

Communication Strategies for Patients Who Are Nonverbal

Abigail Schnaith, MD,^a Jo Schifsky,^b Toby Schifsky,^b Michael B. Pitt, MD^a

PROLOGUE (JO AND TOBY SCHIFSKY)

Charlie never spoke, was unable to walk, and could not feed herself, yet she communicated and expressed her full range of emotions (most of all, joy) to all she encountered. In this article, we share our journey in the health care system advocating for providers to communicate with our daughter, Charlie, who did not communicate with words.

INTRODUCTION (DRS SCHNAITH AND PITT)

Effective clinician-patient communication is linked to better health outcomes and patient satisfaction.^{1,2} Accordingly, there is a growing emphasis on clinicians recognizing that how both what we say and how we say it affects our patients' health and well-being. These efforts tend to focus on modifying the language we use (ie, recognizing how often we inadvertently use jargon³) or learning ways to demonstrate empathy so our patients feel heard.⁴

Although these skills are essential, they inherently rely on the presupposition that our patients themselves communicate verbally. In pediatrics, however, a core demographic of our patients have yet to develop this ability. Additionally, we often care for children with complex medical needs who may never communicate verbally. As pediatricians, we must expand our communication skillset. Failing to consider nuances in communicating with families of children who do not

communicate with words (and with the children themselves) sets us up for predictable challenges.⁵

In our practices, we noticed that communication strategies being taught often failed to address many of the needs of our patients who did not communicate verbally. Or worse, the strategies which would apply, such as warmly greeting the patient and introducing ourselves, were being skipped entirely on the basis of the false assumption that because the patient did not communicate traditionally, this step in forming a therapeutic alliance may not be understood and was, therefore, unnecessary.

This article will share how the Schifskys' experience helped inform our practices and will highlight simple strategies that can be implemented to improve communication with our patients who do not communicate verbally.

CHARLIE'S STORY (JO AND TOBY SCHIFSKY)

One of the first phrases we recall hearing about Charlie was that she was "not compatible with life." This statement was said while we were being encouraged to terminate our pregnancy after Charlie was diagnosed in utero with semilobar holoprosencephaly. Our family, however, decided to let her journey unfold, and we could not be more grateful for the gifts Charlie gave us. Although her life ended prematurely, in her short 7 1/2 years she taught

^aUniversity of Minnesota Masonic Children's Hospital, Minneapolis, Minnesota; and ^bParent

Mr and Mrs Schifsky are parents sharing their story surrounding their daughter Charlie's journey in the health care system, and they were both involved in the conception of this manuscript, wrote the narrative portion, and provided critical revisions to the manuscript; Dr Schnaith is a pediatric resident who cared for Charlie and became a champion for teaching providers strategies for communicating with patients who do not themselves communicate verbally, and she contributed to the conception of the manuscript outline, performed literature review, contributed to drafting and revising the provider sections of the manuscript, and provided critical revisions to the manuscript; Dr Pitt is a pediatrician who teaches relationship-centered communication to providers, and he contributed to drafting the initial content outline for the manuscript and the provider portion of the manuscript, developed the table, and critically revised the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Address correspondence to Michael B. Pitt, MD, Department of Pediatrics, University of Minnesota Masonic Children's Hospital, 2450 Riverside Ave, M653, Minneapolis, MN 55446. E-mail: mbpitt@umn.edu

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lessons to everyone who took the time to engage her.

At age 5, we were surprised (as were her teachers and medical providers) when we learned that Charlie was profoundly deaf after a sedated auditory brainstem response test. Charlie had failed her newborn hearing screen but passed her initial nonsedated auditory brainstem response test and had adapted to her environment so well that none of us had any idea that she was not hearing her world. She used reflective surfaces to see action behind her, intently watched people's eyes and expressions to see what they were reacting to, and felt the pressure change in a room when a door was opened. She was wicked smart.

American Sign Language (ASL) became Charlie's receptive language (she adored sign language videos), and she was figuring out ways to show us that she was capable of reading. Through cued speech, she was even matching rhyming words. Charlie started using an eye-gaze communication device, although she could not hear the output. Charlie had many excellent doctors, but there were a few who dismissed her right away after meeting her. In fact, on multiple occasions when providers chose to ignore her input during a visit, she would clamp her mouth tight, search her eye-gaze device for the right buttons, and in quick succession, repeatedly select the "DON'T LIKE" and "BYE" buttons. This was her way of saying, "If you don't engage with me, I will not engage with you."

