When Beneficence Confronts Non-Maleficence: Reconciling the Bioethical Challenges of Doing Good and Avoiding Harm in Risk Communication

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Thesis submitted in partial fulfillment of the requirements for the degree of Master of Arts in the Department of Bioethics & Science Policy in the Graduate School of Duke University

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ABSTRACT

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Abstract

Risk communication is critical to the patient-provider relationship that informs the health outcomes of patients. Healthcare providers (HCPs) often employ this form of communication when informing patients about their treatment choices. This collaborative process often informs the process of shared decision-making in which patients and HCPs work together to preserve the interests of the patient and attempt to maximize the benefit for the patient. Both parties consider both the patient's values and preferences as well as scientific evidence during the decision-making process. Much of the existing literature identifies the roles risk perception and risk communication theory play in how people disseminate, process, and use information.

This paper explores the intersection of the disciplines of risk perception theory, risk communication theory, and the ethical principles central to medicine (i.e. beneficence, non-maleficence, autonomy and justice), specifically as they relate to measles, mumps, rubella (MMR) vaccinations. HCPs often find that their obligation to uphold these principles may be difficult as they often conflict during healthcare delivery. Furthermore, these principles may conflict when communicating the risks and benefits of vaccines. Using the MMR vaccine as a case study, this paper is an ethical analysis based on bioethics principles of HCPs and their communication of the MMR vaccination, with recommendations for future communication that could result in improved clinical decisions and health outcomes. Included in this paper is an inspection of the risk perceptions of parents who are responsible for their children’s health decisions, varying attitudes and behaviors toward the vaccinations as well as the meaning of the bioethical principles in the context of risk communication guidelines.

The novel contribution of the paper is a proposed resolution for minimizing the conflict between the aforementioned principles during communication. Communication templates were developed based on different parental positions about the MMR vaccine. These templates will ideally facilitate communication between HCPs and patients and inform the shared decision-making process. HCPs will become more aware of the role ethical principles play during communication and ideally strive to uphold them while treating patients. Most importantly, the research, analysis, and recommendations will enhance the clinical decision-makers’ understanding, experience, and level of confidence. Additionally, information provided in this paper support clinical decisions that have direct impact on patient health and public health.
Dedication

I dedicate my thesis work to my family. I appreciate all of the many acts of kindness you have shown during my time in graduate school. I also dedicate this thesis to my friends and church family. Your prayers, tokens of love, and phone calls have undoubtedly shaped this accomplishment.

A special note of gratitude to my compassionate grandparents who have always supported me and continued to ask about my progress on the thesis. Thank you for showing me how perseverance and tenacity always pay off. To my loving parents: your sacrifices and words of encouragement were especially helpful during the long nights where I needed an extra push of patience and strength.

The words, “do good, be good,” rang in my ears many nights, dad. Thank you for those short, yet meaningful words and for always supporting me.

I give special thanks to my biggest cheerleader, my heroine: my mother, Machelle Sanders. Though I faced a difficult health challenge in the beginning of graduate school and later while trying to complete this thesis, you always reminded me of what is now one of my favorite scriptures. Proverbs 3:5-6, “Trust in the Lord with all thine heart; and lean not unto thine own understanding. In all thy ways acknowledge him, and he shall direct thy paths.” Thank you for being my strength here on earth.

A special note of dedication also goes to my best friend, my other half, my twin sister; Robyn Sanders. You have been with me through successes and failures and every moment is “doubly” better because you are there.

I would like to dedicate this thesis to four healthcare providers who have shaped my overall well being: Dr. Robin Koeleveld, Dr. Rhonda Gabr, Dr. Loren Robinson, and Dr. Daniel Sheras. You all have been instrumental in providing a helping and healing hand during my times of need. I hope my work will provide some insight into the profession that you all love.

Lastly and most importantly, I dedicate this thesis to my Lord and Savior Jesus Christ who has been my strength in weakness and my peace during the challenging and tumultuous times. I pray that this work will help healthcare providers in their daily role of serving those in need of care and healing.
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I. Introduction

Bioethics and communication intersect in patients’ risk perceptions, clinical decision-making, and health outcomes. Communication between patients and healthcare providers (HCPs - mainly doctors and nurses) is an important component of the administration of care. Over the past few decades, the relationship between patients and HCPs has shifted from decisions made primarily by HCPs to a more collaborative and patient-oriented approach — a mutual communicative process between patients and HCPs in their quest to reach informed medical decisions. Such shared decision-making is significantly influenced by patients’ perceptions about the risks and benefits of clinical-care options.

Although such communication has begun to change the doctor-patient relationship, patients are still often confronted with the “complexities of life, illness, and death and the frustrations of an inability to deal with these concerns.”¹ As a result, patients often still defer to HCPs in making medical decisions. While there is considerable flexibility in how patients and HCPs define their relationships, HCPs always have the responsibility to engage patients in effective participation in the decision-making process. Patients may understandably find communicating and deciding on medical choices to be difficult, not only because they lack the expertise of HCPs, and the choices are complex, but also because patients may be upset about the illness they face and the potential side effects of

the medical treatment options. Yet patients do want to participate in the process of reaching such a decision.²

Vaccines have recently stirred debate about patients’ choices and their communication with HCPs. Vaccinations have notoriously been controversial treatment options.³ The decision to accept or reject a vaccination (for oneself or a child) may be based on the patient’s understanding of the potential risks and benefits associated with the vaccination — which may be influenced by the communication between patients and HCPs.

Recently, a measles outbreak in California reignited the controversy over patient adherence to receiving vaccinations. This thesis provides an ethical analysis from a bioethics principle-based perspective of HCPs in their communication of vaccinations. Additionally, it will address how communication between patients and HCPs can be improved to foster better decision making about vaccines, and the measles vaccine in particular.

At the crux of the recent measles outbreak is the question of how HCPs should communicate with patients about vaccine choices. There are four dimensions or features of this problem: parents’ requests may not align with what is in the best interest of the child (patient), perceptions versus quantitative estimates of risk and benefit to the child is not the same as the risk and benefit to society, variation across patient populations (different risk profiles), and describing the benefits for both the patient and others of getting


vaccinated. Some patients (typically a minority) find mandatory vaccination policies troubling amidst a clinical reality of limited options and even if they are informed about the benefits of the vaccine. Many of the disapproving sentiments of the measles vaccination diverge from those of the scientific and medical communities in that they are based on scientifically undemonstrated effects.

If some patients refuse vaccines, other members of the community (such as those who cannot be vaccinated because they carry other health conditions) can be at risk of an outbreak. Most HCPs, therefore, favor near-universal vaccination and seek ways to overcome these patients’ resistance. But it can be difficult to prod a worried patient (self or child) to be vaccinated in order to provide benefits to the community as a whole. HCPs generally cannot or will not exert outright coercion, and are unsure what combination of communication, incentives, and penalties can best encourage sufficient percentages of patient communities to get vaccinated to prevent disease outbreaks. Consequently, HCPs bear the challenging responsibility of balancing the ethical principles of non-maleficence (do no harm) and beneficence (do good) when communicating about patients’ vaccine choices. These principles can often be in conflict when communicating about treatment decisions, specifically when addressing vaccine risks.

This thesis addresses how HCPs can better fulfill both of these ethical principles in communicating with patients about vaccine risks and benefits. Beyond the legal requirements of informed consent which include, “disclosures that give the patient an un-
derstanding of his or her condition,” and an appreciation of [the risks and benefits of treatment options, as well as the consequences of the condition treated and untreated],” this paper will address the difficulty that HCPs face in discussing such consequences (risks and benefits) in a manner that is in accordance with their duty to both the principles of non-maleficence and beneficence. There are two versions of this conflict that will be addressed in the paper. One case is how HCPs communicate with a patient if the harm and benefit of the vaccine are described in the context of just that patient, and the other case is how HCPs should communicate about the vaccine if the harm is to the patient, but the benefit of the vaccine is to other children. While these are two important versions of the conflict, the more tractable conflict is where the parent exaggerates the risk to their children, while the latter dilemma is the acutest. Each dilemma requires different communication strategies.

Informed consent can be incomplete, or illusory if patients’ perceptions of risks and benefits diverge from what HCPs think they are communicating to patients. When patients are unsure about their treatment choices, the social benefits of vaccination are large, and the health risks of vaccination are probabilistically small (but not zero), should HCPs downplay these risks by assuring patients that the vaccine is “safe”? Does the principle of beneficence suggest that HCPs have a responsibility to promote vaccines for the benefit of the larger patient community, despite opposition from a smaller subset of that community (and small but non-zero risk to each patient)? Or does the principle of non-

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maleficence require HCPs to inform patients of the small risk of the vaccine, even though patients’ perceptions of that small risk may be amplified? This snapshot of ethical inquiry potentially positions HCPs susceptible to impractical applications of the codes of medical ethics in the context of discussing such choices. Conventional medical ethics may not resolve this dilemma. Are there better ways for HCPs and patients to communicate about these risks and benefits?

Ideally, decisions about vaccination should be reached through HCPs’ and patients’ mutual participation in a shared decision-making process. However, that vision may be idealistic because perceptions and cultural biases on both sides may distract from effective communication and sound decision-making. Furthermore, the “practical constraints created by 15-minute visits and competing demands, (e.g., patient’s chief complaint and institutional needs),” as well as the fact that these conversations often occur in contexts that are stressful for (at least) the patient, can make shared decision-making elusive. Dialogue is premised on both parties sharing in the conversation, including the scientific findings, opinions, and values. Consequently, both parties are liable to “misunderstandings and confusions, false hope or despair, unvoiced fears, anxiety, and questions.” A closer inspection of the common pre-existing social influences on patients is discussed later in the paper. These considerations contribute to how each party delivers and interprets the information presented during communication.


This thesis will examine the challenges associated with how HCPs should communicate with patients about measles vaccine choices, with an aim improving communication. It will address both the ethical principles of non-maleficence and beneficence guide HCPs in their conversations with patients, despite the potential conflict between these principles in the case of vaccines. It is the obligation and responsibility of HCPs to set ethical standards for clinical interactions and clinical-care delivery. This analysis may help guide HCPs in conversations not only about measles vaccinations but also in other dimensions of clinical care. Despite the barriers that may exist between patients and HCPs in their quest for shared decision-making, HCPs should still try to protect patients (both individually and as a community) through ethical approaches to clinical interactions and care. HCPs can communicate with patients about the risks and benefits of the measles vaccine in a practical way that constructively informs patients’ decision-making.

1. Background

1.1 The 2014-15 Measles Outbreak

Before examining communication strategies about vaccine choices and of the competing ethical standards relevant during those discussions, it is important to describe how measles vaccinations became controversial. Measles is a highly contagious viral disease that is widespread in countries such as Europe, Africa, and Asia. Those infected with the virus are usually contagious within a week of contracting the virus. To prevent measles, since 1963 American children have received a vaccine commonly known as the

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measles, mumps, rubella (MMR) vaccine in two doses, initially at one year of age and again before the child starts kindergarten. The latter timing is typically mandated by laws in each state of the US that provide that children must be vaccinated against certain contagious viruses before matriculation into school. While some state laws have been amended to remove exemptions, at the time of the outbreak 48 states allowed religious exemptions from the vaccination and 20 states allowed philosophical exemptions.\(^8\)

Although measles has generally been found only outside the US (at least since the year 2000), a large outbreak started in California in 2014-15 when at least 40 people who were exposed to a measles carrier in the Disneyland theme park in Orange County later contracted measles.\(^9\) Subsequently, the multi-state outbreak resulted in an estimated 125 cases of measles from December 2014 to February 2015.\(^10\) The California Department of Public Health declared the outbreak over on April 17, 2015. The interim between the inception of the outbreak and its conclusion involved confusion and controversy within different facets of the healthcare community. Most importantly, HCPs and patient communities were either affected by the (potential) outbreak, confronted by the vaccine requirements, or both. Within this climate, compliant patients and HCPs became frustrated with non-compliant patients, while the latter became frustrated as public health officials and


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media punditocracy denounced those who refused to vaccinate themselves or their children.

It is difficult to quantify the extent of parental resistance to MMR vaccinations amidst the measles outbreak. “In an outbreak involving a major tourist destination like Disneyland, there is no single state, county or school district that can report the overall vaccination rate.” As a result, mathematical modeling provides an illustration of the role that vaccination rates play in a vaccination preventable disease outbreak. While those who denounce vaccinations were a small subset of the overall U.S. population (or population of similar age), the decisions to not vaccinate some children had a profound public health impact because those few children could spread the disease to others. Below in Figure 1 is a map that quantifies the problem of anti-vaccination rates across the country following the outbreak in California.

