

When Bad News Isn't Necessarily Bad: Recognizing Provider Bias When Sharing Unexpected News

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As providers, we are often part of difficult conversations in which we have to share bad news with families. Increasingly, this skill is being recognized as a necessary competency for effective clinical practice, with curricula and protocols emerging to support training in this art of breaking bad news.^{1,2} In parallel, we are learning more about the role implicit bias plays within our health care encounters, in which our lived experiences provide a lens through which we approach all interactions and unconsciously shape our understanding and behavior.³

In this article, we will share a family's journey that highlights where these 2 concepts (breaking bad news and implicit bias) often intersect. Our purpose is to shine a light on an important lesson for providers: that often we bring our own biases to the table when we frame news as "bad" when ultimately, from a family's perspective, it may not be bad at all. In doing so, we may play an integral role in how we start a family's journey with a new diagnosis. Using 1 family's story as a framework, we aim to help providers consider when an alternative paradigm may be valuable, with a shift from "breaking bad news" toward "sharing unexpected news," and we provide tangible skills to consider when this approach may be ideal.

JACK'S PARENTS' STORY (CARISSA AND CHRISTOPHER CARROLL)

Soon after getting settled in our delivery room for the birth of our second son, Jack, the monitor next to

my bed started beeping persistently. We were told this meant that our son's heart rate was dropping, and the obstetrician on call that evening explained that they would have to do an emergency cesarean to deliver our infant. As they pushed me out of the delivery room to the operating room, a nurse said to my husband, Chris, that they would be back to him after the delivery. The last thing I remember is a man putting a mask over my face. I awoke to a woman saying my name. I asked if she could get my husband, and she replied, "He is with your new baby, and after you recover a little longer, you can go to be with them."

In the meantime, a nurse and a nurse practitioner walked into the original delivery room with our infant, where Chris was waiting. The nurse practitioner handed the infant over to Chris and said, "Are you aware of trisomy 21?" He must have looked confused because she then followed up with, "Down syndrome." She then began listing off characteristics that Jack was showing that made her suspicious of the diagnosis and said, "Well, just enjoy your baby," and left the room.

Chris sat there alone, unsure what this meant for our infant. Would he live 6 hours, 6 days, 6 years? Approximately 45 minutes later, I was brought back to the room where Chris was waiting for my return, in which he handed me our new infant. "Here's our new son. They think he has Down syndrome."

After going through a variety of emotions, including shock, confusion,

Ms Carroll is the mother sharing the story surrounding her son Jack's birth and subsequent journey, she founded a nonprofit organization (Jack's Basket) through which she aims to support families of children born with Down syndrome in celebrating the birth of their children and to empower clinicians with tools to reframe when and how they share this diagnosis with families, and she was involved in the conception of this manuscript, writing of the narrative portion, and provision of critical revisions to the manuscript; Dr Carroll is the father sharing the story surrounding his son Jack's birth and subsequent journey, and he was involved in the conception of this manuscript, writing of the narrative portion, and provision of critical revisions to the manuscript; Dr Goloff is a pediatrician who specializes in palliative care and teaching how to have difficult conversations, and she contributed to the conception of the manuscript outline and the drafting and revision of the provider sections of the manuscript, performed literature review, and provided critical revisions to the manuscript; Dr Pitt is a pediatrician who teaches relationship-centered communication to providers, and he recruited the author team, drafted the initial content outline and the provider portion of the manuscript, developed the figure, 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.

To cite: Carroll C, Carroll C, Goloff N, et al. When Bad News Isn't Necessarily Bad: Recognizing Provider Bias When Sharing Unexpected News. *Pediatrics*. 2018;142(1):e20180503

grief of what we expected, and fear, we were reminded that we were holding our precious infant, whose arrival we had anticipated for 9 months and who deserves our love and celebration. Over the next months, we navigated the new path with encouragement from other parents loving their lives with children with Down syndrome. During conversations with these other parents, however, I kept hearing the same sentiment: they wouldn't change anything about their children, wouldn't give back the extra chromosome even if they could, but they would change how their stories started. So often, the way they were first told about the diagnosis started with, "I'm sorry, I have bad news." Few indicated ever being offered up-to-date resources, and some described that their children were looked at as a diagnosis to be mourned and not as infants to be celebrated. Often, these families described leaving the hospital never having been congratulated on the birth of their children.

