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Lee Honors College

Vaccine Refusal Dilemmas Yessica Garcia Western Michigan University Bronson School of Nursing

Abstract

The topic of the thesis is vaccine refusal dilemmas. The focus is on the current issue of the decreasing immunization rates in children. Children are a vulnerable population and rely on their parents to make healthcare decisions for them. This thesis will address the parents' standpoint on immunizations, the providers' standpoint on the situation, and the sources of vaccination information available, then determine vaccine refusal dilemmas that may result. The main population of focus will be pediatric patients including their families and their providers. Dilemmas associated with vaccine refusal and/or hesitancy will include present and existing issues as well as possible and future problems that may be seen. This thesis will also cover possible ethical dilemmas that may come into play when the physician chooses to discontinue care for a client who is not vaccinated.

Vaccine Refusal Dilemmas

The autonomy given to the public in regards to vaccinations is a hot topic. Vaccinations are considered a form of primary preventative care. This means that their intent is to protect against diseases and stop them from manifesting. The term vaccine-preventable diseases is meant to showcase that we now have the ability and resources to prevent many once potentially life-threatening diseases. However, in recent years we have begun to see an increasing amount of parental vaccine refusals and consequently, a resurgence in deadly diseases that had almost been completely eradicated. Vaccination recommendations are evaluated and updated by the Centers for Disease Prevention (CDC). They have designed a recommended immunization schedule for children under the age of two years. As minors, children do not have the power to decide whether or not to receive the required vaccinations, therefore the decision belongs to their parent or guardian. Children, by definition are considered a vulnerable population. The parental and provider standpoint will be addressed as well as alternative sources of vaccination information.

Literature Review

Parent Standpoint

Vaccinations have been around for many years. However, the adherence to vaccinating has fluctuated over time. The Healthy People 2020 goal is to, "increase immunization rates and reduce preventable infectious diseases" (Office of Disease Prevention and Health Promotion, 2018). In 2016, Michigan was reported to be at 70.2% of vaccination coverage for children aged 19-35 months receiving the recommended combined 7-vaccine series (Centers for Disease Control and Prevention, 2018). Michigan fell below the 2015 reported national average of 72.2% vaccination coverage, and below the Healthy People 2020 goal of 80% (Office of Disease

Prevention and Health Promotion, 2018). To address the dilemmas that may result from parents making the decision not to vaccinate their children, their reasoning must first be explored. There is a plethora of literature that addresses the reasons parents give for denying or hesitating to vaccinate their children. Vaccine hesitancy can be defined as, "an intent to skip or delay at least one of the vaccines recommended by the Advisory Committee on Immunization Practices (ACIP)" (Suryadevara, Handel, Bonville, Cibula, & Domachowske, 2015). Parents have given various reasons as to why they have opted out of immunizing their children and most of them fall under the category of safety, distrust, and lack of effectiveness. Parents are required to give consent for vaccinations making children vulnerable to acquiring a preventable disease.

Parents have expressed concerns regarding the safety of the vaccinations given to their children. The hesitancy and concerns relate to the combination of vaccinations per dose as included in the CDCs recommended immunization schedule. In 1995, there were 15 vaccinations recommended for children under the age of two which provided protection against 9 diseases. Since then, in 2015, the recommended vaccinations has risen to 24, all of which protect against 14 diseases (Salmon, Dudley, Glanz, Omer, 2015). Parents have spoken about the safety of vaccinations in regards to the amount of vaccinations given to their children (Williams, 2014). There are parents that believe this combination of vaccinations is unsafe and that it may increase the possibilities of an adverse reaction when the ingredients in one vaccine interact with those of another. There has also been commentary regarding a faulty study linking autism to vaccinations. Although the study was removed from publication and there has been no proven link between autism and vaccinations, parents still have this concern (Bowes, 2016). However, vaccine approval goes through a very strict and carefully monitored process. Vaccines must be approved by the U.S. Food and Drug Administration (FDA) and even after they are approved,

they continue to be monitored (Centers for Disease Control and Prevention, 2018). The Vaccine Adverse Event Reporting System (VAERS) is a resource for parents because it keeps track of any adverse events following vaccinations. It has been used since 1990 but its major flaw is that not all of the reported adverse effects are necessarily a direct cause of the vaccination itself (Shimabukuro, Nguyen, Martin, DeStefano, 2015). The potential for misinterpretation can lead to an increase in safety concerns on behalf of the parents.

