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*Objectives*-The purpose of this literature review is to identify the health and illness attitudes, beliefs, and behaviors that are unique to parents who refuse to vaccinate their children.

*Methods*-Twelve published studies conducted in the United States between 1998 and 2008 were accumulated from three major database sources: *PubMed*, *EBSCOhost*, and *Science Direct*. Studies were evaluated based on common attitudes, beliefs and behaviors observed in the course of the studies.

*Results*: A total of ten studies were identified between 1998 and 2008 based on the inclusive criteria provided. Studies included one qualitative study, two case control studies, and seven cross-section studies. Parental concerns with vaccine safety ranged from 6.7%-93.4%, with the highest percentages of concern from parent with unvaccinated children.

*Conclusion*: Parental trust in vaccinations and their mandating is diminishing in the United States. Various measures are needed to be enforced in order to regain confidence in vaccination safety.

ATTITUDES, BELIEFS AND BEHAVIORS OF PARENTS TOWARDS CHILDHOOD  
IMMUNIZATIONS

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PROFESSIONAL REPORT

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## CHAPTER 1

### INTRODUCTION

A growing number of parents in the US are choosing to not vaccinate their children. This increasing number of unvaccinated children can be observed in the last eight years (2000-2008) as vaccine coverage rates have begun to fall. In the 2007, US National Immunization Survey for children 19-35 months old, researchers established the US national average for Diphtheria, Tetanus, Pertussis (DTaP), Hepatitis B (HepB), Inactivated Poliovirus, and Measles, Mumps, Rubella (MMR) vaccinations to range between 85.1% and 92.9 % (Center for Disease Control and Prevention, 2007). In 2000-2001 the same survey found the identical vaccinations to have coverage ranges between 89.3% to 94.3% (CDC, 2001). Over a seven year period surveillance of vaccination coverage have observed a 2%-4% decrease in some of the most important childhood vaccines. This decline in rates has been attributed a growing population of parents choosing not to vaccinate their children. Researchers have found most populations with unvaccinated children to encompass parents with similar demographics; the majority of these parents tend to be disproportionately white married mothers with a college degree and household annual incomes exceeding \$75,000 (Smith, Chu, Barker, 2004). Additionally this consistent population appears to have a growing homeschooled community with increasing numbers of unvaccinated children.

A 2005 study found parents who homeschooled have the least belief in the importance of vaccinations compared to parents whose children attend public or private schools. Furthermore, these same parents had the lowest proportion of respondents who would fully immunize if it were not required by law (59%) in comparison to parents of children attending public (77%) or private (86%) schools (Kennedy, Brown, Gust, 2005). One of the greatest barriers to reaching this population is the inability of medical personnel to convince parents to alter their beliefs to

not vaccinate even when valid evidence is presented. In a 1996 study researchers establish the following conclusions, “when nonvaccinators in our study were presented with the sort of risk-benefit information that leads many medical and public health experts to conclude that the risks of the disease are worse than the risks of the vaccine, they became more committed to nonvaccination, not less. Parents in each group apparently focused on that evidence in the information that would strengthen their previously held views, while discounting evidence that would not” (Meszaros, p.697). An essential element for decreasing the growing trend of unvaccinated children is to uncover the reason(s) for parents maintaining such a strong opposition to vaccinations even when scientific evidence demonstrates otherwise. Although many of these parents are making individual choices concerning vaccinations, healthcare providers in the US have begun to observe health impacts to the general population directly related to the growing number of individual decisions.

Currently the United States has begun to observe six consequences attributable to increasing numbers of unvaccinated children: epidemics in various childhood diseases; possible new strains of vaccine preventable diseases; reduction in herd immunity; increase cost related to treatment and disease containment; increasing pediatric dismissals of parents refusing to vaccinate. With many of these parents having similar demographics, an important question is whether their beliefs, attitudes, and behaviors also show comparable categories. Developing a common framework of categories of vaccination concerns is critical for public health professionals attempting to reduce this growing trend through program and policy development.

#### *Purpose of the Study*

The purpose of this literature review is to identify the health and illness attitudes, beliefs, and behaviors that are unique to parents who refuse to vaccinate their children reported in

literature from 1998-2007. Frequently observed beliefs, attitudes and behaviors of anti-vaccination parents will be arranged to identify potentially similar thinking development.

### *Research questions*

- What health and illness attitudes, beliefs and behaviors are observed in parents of unvaccinated children?
- What rationale do most parents state for their apprehension for vaccinations?
- What are the reasons parents provide for not vaccinating their children?
- Which strategies for persuading parents to vaccinate their children have been most effective?

### *Delimitations*

The study was delimited by:

Research data and reports available in the English language from 1998 to 2007.

Studies on the vaccination views of parents of children under the age of eighteen years old.

### *Limitations*

Although there are a variety of vaccinations available to children all over the world, this study is limited to research on vaccinations commonly required in the United States of America to children under the age of eighteen. Also study results focusing on parents with verified religious reasons for exemption will not be included in this literature review due to the *United*

*States of America's Bill of Right Amendment I*, which allows for free exercise of religious beliefs and the differences in population with religious objection compared to philosophical objectors.

### *Assumptions*

For the purpose of the study, the following assumptions will be made:

- Research findings collectively represent anti-vaccine parents with safety concerns in the United States of America.
- Safety concerns raised by anti-vaccine parents are similar.
- Information being selected from research studies are accurate and reflects correctly the data being presented.
- Although side effects have been shown to occur with vaccinations, currently vaccinations provide the most comprehensive prevention method available for Diphtheria, Tetanus, Pertussis, Hepatitis A, Hepatitis B, Poliovirus, Measles, Mumps, Rubella, Meningococcal.

## *Definition of Terms*

### *General terms*

Attitude—"a settled way of thinking or feeling, typically reflected in a person's behavior".

(Lindberg, 2002, p.78)

Behavior—"the way in which one acts or conducts oneself, especially towards others". (Lindberg,

2002, p. 116)

Belief- "an acceptance that a statement is true or that something exists". (Lindberg, 2002, p. 118)

Case Control Study- To examine the possible relation of an exposure to a certain disease.

Identify two groups, individuals with that disease (*cases*) and individuals without the disease (*controls*). Then determine what proportions of cases were exposed and what proportion were

not. The same method is applied to the control group. These long-term or short-term

retrospective studies are then evaluated for causal relationships. (Gordis, 2004, p. 159 and p.174)

Center for Disease Control and Prevention (CDC) – Agency under the department of Health and Human services in the United States of America with a fiscal budget for 2009 of \$8.8 billion.

(CDC, 2008a) The mission of the organization is "to promote health and quality of life by preventing and controlling disease, injury, and disability" and the 21<sup>st</sup> century vision of the agency is "Healthy People in a Healthy World—Through Prevention". (CDC, 2008 b)

Cohort Study- The investigator selects a group of exposed individuals and a group of nonexposed individuals and follows up both groups to compare the occurrence of disease (or rate of death from disease) in the two groups. Due to the identification of new (occurrences) cases of disease as they occur, we can determine whether a temporal relationship exist between the

exposure and the disease, that is, whether the exposure preceded the onset of the disease.

(Gordis, 2004, p. 149-150)

Cross-Sectional Study- Define a population, at a specific period of time, and determine the presence or absence of exposure and the presence or absence of disease for each individual. Based on this information the defined population is divided into four groups: exposed/ have disease; exposed/ to not have disease; not exposed/ have disease; not exposed; do not have disease. Without a chronological relationship between exposure and outcome a causal relationship cannot be established only the frequency of the disease. (Gordis, 2004, p. 173-174)

#### *Vaccination status terms*

Fully Vaccinated Children-minors between the ages of 0-18 who are up to date on the immunization schedule recommended by the CDC and/or their personal pediatrician:

Diphtheria, Tetanus, Pertussis (DTaP) [5 doses], Hepatitis A (HepA) [2 doses], Hepatitis B (HepB) [3 doses], Inactivated Poliovirus [3-4doses], Measles, Mumps, Rubella (MMR) [2 doses], Meningococcal [1 dose]. (CDC, 2008c and CDC, 2008d)

Partially vaccinated Children-minors who have begun the series of vaccinations recommended by the CDC, but are not up to date on their recommended immunization schedule .(Smith, et al., 2004)

Unvaccinated Children-minors who have “received no vaccinations”. (Smith, et. al. 2004, p 188)

*US Childhood preventable vaccinations and diseases*

Common vaccinations- Diphtheria, Tetanus, Pertussis (DTaP); Hepatitis A (HepA); Hepatitis B (HepB); Inactivated Poliovirus; Measles, Mumps, Rubella (MMR); Meningococcal. (CDC,2008c and CDC,2008d)

Diphtheria–This disease develops as the result of the toxin producing bacteria strain of *Corynebacterium diphtheria*. The two most common clinical features of the disease are respiratory diphtheria and cutaneous diphtheria. Transmission of the disease is mainly through direct person-to –person contact through intimate respiratory and physical contact. Common complications for the respiratory diphtheria include myocarditis, polyneuritis, and airway obstruction; 5%-10% of deaths occur due to respiratory cases. Cutaneous diphtheria cases have considerably less complications and deaths. (CDC, 2005 a)

Hepatitis A- An acute liver disease produced by the Hepatitis A virus (HAV) which can produce symptoms up to 6 months after infection. Presently the virus has not been found to lead to chronic infections and death does not usually occur. Generally transmission of the disease has been found to be through the ingestion of fecal matter, even in small quantities. Asymptomatic cases have been found in 70% of infected children younger than 6 years of age. Individuals older than 6 years of age have a 70% chance of developing symptoms. Common symptoms of the disease are: fever, fatigue, loss of appetite, nausea, vomiting, abdominal pain, dark urine, clay-colored bowel movements, joint pain, and jaundice. (CDC, 2008 e)

Hepatitis B- A highly communicable virus, Hepatitis B virus (HBV), that can survive outside of the body at least 7 days and still produce infections. There are three possible stages of infection acute, chronic, and perinatal. Chronic HBV results in an estimated 2,000-4,000 death per year.