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While the national MMR vaccination rate is quite high, around 92 percent, the darker shaded states most likely contain pockets of unvaccinated patients, which serve as breeding grounds for outbreaks. Figure 1 above indicates that while vaccine acceptance or trust in vaccines remains high, anti-vaccination views have permeated specific areas and translated into unvaccinated children. “…Vaccination rates have not declined, even as requests for exemptions have increased. As a result, the likelihood of contracting measles is infinitesimally small, even for those who aren’t immunized.” Therefore, the

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risk lies within the areas where un-immunized children cluster. As Dan Kahan of Yale’s Cultural Cognition Project noted, “…this allowed for spread to occur, mainly in households and community gatherings, before public health interventions could be implemented.” According to the CDC, vaccination exemptions have been shown to cluster geographically, in states such as California, Washington, Oregon, and Utah, which can propagate disease outbreaks. For example, during the beginning of February 2015, the Los Angeles Times reported a “51 percent rate of unvaccinated children in a preschool in Santa Monica.” Furthermore, infectious disease expert Majumder and colleagues of JAMA Pediatrics estimated, “based on historical infection rates and the number of individuals infected in the current outbreak…vaccination rates in some communities might be as low as 50 percent and probably are no higher than 86 percent.” While there are some patients who are unable to receive vaccinations for medical reasons, this subset of the patient community makes up a small portion of those who don’t vaccinate. The CDC also reported that in states with either religious and/or philosophical exemptions


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(e.g. Florida and California), the adherence to vaccinations is lower than those states without such exemptions (e.g. Mississippi and West Virginia).20

The concept of herd immunity is important in understanding how vaccination of each individual helps protect the community. Herd immunity is a threshold inoculation rate that is high enough to protect vulnerable, unvaccinated patients, including pediatric and geriatric patients, as well as those with auto-immune conditions.21 Even if vaccination rates may be above 50 percent, “about 95-99 percent of people in a community need to be vaccinated against measles to effectively halt its spread.”22 Below in Figure 2 is an illustration of the concept of herd immunity in the context of the measles outbreak.


Individuals from the medical community argued that concentrated areas with low vaccination rates were at increased risk for outbreaks of preventable diseases. More importantly, the Disneyland location where the outbreak emanated is critical because the amalgamation of tourists from countries where vaccination rates are low, and U.S. tourists from pockets of non-vaccination and/or incompletion of the recommended two

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doses likely caused the outbreak. Many HCPs agreed that the anti-vaccination movement revived an entirely preventable disease. However, because California’s state law allowed parents with non-specific personal beliefs to opt out of vaccinations, anti-vaccination patient communities in large online communities and social messaging groups, who believed that medical establishments and pharmaceutical industries were concealing the potential risks of vaccines, could rally others to seek exemptions. The attitudes of parents toward vaccinations may change from acceptance to rejection, “from one child to the next, in the course of one child’s vaccination career, or in the case of specific vaccinations, (e.g. the measles vaccination). At aggregate levels, this will lead to dynamic configurations of fully immunized, partially immunized, and non-immunized children.”

The map above and other similarly constructed maps illustrating the measles outbreak show that the outbreak was a direct consequence of the anti-vaccination movement. Parents invoking exceptions to the MMR vaccine and those promoting the anti-vaccine campaign often relied on fears that the MMR vaccine could cause adverse side effects. Clinicians must understand patients’ thinking about infectious diseases, vaccines, side effect risks, and immunization policies to effectively communicate with patients about vaccine choices and assist patients in navigating today’s robust information marketplace.


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Furthermore, an understanding of the reasons for the anti-vaccination efforts is a first step in breaking down the communication barriers in the clinical setting about vaccination choices.

1.2 The Anti-Vaccination Movement: Then and Now

While health and medical scholars have dubbed vaccinations as one of the top ten public health achievements of the 20th century, opposition to vaccinations has occurred as early as the mid-1800s surrounding the smallpox vaccine. According to the Centers for Disease Control and Prevention (CDC), following 1963 licensing of the measles vaccine, approximately 19 million children were immunized over the next decade. By 2000, the CDC declared measles eradicated in the United States. But since the recent outbreaks in 2014-15, the US is now the only country that has measles transmission in the Western Hemisphere. The anti-vaccine movement transcends international borders, but this paper will focus on the movement within the U.S during the 1900s and of that surrounding the outbreak of 2014-15 in question.

The smallpox outbreak of the 19th century led to the formation of vaccine campaigns and related anti-vaccine activity. “The Anti-Vaccination Society of America was founded in 1879, and two other leagues, the New England Anti-Compulsory Vaccination


League (1882) and the Anti-vaccination League of New York City (1885) followed.”

Similarly, some patients amidst the recent outbreak objected to the measles vaccinations, “because they believed it violated their personal liberty, a tension that [has] worsened as the government continues to develop mandatory vaccine policies.”

In 1902, after the board of health of the city of Cambridge mandated residents to be vaccinated against smallpox, Henning Jacobson refused and protested his resistance to the U.S. Supreme Court. It was during this dispute that the court ruled in favor of the state citing that, “the state could enact compulsory laws to protect the public in the event of a communicable disease.”

This case was the first to set precedence regarding the power of the states in public health law. The intersection of anti-medicine and anti-government sentiments resurfaced during the recent 2014 outbreak.

In a similar vein, a 1991 Philadelphia measles outbreak that began in a private school overseen by fundamentalist churches resulted in 350 students never immunized, 1,500 cases of measles, and nine deaths. The political discourse regarding how to balance the rights of the individual against the rights of society has now entered patient waiting rooms in the clinic and become the starting point of conversations between some patients and HCPs about vaccine choices.

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For most of those opposed to the measles immunization, skepticism and discontent reflect their distrust of medicine and the scientific information presented about the disease. This can serve as a barrier to successful communication about measles vaccine choices. Part of the reason is that, due to the success of vaccines, Americans have ironically become unfamiliar with vanquished diseases, such as measles, and are thus unfazed by the risk of succumbing to them. This unfamiliarity leads parents to undervalue the importance of vaccinating their children against an “unknown” disease. As the occurrence of vaccine-preventable disease declines, the challenge of communicating the risk of not being immunized increases.

The challenge is worsened by omission bias, wherein the perceived responsibility for the consequences of inaction, (e.g. infection), is more acceptable than for the consequences of an action, (e.g. adverse event associated with immunization). While the CDC found that the comprehensive immunization of children eliminates the measles, the success of such vaccination programs has now made many Americans immune to fear of the disease. “The improvement of the living conditions and of the effectiveness of preventive public health programs has drastically changed the risks perceived among parents


that their offspring might get a childhood disease." This lack of fear has propelled the vaccine resistant patients to continue their non-compliance.

While critics have taken a variety of positions against the use of vaccinations, more recent controversies, such as that of the 2014-15 outbreak, also highlights skepticism about the efficacy and safety of immunizations. British gastroenterologist Andrew Wakefield is largely associated with propelling the anti-vaccination movement. In 1998, he published a report that suggested a causal link between vaccines and autism. Although it was later proved fraudulent (the results could not be replicated) and retracted, the information from the Wakefield report became incubated within certain patient communities. Investigators from other studies did not find any increase in the relative risk for autistic disorder in vaccinated children as compared to unvaccinated children. For example, Taylor et al. conducted a study that included 498 autistic children in the North Thames health district of the United Kingdom that found no causal association between MMR vaccine and autism. Patja et al. observed 1.8 million individuals in Finland given 3 million doses of MMR vaccine and did not identify any cases of associated autism. Madsen et al. compared the records of more than 400,000 MMR vaccinated Danish chil-

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dren with those of more than 90,000 unvaccinated children and found no linkage with the vaccine and autism. Nonetheless, as highlighted previously, the geographical isolation of unvaccinated children means that herd immunity can be undermined if even a few families believe the results of the Wakefield report and refuse vaccination. Hypersensitivity to the adverse effects of the vaccine, cause some patients to mischaracterize its safety and efficacy.

As a result, examining in particular what causes people with copious resources, both financial and informational, to refuse vaccination measures is critical as HCPs attempt to communicate with these patients. Perhaps what is most interesting about the persistence of anti-vaccination sentiments is how the demographic patterns of unvaccinated individuals have changed. It is important to note the difference between “under-vaccination” and “unvaccinated” patient communities. Generally, when a patient community is described as under-vaccinated, the implication is that while there may be a small number of individuals who adamantly refuse vaccinations, the vast majority of those not vaccinated within the community exhibit unintentional non-compliance. On the other hand, patient groups with a large amount of unvaccinated as compared to vaccinated children are most likely due to intentional vaccine refusal.

In a 2004 study, which sampled 152,000 children, “under-vaccinated children tended to be observed in the Black community, live near the poverty level, live in a cen-

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tral city, and have a younger mother who was not married and did not have a college degree.”41 Characteristics of the “unvaccinated” populations, on the other hand, included, “being White, living about the spectrum of the middle class, and having a college educated, married mother.”42 The study also found that those children who were unvaccinated had, “parents who expressed concerns regarding the safety of vaccines and indicated that medical doctors have little influence over vaccination decisions for their children.”43

Many post-mortems of the measles outbreak in question describe the contrasts between the historical anti-vaccination movement and its re-emergence. During the 1980s and 1990s, under-vaccination in the United States was associated with personal, financial, and structural barriers to immunization and other inequities in the healthcare system that precluded patients from underserved communities from accessing vaccines. This unintentional rate of non-compliance with vaccinations was frequently observed among socio-economically disadvantaged urban children, inner city ethnic and racial minorities, and children whose mothers had limited education and thus poor health literacy.44 However, outbreaks during these years were attributable to specific religious groups (e.g. Christian Scientists and the Amish) who intentionally refused vaccinations.


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Likewise, “reluctance to vaccinate in the San Diego outbreak was associated with health beliefs, particularly among well-educated, upper-and middle-income segments of the population,\textsuperscript{45} which were similar to 2008 outbreak patterns. This anti-vaccination pattern is emblematic of what I will call a \textit{health literacy paradox}. While an unintentional lack of patient compliance to vaccinations is related to low health literacy or apathetic behavior, intentional refusal in “resisting vaccination is time-consuming, expensive,”\textsuperscript{46} and occurs largely amongst health literate patients. Similarly, existing literature by Kahan argues that their view is based on the political/cultural meaning of subscribing to one or another view on vaccines, not based on their science literacy.

A study by Daniel Solomon of the Institute for Vaccine Safety at Johns Hopkins investigated why parents claimed non-medical exemptions and explored the differences in perceptions of vaccines and vaccine information sources between parents of exempt and fully vaccinated children. Common denominators amongst the exempt group included their distrust of authority figures, with the exception of alternative HCPs, parents/ friends, the internet, and other dissatisfied persons.\textsuperscript{47} “Parents who didn’t adhere to vaccination guidelines were more likely to engage in extensive source networks (books, blogs, websites, and magazine articles), to which they turned for vaccine-related informa-


tion.” While access to resources, informational and otherwise, was low for the under-vaccinated in the 1980s and 1990s, the unvaccinated groups of today devote considerable resources to accessing “a flood of information made possible in the digital age.”

One aspect of the interdisciplinary approach (i.e. sociology, psychology, anthropology, and communication theory), the Social Amplification of Risk Framework (SARF) applies here. Various mechanisms of communication induce the amplification of risks (e.g. increasing public attention), or attenuation (reducing public attention) of risks. The information marketplace that exempt parents participate in can be used to compare their response to that of compliant parents. The effects of amplification include its impact on mental perceptions as well as changes in personal behavior by those engaged in communication. Thus, patients integrate the “technical assessment and the social experience of risk.”

Participation in this social dimension has shaped and influenced the way patients perceive, interpret, and understand their health choices. NYU professor of sociology Dalton Conley coins these behaviors “parentology,” or “patient-driven medicine, in which informed patients advocate to their doctor rather than just passively receiving informa-

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tion.”52 Patients may be less likely to heed to the advice of HCPs and instead “interpret and generate the scientific evidence for themselves.53

In a society that is awash with advice, much of the socialized and public discourse surrounding measles vaccinations may cloud the clinical judgment of already resistant patients. Many members of the anti-vaccination group claim vaccinations are unsafe and ineffective. Some individuals within these communities are particular about which vaccines they will choose for their children to receive, while others object to the schedule school districts have adopted for immunizations.54 “Then there is a particular subculture of largely wealthy and well-educated families…who are trying to carve out “all-natural” lives for their children.”55 Additionally, a Pew Research Center Report revealed significant age differences in views about vaccines. While young adults across all age groups believe that vaccinating children should be a parental choice, “68% of U.S. adults say childhood vaccinations should be required, while 30% say parents should be able to decide.”56 Americans 31 years of age or older are stronger supporters of requiring childhood vaccinations — with 79% holding this view. Researchers suspect that this


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higher support among older people stems from the fact that many among them recall when measles was common, as opposed to the younger generation who have not experienced measles. While men and women held similar views on the requirement, slightly more parents of minor children than those without children favored parental choice. Concerning political party lines, the majority view is that vaccines should be required, but with Republicans and Independents more inclined to agree with parental choice than Democrats. This finding parallels concepts discussed in the Psychometric theory, in which Paul Slovic suggests trust is one influence on risk perception. This theory is discussed in greater detail in the next section.

