



Family Matters

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Empowered by Nurses

Cara L. Coleman

The first nurses to empower my husband and me in our roles as parents of a child with multiple disabilities and complex medical needs did so even before our daughter, Justice Hope, was born. Two nurses in the antenatal testing center spent time with us over the course of several weeks to impart words of wisdom and encouragement when the doctors had callously brushed off our feelings and concerns, focusing instead on testing and the search for a diagnosis. Sometimes the nurses' words were direct: "When she is born, you will love her no matter what – that is your job as parents. You will figure out the other stuff." At other times, their support was more subtle as they wove into discussions with us stories of their struggles and triumphs in parenting, making sure not to distinguish that our parenting of a child with a disability would in any way be different from their parenting of a child without a disability. Both methods of empowerment, teaching and comfort, were powerful and have continued to guide us to this day.

Justice spent the first two months of her life in the NICU, coming home just in time for Thanksgiving Day. Her big brother, Gibraltar, excitedly welcomed her home and accepted every part of life with her, including the intense first two years of seemingly constant appointments. In this way, we settled into life as a family and began to learn how to value flexibility and make accommodations for differences in Justice's abilities and needs. As time marched on, we welcomed two more children, Kezziah and Titus, into our family, and we officially nicknamed our family the "Coleman Chaos." Life was hectic and full!

Just after Titus' one year birthday, Justice became very sick. She spent four months in the hospital after suffering a right colonic volvulus complicated by fungemia, sepsis, and *Clostridium difficile*. Our family was reeling. Justice was then home for a month before entering another hospital for two months after discovering yet another obstruction and related complications.

Before Justice Hope Coleman was born, nurses in an antenatal testing center provided her parents with support and encouragement, the first steps in empowering them in their roles as parents of a child with multiple disabilities and complex medical needs. Over time, other nurses supported Justice's parents as they learned to communicate clearly and collaboratively with professionals; to provide a high level of care for their daughter in a loving, family-oriented way; and to advocate not only for Justice and their family as a whole, but also for other children and families in the healthcare system. This article describes the important role nurses played in empowering Justice's parents.

Together, my husband and I worked to infuse meaning into the days at home filled with uncertainty and the chaos of poor home healthcare; joy into the weeks at home between hospital stays; and love into each and every day in the midst of pain, discomfort, and hurt for Justice and all of our family.

Four years later Justice's gut is considered "stable" and "rehabilitated," but those are mere medical terms, and many other issues require increasing care. Our family values joy, love, and meaning before all else, even though we often struggle to ensure Justice has the energy and health to make it through each day. Many nurses have touched our lives as we've cared for Justice. The touch from some has been rough and uncaring (one nurse actually broke Justice's leg trying to force her into knee braces), but far more prevalent are both the bold and gentle touches of encouragement, love, and empowerment. The nurses who have been both bold and gentle are the nurses who have empowered us and changed our lives.

Empower to Communicate

The first time I heard a nurse say she had to give "report," I was a bit unnerved. Was I being reported? Was she giving a book report? It sounded so formal, and I could feel the atmosphere change in the hospital during "report." I wondered what was being discussed. Were decisions being made without me? I felt similar discomfort with "rounds" and wondered what role, if any, I could play.

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The **Family Matters** series focuses on issues, information, and strategies relevant to working with families of pediatric patients. To suggest topics, obtain author guidelines, or to submit queries or manuscripts, contact Co-Editors Elizabeth Ahmann, ScD, RN; or Deborah Dokken, MPA, *Pediatric Nursing*; East Holly Avenue/Box 56; Pitman, NJ 08071-0056; (856) 256-2300 or FAX (856) 589-7463.

Justice Hope and Mom



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The importance of nurses empowering patients and families to partner in communication cannot be emphasized enough. Families of children with complex care needs experience many people – and agencies – asking, telling, poking, and prodding into our daily lives. Support for empowered communication helps parents negate the grip of “us vs. them” that can interfere with the lives and health of families of kids with disabilities and special healthcare needs. All parenting is full of challenges, particularly amidst advice from family, and occasionally, the random stranger.

