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PARENTAL REFUSAL OF CHILDHOOD IMMUNIZATIONS: STRATEGIES FROM AN ANP PERSPECTIVE

by

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APPROVAL PAGE

This independent study, submitted by Jaime R. Mattson in partial fulfillment of the requirements for the Degree of Master of Science from the University of North Dakota, has been read by a Faculty Advisor under whom the work has been done and is hereby approved.

Faculty Advisor

This independent study meets the standards for appearance, conforms to the style and format requirements of the Graduate School of the University of North Dakota, and is hereby approved.

Dean of the Graduate School

PERMISSION

Title: Parental Refusal of Childhood Immunizations: Strategies from an APN perspective

Department: Nursing

Degree: Master of Science

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Parental Refusal of Childhood Immunizations:

Strategies from an Advanced Practice Nurse perspective

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Abstract

While immunization rates have increased and vaccine-preventable diseases have decreased, we continue to see hesitancy in vaccine acceptance from parents with small or school aged children. Parents have fears and barriers leading to refusal of immunizations for their children, in order to correctly address these fears and barriers we as advanced practice nurses must fully understand them. Parents have rights to their children and without the correct information and correct understanding of immunizations they have the right to refuse.

Key words

The keywords vaccine and immunizations were used in combination with compliance, parental compliance, parental refusal, childhood.

Introduction

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Immunization rates are at an all time high and the rates of almost every vaccinepreventable disease continues to decrease ¹. Even though we are seeing fewer
infections, advanced practice nurses (APN) are beginning to encounter an increase in
parental hesitancy and vaccine acceptance ¹. In 2000, a national survey of 1500 APN
found that over 90% of providers reported at least one parent who refused child
immunizations in the previous year and 69% of providers saw a substantial increase in
patient concerns about immunization safety issues ². With an increasing trend of
immunization delays and parental refusal, the likelihood of an infectious outbreak
occurring today has increased from a decade ago ³.

Parents have fears that create barriers, leading them to refuse or delay immunizations for their children. APN need to understand and address these barriers with hesitant parents to ensure the safety of the child and the public. Immunizations are one of the most important things parents can do to ensure the healthy future of their children. When children are not administered immunizations according to the recommended schedule, they risk never fully completing their immunization course and may fail to receive timely protection from numerous preventable diseases ⁴. The purpose of this paper is to educate APN about parental barriers and fears that are most commonly lead to parental refusal of childhood immunizations. By doing so APN will have a greater understanding and better leverage to address such barriers and help parents make the right decision to vaccinate their children.

Mechanisms of immunization mediated disease prevention

Vaccines protect children by preparing their bodies to fight often serious, and potentially, deadly diseases, while providing immunity against numerous diseases, vaccines also prevent weakening of the immune system ⁵. Vaccinations produce what is called active immunity, this immunity depends on how the body responds to a specific antigen. Within hours of the initial antigen being injected intramuscularly or inhaled and absorbed into the nasal mucosa, the body is able to recognize it as foreign and a primary immune response occurs. When the antigen is seen again, the secondary response occurs which is more robust and rapid. The immunization is designed to stimulate the initial production of antibodies against a specific antigen, allowing immunologic memory to kick in for the secondary response if they encounter the antigen in the future. ⁶. The body has cells of the immune system which recognize and rid of disease causing antigens. These cells consist of lymphocytes, B cells which produce antibodies and T helper cells or cytotoxic cells, which present the antigen and eliminate the antigen-carrying cell, respectively ⁶.

Vaccines are divided into two different types; attenuated and inactivated.

Attenuated, otherwise known as live immunizations, contains a live virus which is weakened, therefore stimulating an immune response without the harsh effects of the actual disease process itself ⁷. Inactivated immunizations, otherwise known as killed immunizations, are exactly as they sound. The virus is inactivated with formaldehyde, stimulating a specific antibody response to the antigen without causing disease.

Inactivated vaccines take longer to work in the body and may require more doses over

time, often delivered via a booster. These specific types of vaccines do not typically cause a physical disease process ⁷.

Immunization schedule

Many parents ask APN which immunizations to give and at which ages to give them. The recommendations for which ages children receive immunizations and the dosages administered are influenced by age-specific risks for disease, complications, ability to respond to immunization, and potential interference with the immune response transferred by the maternal antibody ⁸. The CDC provides recommended immunization schedules for persons age 0-18 years which is approved by the Advisory Committee on Immunization Practices, the American Academy of Pediatrics, and American Academy of Family Physicians. Table 1 depicts the immunization type, ages at which the child will receive each immunization, and number of total doses the child will receive for children ages 0-6 years.

