Difficult Conversations in the Ambulatory Pediatric Setting

Sheldon Berkowitz

ABSTRACT

Complex conversations about pediatric care occur in many different settings. Some of the most difficult conversations surround vaccine resistance which is a topic that is frequently discussed in ambulatory pediatric clinic visits. The MMR (measles, mumps, and rubella) vaccination has prompted significant resistance in some communities, leading to ongoing discussions in the primary care setting. The recent measles outbreak in Minnesota[1] provided a unique opportunity to broaden this discussion about vaccination to include community leaders, leading to more effective changes in parental perceptions about the vaccine.

Most people assume that all difficult and complex conversations with patients and families occur in an in-patient setting, either in NICUs or PICUs (neonatal or pediatric intensive care units) or oncology units. However, difficult conversations can and often do occur both in out-patient clinic settings and also within broader community settings. In some situations, the community conversations have even more of an impact on patient care than what happens in the exam room.

CASE

The mother of a 20-month-old child brings her daughter in for a well-child visit. The pediatrician, while reviewing her immunization records, notes that she is up to date for all immunizations except for her MMR vaccine, that is typically given between 12 and 15 months of age. In further discussions with the mother, the pediatrician is informed that, in this family's community, there are concerns about many children being diagnosed with autism, and the subsequent conviction that it is due to MMR vaccination. Despite extensive conversation with the mother about (1) the lack of scientific evidence for any association between the MMR vaccine and autism, (2) discussion about the risk of contracting measles if another outbreak was to occur, (3) a reminder of a recent large outbreak of measles in this community, and (4) the information that other members of this community are vaccinating their children with the MMR vaccine, the mother refuses to give consent for the MMR vaccination.

These challenging situations occur frequently in our general pediatric practice, which cares for a large number of Somali children.[2] However, vaccine refusal is not unique to the Somali population, and is also seen in many other settings where some or all vaccines may be refused by parents.[3] Since the clinician's (pediatrician's, pediatric nurse practitioner's, or family practitioner's) primary obligation is to meet the needs of the child, those needs can at times be in conflict with the needs or desires of the parents, who are acting in their role as surrogate decision makers for their child, who is unable to

Sheldon Berkowitz, MD, FAAP, is a Pediatrician in practice at Children's Hospitals and Clinics of Minnesota in Minneapolis, Minnesota. *Sheldon.Berkowitz@childrensmn.com*

express a preference or is not legally of age to make medical decisions. There are multiple issues for clinicians to keep in mind when having challenging discussions about care decisions with families, such as (1) what is motivating the family to act in a way that is contrary to what is being recommended, (2) how to work with the family to follow the recommendations offered by the clinician, (3) how much to push on an issue at a particular visit versus ongoing conversations with the family over time, and (4) when the refusal to follow through on a recommendation rises to the level of neglect and requires clinicians to contact child protective services.

In the case described, the clinician needs to balance doing what is right for the child—by balancing the benefits of the vaccination against its known side-effects—while trying to respect the family's belief that the vaccine may cause their child to develop autism, and the family's right to refuse the vaccine (in their role as surrogate decision makers).

In the spring and summer of 2017, this particular issue of vaccine resistance took on additional importance as Minnesota experienced the largest measles outbreak in decades.[4] Ultimately, close to 80 patients were infected with measles, and a large percentage of those patients were children in the Somali community who had not been immunized by the MMR vaccine.[5] Most of the families in this community were not resistant to all vaccines, but were specifically resistant to the MMR vaccine. This fear started more than 10 years ago when a British physician, Andrew Wakefield, claimed an association between MMR vaccine and autism. He later came to the Twin Cities' Somali community to promote this belief during the 2011 measles outbreak in Minnesota.[6] Despite the fact that Wakefield's views had been discredited and he lost his license to practice medicine,[7] his views, as well as those of others in the anti-vaccine community at large, led to a significant decline in MMR vaccination.[8] Many articles were written dealing with how to overcome vaccine resistance from families,[9] and much was learned during the recent measles outbreak about working with community leaders (religious and cultural leaders) to help them understand and share knowledge with their communities. While the discussions that occur in the community are important, in the end, it's the discussion that occurs in the exam room between a family and their clinician that either results in agreement or a refusal to immunize. One of the main lessons I have learned is to listen and respond to the family's fears without solely focusing on the goal of immunizing their child. In partnering with a family, there is a greater chance of accomplishing the ultimate goal of protecting the child from contracting vaccine preventable illnesses, such as measles.

