Improving Vaccination Compliance Among Amish Children in Knox County, Ohio

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#### Abstract

Children living in Amish communities in Ohio are under-immunized and under-immunized communities are reservoirs for preventable childhood diseases. A recent measles outbreak in central Ohio involved 9 counties and 377 cases of this vaccine-preventable disease. There were 5 hospitalizations related to this measles outbreak in Knox County. Vaccine-preventable illnesses contribute to pediatric morbidity and mortality and are cost prohibitive to individuals and society. The purpose of this study was to identify real and perceived barriers to immunizations among Amish parents in Knox County, Ohio. The information obtained in this study will be disseminated to the Knox County Health Department to be utilized to improve vaccination rates among children in these communities. A qualitative research design was used for this study. Criteria for subject participation included parents of Amish children ages 0-18 who live in Knox County, Ohio. Interviews with parents of Amish children explored research questions regarding the current vaccination status of their children, their perceptions of immunization safety, risks, side effects, perceived severity of vaccine-preventable illness, and perceived and real barriers to vaccinations. NVivo software was utilized to analyze the content of the interviews. Qualitative analysis revealed common themes among the interview responses. The findings of this study indicate that concerns about side effects are the most significant barrier to vaccinations among Amish parents in Knox County, Ohio. Identifying strategies to allay concerns related to side effects and other barriers to vaccinations among Amish families will be valuable in improving vaccination compliance among these communities, leading to decreased outbreaks of vaccine-preventable diseases.

# IMPROVING VACCINATION COMPLIANCE AMONG AMISH CHILDREN IN KNOX COUNTY, OHIO Introduction

Most Amish children in Ohio, including Knox County, are under-immunized (Wenger, McManus, Bower, & Langkamp, 2011) and these under-immunized communities are reservoirs for preventable childhood diseases. In 2012, there were 48,277 reported cases of Pertussis in the United States, and many other unreported cases. While most vaccine preventable diseases cause only temporary symptoms of illness, some diseases can be fatal. According to the World Health Organization (WHO) 540,000 children died globally from measles in 2002 (MMWR, 2006). Containing an outbreak of a contagious disease is very expensive. In one estimate, "the cost of containing a single community outbreak of measles could easily run into millions of dollars" (Dayan, Orgtega-Sanchez, Lebaron, Quinlisk & The Iowa Measles Response Team, 2004). This is a relevant public health issue.

#### Background

Amish are a conservative Christian protestant reform group from the Mennonites. The community they reside in is known as their church district. There is a strong focus on family, community, church, and tradition within the Amish culture. Amish families generally do not participate in health insurance or preventive health care. They attend school through the eighth grade, are more interested in folk remedies than traditional medicine and are known to be frugal and pragmatic. As noted by Hurst and McConnell (2010), while Amish are a separatist group, they share features of ethnic groups, including a common history, language, symbols, rituals, and beliefs (p.14). In the Ohio Measles Outbreak Unified Command Report submitted by Richland Public Health, we are reminded that the Amish population in the United States is one of the fastest growing subcultures because of sizeable nuclear families. There are approximately 3500 Amish

residing in Knox County and approximately 33,000 in the central Ohio area involved in the 2014 measles outbreak.

The specific barriers to vaccinations among Amish children are unclear, but may include the administrative fee for vaccinations, poor access to vaccines, lack of transportation resources to travel to vaccine clinics, religious beliefs, fear of adverse vaccine effects, and concern regarding the source of vaccines. Identification of the barriers to vaccines among Amish families in Knox County will enable caregivers to develop strategies to eliminate those barriers and improve vaccination compliance in this area. Previous studies regarding low immunizations rates among Amish families have been conducted in Holmes County, Ohio (Wenger, et al). Wenger et al. concluded that religious influence is usually not the reason for incomplete vaccinations among Amish children as Amish parents will typically allow some vaccinations for their children but not others. This emphasizes the need to further explore barriers to vaccinations among Amish communities.