Immunization Schedule (0-18ys)

Immunization Type	Ages	Total doses
DTaP (Diphtheria, Tetanus, & Pertussis) vaccine:	2 months, 4 months, 6 months, 15-18 months, 4-6	5 doses
	years	
Hepatitis B vaccine:	birth, 1-2 months, 6-18 months	3 doses
Polio vaccine:	2 months, 4 months, 6-18 months, 4-6 years	4 doses
Hib (Haemophilus influenza type b) vaccine:	2 months, 4 months, 6 months, 12-15 months	3 or 4 doses
Pneumococcal vaccine:	2 months, 4 months, 6	2 or 3 doses

months				
Rotavirus	2 months, 4 months, 6 months	3 doses		
Measles, Mumps, Rubella (MMR)	12-15 months, 4-6 years	2 doses		
Varicella	12-15 months, 4-6 years	2 doses		
Hepatitis A	12months, 2 doses 6 months apart	2 doses		
Influenza	Yearly			

Table 1:Immunization Schedule (0-18 yrs) US Department of Health and Human Services; Centers for Disease Control ⁹.

Exemption from childhood immunizations

Laws requiring up to date Immunization Exemptions by state immunizations for school or daycare Religious exemption: All states but Mississippi, and West Virginia attendance have greatly contributed to the Personal belief exemptions: Arkansas, Arizona, California, Colorado, Idaho, success of the US immunization status 11. All Louisiana, Maine, Michigan, Minnesota, Missouri, Nebraska, New 50 states allow for medical exemptions, with Mexico, North Dakota, Ohio, 48 states allowing for religious exemption and Oklahoma, Texas, Utah, Vermont, Washington, Wisconsin 20 states allowing for personal belief

exemptions from daycare and school ¹⁰. Exemptions create a greater risk for disease toward not only the child that is exempt but also toward children that have not yet met the age criteria for immunizations, persons with medical contraindications toward receiving immunizations, and those who encounter vaccine failure ¹¹. Many parents that exempt their children from immunizations believe in herd immunity, thinking that as long as others are vaccinated then their immunity protects others. Herd immunity can

only exist if a high proportion of the population is immunized therefore the transmission of the disease is interrupted. The problem with herd immunity is that society cannot rely on the indirect protection by vaccinated members because then community protection unravels as everyone tried to get by on the efforts of those that are vaccinated creating the potential of decreased immunization rates ¹². For this specific reason, compulsory vaccination laws were initiated. This ensures the whole population will receive immunizations, therefore helping and protecting those who are unable to receive immunizations ¹².

Barriers for Parental Refusal

The most significant determinant of whether or not parents will immunize their children is the perception of the dangers the immunization may hold. Therefore, these perceptions increase the concerns and misconceptions parents have regarding immunization safety ¹³. Parents fear the side effects of immunizations which range from mild to severe; mild being tenderness to site, rash, itching, bruising, muscle aches, headaches and fatigue, severe being a severe allergic reaction, seizures, coma and loss of consciousness. Parents' concerns about safety provide evidence as to why it is so critical for all APN to be up to date with the most current information regarding immunizations and be willing to give guidance and education to those parents that are insecure about immunizations with a fair and open mind. Recognizing and addressing parental concerns helps prevent further decline of childhood immunization rates ².

Barriers towards parental refusal generally fall into one of the following categories, fears

toward risks and side effects of immunizations, insecurities toward APN, and ineffective cost measures.

Fears toward risks and side effects of immunizations

Nationwide, almost 25% of parents believe their children receive too many immunizations and the administration of all the required immunizations is not healthy ¹⁴. Many parents have misconceptions regarding childhood immunizations such as the possible links between vaccines and autism or immunization overload. These misconceptions underlie the response of parents to question the perception of vaccinating their children even when many parents do not believe there are risks associated ³. Chronic disease states such as autism, asthma, diabetes, or multiple sclerosis are often an attribute to childhood immunizations and underlie fear for parents. Due to the relationship between the immunization time and the time of manifestation for these disease processes, parents become increasingly frustrated and link the immunization with the disease process that happened to manifest around the same time 15. The new combination immunizations and their potential side effects of immunization overload also produce fears in parents. Many parents believe that these vaccines place an unneeded stress on the immune system which could potentially cause an adverse reaction. When vaccines are combined, this leaves parents and APN without understanding of which component of the vaccine is the culprit ¹⁶.