While many articles have used the data on immunization rates to sketch a demographic profile of at-risk patient demographics, a closer inspection of how those individuals opposed to immunizations perceive and conceptualize risks could help HCPs to better address how such choices should be communicated in the clinic. With a better sense of perspective about the groups opposing immunizations, HCPs can incorporate this knowledge as a basis for different ways of communicating about the decision to vaccinate.

The epidemiological findings espoused by the CDC and other health institutions underscore that the importance of preventing outbreaks is not only a matter of health policies that mandate vaccinations, but also and perhaps more importantly of understanding patients’ concerns while fostering patient acceptance and compliance. HCPs who are engaging patients in conversations about vaccine choices may be able to promote

compliance through better communication. HCPs must focus on the nature of information exchange and delivery rather than just the amount of information provided to patients. Physicians should not dismiss parents' concerns regarding vaccination compliance. As HCPs seek to share accurate information about the benefits and risks of the MMR vaccine, it is also important for HCPs to understand the reasons for patients’ concerns.

1.3 Beliefs, Perceptions and Other Attitudes of Vaccine Resistant Patients

This section examines how the risks and benefits of vaccinations are understood by the public, in particular by patients who exempt vaccines. These considerations will enable HCPs to better understand what informs the decision-making process of parents, specifically those who are hesitant to comply with vaccination their children. Furthermore, this section will clarify how parents identify sources of information related to measles vaccines, develop perceptions and beliefs of vaccine-associated risks and benefits, and thus make the decision not to vaccinate. I will also discuss the importance of understanding patient perceptions of vaccinations within particular sociopolitical contexts, and the role of the state (government) in supporting public health interventions. As the incidence of vaccine-preventable diseases (e.g. measles) has declined, HCPs may become convinced that vaccines have succeeded and that the importance of vaccines for public health has increased, while simultaneously the public may perceive less threat from such diseases and thus less need for vaccines. This irony justifies the need for HCPs to further understand and address the factors associated with vaccine-resistant beliefs.

At play during the measles outbreak were two motivations for anti-vaccination behavior: perceptions of the risks of the measles vaccine and resistance to compulsory
legislation — (i.e. the rights versus responsibilities of citizens and trust in government).

It was particularly after the epidemic that the social debate erupted about parental freedom and choice versus public health safeguarding measures.

The demographic features of “unvaccinated” patient groups were noted in the previous section — in recent years; they have tended to be middle-class or wealthy, Caucasian, health-conscious mothers. These parents may demand rigorous and lengthy communication about the option to vaccinate. In the article, *Anti-Vaccinationists Past and Present*, Wolfe and Sharp culled and compared arguments from the present-day anti-vaccination movement with those from the 19th century. They also summarized the characteristics and impact of the movements during these specific time periods and concluded that the similarities between the movements suggested “an unbroken transmission of core beliefs and attitudes over time.” Such comparisons emphasize that the medical establishment should be attentive to vaccine resistant consumers of health, “who often have a complex rationale for their beliefs, related to a mixture of world views held about the environment, healing, holism . . . and a critical reading of the scientific and alternative literature.” Thus, the medical establishment should pay attention to these constant factors.

A study published in 2000 under the direction of The National Network for Immunization Information Steering Committee assessed parents’ understanding of vaccine-preventable diseases, vaccines, immunization practices, and policies, by conducting a na-


The researchers discussed the nature and extent of the public’s concerns about vaccines as well as their knowledge, attitudes, and misconceptions. The survey found that “immunization was deemed extremely important (a score of 10 from 0-10) by 86.9%,” while 82.8% of the respondents cited disease prevention (e.g. protect my child’s well-being) as the reason for compliance. Of the respondents who indicated a preference to opt out of a particular immunization, the MMR vaccine was one of the immunizations specified. Perceptions of disease severity and likelihood of infection varied, with polio and hepatitis B being perceived as most serious, and pertussis and measles being perceived as somewhat less serious. A substantial proportion of respondents held beliefs that were inconsistent with the scientific evidence regarding immunization safety and efficacy, with nearly one-quarter of respondents being concerned about the number of vaccines given and of their child’s immune system response after being immunized. The researchers concluded that the increasing complexity of immunization schedules and the advent of new technologies would cause parents to become more rather than less alarmed about vaccines in the future, as was evident during the measles outbreak in question.

Interestingly, the survey results indicated that respondents had a low perceived need for information, which poses a distinct challenge for HCPs. The researchers noted, “When people feel little need for additional information, they are unlikely to attend to

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new information unless it is in some manner striking, such as when it is in conflict with their beliefs.” In section 3.1, this study result is described in the context of the deficit model as a framework for understanding how people make decisions. One of the most important conclusions reached from the survey for the purposes of this paper was that HCPs were cited by survey participants as the most important source of information on immunizations. There was a parallel finding in another national survey, in which 84% of respondents indicated that they received immunization information from a doctor. While it is unclear what fraction of the 84% view immunizations as important or unimportant, that the majority of respondents from both surveys cited HCPs as an important source of information is critical. This finding suggests that HCPs can play an important role in modifying misconceptions and advising parents about immunizations in children’s health.

With respect to the attitudes about the safety and efficacy of the vaccine, a study of the effects of vaccine safety concerns on immunization status was published in 2004 in The Journal of The American Academy of Pediatrics. A case-control study of subjects who didn’t complete their vaccination schedule, (missing at least 2 of 3 vaccines (diphtheria-tetanus-pertussis or diphtheria-tetanus-acellular pertussis, hepatitis B, or measles-containing vaccines), and fully immunized control subjects was conducted to examine the

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attitudes, beliefs, and behaviors of these two groups of parents. Interviews included specific questions on vaccine safety attitudes, beliefs, and behaviors that had been cognitively pretested. The study provided the first nationally (U.S.) representative survey data that linked lack of immunization with vaccine safety concerns. The study documented that, “many parents of fully vaccinated children demonstrated the same attitudes, beliefs, and behaviors of those [that did not complete their vaccination schedules]…regarding the risks and safety of full vaccine coverage.” These findings parallel those documented during the 2014-15 measles outbreak and suggest that “interpersonal factors (doctor-patient relationship), community factors (social norms), and public policy factors (immunization laws), all may play important roles in maintaining immunization coverage.”

The conclusions of this study support the view that “efforts to maintain and improve measles immunization coverage need to target those with beliefs or behaviors indicative of vaccine safety concerns.” Therefore, achieving disease prevention goals depends, in part, on the success of HCPs’ communication with patients.

In the article, Public Doubts About Vaccination Safety and Resistance Against Vaccination, Streefland focuses on the forms and implications of public doubts about vaccines. He asserts that “routine immunization should be based on trust and social de-


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mand.” With respect to the hegemony of the state in matters of public health, Streefland suggests that “one of the elements in these forms of public opposition is doubt in the legitimacy of the state as the keeper of public health.” This is key because it suggests that communicating about science is not enough and that trust, as cited in the literature, has been found to be an important risk perception factor.

To the extent that distrust in the government is a common feeling amongst citizens in the U.S., this contextual factor is important in understanding measles vaccination resistance. As part of these beliefs, “resistance against vaccination among parents is embedded in the conviction that it is ultimately the parents who decide.” Furthermore, parents who distrust government and prefer to make their choice may also believe that an alleged risk of adverse side effect from the vaccination outweighs the risk of contracting measles. While resistance to vaccinations may reflect a lack of trust in systems of expertise, such as HCPs, Streefland proposes that “HCPs have a growing tendency to defer important medical decisions regarding children’s health to parents, often leading to uncertainty among parents and thus non-compliance.” As such, it becomes increasingly important for HCPs to construct a proper balance of communication in order for the decision-making process to be a shared experience.

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An understanding of vaccination patterns must be guided by sensitivity to differences in social experiences. The clustered groups of anti-vaccination parents tend to have shared experiences. In another article by Streefland, *Patterns of Vaccination Acceptance,* he describes how social context affects patterns of vaccination acceptance and refusal. Extra media attention and new vaccination technology are experienced as campaign, which provokes rejection from patients about vaccination. As previously reviewed, “local vaccination cultures” develop among clustered groups of patients, amplifying their resistance to getting vaccinated and thereby diminishing the likelihood of achieving herd immunity.73 “Relatives or neighbors exchange accounts of their vaccination experiences (e.g. bad treatment by a health worker, a childhood vaccination with a painful side-effect), which then color their subsequent experiences.”74 These groups often adopt shared beliefs about “disease etiology, the potency and efficacy of modern medicine, and the need for preventive health measures.”75 While many parents who refuse immunization for their children have personal, cultural or religious reasons, experiential reasons may also provoke their refusal.

However, parents do not simply accept or refuse vaccines; there are gradations among their perspectives. Grouping parents into categories of acceptance and non-acceptance can be problematic because there are variations in why patients within the same group may espouse those sentiments. Therefore, the prevailing reasons for accepting or

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not accepting the measles vaccination may differ, although the decision reflects either of the two patterns. Although outside of the scope of this paper, the social demand for vaccinations is another determining concept of patterns of acceptance. Streefland suggests that active acceptance entails adhering to specific vaccination schedules based on a perception of benefit. Passive acceptance denotes compliance by patients who yield to the social pressures and cajoling of health authority recommendations. Continuous participation in the vaccination process reinforces the notion of normality. “In this sense, all vaccination users are interdependent, as they support and are supported by each others' decisions.”

Streefland asserts that “acceptance might or might not be rooted in an informed and knowledgeable vaccination culture.” Therefore, the type of communication that HCPs offer may need to vary with their reasons of greatest salience to each patient. This information will be received by patients in light of their varying perspectives. HCPs who seek to foster acceptance by patients based on providing accurate information in the context of the patients’ values may need to adjust their communication approaches to specific patients.

How patients communicate and interpret communication about measles vaccine choices is also influenced by their exposure to various forms of socialized messaging. “Towards the end of the 20th century, a wave of anti-vaccination activity led to an increase in media interest in the arguments attacking childhood immunizations.”

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the measles outbreak, the media represented the individual actions of those opposed to vaccinations as collective non-compliance — many people organized their resistant efforts together. If collective decisions regarding resistance to vaccinations are based on emotionally-charged convictions, they may be unsound from a scientific and clinical perspective. Kahan describes this phenomenon as the “science communication problem—the failure of compelling scientific evidence to resolve public dispute over risks and similar facts.”79 The implication is not that the people are emotional/irrational, rather that explaining the science and appealing to people’s political values is important during communication. Kahan suggests that because people consider other attributes of a dispute, not just the scientific evidence, providing them with scientific evidence is not enough to resolve risk disputes. In the context of the choice of whether to vaccinate, Kahan would affirm that whether or not the potential remedies for the scientific problem align with people's political values plays into their decision. Relatedly, Kahan asserts that who communicates the scientific information, (whether the audience views the speaker as sharing the same political values) influences decisions more than the content of the communication. As was the case in the 1970 study investigating the divergence between expert and public opinion on nuclear power, “this body of work can be used to explain not only controversy over risk, but also to predict, manage, and, in theory, avoid conditions likely to trigger it.”80


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In the context of the recent measles outbreak, parents were publicly introduced to the vaccination in a manner that was likely to generate cultural conflict — through various forms of social media/news media outlets. This aspect of the outbreak draws on the aforementioned Kahan cultural cognition theory and the social amplification of risk. The resulting polarization of parents is amplified when they are exposed to social messaging cues — news reports of vaccine side effects or statements by famous advocates such as television celebrities. The media also had a tendency to erroneously characterize the nature of the measles problem, by suggesting that everyone, even those vaccinated against measles were at risk of contracting the virus and failing to discuss the concept of [lack of] herd immunity which contributed to the inception of the outbreak. As noted by Streefland, “…something that was hitherto automatic, like taking a child to be vaccinated, may no longer be so automatic if a new vaccine is introduced that, for example, gets specific media attention.”

Kahan cites a similar instance with the 2006-2007 controversy over the HPV vaccine. “Merck, the manufacturer of the HPV vaccine Gardasil, sponsored a nationwide lobbying campaign directed at state legislatures to add the vaccine to the schedule of immunizations required for school enrollment.” This mechanism incited political controversy, which was re-emphasized as a political issue by media punditocracy covering high-profile legislative enactments. It should be noted that the HPV vaccine was contro-


versial for other reasons, not just seeking legislation for mandatory vaccination that sparked controversy. With respect to the latter reason, Kahan suggests that vaccination schedules should be introduced to the public through the customary mechanism of public health administrators who operate outside of the political realm. The measles vaccine was often discussed using a polarizing messaging scheme. More importantly, “parents’ initial exposure to information on the [measles vaccine] should come from their pediatricians.”