Our hearts broke as we replayed these stories. Jack's diagnosis of Down syndrome wasn't bad news to us; it was simply unexpected. We wished our providers and others sharing diagnoses such as these had understood this nuance or been equipped with strategies to reframe the experience.

THE ROLE OF BIAS WITHIN THE BREAKING BAD NEWS PARADIGM (DRS GOLOFF AND PITT)

Our words are powerful. Clinicians are required to communicate many types of information, often in rushed situations. How this information is delivered creates a framework for patients and families and may eventually become imprinted as their stories. Because these conversations can be challenging, the need for improvement of the skill of communicating bad news has

emerged into a new paradigm for clinicians and clinicians in training.^{1,2} These approaches typically focus on setting the stage, recognizing emotion invoked in the provider and the patient and/or parents, and disseminating knowledge in digestible amounts. As part of setting the stage, most of these guidelines emphasize using language that makes clear that bad news is coming, such as "Unfortunately, I've got some bad news to tell you."² Yet as we see from Jack's story above, this framing may not always reflect the ultimate views of the family or may even shape that view unintentionally.

Sometimes the "bad" or "difficult news" presented might be viewed differently by the person presenting the news compared with the person receiving the news. Often, this framing may represent the bias of the clinician. In the example of Down syndrome, a provider might only take care of hospitalized children with complications and never managed them when they are healthy. Through this lens, this news may seem objectively bad. Additionally, health care providers, who have had years of postgraduate training, may be particularly prone to valuing the potential of intellectual achievement and unconsciously view any diagnosis that may involve an intellectual disability as particularly devastating. Yet the Carrolls' experience in talking with other families who felt their children's diagnosis of Down syndrome was not ultimately bad news is actually the norm; the overwhelming majority of family members ultimately view the impact of their children's diagnosis as a positive experience for their families.⁴ There are, of course, scenarios in medicine in which the news is undeniably bad (eg, severe trauma after an automobile crash), yet it is possible that many diseases and diagnoses we may disclose through the breaking bad news lens (eg, deafness and spina bifida) may

ultimately reflect our own biases rather than an objective reality.

Researchers of most literature focused on implicit bias point to negative stereotypes that might impact clinical decision-making and ultimately perpetuate health care disparities.⁵ What we are highlighting here, however, is that our own implicit biases or ideas about specific types of diagnoses, particularly those involving physical or intellectual disabilities, may influence how we present this news to family members or patients. Accordingly, it is important to check our own biases and take an active approach to reframing the situation to improve our communication in these situations. This is a subtle yet powerful distinction and has applications in many of the conversations we have when expectation-altering news needs to be shared, where we as providers play an integral role in framing how families receive this information.

IF WE COULD REWRITE THE START TO JACK'S STORY (CARISSA AND CHRISTOPHER CARROLL)

We're often asked, "What would you have liked to have heard when you were given Jack's diagnosis?" After reflecting on our experience and hearing other families' stories, I would choose these 4 words. "I have unexpected news." These words are validating yet not biased. And then proceed, "We have reason to believe, based on characteristics your child is showing, he may have Down syndrome, which is also called trisomy 21. We believe Jack has an extra 21st chromosome that may affect his development. I'm here to help you understand the diagnosis better and will provide you time to grieve what you may have expected, but love the baby you were given, and when the time is right, I will connect you to resources that can support you on this new, unexpected journey."

Strategies To Implement

Things To Avoid

Recognize that your words and conversation will be a **part of the family's story forever**; take that role seriously, and consider how the family will retell this moment for years to come.



Entering a conversation unprepared

Remember to **congratulate the family on the birth** of their child; encourage them and others to celebrate their infant.



Treating the remainder of the hospitalization as a **somber procession** in which the medical team indicates they are "sorry" about the news

Consider phrases such as, "**I have some news to share that may be unexpected.**"



Framing the news as "**I have bad news**"; this reflects your possible bias and may forever frame their child in that paradigm

Offer hope that although it may not be what they expected, their **child will be able to bring their family joy** and have a life filled with happy family memories.