Yet despite Charlie's ability to communicate, because she could not answer questions with her voice, those not willing to learn about her had no way of knowing what she could tell them. Charlie was a child with profound disabilities and

complex medical needs, and most assumed she had nothing to offer or contribute.

Unlike many stories shared by other families of children who do not communicate verbally, we were blessed with mostly engaged providers. Yet the insights we gained from the occasional rushed or poorly nuanced meeting with a provider who failed to see Charlie's ability to communicate could mean weeks of effort to rebuild trust with the professional. For a little girl who spent so much time in a hospital or clinic, she needed to feel heard and safe to endure the numerous appointments and procedures that comprised so much of her life.

COMMUNICATION AS A MODIFIABLE SKILL (DRS SCHNAITH AND PITT)

Learning to use a new surgical technique and attempting a new communication approach are both expanding on modifiable skills. Just as surgeons must prepare for a different approach when faced with a difficult anatomic case, clinicians must be prepared for how to approach common challenging conversations. Improving communication in health care is often focused on helping providers prepare for these triggers by first recognizing common cues (eg, a patient is frustrated because they have been waiting) and equipping them with tools to respond that show they understand (eg, validating the frustration with "I hate waiting for a doctor and I'd be frustrated too"). To better demonstrate empathy at the bedside, we must first learn to identify when our patients' communication (verbal or nonverbal) requires an empathic response rather than pure data and then be prepared with useful types of responses. Data reveal that even

these prepared remarks manifest as empathy with our patients.^{4,6}

Being prepared with phrases for communication challenges goes beyond demonstrating empathy. Prepared, simple word swaps can change the meaning of a conversation for a family. For example, Carroll et al describe how if providers simply change the phrase "I'm sorry, we have bad news ..." when sharing a diagnosis, such as Down syndrome, to "We have some news which may be unexpected," providers' value judgement based on our own implicit biases is taken out of the equation.⁷ Similarly, the learned phrase not compatible with life, which was clearly disproven by Charlie, should be removed from our lexicon. In fact, as we look further into Charlie's story, her life teaches us several modifiable skills for how to communicate with patients who do not communicate verbally.

CHARLIE'S STORY, CONTINUED (JO AND TOBY SCHIFSKY)

Charlie had a favorite provider who always took the time to listen to her communication. He sat face to face with her at her wheelchair level and explained what he would be doing before he did it, gave her space to respond, and even knew when she was missing her sparkle. They had a lovely rapport, and she had faith in his care. Each time they met, she was poked for a blood draw, and it hurt. Yet when she would spot him, she would squeal with delight! They had an understanding, and she appreciated and adored him because of it. Yet even this doctor, who was the most beautiful example of how to treat all patients, was surprised the day we showed up with an ASL interpreter to provide the dialogue for Charlie in the language she best understood, and Charlie became

even more engaged in the appointment. Once again, our little girl, locked in her body, understood so much more than anyone expected she did.

CHARLIE'S MESSAGE: STRATEGIES FOR COMMUNICATING WITH PATIENTS WHO DO NOT COMMUNICATE VERBALLY (ALL)

We created a tool that highlights several techniques for communicating with patients who do not communicate verbally (see Fig 1). First, we should note that several of the best practices we are taught to use when working with patients who communicate verbally also apply for patients who do not. We should demonstrate that we see the patient first by greeting them and introducing ourselves. Acknowledging something about the patient other than their medical condition helps us build rapport and also allows the family to feel like their child is being cared for as a person, not a disease. For example, curious providers would learn that Charlie would squeal and select "LIKE" for the color pink, for butterflies, and for having her feet tickled. Asking children about favorite movies, colors, etc is something we do for our other patients while building rapport, and this should be no different for our patients who communicate nonverbally.

Secondly, children who communicate nonverbally often have unique ways of communicating with their family. We suggest asking open-ended questions such as "How does she communicate with you?" as opposed to the yes or no question "Can she talk?" The former shows that we understand and expect that the parents and patient have ways they communicate with each other, either formally through an eye-gaze device like Charlie or more nuanced through shared gestures of facial

cues. As providers, we should share in the responsibility of advocating for our patients with the parents, and by seeking understanding on how a patient communicates we are better equipped to advocate for services such as an ASL interpreter or communication devices.