There are many sources of information about pediatric immunizations, unfortunately, they do not all share the same credibility. This mismatch in information has contributed to the distrust parents have expressed. There is also distrust between parents and providers when there is not a good relationship. If the parent does not believe the provider has his/her child's best interest at heart, then there is more likely to be a distrusting relationship. A poor relationship may be the result of inadequate patient-provider communication (Chung, Schamel, Fisher & Frew, 2017). Providers are a major influence when it comes to the recommendations of vaccines. However, a providers' own vaccination may be a contributing factor towards vaccine hesitancy because they are more likely to recommend vaccinations if they are also vaccinated whereas providers who are not vaccinated, will be less likely to recommend certain immunizations (Collange, Verger, Launay, & Pulcini, 2016). This could negatively impact the parents' decision to follow the providers' recommendation on vaccinating their child. There has also been reported distrust towards the vaccinations and towards the governing body who has imposed the recommended immunization schedule for children (Williams, 2014). Over the years there has been a decline in the overall public trust towards the U.S. government. Parents trusting the government to do what is right always or most of the time declined from 73% in 1958, down to 39% in 1997 and only 19% of parents reporting they trust the government in 2013 (Lee,

Whetten, Omer, Pan & Salmon, 2016). Evidence-based information about vaccinations comes from the CDC, the ACIP who makes the vaccination recommendations, and other government agencies (CDC, 2018). These sources may not be effective for parents who have distrust towards the government. The change in the vaccination schedule to fit the increased number of vaccines required for children for school entry is another reason that parents have distrust towards the governing body and vaccinations (Lee et al., 2016).

The questioning of whether or not vaccines are truly effective has emerged in recent years. When people believe a vaccination is not effective, they will be less likely to vaccinate their child (Williams, 2014). Questioning the effectiveness of a vaccine can be a red flag because it leads to questioning the necessity of the vaccination itself. The vaccines that children receive are a form of preventative care for many diseases that were once deadly. Since the diseases are no longer a threat to us today like they used to be, many parents are unaware of how deadly those diseases once were. This has caused a shift from parents fearing the diseases years ago when they were prevalent, to the fear of possible adverse effects of vaccinations (Salmon et al., 2015). Others believe that their child's immune system can be just as effective as the vaccination without needing to be exposed to the vaccine (Williams, 2014). Influence on vaccine effectiveness has been seen from the practice of Complementary and Alternative Medicine (CAM). CAM practitioners such as chiropractors have stated to parents that there are other methods to strengthen a child's immune system, such as through nutrition and manipulations (Gilmour, Harrison, Asadi, Cohen, & Vohra, 2011). This also leads to the belief that alternative methods provide the same effectiveness as vaccines.

Regardless of whether or not it is believed that the parents have a legitimate claim towards a vaccination, it must be addressed. It is the role of the parent to make health decisions

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for their child. This marked responsibility to do what is right and best for their child puts increased pressure on the parents. It is important to decipher and find out the reasoning behind a parents decision not to vaccinate their children in order to provide them with the accurate information to make an informed decision.

Not all parents hold a strong anti-vaccination view. A majority of the parents are actually considered to be vaccine hesitant, and this group continues to grow (Capurro et al., 2018). Since the first vaccination available, parents have had hesitation and doubts. A huge influence on this view in the early 2000's stemmed from a faulty study in 1998 linking the MMR vaccine to autism. After that study was heard by the public, the anti-vaccination movement along with nonmedical school exemptions, increased (Omer et al., 2017). This connection, although non-existent and disproven countless times, is still embedded in the minds of parents. Parents continue to question the safety of vaccinations, while expressing their frustration when they do not receive the answers they are looking for. Parents who are vaccine hesitant may not feel confident enough to ask vaccine related questions, and when they do, they are unsatisfied with the amount of time their provider spends with them discussing the vaccinations (Leask, & Kinnersley, 2015). The communication is found to be inadequate and dismissive.

Provider Standpoint

Providers and health care professionals can play an important role in whether or not a parent chooses to vaccinate their child. Health care professionals are highly trusted when it comes to vaccination education, and parents often base their decisions on the recommendations their provider has given them. However, tension can arise when this is not the case. Sometimes the values of the family differ from those of the provider on the topic of vaccinations. Some providers express frustration when parents choose not to follow their recommendations. Others express concern that non-immunized children can expose other patients to disease (Gilmour et

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al., 2011). Providers have dismissed parents from their practice for choosing not to adhere with the CDCs recommended immunization schedule (Jones, et al., 2017). There has been a debate on whether Pediatricians should or should not dismiss parents who do not vaccinate their children because of the dilemmas that may result. Pediatricians dismiss parents based on two major claims, the first being that unvaccinated children pose a risk to those who are immunocompromised, too young to be vaccinated, or cannot receive a vaccination for another medical reason. The second claim is that the patient-provider trust is broken if the parents are unwilling to follow the recommendations the pediatrician gives them (Alexander, et al., 2016).