Providing a perspective of what the diagnosis means their child **won't be able to do**

Provide expectations of what **may need to happen in the short-term** (additional testing, follow-up).



Volunteering an extensive timeline of possible outcomes and complications well beyond this hospitalization

Check the pulse of the conversation and meet families where they are; recognize for some, this may be devastating news and support them in that possible grief while offering encouragement (normal to grieve what was expected).



Feeling that your job is solely to be a peptalker or positive spinner or to ignore the family's concerns about the news

Offer resources, including linkages to families with children with the same diagnosis, if possible.



Failing to offer support beyond the hospital

FIGURE 1

Reframing breaking bad news as sharing unexpected news by using the example of sharing a diagnosis of Down syndrome.

AN APPROACH TO SHARING UNEXPECTED NEWS (ALL AUTHORS)

As we consider this subtle paradigm shift toward providers removing their own value judgments when sharing unexpected news, a few strategies emerge. First, it is essential to prepare for these conversations, realizing that our words are the beginning of this family's story about their child's diagnosis. Accordingly, we must begin by examining our own biases about the condition we are about to disclose. Have I only encountered children

with this condition in the hospital setting? How might that affect my understanding of what life is like with the given diagnosis? If possible, we should familiarize ourselves with resources that may be available for that particular diagnosis.⁴ Team leaders should model just-in-time teaching surrounding communication strategies, including real-time simulation practice, before the conversation and, ideally, debrief with the health care team afterward.⁶ In a 2-parent household, make every effort for both parents to

be present, and in the case of a diagnosis made at birth, remember to congratulate them on the birth of their new child. We recommend taking the Carrolls' advice and use phraseology such as, "We have some news that may be unexpected," and avoiding framing the news with, "I'm sorry." This recommendation is grounded in studies that reveal that specific communication styles and framing influence the effectiveness of conversations, medical decision-making, and psychosocial distress experienced.⁷ Positive framing in these studies resulted in significantly less psychological distress. These results reveal that subtle differences in communication strategies contribute to meaningful differences in response to information, both short-term and long-term. Simple awareness of the impact of specific words and message formulation may improve communication effectiveness.

It is also important for providers to recognize the possible grief families will experience when encountering unexpected news and respond to their cues (verbal and otherwise). The presence of grief, however, does not mean the news is objectively or indefinitely bad, and this again reveals the importance of framing by the provider. The Carrolls describe the sentiment they and others go through as "grieving what you thought, loving what you've got," and others have made the analogy to being rerouted on vacation to a different destination than planned and realizing that although it wasn't what was expected, they are grateful for the joy this new destination afforded them. Additionally, we are not reliably good at predicting our own future happiness in the aftermath of unexpected events. One of the best ways to assist with this is to connect with people who have experienced the same news because they can provide a tangible view

into the future.⁸ Providers should strive to support families making these connections with other families with children who have the same diagnoses.

We have compiled a list of strategies for reframing conversations with the sharing of unexpected news paradigm using the diagnosis of Down syndrome as an example (Fig 1).

CONCLUSIONS (CARISSA AND CHRISTOPHER CARROLL)

Like many parents who have a child with Down syndrome, we consider ourselves “the lucky few.” Our son’s life continues to have a positive impact on those around him, and his worth has never been based on the number of chromosomes he has. We are grateful for the opportunity to use his story to help

pediatric providers consider the role unintentional bias may play in the sharing of new diagnoses with families. It is our hope that we can contribute to the subtle shift toward the realization that because providers help families start a journey with an unexpected diagnosis, assigning this news the value judgment of being objectively bad is an opinion that rarely reflects the ultimate reality for these families.

DOI: <https://doi.org/10.1542/peds.2018-0503>

Accepted for publication Apr 17, 2018

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

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FINANCIAL DISCLOSURE: The authors have indicated they have no financial relationships relevant to this article to disclose.

FUNDING: No external funding.

POTENTIAL CONFLICT OF INTEREST: The authors have indicated they have no potential conflicts of interest to disclose.

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Pediatrics originally published online June 25, 2018;

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