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During the most recent measles outbreak in Minnesota, I was fortunate to participate in conversations about how to effectively immunize our patients against measles with a variety of stakeholders. The conversations began in our own institution as we grappled with the best way to reach out to our patients and whether to confront the anti-vaccine groups who were planning "events" in our community. There were concerns that attending such events could do more harm than good, and alienate the families we were trying to reach. To add to the complexity of the situation, when Wakefield had spoken in Minnesota years earlier, with no organized clinician response against his views, the Somali community felt that no one cared about investing in their health.[10] Ultimately, a number of clinicians (including myself) attended the first of these "anti-vaccine" events, but did not acknowledge what institution we were from. Over time, working groups developed between Children's Minnesota, the University of Minnesota, Mayo Clinic, Hennepin County Medical Center, as well as the Minnesota Chapter of the American Academy of Pediatrics, the Minnesota Department of Health, and a number of imams and other leaders of the Somali community. In the work groups that I participated in, it was agreed that the best way to reach out to the Somali community and

effect change was to meet with religious and other leaders of the community in their mosques.

I had the opportunity over several months to meet with and talk with imams, sheikhs, and other community members in four different mosques. It was at the first meeting, early in the epidemic, that one of the imams stated that he could not stand by and risk seeing his community's children get infected with measles and possibly die, and that seemed to make the difference. He stated that it was the imam's responsibility to make sure this doesn't happen. From there, many clinicians started being invited to mosques to meet with the community and talk about measles, MMR vaccine, and autism. While the conversations were always cordial, they were not always easy. We clinicians learned to listen to the stories of the Somali community, including stories from parents who were convinced that their children "changed" or "stopped talking" after getting the MMR vaccine, and were later diagnosed with autism. I listened as parents talked about not having known about autism prior to immigrating to the United States. I listened as families talked about the shame in their community of having a child who was "different" with autism. Even though I have often heard that the Somali community has a strong "oral tradition," which is why written Somali documents have typically not been utilized, learning that this oral tradition also includes more attentive listening was an important lesson. In addition to listening, we shared what we knew about measles, the MMR vaccines, and autism. We talked about the current outbreak and why it was spreading, the benefits and risks of the MMR vaccine, and what is known about autism—incidence,[11] presentation, and causes. We also made a point to answer every question asked of us to the best of our ability. In the end, it was these conversations within the Somali community, in their houses of worship, that had the most impact and led to large numbers of previously underimmunized children now receiving the MMR vaccine.

In the first one to two weeks of the measles outbreaks, families in our clinic continued to refuse the MMR vaccine. However, after the first few weeks, as the number or infected children started to increase, we all started seeing more willingness of families to vaccinate their child with the MMR vaccine. The parents heard the message, both at their mosques as well as from others in the community, that the theoretical (and nonscientifically supported) risk of that their child might develop autism after the MMR vaccine was less important than the real risk of their child contracting measles and needing to be hospitalized, or, in the worst-case scenario, dying (as happened in Minnesota's previous measles outbreak in 1990, when 460 people became ill and three people died[12]). Unfortunately, now that the outbreak is over, I am once again having the same conversations with families about refusing the MMR vaccine due to their fear that their child will develop autism.

I have had patients die of vaccine-preventable diseases, and I watched an older cousin live with the effects of polio when he was a young child in the 1950s, before polio vaccination was available. As a pediatrician, my conversations with parents who refuse to vaccinate their child for one or more preventable diseases are among the most difficult conversations I have. Even though I try to use the lessons learned over the previous several months, during the Minnesota measles outbreak, I fear that community-held beliefs about the MMR vaccine are again taking hold. If we are to make long-lasting changes in vaccination rates, it is essential that we continue to work on this issue, not only inside our clinics, but also in the communities where our patients and their families live, work, and worship. We will need to build on the trust that has developed between the Somali community and healthcare providers by continuing to meet with them and address their concerns.

