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Vaccination in a Private Pediatric Practice

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Vaccination in a Private Pediatric Practice

by

KAREN TIFFANY JOSEPH

B.S., Psychology
KENNESAW STATE UNIVERSITY

A Thesis Submitted to the Graduate Faculty
of Georgia State University in Partial Fulfillment
of the Requirements for the Degree

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APPROVAL PAGE

Vaccination in a Private Pediatric Practice

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I would also like to express my gratitude to my Thesis Chair and Academic Advisor, Dr. Richard Rothenberg. His expertise, guidance, humor, and never failing patience have aided me in completing many projects throughout this program in addition to this thesis. I also want to thank Dr. Patricia Nevius, my second committee member who marvelously edited every draft and was incredibly supportive.

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ABSTRACT

KAREN TIFFANY JOSEPH

Vaccination in a Private Pediatric Practice.

Background: Following the publication of Andrew Wakefield's article claiming a link between Autism and the MMR vaccine in 1998, the U.K. and U.S. have experienced a decline in vaccination rates. Celebrities with strong voices dominate the media and propel the vaccine-myths which contribute to parental decision making regarding vaccines. Combating the anti-vaccine messages are the medical providers, who are consistently reported as an influential source of information for parental vaccine decision making. Despite efforts of the medical and public health community, some developed countries have seen a resurgence of vaccine preventable diseases (VPDs).

Purpose: This study seeks to examine parental vaccination concern in a private pediatric practice in metropolitan Atlanta. The relationship between vaccination concerns and parents' feelings toward the practice and provider is also examined.

Methods: A questionnaire was created by the PI to assess parental vaccination concerns, including items to assess parental feelings toward the providers and nurses regarding preventative care. The questionnaire was available in each of the four office locations and online. Data was analyzed in SPSS version 19.0. Descriptive analyses and bivariate correlations were used to assess parental vaccination hesitancy in this sample. The study was approved by the Institutional Review Board at Georgia State University.

Results: A total of 283 participant responses were included in the sample. Overall vaccine adherence was 96.1% (272). However, a large minority of participants who were considered to have vaccine concerns were identified: 40.3% (114) of participants responded yes to at least one vaccine hesitation item. Although the cells were too small to complete any statistical testing, frequencies indicate that there may be differences in the prevalence of parents with vaccine concerns among parents who choose to discuss them with providers and those who do not.

Conclusion: Vaccine adherence in a private pediatric practice remains high. However some parents continue to have vaccination concerns and may be at risk for deviating from the vaccine schedule. Using qualitative methods to obtain parental beliefs may provide a deeper understanding of parental decisions to aid in the development of public health education programs. The feasibility of collecting data at a private pediatric practice is discussed.

INDEX WORDS: VACCINES, IMMUNIZATIONS, ANTI-VACCINATION, PARENTAL VACCINE DECISIONS, PARENTAL VACCINE BELIEFS.

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February 2008 – July 2011 **Administrative Assistant**
Pediatric and Adolescent Medicine, P.A., Metro Atlanta, GA.
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Chapter I

INTRODUCTION

1.1 Background

Immunizations are considered to be the greatest public health achievement of the 20th century¹. Vaccines have saved countless lives by leading to the eradication of smallpox, elimination of poliomyelitis (polio) in U.S. and other developed countries, and controlling several other debilitating infectious diseases. In the first decade of the 21st century, two vaccines, pneumococcal conjugate and rotavirus were added to the recommended vaccination schedule. Following their implementation an estimated 13,000 deaths and 211,000 serious pneumococcal infections were prevented, and as many as 60,000 estimated rotavirus hospitalizations averted^{2,3}.

The National Immunization Survey (NIS) is the primary measure used to track vaccine coverage among children annually. Thankfully, immunization rates are generally high in the U.S. and appear to have increased in 2010 from 2009⁴. In the U.S., the Centers for Disease Control and Prevention (CDC) and the American Academy of Pediatrics (AAP) recommend vaccinations for 17 vaccine-preventable diseases (VPDs), 15 of which are included in the routine vaccination schedule (H1N1/season influenza and HPV do not appear on the schedule)⁵. Children receive as many as six shots per recommended check-up at 2, 4, 6, and 9 months of age. For a first-time parent, the sheer number of vaccines can be confusing and frightening.

Because of the successes of vaccines, most parents living in developed countries today typically do not have to worry about their children having fatal or severe consequences of vaccine preventable diseases (VPDs) such as Polio, Diphtheria, Pertussis, Measles, Rotavirus, and others. Most of these parents have never seen these diseases; they do not have stories from other parents describing permanent damage or fatal outcomes from these diseases. The decline of VPDs is certainly something to be thankful for, however some parents see this decline as evidence that the diseases do not seem as bad as they once were or that their children are not as vulnerable to them⁶. Many parents today fear the vaccines themselves more than the diseases they prevent. As more parents decline these vaccines, VPDs have more and more opportunities to resurface.

There is epidemiological evidence showing that disease outbreaks typically start with an unvaccinated person, spread to other unvaccinated persons, and eventually can spread to virtually anyone⁷. The more unvaccinated children that exist in a community, the greater the risk of VPD becomes. Herd immunity is the concept that when enough people are immune to a specific antigen, the entire community (including those people susceptible to the antigen) will remain protected⁸. The proportions of people who must be vaccinated in order to achieve herd immunity vary by disease and level of virulence. Measles, a highly communicable disease, requires about a 94% vaccination rate⁸. When community immunization rates fall below the necessary levels, the entire community becomes susceptible.

Due to the successful efforts of vaccination programs, measles was declared eliminated from the U.S. in 2000⁹. Unfortunately, this success was short-lived. Between 2001-2008 there were over 550 confirmed measles cases U.S., of which 65% of the patients were considered to be preventable: they were eligible for vaccination but had not received the vaccine¹⁰. The three

largest outbreaks that occurred had an index patient whose parents had intentionally withheld vaccination because of their personal beliefs. International travel considerably impacts disease transmission: nearly half of the measles cases (42%) were imported from 44 other countries¹⁰. In 2008, a 7 year old unvaccinated child infected with measles returned home after a family visit to Switzerland and subsequently 12 other children became infected¹¹. These children were also all unvaccinated; nine were due to personal parental beliefs and three children were too young to receive the vaccination. The decisions that parents make to hold vaccines from their children are not only affecting their child but leaving entire communities vulnerable.

The prevalence of undervaccination is concerning. In 2003, a study using NIS data revealed an overall rate of 22% of intentionally delayed vaccines children under 35 months old¹². An NIS study in 2003 found approximately 15% of children were not up to date on vaccinations for more than half of their first two years of life, and 52% were not up to date for more than 6 months of their first two years of life¹³. This study also found 11% of children were not up to date on their measles vaccination and 16% were not up to date for their DTaP vaccination by two years old. In 2001, NIS data revealed an overall undervaccination rate of 36.9% with varicella and DTaP being the most common vaccines not up to date¹⁴.

How likely are these children who are unvaccinated to develop diseases? Studies examining exemption status in some states has shed light on this question (parents must have their children immunized to enter daycare and schools; however parents who do not want to immunize their children can obtain exemptions based on state laws). In Colorado researchers found that children with vaccine exemptions were 6 times more likely to contract pertussis and 22 times more like to contract measles than their vaccinated counterparts¹⁵. In a study examining the risk of measles to unvaccinated versus vaccinated children (as determined by exemption

status), Salmon et al found that unvaccinated children ages 5 through 19 were 35 times more likely to contract measles¹⁶.

There are clearly huge risks of refusing all or even only certain vaccinations. More problematic than refusing vaccines is delaying them. Some parents choose to alter the vaccine schedule, believing that it is better to wait until the child is older or that multiple vaccines at once present greater risk of an adverse reaction. These parents claim to be pro-vaccination; they instead want to vaccinate on their own schedule or the schedule provided by an alternative medical provider. While it may be true that any vaccines are better than no vaccines, delaying or altering the vaccination schedule may be just as dangerous as refusing vaccinations. Waiting until the child is older or spacing out the vaccinations continues to leave the child vulnerable to VPDs in their younger years⁷.

Delaying vaccinations is much more common than refusing them, and unfortunately it is a widespread practice in the U.S. today. A recent study of a nationally representative sample of parents, Dempsey et al found that at least 1 in 10 parents deviate from the recommended vaccination schedule¹⁷. Most frequently parents refuse only specific vaccinations or would give only specific vaccinations when their child is older than the recommended age. Among these parents 41% said that they alone developed their individual vaccination schedule and the majority also agreed with anti-vaccination statements. Some of these parents understand that undervaccination rates increase the risk of vaccine preventable diseases, despite the fact that by delaying vaccination they themselves have an undervaccinated child. Salmon et al found that parents who refused vaccines were more likely to believe their children were at a low risk for VPDs and that VPDs were not severe¹⁸.