There are several factors that make it difficult to obtain data on the vaccination status of Amish children in Knox County. Most Amish mothers in Knox County go to a birthing center in another county for the delivery of their children or have a midwife assist with a home delivery. Because of these birthing choices, we lack data on Amish births in Knox County. Amish data cannot be extrapolated from health department data because there is no identifier of cultural diversity in the demographic information at the time of vaccine administration. In addition, there is significant migration of Amish families from one home to another in the same district, from one church district to another, and from county to county or state to state.

Currently in Knox County, vaccines are offered by the Knox County Health Department (KCHD) at the Mount Vernon location 3 days a week. The KCHD also offers a late immunization clinic until 6 pm once a month in Mt. Vernon and from 3 pm to 6 pm once a month in Danville. All vaccination clinics are by appointment only. Two pediatrician offices in Mt Vernon also offer pediatric vaccinations but less than 1% of their patient population is Amish. Childhood immunization efforts are one of the most cost-effective activities in health care, and failure to administer timely scheduled vaccines results in disease epidemics (Turner, Grant, Goodyear-Smith & Petousis-Harris, 2009). , A Colorado study revealed that children exempted from vaccinations were 22 times more likely to develop pertussis than were vaccinated children, (Kimmel, Burns, Wolfe & Zimmerman, 2007). Spratling and Carmon (2010) emphasize the high communicability of pertussis, and the debilitating effects of this disease with symptoms lasting weeks or even months that can prove fatal for infants. A measles outbreak in central Ohio last year involved over 350 people. During the Ohio measles outbreak last year, 45% of the cases involved children and adolescents 5-19 years of age and there were 11 cases of measles involving infants less than 6 months old (McFarren, 2014).

## The Significance of the Problem

Advanced Practice Nurses are filling the gaps as primary care providers in underserved rural settings and they will encounter Amish patients with acute illnesses including vaccine preventable diseases. Nurses are in an excellent position to provide education and answer questions to Amish parents regarding pediatric vaccinations. Advanced Practice Nurses are caring for other patients that may be at risk for the development of vaccine preventable disease, including infants too young for complete vaccinations or immunosuppressed patients. Being knowledgeable about barriers to vaccinations allows nurses to tailor interventions to groups that are at risk for low immunization rates. Nurse practitioners play an important role in educating patients and families about vaccinations, caring for patients with vaccine preventable diseases, and reporting cases to the appropriate health authorities (Spratling and Carmon, 2010).

As a Certified Nurse Practitioner (CNP) in a family practice office in rural Knox County, I provide care for many Amish families. We frequently see intentionally unvaccinated Amish children with symptoms of vaccine preventable illnesses. In most cases, parents decline diagnostic testing unless the child is medically unstable, or there are concerns about illness outbreak.

#### **Problem Statement**

Vaccine preventable disease cause patient pain and suffering and contribute to exorbitant societal and economic costs (Roush & Murphy, 2008). Exploring barriers to vaccines among this population and developing specific strategies to overcome those barriers will improve vaccination compliance and decrease morbidity and mortality among the Amish in Knox County, Ohio.

## **Project Purpose**

The purpose of this research study is to increase the vaccination rates among Amish children in Knox County, Ohio. The specific objectives of the project are to identify parental barriers to vaccinations, develop strategies to eliminate those barriers within this diverse culture, disseminate the study results to the KCHD, and provide the agency with information that will allow the health department to further meet the needs of Amish families in Knox County.

#### **The Theoretical Framework**

The theoretical framework for this project is based on the Health Belief Model (HBM) that was developed in the 1950s by a group of United States Public Health Service social psychologists who were interested in explaining the low participation in programs to prevent and detect disease (Butts & Rich, 2011, pp. 250-251). The HBM is an appropriate model for addressing the relationship between a person's beliefs and their behaviors and is a popular model applied in nursing, especially regarding the dynamics of patient compliance and preventive health recommendations. This model allows investigation into what encourages or discourages people from participating in health programs.