Understanding the attitudes, perceptions, and beliefs that shape parents’ thinking about vaccines is the first step in the ability of HCP to effectively compete in today’s robust information marketplace. Furthermore, this understanding undoubtedly shapes how patients interpret communication about the risks and benefits of the measles vaccines. Using this knowledge, HCPs should be informed about opposing views to vaccinations and anticipate these responses from their patients. The notion of informed consent includes an understanding of the measles disease and the consequences of immunizations. While attitudes, perceptions, and beliefs about vaccinations guide the way in which patients communicate about vaccines, the ethical principles of beneficence and non-maleficence guide HCPs in their interactions with patients. The next part of this thesis examines how these principles conflict with respect to risk communication about the measles vaccine and how HCPs can resolve this conflict through effective communication. I will propose ways that HCPs can resolve conflicts among ethical principles based on patients’ risk perception factors and address factors important for attitude formation.

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2.0 Beneficence and Non-Maleficence

How does HCP’s duty to the principle of beneficence and non-maleficence guide their conversations about measles vaccine choices? “Health communication is a means of combating disease and improving or protecting health and should therefore be conducted in accordance with certain ethical principles, namely those of beneficence, non-maleficence....”1 While the scope of this paper specifically focuses on beneficence and non-maleficence, the ethical principles of autonomy and justice are at the intersection of how to balance the two when they are in conflict and are mentioned in this analysis. Below is a table that summarizes the definitions of the four principles explored in this paper. A detailed analysis of these principles will follow.

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Table 1. Ethical Principles Central to Medicine

<table>
<thead>
<tr>
<th>Principles</th>
<th>Key Takeaways</th>
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| **Non-Maleficence** | • Do no harm (i.e. physical, psychological, emotional)  
• Avoiding the risk of harm - (don’t subject patient to unnecessary risk)  
• Upholding principle means benefits of an act must outweigh harm — net benefit |
| **Beneficence** | • Doing good for the benefit of the patient  
• Going beyond prevention of harm to ethical action  
• Fostering trust in patient-physician relationship  
• Communicating compassionately  
• Creating environment/conditions necessary for autonomous choice  
• Considering individual differences/circumstances of each patient |
| **Autonomy** | • Right of self-determination — free from coercion  
• Helping to prevent or remove harms  
• Rooted in respect for person’s as agents of choice and decision-making |
| **Justice** | • Equal distribution (in society) of burdens and benefits of a treatment  
• Legally permissible and fair to all parties involved  
• Considering the following in evaluation: competing needs, rights/obligations, legal challenges, equitable distribution of scarce resources |

The dichotomy between the two principles of beneficence and non-maleficence is the foundation for risks versus benefits analysis that both HCPs and patients construct.

The decision about whether to immunize children against vaccines, specifically measles, is made in the context of communicating the risks and benefits associated with such a choice. In this respect, “communication itself is a component of treatment.”²

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The principles of beneficence and non-maleficence were historically interpreted and applied by HCPs (not by patients), as part of HCPs making medical care decisions for patients (i.e. paternalism). Paternalism is deemed ethically dubious in medical practice today largely because the educational gap between physician and patient has narrowed. The shift in the doctor-patient relationship involved a move towards greater respect for patient autonomy, whereby patients engage in a more active decision-making role. As a result, striking a practical balance between the principles of beneficence and non-maleficence is a challenge that HCPs must overcome if they are to appropriately and effectively engage patients in the decision-making process. The principle of beneficence is often paired with non-maleficence because of their linkage in the context of clinical care delivery; however, there are distinctions that should be drawn about how the two are applied.

I. Non-Maleficence

The principle of non-maleficence or *primum non nocere* - first do no harm, is a cardinal ethical principle sacred to medicine. In practice, however, it does not have the simplicity or absoluteness that it suggests. In the clinical context, the principle requires that HCPs prevent individuals from being harmed. This encompasses physical, psychological, and emotional harm. Beauchamp and Childress point out the difficulty in defining the nature of harm, but for the purposes of healthcare, the primary focus on harm relates to a narrower definition including pain, disability, or death. During communication, HCPs should avoid creating a sense of fear, anxiety, anger, or mistrust, which stifles autonomy by distracting patients and causing them to make misinformed decisions. In par-
ticular, they should not cause avoidable or intentional harm — avoiding even the risk of undue harm. It is important to note that the principle can be violated unintentionally and that HCPs don’t have to cause harm to violate the principle. If they have knowingly or unknowingly subjected a patient to unnecessary risks, they have violated the principle.3

During communication with patients, non-maleficence takes the form of HCPs being selective of the scientific findings used to describe risks and benefits, not concealing study findings, and not over- or under-interpreting data. HCPs possess a repository of epidemiological knowledge which tends to breed paternalism. Thus, they must remember that “science is important in setting or making other decisions affecting individuals or groups.”4 HCPs often find that the principle provides minimal concrete guidance in the care of patients because more than one level of harm may come into play in a situation. For example, in communication about the measles vaccine, HCPs may inflict a level of emotional harm in the form of anxiety for patients resistant to vaccinations. Also, the certain physical harm associated with administering vaccines is weighed against avoiding the less certain but more secure harm of a measles infection. The best way to minimize each harm is discussed in the next section of the paper. Additionally, harm may be undesired and unintentional. This invokes the principle of double effect (discussion will follow) in which there is an unintended consequence of harm following a particular medical intervention.


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If the injunction of non-maleficence were to govern all clinical decision-making, HCPs would have to avoid intervening whenever there was a risk of harming patients or others — which would be inevitable in most cases. When non-maleficence conflicts with other principles, such as beneficence, it must be considered in that context. Therefore, the principle is most helpful to HCPs when it is balanced against beneficence. In this context, non-maleficence posits that a particular act is viewed as ethical if the provided benefits of the procedure/intervention outweigh the harm or risks of harm (any of the previously mentioned forms) caused. Ultimately, the patient gives weight to the potential benefits and harms and is led to a decision based on this conception. Thus, the principle of non-maleficence implies that the harm of treatment should not be disproportionate to its benefit.\(^5\) As evidenced by the studies cited in the previous section, “in some cases, patients consider the risk of harm to weigh heavier than the prospect of some benefit.”\(^6\) It is important for HCPs to be aware of individual patients’ assessment of what constitutes harm. As discussed, “people’s perception of harm and benefit is idiosyncratic, an integral part of the way they see themselves and of their life plan.”\(^7\)

American Lawyer Charles Fried defined one aspect of people’s lives as their “risk budget”- which describes how people decide which risks they are prepared to take to pur-


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sue certain ends. In this way, the principle of non-maleficence may conflict with the principle of autonomy or justice. For example, a vaccine resistant patient may want to accept greater risks of harm than the HCP would have chosen, in order to make the decision by him or herself (conflict with autonomy).

At an interpersonal level, the promulgation of compulsory measles vaccination may harm a few (emotional harm from compulsion, and possibly a small risk of physical side effects) for the greater benefit of many. The current policies promoted by HCPs for the safety and protection of patient’s physical health and dignity are applied to avoid the harm that could result in a lack of infection control. However, they may also consider the harm that results to family integrity by interfering with the parental decision of whether to vaccinate. According to the principle of non-maleficence, the harm prevented must be more substantial than the harm that will result by interfering with parental choice. Is there a net benefit over a parental choice of no treatment or does it simply replace one serious harm with another? How can these different types of impacts be compared? The fundamental justifications for constraining the principle of non-maleficence include “utilitarian grounds — maximizing welfare” — or on “Kantian grounds — respect for persons and their autonomy.” Discussion of these constraints will follow in the next section.

Other challenges arise when the primary patient can’t decide for himself or herself, and a surrogate decision-maker must determine what is in the best interest of the pa-

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tient, or what constitutes the lesser harm. In the context of communication about measles vaccine choices, parents act as the surrogate for their children, who are often the patients that are non-compliant with the vaccination schedule. The children are non-compliant because their surrogates (parents) follow a course of action that they feel serves the best interests of their child. In the article entitled, *The Conflict Between Autonomy and Beneficence in Medical Ethics: Proposal for a Resolution*, Pellegrino and Thomasma, suggest, “we may presume that were they autonomous, children would choose to be treated — provided there is sufficient benefit to be gained from the treatment.” Therefore, the infliction of harm is only justified in the interest of the primary patient’s benefit (children), so as medical ethicist Albert Jonsen suggests, “it is important to distinguish between benefit to the patient, (the primary and special obligation of the HCP), and benefit to others (patient’s family, other patients, or people more generally).”

This quote lends itself to the key dilemma addressed by this paper: the socially optimal decision would be to encourage patients to receive the MMR vaccination because it has overall benefits for both the primary patient and society that justifies the risks. However, these benefits may be mainly accrued by others in the community (those who are shielded by herd immunity), so that the benefit-risk comparison for the primary patient may not yield as much of a benefit. While the MMR vaccine produces more social benefits in return for personal risks and loss of autonomy, under the doctrine of (weak or

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strong) paternalism, the HCP can’t presume or impose altruism on the patient. Furthermore, as Pellegrino et al. notes, “when the clinical context is clear…and the patient’s competence certain, autonomy can and should be given primacy.” This implies that if an HCP is communicating in a way in which they are only describing the benefits of the vaccine (socially optimal decision), they are violating the principle of both non-maleficence and autonomy.

II. Beneficence

Beneficence is the act of doing good for the benefit of the primary patient. It requires that HCPs go beyond prevention of harm to ethical action. “For centuries, beneficence was actualized through the process of the patient presenting himself to the physician for examination and inquiry and then following the advice of the physician.” Kantian philosophy asserts that these obligations exist because HCPs are dealing with the basic needs of humanity which have intrinsic value. In the clinical setting, this translates into HCPs, “obligation to create benefit and contribute to optimum health for individuals and the community at large…and includes the obligation to help those in trouble, protect patients’ rights, and provide treatment for those who need it.” Societal needs for self-determination have reshaped the ways in which HCPs understand and apply the principle of beneficence.

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In the context of the decision to comply with the MMR vaccination, the utilitarian view of beneficence is used which balances the benefits of a decision against its harms. Beneficence holds that the most important ingredient of the patient-physician relationship is trust. Thus, HCPs have an obligation to inform, develop trust, and produce an environment that fosters participation from both parties in allaying fears about perceived risks. As noted by Benin et al., the trusted HCP uses a holistic approach that doesn’t patronize, spends time with both the child and parent, and treats them as individuals. HCPs employs beneficence when they treat expressions of concern with respect irrespective of whether those concerns are scientifically based. Without this element of trust, it would be very difficult to treat patients.

As a similarity to the principle of non-maleficence and respecting patients’ conceptions of harm, beneficent HCPs communicate compassionately with the patient about the logistics of administering the measles vaccination and why it is important. Furthermore, they must consider the patients’ needs and feelings about the decision to vaccinate. As noted by Pellegrino and Thomasma, “any mode of clinical decision-making, by virtue of the fact that it is clinical, must take into account the particularities and uniqueness of each person’s experience of illness.” Variability in what HCPs and patients deem as

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“good” is based on the “subjective values of these interpreting parties and is the product of rational disagreements about the risk-benefit calculus.”19

Pellegrino ant Thomasma describe the different levels of beneficence and how an interpretation of the various levels, “determines the moral obligations HCPs feel they owe patients and the degree of altruism HCPs feel obliged to practice.”20 The first level of beneficence is non-maleficence. The next graduation on the beneficence continuum consists of, “the duty to prevent harm to others, (i.e. to remove or limit the possibilities of harm).”21 This may come in the form of active intervention by HCPs to promote the measles vaccine on behalf of others or social beneficence. “Even further along the scale is to interpret the duty of beneficence as binding even at some risk of discomfort or pain to the benefactor.”22 The degree of self-effacement encompasses HCPs obligations based on altruistic motives, “which enters the realm of agapeistic ethics — one grounded in love and charity for others.”23 Each of these levels of beneficence delineates three specific obligations of HCPs: the primary concern is the interests and needs of the patient, the avoidance of harm, and providing maximum benefit to the patient should be based on fostering autonomy.24 Fostering autonomy involves HCPs’ creating the conditions/envi-

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ronment for patients’ to exercise autonomous choice. In doing so, HCPs adhere to the
principle of beneficence and promote autonomy by presenting all treatment options to the
patient, and explaining the risks and benefits of an intervention in a way that is under-
standable.

It is clear that beneficence can encompass benefit for both the primary patient and
others, so in the context of communicating about the MMR vaccine is it possible to max-
imize both?

As noted previously, conflicts may arise between the interests of society and the right to
privacy of individuals. In the analysis of non-maleficence, an example was highlighted
which posited that a vaccine resistant patient may want to accept greater risks of harm
than the HCP would have chosen, in order to make the decision by him or herself (con-
flict with autonomy). In this scenario, the patient’s behavior does not align with the so-
cially optimal decision of vaccinating. Therefore, there is not just a conflict between non-
maleficence and autonomy but also a conflict between beneficence and autonomy in this
example. It is difficult for HCPs to navigate this ethical issue in which the patient’s au-
tonomous decision conflicts with the HCPs’ beneficent duty to consider the patient’s best
interests.