Additionally, it is important to listen to families and view them as the expert in their child. For example, Charlie had a distinct scream that she would make only when her sodium was too low. Over the years, providers often assumed that when she was screaming in the emergency department this was her normal and often refused to do anything because her vitals were stable. It took her parents advocating that this only occurred when her diabetes insipidus was causing electrolyte abnormalities. Asking questions, such as "Is this behavior different from her baseline?" or "When she acts differently like this, what do you think she is telling you?" can invite important insights and lead to better care.

As mentioned above, Charlie loved when her feet were tickled. Children who communicate nonverbally often appreciate touch. It has been shown that physical touch can improve perceived politeness and warmth and improve communication.⁸ Asking permission from the patient and family to shake the child's hand or place a hand on their shoulder when you talk to them likely has similar effects to patients who communicate nonverbally and removes the paradigm that the only time they experience physical touch in the clinical setting is during an uncomfortable examination or laboratory draw.

During our physical examination, we should narrate what we are doing through words and actions. By assuming that children who

communicate nonverbally cannot understand us, we place limits on their abilities. Charlie often had physicians examine her from head to toe before saying anything to her. She would become nervous and scared. When providers simply explained and showed her what they were doing, her nervous feelings improved and she was often much more cooperative with the examination, similar to children who communicate verbally.

In addition to thinking about how we communicate with these patients, we should revisit how we often communicate about them. Focusing on how a patient does communicate, as compared with how they do not, should be part of how we discuss the patient with other medical providers. Additionally, we should all aim to use person-first language. For many conditions, person-first language allows us to separate the child's condition from their identity (a child with holoprosencephaly, as opposed to a holoprosencephaly patient). This separation of diagnosis or disability from a patient's identity is essential to providing personal care.⁹ It reminds us Charlie was not just a nonverbal patient. Rather, Charlie was 7-year-old, cheerful girl with holoprosencephaly who communicated nonverbally and whose wicked sense of humor and smile are missed every day by those who knew for her and cared for her. We are grateful to Charlie for her ability to communicate to us still by improving the way we care for other children who may not communicate verbally. It is our hope that through this work she can continue to teach providers how to improve their communication with patients like her.


Do	Don't	Example Phrase
<p>Acknowledge the patient first, regardless of whether you think they will be able to communicate verbally back</p> <p>Say hello and introduce yourself and give them a compliment, if appropriate, or acknowledge they aren't feeling well</p>	<p>Immediately start taking a history from the family without directly acknowledging their child as your patient</p>	<p><i>Walking into room, looking at patient, and talking directly to them:</i></p> <p>"Hi, you must be Charlie. I'm Dr Jones, and I'm going to be one of the doctors taking care of you while you're here. I'm sorry you feel sick. I'm going to chat with your mom to see how I can help you feel better."</p>
<p>Seek to understand how the patient communicates with the family</p>	<p>Assume that because a patient does not communicate verbally, they have no way of communicating</p> <p>Ask "does she talk?"</p>	<p></p> <p>"Help me understand how Charlie communicates with you. How does she let you know she needs something?"</p>
<p>Listen to families because, they are the experts in their child's communication</p> <p>Ask the family how their child's behavior is different from baseline</p>	<p>Assume your previous experience with patients who are nonverbal translates to this patient</p> <p>Assume grunts, extremity movements, or decreased energy are normal for this child</p>	<p></p> <p>"How has Charlie been showing you she feels uncomfortable? What's different about how she is acting today than her usual?"</p>
<p>Consider touching the arm, hand, or foot to connect with the patient, asking the patient and family if it is ok first</p>	<p>Have the only physical connection be via the examination</p>	<p></p> <p><i>To the family:</i></p> <p>"How does Charlie respond to touch? Charlie, can I shake your hand to introduce myself?"</p>
<p>Inform the patient about the various steps of the physical examination or the plan for their care, through words and actions.</p>	<p>Talk only to the family about the examination or plan or not talk at all during the examination</p>	<p></p> <p>"I'm going to use my stethoscope (showing the child) to take a listen to your heart and then listen while you take some breaths."</p>
<p>Use person-first language (child who is hearing impaired; child who is nonverbal).</p>	<p>Use diagnosis-first language (deaf child; nonverbal patient)</p>	<p></p> <p><i>Presenting patient and/or dictating note:</i></p> <p>"Charlie is a 5-year-old little girl who is nonverbal and communicates to her family with simple signs."</p>

FIGURE 1
Strategies to consider when caring for patients who do not communicate verbally.

ABBREVIATION

ASL: American Sign Language

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