The six constructs of the HBM include: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cue to action, and self-efficacy (Butts & Rich, 2011). The central focus of HBM is health motivation and this study will attempt to identify the barriers to vaccinations among Amish and strategies to motivate vaccination compliant behaviors.

#### **The Literature Review**

A review of the literature revealed most Amish do not subscribe to health insurance, but instead, health care costs are paid first by families and then by the church district in which they are members (Donnermeyer and Friedrich, 2006). Many Amish utilize various folk remedies which are passed down from mothers to daughters and help to maintain the focus on the tradition of family while being considered less costly than traditional medical care.

Vaccinations reduce morbidity and mortality and have been hailed as one of the top ten public health accomplishments of the twentieth century (Jacobson, 2012). Jacobson presents statistics that indicate there were 900 deaths from measles in the United States in 1962 and zero deaths from that disease in this country in 2007. Since the development of the smallpox vaccine by Edward Jenner, fear of side effects from vaccines was the greatest barrier to vaccinations in the past and continues to be the greatest barrier in the present (Jacobson, 2012).

The societal cost of treating or containing an outbreak of a vaccine-preventable disease is high. In one study, (Dayan, et al, & the Iowa Measles Response Team, 2005) 2525 hours of staff time and \$142,452.00 were spent on containment efforts during the 2004 measles outbreak. The cost of the 2014 Ohio measles outbreak was \$217, 675 (McFarren, 2014).

The vaccination rates among Amish have been persistently low and outbreaks of vaccinepreventable diseases continue to occur among Amish communities (MMWR, 2006). Previous studies of low vaccination rates in Amish communities have suggested that poor access to immunizations or religious beliefs may be the most significant barriers to vaccination compliance. Wenger, et al. (2011), however, provided a new perspective with their study of vaccination rates among Amish in Holmes County, Ohio. This study revealed parental fears of vaccine adverse effects are more of a barrier for the Amish, at least in that county, than poor access to vaccines. No studies regarding barriers to vaccination among Amish in Knox County, Ohio have been completed to date.

In a survey exploring parental refusal of vaccines in Wisconsin by Salmon, et al., (2009) they found 57% of parents indicated concerns regarding potential harm from the vaccines, and this was the most common reason noted for immunization noncompliance. Although this study was not specific to the Amish population, the findings are consistent with the findings noted by Wenger et al. (2011).

*The Amish and the State*, a book written by Donald Krabill (2003) provides a chapter contributed by Gertrude Huntington regarding health issues of the Amish. In the chapter she discusses the pragmatic nature of Amish that may contribute to the low immunization rate among these communities. Huntington also mentions fears Amish parents have of adverse vaccine effects and alludes to the anti-immunization materials that are circulated among Amish parents by antivaccine groups. She emphasizes the need for a trusting relationship between the health care provider and the Amish patients and she suggests that easy access to vaccinations and low cost will enhance compliance. Another book, *The Amish Paradox* (Hurst & McConnell, 2010) suggests Amish may not appreciate the purpose of vaccinations and because their parents had vaccine-preventable disease and survived to tell about it they may not fully appreciate the severity of illness that may occur. This reading further suggests the multifaceted dimensions of each barrier Amish parents have about vaccinations.

Researchers studied the effectiveness of current public health promotions to increase vaccination rates, specifically Measles, Mumps, and Rubella (MMR) (Nyhan, Reifler, Richer & Freed, 2014). The results of their web-based research study suggest that the current promotional materials are ineffective in increasing vaccination and may in fact decrease parental compliance regarding children vaccinations. This study did not include Amish parents but still provides thought provoking information about the effectiveness of communications used for promotion of vaccines. In summary, the literature review provided a wealth of information about historic and recent studies regarding barriers to vaccination compliance. Most of the research studies were not specific to the Amish population but are still valuable. Further study is necessary to explore barriers to vaccine compliance and establish strategies to improve vaccination rates, including the population area for this Doctor of Nursing practice project, the Amish communities of Knox County, Ohio.

