to the informed consent that was sent to you via email. Do you have any questions regarding the research process or the informed consent?

First, how many children do you have and what are their ages?

Which child has received some, none, or all vaccines?

1. How would you describe that a vaccine works in the body?

2. I am going to ask you about a series of factors that may have contributed to your vaccine hesitancy. With each question, please answer yes or no. If no, I will continue to the next factor. If yes, I will ask you to explain how that has had an impact on your vaccine hesitancy and where you feel that you have received this information from.

a. Religion: Yes or No
    I. How has this been influential to your vaccine hesitancy?
    II. Where do you feel that you have received this information from?

b. Media: Yes or No
    I. How has this been influential to your vaccine hesitancy?
    II. Where do you feel that you have received this information from?

c. Fear of side effects or vaccine injury: Yes or No
    I. How has this been influential to your vaccine hesitancy?
    II. Where do you feel that you have received this information from?

d. Fear of autism: Yes or No
    I. How has this been influential to your vaccine hesitancy?
    II. Where do you feel that you have received this information from?

e. Government distrust: Yes or No
    I. How has this been influential to your vaccine hesitancy?
    II. Where do you feel that you have received this information from?

f. Pharmaceutical distrust: Yes or No
    I. How has this been influential to your vaccine hesitancy?
    II. Where do you feel that you have received this information from?

g. Has your experience with Healthcare providers and their views towards vaccines influenced your own view of vaccines: Yes or No
    I. How has this been influential to your vaccine hesitancy?

h. Do you feel comfortable talking to your healthcare provider about vaccines? Yes or No

    I. If no, why not?

i. Have you ever had contact with complementary and alternative medicine (CAM)? Popular CAM therapies include, but are not limited to, treatment such as acupuncture, chiropractic manipulation, massage therapy, energy healing, homeopathic treatment, naturopathy, natural products, tai chi, yoga, and meditation

    Yes or No. (If no, skip J.)

j. Has CAM influenced vaccine hesitancy? Yes or No
    I. How has this been influential to your vaccine hesitancy?
    II. Where do you feel that you have received this information from?

3. Are there any other factors that contribute to your hesitancy to vaccinate that we have not discussed?
    I. How has this been influential?
    II. Where do you feel that you have received this information from?

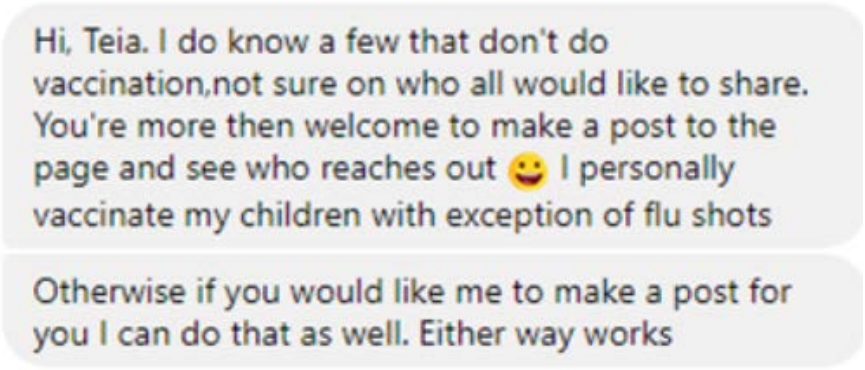
Thank you again for your time and responses to the questions

Appendix D

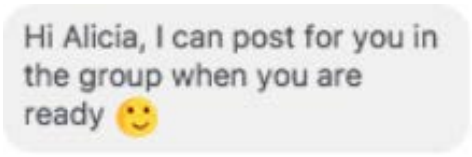
Population Agreements

Population Agreements

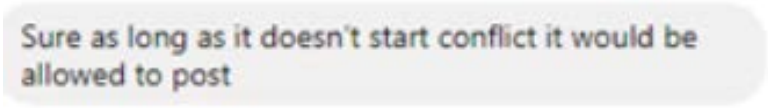
Facebook Group A Population Agreement from Administrator:



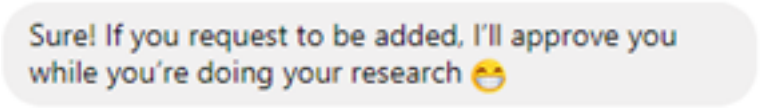
Facebook Group B Population Agreement from Administrator:



Facebook Group C Population Agreement from Administrator:



Facebook Group D Population Agreement from Administrator:



Appendix E

Facebook Post to Recruit Participants

Facebook Post to Recruit Participants

Hello, two of my classmates and I are conducting research for our Master's Degree in Physician Assistant Studies from Bethel University. We hope to gain a deeper understanding of the factors that contribute to mothers' vaccine hesitancy who have children 0-18 years old. Interviews will be performed through phone interviews that will take 10-30 minutes. If interested, please contact us at bethelparesearch@gmail.com, and we will send you further information, the informed consent, and set up an interview time.

Appendix F

Bethel University IRB Approval

Bethel University IRB Approval

BETHEL UNIVERSITY

Institutional Review Board
3900 Bethel Drive
PO2322
St. Paul, MN 55112

March 9, 2018

Annie Vasterling
Bethel University
St. Paul, MN 55112

Re: Project SP-06-18 A qualitative examination of vaccine hesitancy

Dear Annie,

On March 8, 2018, the Bethel University Institutional Review Board completed the review of your proposed study and approved the above referenced study.

Please note that this approval is limited to the project as described on the most recent Human Subjects Review Form. Also, please be reminded that it is the responsibility of the investigator(s) to bring to the attention of the IRB any proposed changes in the project or activity plans, and to report to the IRB any unanticipated problems that may affect the welfare of human subjects. Last, the approval is valid until March 8, 2019.

Sincerely,

Peter Jankowski, Ph.D.
Chair, Bethel University IRB

Appendix G

Bethel University IRB Addendum

Bethel University IRB Addendum

Alicia Benner <alicia-benner@bethel.edu> May 2, 2018, 1:17 PM
to Peter, Teia, Annie

Hello Peter,

We would like to submit an addendum to our IRB, as we have had no responses through Facebook posts on Facebook groups for mothers. Therefore, we would like to change our methods of recruitment of participants to word of mouth. We will have family, friends, and classmates contact individuals that they believe would qualify for the study and provide them the researcher's contact information in which participants will voluntarily send an email to the researchers at bethelparesearch@gmail.com for more information about the study. The researchers will then send interested participants more information about the study, inclusion criteria, and informed consent. A phone interview time will then be set up. Participants confidentiality will be maintained as they will be voluntarily contacting the researchers, and a pseudonym will be given to each participant as soon as they contact researchers. Contact information of participants will be deleted to ensure confidentiality after the interview is completed. Individuals that family, friends, and classmates reach out to are under no obligation to email the researchers and may choose not to participate in the study.

Attached is our original IRB for your reference.

Thank you,
Alicia Benner, Teia Koopmeiners, Annie Vasterling

Peter Jankowski <pjankows@bethel.edu> Thu, May 3, 2018, 7:21 AM
to Lisa, Alicia, Teia, Annie

Alicia, Teia, and Annie,

Your proposed changes are approved as an amendment to your previously approved study (IRB SP-06-18).

Peter