Even parents who begin by following the recommended schedule may change their minds. This may be due to opinions that an individual schedule is safer, less stressful to the child, or more effective¹⁷. Of parents that follow the recommended schedule, 1 in 4 indicates that they are not convinced it is the best schedule. In 2009, a study involving a nationally representative sample of parents revealed that while 90% of parents agreed vaccines were a way to protect children from disease, 54% were concerned about adverse reactions¹⁹. Public health and medicine must work together to educate these parents. Targeting parents who specifically delay vaccines or refuse them may not be enough, as even parents who follow the schedules seem to have vaccine concerns.

1.2 Study Rationale and Purpose of Study

To maintain high levels of immunization coverage and prevent VPDs, it is imperative that research be conducted in an effort to understand parents' decision making and the influences that impact those decisions. Understanding the parents and their influences may lend insightful information for the development or alteration of medical and public health interventions and is essential to minimizing the danger of VPD's in the U.S. and globally.

Much of the current literature in this area utilizes NIS data. The NIS has two parts, a random-digit dialing telephone survey followed by a survey to the child's provider²⁰. While this ongoing study offers the most comprehensive examination of the U.S. population of parents and provides excellent data to track vaccination coverage rates, limitations do exist. One problem with NIS data is that parents who do not vaccinate or do not agree with vaccination may purposely not respond to the survey. Those parents who do respond may not be able to remember

the details of their children's vaccinations, a concept known as a recall bias. Parents may feel more comfortable answering vaccine questions in a familiar setting, such as through their own pediatric practice. Using parents from a pediatric practice may also lower the chance of recall bias, as the parents participate under settings that they are already used to thinking about or dealing with vaccines and vaccine choices. Recruiting patients as participants from private clinics may also provide a setting for more in-depth analysis and thus the potential for a deeper understanding of their beliefs. Assessing the feasibility of recruiting patients through private practices as study participants is therefore worth exploring.

The literature shows that medical care providers are the most influential source of vaccine information for parents and that the relationship the parents have with a provider can impact their decisions and beliefs about vaccines^{18,19,21-24}. It is important to continue gathering information on how parents feel about their providers and the possible relationship this has on their vaccine beliefs. The purpose of this study is to examine parental vaccination beliefs in the context of a private pediatric practice. Additionally, this study will aim to assess the feasibility of recruiting patients from a private pediatric practice. A survey will be given at a large private pediatric practice in metropolitan Atlanta.

1.3 Research Questions

1. What is the overall prevalence of parents with vaccination concerns in a private practice?
2. Is there a relationship between parental feelings toward the practice and provider and their vaccination beliefs?
3. What is the feasibility of recruiting parents from a pediatric practice for use in in-depth research analyses? What are the barriers, if any, to doing research in private clinics?

Chapter II

LITERATURE REVIEW

2.1 A Brief History of the Anti-Vaccine Movement and its Influences.

In 1796, Edward Jenner invented the smallpox vaccine and effectively created a way to prevent what was then the deadliest disease in the world. By 1820, the vaccine had halved the number of deaths from smallpox²⁵. For the most part this news was accepted with praise and the vaccine taken with open arms, but there were many who distrusted and feared it. In the 1850's a group of advocates gained attention vocalizing their concerns, leading to a major resurgence for smallpox in the UK in the 1850s²⁵ and in the U.S. in the 1870s²⁶. This opposition was generated primarily from alternative medical providers²⁶. In an effort to increase vaccine rates and control this deadly disease, both the UK and US passed mandatory vaccination laws²⁷. While these laws were the start of the legal policy that eventually eradicated smallpox, they were at the same time the birth of organized anti-vaccine opposition. Largely in response to this government involvement, several anti-vaccine organizations were founded: The New England Anti-Compulsory Vaccination League, The Anti-Vaccination League, and The American Anti-Vaccination Society are a few examples²⁶.

The organized opposition to the smallpox vaccine quieted down and eventually died out in the early 1930s when governments became more involved and medical science advanced²⁶. In

1979 smallpox was declared to have been eradicated from the world²⁸, making this perhaps the greatest public health achievement in the 20th century. This is a story of success: public health, government, and medicine all worked together to eradicate this disease despite the opposition they faced. Thankfully, the original anti-vaccination movement lost its battle. However, the original anti-vaccination movement and associated organizations provided a foundation for the anti-vaccine movement that currently threatens us.

In 1982, NBC aired a documentary by journalist Lea Thompson entitled *DPT: Vaccine Roulette*²⁵. The documentary had vivid and emotionally engaging stories about children allegedly severely brain damaged by the diphtheria, tetanus, and pertussis (DTP) vaccine. In 1998, Dr. Andrew Wakefield published a paper in *The Lancet*, a prestigious medical journal, claiming that the measles, mumps, and rubella (MMR) vaccine was linked to the development of autism²⁹. These two events have given the modern-day anti-vaccine movement the majority of its momentum; modern media playing a significant role in both events. An overwhelming number of epidemiological studies have been published disproving these claims and showing the safety of vaccinations. Not only do these studies show that there is no association between the MMR vaccine and autism, they also show that there is no association between thimerosal and Autism (another prominent argument in the debate)³⁰. Andrew Wakefield's article was even retracted from *The Lancet* in 2010³¹, but the damage had already been done: doubt entered the minds of parents and anti-vaccination leaders had fuel for their campaigns.

The anti-vaccine movement of the 19th century was not all that dissimilar to the current anti-vaccine movement. In his book *Deadly Choices: How the Anti-Vaccine Movement Threatens Us All*, Dr. Paul Offit, a leading author and researcher in this area, outlines the history of the anti-vaccine movement in both the UK and US. In the late 1900s and early 2000s (when

the most recent anti-vaccine movement gained momentum) public rallies, paranoia, false accusations of vaccine harm, claims that vaccines are unnatural, and arguments for alternative medicine all have parallel precursors from the original anti-vaccine movement against smallpox [1]. The remarkable difference between then and now however, is the role of the media and celebrity influence.

In the 1800s pamphlets, books and journals were frequently published and widely circulated²⁷, but nothing then had a fraction of the effect that the internet has now. The internet makes consumer research quick and simple, and parents wanting to research vaccines will undoubtedly come across an anti-vaccination website in their searches. Using seven different search engines and entering the term “vaccination”, Davies et al found that nearly half of the websites returned portrayed anti-vaccination messages (43%)³². For a first-time parent with no prior knowledge of vaccines, these internet searches yield confusing and conflicting information; especially when anti-vaccination websites portray themselves as experts, which is frequently the case³².

Studies examining anti-vaccination websites have found several common themes. Some of these include, but are not limited to claims that: vaccines cause idiopathic illnesses (i.e., diabetes, autism, multiple sclerosis); they harm the immune system or immunity is only temporary; adverse reactions are underreported; vaccines are not the reason diseases have declined; the government is violating civil liberties by requiring vaccinations; the government is conspiring with pharmaceutical companies for profits; multiple vaccines given at the same time increase the risks³²⁻³⁴. These are just some of the claims made by anti-vaccination websites and are the primary arguments used by anti-vaccination organizations and advocates. Arguments also often contain personal stories and pictures of allegedly damaged children and information on

how to evade the mandating laws. Parents do obtain some of their vaccine information from such websites³⁵ and by eliciting emotional responses these websites may be influencing parental decision making. Not surprisingly, such websites are not objective; they do not include information from research that would refute their hypotheses. For example, there are articles published to specifically address parental concerns such as: ingredients in vaccines are generally harmless to people³⁶, vaccines do not cause or exacerbate chronic diseases such as diabetes, arthritis, or autoimmune diseases³⁷, and that multiple vaccines do not overwhelm the immune system³⁸.

Adding to inaccurate and often graphic websites claiming unsupported effects of vaccinations are celebrities and well-known doctors who use their status to broadcast their opinions. One of the most prominent of these figures in the U.S. is Jenny McCarthy, who promotes anti-vaccination messages and argues that vaccines triggered her son's autism. She is currently the President and spokesperson of an advocacy organization called Generation Rescue³⁹, which is dedicated to the "recovery of autism". The website features pediatricians, personal stories from parents of autistic children, therapies that can help "recover" the child, and messages and videos from McCarthy. She has appeared on popular television shows such as *Larry King Live*, *Oprah*, *The Doctors*, and more. She has published books, written articles, given radio interviews, all spreading her anti-vaccine message²⁵. Her influence is far reaching and frightening to public health professionals.