#### **Project Implementation**

The original qualitative research design plan was to conduct focus group interviews with 8-10 Amish parent participants and to digitally record the interviews. I particularly hoped both mother and father parents would be available for the focus group interviews and therefore, planned to conduct the interviews in the evening at a centrally located venue. Because of the pragmatic unwillingness of participants to go out during winter evenings, it was decided that participation would be better if the interviews were conducted in their homes. I was also informed by one of the matriarchal members of the local Amish community that they were generally opposed to the interviews being recorded. Knowing this could negatively influence participation, a decision was made to record the interviews with pen and paper. Approval was granted from the Otterbein University Institutional Review Board for data collection during home interview with recording of written notes.

Qualitative research methodology involving semi-structured home interviews with Amish parent participants and a discussion of open-ended questions was used for this study. The research design is one of ethnography with a focus on the study of the culture and social perspectives of this diverse group. Ethnology allows investigation into social actions and conditions that influence experience (Munhall, 2012). The research questions were designed to explore understanding of parental beliefs, perceptions and understanding of vaccinations. The participants of the interviews were Amish parents from Knox County with children from birth to 18 years of age. Interview participants were recruited by developing trusting relationships and personal communication with Amish parents through neighbors and patients in the family practice where I work as a health care provider. There were a few instances of chain sampling as interview participants would suggest their neighbor or another family member that may have insightful opinions or experiences to share regarding vaccinations. Demographic data including parental age, number of children and vaccination status of family members was obtained.

Nine interviews were completed during the cold and snowy months of January and February, 2015 and data saturation was achieved. The average number of children per family was 5.8. All but two of the interviews involved both the mother and the father of the family. The interviews occurred in the evening, after the participating family had eaten dinner. Each interview lasted approximately one hour. The families welcomed the researcher into their homes, usually offered a cup of hot coffee, and lit lamps suspended from the ceiling for lighting to accommodate note taking. The smell of kerosene was strong as stoves and lamps were used to offset the cold and dark nights. The children of the family were almost always sitting quietly around the table where we were meeting listening to the adults discuss the topic.

Written consent (Appendix B) was obtained from interview participants after they were provided with an explanation of the study purpose and procedure, and an assurance of confidentiality. The prepared guide of questions was used for these semi-structured interviews. The interviews were recorded verbatim using pen and paper, accurately writing down the verbal responses to the interview questions during the conversation. Neutrality regarding vaccinations was maintained by the researcher during the interviews. Twenty dollars and a thank-you card as a gift of appreciation for participants' time and effort were provided at the completion of the interview.

## Timeline

August 2014	Sept- Dec	January 2015	February 2015	March 2015	April 2015
	2014				
IRB	Revision of	Project	Project	Data	Present
Application	IRB, Project	Immersion and	Immersion and	Analysis,	Final
	Immersion	Implementation	Implementation	Complete	Report
	and			Final Report	
	Completion			and Submit	
	of Research			Final Report	
	Design			_	

#### **Budget Table**

Expenses	Calculation	SRF Request	Additional	Total
			Funding	
Travel Costs	\$220.00	\$220.00	0	\$220.00
Interview	\$180.00	\$180.00	0	\$180.00
Participant Fee				
TOTALS	\$400.00	\$400.00	0	\$400.00

#### Analysis

The documented field notes were transcribed into a word document. The transcripts were systematically analyzed by two researchers for clarity of meaning using content and theme analysis with the qualitative data analysis (QDA) NVivo software. Themes that emerged from the data were described, searching for trends of behavior, opinions, and perceptions regarding vaccinations. Analysis revealed 4 broad themes: (1) personal experiences, (2) attitudes, (3) vaccine knowledge, and (4) access.

## **Personal Experiences**

Comments grouped under the Personal Experiences theme were related to the recent local measles outbreak, the influences of family members, and their personal experiences of vaccinations and vaccine preventable illnesses. A few of the parents interviewed expressed positive experiences with vaccinations: "I grew up with the baby shots, we all got them as kids," "I had vaccines as a child." More prevalent were negative personal experiences: "I never had vaccines," "we just never

got the baby shots," "I had the measles, chickenpox, and whooping cough when I was a child," and "my husband had shots and he still had the whooping cough."