Common transmissions of the disease are as follows: sex with an infected partner, injection drug use that involves sharing needles, syringes, or drug-preparation equipment, birth to an infected mother, contact with blood or open sores of an infected person, needle sticks or sharp instrument exposures, and sharing items such as razors or toothbrushes with an infected person.

Complications for the disease are permanent liver damage and cirrhosis. (CDC, 2008 e)

Measles- A respiratory disease from the virus *Rubeola* that develops in the back of the throat and lining of the lungs. About one out of one thousand children will develop encephalitis which can lead to mental retardation and/ or deafness. Since the disease can be spread up to four days prior and after to symptoms, infected individuals are able to spread the disease quite rampantly.

Individuals in close contact with the infected individual have a 90% chance of developing measles. (CDC, 2008 f)

Meningococcal- A severe bacterial infectious attributed most commonly to *Streptococcus pneumoniae* and *Neisseria meningitides*. Infection of the disease is called meningitis and can also be the result of a viral infection, which usual is less severe and requires less treatment. Although there are antibiotics for bacterial meningitis, the risk of dying from the infection can only be reduced to ~85%. (CDC, 2008g)

Mumps- An acute viral infection that develops due to the mumps virus and currently does not have medical treatment options. Common symptoms of the disease are fever, headache, muscle aches, tiredness, and loss of appetite; followed by swelling of salivary glands. In many cases the parotid salivary glands are impacted the most. Rare complications associated with this disease are inflammation of the brain and/or tissue covering the brain and spinal cord (encephalitis/meningitis), inflammation of the testicles (orchitis), inflammation of the ovaries

and/or breasts (oophoritis and mastitis), spontaneous abortion, and possible permanent deafness. (CDC, 2008 h)

Pertussis- An extremely communicable bacterial disease, *Bordetella pertussis*, which can manifest itself for many weeks in children causing severe coughing, whooping and posttussive vomiting. The most vulnerable for this disease are infants and young children; complications include hypoxia, apnea, pneumonia, seizures, encephalopathy, and malnutrition. In 2003, 13 American deaths were attributed to Pertussis infections. (CDC, 2005 b)

Poliovirus- A highly infectious nervous system disease with up to 95 % of infected individuals being asymptomatic. Less than 1% of infected individuals will result in permanent paralysis. (CDC, 2007 a)

Rubella- An acute infections due to the Rubella virus that mildly impacts children and young adults. The most serious cases are found mainly in pregnant women who can develop the following complications themselves or in the unborn fetus: birth defects, deafness, cataracts, heart defects, mental retardation, and liver and spleen damage. There are no current treatment options for infected individuals at the present time. (CDC, 2008i)

Tetanus - An acute bacterial disease attributed to *Clostridium tetani*; this disease has become well known for muscle rigidity and painful spasms through out the development of the disease. A neurotoxin produced by the bacteria through anaerobic tetanus bacilli grows in contaminated wound where it flourishes. There are three clinical syndromes associated with tetanus: generalized, localized, and cephalic; although these various syndromes exist, the clinical course of tetanus is extremely variable on prior amounts of immunity, amount of toxin present, and age

and general health of the patient. Currently generalized tetanus, the most common form (80%) of tetanus infections, has a mortality rate of 10%-20%. (CDC, 2007 b)

### *Importance of the study*

An individual parent choosing not to vaccinate their children poses a critical threat to the health of other individuals living in their communities. This threat becomes amplified when large numbers of parents begin to make similar decision in clustered communities. Being able to understand variables leading to such an intense belief is essential to developing programs targeting this growing population and improvement of specific governmental policies. Through identifying frequently observed beliefs, attitudes and behaviors of anti-vaccination parents, researchers are able to build up a systematic framework for helping high risk populations of parents make vaccine decisions.

## CHAPTER 2

### LITERATURE REVIEW

Unvaccinated children create a health threat to both themselves and communities surrounding them. Investigating the causes of this developing trend in the United States is vital to evaluating current vaccination laws, reducing disease outbreaks, and ultimately allow parents a realistic view of vaccinations benefits and risks. One of the primary reasons for a recent increase in unvaccinated children is the growing trend for states to allow for various exemptions to vaccines.

#### *Current vaccine exemption laws*

As of 2008 all states in the US except Mississippi and West Virginia allow for religious exemptions from vaccination; 21 states allow additional exemptions for personal beliefs (Institute for Vaccine Safety, 2007) or philosophical reasons. Among those states offering the additional nonmedical exemptions, there has been an observable increase in rates of exemptions compared to states with only religious exemptions (Omer, Pan, Hasley, et al., 2006). In addition many of the states offering nonmedical exemptions make it simpler and less time consuming to submit the exemption rather than comply with the current vaccine regulations. Few of the nonmedical exemptions states require any type of vaccine counseling or interventions for parents submitting the exemptions and most states do not have any system in place to register the vaccination status of home-schooled children. (Rota, Salmon, Rodewald, Chen, Hibbs, Gangarosa, 2001) North Carolina is one of the few states which requires proof of vaccinations or records of approved exemptions regardless of a child's school status. (Khalili, Caplan, 2007, p 474). In a comparison to 2007 the national vaccination averages, DTaP (85.1%), MMR(92.4%), Polio(92.7%), and HepB (92.9%), North Carolina has a high vaccination coverage of DTaP (88.5%), MMR(97.6%), Polio(94.4%), and HepB (92.4%). (CDC, 2007) With an increase in

exemption options, various states and healthcare communities have begun to experience the impact of unvaccinated children.

#### *Current health related dilemmas attributed to unvaccinated children*

Throughout this year (2008) the CDC has reported an epidemic number of measles cases in the US. In the first four months of this year 64 cases of measles have been reported in comparison to only 55 cases for the entire year of 2007(CDC, 2008e). A 1999 study found that individuals who have not received the measles vaccine are highly more vulnerable for contracting measles (Salmon, Haber, Gangarosa, Phillips, Smith, Chen) and potentially developing an extensive list of complications: ear infection, encephalitis, pneumonia, diarrhea or vomiting, bronchitis, laryngitis or croup, pregnancy complications, and low platelet count (MayoClinic.com, 2008). Among health providers one of the greatest concerns with unvaccinated children is their ability to spread preventable diseases to individuals with valid medical contraindications to immunizations, young infants not yet of age to be vaccinated, individuals whose vaccination was not effective, and individuals undergoing medical treatments reducing their immunity and vaccination status (Kennedy, Brown, Gust, 2005) such as cancer patients and HIV patients. Currently the medical community has become concerned with the spread of various vaccine preventable disease and the possibility of new vaccine resistant strains of these diseases entering the US. Over the past 30 years such concerns were nominal in the US due to high vaccination rates although many countries around the world are experiencing the deadly impact of these diseases.

#### *Evolution of viruses*

As recently as 1998, researchers warned of the evolution of measles virus into hypermutated forms which have been associated with subacute sclerosing panencephalitis (SSPE) (Domingo, Baranowski, Ruiz-Jarabo, Martin-Hernandez, Saiz, Escarmis, 1998).

According to the *National Institute of Neurological Disorders and Strokes*, a more familiar name of the disease is Dawson Disease. This mutated measles virus is a chronic persistent infection of the central nervous system which is found primarily in children and young adults and usually has a progressive downhill course which results in death. Those who survive the general measles virus, they have a 5% chance of spontaneous remission with SSPE. It can occur anywhere from two to ten years after the original measles illness, and generally results in progressive neurological deterioration due to brain inflammation and nerve cell death. Current research has shown high incidence of SSPE in the Middle East and India (2007). Although currently this disease has been mostly eliminated in the US, between 1956 and 1981 the CDC discovered 368 individuals who met the case definition of having SSPE in the US; 55% (202) had a history of only measles infection; 14% (51) had a history of only measles vaccination; and 17% (63) had a history of both, with the natural illness most frequently preceding the vaccination. The remaining 14% (52) gave no positive history of having natural measles infection or measles vaccination (CDC, 1982). In a follow up study in 2005, researchers discovered that data in the this more current study suggest a risk of developing SSPE that is approximately ten times higher *after measles virus infection* in young children than the original risk of developing SSPE estimated in 1982 (Bellini, Rota, Lowe, Katz, Dyken, Zaki, Shieh, Rota, 2005,). Although this disease is rare in the US, in 2000 a notice from the CDC attributed the death of a 13 year old adopted child from Thailand to SSPE. Apparently the child may have contracted measles nine years earlier in an orphanage in Thailand (Bonthius, Stanek, Grose). Even though this mutated virus has not become epidemic in the United States, it does appear that if the measles virus is spread and contracted by unvaccinated children this can lead to this mutated virus two to ten years after the original infections.