Providers are advised to maintain and keep the relationships with the families who choose not to follow the routine vaccination schedule for their child because they are still responsible for providing care to the patient in other areas. Unfortunately, due to these differences, some pediatric providers have chosen to dismiss families from their practice due to the belief that severed trust in the provider-patient relationship will impact future recommended care on behalf of the provider (Jones et al., 2017). Parents who are referred to as vaccine hesitant, are already less likely to visit their provider for primary care than those who adhere to the routine vaccination schedule (Jones et al., 2017). When the relationship between vaccine hesitant parents and their providers is terminated, it may make them more reluctant to establish a relationship with another provider.

The communication between the provider and the patient is a very important key factor. The conversation that a provider has with their patient when addressing vaccine concerns and reasons for not vaccinating may be a determining factor in the parents' final decision. Parents who were hesitant were more likely to report knowing a friend or family member who had experienced adverse effects from vaccines or who had also refused or delayed vaccinations (Chung et al., 2017). Since vaccine refusers or those who are vaccine hesitant may anticipate a difficult discussion with the provider, it is crucial for the provider to use effective (or therapeutic) communication to address the patient concerns (Collange et al., 2016). Although communication about vaccinations and vaccination risks is important, the patient visits are brief and reimbursement for vaccination education is insufficient which leaves little room to effectively discuss vaccinations and the parents' concerns (Salmon et al., 2015). Little is known about what happens after providers dismiss patients from their practice and the impact that it could have for patients on future interactions with other health care providers.

Alternative Resources

Information about vaccinations has many origins and not all of the sources share the same credibility nor trustworthiness. Each parent has different sources of information including family members, friends, health care professionals and the internet or social media. Vaccination information may even vary between health care professionals such as those who practice (CAM) (Collange, et al., 2016). Parents, who refuse vaccinations or were hesitant, reported getting vaccine information from the internet or a spouse/partner at a higher rate than parents who were not vaccine hesitant (Chung et al., 2017). It may even be easier to do a quick online search to gather and form their own opinion about vaccinations. Since the topic of vaccinations has been increasingly researched, there are a lot of results that will appear if parents did a search online. In fact, a parent who searches for vaccine risks will encounter 3.6 times more vaccine myths per website than a parent who uses neutral terms to conduct the search (Ruiz & Bell, 2014). Unfortunately, just because there is more information available online, does not mean it is true nor accurate. Many of the pro-vaccination pages are often authored by medical professionals or medical organizations in contrast to the majority of anti-vaccination pages that tend to be more

opinionated in nature (Sak, Diviani, Allam, & Schulz, 2016). This could be misleading and frustrating for parents when they find opposing arguments equally convincing on the internet.

Searching for information online can be cheaper, faster, and provide a sense of autonomy for the parents. Ultimately, the decision to choose to vaccinate their child or not belongs to the parent or guardian responsible for that child. When they receive information about vaccinations from a health care professional, they may not always understand the information given to them. On the other hand, if they do a quick search online, they will keep searching until they find something that makes sense. The way that information is presented to the parents is important because health literacy can impact their ability to engage in their child's care (Rowlands, 2014). As accurate as the data supporting vaccinations is, it will not make a difference if the parent does not understand the terminology. The information should be presented at a 7th grade level because health literacy can be more complex (Sak et al., 2016).

Another source of information for vaccinations that has become increasingly utilized by the public, is social media. YouTube, to be specific, is widely utilized for health care related searches (Madathil, Rodriquez, Greenstein, & Gramopadhye, 2015). Due to its large audience, YouTube has a lot of power and influence to sway parental beliefs towards vaccinating their children. Its increased usage can lead to misinformation, especially because the majority of vaccination informative videos are emotionally charged with little to no scientific evidence to support their stance (Basch, Zybert, Reeves & Basch, 2016). There are still videos on YouTube that support the faulty study of a link existing between vaccinations and autism long after it has been disproved, revoked and removed. This misleading information can negatively influence parents to take an uninformed stance towards vaccinations.

Implication for Practice

When making the decision to not vaccinate a child, the dilemmas that result may be faced by the child, the parent, the provider and the community as a whole. Vaccinations continue to be a popular topic in discussions because there are many views on the matter and the potential for deadly consequences is unsettling. The development of vaccinations have improved the survival rates of children in the 20th century, increasing life expectancy (CDC, 2018). However, the risks of not vaccinating have become more evident as diseases are reappearing. There have been recent outbreaks of measles and pertussis, both of which can have devastating effects to the vulnerable infant population due to their highly contagious nature (Chung, Schamel, Fisher, & Frew, 2017). The outbreaks that this country has seen in recent years could have been prevented. In the year 2000, the United States declared that measles was no longer endemic meaning that we no longer had the disease circulating throughout the population (Smith, n.d.). However, as vaccination rates continued to fall far below the needed 96% child vaccination to maintain herd immunity, our population was left vulnerable and more susceptible to an outbreak (Bowes, 2016).