### Recent measles outbreak.

When the measles outbreak began last spring the Knox County Health Department immediately began door-to door Measles, Mumps and Rubella (MMR) vaccinations and established vaccination clinics at satellite sites close to the affected Amish communities. All of the interview participants either had the measles among their family, or knew someone that was affected by measles at that time. Some parents were motivated to get the MMR vaccine after the outbreak began: "We had a little bit of thinking about not getting the rest of the vaccines then the outbreak started so we decided to get the rest," "my ideas have changed somewhat since the measles and I saw how sick some of the grownups especially pregnant women went through with the measles," "we chose to get the measles shots because we saw so many people sick," and "some of the older children chose for themselves to get the measles shot, they said if there is something to prevent it, why not do it?", and "the older boys would have to miss work if they had the measles." One father who had the measles stated "before I would rather have the measles but after the measles outbreak I would get the shots."

Other parents decided against MMR vaccinations during the outbreak: "we just stayed home most of the time," "If you're healthy, you'll probably get through the measles," and "our ideas have not changed about not getting the shots since the outbreak." The measles created parental reflection and query about the vaccine: "we were back and forth about getting the shot," "I did call the local doctor for advice and he said to get the shot," "the outbreak caused a lot of talk, should we get the shot or not," and "when you hear this or that, it's hard to make a decision about shots."

#### Family influences.

Several of the parents eluded to the significance of family influences, either positive or negative, regarding vaccinations: we don't get any vaccinations because of generation to generation

of not getting vaccinations," my mom wouldn't let us take the chickenpox shot," "even today my parents would not touch a shot, they think the shots do more harm than good," and "my parents thinking the shots were bad prevented me from getting the shots for my family." One mother had a positive family influence regarding vaccinations: "I had vaccines as a kid, so got them for our kids."

# Attitudes

Responses coded under the Attitude theme included the participant's personal attitude about vaccinations, expressions of a fatalistic life view, the desire to avoid illness, and feelings of parental responsibility. Attitudes about vaccinations varied from family to family. When mother and father were present, they expressed shared views about vaccinations. Some families were indifferent to vaccinations: "we talked about getting shots, just haven't gotten around to it," If everything is fine, why get the baby shots?" "I never really gave much thought to the vaccines," and "we had not thought about shots until the measles outbreak." One of the mothers expressed concern that if her family had the shots they might actually start an outbreak of an illness. A common belief within the Amish culture is the need to be conscious of the impact your decisions will have on others (Hurst & McConnell, p.234).

The view of some parents was unwaveringly negative about vaccinations: "we think the shots are just as worse as the disease," "most of the reason we don't get shots is that we just don't get them," and "we are opposed to baby shots because we stay away from drugs as much as we can." There were a few optimistic feelings about vaccinations as one father stated: "the majority of people get shots and are just fine." Another father shared that their horses are vaccinated regularly.

The perceived severity of the illnesses vaccinations are designed to prevent influences most Amish parents in their decision to participate in vaccination programs. Comments included: "if the disease doesn't look serious enough, we don't get the shots," "the question we ask is does the good outweigh the bad?" "you have to weigh the pros and cons of getting the shots," and "the seriousness of the disease might change our mind about getting the vaccines." One father commented that "we would do the polio vaccine because polio can affect you for the rest of your life."

#### Fatalistic life view.

Some parents expressed the belief that all events are predetermined by fate and are therefore inevitable: "if we get the measles, we get the measles," and "if the kids get sick without getting the shots, it was meant to be."

# Avoiding illness.

References to avoiding illness for themselves or their children were prevalent among the interview participants: "we socialize a lot and have to stay home for months if everyone is sick," "I don't want my children to get sick," "we don't want them to go through the illness." A father offered that he would get the Ebola and Respiratory Syncytial Virus (RSV) vaccine for his children if these vaccines were available "because it would be good to keep the little ones from getting sick."