In this context, following each ethical principle without consideration for the oth-
er would result in different actions by the HCP. Therefore, they must be considered to-
gether. Because the parent (the proxy for the child — primary patient) can make an au-
tonomous choice, in which he or he understands the consequences of each decision, the
HCP must respect the patient’s decision not to comply with the vaccination. Furthermore,
this course of action minimizes the conflict between beneficence and non-maleficence.

Part of doing good and avoiding harm is respecting the autonomy of the patient — their decisional capacity to assess options and make choices. Respect of the principle of autonomy is the ethical basis by which HCPs seek and obtain informed consent (i.e. informing patients of the purpose, nature, and alternatives of the intervention).

The principle of beneficence values both HCPs and patients as able to express concerns in discourse without the imposition of values or coercion. Respecting the integrity of the medical enterprise, while HCPs serve the good and serve the good of the patient requires that benefice and autonomy mutually reinforce each other. Furthermore, physicians have the greater responsibility in the relationship to provide information in a way that allows patients to make informed decisions. The good of the patient depends on the extent to which HCPs can be trusted to keep this goal as their primary aim.

Notions of risks (harm) and benefit are a function of context and socio-cultural and socio-political contribute to how non-maleficence and beneficence are used for ethical decision-making. Informing patients about health related risks poses ethical dilemmas for the HCP as the communicator of this information. Given the content of information shared, HCPs walk a delicate balance to respect the principles of non-maleficence, beneficence, autonomy and justice. While the principles provide action guidelines that are appropriate for clinical ethics, the principles can conflict in risk communication and the ethical theory and principles doesn’t provide a decision-making procedure to resolve these

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conflicts. However, the principles are flexible and thus responsive to particular situations which can assist HCPs in their quest to weigh and balance them. Risk communication guidelines must minimize the conflict between the ethical principles discussed. Before addressing those guidelines, it is important to clarify how HCPs should structure their communication with patients about their decision to vaccinate. The next section of the paper will discuss the goal of risk communication in the context of discussing the MMR vaccine.
3.0 The Aim of Risk Communication About Measles Vaccine Choices

The previous section informs how people perceive risks. Now, using the MMR vaccine as a case study, the focus will shift to the novel contribution of this paper which is an analysis of lessons for risk communication in the context of bioethics principles. The changing face of risk communication consists of understanding how people assess risks and weigh information before making a decision. The rise of nuclear technologies in the 1960s fueled panic in the public despite the scientific community’s efforts to dispel fears of the technologies being unsafe. As evidenced by the anti-vaccination culture, there was a disconnect between the scientific evidence and public perceptions of risks. In studies about the public understanding of science, the deficit model was developed as a way to attribute public resistance or skepticism to a lack of understanding based on a lack of information. The deficit model assumes that simply increasing the provision of information alters people’s perceptions of risk. This explanation has served fruitless in the clinical setting, as HCPs now approach information exchange as a form of bi-directional communication. Research has demonstrated that simply providing more information does not mitigate people’s risk-aversion tendency caused by “irrational” fear. Contrarily, risk perception is a psychosocial experience involving personal values and biases that people employ during communication, as defined by Paul Slovic.

Given these findings, HCPs should seek to provide information in a way that fosters understanding from the perspective of the patient. Therefore, based on the principle of beneficence, the overall goal of clinical risk communication should be to inform deci-
sion making, as opposed to influencing behavior. While some may argue that mandatory vaccination policies undermine patient autonomy, the HCPs can respect patient autonomy by structuring conversation with this goal in mind. Presenting information in a manner that promotes the socially optimal decision — vaccination compliance — is ethically distinct from communicating information in a way that respects the right of the patient to make up his or her mind.

This goal creates a space where the inducement of harm or even the risk of harm is almost non-existent. If the goal is to inform decision-making, the outcome of the decision-making process, (in this case the decision of whether to vaccinate), is unimportant irrespective of whether this choice reduces prospective risks. What is of importance in light of this goal is structuring communication in a way that is transparent in the delivery of accurate information and a way that presents risks and benefits in an appropriate context. This goal of communication aims to restore the autonomy of the patient (e.g. allows them to make a choice between different alternatives). In consonance with upholding the principle of beneficence, “to violate the patient’s autonomy is to deprive him of one essential component of his own good, and thus to violate medicine’s promise to act for the good of the patient.”

If the goal of risk communication in this context was for HCPs to persuade patients to comply, they might inadvertently use sensationalism and scaremongering as tactics during communication, leading to overall (psychological/emotional) harm of the pa-

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tient. Furthermore, structuring communication with the goal of influencing behavior in this context, does not align with promoting informed choice, “and assumes that medical values or medical good is the highest good and an absolute quality that overrides other values.” If HCPs adopted this goal, they would be naturally inclined to communicate in a way that would influence a compliant pattern of behavior. This can create unnecessary emotional harm in that; the patient may decide to forgo the scientifically preferred option for one of lesser efficacy, such as homeopathy.

As such, both the HCP and patient make intervention preferences based on their values and scientific data. An effective interaction with the proposed aim addresses both the concerns of vaccine supportive parents, while also motivating a hesitant parent towards this behavior of acceptance. Conversely, the alternative aim can result in poor communication stemming from, “from a belief by the HCP that vaccine refusal arises from ignorance that can simply be addressed by persuading or providing more information. Such an approach is counter-productive because it fails to account for the complexity of reasons underpinning vaccine refusal…” This also touches on the shortcomings of the aforementioned deficit model.

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The alternative goal of communication — to convince — also, “subsumes all patients’ good under one good — the medical good, and other dimensions of the good — namely, the preservation of the human good to make one’s own decisions about the risks one wants to take.”\(^6\) The legitimacy of trying to induce a pattern of behavior in the face of less immediate risks (i.e. those perceived by the patient) is difficult to qualify. In his psychometric paradigm, Slovic describes immediate vs. delayed risks as risk perception factors. This theory quantifies people’s responses to various risks and also identifies the characteristics that people use to evaluate specific risks. With the goal being to inform decision-making, “increased involvement by patients and risk communication as a means towards this may therefore be based more on values than on evidence.”\(^7\) HCPs may often become distracted by the goal of public health campaigns which actively seeks to persuade the public to adopt vaccines as a preventive strategy. The media then uses scare tactics and other forms of coercive messaging that inaccurately describes the risks associated with contracting the illness in question.

This form of communication may convey a false sense of the certainty of the benefits of the vaccine as an intervention, engendering unrealistic expectations. Subsequently, those individuals diagnosed with measles may blame themselves, (psychological harm) as a result of heightened emphasis on taking personality responsibility for reducing

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one’s risk. “Rather than promoting a sense of health, such tactics may simply increase everyone’s sense of vulnerability and anxiety about the diseases,” reduces the trust of the HCP and may induce feelings of coercion from the patient. All of these considerations violate the principle of non-maleficence.

While HCPs may be tempted to over-interpret data for the benefit of public health (parties other than the primary patient), they must be cognizant of the harm that can result from providing unnecessary information and describing risks incorrectly. Since much of the data used by HCPs operates in gray areas, the best way to avoid violating the principle of non-maleficence or beneficence is for HCPs to be as clear as possible in communicating their reasoning. HCPs must remain focused on the goal of using risk counseling as a mechanism to provide information that enables patients to make informed decisions. “This model of communication places increasing emphasis on the role of patient preferences and values in medical decision making—because physicians and patients may have different interpretations of well-being.”

I. **How Do The Ethical Principles Fit Into The Risk Communication Goal?**

The ethical principles under analysis must be interpreted in the context of this proposed goal of risk communication. Here, let’s revisit the principle of beneficence and

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how it relates to this aim of risk communication — which is to foster shared decision
making. “It is beneficence, not authoritarianism, as he incorrectly supposed, that prompt-
ed Ingelfinger to argue that doctors must recommend a course of action, not just lay out
alternatives and abandon patients.”11 Beneficence includes HCPs supporting the measles
vaccine as a preventative intervention, not merely discussing options outside of the realm
of allopathy. Consider that a patient specifically asks, “what course of care do you rec-
ommend and why?” In this case, HCPs duty to the principle of [social] beneficence im-
pels them to support the vaccination.

This position also respects their duty to the principle of justice which means the
HCP has an important responsibility to see his result in the larger picture. This addresses
the question posed earlier during the discussion of non-maleficence about whether the
HCP should consider harm in the context of parties other than the primary patient (i.e. the
child waiting to get vaccination vs. parent, other patients, the larger community, etc.)
Where the principle of non-maleficence would be violated is if the communication is
structured in a way in which the goal is to persuade patients to comply with the vaccina-
tion policy. Communication with this aim would include biased framing risk discretion.
The former supposition for beneficence is only acceptable when the patient specifically
asks for the advice or input of the HCP, not as the starting point of communication with a
patient who hasn’t raised this specific concern or inquiry and is simply assessing the op-
tions.

11 Edmund D. Pellegrino and David C. Thomasma, “The Conflict between Autonomy and Beneficence in Medical
3.1 The Elements of Risk Communication About Measles Vaccine Choices: How to Best Communicate

Much of the discussion in this section is concerned with the questions of what information HCPs should present to patients and in which particular form or format. Effectively addressing issues such as these required a presupposition about the overall purpose of risk communication — to inform shared decision-making. This section involves a look at the ethical considerations discussed in the previous section, namely non-maleficence and beneficence, and how they should reinforce the process of shared decision-making. Appropriate harm/benefit analyses consist of understanding, weighing, and specifying the harm that is being risked — (e.g. contracting measles) — and the likely benefits of an item of information — (e.g. herd immunity). A discussion of the elements of risk communication as they relate to informing shared decision-making follows. In section 1.3, HCPs were encouraged to integrate common risk perceptions and concerns from hesitant and exempt parents. This section will also review Risk Perception Theory as it relates to the discussion in 1.3 and thus what and how to supply information during communication.

Risk is the probability that a hazard will give rise to harm and the severity of that harm. Often, HCPs find that discussing medical risks is increasingly difficult given the confusing and imprecise use of language. HCPs should be cognizant of the multiple meanings of the word “risk,” how to use words in describing risks and ways to quantify

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risks (probability, percentages, proportions and rates). Studies suggest that “most people usually prefer the numerical presentation of information, but approximately one-third of consumers prefer verbal descriptions.”¹³ These considerations of the content of risk related discussion lend itself to how risks are interpreted. Thus, these elements can be condensed into two categories. The first is the probability of some hazard occurring and the second concerns the actual harm, and its severity for the patient.

Probabilities can be expressed in multiple ways, (using qualitative or quantitative language), which inevitably shapes how information is perceived. Some of the contributory factors of these variations is discussed later. “The term subjective probability describes this component of risk interpretation.”¹⁴ Similarly, the importance or value assigned to an adverse event (harm), such as contracting measles or an adverse reaction to the vaccine, varies based on the patient’s knowledge and personal experiences. “These values may be termed outcome utilities. Other terms used for the concept of severity include adversity and burden.”¹⁵ The utilities are likely to affect how one uses the risk information when deciding whether to modify their own risks. For example, patients’ understanding of the word measles and the significance they attach to it may affect the degree to which they are motivated to choose to vaccinate their children or themselves.

Given these considerations, HCPs should tailor their discussions of risks and provision of

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information in a way that, “addresses both the probabilistic aspects and the importance and nature of the adverse events being described.”  

Risk acceptability and parental risk decisions may also be complicated by the types of risks that patients understand. In the article, *Risky Business: Challenges in Vaccine Risk Communication*, researchers describe voluntary controllable risks as more acceptable than involuntary risks. Parents advocating parental choice in vaccination decisions contend that compulsory legislation renders vaccination an involuntary risk, and thus less acceptable. Ball et al. notes, “the acceptability of a risk is determined by whether it induces *fear* or *dread* and whether it is *memorable*. When a perceived threat is low, individuals are unlikely to accept a health intervention regardless of the efficacy of that intervention.” Thus, HCPs can presume parents who recognize the threat of measles and perceive vaccination as an appropriate resource to control it are most likely to reach a decision of vaccination.

These patterns of perception and subsequent risk-tolerance can also be explained based on the theory of *cultural cognition*. Dan Kahan and a coterie of other researchers study the mental processes behind cultural cognition. In *Fixing the Communication Failures*, Kahan notes that while “various cognitive biases — excessive attention to vivid dangers…or self-reinforcing patterns of social interaction — distort people’s perception

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of risk, [and they] fail to explain why subscribers of competing moral outlooks react differently to scientific data.”19 His research suggests that the process of “cultural cognition” accounts for this distinctive form of polarization. “Cultural cognition refers to the influence of group values — ones relating to equality and authority, individualism, and community — on risk perceptions and related beliefs.”20 The cultural cognition process causes people to interpret evidence in a biased way, which inhibits their ability to process scientifically sound information.