Jenny McCarthy and other celebrities have strong voices in the anti-vaccine movements and they have grown louder from media attention. The media gives celebrities air time to spread their messages and regardless of their background they are often portrayed as experts³⁵. How many parents actually listen to these celebrities? In a case-control study of parents with children

who had school exemptions and parents of fully vaccinated children, Salmon and colleagues found that while the majority of all parents cited their provider as their main source of information for vaccines, parents who chose exemption were more likely to refer to non-medical or non public health sources such as the internet than parents of fully vaccinated children who did refer to the medical and/or public health sources⁴⁰. In a study of a nationally representative sample of parents, Freed and colleagues found that while the majority of parents trusted their provider, a large minority (26%) of parents placed at least some trust in celebrities³⁵. Other concerning findings of this study were that 73% of parents placed at least some trust in other parents claiming adverse vaccine reactions and that mothers more often placed some trust in other parents, celebrities, and other media outlets than fathers. Mothers are generally the primary care giver. They are the ones who take the children to their doctor appoints where they receive vaccines. Modern media most certainly provides easy access for mothers to find such personal stories from other parents and other non-expert sources such as Jenny McCarthy.

While media clearly plays a large role in spreading anti-vaccination sentiments, these are not the only influential sources of information to which parents look for advice. In a study examining NIS data and media coverage of the MMR-Autism controversy, Smith and colleagues found an increase in MMR refusal in the US for the year 2000⁴¹. This was after Dr. Wakefield came on the scene with his theory, but before the controversy was highly publicized in the U.S. MMR refusal had returned to normal by the time the media coverage increased, suggesting that media coverage is not the only source of information and may not be the most important⁴¹. In 2003, another study using NIS data found that parents who intentionally delayed vaccines were more likely to have obtained their vaccine information via the internet, library or media sources than parents who delayed because their child was sick¹². In Wisconsin, parents concerned about

vaccinations most frequently cited family and friends, the internet, and alternative medical providers as their source of information⁴². This trend is seen across several studies^{21,41} and is not exclusive to the U.S. A qualitative study in Scotland found that parents cited other parents as a source of credible information; parents could understand and access messages from other parents while they felt they could not do the same with scientific studies⁴³.

The role of family, friends and other parents is a vital part of how parents are getting their information. It is possible that social media outlets (i.e., Facebook) are venues in which parents can share their stories and thus perpetuate parental concern, although no previous literature has examined this. The finding that parents often view other parents as a credible source of information is particularly worrisome, especially when combining the celebrity power of people like Jenny McCarthy, who is also viewed as just another parent sharing her story. On the reverse side of this however is the role that a provider who is also a parent can have. In 2009 providers in the US reported that by sharing what they would personally do with their children they were able to effectively convince a hesitant parent to vaccinate⁴⁴.

Media coverage, widespread use of the internet, advocacy by celebrities, and stories of allegedly damaged children are spread quickly through modern technology. The anti-vaccine sentiments of today are arguably much more dangerous than the anti-vaccine sentiments of the 1800s. Despite the striking similarities in fundamental beliefs, the messages today are far reaching and more accessible to parents. Thankfully, the world no longer has to worry about smallpox, but humanity is still in danger of the many other infectious bacteria and viruses waiting for immunity to weaken. What were once thought of as rare diseases in developed countries are now beginning to reemerge.

2.2 Geographical Clustering and the Role of Government

For roughly three decades, all 50 states in the U.S. have had vaccination mandates that are a requirement for children to enter schools and daycares⁷. The policies regarding vaccines are left up to the state governments, and thus states have varying policies and exemption clauses. Exemptions are granted for medical, personal, religious, or philosophical reasons when a parent does not want to vaccinate their child⁷. By claiming one of these reasons a parent can bypass the mandating laws and place their child into school without having had the recommended vaccinations. According to the Institute for Vaccine Safety at the Johns Hopkins Bloomberg School of Public Health, there are 48 states that grant exemptions for religious reasons and 20 states that grant exemptions for personal or philosophical reasons⁴⁵. West Virginia and Mississippi are the only states that do not allow anything except medical exemptions. State policies are vitally important: rates of unvaccinated children are higher in states that grant personal or philosophical exemptions¹⁴. These exemption laws exist due to a long history of separation of church and state in the U.S., but many parents may not actually have a religious reason for exempting their child. In a study with parents of exempt children in 2002 and 2003, only 8.6% of parents in Massachusetts and 22.9% of parents in Missouri indicated they had religious reasons for refusing vaccinations¹⁸. In these two states, the only non-medical exemption that can be obtained is a religious exemption.

The ease or difficulty of obtaining exemptions varies from something as simple as a parent signature on a standardized form to a notarized statement and signature from a health department official⁴⁶. The degree of hassle that a parent has to go through to get their child into school without vaccinations does appear to influence vaccination rates. A study analyzing

exemptions at the state-level from 1991 – 2004 demonstrates the importance of governmental regulation in immunization uptake. Omer et al found that states allowing exemptions for personal reasons saw an increase in exemption rates while states offering only religious exemptions did not see an increase⁴⁶. In the early 2000s, states where it was relatively easy to acquire exemptions had higher rates of those exemptions (meaning more unvaccinated children) than states where it was more difficult⁴⁶.

Tracking these exemptions can be an excellent measure of vaccine refusal and uptake per state and the subsequent consequences of refusal. Parents must either file an exemption or file vaccination records in order for their children to be registered in school. The schools report the numbers of exemptions to the state health departments who in turn report the numbers to the CDC⁴⁶. These exemptions provide the state not only with a measure of vaccine rates but also reasons why parents are choosing to decline vaccines. Parents must file a religious, personal, philosophical, etc. exemption (depending on the state) which can shed light on changing trends in reasons for deferment. The types of exemptions available to parents per state also have an impact on immunization uptake. A study in Wisconsin showed an increasing trend in “personal conviction” waivers from 1990 to 2003, while medical and religious waivers appear to have only slightly increased⁴². Similarly, in Colorado from 1987-1998 the rates of philosophical exemptions increased over the decade¹⁵. These findings are consistent across many studies^{16,41,46}. NIS data from 2001 showed that the rates of unvaccinated children were the highest in states that allowed philosophical exemptions¹⁴. It is clear that governmental policies play a key role in state vaccination rates and that vaccination rates determine VPD outbreaks. From 1986 to 2004, states allowing personal or philosophical exemptions in addition to religious exemptions had twice the

rates of pertussis cases as states where parents can only obtain religious exemptions⁴¹. The consequences of not adhering to governmental policies can be severe.

Unvaccinated children tend to be clustered geographically¹⁴. Gust and colleagues using NIS data from 2003 and 2004 found that parents who refused vaccinations were most likely to live in the Western region of the U.S.⁴⁷. Omer et al examined geographical clustering of non-medical exemptions and clustering of pertussis cases in Michigan. Researchers found overlaps between exemption clusters and pertussis clusters, showing that where there are communities with high exemptions rates there are also VPD outbreaks⁴⁸. In Colorado, the incidence rates of measles and pertussis were found to be significantly associated with the rates of exemptions at the county level¹⁵. In this same study, researchers discovered that the risk of a school pertussis outbreak increased by 12% for every 1% increase in children who had exemptions in that school. This evidence indicates that wherever there are high rates of vaccination exemptions the risk of VPDs extends to others within the communities, counties, or schools. Parents filing exemptions are not only putting their own children at a higher risk of contracting VPDs, but also other children in the community.

2.3 The Role of the Provider

The child's doctor, whether a family practitioner, general practitioner or pediatrician is the most crucial place of focus for all parents, regardless of vaccination status. Providers are consistently referenced as the most important source of vaccine information that influences decision making for parents^{18,19,21-24}. NIS data from 2003 and 2004 revealed that among parents who changed their minds regarding delays or refusal of vaccines, the provider was the most

frequently cited reason for the change⁴⁷. Because providers are such a crucial source of information for parents, the relationships formed between provider and parent represents one of the most important ways to educate parents about vaccines and the dangers of not vaccinating children. Despite providers' knowledge that they are key informants, several barriers exist in the dissemination of vaccine information.

In 2002 in a randomly selected sample of pediatricians registered with the AAP, 85% reported they had a family who had refused a specific vaccine and 54% reported a family who had refused all vaccines during the previous year⁴⁹. In a more recent study from 2009 with a nationally representative sample of pediatricians and family physicians, 89% of the providers had at least one parent per month request to alter their child's immunization schedule⁴⁴. Nearly half these providers felt that parents' levels of vaccine concerns had greatly increased in the past 5 years overall; the most common reason cited related to long-term adverse reactions (including autism) from vaccines and thimerosal. The reason these types of provider-studies are vital to the body of research for this issue is simple: the way providers feel about their jobs impacts their ability to discuss vaccines with parents.