#### Parental responsibility.

Amish parents, like most parents from any culture want to protect their children from harm and this is really the basis for their decisions regarding vaccinations. One mother commented that 'if we make the wrong decision, about baby shots, we could never live with ourselves if there was a bad reaction," while another mother questioned "I wonder if the shots will harm my child?" and still another stated "I don't want the children to get sick with something permanent from side effects to the shots."

#### Vaccine Knowledge

The responses under the Vaccine Knowledge theme included ideas regarding how Amish parents are informed about vaccinations, vaccination side effects and alternatives to traditional medicine. There were more interview references to side effects that any other phrase.

Exploring how Amish parents are informed about vaccinations and vaccine preventable illnesses proved interesting but discouraging for this health care provider. Several of the parents

admitted they had little knowledge about vaccinations or the illnesses they are intended to prevent. Several fathers reported they get opinions about vaccines from the drivers that take them to work. Four parents acknowledged they get vaccine information from the KCHD if and when they get shots but don't get any information before the shots. Another mother admitted; "we don't really know much about baby shots," still another stated she'd "like to know what is in the shots." Several parents indicated they read vaccine information published by chiropractors in the local magazine 'Plain Interest' that is distributed in their community. One mother reported her source of vaccine information as "the grapevine, hearsay and the magazine we get (Plain Interest)." Still another mother reported "we have two doctor books and the books say we shouldn't get baby shots," and another also commented that "I read books about health and get information from family and friends," A father reported he has heard information about vaccines from the websites "whistleblowers.com" and "naturalcures.com." A mother expressed concern that "they use fetal tissue to make vaccines."

# Side effects.

Concerns regarding side effects was the most frequently cited barriers to vaccinations during the interviews: "permanent side effects from the shots are our biggest fear," "my biggest concern about the vaccines is that I worry the kids will have a reaction, "we have heard some children have adverse effects, there's always a possibility," "the shots can have after effects," "if a child is run down or not healthy, it can get worse if they have the baby shots," "I'm more concerned about the long term side effects of the shots," and "we hear about people that had sickness from getting the shots."

A few parents had specific concerns about vaccinations and autism and express distrust of medical providers regarding vaccine recommendations: "our biggest concern about baby shots is getting autism or getting side effects," and "I've heard some people have problems with their nerves after getting the shots," "we know about the doctor that wrote the article about autism and wonder if he was paid money to change his story," and "drugs have side effects, someone wrote a book about drug companies, selling their drugs with side effects."

#### Alternatives to traditional medicine.

I have observed, as a CNP in the family practice where I work, that many times Amish patients will come to our office at the recommendation of someone else they've already been seeing for the health problem they are concerned about. Usually this person is described by the Amish patient as a healer, a natural doctor, a chiropractor, or a midwife, and in most cases this person has attempted to cure whatever the symptoms are by using remedies such as salves, supplements, adjustments, herbals, cleanses, and reflexology. So I was not surprised to hear some of the responses regarding vaccinations and vaccine preventable illnesses. Hurst and McConnell suggest the appeal of alternative medical treatments to the Amish "lies in the common sense and understandable manner by which the medical treatments are explained by providers who appear sincere and concerned about their patients" (p 238.).

Comments about alternative remedies included; "if you take an herbal supplement for a month, you won't get the measles," and "we have books with stories about medicine and what home remedies helped people." A young mother whose child I'd previously seen in the office for an acute otitis media shared her story of a recent trip to Adrian, MI with a van load of other Amish parents to see a "natural doctor." She related her experience of having a diagnostic test involving a "cuff applied to the arm which tested them for allergies, he used totally natural techniques." She paid \$550.00 for the test for the family and spent another \$500.00 on the supplements that were recommended by the doctor to cure the ailments he had discovered with the cuff test. She was informed by this doctor that her "son shouldn't get vaccines because his system can't handle the mercury."