He draws upon an analogy to sports fans rooting for opposing teams, but distinguishes the two ideas by highlighting the fact that, for example, those who support and denounce vaccinations, “…are rooting for the same outcome: the health, safety and economic well-being of their society.”21 Given this consensus, a remedy for diminishing the interference cultural cognition plays in receiving scientific/medical information is to encourage HCPS to present information in a manner that affirms rather than threatens people’s values. His research affirms that “people tend to resist scientific evidence that could lead to restrictions on activities valued by their group,”22 thus presenting information that is agreeable to culturally diverse groups is a necessary obligation of HCPs.


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Based on the previous discussion of risk perception theories, elements of effective communication should seek to anticipate how patients perceive and understand information. The three most important aspects of effective risk communication in this context include: delineating the main message clearly, providing context (framing), and acknowledging uncertainty.23 The next three sections explore these further.

A. Delineating The Main Message Clearly

Delineating the main message involves communicating in a way that is complete, objective, and understandable. Many aspects of this strategy can be difficult regarding HCPs deciding when a risk is significant and should therefore be communicated to patients. Here, the HCP is necessarily confronted with balancing the principles of non-maleficence and beneficence while trying to present information.

Earlier in the discussion of non-maleficence, there was a discussion of the importance of selectively choosing which information to include in the risk profile. While society has adopted the principle that more information is inherently good, HCPs may be tempted to err on the side of over-communication rather than under-communication. In order to avoid violating one the two principles and the best way to keep them balanced when discussing risks in this context is to under-communicate. This is not an endorsement of providing misleading information or only using information that conforms to an overall biased decision, but suggests that HCPs should carefully consider how and why

they include specific facts. There are certainly great risks of violating the principle of both beneficence (informing patients) and non-maleficence (harm in misleading patients), which depends on how the information is presented. A focus on how information is presented follows in the section on Framing.

Additionally, risk communication research drawing from the disciplines of cognitive and social psychology, as well as behavioral decision theory can be used to justify why less is more. Patients often categorize interventions, such as the measles vaccine, as safe or unsafe without acknowledging the spectrum in between. As such, patients may be encouraged to simplify information on risk decisions that would otherwise involve the processing of a slew of information. Ball et al. discusses this process as, “heuristics — cognitive shortcuts that people use to simplify complex decisions and judgments.” While some heuristics are used to support vaccination, I will focus on those that do not. Heuristics are used by parents to qualify risk and this processing may result in a decision not to vaccinate. Specific heuristics includes, “compression, or overestimating the frequency of rare risks and underestimating the frequency of common risks.” [For example], concerns about vaccine-associated autism, which is unsupported by most scientific studies, may be increased by use of this heuristic. “Moreover, the availability of an event


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(one that is accessible or easily remembered) can lead to overestimation of its frequency; witness the effectiveness of sensationalized media reports alleging vaccine injury.”

*Omission bias* has also been elucidated as an explanation for the reluctance of certain parents to vaccinate their children. This consists of the perception that actions (commissions) are more harmful than inactions (omissions). “A study by Ritov and Baron using a hypothetical vaccine scenario found that some individuals would feel more responsible if their child died after vaccination than after a vaccine-preventable disease.”

Also, some parents may *eliminate risk*, choosing to vaccinate only if the risk of vaccination was zero. Moreover, when given a choice, individuals tend to *avoid ambiguity*. For example, “a risk from a known disease may be more acceptable than an equivalent or smaller risk that is perceived as more ambiguous (e.g. from a new vaccine).” Since their exposure to it was in a new light, “this heuristic may be operative in some parents’ avoidance of the [measles vaccine].”

Some parents who withhold vaccinations may use *freeloading* logic, relying on high vaccination rates to protect their unvaccinated child. Here, HCPs should focus on

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discussing the concept of herd immunity and the incidence of vaccine preventable diseases in unvaccinated populations. Successful risk communication must also address vaccine decision heuristics. The first step toward correcting compression and other biases in estimating risks is for HCPs to provide parents with accurate, consolidated risk data. “Although respect for individual autonomy implies truthfulness on the part of the HCP, benefit may be achieved and harm avoided by giving information that is incomplete…provided that it is accurate and not misleading.”32 Thus, HCPs must be mindful of the potential for the creation of harm in the process of over-communication. Other aspects of delineating the main message clearly include: defining the outcome (e.g. diagnosis), providing context (e.g. who data apply to, a time frame for expected effects or exposure to harm), and balanced framing.33 This list of guidelines was used by Ball et al. and is not exhaustive, but provides a basic communication framework. This squares with above discussion of heuristics and ethical principles because providing information clearly using these guidelines may eliminate the tendency for patient’s to fill in the gaps of information that aren’t specified. Furthermore, harm may result in a misinformed decision, which violates the principle of non-maleficence. Following these guidelines will reduce the likelihood of patient’s making a decision based on a lack of specific information (e.g. context of the risks and benefits).

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Part of this framework includes communicating honestly, clearly, and compassionately. In their *Risk Communication Handbook*, Lundgren and McMakin elucidate how these can be applied in practice. They note that communicating honestly consists of differentiating between opinions and facts. Any risk communication message…can be questioned by the audience. Responding credibly to a question about a fact is much easier than substantiating an opinion. Communicating clearly involves presenting information at the audience’s level of understanding. In this context, patients may reject information that is too difficult for them to process, and HCPs should temper the messages as not to patronize patients or incite hostility. To communicate compassionately, (observing the ethical principle of beneficence), HCPs should not ignore the concerns of parents, even if they are unrelated to risks. The authors note that it is best to deal with concerns as they come up and listen to the concerns as a way of guiding communication along. How should HCPs discuss those risks when they are prompted? Knowing how to answer this question challenges the risk communication efforts. The next section focuses on the framing of risk messages during communication.

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B. Framing: Providing Risk Context

With minimal experience interpreting data, patients may be especially susceptible to the framing effects frequently discussed in the cognitive psychology literature. Framing is defined as presenting logically equivalent information in different ways. Therefore, “simple changes in the format of otherwise identical numerical information can profoundly influence its interpretation.” This is important when HCPs decide the content and format of risk messages. While message framing can influence parental vaccination decisions, its effects are likely to depend on parents’ prior beliefs and perceptions of risks and benefits (cultural and psychometric factors), as previously mentioned. Discussion of the harms and benefits of the measles vaccine by HCPs can take the form of describing the broad advantages or disadvantages of the option to vaccinate or not vaccinate.

With respect to the two ethical principles in question, “there are clear risks of manipulating patient decisions [violating non-maleficence and beneficence] by the way information is presented, thus restricting opportunities for informed choice.” As a result, the HCPs role in risk communication begins with a responsible and careful interpretation of data, of which is appropriately balanced and non-judgmental way. Framing essentially


involves two elements: the quantitative vs. qualitative presentation of risks, and putting risks into context.

An essential component of framing involves the context of risks. Questions such as, “What is the risk under discussion (e.g., is it the risk of being diagnosed or of dying?)? What is the time frame under consideration (e.g., next five years or lifetime—and what does “lifetime” mean?)? Who is at risk (i.e., does the statement refer to all [children]? Children of a certain age? Children with specific characteristics?), help to define the risk context. Contextualizing risks also includes the need for HCPs to put risks into perspective. A rare outcome but one that is often discussed outside of the clinic, such as a celebrity’s child getting autism after vaccination may cause patients to overstate health risks. Thus, HCPs should attempt to clarify the severity of the measles, and how the measles compares with the familiarity of other illnesses. While not all risk factors and interventions are equally important, competing risks may arise. Additionally, “providing comparisons with the chance of familiar events—such as having a minor car accident—may help make the numbers more meaningful.” Such comparisons might help patients put their risk of contracting measles into perspective.

Also, HCPs should emphasize that not all risk factors have the same effect on certain risks. In such cases, the HCP should seek to understand how the patient appreciates


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each risk. “Problems with numeracy (i.e. low quantitative literacy) strongly relate to the difficulty in making use of quantitative data about the risk reduction.”\[^43\] HCPs should be mindful that patients have different preferences for the way they wish information to be presented and discussed with them (prefer descriptive terms versus numerical terms). Use of quantitative descriptions to define risks and probabilistic outcomes requires interpretation of statements that measure changes in risk given some exposure or intervention (measles) and introduces another key concept of framing. When expressing changes in risk, it is best to present absolute event rates or absolute changes from a baseline risk.\[^44\]

Quantitative risk framing may involve using relative and absolute risk reduction or the number needed to treat. While there is little guidance available on how to best present quantitative information, “some prior studies suggest that counts (e.g., imagine 1000 women, 10 die) may be easier to understand than percentages and… demonstrated that people have great difficulty with expressions of the form “1 in ___.”\[^45\] Expressing small risks with percentages or in the latter form may violate the principle of non-maleficence, more than if this risk was not mentioned. Small risks should be discussed in a qualitative context when de-risking the benefits of the measles vaccine, and to avoid patient heuristics in interpreting such probabilistically small cases. This brings together how people perceive risks with the ethical principles under consideration.

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Another approach is to use a scale (presented later) designed to facilitate expression of small probabilities. An unbalanced and incomplete presentation of data suggests an underlying attempt to persuade rather than inform. Given this, should HCP’s frame the information that they present in a negative or positive way knowing that whichever wording they choose is likely to influence the patient’s reactions to the vaccine? Several studies have shown that HCPs and patients focus on the benefit of intervention when it is expressed as a relative risk reduction (with baseline risk) rather than an absolute risk reduction. Consider the following hypothetical: “Children who received the measles vaccine in this study had about 40% fewer cases of allergic reactions to the vaccine.” Such a hypothetical is framed as a relative risk reduction. Additionally, salient potential harms of an intervention are likely to be presented using absolute event rates. For example, “…annual rate of measles in children was 30 per 10,000 compared to 8 per 10,000 in vaccinated population.” This asymmetric framing tends to emphasize the benefit of the vaccine while minimizing the harm. Therefore, both the harms and benefits of a treatment or intervention should be presented using the same frame.

Other framing variations include expressing the figures as, “40% more children remaining free of allergic reactions with the measles vaccine” (positive framing) or “60% more children suffering allergic reactions from getting the measles vaccine” (negative framing). “These different expressions have different motivational effects and substantial-

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ly influence whether individuals choose treatment options or adhere to chosen plans.”

This manipulation of patient decisions restricts opportunities for informed choice and violates the principle of both non-maleficence and beneficence. Potential psychological harm has been inflicted by the presentation of manipulative framing, and the autonomy of the patient has been fettered by shaping the conversation in a persuasive or biased way. This frame does not maximize benefit for the patient. When using qualitative information to frame risks, “it is best to, “avoid words like “significant,” “negligible,” and “minor.” They beg the questions, “Significant to whom? Under what conditions? Based on what evidence?” To avoid this subjective nature, pairing these descriptors with quantifiable information can add perspective for the patients. Framing information in a reasonably fair and balanced way, set in contexts that are appropriate of everyday risks the patient is familiar with is a guideline HCPs should follow. Furthermore, “it seems that a range of complementary data formats should be available to professionals…. a “shopping basket” of options with enough flexibility to address the needs of a great range in requirements of [patients].”

HCPs may still grapple with patients becoming inattentive to a risk message and thus not taking the appropriate prevention steps to effectively lower some risk. On the other hand, there is the potential for parents to become inundated by anxiety over a risk in

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which they believe they live. The HCP has a responsibility to focus on the societal significance of these conceptions in accordance with the principle of justice. This will also help to focus on the nature and meaning of the risk for the patient. “Clear health risks should be clearly communicated. Potential health risks which are not clear should have appropriate caveats expressed in a manner clearly understandable by the audience of the communication.”  

Below are examples of each of these types of health risks (clear and potential) associated with the measles vaccine.

**B1. Demonstrated Vaccine Risks**

Common local reactions at an injection site include pain, swelling, and redness. Common systemic reactions include fever and irritability which may be attenuated by taking analgesics. HCPs may be concerned with violating the principle of non-maleficence, as these are clear harms to the patient. “However, local reactions to vaccines or their components usually are not considered contraindications for vaccine administration.” This introduces the principle of the double effect, in which a single action (giving a vaccination), may have two effects — one good (preventing measles contraction) and one bad (local reaction). How should their duty to the principle of non-maleficence guide HCPs in such cases? “Double effect was designed to answer—notably, that one needs a way of assessing how to act when a proposed good action also has a risk

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or certainty of unintended but clearly foreseen bad effects.” There are four conditions that usually apply to the principle of double effect:

1. “the action itself must not be intrinsically wrong; it must be a good or neutral act.”
2. “only the good effect must be intended, not the bad effect, even though it is foreseen.”
3. “the bad effect must not be the means of the good effect.”
4. “the good effect must outweigh the evil that is permitted.”