### *Decrease in herd immunity*

Another essential aspect to the increasing epidemic of vaccine preventable diseases is a decrease in herd immunity. For years parents of unvaccinated children and individuals with reduced immunities have been able to depend on the assumption that most individuals in a community were vaccinated and thus reducing exposure to various life threatening diseases. This belief in the herd immunity has been a huge component of anti-vaccination argument.

Unfortunately the herd immunity only can function if the immunization rates of coverage stay between 92%-95% (Marfe, 2007). The 2007 immunization coverage rates for four of the major vaccines are on the edge of falling below the 92% limit. With many parents choosing not to vaccinate and state accountability for vaccination low, many areas with large clusters of unvaccinated children may have rates even lower than the 92% limit. Overall, those individuals, including immune suppressed individuals, depending on the herd immunity may not be able to depend on the herd immunity in the near future.

### *Cost attributed epidemics*

An additional dilemma attributable to the increase in US epidemics is the cost involved in hospitalization and quarantines. An example of this was the 2005 measles outbreak in Indiana which cost the state \$167,685; this charge does not include medical expenditure associated with treatments. The entire epidemic was the result of a total of 34 individuals with only two of the cases due to vaccine failure. Overall, 64% of the total unvaccinated individuals who attended the event and came in contact with the virus became infected with measles (Parker, Staggs, Dayan, et al., 2006). Currently the number of uninsured children without vaccinations is unknown, but the potential medical cost for treating many of these preventable diseases is quite high due to many of these diseases being attributed to viral infections which cannot be treated with one

specific treatment. As in the case of the Indiana outbreak, local hospitals are forced to sustain large financial cost to contain individuals with these diseases from infecting other susceptible patients. Also there is the potential for insurance companies to eliminate or reduce their treatment and/or hospitalization coverage for vaccine preventable childhood disease due to exemption statuses. Ultimately these outbreaks result in unnecessary financial burden on the local and state health department for the investigation and evaluation of the outbreak. Most health departments have annual allotted funding for infectious disease control. In the event of large than expected epidemics, funding would come from other sources such as reducing or eliminating programs or increasing local taxes.

#### *Increasing pediatric physician dismissals*

Primary health care and pediatric physician are becoming frustrated by an increasing number of parents refusing to vaccinate. According to a 2005 study, over half (54%) of the 302 pediatricians surveyed reported encountering parents who refused all vaccines. In the same study 39% of the sampled pediatricians stated that they would refer the family to another physician mainly for a “lack of shared goals” and “lack of trust” (Flanagan-Klygis, Sharp, Frader, p. 931). One of the major concerns is that dismissed parents may leave the traditional medical community permanently and seek healthcare from alternative medical sources (chiropractors, etc.) (Gellin, 2000). Increasing distrust in traditional medical systems and dismissal from practices may lead parents to permanently seek healthcare from other sources. Without children being seen by a pediatrician on a regular basis, these children may be more vulnerable to spreading and contracting childhood diseases into the general population. Also lack of traditional medical treatments and diagnosis in the early stages of disease could lead to more severe symptoms among unvaccinated children.

### *Historical and present viewpoint of nonvaccinators*

Ever since the development of the small pox vaccine by Edward Jenner in the early 1800s, individuals have radically opposed vaccination (Wolfe, 2002). Although vaccinations were still in their developing stages, the success and improvements observed by the public health community encouraged the enforcement of mandatory vaccinations in various industrial nations through out the 19<sup>th</sup> century. Lagging behind its European counterparts by approximately eight years, the United States did not experience a large anti-vaccine movement until 1878 (Blume, 2006). One of the main reasons for the delay in American reaction was due to the prevalent use of smallpox vaccination during the first part of the century which contained the smallpox epidemic. Unfortunately with the decrease in the small pox epidemic, the use of vaccinations also diminished. A smallpox epidemic during the 1870s showed the vulnerability of the population due to the lack of state enforcement of vaccinations laws and the need to develop new legislation (Wolfe, 2002).

In 1879 the *Anti-vaccination Society of America* was founded following the New York visit of William Tebb, “the leading British anti-vaccinationist” (Wolfe and Sharp, 2002, p. 432). During the following years of 1882 and 1885 the *New England Anti-compulsory Vaccination League* and the *Anti-vaccination League of New York City* respectively were founded in the United States. These organizations instigated persistent conflict with public health authorities in the courts and through riots in Montreal and Milwaukee. This movement was successful in repealing mandatory vaccination laws in California, Illinois, Indiana, Minnesota, Utah, West Virginia, and Wisconsin (Wolfe, 2002). One of the key objectives of this opposition was to influence or repeal the public health legislation. This movement was different from their European counterparts who consisted of clerics and other individuals opposing the vaccination

on individual liberties issues (Blume, 2006). Many of the leaders of these American organizations were “irregular physicians’ (including homeopaths)”. These individuals were threatened economically due to possible state regulations of healthcare. Other leaders in the interest group were the manufactures of patent medicine that would also be impacted by state regulations. With the improvement of medical practice through rigid medical licensure laws reducing “irregular physicians”, increased control of the state and federal governments over public health, and fewer vaccination accidents the American anti-vaccination movement subsided (Allen, 2007, p. 104). The subsiding of the movement can also be attributed to the 1898 removal of penalties and permitted exemptions for anti-vaccination parents through a conscience clause. (Wood-Harper, 2005) Similar legislation was not passed in the United Kingdom until 1907. (Blume, 2006)

Throughout the early 20<sup>th</sup> century vaccine development began to thrive and various vaccinations were introduced to the public. With the new development of vaccinations there were also severe health side effects and sometimes death. In 1901 scientist and medical professional began to observe tetanus outbreaks among children receiving the smallpox vaccine. Later most of these deaths were attributed to the contamination of the vaccine with tetanus bacilli. Ultimately these medical catastrophes lead to the initial steps to developing the United States food and drug regulation system. Although in 1902 a full investigation was conducted into the vaccine safety, four years later the anti-vaccine movement began to receive the funding they needed to further their cause(s) through John Pitcairn, a Scottish immigrant and millionaire in the steel and oil industry. Mr. Pitcairn’s oldest son had experienced blood poisoning in 1885 as an infant due to the smallpox vaccine. With the funding provided the anti-vaccine movement began

to boom. One of the main arguments presented during this movement can be observed in the present arguments presented by alternative medicine systems,

“The opponents of vaccination emphasized individual responsibility and control of one’s own body. Healthy people didn’t get smallpox, they said- a state of ‘perfect health... resists and repels the assaults of all morbid influences.’ This was a circular argument, since falling sick was always proof of one’s imperfect state of health” (Allen, 2007, p.104).

One of the remarkable aspects of the anti-vaccine movement is the remarkable consistency in the argument from the late 19<sup>th</sup> century to the current 21<sup>st</sup> century, even though such though has not been established or proven (Wolfe, 2002). By 1947 during the final outbreak of small pox, many of the initial crusades of the anti-vaccination movement observed in the early 1920’s had been reduced immensely. This change in perspectives appears to be attribute to four main reasons: (1) Public health official began to use persuasion techniques instead of compulsory methods, (2) Individuals had seen the health benefits of vaccinations; (3) vaccine safety had improved from the earlier error of the smallpox vaccinations (Colgrove, 2006); (4) increased association between patriotism with public health during World War I which encouraged respect for government mandates (Allen, 2007). Although vaccinations observed a turbulent beginning during the early twentieth century, it was the scientist who argued for vaccine safety throughout that era. In the late 1970s and early 1980s a new rise in the anti-vaccination movement would begin to question vaccine safety even though vaccines were safer than they had ever been before (Allen, 2007).

A rise in anti-vaccine movement would reemerge during the late 1970’s and early 1980’s in America. One of the key instigators of this movement was the April 19, 1982 airing of *DPT*:

*Vaccine Roulette* by the NBC-TV affiliate in Washington, D.C. (Allen, 2007). Within a matter of weeks, parents throughout the United States were swamped their pediatricians office with serious concerns over the Diphtheria, Tetanus, and Pertussis (DTP) vaccination due to the sensational television airing. (Colgrove, 2006) Due to this rise in vaccine safety concerns a parent advocacy group was established, Dissatisfied Parents Together (DPT): some of the key objectives of the organization were to produce “safer vaccines, better medical education on the risks of vaccinations, and parental rights to decide whether to vaccinate their children.” (Allen, 2007, p. 254 ). Throughout the 1980s a rise in legal battles concerning possible side effects of the DTP vaccine were brought against the government and manufacturers of vaccinations. Many manufacturers began to raise considerably their prices for the vaccines to compensate for the legal cost. One of the most remarkable aspects of this unsettling time was the how the debate appeared to have little effect on immunization rates nationwide. During the 1970’s debate in Great Britain over the DTP vaccination, almost immediately parents began to not immunize their children for Pertussis which led to an outbreak of the disease (Colgrove, 2006). Over the next few years various studies were conducted to test the hypothesis of a causal association between DTP and various neurological disorders allegedly attributed to the vaccine. One of the largest studies was conducted in 1994 with a large population study of 218,000 children living in Oregon and Washington states. From this study 424 “confirmed cases of neurological illness were identified prospectively during a 12-month period by statewide active surveillance” (Gale, 1994, p.68). Throughout the study odds ratios, the ratio of the odds of one event occurring in another separate group, were statistically insignificant for an “increased risk of onset of serious acute neurological illness in the 7 days after DTP vaccine exposure for young children” (Gale, 1994, p. 69). Although the organizations such as Dissatisfied Parents Together maintained to be

concerned with vaccine safety, they were not satisfied with the result of the research being conducted.