There is evidence suggesting that providers who treat children are experiencing a decline in job satisfaction⁴⁴ directly relating to the vaccine issues they face. Leib et al suggests that pediatricians job satisfaction has a negative impact on their ability to establish and maintain trusting relationships with parents; more than 45% of the pediatricians in their study reported feeling "mildly annoyed" and 28% reported that it negatively affected their job satisfaction when encountering parents with vaccine concerns or parents who refused vaccines⁵⁰. More than 30% of providers in this study had dismissed a family from their practice for vaccine refusal. An open response question from the survey yielded many comments regarding the feeling that dealing

with these parents was time consuming; one provider stated that it took time away from other patients. In another study of providers, as many as 62% felt that the time it takes to discuss vaccines with parents was the greatest communication barrier they faced⁴⁴. These providers also felt that they would be unlikely to change the parents' minds and that the parents were unlikely to understand the risk/benefit considerations. These findings undoubtedly represent several barriers to communication and relationship building.

When barriers are overcome or do not exist, providers not only influence decision making but can strengthen parents' convictions about vaccine beliefs. Using data from the NIS from quarters in 2001 and 2002, Smith et al found that parents whose providers were influential in their decision making were twice as likely to believe vaccines were safe; conversely, parents were less likely to be influenced by their provider when the parent believed vaccines were not safe⁵¹. Providers can also influence vaccine uptake even when they do not change parent's ultimate beliefs about vaccines. There were more vaccinated children among parents who felt that vaccines were unsafe when they were influenced by a provider than among parents who felt vaccines were unsafe but were not influenced by a provider⁵¹.

Recently, a new trend has emerged among pediatricians and family care doctors: they are discharging patients who refuse to vaccinate. While the AAP strongly advocates immunizations, they do not recommend that a provider discharge families solely on the premise of refusing to vaccinate⁵². The AAP understands that there are times when the provider must discharge a family. In 2002, 28% of pediatricians in the study sample reported they would discharge a family for refusing only specific vaccines and 39% reported they would discharge a family who refused all vaccines⁴⁹. Pediatricians who report decline in their job satisfaction are also more likely to dismiss a family for refusal⁵⁰. Providers report families with higher socio-economic status (SES)

are the most likely to have vaccine concerns or to refuse vaccines; these doctors are also more likely to dismiss families with higher SES than families with lower SES⁵⁰. Flanagan-Klygis and colleagues raise the question that if a family is discharged from a practice, that family may leave the practice less likely to seek continued medical care⁴⁹. This may also exacerbate distrust of the medical community and drive parents toward seeking care from alternative medical providers. The threat or action of dismissing a family from a practice may indeed encourage vaccine adherence, but it may also be contributing to the rates of intentional vaccine refusals.

2.4 Parental Decision Making and Parent Demographics

Why do parents believe that vaccines cause autism when there is so much scientific evidence disputing it? There are several cognitive theories suggested. In a commentary by Dr. Dennis Flaherty, he writes “the vaccine-autism connection provides a simple explanation to a complex problem while excluding the possibility of a genetic pre-disposition or in utero exposure...”⁵³. It may be easier for parents to accept that their child developed autism due to a vaccine rather than the unknown cause or scientific jargon-riddled theories. Two logical fallacies have also been proposed³⁴. The first of these is what is referred to as ‘confusion between time and causation’: *because my child developed autism after his vaccine it must have occurred because of the vaccine*. The next is referred to as a ‘faulty dilemma’: *my child either has autism because of the vaccine or he does not have autism*. These seem easily refutable when looking at them on paper, but when considering the emotional response of a parent who has just found out her child has a developmental disorder they would seem valid explanations.

There also exist important biases. The first is a false consensus bias, a psychological theory which in this context means that people rely on stories of personal experiences above science³³. This concept explains why parents give such credence to other parents^{35,43} as well as the emotionally charged stories that anti-vaccination websites report. The next bias to consider is the concept of an omission bias, which deserves special attention. This essentially means that parents are more concerned with what will go wrong if they do vaccinate than they are with what could go wrong if they do not vaccinate⁵⁴. This bias could explain findings in the literature that parents believe their children are at higher risk for adverse reactions than they are to the VPDs themselves. This may also explain the difficulty some parents seem to exhibit in conducting a risk/benefit analysis of vaccinations. In a study of nearly 300 parents across five states, researchers found that 90% of parents classified as non-vaccinators believed their child was more likely to have a long term injury from a vaccination than if they developed pertussis⁵⁵. The last point of cognitive reasoning to consider is what is has been termed the “reverse social contract” belief²¹. This is the belief that enough other children are vaccinated to protect their child from VPDs, and therefore vaccination is not necessary.

The most frequently cited reason for not vaccinating, delaying vaccines, or being vaccine hesitant is parental concerns relating to vaccine safety. These concerns are consistently reported throughout the literature: vaccine ingredients are unsafe (particularly thimerosal), vaccines are not tested enough for safety, vaccines cause autism or other developmental disorders, vaccines cause or exacerbate chronic diseases, too many vaccines at once are harmful to the child, and vaccines overload the child’s immune system and/or weaken the immune system^{14,23,24,40,49,56}. Concerns regarding safety are not isolated to the U.S. A systematic review of qualitative studies exploring parental vaccine beliefs, including studies from the U.S., the U.K., Canada, Australia,

Ireland and New Zealand, found the most frequently referenced concern was adverse vaccine effects⁵⁷. The prevalence of such concerns is alarming. A study of providers in 2002 found that 73% believed parents refused vaccines due to safety concerns and an additional 22% believed it was due to multiple vaccines being given at once (which could also be considered a safety concern)⁴⁹.

While safety concerns are the primary reason parents are hesitant, delay vaccines or refuse vaccines, there are several other reasons to consider. A case-control study in Wisconsin revealed that some parents simply perceive the child is not at risk of contracting a VPD, parents believe VPDs are not serious even when the child contracts one, and some parents believe that it is better for the child to develop natural immunity to a VPD than via immunity by vaccination⁴⁰. These findings are seen in other literature^{18,22,23,56} and include supplemental ideas such as vaccines are simply ineffective or unnecessary and that vaccines should be delayed until children are older than the recommended age. Even parents of fully vaccinated children report having some of these reservations¹⁸. The knowledge parents have about vaccines is also vital to their decisions, regardless of their belief in vaccines. In a qualitative study of 33 postpartum mothers, only two of the mothers could correctly name even one of the vaccines that are recommended at two months of age when they had been given multiple choice options²¹. A nationally representative study of parents in 1999 revealed that between 19% and 25% of parents had a misunderstanding of vaccinations that could have contributed to their decisions²².

As previously discussed, many parents perceive that some VPDs are not serious if their children were to become ill with one. This concept helps explain some of the specific vaccines that are more commonly refused. Despite the fact that parents perceive their children to be at a high risk of contracting the chicken pox, parents most frequently opt out of the varicella vaccine

because they perceive chicken pox to be one of the least serious VPDs²². Across the literature, varicella is overwhelmingly reported at the most commonly refused vaccination; other commonly reported vaccines that are refused or delayed include H1N1, seasonal influenza, MMR, DTaP, HepB and Rotavirus^{14,17-19,21,22,40,42,47,50}.

The final and arguably most important consideration to vaccine hesitancy is exploring who these parents are. There is strong evidence to support that parental demographics significantly correlate with vaccine delays or refusals. The literature shows that parents who are hesitant about vaccines, delay vaccines or refuse vaccine are primarily mothers who are white, married, over 30 years old, have college-level education and live in households earning an annual income of at least \$75,000^{12,14,17,18,22,24,47,51,56,58}. A study in 2000 found that parents with less education were more likely to believe vaccines were important than parents with higher education; the parents with college degrees were more likely to forgo specific vaccinations²².

There is a very different demographic profile for parents of children who are undervaccinated unintentionally because of a lack of access to healthcare or other socioeconomic factors. Undervaccinated children are more likely to be black, be foreign born, have a single mother, have a young mother with low education, and live in a household under the poverty level¹⁴. The only demographic variable that appears for both undervaccinated and intentionally unvaccinated is the number of children in the household, with more children in the household as variables for both parents¹⁴. For undervaccinated children, it can be reasoned that the single mothers have barriers to actually taking all of their children for their vaccines. Parents who intentionally do not vaccinate or delay vaccines may feel vaccines are less important as they have had more experience with them with previous children.