In 2014, a single unvaccinated person traveled abroad to the Philippines and contracted measles. This person then infected over 100 people, all of which spread to 17 states (Smith, n.d.). This outbreak in 2014, known as the Disneyland outbreak led to 668 cases of people exposed with only 23 actually being diagnosed with measles (Smith, n.d.). Although, measles was no longer considered endemic in the United States in 2000, the same could not be said for other parts of the world. In the 20th century, travel has become easier, but with it, so has the ability to spread and contract diseases. Not only did we contract measles by an outside source, in this case it was the trip to the Philippines, but we also spread the disease. This outbreak reached our northern and southern neighbors, Canada and Mexico. In fact, the province of Quebec, who

has low vaccination rates, reported 159 people to have been infected and sickened (Capurro, Greenberg, Dubé, Driedger, 2018).

All children in the United States, and in several U.S. Territories are required to be vaccinated with the MMR vaccine dosage (Bowes, 2016). This requirement for kindergartners is put in place to support the high vaccination rates needed for herd immunity to indirectly provide protection to those who cannot be immunized. Despite these recommendations, there are vaccine exemptions that vary by each state. Vaccine exemptions fall into two categories, which include exemptions due to medical reasons and exemptions due to non-medical reasons. The medical reasons include children who are unable to receive immunizations, and the latter includes religious beliefs and personal or philosophical beliefs (Omer et al., 2017). Interestingly enough, after the measles outbreak in Disneyland, California made a major policy change. They went from allowing all medical, religious and philosophical exemptions prior to 2015, to eliminating all non-medical exemptions (Bowes, 2016).

When parents speak out with the claim that choosing to vaccinate their child or not is an individual decision and a right that they have, they are not treated with the same level of respect. However, the question still remains: Should this be an individual choice when the consequences have the potential to impact the entire population? The opposing views each have their reasoning and although the pro-vaccine supporters have taken a community and public health approach, parents' views and concerns should be addressed in a respectful manner (Bowes, J. 2016). If these concerns are not adequately addressed, there may be an increase in the parents' anti-vaccination standpoint.

The duty of a provider is to implement the best care for the child, and if they feel they cannot do so because of the opposing views or compromised safety to others, they may take the

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action to dismiss that family (Leask, & Kinnersley, 2015). However, this action may be more punitive than therapeutic or helpful for the family and the child. Although the process of dismissing families from practice includes referring that family to another physician, families have simply disappeared from the practice (Alexander, et al., 2016). This is troublesome because dismissal of the family for being vaccine-hesitant will not increase the odds that they will immunize, and that child will no longer be receiving all other non-vaccine related health care. The communication about vaccinations that providers have with parents is not ideal, but it is important because it is a community wide intervention (Leask, & Kinnersley, 2015).

To encourage vaccinations, providers must self-reflect on their own views and biases towards vaccine-hesitant parents. The attitude and the view of healthcare providers towards parents who choose not to vaccinate has been shown to impact the effectiveness of the vaccine recommendation and implementation (Survadevara, Handel, Bonville, Cibula, & Domachowske, 2015). Parents have the right to be autonomous and make the decision for their child to follow the recommended vaccine routine or not. In fact, it is rare that parents choose to opt their children out of all vaccinations entirely but rather to request an alternative schedule (Jones, Carter, Cameron, & Smith, 2017). Providers must have different, individualized approaches for addressing the concerns of each parent. They may have a better outcome when encouraging vaccinations through the use of open dialogue, personalized education and presenting information at the literacy level of the patient (Williams, 2014).

To address the safety concern for immunocompromised patients, there are precautions that can be taken to protect those children from being exposed to disease. Precautions could include having the unvaccinated child wear a mask at all times in the waiting room, asking the child and parent to wait in the car until an examination room is ready, or having the examination rooms set up so that an immunocompromised child does not go into the same room as a nonvaccinated child (Alexander, Lacy, Myers, & Lantos, 2016).

Conclusion

Parents have the autonomy to decide if their child receives the recommended vaccinations as outlined by the CDC. There are many views that differentiate in regards to vaccinations from the standpoint of the parents and the providers. Vaccinations have increased life expectancy and significantly decreased the risk of contracting once deadly diseases. Immunization rates have decreased in recent years and with it, a surge of dilemmas. The topic of vaccinations is important, but it is one of many that contribute to the overall health and wellbeing of the community. Physicians care for patients everyday who have different beliefs, values and practices. Patients do not always follow the recommendations a provider gives them such as smoking cessation and healthy nutrition (Alexander et al., 2016). This is similar to parents who hold different beliefs about vaccinations and parents who choose not to follow the providers' recommendation to immunize their child. There are many dilemmas that can result from parental vaccine refusal, but dismissing families from practice will not amend nor bridge the gap for those same parents to understand the providers' standpoint. It is important to keep those lines of communication open to better understand the concerns that parents have regarding vaccinations.

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