Although DTP vaccination has become under scrutiny of vaccine safety, nothing would compare in the United States to the publicity involved in the MMR and possible Autism correlation. The commencement of this controversy can be attributed to a single study published in 1998 by a collection of scientist in the United Kingdom. A total of twelve already diagnosed autistic children with severe intestinal disorders were evaluated for a correlation between “chronic enterocolitis and regressive developmental disorder” (Wakefield, 1998). Based on this study the lead researcher Andrew Wakefield made the following claim “that the MMR vaccine should be withdrawn (a position not held by his co-investigators in the study)” (Jeremy Laurance (as cited in Colgove, 2006). Through out the study various methodological errors can be identified: using a cross sectional study to make a correlation conclusion, extremely small sample sizes for such a generality and most importantly no control measurements. Even with such a faulty foundation, anti-vaccination organizations clung to the new findings as support for their belief in their now beliefs of vaccines and autism. With the turn of the 21<sup>st</sup> century, the debate of vaccine safety has continued. Most of the debate surrounded the growing hypothesis that MMR vaccinations were correlated to the increase in autism cases. In 2002 a cohort study of 537,303 total children born in Denmark between January 1991 through December 1998 was conducted with 440,655 of the total children being vaccinated for MMR. The findings of the study were as follows:

“First, the risk of autism was similar in vaccinated and unvaccinated children, in both age-adjusted and fully adjusted analyses. Second, there was no temporal clustering of cases of autism at any time after immunization. Third, neither autistic disorder nor other

autistic-spectrum disorders were associated with MMR vaccination. Furthermore, the results were derived from a nationwide cohort study with nearly complete follow-up data” (Madsen, Hviid, Vestergaard, Schendel, Wohlfahrt, Thorsen, Olsen, Melbye, 2002, p. 1480).

Two years after this study, two books were published Michael Fitzpatrick’s *MMR and Autism: What Parents Need To Know* and Richard Horton’s *MMR: Science and Fiction*. In Horton’s book, a reporter discovered information concerning Andrew Wakefield, the lead investigator for the original 1998 study on autism, which led *The Lancet* to retract the study *Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children* and most of the coauthors denounced the study. Mr. Wakefield had received \$100,000 to conduct his autism research from the Legal Aid Board which represents parents in the UK who believe their children are damaged by vaccines. Additionally, in 1997 Mr. Wakefield had also applied for patents for his single measles shot and his alleged cure for MMR-related autism (as cited in Allen, 2007). Even with such a large volume of studies disproving the hypothesis for a correlation or causation between the MMR vaccine and autism, many parents and organizations continue to fuel the fear. Now instead of using pamphlets and brochures as a main way to circulate information, anti-vaccinationists use the internet. A review of 78 anti-vaccination websites, the most common factor was “the inclusion of statements linking vaccinations with specific adverse reactions, especially idiopathic chronic diseases such as multiple sclerosis, autism, and diabetes” (Zimmerman, Wolfe, Fox, Nowalk, Troy, Sharp, 2005, p. 17). Also the study found that 75 % of the websites also provide links to other sites which contain radical vaccine safety conspiracies, resisting the “establishment”, and assertions that vaccines “provide

only temporary protection and are therefore not worth the risk” (Zimmerman, Wolfe, Fox, Nowalk, Troy, Sharp, 2005, p.17).

Historically three major groups of individuals have been associated in developing nations with the opposition to vaccinations: religious objectors, civil liberties groups, and alternative medicine practitioners. Past religious objectors to vaccinations have been orthodox Protestants, anthroposophy and New Age followers in the Netherlands and the Roman Catholic Church in the Philippines (Streefland, Chowdhury, Ramos-Jimenez, 1999). In America, traditionally churches such as Jehovah Witnesses, Amish (Streefland, 2001), and Christian Science Church (Christian Science, 2008) have opposed vaccinations. Presently many of the religious organizations originally opposed to vaccinations are taking a less harsh stance. One of the only mainstream religious organizations to still uphold an anti-vaccination stance is the Christian Science Church (Christian Science, 2008). Even though the Amish church has not made a formal statement concerning vaccinations, a 2006 study found that 84% of Old Order Amish households in the study reported having vaccinated all their children and only 8% of respondents “attributed their children’s unvaccination status to religious objectors” (Yoder, 2006, p.1183). This change in perspective may be attributed to the Pertussis outbreak and other epidemics of vaccine preventable diseases observed in this community during the past few years (Center for Disease Control and Prevention, 2006).

Whereas many of the traditional objectors to vaccinations appear to currently be revising their stand on vaccinations, a new movement of vaccine objectors has begun to develop in the late 20<sup>th</sup> and present early 21<sup>st</sup> century. This fresh movement of individuals is established generally by parents opposing immunizations based on alleged adverse effects and/or reservations about the constructive value of immunizations and not on religious beliefs

(Streefland, 2001). Unlike previous religious objectors, these anti-vaccination parental organizations promote their beliefs through the internet and other advanced technological sources which portray a sense of legitimacy to their objections (Allen, 2007). Furthermore many of the spokespersons for anti-vaccine groups focus on information that appears to be covered up by the mainstream medical community. The majority, if not all, of the information being presented can be refuted, but this is often difficult to communicate to a lay audience due to the epidemiological concepts or data interpretations necessary for a suitable explanation (Leask, McIntyre, 2003). In most cases these individuals fail to acknowledge that individual reports or studies expressing apprehension are only the first step in determining if a true contributory relationship exists (Chen, DeStefano, Pless, Mootrey, Kramarz, Hibbs, 2001). Like their predecessors before, many of those individuals upholding the anti-vaccination stance present a sense of social pressure or discrimination towards those parents or individuals in their social groups who may choose to vaccinate their children. In addition objectors rarely discuss the number of individuals who receive the vaccine without any difficulties rather they focus on extreme cases and situations.

In summary, a variety of information can be attributed to the current anti-vaccination movement. Although the extents of influence of these views and opinions are still unknown, identifying them is one of the key steps to addressing the growing movement. Through this literature review, the dilemmas associated with current vaccination laws, current health outbreaks attributed to unvaccinated children, and historical influences have been discussed. Even though this movement appears to be a new phenomenon, it is not radically different from that of previous generations. These movements appear to follow a general cycle: communities oppose a vaccination(s); outbreak comes upon their community; due to deaths incurred during the outbreak regulations are enforced or developed to reduce the outbreak; with the reduction of

observable epidemics, individuals begin the cycle again by opposing vaccine(s). Historically it appears that until large numbers of persons are drastically impacted through death or permanently disabled, these anti-vaccination movements continue to flourish without regulations or policies. One of the greatest debates currently presented to public health professionals is the balance between individual's rights and wellbeing of the community. The growing 21<sup>st</sup> century anti-vaccination movement presents a test to the process for determining mandated vaccinations and enforcement methods.

## CHAPTER 3

### METHODOLOGY

Published US studies from 1997-2007 were accumulated through three major database sources: *PubMed*, *EBSCOhost*, and *Science Direct*. The following terms were used to identify relevant information:

- “anti-vaccine parents”
- “ anti-immunization parents”
- “why parents choose not to vaccinate their children”
- “parents against vaccinations”
- “unvaccinated children”
- “anti-immunization movements”
- “Individuals that choose not to vaccinate their children”
- “populations with unvaccinated children”
- “public opponents of vaccinations”

A search of multiple databases from 1997-2007 yielded a final set of 10 relevant articles. Systematic review of the articles consisted of three main criteria: (1) report results of an original qualitative or quantitative study concerning potential attitudes, beliefs and/or behaviors of parents towards childhood vaccinations, (2) maintain a systematic method of identifying the sample parent’s of unvaccinated children, and (3) describe the method used to identify unvaccinated parents. Each of the articles were evaluated for main results and then placed into a spread sheet. Themes were selected based on recurrent results found through this process.

## CHAPTER 4

### RESULTS

A total of ten studies were identified between 1998 and 2008 based on the inclusive criteria provided. Out of these total studies, the breakdown of individual studies is as follows: one qualitative study, two case control studies, and seven cross-section studies (Table 1). In the quantitative studies participant numbers ranged from 642 to 151,720 and varied in their selection methods for parental sampling. Both quantitative and qualitative studies relied heavily (80%) on data collected through parental self report information concerning their child's vaccine status; 20% of the studies requested physician verification on the child's vaccine status. Most (85.7%) of the cross-sectional studies relied on national data from the *National Immunization Survey* and *HealthyStyles* and *Consumer Styles* surveys conducted annually. The majority (80%) of the studies focused on national data results rather than individual state results. Each of the studies varied in the controlled confounders for the studies, but the most frequently controlled confounders were age, sex, race, education, and household income.