#### Access

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The Access theme included responses about cost and transportation as related to vaccination access. Access to vaccinations is a real barrier to vaccination compliance among Amish families in Knox County. While most of the interview participants felt access to vaccines in Knox County was not good and therefore a barrier to vaccinations, there were a limited number of respondents that were indifferent to issues of cost or transportation. "It doesn't make a difference between what makes it easy and what makes it hard to get shots because we just don't get them."

Other parental responses emphasized the inconvenience of needing an appointment for vaccinations: "what makes it hard to get the shots is getting it scheduled, getting a driver and having to go to Danville or Mt Vernon," "what makes it hard to get shots is needing an appointment now," and "what makes it hard to get the shots is the time for it, you need an appointment, we have 7 children." One father stated "it might make a difference if vaccines were free and closer," another claimed he "wouldn't go out of my way to get the shots."

#### Transportation.

Amish mothers are usually home during the day managing the household and children while most fathers work away from the home during the day. Travel for these mothers requires harnessing the horse and buggy or hiring a driver for a fee to take them to the clinic for vaccinations. Interview responses by Amish mothers revealed they are not comfortable taking the buggy to town: "what makes it hard to get the shots is getting it scheduled, getting a driver, having to go to Mt. Vernon or Danville," "I don't often use the buggy to go to town, it's too dangerous on the roads in the buggy," "it's hard to take the children to get shots alone," and "I skipped the shots when they (the children) were little because I couldn't manage it by myself."

The issue of transportation is made easier for some families by having the clinic at the closer Danville site, "having shot clinics late in the day helps us to get the shots," and "some friends that are willing to take us to the clinic."

During the measles outbreak last summer, I assisted with one of the vaccinations clinics and was surprised by the large number of Amish fathers bringing children in for vaccinations, many times without the mother present. One mother explained that the children were frightened when she took them alone for vaccinations and how much braver they were when their father was present. Another mother reported "I'd like their dad to go along with me to get the shots for the 3 boys, it's not easy to go alone during the day."

# Cost.

Most of the parents reported that costs influence their decisions regarding vaccinations: "the shots used to be free, now there is a charge," "it might make a difference if vaccines were free and closer," "the cost is difficult," "the opportunity to have it free like they did when we had the measles outbreak would make it easy for us to get the shots, that helped."

# **Outcomes/Evaluation**

The data gleaned from the interviews provided valuable information about how Amish parents are informed of vaccinations and vaccine preventable diseases and how they make decisions regarding vaccinations for their families. Anderson (2015), describes parental acceptance of vaccination as ranging from the vaccine-acceptor to the vaccine-hesitant to the vaccine-rejecter. The findings of this qualitative research were consistent with those perceptions.

Based on the interview responses we know that Amish parents are generally misinformed about vaccines and some the sources of their information are inaccurate and are not based on evidenced based practice (EBP). The research helps us to understand that Amish parents are motivated to keep their children safe from harm. There is potential to improve vaccinations rates by improving access to vaccinations and customizing clinics to meet the needs of the target population. For the parents who are undecided about whether or not to vaccinate their children, providing clinics that eliminate the barriers of costs and transportation will likely help these parents choose in favor of vaccinations. Extensive literature review and analysis of reports following the local measles outbreak have emphasized the lack of knowledge about Amish culture among medical professionals and health care providers.

Limitations of this research study include a small sample size of interview participants and the possible inaccurate representation of all Amish parents in Knox County. Potential barriers to achieving the project objectives include lack of resources including time, staff, and funding to implement strategies to improve vaccination rates in Knox County. Another potential barrier involves the potential for complacency among Amish and the medical community because of the recent measles outbreak, the number of vaccines administered at that time, and the number of persons affected. There were 12,111 doses of MMR administered during the 2014 measles outbreak.