Antivaccine messages have also induced a different fear into today's parents.

These messages are developed to make parents and APN feel guilty and intimidated for vaccinating their children ¹⁷. With growing antivaccine literature stating that the risks far

outweigh the benefits of immunizations, parents today are often confused with path to choose ¹⁸. Antivaccine activists are also frightening parents with the statements that immunizations cause diseases such as autism, bowel disease, multiple sclerosis, diabetes, and allergies, stating that there is no coincidence between the first symptoms of autism and the series of immunizations containing thimersal ¹².

Insecurities toward APN

Parents are feeling a sense of uncertainty toward healthcare providers regarding the amount of information and education provided to them regarding vaccinations. This uncertainty can be a strong determinant in the decision to immunize their child.

Parents today are feeling that unless they really question the immunizations process or gather information on their own, they enter into immunization process blindly without any knowledge of what could potentially happen to their child.

The role of the healthcare professional is to provide accurate and evidence based information to their patients or patients' families when questions arise. When parents feel that physicians or APN are giving unclear or no information at all regarding the immunization process and the potential side effects, this can create a substantial level of distrust toward APN and the medical community which has the potential to impede parents' decisions regarding the immunization status of their child ¹⁹. Attitudes of health care workers towards parents' decisions regarding immunization are very important factors when discussing immunizations services. Many times parents have been reprimanded severely when wrong practices are used, such as when an immunization is missed or when parents have questions. Parents then become scared or

upset and no longer want to seek immunization services ²⁰. Many parents also state that they feel the APN relay unbalanced and biased information to stress the positive side of immunizations and often discuss in little detail about the actual side effects of immunizations ²¹. There is also the insecurity and distrust that the APN is influenced in their attempt to get parents to vaccinate or that they have specific hidden agendas, including gaining a profit from the sale of vaccines ²².

The feelings of being rushed and APN not having enough time has also been cited as barriers to communication with parents. Many parents address the concern of receiving what they call an "information overload" regarding immunization risks and benefits with little or no time to digest what they are being told before someone comes into the office to give the immunization ²². When parents feel rushed they feel unable to ask appropriate questions or address their specific concerns regarding immunizations. Therefore, they either immunize their child without adequate knowledge or they immunize their child at one specific visit but then they do not return for follow-up immunizations therefore putting their child at risk for vaccine-preventable illness.

Ineffective cost measures

Poverty and near-poverty are enormous barriers toward compliance of childhood immunizations. With the introduction of new vaccines and recommended number of doses for existing vaccines increasing, the cost of immunizations has significantly increased. Since 1994, the Vaccines for Children program (VFC) has provided immunization funds for the uninsured and Medicaid-insured, as not all of

these children have access to their usual health care source and so are unable to receive immunizations free of charge ²³. Although there is some immunization coverage with VFC, cost continues to remain a barrier. Healthcare provider charges are usually not reimbursed by the government, therefore this charge is the responsibility of the parents, insurers, or the providers. Many times parents have to take the day off from work to vaccinate their child. The problem is further exaggerated if distance is a factor. Furthermore, the cost of transportation to the doctor's office can be a factor for families living at or below poverty level ²⁴. With costs a major concern to families, APN need to be organized and educated regarding each patients vaccination status to make the most out of the limited opportunities one may get to provide healthcare to these children.

Strategies to increase Parental Vaccine Acceptance for APN's

Parents who refuse vaccinations for their children have a variety of reasons to do so, including religious, personal, or cultural beliefs. Every APN needs to acknowledge these concerns and allow parents to express their individual concerns in order to develop a growing relationship and increase parent's willingness to listen to options ¹⁵. By trying new strategies daily such as providing parents with reputable resources and providing understandable vaccine information, advance practice nurses will be working together with parents to make informed decisions. It is also important to always keep in mind that parents' trust is garnered through confidence that their child's well-being should be a primary focus in everyday practice ³.

Provide vaccine information

Every APN needs to provide parents with accurate and adequate information regarding the risks and benefits of immunizations, as well as interpret misinformation or misconceptions³. Parental trust is gained through confidence that their child's welfare is in the best interest of the healthcare professional, and the healthcare professional understands and respects the parental decisions regarding immunizations ³. Parents also need to be aware that no vaccine offers 100% protection from disease and that while vaccines are essentially safe, there is a chance for rare adverse reactions which can and do occur ²⁵.