Throughout the evaluation of ten studies (Table 2), three consistent belief/attitude themes emerged: vaccines can/could harm child (vaccine safety); children receive too many vaccinations (decrease in immunity due to clinical interventions); vaccinations are given to prevent diseases that are not serious (risk of disease is low). Although each of the studies demonstrates significant percentages of parents (6.7% to 93.4%) concerned with vaccine safety, parents with unvaccinated children were found to have the highest percentages of apprehension. In addition almost half of the research studies revealed an alarming concern among parents of unvaccinated children for a potential over immunizing of children. Finally, three studies found 20.9% to 80.0%

of parents with unvaccinated children believe that diseases being prevented through vaccinations are not hazardous to their child's health

Table 1 Summary of study characteristics

Quantitative Studies

*Case Control Studies*

First author, Year, Setting	Cases and controls	Exposure Measure	Confounders Controlled for	Comments
Bardenheier et al., 2004, United States, 2000-2001.	<u>Cases</u> (1016): parents of children (ages 19- to 35 month-old) not up-to-date for 1 or more of the specified vaccines.  <u>Controls</u> (1299): 3 control groups of parents of children (ages 19- to 35 month-old) not mutually exclusive of cases.	Physician-verified vaccination status of not up-to-date for 1 or more of the specified vaccines.  Those up-to-date for all vaccines; ≥ 2 doses of DTP/DTaP, ≥ 3 doses of polio vaccine, ≥ 3 doses of <i>Haemophilus influenzae</i> type b vaccine, ≥ 3 doses of hepatitis B vaccine; ≥ 1 doses of varicella vaccine.	Race, marital status of parent, firstborn status, maternal education, child's age, mother's age, annual family income, participation in WIC.	This study may be impacted with the lack of matching cases and controls by age, education or other demographic features.  Cases overall: mothers tended to have lower level of education, younger than controls, younger (20-29 years old), and lower annual income (<\$20,000).
Salmon et al., 2005; US states of Colorado, Massachusetts, Missouri, and Washington; February 2002 and February 2003.	<u>Cases</u> (815): Children claiming vaccination exemption per school records for any reason including medical.  <u>Controls</u> (1630): Fully vaccinated children per school records randomly selected from the same grade and school.	Parental reports  Parental Reports	Respondent's age, education, and income.	Study excluded children whose parents claimed their child was fully vaccinated although the school records stated an exemption and parents who provided plausible medical contradictions.

*Cross Sectional studies*

First author, Year, Setting	Cohort	Objectives	Confounders Controlled for	Comments
Gellin et al., 2000, United States, April- May 1999	1600 interviews completed. 99.6 % of survey respondents were parents or legal guardians of a child 6 years of age or younger.	Respondents self reported medical orientation (conventional vs. alternative) and conceptions about immunizations.	Age, sex, race, education, household income	19%-25% of parents surveyed have important misconceptions about immunizations.  Difficult to conclude how vaccine conceptions may be impacting vaccination status without data on child's vaccination status.
Smith, P., et al., 2004, United States, 1995-2001	151,720 parents of children ages 19-35 months.	Provider verified vaccination status of "fully vaccinated", "undervaccinated" or "unvaccinated". Possible relationships or associations with child, maternal, and household sociodemographic characteristics; parental concerns about vaccine safety and individuals who influence parent's decision to vaccinate their children; geographic areas.	Child characteristics: age, race, gender, foreign born. Maternal characteristics: marital status, educational attainment, preferred language, age, annual family income, number of children ≤ 18 years in the household, moved from	Data from National Immunization Survey 1995-2001.  Study mainly focused on <i>location</i> of unvaccinated children rather than attitudes, beliefs and behaviors of parents  * Limitations: households that choose not to respond to the NIS may be more likely to have

			different state since child's birth, Living in a metropolitan statistical area.	unvaccinated children. In that case, the estimates of the number of unvaccinated children that we report would underestimate the true values, particularly in geographic areas in which the NIS non-response rates are high because of negative attitudes toward vaccinations and negative attitudes toward vaccination surveys.
Gust, D., et al., 2005, United States, May-August 2002.	697 parents who had at least one child $\leq$ 6 years of age.	Self-reported belief that immunizations are necessary and safe; interest and involvement in health issues; trust in provider and influence of others on immunization decisions; Dependence on doctor's advice; concern about safety of childhood immunizations; belief that health issues are complex; Influence of friends and family on immunization decision; religious objections to immunizations; immunization information seeking; plan to immunize child.	Parental gender, age, race, education, household income, marital status.	Data from HealthyStyles and ConsumerStyles 2002 mail surveys with a joint total of 10462 respondents. *Respondents were not identified based on children's vaccination status rather the categories were: Immunization advocate (n=193), Go Along to Get Along (n=154), Health advocate (n=145), Fencesitter (n=77), Worried (n=15).
Gust, D., et al., 2005, United States, July-August 2003.	642 Parents who had at least one child $\leq$ 6 years of age.	Self-reported views on access to information on decisions about immunizing their child; parental differences in sociodemographic characteristics and attitudes about immunizations, child's health provider, immunization requirements/ exemptions and immunization policy makers; identifying potential differences in specific immunization concerns.	Parent's gender, age, race, education, income, marital status, household size, attitudes of parents regarding immunizations, child's provider, immunization requirements/exemptions and immunization policy makers.	Data collected from HealthStyles Survey and ConsumerStyles 2003 with a joint total of 9908 respondents. *Respondents were not identified based on children's vaccination status rather on the answer to the question "I have access to all the information I need to make good decisions about immunizing my children". Disagree, Neutral, Agree were the optional categories.
Kennedy et al., 2005, United States, May-August 2003.	936 Parents or guardian of at least 1 child aged 0-18 years and answered the survey question "What type of school does your youngest child attend?"	Self-reported belief in general safety of childhood immunizations; confidence in safety of routine childhood immunizations; concern that vaccines may cause learning disabilities, concern that vaccine ingredients are unsafe; general importance of immunizations in keeping kids healthy; concern that vaccines are given to prevent nonserious illnesses; concern that vaccines are given for disease kids are unlikely to get; unvaccinated children may get or transmit diseases such as measles.	Youngest child's school type, respondent's educational attainment, annual household income, age, and race.	Data collected from HealthStyles Survey 2003 with total of 5845 respondents.
Kennedy et al., 2005, United States, 2002	1540 parents of children aged $\leq$ 18 years	Level of agreement with allowing children to go to public school even if they are not vaccinated	Respondent's gender, race, age, household income, education, household size, state of residence and philosophical exemption available	Data collected from HealthStyles survey 2002 with a total of 4,397 respondents.

Gust et al., 2006, United States, 2001.	2286 parents or guardians of children (19-35 month old) reporting adverse event following immunization (AEFI) or reporting none of their children experienced a AEFI.	Attitudes, belief, and behavioral trend in three parent groups: parents who sought medical attention for AEFI, parents who treated their children at home for AEFI, and parents who reported no AEFI.	Age, Race, income, education, child's vaccination status, and individual's responses to the immunization belief, and behavior questions.	Data was collected from the National Immunization Survey 2001  "AEFI" in this paper does not imply causality, but only a temporal relationship to an immunization that the parent judged to be vaccine related.  Parents who sought medical attention may have only called the physician's office and still treated the children at home. Study does not account for this.
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### Qualitative Studies

First author, Year, Setting	Study Type	Cohort	Data Analysis	Findings	Comments
Fredrickson et al., 2004, United States, 1997-1998.	Focus group	5 groups of family physicians, 5 groups of pediatricians, 6 groups of family medicine and pediatric clinic nurses who immunize children, 3 groups of public health immunization clinic nurses; 11 groups of parents and 2 groups of parents who had refused vaccines in six cities (Albuquerque; Cleveland; Shreveport, La; Rochester, NY; Santa Fe, NM; and Wichita, Kan).	Themes in focus groups, ANOVA for refusal rate estimate and demographic information.	Four common themes pertinent to refusal: (1) concerns and refusals, (2) sources of information that might influence refusal, (3) trusted sources of information, and (4) doctor-patient refusal communication.	All participants in the refusal groups were white with variable income levels.

Table 2 Frequently observed beliefs, attitudes and behaviors of anti-vaccination parents.