Thus, HCPs may apply these four criteria to the case in question, and find that the principle of double effect applies. The intervention does not violate the principle of non-maleficence in such cases. Secondly, while the vaccine may constitute pain, there are ways to alleviate and palliate the pain, making it temporary. During the risk counseling, parents should be advised about how to manage the common side effects of vaccinations and how to seek help if their child experiences one or some of them.

**B2. Demonstrated and Unlikely Vaccine Risks**

“Allergic reactions occur infrequently after immunizations. Gelatin, a vaccine stabilizer, is used in the production of the MMR vaccine.” Neomycin may cause a delayed-type local hypersensitivity reaction may occur 48 to 96 hours after the vaccine is adminis-

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tered.\textsuperscript{55} However, HCPs should discuss with parents that, “the temporal relation of adverse events to vaccine administration does not prove causation.”\textsuperscript{56}

B3. **Controversial Undemonstrated Risks**

As previously mentioned, chronic diseases such as autism are often attributed to the measles vaccine. While the medical and scientific communities are not 100% sure that autism is not caused by vaccines, the level of certainty is high enough to claim there is no correlation. This may be a consequence of the temporal relationship between when vaccines are administered and disease manifestation. As a result, “parents are understandably frustrated by the lack of an identifiable cause of their child's autism and, in their search for answers, may allege that vaccines caused their child's illness…” Public perceptions of vaccine safety are usually grouped with controversial and unproven vaccine risks. However, based on the previously delineated research, both parents of un-immunized and fully immunized children express such concerns. Therefore, it is important that HCPs attempt to dispel them when communicating risks.

While many parents, 25\%, believe that, “children get more immunizations than are good for them,”\textsuperscript{57} they may not realize that the number of antigens in the vaccines have decreased. An appropriate element of HCPs’ risk information may include that the measles vaccine prevents an infection that predisposes their child to measles, rather than

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weakening the immune system. They should inform parents that the vaccine is intended to *stimulate* immunity.

Assuaging concerns regarding side effects may also include telling patients about the Vaccine Information Statement (VIS), which records information in the event of a bad outcome. “Each time [HCPs] administer a vaccine covered under the National Vaccine Injury Compensation Program… or purchased through a CDC grant, they must record in each patient's medical record the date of administration, the vaccine manufacturer, the lot number….along with the edition of the VIS that was given to the patient and the date on which the vaccine was administered.”58 Patient awareness of such protocols is a way that HCPs can uphold the principle of beneficence when risk counseling. It is recommended that HCPs, as means of upholding beneficence, provide patients with information about common but minor side effects, and rare but serious ones.

Risk framing is an important element of the communication process between HCPs and patients. Allowing parents to express their concerns will increase their willingness to respond to the HCPs views in a positive way. “In some cases, parents may be willing to accept partial vaccination or to allow the physician to gradually administer vaccinations if they are provided slowly over several visits.” Important guidelines to consider when framing risks include: clarifying the risk being discussed (risk factor or intervention under consideration), specifying competing risks, comparing risks with familiar

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events (helps to calibrate patient to risk magnitudes), and appropriately using quantita-
tive and qualitative presentations of risks.

Below is a table summarizing suggestions for ways to mitigate the risks discussed.

**Table 2. Risks and Mitigation of MMR Vaccine**

<table>
<thead>
<tr>
<th>Risk</th>
<th>Mitigation</th>
<th>Risk Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Injection Site Reactions (e.g.</td>
<td>Medicine to treat symptoms</td>
<td>Demonstrated Risk</td>
</tr>
<tr>
<td>pain, swelling, redness)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Allergic reaction to MMR</td>
<td>Medicine to treat symptoms</td>
<td>Demonstrated and Unlikely Risk</td>
</tr>
<tr>
<td>vaccine</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autism</td>
<td>Treatment for autism varies</td>
<td>Undemonstrated Risk</td>
</tr>
<tr>
<td></td>
<td>but is not demonstrated to be associated with MMR vaccine</td>
<td></td>
</tr>
</tbody>
</table>

**C. Acknowledging Uncertainty**

Some have described the Achilles Heel of the medical community as an unwillingness to acknowledge sources of uncertainty related to the measles vaccine. HCPs as supporters of the vaccination should acknowledge that they are neither 100% effective nor 100% safe, “while emphasizing that very exacting standards of safety and effectiveness are required for licensure and that approaching 100% is a key aim.”59 The section about the attitudes and beliefs associated with patient communities allows HCPs to reflect or become familiar with the most common claims that vaccination opponents put forward. Being aware of these claims can help shape conversation and alert them to the need to discuss risk uncertainty.

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Spivey points out that science is always value-laden in that there is uncertainty in what [HCPs] know. “The findings from a study, which incorporate the biases of the investigator, can create an imbalance that will in turn cause an injustice.” HCPs should highlight the basic concepts of study design (e.g. observational study versus randomized clinical trial) as a preface to quantitative or qualitative descriptions of risks. Other sources of uncertainty may include, how the data was gathered, analyzed and how the results were interpreted. This is an example of applying beneficence during communication.

HCPs must accurately portray the benefits of the measles vaccine while also acknowledging that vaccines are not always effective and in rare cases, may be accompanied by serious adverse events. In doing so, HCPs are upholding the principle of both beneficence and respecting the autonomy of the patient by presenting information in a fair way that allows them to exercise choice. In the article, Public Opponents of Vaccination: A Case Study, Leask et al., notes that not all claims of vaccination opponents are completely erroneous. The study focused on the effects of unfounded claims espoused by a micropalaeontologist Dr. Viera Scheibner. Leask et al., mentions how, “Dr. Scheibner is critical of doctors for their reluctance to report adverse events after vaccination …and that many share a desire for accurate data on adverse events…over-arching concern over scientific arrogance…define much of the appeal of public opponents.” Trust is important in maintaining public confidence in vaccine programs. The authors note an instance,


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(UK’s Creutzfeld–Jacob Disease (CJD) affair), when over confidence in vaccine safety estimates that are later shown to be incorrect erodes trust. An erosion of trust violates the principle of beneficence.

The Risk Communication Handbook posits that HCPs as risk communicators must be transparent about what they do not know and emphasize what they do know and what they are doing to resolve the uncertainties. Framing what the sources of uncertainty are when a question such as, “Is it safe?,” is posed is a critical component of the conversation. Thus, HCPs should promote the importance of vaccine adverse events reporting and make verifiable data integral to the conversation. Controversies about vaccine safety tend to draw attention from the goal of vaccines, which is to promote health. Leask et al., suggests that HCPs, “…respond to the emotions raised by the claims and then reframe the debate to center on protecting children from diseases.” This insight helps patients make considered and balanced decisions about the measles vaccine, thus respecting their autonomy.

3.3 Shared Decision Making in the Context of Risk Communication

Risk counseling is a mechanism by which HCPs structure and express information. The communication should enhance respect and support a cooperative, consensus building effort. In the article, Shared Decision Making: Really Putting Patients at The


Centre of Healthcare, researchers discuss the steps involved in the shared decision-making process. “The first and most important step in shared decision-making in preference sensitive decisions is creating awareness of equipoise —that is, explaining to the patient that there is no best choice, that a decision has to be made, and that doing nothing or keeping the status quo is also an option.”\(^\text{64}\) This step corresponds to the initial step of any good risk communication: defining the goal of the communication.

The goal was determined based on consideration for the principle of non-maleficence. “After having laid out the options, the next step is to discuss the benefits and harms of each, as well as their respective probabilities.”\(^\text{65}\) Here, the mentioned framing variations are useful. Specific framing techniques minimally violate the principles of beneficence and non-maleficence. For example, asymmetric framing (e.g. presenting risks and benefits differently) can confuse the patient and may misinform them, thus violating the principle of non-maleficence.

“Patients’ ideas, concerns, and expectations about the options, their benefits, and their harms should be elicited, and the patient should be supported in the process of deliberation.”\(^\text{66}\) This is achieved by engaging the patient— asking questions about their personal experiences and their interpretation of the risk information presented. This also in-


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volves exploring the patient’s preferred role after the information has been provided. “Research shows that patients who initially may be reluctant to participate in the decision often change their mind after the options have been laid out.” HCPs should empathically, (in accordance with beneficence — restore autonomy), engage patients to the maximum extent they desire in making a decision about vaccinating their child.

The researchers note that the partnership between HCPs and patients is successful when they share responsibility. HCPs should assess what patients need to make a decision and provide appropriate support. However, in some cases responsibility can be a burden on patients so HCPs should explain at the outset that decision-making is preferably a shared process. This prevents patients from feeling abandoned if they want input from the HCP and supported if they don’t. Some patients may prefer to defer to HCPs and not participate fully in the decision-making process. In such cases, forcing decision-making responsibilities on these patients may cause harm and distress, thus violating the principle of non-maleficence.

The concepts of shared decision making and risk communication are inseparable. Patients frequently desire information about treatment options more than they desire involvement in the decision making itself, which suggests that patients can distinguish the

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two concepts. HCPs should interpret risk communication as a shared decision-making process that involves the engagement of all parties at some or all stages of the process.

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4.0 Risk Communication Templates: Balance of Non-Maleficence and Beneficence

In section 1.3, I identified parental positions on the measles vaccination. The challenge is matching strategies to parental positions in a way that best minimizes the conflict between the ethical tenets of beneficence and non-maleficence in risk communication. Below is a Venn diagram representing the contribution of this paper to the field of risk communication.

**Figure 3. Venn Diagram Illustrating Contribution**

The Venn diagram above depicts the three elements of analysis discussed throughout the paper. The red intersection is this new analysis that uses an interdisciplinary approach to address risk communication. Drawing on concepts from risk perception theory, ethical principles, and risk communication guidelines, a template was designed that serves as a tool to help facilitate risk communication about the MMR vaccine. As the research suggests, risk communication is best tailored to individuals. In recognition of the need to support HCPs in the challenging risk communication task,
templates below serve to help guide risk communication efforts. Most of the recommendations from the literature have focused on what information is provided, whereas my template specifically addresses how HCPs should communicate in ways that align with their duty to the principles of non-maleficence and beneficence. “Since it is clear that parents want an improved dialogue about vaccinations,”¹ it is essential to orient communication toward maximizing benefit to the patient.

For two of the parental positions on vaccines a template was designed to be used ideally during communication in the clinic. The template includes identified areas of potential challenge and offered specific guidance tailored to minimizing violation of the non-maleficence and beneficence principles, while also considering autonomy and justice. The framework was informed by the literature on risk communication and shared decision-making. Below is a profile taken from, Communicating With Parents about Vaccination: A Framework for Health Professionals, of a parent who is hesitant to accept a vaccine. This profile was consistent with evidence from the literature review of the MMR vaccine highlighted in this paper. Thus, this profile can be reasonably applied to a parent hesitant to accept the measles vaccine for their child.

<table>
<thead>
<tr>
<th>Parental Position (based on Attitude, behavior and risk perception of vaccine)</th>
<th>Profile</th>
<th>Most Important Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hesitant Parent</td>
<td>“These parents vaccinate their child but have significant concerns. […] They most closely correspond to the ‘fence-sitter’ who only slightly agrees about the benefits and safety of vaccination and is neutral about their relationship and trust with their healthcare provider. Hesitants are also more focused towards vaccine risk, and are aware of issues surrounding the MMR vaccine and of other parents not vaccinating their children. Trust in their doctor or nurse is key for this group who are keen to have discussions in which their questions are answered satisfactorily and completely by knowledgeable health professionals with relevant information.”</td>
<td>• concerned about the safety and efficacy of vaccine • aware of other parental concerns (may include undemonstrated risks) • trusting of the HCP’s role in facilitating conversation</td>
</tr>
<tr>
<td>Cautious Acceptor</td>
<td>“These parents vaccinate their children despite minor concerns. They may exhibit a ‘hope and pray’ mentality recognising that vaccines carry rare but serious side effects and hoping that their child is not affected.”</td>
<td>• most likely to comply with vaccine • concerned about rare risks with serious consequences (e.g. my child could be the “1”) • understands the efficacy of the vaccine</td>
</tr>
</tbody>
</table>

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Below are templates of how to resolve the conflicting principles in risk communication with the hesitant patient and the cautious acceptor. These templates should serve as a “conversation algorithm” during the discussion about the choice to vaccinate a patient or child. The template is divided into three parts, as depicted below.