Discussion about vaccine risks and benefits should begin at the first visit to the office or clinic with the goal of educating parents as early as possible in order to establish open communications. At the very first visit, parents can be provided with immunization information packets which should enclose vaccine information sheets for each immunization, a question/concern form for the parents to fill out and discuss at each visit, a handout with detailed information on how to care for a child after he or she has been immunized, and a list of reputable vaccine information websites and resources

Delivering information in a timely manner will not only benefit the healthcare provider but also the parents. One may do this by layering information which entails providing education to parents using handouts, videos and discussion on a continuous basis which helps with information overload ²⁶.

Reputable internet sources

- Centers for Disease Control and Prevention(CDC)-CDC.org
- Immunization Action Coalition(IAC)immunize.org
- American Academy of Pediatrics(AAP)-aap.org

Provide parents with reputable resources

Many parents seek out health care information from sources other than their health care providers, relying on the internet and family members for help, answers and advice.

Unfortunately, parents do not realize that a large proportion of the information that they are

accessing is not evidence based, which means there are no scientific data to back this information up and many times information can be fabricated by its authors ²⁶.

Acknowledging and addressing concerns in a caring manner

It is essential that APN encourage clear and open communication with parents regarding childhood immunizations. Immunization rates have dramatically improved when direct open communication along with a clear discussion of risks and benefits occurs between the parents and APN ²⁷. Parents find that easy communication and trust in the advice of a child's healthcare provider have been two key factors associated with the belief that they have had access to enough information to make an educated and accurate decision about immunizing their child ¹³. The following are guidelines for communicating with parents who refuse to vaccinate their children.

- Be respectful and listen carefully to parents' concerns
- Have an increased knowledge base about the current misconceptions regarding immunizations
 - Take appropriate steps to reduce the pain of the injection
- Implement an appropriate immunization schedule one that benefits the parents and child and minimizes the number of injections at a single visit
- Understand that parents have barriers of cost, work with them to extinguish or minimize that financial barrier
- Be respectful of parents decisions not to vaccinate at a specific time which always leaves the door open for discussion when they are ready

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Responding to Parents who Refuse Immunizations

When an APN encounters a parent who is refusing childhood immunizations, exploring and addressing parental concerns may be an effective strategy and may also help correct any misinformation or misperceptions that exist. The APN should also provide parents with the information necessary to make an informed decision which includes immunization risks and benefits ²⁸. Therefore if after adequate discussion the parent continues immunization refusal, then the parent's wishes should be respected unless there is serious harm involved. Only when significant risk or serious harm is involved should state agencies be notified to override the parental decision on the grounds of medical neglect ²⁸. Good documentation of the discussion with parents regarding the risks and benefits of immunization and the risks of remaining unimmunized can decrease the concerns of a liability; also a waiver can also be signed by the parent and healthcare provider stating intent of refusal to immunization ²⁸.

Consequences

ereserves established

If a substantial level of distrust builds between the parent and the provider, one may suggest or encourage the parents to find another healthcare provider. Providers also have the option of ceasing care though they cannot do so without adequate advanced notice to the parent or legal guardian to authorize another health care provider to be secured. Providers should avoid discharging patients from their care, even though the parent has refused immunizations the child continues to need adequate healthcare. It is during these other visits that a provider continues to build a trusting relationship and is given time for continuing education regarding the importance of immunizations ²⁸.

Updated Information

In January 2011, the scientific accuracy of Andrew Wakefield's conclusion of a link between the MMR vaccine and a "new syndrome" of autism was challenged based upon falsified information ^{29 30 31}.

The report by Wakefield (1998) included a case series of 12 children from which he proposed a "new syndrome" of enterocolitis, and regressive autism, associating these events with the MMR vaccine ^{30 31} there is new information found that patients were recruited by anti-MMR activists. Of the 9 children with supposed regressive autism 3 of them did not have the actual diagnosis, 5 of the children had pre-existing developmental concerns and in the 9 cases that revealed unremarkable colonic histopathology results were stated to have been changed ²⁹. Wakefield's records documented the symptoms of enterocolitis and regressive autism starting months after

the vaccination in all actuality some of the children had behavioral symptoms within days of the MMR vaccine.

Conclusion

Primary health care providers are the best and most reliable source of information regarding childhood immunizations. This underlines the necessity for APN to be well informed and up to date in regards to current parental barriers and be able to relate relevant findings from medical research to parents. Understanding parental barriers and ways to address them will only ease parents' minds and increase the immunization rates for the children of the future. So the next time an apprehensive parent approaches ones clinic to discuss childhood immunizations, remember some of the discussion points of this review and provide reliable information. The children of our future will thank you for it.

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