Year, first author	Top findings
2000, Gellin et al.,	<ul style="list-style-type: none"> <li>• Immunization deemed extremely important by 86.9% respondents.</li> <li>• If you have another child in the future, are there any immunizations that you would not want your child to have? (83.6% would not opt out of any vaccinations)</li> <li>• Children should only be immunized against serious diseases (39% Agree).</li> <li>• I am concerned that my child's immune system could be weakened by too many immunizations (25% Agree).</li> <li>• Children get more immunizations than are good for them (23% Agree)</li> <li>• Immunizations are always proven safe before they are approved for use (19% Disagree)</li> <li>• Statement Immunizations "<i>extremely important</i>". <b>Lowest</b> rating of importance: males (81.8%), Hispanic (71.7%), respondents 40 years of age and older (81.4%), college graduates (83.8%), alternative medical orientation (75.5%).</li> <li>• Whether parent would choose to opt out of any immunizations. <b>Highest</b> ratings: females (17.1%), white (15.8%), college graduates (16.9%), alternative medical orientation (24.9%).</li> </ul>
2004, Bardenheier et al.	<ul style="list-style-type: none"> <li>• Majority of respondents (&gt;90%) in all groups believed vaccinations are important, there was not significant difference between cases and control parents.</li> <li>• Case parents (unvaccinated children) gave concern for side effects [MCV/MMR 6.7%, DTP/DTaP, 5%, Hep. B 8.2%] as the top reason for not having their child vaccinated. Second was the reason for not vaccinating was that children receive too many vaccinations</li> <li>• Heard that MCV/DTP/ Hep B caused side effects? [Cases 47.9%, 48.5%, 45.4% / Controls 49.7%, 42.1%, 46.2%].</li> </ul>
2004, Fredrickson et al.	<ul style="list-style-type: none"> <li>• Two focus groups of refusers believed that breast-feeding their babies into child hood and keeping them out of day care would protect their children from most vaccine-preventable diseases.</li> <li>• Parents trusted vaccine information given orally by physicians and public health nurses</li> <li>• Parents saw their children as the most important thing to them</li> <li>• Some [<i>numbers not given</i>] (refusing to vaccinate) parents believed medical science/pharmacology should not interfere with nature and immunity acquired from having the disease was preferable to that acquired from vaccines.</li> <li>• Refusing parents felt that information on childhood immunization issued by either the Centers for Disease Control (CDC) or some anti-immunization Internet sites was [sic.] likely to be biased.</li> </ul>
2004, Smith, P., et al.	<ul style="list-style-type: none"> <li>• Compared with fully vaccinated children, unvaccinated children were significantly more likely to be non-Hispanic white than Hispanic and more likely to live in a household with <math>\geq</math> 4 children than in a household in which he/she was the only child.</li> <li>• Among unvaccinated children, the proportion of boys was 57.3% and significantly exceeded that of girls by 14.6% (P=.05)</li> <li>• Unvaccinated children tended to be disproportionately white children whose mother was married, had a college degree, and lived in a household with an annual income exceeding \$75,000.</li> <li>• Parent of unvaccinated children are much more concerned about vaccine safety.</li> </ul>
2005, Gust, D., et al.	<ul style="list-style-type: none"> <li>• Within each cluster, the greatest % of college graduates and those with higher education were in the Immunization Advocate cluster (42.2%) compared to the Worried (33.3%).</li> <li>• Regarding parent age, the Worried cluster had the highest % of parents aged 40 or over (46.7%).</li> <li>• In the Worried cluster it is important to note that from 73.3% to 93.4% of parents reported the following safety concerns: ingredients in vaccines are unsafe (93.3%), vaccines are not tested enough for safety (93.3%), children get too many vaccines during the first 2 years of life (86.7%), vaccines are given to children to</li> </ul>

	<p>prevent diseases that they are not likely to get (86.7%), vaccines are given to children to prevent diseases that are not serious (80.0%) and vaccinations may cause chronic disease (73.3%).</p> <ul style="list-style-type: none"> <li>66.7% of Worried parents reported their first child had not received all recommended immunizations. Other categories reported between 3.4 and 0% of parents having not vaccinated their first child.</li> </ul>
2005, Gust, D., et al.	<ul style="list-style-type: none"> <li>Parents who disagreed that they had enough information were more likely to feel somewhat or not confident in the safety of childhood immunizations (OR 5.4, 95% CI=3.3-8.9); to believe that immunizations are not important (OR=2.9, 95% CI=1.2-7.2); to disagree that they trust their child's healthcare provider's vaccine advice (OR=5.2, 95% CI=2.2-12.9); to disagree that their child's healthcare provider is easy to talk to (OR=10.8, 95% CI =3.7-28.1); to report that they would not have their child immunized if it were not required by law (OR=4.2, 95% CI 2.1-8.2); to believe states should grant exemptions based on religious (OR=2.4, 95% CI=1.4-4.1) and personal beliefs (OR=2.7, 95% CI=1.6-4.9); and to not trust the government (OR=4.1, 95% CI=2.3-7.5) or the Centers for Disease Control and Prevention (OR=4.5, 95% CI 2.2-9.2) to establish policy for childhood immunizations. Parents who disagreed also were more likely to believe that parents should be allowed to obtain exemptions for their child even if it raised the risk of disease for everyone else (OR=2.2, 95% CI 1.2-3.9).</li> </ul>
2005 Kennedy et al.	<ul style="list-style-type: none"> <li>At 25%, homeschools had the largest proportion of parents who were concerned that vaccines are given to prevent non serious illnesses, compared to 10% and 4% of public and private school parents respectively (p&lt;0.01).</li> <li>25% of homeschool parents were concerned that vaccines were given to prevent illnesses that children are unlikely to get, compared to 13% of public and 8% of private school parents (p=0.04).</li> <li>19% of homeschoolers trusted the federal government to set policy for childhood vaccines compared to 57% for public and 58% for private school parents (p&lt;0.01).</li> <li>Homeschool parents have the lowest proportion (68%) that agreed or strongly agreed in trusting the vaccine advice of their child's health care provider compared to public 88% and private school parents 91% (p&lt;0.01).</li> <li>Homeschool parents had the lowest proportion of respondents who would fully immunize if it were not required by law (59%), followed by public (77%) and private (86%) school parents (p&lt;0.01).</li> <li>Home school parents had the lowest proportion (56%) who agreed or strongly agreed that they had access to enough immunization information.</li> <li>Homeschooling parents appeared to have the most concern for vaccine safety as well as the least belief in the importance of necessity of vaccinations (p.279).</li> </ul>
2005 Kennedy et al.	<ul style="list-style-type: none"> <li>Opposed parents were likely to agree that (1) the body can protect itself without vaccines (24% vs. 10% of supportive parents; p_0.001) and (2) vaccines are not or only somewhat important to a child's health (36% vs. 17% of supportive parents; p_0.001).</li> <li>A greater proportion of opposed parents disagreed that vaccines are necessary to prevent certain diseases (30% vs. 14% of supportive parents; p_0.001).</li> <li>Opposed parents also were more likely than supportive parents to be concerned that vaccines are given to prevent diseases that are not serious (18% vs. 6%; p_0.001), as well as diseases that children are not likely to get (22% vs. 9%; p_0.001).</li> <li>A greater proportion of opposed vs. supportive parents were likely to (1) believe that vaccines were unsafe or only somewhat safe (47% vs. 32%; p_0.001), (2) be not or only somewhat confident in the safety of childhood vaccines (28% vs. 15%; p_0.001), and (3) report concern that children get too many vaccines in their first two years of life (29% vs. 13%; p_0.001).</li> <li>Opposed vs. supportive parents were significantly more likely to report that their child would receive none or only some of the recommended childhood vaccines (10% vs. 1%; p_0.001).</li> <li>This study shows that a parent's opposition to compulsory vaccination is associated with negative attitudes and beliefs about the safety and utility of vaccines.</li> </ul>
2005, Salmon et al.	<ul style="list-style-type: none"> <li>Parents of exempt children were less likely than parents of vaccinated children to report that children benefit a moderate amount or great deal when fully vaccinated (47.0% vs 95.5%, respectively; odds ratio [OR], 0.04; 95% confidence interval [CI], 0.03-0.06) or that the community benefits a moderate amount or great deal when a child is fully vaccinated (47.3% vs 89.6%, respectively; OR, 0.10; 95% CI, 0.07-0.14).</li> <li>The most common reasons stated for not vaccinating related to perceived vaccine safety, including (not mutually exclusive) that the vaccines might cause harm (n=190,68.6%) and that they might overload the immune system (n=136; 49.1%). Other reasons given for forgoing vaccination included the perceptions that the child was not at risk for the disease (n=103; 37.2%), that the disease was not dangerous (n=58; 20.9%), or that vaccines might not work (n=36; 13.0%); ethical or moral issues (n=25; 9.0%); and religious beliefs (n=25; 9.0%). The ethical and moral issues included use of aborted cell lines, fetal tissue and blood, and animal</li> </ul>

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	<p>testing as well as opposition to the requirements.</p> <ul style="list-style-type: none"> <li>• Parents of exempt children were less likely to report their child’s primary health care professional to be a physician (75.8% vs 93.9%; OR, 0.20; 95% CI, 0.14-0.30) and were more likely to report their child’s primary health care professional to be a nurse practitioner (7.4% vs 2.7%;OR, 2.90; 95% CI, 1.59-5.28) or CAM* professional (11.5% vs 0.3%; OR, 41.77; 95% CI, 12.66-137.78) compared with the parents of vaccinated children.</li> <li>• Parents of exempt children were more likely than parents of vaccinated children to consider CAM* professionals and the organization Dissatisfied Parents Together as good or excellent sources for vaccine information.</li> <li>• (CAM): chiropractor, acupuncturist, or other complementary/alternative medicine professional.</li> </ul>
2006, Gust et al.	<ul style="list-style-type: none"> <li>• Parent who sought medical attention for an “AEFI” were more likely to be white, aged 35, believe that immunizations cause minor side effects, report unwanted yet required childhood immunizations, not want a new baby to be fully immunized, report concern about immunization safety, believe that immunizations are dangerous, and have a child missing one or more doses of three immunizations.</li> </ul>