Both undervaccinated and intentionally unvaccinated children are at risk for VPDs but the rise of intentional undervaccination is what is of particular concern: those children contribute to the increased risk VPDs for the community, including the children who do not have the proper vaccinations because (for example) their parents cannot afford them. The children of the lower income families may have limited access to healthcare for vaccines and thus it would follow that they would have less access to care if they were to contract a VPD.

Chapter III

METHODS AND PROCEDURES

3.1 Practice Information

A metropolitan pediatric practice near northwest Atlanta consented to participate in this study. The practice is fairly large, with more than 15 providers (Pediatricians and Nurse Practitioners) and four office locations (Sandy Springs, Roswell, Marietta, and Woodstock). These locations have patients primarily in Fulton, Cobb and Cherokee counties in Georgia. The practice sees children from birth to 21 years of age. They have been in practice for over 25 years. The practice accepts most managed care insurance plans and families who choose to self-pay for their medical care (including both parents who strictly self-pay and who self-pay and then file their own claims to insurance plans that practice does not accept). The practice does not accept Medicaid or any other government sponsored programs. Overall demographic data for the practice was not accessible to the researcher.

The practice provides information and links to prevention topics on their website. Among these topics are links to the CDC website for recommendations of vaccines and the Georgia vaccine requirements for schools and daycare centers. They provide a “Vaccine Statement”, which explains the practice’s policy on vaccines. Essentially, this says that the practice strongly recommends vaccination. They endorse and quote the statement from the Georgia Chapter of the

American Academy of Pediatrics. The practice does not discharge patients for refusal to vaccinate. However, each time that a parent declines a recommended vaccine that parent is required to sign a “Refusal to Vaccinate” form. This form must be repeatedly signed during each well-child check up where the parent declines a vaccine. The practice also participates in clinical trials for antibiotics and vaccines through their medical research department. Because of their philosophy on strongly supporting vaccinations and because they do not discharge patients from the practice for not vaccinating the PI felt this practice would be an ideal location to recruit participants for this study.

3.2 Study Design and Data Collection

An anonymous, cross-sectional survey tool was designed (Appendix A). The questions on the survey tool and the procedures for data collection were somewhat limited by practice contingencies. The PI created the survey tool based on research questions and designed it to be practice-specific. The questionnaire and all study procedures were approved by the board at the practice. This study was approved by Georgia State Universities Institutional Review Board (IRB) before any data collection commenced (Appendix B). A waiver of documentation of consent was approved by the IRB, as documentation of consent would violate the Health Insurance Portability and Accountability Act (HIPPA) by retaining protected patient information.

The practice manager informed the PI that surveys online had not been well received by their patients in the past. Therefore, the PI originally attempted to obtain surveys in each of the offices using signs and collection boxes. A stipulation of the practice was that this research could not take any staff time, therefore the only advertising available was via a sign in the offices

(Appendix C). This sign was placed around the office on patient-visible areas. It was also placed near the Check-in counter where all patients entering the office would most likely see it. A box containing the informed consent and questionnaire (stapled together) was also near the Check-in counter, as well as a collection box. Instructions were clear in both the informed consent and on the boxes containing the materials. All parents of children who were current patients at the practice were eligible to participate. Data collection began on December 19th, 2011. The PI periodically traveled to each of the office locations to pick up the surveys from the collection boxes.

During the first three weeks of data collection, we obtained a very small number of responses. It was clear that this method of data collection would not yield a sufficient number of responses. The PI filed an amendment with the board of the practice and the IRB to put the questionnaire online for an additional form of data collection; both were approved. An email invitation (Appendix D) was sent out through an independent IT company that the practice uses for IT management to a database of patient emails. The email invitation contained a link to the questionnaire which was administered by Psycdata, an academic survey tool that operates without advertisements and provides a secure method of data collection. The Informed Consent was modified to reflect an online data collection, and one additional item was added to inquire which office the participant used as this information could not be documented directly by the PI. The survey was sent on January 26, 2012 and remained online for approximately five weeks. The survey was closed on February 22, 2012.

3.3 Survey Instrument

The questionnaire was titled “Prevention Services Survey” (Appendix A). It contained 18 items regarding preventative care: A check-list of possible prevention topics that had ever been discussed with a provider, 4 items using a Likert-type scale to assess the participants’ feelings about their accessibility and comfort with providers and nurses for preventative care, 2 items regarding well-child check-ups, and 11 items regarding vaccines. There were 12 items assessing demographic variables: race, gender, relationship to child, age range, household income, marital status, education, county of residence, number of children, ages of children, profession and partners’ profession if applicable. The office location was documented by the PI on the in-office responses and this item was added to the online questionnaire. The vaccine items inquired about vaccine status, adherence to the recommended vaccine schedule, and feelings about safety. The questionnaire had items of both a quantitative and qualitative nature.

3.4 Statistical Analysis

The data from Psycdata was downloaded into the Statistical Package for Social Sciences (SPSS), Version 19.0, software program. The responses obtained from the offices were manually entered into SPSS by the PI. Descriptive statistics were used to describe the relevant variables and parental demographics. Frequencies and bivariate correlations were used to determine the prevalence of parents with vaccine hesitancies. To examine the relationship between vaccination beliefs and parents’ feelings toward the practice and providers, frequencies and crosstabs were used. The small sample of parents with vaccine hesitancy prevented any further statistical analysis.

Chapter IV

RESULTS

4.1 Participant Demographics

A total of 293 people completed the questionnaire; 38 in-office questionnaires were completed and 255 online responses were collected. Ten responses were deleted from the dataset because more than half of the items were incomplete, leaving a sample of 283. The participants were predominantly mothers, 95.4% (270) were women and 98.9% (280) were parents; 4.2% (12) were male and there was 1 grandparent and 1 guardian who responded. Participants were primarily between the ages of 31 and 50: 5.3% (15) were 21-30, 44.2% (125) were 31-40, 44.2% (125) were 41-50 and 6.4% (18) were older than 51. The majority of participants (93.6%, 265) were married. The majority of the participants were white (69.6%, 197), 4.2% (12) were black. A small number of participants (16) identified as Hispanic, Asian or of mixed race, however a large minority of participants (20.5%, 58) did not respond to this question.

The total household annual income distribution is as follows: 6% (17) made between 40,000 to 59,000; 13.8% (39) made between 60,000 to 79,000; 8.8% (25) made between 80,000 to 90,000; and 63.6% (180) made over 91,000 (6%, 17 were missing and there were 3 participants who made under 20,000 and 2 participants who made between 21,000 and 39,000). The majority of participants had attended at least some college (96.2%, 272), over a third of the

sample were college graduates or had a graduate degree (54.8%, 155 and 26.9%, 76 respectively).

4.2 Parents with Vaccination Hesitancy

Research Question 1: What is the overall prevalence of parents with vaccination concerns in a private practice?

Overall vaccine adherence was 96.1% (272), 3 (1.1%) participants responded that they did not vaccinate and 7 (2.5%) participants responded that they sometimes vaccinated. Of the 10 parents who responded that they did not vaccinate or only sometimes vaccinated, 6 selected “personal reasons” for the decision, 2 participants skipped the question, and 2 participants selected “other”. Both stated that they specifically skipped the Flu and Gardasil (HPV) vaccine.

The overall adherence to the recommended vaccination schedule was 89.8% (254), 7.1% (20) participants responded that they sometimes followed the schedule and 3.2% (9) responded that they did not follow the schedule. Of the participants who responded that they only sometimes followed the recommended schedule, 16 (80%) had responded “yes” to the overall vaccine adherence question. Of the 9 participants who responded that they did not follow the recommended schedule, 5 had responded “yes” to the overall vaccine adherence question.

The two adherence items, vaccine adherence and recommended schedule adherence were combined to create an overall vaccine adherence variable. There were 31 (11%) participants total who responded that they either did not vaccination or did not follow the recommended schedule or who only sometimes vaccinated or sometimes followed the recommended schedule. Parents had an open-ended item where they could discuss specific vaccines or specific concerns they

had. The most frequent vaccine declined was the Gardasil (HPV) vaccine (12), followed by either the seasonal or H1N1 influenza vaccine (9) and the MMR vaccine (8). Other comments included anything relating to preservatives, mercury or ingredients (5) and anything related to “new” vaccines (4).

There were four items used to assess parental vaccination concerns as well as three items regarding their vaccination practices. Table 1 shows the frequencies of responses to these items. In addition, there were three open-ended items inquiring which vaccines parents were most concerned about, to what age of the child did they want to wait to receive vaccines, and any other comments or concerns the parents had about vaccines.