When I began this project in 2012, before the outbreak of measles in this community, I aspired to impact the Amish families we see in our family practice in Fredericktown. A challenge for me associated with this project was the effect the recent measles outbreaks had on the thoughts and perceptions of the population of interest. Additionally this subject has become much more a topic of politics, religion, morality, and personal autonomy and the information available for review is overwhelming. It was challenging for me to keep the perspective of the study on the purposes I had initialed identified.

#### Recommendation

As health care providers working with this diverse population, we should provide patient education regarding complications of vaccine-preventable diseases such as the potentially fatal neurologic complications associated with measles including encephalitis and Subacute Sclerosing Panencephalitis (Buchanan & Bonthius, 2012). Furthermore, the establishment of trust relationships with Amish parents and providing education in simple, friendly, but consistent ways will help to eliminate some of the barriers of mistrust and lack of vaccine knowledge. The antivaccine groups are getting their message out and the medical professional and agencies promoting vaccines need to be creative in getting their therapeutic message out in a manner that is not intimidating, threatening, or authoritative. An approach of providing education in easily understood language while establishing a relationship of trust, transparency, and respect as suggested by Lang (2014) will prove valuable in the development of strategies to improve vaccination rates among Amish children in Knox County.

Ideally a mechanism of identifying infant births in Knox County and contacting the parents about vaccination schedules can be developed. Furthermore, providing clinics in the evening, close to the Amish communities, and without costs are strategies that will eliminate barriers of cost and transportation.

Specific training for medical professionals regarding Amish culture will enhance their knowledge and enable them to confidently and effectively educate Amish parents about vaccine preventable diseases and maintaining health for their family. The information gained from this study will be used to create change in my current practice. I have strengthened my efforts to make education of EBP vaccinations guidelines more available to the Amish families as well as initated discussions regarding vaccination myths. This is consistent with the goals of qualitative research, as stated by Isaacs: (2014) "the ultimate goal of qualitative research is to transform data into information that can be used."

#### Summary

By understanding the barriers to vaccinations among Amish parents and addressing their concerns, while displaying genuine interest in their families and utilizing knowledge based on scientific data, there is potential to improve vaccination rates among Amish children in Knox County. Through collaboration of medical professionals in the community, this potential may be realized.

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# Appendix A

# **Consent for Participation in Interview Research**

**<u>Purpose of the Research</u>**: The purpose of this study is to explore barriers to baby shots among Amish parents in Knox County.

**Procedure**: If you participate in this research you will be interviewed during a casual discussion about baby shots. The interview will take approximately 60 minutes. A written record of the interview will be completed by the researcher. The researcher will ask questions and lead the discussion. **Your participation is completely voluntary. You may choose not to answer a question and you may choose to withdraw from this study at any time without penalty.** 

**Benefits and Risks:** Your participation in this research may benefit you and your family, other members of your community, and society by helping the researcher and the local medical community to understand perceptions about baby shots. There are no anticipated risks associated with this study.

**<u>Confidentiality</u>**: Your confidentiality will remain secure. No study participant identity will be disclosed in any reports or documents that are created as a result of this research.

**<u>Consent</u>**: By signing this consent form, you are indicating that you fully understand the above information and agree to participant in this interview.

If you need further information or have questions about this research, please contact Laura Segraves at 740-398-0274.

Participant's Signature: \_\_\_\_\_

Participant's Printed Name: \_\_\_\_\_

Researcher's Signature: \_\_\_\_\_

Date: \_\_\_\_\_

# Appendix B

## **Interview Guide**

- 1. Have you thought about baby shots for your children?
- 2. Tell me what you think about baby shots?
- 3. What are your greatest concerns about baby shots?
- 4. Have your opinions about baby shots changed since the recent measles outbreak in Knox County?
- 5. What has prevented you from getting baby shots for your children in the past?
- 6. What makes it difficult for you to get baby shots for your family?
- 7. What has made it easy for you to get baby shots for your family?
- 8. If your children had baby shots, why have you chosen to get them?
- 9. Where do you get information and advice about baby shots?
- 10. Do you know anyone who has had a bad side effect

from baby shots?