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## CHAPTER 5

### CONCLUSIONS AND RECOMMENDATIONS

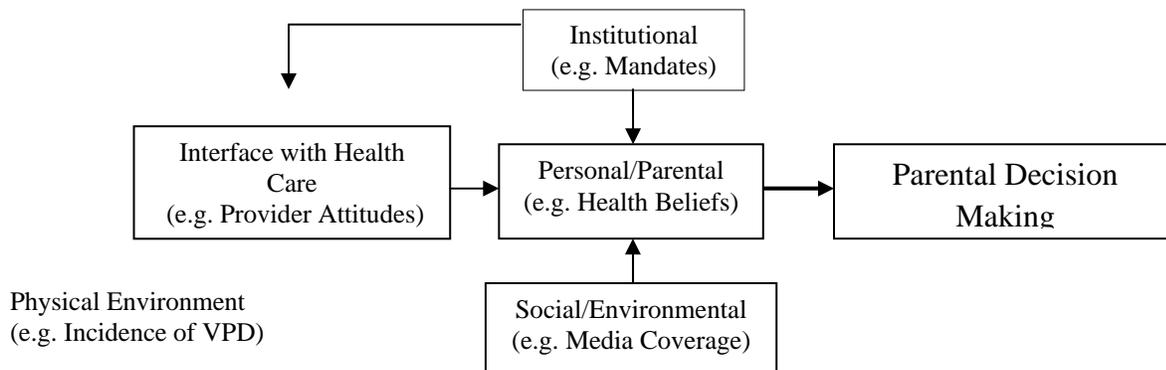
Over the past twenty-eight years parental concerns regarding vaccine safety have been escalating. These uncertainties with vaccine safety have begun to translate into tangible decisions for a mounting number of parents by their choice not to vaccinate their children. Many of these parents naively believe the assumption that their decision only impacts their individual families. In actuality, public health officials are observing the compounding consequences of each of these “individual” decisions. One of the most visible consequences is the decrease in herd immunity which protects many of the most vulnerable individuals in a community. Although this decrease in herd immunity can be directly attributed to this emergent movement, parents choosing not to vaccinate appear to become even more concrete in their belief even when they are presented with this scientific evidence of their decisions. Understanding the reckoning behind this deep-seated view is important for researchers attempting to develop programs to encourage vaccination coverage among these high risk populations.

In this literature review of ten studies relating to unvaccinated children based on parental choices, three emerging themes were observed: vaccines can/could harm child (vaccine safety); children receive too many vaccinations (decrease in immunity due to clinical interventions); vaccinations are given to prevent diseases that are not serious (risk of disease is low). First, parental concerns over vaccine safety have become a growing fear even among parents choosing to vaccinate their children. Similar to most prescription drugs, scientists and pharmaceutical companies have attempted to reduce side effects, but complete elimination of potential side effects is impossible. In the case of the two major vaccines of concern DTP and MMR, current

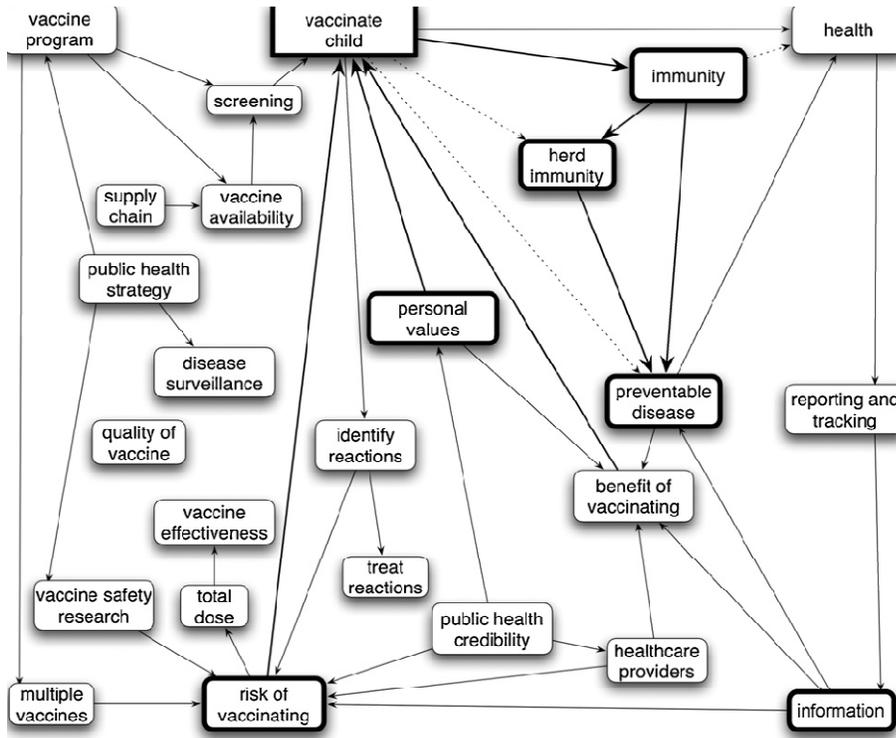
studies have not revealed any correlation between these vaccines and any long-term side effects (Madsen, 2002 & Gale, 1994). The latter two beliefs, although scientifically unproven, are based on the individual desire to feel security that “if we think right, feel right, eat right, and breathe right, we will never be afflicted by a terrible disease” (Campion, 1993, p.2). Reinforcement for this belief system is through parental decisions to reduce the risk of obtaining the disease while emphasizing the potential side effects involved with vaccinating. This provides parents with a sense of safety, whether true or not, in their decision making process.

Although these three themes appear to be simplistic, in reality parental decision making towards vaccinations is quite multifaceted. Two decision models expressing this complexity can be found in the following articles: *Parental Beliefs and Decision Making About Child and Adolescent Immunization* and *Parent’s vaccination comprehension and decisions*. The following are the figures of the models presented in these articles:

**Figure 1** : Factors influencing parental decision making about childhood immunizations (Sturm, Mays, Zimet, 2005, p. 442).



**Figure 2:** Integrated assessment: Solid black arrows indicate links between variables described by experts; dotted black arrows indicate unmediated links mentioned by respondents; links mentioned by experts but not interviewees are not shown. (Downs, Buine de Bruin, Fischhoff, 2008 ,p. 1597)



Both of these models confirm the hypothesis that *parental belief and attitudes* towards overall health care greatly influence behavior toward vaccinations (Downs, et al., 2008 & Sturm, et al. 2005). In a 2006 study researchers found that many of the parents with unvaccinated children already utilize services from alternative medicine providers (Gust, 2003). With a rise in vaccine safety concern, many of these parents with apprehension towards traditional medicine are appear to be the most influenced into not vaccinating their child. Since the majority of the parents making this decision do not have a medical or scientific background, they depend on ‘rules of thumb’ or heuristics for their vaccination decision making (Poland & Jacobson, 2001). Heuristics occurs generally when an individual is presented with a complicated decision; it provides a cognitive shortcut for recalling information. In some situations, the information is compressed

into overestimating extraordinary risks and underestimating frequent threats. Other times a parent may defer to an omission bias which is similar to the concept 'better safe than sorry'. Some rare parents choose protected values which is zero lenience for any hazard whatsoever (Strum, Mays, Zimet, 2005). Ironically the same parents who present many of these objections to vaccinations advocate for complementary and alternative medicine usages even when researchers have found severe side effects related with many of these procedures and medications. Various studies have found many herbal treatments are not labeled with proper warnings as to the potential toxicity of their contents and examples of the permanent health damages caused by these medicines have been observed all over the world. In 1992, a 5 year old boy with eczema in England was found to have received for months a potent topical steroid provided by a Chinese herbalist with out any kind of warning provided to the parents (Niggemann, Grüber, 2003). Tragically many parents are not even aware of the risk involved with alternative medicine due to the lack of media attention and proper warning labels. Nonetheless these parents continue to place their trust more in these methods than minimized side effects of vaccinations based on years of scientific research.

Even though parental decisions towards vaccinations appear to be complicated, one of the greatest influences in assisting with this decision are individuals who surrounding the parent. Research has shown that parents who have discussed vaccination information with siblings, partners, and/ or mother who are health professionals appear more settled in their vaccination decisions (Leask, Chapman, Hawe, Burgess, 2006). These personal contacts appear to have the greatest influence on whether a parent chooses to vaccinate. One of the key reasons public health professionals may be observing the clustering of these communities is due to this occurrence. A

parent's reliance on the recommendation of other parents can be helpful in some situations, but when that dependence leads to blind following the consequences can be deadly.