Table 1. *Frequencies of vaccine hesitation responses.*

Survey Item	Response		
	Yes	Unsure	No
“I believe too many vaccines at once are too painful for my child.”	27.9% (79)	16.6% (47)	54.4% (154)
“I believe too many vaccines at once are dangerous for my child.”	17% (48)	31.4% (89)	51.2% (145)
“I believe that certain vaccines are not safe.”	8.8% (25)	30% (85)	60.4% (171)
“I want to wait until my child is older.”	5.7% (16)	3.9% (11)	83.4% (236)

Notes. The fourth item had a large minority (7.1%, 20) of participants who skipped it.

To examine patterns that may exist between parent responses, crosstabulation procedures were run. Table 2 shows the frequencies and bivariate correlations of responses.

Table 2. Crosstabs and correlations of vaccine hesitancy responses.

	“I believe too many vaccines at once are dangerous for my child.”	“I believe that certain vaccines are not safe.”	“I want to wait until my child is older.”
“I believe too many vaccines at once are too painful for my child.”	34.3%, 96 $r=.50^{**}$	25.1%, 70 $r=.30^{**}$	5.3%, 14 $r=.07$
“I believe too many vaccines at once are dangerous for my child.”	-----	33.1%, 93 $r=.57^{**}$	9.1%, 24 $r=.28^{**}$
“I believe that certain vaccines are not safe.”	-----	-----	8.4%, 22 $r=.32^{**}$

Notes. Percentages are based on the total “yes” and “unsure” responses for each cell.

**Indicates correlation was significant at $p \leq .000$

In order to view groups of parents who may be classified as a “vaccine hesitant parent”, four new variables were created. Table 3 describes the frequencies of the different types of hesitancy classifications.

Table 3. Frequencies of hesitancy classifications

New Variable	Responded to indicate Vaccine Hesitancy	Responded to indicate no Hesitancy
Participants responded “yes” to any one of the four hesitation items.	40.3%, 114	59.0%, 167
Participants responded “unsure” to any of the four hesitation items.	48.4%, 137	50.9%, 144
Participants responded “unsure or yes” to any one of the four hesitation items.	63.3%, 179	36.4%, 103
Participants responded “unsure or yes” to any of the four hesitation items and responded “no or sometimes” to the two adherence items.	64.7%, 183	35%, 99

Notes. Percentages may not equal 100 due to missing responses.

Although only a small number of participants responded that they did not vaccinate or did not follow the recommended vaccine schedule, it is important to consider their reasons and statements. There were two open-ended items where participants could express any vaccine concerns or comments. Many parents chose to elaborate on their vaccine beliefs in these open-ended items. Table 4 provides a selection of those statements.

Table 4. Selected statements from open-ended items regarding vaccine beliefs.

Regarding “newness” of vaccines.

“We did not get Gardasil when it was new. Now that it has been available for several years and has a reasonable track record, we will allow it.”

“I do not feel comfortable giving my child vaccines that are brand new to the market or that have not been studied long.”

Regarding “spreading out” vaccinations.

“I believe vaccines are important, but there are just too many scheduled within the first two years of life. I did spread my child’s vaccines out, but not by more than a few months. I moved my child to [this] practice due to other practices not accommodating to spread vaccines out.”

“In general, too many vaccines are given at one time and too many in the first year. Yes, these are diseases that can cause serious harm but the flurry of vaccines overloads the immune system and creates a traumatic relationship between doctors and children at impressionable ages.”

“There is not a specific age that I target for completing vaccines but I like to separate them into multiple visits. We usually complete them in line with the schedule. I believe that too many vaccines at one time impairs the body’s ability to process in a healthy manner. I do not believe in receiving the flu vaccine, I believe it is lucrative for doctors and pharmacies and has little proven success.”

Regarding the HPV vaccine specifically.

“We did not get Gardasil when it was first recommended because it was brand new and no real track record for safety. There have been too many pharmaceuticals pulled off the market after just a few years for unacceptable side effects and risks. My children are not guinea pigs and will not supply free best testing for pharmaceutical corporations. The intense lobbying effort by the manufacturer to make Gardasil mandatory was a red flag that it was nothing more than a profit-maker. However, now that the vaccine has been around for half a decade and seems to be safe enough, we will allow our children to get it.”

“My child is not sexually active so I do not think that HPV or Hepatitis vaccines are necessary at my child’s current young age.”

Parents with concerns who vaccinated anyway.

“I know there is a lot of discussion going on in the media surrounding the vaccine issue. I don’t want them to have anything unnecessarily, but I would also hate for them to become ill in the long run because they were not vaccinated in their early years. I’m also concerned that children who aren’t vaccinated would get sick and pass something to others.”

“While I do believe that babies (especially) and toddlers receive too many vaccines at once, I do follow the recommended schedule for both my children.”

4.3 Parent attitudes toward practice and vaccination beliefs.

Research Question 2: Is there a relationship between parental feelings toward the practice and provider and their vaccination beliefs?

Parents were given a list of seven “prevention topics” and asked to select which ones they had spoken about to a practice provider or nurse during any visit or phone call with the practice. The topic selected most by participants was the “vaccines and/or vaccine schedule” choice. Table 5 shows the frequencies of items selected.

Table 5. *Frequencies of prevention topics discussed at practice.*

Prevention Topic	Frequency Checked
Seatbelts and/or car seats	65.7%, 186
Helmets and/or bicycle safety	42%, 119
Vaccines and/or vaccine schedule	89.8%, 254
Nutrition and/or vitamins	79.2%, 224
Hygiene and sanitation	40.3%, 114
Well child check-ups and/or schedule	88.3%, 250
Other	8.8%, 25

Notes. Percentages may not equal 100 due to missing responses.

To examine the prevalence of parental vaccine hesitation among parents who had discussed vaccines with providers or nurses at the practice, crosstabulation procedures were run. Table 6 shows the frequencies of hesitation responses among parents who had selected the vaccine and/or vaccine schedule response in regards to prevention topics they had discussed with a provider or nurse at the practice.

Table 6. *Frequencies and crosstabs of parental vaccine hesitancies among parents by discussion with Practice.*

	Vaccines and/or Vaccine Schedule selected by a parent as a topic of discussion		
	Yes	No	Total
“I believe too many vaccines at once are too painful for my child.”	88.1%, 111	11.6%, 15	126
“I believe too many vaccines at once are dangerous for my child.”	88.3%, 121	11.7%, 16	137
“I believe that certain vaccines are not safe.”	85.5%, 94	14.5%, 16	110
“I want to wait until my child is older.”	77.7%, 21	22.2%, 6	27

Notes. The hesitancy items include only participants that responded “yes” or “unsure” to each item. Percentages based on total number of participants considered hesitant.

There were four items that assessed the participants’ overall feeling and comfort toward the practice providers and nurses at visits and during phone calls. Regarding participants’ feelings toward nurse accessibility at the practice, 48.4% (137) strongly agreed, 42.8% (121) agreed, 7.8% (22) neither agreed nor disagreed, and 0.7% (2) participants disagreed. Regarding participants’ feelings toward provider accessibility at the practice, 41.3% (117) strongly agreed, 46.6% (132) agreed, 9.5% (27) neither agreed nor disagreed, and 2.1% (6) disagreed. Regarding participants’ feelings toward calling the practice, 53.4% (151) strongly agreed, 39.2% (111) agreed, 4.2% (12) neither agreed nor disagreed, and 2.8% (8) disagreed. Regarding comfort with the provider at office visits, 67.8% (192) strongly agreed, 29.7% (84) agreed, 1.4% (4) neither agreed nor disagreed, and 0.4% (1) disagreed. Because the overwhelming majority of participants strongly agreed or agreed with all of the items relating to the practice, the cells became too small among the neutral and disagreed participants to examine any relationship between feelings toward the practice and vaccination hesitancy.

Chapter V

DISCUSSION AND CONCLUSION

5.1 Discussion

This study sought to examine parental vaccination concerns in a private pediatric setting. Although we found a high rate of vaccine uptake among participants we did identify a large group who could be viewed as vaccine hesitant. The majority of participants also reported that they followed the recommended vaccination schedule; however there was a small group who reported not following the schedule. Among the small group that either did not vaccinate or did not follow the recommended schedule, the most frequently cited vaccine refusals were HPV, either H1N1 or seasonal influenza and MMR. If participants who responded as “unsure” are considered hesitant along with those who responded “yes”, then nearly half of the sample exhibits vaccine concerns regarding vaccines being too painful and that there are too many vaccines given at once. Vaccine safety is also a concern for a large minority of participants. Significant correlations existed between responses in each of the vaccine hesitancy categories, suggesting the presence of more than one type of hesitancy among parents with concerns. When looking at parents who responded “yes or unsure” to one of the hesitancy items or who responded negatively to either of the two vaccine adherence items we found 65% of the sample to have some type of vaccine concern. Considering the overall prevalence of vaccine uptake was

extremely high in the sample, this observation is of particular notice. Even parents who vaccinate may change their minds if their concerns grow, or they may begin to decline vaccines they perceive as less important (such as HPV or Flu).