Table 4: **Hesitant Parent Template: Balancing Principles**

<table>
<thead>
<tr>
<th><strong>Review of Principles:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What are the potential violations of non-maleficence with this patient?</strong></td>
</tr>
<tr>
<td>This patient slightly agrees about the benefits and safety of vaccinations. Therefore, it can be assumed that they are well read on the scientific literature about the considerations. As such, providing information that focuses mainly on the scientific and clinical evidence of the measles vaccine could result in harm in the form of creating anxiety or frustration. The patient is also more focused toward vaccine risks, so negative framing could potentially cause harm because it could inappropriately manipulate the patient into a decision to vaccinate.</td>
</tr>
<tr>
<td>As discussed during the analysis of principles (Section 2.0), given the goal of risk communication—which is to inform shared decision-making, not to induce a decision of compliance — constraint of the principle of non-maleficence can be justified on Kantian grounds in which respect for persons and their autonomy is fundamental justification.</td>
</tr>
</tbody>
</table>

| **What are the potential violations of beneficence with this patient?** |
| Trust of the HCP is important to this patient, thus conversations that are centered around providing information that is unsupported by HCPs may negatively diminish this level of trust. The patient is hesitant to oblige with vaccinations. Therefore, the principle of social beneficence, which considers patients in the larger community as opposed to the primary patient or child of the hesitant patient, may involve the HCP structuring conversation in a way that promotes the vaccine, which is in violation. Address fears that interfere with a patient’s ability to make decisions |

| **What are the patient’s preferences, values, attitudes, beliefs concerning the measles vaccine?** |
| The patient does not have a clear preference for or against the vaccine, but appears to have reservations. Their attitude toward the vaccine lends itself to concerns about the safety and efficacy of the vaccine. Furthermore, it is important that the HCP not assume the parent’s expectations and needs during the appointment. The hesitant parent may only seek information about the vaccine. Thus, the HCP should not pressure the parent into thinking they have to get vaccinated that day or at all. Losing the trust of the patient may cause him or her not to return or leave the appointment, thus violating both the principle of autonomy and non-maleficence. |
Risk Assessment:

What are the identifiable risks?

The identifiable risks include: the child contracting measles if the patient forgoes the vaccine and the local reaction at the injection site after the vaccine is administered. As previously discussed, a hesitant parent may weigh arguments and doubts regarding the measles vaccine and oppose based on the notion that natural immunity gained by contracting the disease is seen as a protective resource as opposed to a threat or burden (Anthroposophy).

What does the patient already know? What are the risks potentially of concern for the patient?

The patient is aware of issues surrounding the vaccine and of other parents not vaccinating their children due to safety or efficacy reasons. The risks most salient to the patient are related to adverse reactions after receiving the vaccination, as opposed to the risk of contracting the measles. The HCP should mention that measles is a serious disease that has decreased in prevalence through the vaccination program.

What factors potentially influence the patient’s risk perception? What are possible decision heuristics?

Safety and efficacy of the vaccine, other parents experiences with the vaccine. Overstating the risks of contracting measles or of the side effects of the vaccine impairs the patient’s ability to make informed decision and violates their right not to be harmed (e.g. inducing anxiety)
Balancing the Conflicting Principles Through Framing:

Which method of framing the estimation and evaluation of the risks violates the principles most? (no treatment vs. treatment side affects)

Because the patient is uneasy about the vaccine due to the risks associated with getting one, negative framing (emphasis on risks) may further increase these feelings and cause emotional or psychological harm. When risks are discussed, they should be discussed in the context of whether they are demonstrated, undemonstrated and potential ways to mitigate them. Vague qualitative descriptors may leave the patient feeling more uneasy and not using examples relatable to the patient to connect risks may also limit his or her engagement with the decision-making process. The patient values the trust level and it should be preserved by creating an environment in which his or her values are an integral part of the conversation. (shows concern and care)

Which method of framing the estimation and evaluation of the risks violates the principles least?

Because the patient is more focused on vaccine risks, the HCP should start out addressing the risks of getting and not getting the vaccine. The HCP should avoid negative framing and apply neutral frames to risk information. This is always best from the perspective of autonomy. It may be best to provide information in a quantitative format and use the risk scale (see below) to show probabilistically small risks associated with adverse effects. Discussion of how to palliate or alleviate injection site reactions is critical. Quantitative data about the efficacy of the vaccine in preventing measles may be more helpful than descriptors, since risks are generally expressed in this format.
Table 5. Cautious Acceptor Template: Balancing Principles

<table>
<thead>
<tr>
<th>Review of Principles:</th>
<th>What are the potential violations of non-maleficence with this patient?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Because these parents typically vaccinate their children, that they are cautious may</td>
</tr>
<tr>
<td></td>
<td>raise concerns for HCPs. Like the hesitant parent, this parent shares concern about the risks</td>
</tr>
<tr>
<td></td>
<td>(rare but serious) associated with the vaccine. Focusing on the fact that they are likely to</td>
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<td></td>
<td>comply may tempt the HCP to communicate in a way that attempts to persuade the patient</td>
</tr>
<tr>
<td></td>
<td>rather inform share decision-making. This would violate the principle of non-maleficence.</td>
</tr>
<tr>
<td></td>
<td>Assuaging their fears of vaccine risks is an important component of the communication.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What are the potential violations of beneficence with this patient?</th>
</tr>
</thead>
<tbody>
<tr>
<td>One aspect of beneficence as discussed in section 2.0 is creating conditions in which</td>
</tr>
<tr>
<td>patients can exercise autonomous choice. Thus, if the HCP does not communicate in a way</td>
</tr>
<tr>
<td>that reinforces that the parent can make the ultimate decision violates the principle of</td>
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<tr>
<td>beneficence. Similarly, the HCP must provide informed consent — give the patient the in-</td>
</tr>
<tr>
<td>formation necessary to define the scope of the risks and benefits of the vaccine — and al-</td>
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<tr>
<td>lowing the patient to assign the weight to these considerations. If the HCP assigns the</td>
</tr>
<tr>
<td>weight to these factors during communication, they potentially violate the principle of</td>
</tr>
<tr>
<td>beneficence.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What are the patient’s preferences, values, attitudes, beliefs, concerning the measles vaccine?</th>
</tr>
</thead>
<tbody>
<tr>
<td>The patient is most likely to comply with the vaccine, but are worried that their child</td>
</tr>
<tr>
<td>might experience some of the rare but serious side effects. They value protecting their child</td>
</tr>
<tr>
<td>against the potential disease, but also want to make sure that the risks are minimal before</td>
</tr>
<tr>
<td>making a decision.</td>
</tr>
</tbody>
</table>
Risk Assessment:

What are the identifiable risks?

The identifiable risks include: the child contracting measles if the patient forgoes the vaccine and the local reaction at the injection site after the vaccine is administered. Since the patient is aware of the risks associated with vaccination, the HCP should discuss how the injections work and what may occur at the injection site. They should also discuss how long this symptom will last and provide how mitigation is achieved. Allowing the patient to ask questions maximizes their autonomy.

What does the patient already know? What are the risks potentially of concern for the patient?

The parent is aware of the risks associated with vaccination and not vaccinating. They are particularly concerned about rare risks of large impact (e.g. getting sick after vaccination).

What factors potentially influence the patient’s risk perception? What are possible decision heuristics?

Safety of the vaccine, as opposed to efficacy. The parent is aware that the vaccine does protect against measles, so the focus of communication should not be about how the vaccine works, rather how to avoid or treat symptoms that occur following vaccination. Possible decision heuristics include compression, or overestimating the frequency of rare risks and underestimating the frequency of common risks. Thus providing the context of risks is important.
Balancing the Conflicting Principles Through Framing:

Which method of framing the estimation and evaluation of the risks violates the principles most? (no treatment vs. treatment side affects)

Framing the risks using just qualitative or just quantitative data may induce the parent to use heuristics. Also, failing to provide an appropriate context (e.g., who is at risk, what is the potential harm that can occur) violates the principles most because this would not lead to the parent making an informed decision (autonomy).

Which method of framing the estimation and evaluation of the risks violates the principles the least?

Framing should consist of both qualitative and quantitative expressions of information, preferably when describing the same risk or benefit. For example, the HCP may positively frame risk using percentages but also say this is most common before giving a high percentage. Observing the body language of the parent and allowing the parent to interject when they have concerns may help guide the framing techniques used by the HCP. When the HCP describes a demonstrated risk (e.g., fever) the HCP should provide how the harm is mitigated immediately after discussing the adverse reaction. The HCP can build rapport by eliciting concerns — asking what they are — and presenting risks up front without prompting from the parent. Inviting the patient to come back to the clinic should they experience an adverse reaction embodies beneficence.
Using these templates, the HCP can appropriately consider the competing principles and identify which of the framing techniques minimizes this conflict. After addressing the concerns in the template, the HCP should explore other competencies of shared decision-making. This includes: exploring the concerns and expectations of the patient, checking the role preference that the patient wishes to have in the decision-making process, and asking questions of the patient regarding the information they wish to have to weigh options, what aspects are important for the patient to consider, and exploring a comparison of the harms and benefits. Retrieval of this information is facilitated by using the questions provided in the section on elements of risk.

Research has been conducted regarding how parents of various positions about the MMR vaccine react to different ways that HCPs may communicate about the benefits and risks of vaccines. For example, in the article cited for the parental positions, *Communicating With Parents About Vaccination: A Framework for Health Professionals*, researchers sought to understand how certain elements and ways of communication affected parents’ reactions to vaccines. They provided a framework for HCPs that consisted of recommendations tailored to specific parental positions on vaccinations. Similar to the premise of this paper, researchers advocated, “respectful interactions that aim to guide parents towards quality decisions.” They also posited that the best way to increase the likelihood of the parent making a decision was to employ strategies such as, “verbal and numerical descriptions of vaccine and disease risks, explaining common side effects and rare, important risks, using a guiding style.” One of the most important takeaways was

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that flexibility in addressing parent’s needs was the best way to structure communication, which is consistent with the previous analysis of the differences in risk perceptions about the MMR vaccine. The researchers provide example of dialogue between an HCP and parents of different positions. These conversations were brief and there was no mention of the ethical principles serving as a basis for this dialogue. This paper seeks to structure communication in a way that best observes the ethical principles central to medicine and minimizes potential conflict between them.

Evidence of effective communication strategies from other areas of healthcare practice include the concept of motivational interviewing. “This is a form of communication that uses a guiding style, rather than a directing style…for discussions where there is ambivalence and resistance to change.”\textsuperscript{4} The proposed template can be applied to patients of varying attitudes and behaviors associated with the vaccine. Motivational interviewing may be most appropriate for those with hesitant or cautious acceptor profiles.

\textsuperscript{4} IBID
5.0 Conclusion

Vaccine risks — irrespective of their rarity and scientific verifiability — influences public policy and affects patient attitudes and compliance towards immunizations. Resistance to vaccination arises from many factors, including declining prevalence of diseases, uncertainty in scientific information, and the desire for autonomy and freedom of choice. Effective risk communication acknowledges the factors associated with the process and engages patients appropriately in making vaccination decisions. Doctor-patient communication that focuses on applying the principles of medical ethics salient to the practice can lead to striking improvements in risk communication and shared decision-making. As a result, templates were developed that can assist HCPs in communicating with patients of varying concerns, values, and perceptions of risks and benefits. Ideally, these templates could be improved given input from a panel of experts from the fields of Bioethics, Medicine, Sociology, and Psychology. Additionally, a study design that tested the effectiveness of using these templates may provide insight in how practical they are during clinical appointments.

HCPs have an obligation to maintain a neutral balance of the principles of beneficence and non-maleficence. Furthermore, they should communicate with a level of transparency that assists in building trust and mutual cooperation during communication. Risk communication should enable patients to make informed choices, rather than simply to modify behavior toward compliance. Ultimately, the responsibility of risk communication lies with public health officials as well as HCPs who are ideally situated to communicate
the benefits and risks of vaccines and recommend/administer vaccinations. Rather than relying on public health administrators to interpret information for the public, I proposed a framework that develops HCPs’ capacity to be critical disseminators of health information.

While this paper attempts to mitigate one dimension of the risk communication challenges, public health and medical communities still face additional challenges. HCPs and bioethicists should continue to review the ethical principles discussed and strive to uphold them in all aspects of healthcare delivery. The pharmaceutical industry follows guidelines on how to communicate with consumers about the safety of products. The research enterprise follows codes of ethics, especially when conducting human subjects research. Perhaps codes of ethics could be developed for the communication of health-related information to the public. Hospitals and clinics may consider adopting internal policies that provide ethical guidelines for communicating about interventions that are likely to have variability in compliance and/or that are likely to be controversial.

Additionally, another challenge to consider is when there is a future alternative intervention to vaccines. The advent of new vaccine products will inundate the current immunization schedule and thus may complicate risk communication efforts. The ethical dimensions of emerging technologies in the pipeline, such as DNA vaccines, have yet to be explored. While this alternative, (involves vaccine combinations that diminish the need for boosters), may increase vaccine compliance rates, the safety of such technologies has not been evaluated and may exacerbate safety concerns. HCPs must remain
aware of data on vaccines and apply them to the principles of ethically responsible and appropriate risk communication.


Novella, Steven. "The Lancet Retracts Andrew Wakefield’s Article « Science-Based Medicine." The Lancet Retracts Andrew Wakefield’s Article « Science-Based