BLINDING OF THE CASE

Details of this case were altered to protect the identities of the patient and the family.

NOTES

1. D. Hall et al., "Measles Outbreak—Minnesota April-May 2017," [U.S. Centers for Disease Control and Prevention] *Morbidity and Mortality Weekly Report* 66, no. 27 (14 July 2017): 713-7, *https://www.cdc.gov/mmwr/volumes/66/wr/mm6627a1.htm.*

2. "Minnesota is home to the largest Somali population in the United States. Estimates range from 30,000-100,000." "Somali and Somali American Experiences in Minnesota," *MNopedia,* 27 February 2018, *http://www.mnopedia.org/somali-and-somali-american-experiences-minnesota.*

3. C. McKee and K. Bohannon, "Exploring the Reasons Behind Parental Refusal of Vaccines," *Journal of Pediatric Pharmacology and Therapeutics* 21, no. 2 (March-April 2016): 104-9.

4. Hall et al., "Measles Outbreak," see note 1 above.

5. M. Osterholm, "Unfounded fears about vaccine put kids' lives at risk," [Minneapolis] *Star Tribune,* 4 May 2017; L.H. Sun, "Measles outbreak in Minnesota surpasses last year's total for the entire country," *Washington Post,* 1 June

2017, *https://www.washingtonpost.com/national/health-science/imams-in-us-take-on-the-anti-vaccine-movement-during-ramadan/2017/05/26/8660edc6-41ad-11e7-8c25-44d09ff5a4a8_story.html?utm_term=.ef8e9407e354.*

6. L.H. Sun, "Anti-vaccine activists spark a state's worst measles outbreak in decades," Washington Post, 5 May 2017, *https://www.washingtonpost.com/national/health-science/anti-vaccine-activists-spark-a-states-worst-measles-outbreak-in-decades/2017/05/04/a1fac952-2f39-11e7-9dec-764dc781686f_story.html?utm_term=.2b4224b0e27d.*

7. L. Eggertson,. "Lancet retracts 12-year-old article linking autism to MMR vaccines," *Canadian Medical Association Journal* 182, no. 3 (2010): E199-200.

8. B. Mole, "Anti-vaccine groups step up work as Minnesota measles outbreak rages," *Ars Technica,* 2 June 2017, *https://arstechnica.com/science/2017/06/anti-vaccine-groups-step-up-work-as-minnesota-measles-outbreak-rages/*; J. Belluz, "Minnesota's measles outbreak is what happens when anti-vaxxers target immigrants: A new study found Minnesota children with foreign-born parent were 25 percent less likely to have their vaccines," *Vox,* 26 October 2017, *https://www.vox.com/science-and-health/2017/10/26/16552864/minnesotas-measles-outbreak-immigrants-anti-vaxxers.*

9. S.E. Williams, "What are the factors that contribute to parental vaccine-hesitancy and what can we do about it?" *Human Vaccines & Immunotherapeutics* 10, no. 9 (September 2014): 2584-96; Public Health Agency of Sweden, Barriers and motivating factors to MMR vaccination in communities with low coverage in Sweden: Implementation of the WHO's Tailoring Immunization Programmes (TIP) method, 2015, *https://www.folkhalsomyndigheten.se/contentassets/5db4b41a40f94e98b0e1d0d4a596bae8/barriers-motivating-factors-mmr-vaccination-communities-low-coverage-sweden-15027.pdf;* L Bahta and A. Ashkir, "Addressing MMR Vaccine Resistance in Minnesota's Somali Community," *Minnesota Medicine* 98, no. 10 (October 2015): 33-36.

10. Sun, "Anti-vaccine activists," see note 6 above.

11. Institute on Community Integration, *Minneapolis Somali Autism Spectrum Disorder Prevalence Project: Community Report 2013* (Minneapolis, Minn.: University of Minnesota, 2013).

12. Minnesota Department of Health, "Health officials declare end of measles outbreak: Response required extensive collaboration among many partners," 25 August 2017, *http://www.health.state.mn.us/news/pressrel/2017/measles082517.html.*