We also wanted to see if a relationship existed between how the parents felt about the providers and nurses at the practice and their vaccine concerns. Due to the small size of the group identified we were unable to statistically look at any relationships. However, there are two important results to note. First, out of a list of six prevention topics that may have been discussed with a provider, the vaccine response was most frequently selected. Second, many of these parents (who had spent some time discussing vaccines and/or the schedule with a nurse or provider) had also responded hesitantly to one or more of the vaccine concern items. The meaning of this observation is unclear; however, there are several possible explanations. Perhaps parents who discuss vaccines with providers and nurses are more comfortable expressing their concerns, or perhaps fundamental differences exist in the thought processes of parents who discuss or do not discuss their concerns. Another possible explanation is that parents still have vaccine concerns; however, through vaccine discussion they continue to receive vaccines despite those concerns.

The study instrument included several qualitative items where parents could express their specific vaccine concerns or beliefs. Although only a small group of participants chose to utilize this space, the comments they made provide a vital insight to their beliefs and decision making. In this study, participant comments were generally able to be grouped into four areas; parents with concerns regarding the “newness” of vaccines, parents who feel there are too many vaccines, specific concerns regarding the HPV vaccine, and parents who were concerned but vaccinated anyway. Several parent comments in these areas reflect claims made by anti-

vaccination advocates through various media avenues; some parents even cited media sources suggesting an anti-vaccine media influence that affects decision making. Other comments reflect a misunderstanding of some vaccines, a belief that some VPDs are not serious, and the belief that vaccines are not studied accurately before released on the market. These comments are consistent with the main ideas of why parents choose to refuse or delay vaccines in the literature; however, looking at them from a qualitative perspective adds a unique insight allowing for a deeper understanding of these parents' beliefs.

5.2 Feasibility of Study and Limitations

The third research question in this study was to look at the feasibility of conducting research in this type of setting. As previously discussed, the majority of research in this area utilized NIS data; an excellent source of information regarding vaccines in this country. However, given the complexity of this issue and the cognitive thought processes of parents, smaller more detailed research is warranted. Parents of children at private practices will typically match the demographics that research has shown can predict parental vaccine concerns or refusals. While we would expect to find a higher uptake of vaccination in this population as opposed to the general population, findings from this type of population isolate these parents from parents whose children are unvaccinated due to lack of access to health care or SES.

While research in private settings is warranted, significant limitations exist and it may not be entirely feasible. Practices may place upon the researcher stipulations in which they can conduct their research that inhibits the design of the study or the data collection. A limitation of this study was that the practice stipulated that the research would not add any work or time to normal staff duties. Therefore, staff could not be instructed to hand out the survey to every

patient who checked into the office. Private practices have a day to day routine that ensures the success of their business and they have little incentive to interrupt that routine without vested interest in the research. This limited the number of responses we were able to obtain. Another stipulation was that the survey be only one page front and back, which limited the number of questions we were able to ask participants.

Many other limitations of this study exist outside of the feasibility of collecting data at a private practice. Due to the limited amount of time and finances to complete this research we were unable to provide any incentive for participation. While we had nearly 300 responses, this is an incredibly low response rate. An estimated 1200 patients are seen monthly by the four practice locations, and the email database has over 15,000 contacts. There was no way of accurately recording the response rate in this study, the email contacts may not accurately reflect the parents of current patients at the practice and as parents were not actually approached about the study there was no way of recording an accurate number of parents who were aware of the study. In addition to the low response rate, some participants who did participate chose to skip several items in the survey which required their responses to be omitted from analysis. Participants may have answered more questions or taken more time to complete the survey had they been offered an incentive.

Another limitation to this study is that there appears to be a self-selection bias. Parents who are anti-vaccination or who have severe vaccine concerns may not feel comfortable answering such a survey. Even though the protocol specified the surveys anonymity and that individual surveys would not be shared with providers, patients may still have felt insecure about answering such questions. The group we identified as vaccine hesitant was small, but this group could be widely underrepresented because of the self-selection bias.

5.3 Suggestions for Future Research

To prevent any further VPD outbreaks due to intentionally undervaccinated children, more research in this area is necessary. The existing literature in this area covers a wide range of topics surrounding this issue but there are gaps in the current research that should be addressed to accurately understand this complex issue. There are fundamental differences between parents of children who are unvaccinated because of personal decisions and parents of children who are undervaccinated because of traditional health disparities. Future research must make a distinction between the two groups as public health interventions for each group would likely need to be different in order to effectively communicate appropriate vaccination advocacy to the contrary demographic profiles of the families.

As providers are consistently cited as an important influence on vaccine decision making, it may be beneficial to examine the relationships between providers and parents on varying levels. For example, topics such as the differences between nurse practitioners or physician assistants and MDs or the amount of time a provider spends discussing vaccines and the effect those factors have on vaccine decision making and strength of convictions. Another area of research would be ways of approaching or responding to patients with vaccine concerns. Parents may be more inclined to be influenced by a provider if the provider is a parent as well, and shares their vaccine decisions with the patient. Finding the right model for educating parents about the dangers of not vaccinating is crucial.

In addition to the ongoing NIS studies that provide essential information to this issue, additional qualitative analysis is vital. Interviews or focus groups with parents regarding the influences on their decision making, their sources of information, and their understanding of

vaccines and VPDs would undoubtedly contribute to the deeper understanding of this issue. Knowledge of these issues may also aid the public health and medical communities to work together to develop more appropriate responses to parents who may not want to vaccinate their children.

Some studies have looked at providers who are discharging patients on the grounds of parent vaccine refusal. Conversely, it may be beneficial to gather information from parents who are leaving practices because providers do not discharge patients or who will change daycare centers because of the attendance of other children who are unvaccinated. In the current study, one participant wrote: “It’s shocking to me the public’s ignorance about vaccines these days. When did Jenny McCarthy become an authority on what millions of people do regarding vaccines?” Parents who share this participant’s feeling may have useful opinions on the opposing anti-vaccination sentiments that may help the public health community aid these parents to become advocates for vaccination in their own local communities.

5.4 Recommendations

When a parent refuses all or specific vaccines, the AAP recommends that the provider listen to the parent, share the evidence for risks and benefits of vaccines and vaccine-preventable diseases, refer parents to reputable sources of information, discuss vaccines separately, and should revisit immunization discussions with the family at every visit⁵². In order to reach families before they make the decision to refuse vaccinations, it may be beneficial to screen for parents who have concerns or hesitations around vaccines. By screening for these parents, providers may be able to more effectively communicate vaccine information. Opel et al.

developed a survey to identify vaccine hesitant parents using qualitative methods⁵⁹. If a survey such as this was used as a screening tool it could alert the provider of a vaccine hesitant parent. If the provider was prepared for this encounter perhaps he or she could schedule more time for that visit to allow for more involved vaccine counseling. While that may help the parent feel more comfortable in vaccinating, payments to providers are based on diagnosis codes and providers would not be compensated for their extra time.

When providers discharge a patient from their practice on the grounds of vaccine refusal, these patients may be leaving disgruntled with medical care. They may be less likely to seek additional medical care, or perhaps they are more likely to seek non-traditional care (such as chiropractors). In both of these scenarios, the child will probably remain unvaccinated. Discharging families from practices when they refuse vaccines is understandable; those practices are protecting other patients from exposure to disease. However, there is a missed opportunity to appropriately counsel parents regarding vaccinations when these families are discharged and the rates of intentionally unvaccinated children are unlikely to improve without provider intervention. Providers should be made aware of the impact they can have on parents with vaccine hesitations and should be encouraged to spend time counseling these parents before discharge. Providers should be fully aware of the scope of parental vaccination concerns and be prepared to face parental opposition by providing parents with accurate and complete information, without medical or statistical jargon that the parent can understand. The public health community should stress upon the medical community the importance of trusting and open relationships when dealing with parents who have vaccine concerns. Providers should be encouraged to continue trying to work with patients and to not discharge them on the grounds of vaccine refusal.