Although parents in the general population continue to vaccinate, many parent's lack exposure to anti vaccination materials. When presented with this information these individuals either turn to medical professionals or their social network for support. Parents, especially mothers want to be informed decision makers; medical professionals addressing both risk and benefit of vaccinations appear to have the greatest influence on parents choosing to vaccinate (Leask, Chapman, Hawe, Burgess, 2006). If parents are allowed to maintain a simplistic or superficial understanding of vaccinations, when presented with harmful materials they are more likely to be persuaded into accepting the materials (Downs, Bruine de Bruin, Fischhoff, 2008). One of the first key components to combating anti-vaccination material and agenda is to provide parents accurate information on vaccination at the primary care level. Medical professionals providing truthful information on the risk and benefits of vaccines, appears to have the greatest influence over parental decision making. Although vaccination materials are important, many parents desire to be partners in the learning enterprise instead of just receptors. One suggestion is to offer community information opportunities for parent to engage with primary care, health promotion, and the scientific community. These discussions appear to be more influential in presenting the different perspective and receiving answers from trusted sources than providing information in a medical setting (McMurray, R., Cheater, F., Weighall, A., Nelson, C., Schweiger, M., Mukherjee, 2004).

Currently there do not appear to be any specific programs directed toward reducing the number of unvaccinated children although there are numerous research studies being conducted. It appears based on this limited research that the best public health model for potentially

developing programs towards unvaccinated children is the Health Belief Model (Kennedy, 2008). In Appendix C an example of a potential research intervention based on this model can be observed. With the complex nature of how parents communicate and are communicated information on vaccinations, using social network analysis could help establish a systematic method for program development as well (Wasserman and Faust, 1994). Another important research aspect should be the apparent high levels of vaccination status among adults using complementary/alternative medicine (Stokley, Cullen, Kennedy, Bardenheier, 2008) although the children in these populations appear to be decreasing in vaccination status. Potentially this could be the result of previous vaccinations, but it appears that many of these adults are current on their vaccinations such as tetanus. Understanding at what age of the children the concern for vaccine side effects diminishes could provide valuable information.

Even though further research will be needed prior to developing extensive programs, there are other ways that communities and states can begin to address the problem. First, states with high numbers of unvaccinated children should reevaluate their vaccine legislation and whether their current policies encourage exemption status. Also, potential barriers should be put into place to advise parents of the consequences of their decision. Based on the information above, it appears that requiring parents to discuss their decision with a pre-selected medical professional may be a solution. Second, governmental health professionals should set standards for determining what vaccinations will be mandated; currently there appears to be little, if any, clear standards for what constitutes mandating a vaccine. Providing these reasons to the general public and the research behind these decisions is an important method for encouraging parental involvement. Third, although many states have vaccine registries many of these registries are unorganized and sporadically used. Mandating the use of registries for mandated vaccines status

and exemption status provides a disease surveillance system for public health providers. In areas where the surveillance reveals low herd immunity, these professionals are able to develop intervention plans prior to outbreaks.

### *Summary of Recommendations*

- Provide accurate information concerning vaccinations at the primary care level.
- Support medical personnel who deal with immunization issues with further educational programs concerning target messaging techniques and latest informational information.
- States with high numbers of unvaccinated children should reevaluate their vaccine legislation and whether their current policies encourage exemption status
- Governmental health professionals should set standards for determining what vaccinations will be mandated.
- Mandate the use of vaccine registries for vaccination status and disease surveillance.
- Further research tailor messaging and potential impact on this population.

In conclusion, during the 2008 year the anti-vaccination movement has been quite vocal in expressing their distain for vaccination. Combating the aggressive and sometime illogical statements from these organizations is difficult. Many individuals have lost confidence in the public health system. Regaining that trust will be difficult, but it needs to start with defining the standards for mandating vaccines. Public health professionals need to be willing to show that they are not being sold out to pharmaceutical companies, but rather they are truly interested in the well-being of the community concerning vaccination.

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APPENDIX A:  
SIDE EFFECTS OF COMMON VACCINATIONS

Information taken from the Website of the Center for Disease Control and Prevention

<http://www.cdc.gov/vaccines/vac-gen/side-effects.htm>

*DTaP:*

Mild Problems (Common)

- Fever (up to about 1 child in 4)
- Redness or swelling where the shot was given (up to about 1 child in 4)
- Soreness or tenderness where the shot was given (up to about 1 child in 4)

These problems occur more often after the 4th and 5th doses of the DTaP series than after earlier doses.

Sometimes the 4th or 5th dose of DTaP vaccine is followed by swelling of the entire arm or leg in which the shot was given, for 1 to 7 days (up to about 1 child in 30).

Other mild problems include:

- Fussiness (up to about 1 child in 3)
- Tiredness or poor appetite (up to about 1 child in 10)
- Vomiting (up to about 1 child in 50)

These problems generally occur 1 to 3 days after the shot.

Moderate Problems (Uncommon)

- Seizure (jerking or staring) (about 1 child out of 14,000)
- Non-stop crying, for 3 hours or more (up to about 1 child out of 1,000)
- High fever, 105 degrees Fahrenheit or higher (about 1 child out of 16,000)

Severe Problems (Very Rare)

Serious allergic reaction (less than 1 out of a million doses) Several other severe problems have been reported after DTaP vaccine. These include:

- Long-term seizures, coma, or lowered consciousness
- Permanent brain damage.

These are so rare it is hard to tell if they are caused by the vaccine.

*Hepatitis A:*

Mild problems

- soreness where the shot was given (about 1 out of 2 adults, and up to 1 out of 6 children)

- headache (about 1 out of 6 adults and 1 out of 25 children)
- loss of appetite (about 1 out of 12 children)
- tiredness (about 1 out of 14 adults)

If these problems occur, they usually last 1 or 2 days.

Severe problems

- Serious allergic reaction, within a few minutes to a few hours of the shot (very rare)

*Hepatitis B:*

Mild problems

- Soreness where the shot was given, lasting a day or two (up to 1 out of 11 children and adolescents, and about 1 out of 4 adults)
- Mild to moderate fever (up to 1 out of 14 children and adolescents and 1 out of 100 adults)

Severe problems

- Serious allergic reaction (very rare)

*Inactivated Poliovirus:*

- In countries using IPV, no increased risk for serious adverse events has been observed. Some people who get IPV get a sore spot where the shot is given. The vaccine used today has never been known to cause any serious problems, and most people don't have any problems at all with it.
- IPV should not be administered to persons who have experienced a severe allergic reaction after a previous dose of IPV or to streptomycin, polymyxin B, and neomycin.

*Measles, Mumps, and Rubella:*

Mild Problems

- Fever (up to 1 person out of 6)
- Mild rash (about 1 person out of 20)
- Swelling of glands in the cheeks or neck (rare)  
If these problems occur, it is usually within 7-12 days after the shot. They occur less often after the second dose.

Moderate Problems

- Seizure (jerking or staring) caused by fever (about 1 out of 3,000 doses)
- Temporary pain and stiffness in the joints, mostly in teenage or adult women (up to 1 out of 4)

- Temporary low platelet count, which can cause a bleeding disorder (about 1 out of 30,000 doses)

#### Severe Problems (Very Rare)

- Serious allergic reaction (less than 1 out of a million doses)
- Several other severe problems have been known to occur after a child gets MMR vaccine. But this happens so rarely, experts cannot be sure whether they are caused by the vaccine or not. These include:
- Deafness
- Long-term seizures, coma, or lowered consciousness
- Permanent brain damage

#### *Meningococcal*

##### Mild problems

- Up to about half of people who get meningococcal vaccines have mild side effects, such as redness or pain where the shot was given.
- If these problems occur, they usually last for 1 or 2 days. They are more common after MCV4 than after MPSV4.
- A small percentage of people who receive the vaccine develop a fever.

##### Severe problems

- Serious allergic reactions, within a few minutes to a few hours of the shot, are very rare.
- A serious nervous system disorder called Guillain-Barré Syndrome (or GBS) has been reported among some people who received MCV4. This happens so rarely that it is currently not possible to tell if the vaccine might be a factor. Even if it is, the risk is very small.

## APPENDIX B

### RESOURCES FOR PARENTAL VACCINATION RESEARCH

#### Vaccine Controversy and History

- Allen, A. (2007). *Vaccine: The Controversial Story of Medicine's Greatest Lifesaver*. New York: W.W. Norton & Company.
- Colgrove, J. (2006). *State of Immunity: The Politics of Vaccination in Twentieth-Century America*. University of California Press.
- Offit, P. (2008). *Autism's False Prophets: Bad Science, Risky Medicine, and the Search for a Cure*. Columbia University Press.
- *MSNBC News documentary*-<http://www.msnbc.msn.com/id/27440647/>

#### Vaccine Contents

- US Food and Drug Administration (2009, January 19). *Thimerosal in Vaccines*  
<http://www.fda.gov/cber/vaccine/thimerosal.htm#t1>
- Center for Disease Control and Prevention. <http://www.cdc.gov/vaccines/vpd-vac/default.htm>

## APPENDIX C

### RECOMMENDED RESEARCH DESIGN

#### Abstract

*Background:* Growing trends of parents are choosing not to vaccinate their children. These children pose a threat to their own health as well as individuals surrounding them. Evaluating methods to encourage vaccinations in these communities is essential for reducing these increasing rates.

*Objective:* Research childhood vaccine education interventions and mediating variables within the target population of parents of unvaccinated children.

*Methods:* Participants will be randomly selected based on unvaccinated status of their child in the vaccination registry databases from Utah, Montana, and Oregon. Four experimental groups and one control group will be observed as to the varying impacts of vaccine health education materials, vaccine web education, and pediatrician counseling on vaccination concerns. The research is a 6 month study with a three year follows up.