Another recommendation regards policy. The research shows that states with stricter mandates have lower rates of unvaccinated children. It would perhaps be beneficial to the vaccine uptake rates if states had more stringent policies on vaccine exemptions. The public health policy community should lobby for stricter mandates and make it more difficult to obtain an exemption in states where it is relatively easy. If it is more difficult to obtain an exemption, parents may take more time to think about vaccinating or not vaccinating which may affect vaccine uptake.

Finally, there exists a plethora of anti-vaccination websites and other media venues spreading false information about vaccines and VPDs. Public health and medical communities should make an effort to combat these websites with pro-vaccination websites including accurate information about the dangers of not vaccinating children. It may be beneficial to create pro-vaccination websites that employ some of the same tactics that anti-vaccination websites use. Emotional stories from parents about their children who were harmed or killed by a VPD (as opposed to a vaccine), information with accurate vaccine information that combats some of the false claims made by anti-immunization websites, links to the CDC or AAP (instead of other anti-vaccination websites), and information about the dangers of unvaccinating. Having easy to read and emotionally gripping pro-vaccination websites may combat the anti-vaccination websites. This is particularly important for the parents who are not speaking to their providers about their concerns. The public health community should reach out using media avenues to educate all parents about the safety and efficacy of vaccinations.

5.5 Conclusion

We were able to identify a small group of parents who had vaccine concerns within this private pediatric setting, but because of the adverse research environment there are limitations that inhibit research and interpretation and this group may be underrepresented. The relationship between provider and parent may be the most important variable in vaccine decision making and should be a focus of future research studies. In order to examine this crucial relationship, the barriers to conducting research in the private practice setting need to be overcome. The public health community should focus on working with the medical community in order to accurately educate providers on the best way to build relationships and present vaccine information plainly and counsel parents regarding vaccine decisions.

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APPENDIX A: IRB Approval



INSTITUTIONAL REVIEW BOARD

Mail: P.O. Box 3999
Atlanta, Georgia 30302-3999

In Person: Alumni Hall
30 Courtland St, Suite 217

Phone: 404/413-3500
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December 14, 2011

Principal Investigator: Rothenberg, Richard B

Student PI: Karen T Joseph

Protocol Department: Institute of Public Health

Protocol Title: Vaccination Rates and Parental Demographics: A survey of Parents and Caregivers in a Private Pediatric Practice

Submission Type: Protocol H12240

Review Type: Exempt Review

Approval Date: December 14, 2011

The Georgia State University Institutional Review Board (IRB) reviewed and approved your IRB protocol entitled Vaccination Rates and Parental Demographics: A survey of Parents and Caregivers in a Private Pediatric Practice. The approval date is listed above.

Exempt protocols do not require yearly renewal. However, if any changes occur in the protocol that would change the category of review, you must re-submit the protocol for IRB review. When the protocol is complete, a Study Closure Form must be submitted to the IRB.

Any adverse reactions or problems resulting from this investigation must be reported immediately to the University Institutional Review Board. For more information, please visit our website at www.gsu.edu/irb.

Sincerely,

A handwritten signature in cursive script that reads "Susan Vogtner".

Susan Vogtner, IRB Member

Federal Wide Assurance Number: 00000129

APPENDIX B: Informed Consent

Georgia State University
Institute of Public Health, College of Health and Human Sciences
Informed Consent

Title: A survey of Parents and Caregivers in a Private Pediatric Practice
Principal Investigator: Richard Rothenberg, MD, Tiffany Joseph
Sponsor: Georgia State University, Institute of Public Health.

I. Purpose:

You are invited to participate in a research study. The purpose of this study is to learn your opinions on prevention services offered at this pediatric practice.

II. Procedures:

If you choose to participate, you will complete a one page, front and back, survey. This will take you approximately 5-10 minutes.

III. Risks:

There are no known risks.

IV. Benefits:

Participation in this study may not benefit you personally. However, results from this study will be shared with the doctors of this pediatric practice. These results may impact the practice procedures based on your beliefs regarding some of the prevention topics, which may benefit your family.

V. Voluntary Participation and Withdrawal:

Participation in research is entirely voluntary. You do not have to be in this study. If you decide to be in the study and change your mind, you have the right to drop out at any time. You may skip questions or stop participating at any time.

VI. Confidentiality:

This survey is entirely anonymous. No identifying information will be asked. Once you have completed the survey, please place it in the designated collection box. They will be collected and reviewed by the researchers only.

VII. Contact Persons:

Contact Tiffany Joseph at [REDACTED] or karentiffany@gmail.com if you have questions about this study. If you have questions or concerns about your rights as a participant in this research study, you may contact Susan Vogtner in the Office of Research Integrity at 404-413-3513 or svogtner1@gsu.edu.

VIII. Copy of Consent Form to Subject:

You may keep this copy of the consent form.

If you agree to participate in this research, please continue with the survey.



Consent Form Approved by Georgia State University IRB December 14, 2011 - Indefinite

APPENDIX C: Survey Instrument

Prevention Services Survey

The purpose of this survey is to gather your opinions on prevention services at PAMPA. This research will be used by a Master's student at Georgia State University for a Thesis. This survey is completely anonymous and voluntary. Surveys will be seen by the researcher only. Overall findings will be shared with the doctors and nurses at PAMPA. If you have completed this survey at a previous visit please do not complete this again. Thank you for your participation!

Please check which Preventive care topics you have discussed with a nurse or provider at PAMPA during phone calls with PAMPA Staff or visits to the office.

PREVENTIVE CARE:

	Seatbelts and/or Car Seats		Hygiene and Sanitation
	Helmets and/or Bicycle Safety		Well Child Check Ups and/or Schedule
	Vaccines and/or Schedule		Other:
	Nutrition and/or Vitamins		

Please rate your level of agreement with the following statements by circling the most appropriate response. Please refer to the table above for examples of Preventive care.

I feel that PAMPA nurses are easily accessible when I have questions regarding Preventive care.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

I feel that the PAMPA Providers are easily accessible when I have questions regarding Preventive care.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

I feel comfortable calling PAMPA to ask questions regarding preventive care.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

I feel comfortable discussing Preventive care with providers at office visits.

Strongly Agree Agree Neither Agree or Disagree Disagree Strongly Disagree

I bring my child for Well Child Check-Ups at the recommended intervals.

YES NO SOMETIMES

If you do not bring your child in for Well Child Check-ups, please select the reason why:

Scheduling conflict for the doctor I want during the time I am available

Insurance Issues

Financial Reasons

Personal Reasons

Other: _____

I vaccinate my child.

YES NO SOMETIMES

(Please flip page to complete survey)

I do not vaccinate my child because of:

Religious reasons.

Financial Reasons

Personal Reasons

Other: _____

I follow the recommended Vaccine Schedule at PAMPA

YES NO SOMETIMES

I believe too many vaccines at once are too painful for my child YES NO UNSURE

I believe too many vaccines at once are dangerous for my child YES NO UNSURE

I believe that certain vaccines are not safe. YES NO UNSURE

Which vaccines ? _____

I cannot afford the vaccines YES NO UNSURE

I want to wait until my child is older. YES NO UNSURE

What age? _____

Other reasons/comments: _____

Please answer the following questions about yourself by circling the most appropriate response. These questions are for research purposes only and will not be used to identify you in any way.

Gender: MALE FEMALE Are you a: parent guardian/caretaker grandparent

Age Range: Under 20 21-30 31-40 41-50 51+

Annual Household Income: Under 20K 21-39K 40-59K 60-79K 80-90K 90K+

Marital Status: Single Divorced Married Partnered Widowed

Education Level: Highschool Some College Vocational School College Graduate

Graduate Degree Multiple Graduate Degrees

Race/Ethnicity: _____

Please state in which county you live: _____

Number of children: _____ Ages of Children: _____

Profession: _____ Partner's Profession (If Applicable): _____

Thank you for your participation!



PREVENTION SERVICES

██████ *is participating in a research study regarding prevention services offered at the practice.*

*Please take a survey and share your opinions!
Surveys are available near Check-In.*

*This will only take 5–10 minutes of your time.
Participation is entirely voluntary and anonymous.*

THANK YOU!!!



APPENDIX E: Email Invitation

Dear [REDACTED] Parents,

Hello! This email is to inform you about a research study which [REDACTED] is participating in. The survey is about prevention services offered at our practice. It takes only 5-10 minutes of your time, and we would appreciate your participation!

*Please follow this link to complete the survey online:
<https://www.psychdata.com/s.asp?SID=146508>*

The surveys are also available in each of the office locations. You may fill it out during any office visit if you prefer. Participation is entirely voluntary and completely anonymous.

Thank you!

[REDACTED]