For example, at a minimum, as Justice’s parents, we have 16 doctors, over 20 advanced care nurses and professionals, multiple teachers, therapists, school administrators, social workers, and case managers, as well as innumerable office support staff, home health and supply companies, and the like, all providing input as well. It can be overwhelming, and it is not hard to slip into feeling questioned at every turn. Often we not only feel, but we are, literally alone on our side of the examining table in the medical office or the conference table during an IEP meeting at school. Figuratively, language or educational barriers, cultural differences, and lack of health literacy cause isolation for many parents as well. Our best nurses equipped us with communication as our most powerful tool. Through plain, honest, and direct communication, they made “report” and “rounds” accessible to us, regardless of our experience, knowledge, or comfort level. Most importantly, they showed us how clear communication was the vital link to the best care for our daughter and the way to build relationships so there would be only an expanded “us,” and no more “them.”

Although many nurses over the years have helped us hone our communication skills, the most thorough training occurred during Justice’s two-month PICU stay. The PICU nurses refused to allow the fear and complexity of the setting to swallow us as parents. They taught us how to function amidst chaos by carving out clearly defined pockets of space and time for thinking. They explained how the care of our daughter was organized throughout the day and how to participate in developing and altering Justice’s plan of care.

These nurses painstakingly walked us – system by system – through assessment of our daughter and explained what details to report, and how to do so, for each specific

The Coleman Chaos



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recipient of information. My “muscle memory” for skilled communication is now set, and I can move into high-level PICU organization and communication as needed. Additionally, when I feel either backed into a corner regarding a decision or unsure of Justice’s health status, I easily set aside emotions and slip into my “checklists” mode. I “report” to a lot of people who need a lot of information in a variety of forms. I am not sure what my report sounded like before that time of tutelage by PICU nurses, but I do know how it sounds now: people sometimes ask if I am a nurse or doctor. Nope. Just a mom empowered by nurses to communicate and partner more fully in my daughter’s care.

Empower to Provide Care

Even though Justice was my second child, I remember being extremely nervous the first time I gave her a bath in the NICU. Her NICU nurses taught us the big tasks of working with her g-tube, oxygen line, and apnea monitor, as well as how to bathe, cuddle with, and love our child regardless of her special needs. I had thought a bath while attached to monitors and tubes would be impossible. I learned that it wasn’t impossible, just different. This was our first introduction to accommodations. The NICU nurses taught us how to shift our mindsets, how to think outside the box, and how to be flexible. While those nurses loved to take care of Justice, they recognized that Justice was going home with us, so we, as her parents, needed to do more than just watch them care for her.

Now, when we meet a nurse who is new to Justice and our family, he or she inevitably asks, “Do you have nursing care at home?” While it is good to ask this question as part of getting to know a patient and her needs, I always worry that the nurse will stop thinking about the issue once I reply “yes.” Please don’t ever assume that nursing at home is adequately helpful. I remember the first day Justice returned home after four long months in the hospital. When we met with the home health agency to discuss the plan of care, they informed me that they could only provide LPNs who, in our state, could not hang TPN. Justice was on TPN 23 hours a day. Nursing care? Check. Helpful? No.

In a related vein, please do not assume that because a family has nursing care at home, you do not need to teach them how to provide care, or even that the home health

agency can or will teach families to provide care. If a child has a disability or special healthcare needs, then it is crucial to empower families to provide care themselves because while the need for care of the child may change, it is unlikely to ever go away. If families do not know how to fully provide needed care for their child, they are, in fact, disempowered. Families must be prepared to assume full care when the inevitable home health situations arise: nurses who have no experience, training, or supervision, or those who do not show up for shifts. Our best hospital nurses made sure we knew how to provide ostomy and central line care, for example, so we could lead care, provide back up, or work as part of the home health team. It is important to partner with family members in care provision from the start. If parents and family members are cut out of providing care from the start of life or the beginning of an illness, then a “wall” of sorts is likely to form that may never be broken down. The wall might consist of fear and insecurity on the part of the family about their understanding their child’s health condition, or it might be a lack of belief in their ability to communicate about their child’s needs or manage the complexity of care.

For parents, the transition from inpatient to outpatient care setting is almost always like falling off a cliff. This is true even if you are an experienced parent and have tremendous support. I work most comfortably with nurses who can think critically, who view my child with a disability as a child with value, and who possess both the basic skills of good nursing care and openness to managing the particulars of Justice’s care.

After four years of working with five different home care agencies and an average of 10 different home health nurses a year, I am glad to report that we have had the same two nurses for nearly one year now. This turnover rate has been traumatic to Justice and our whole family, and it is not uncommon among families whose children receive home care services. In addition, it is not emblematic of either quality care or patient safety. While I am grateful that we have access to home healthcare, I am unwilling to tolerate care that disrespects Justice or jeopardizes her health. I have been called names by nurses and told to “back off” many times. I have questioned myself and wondered if maybe I am just a bit too demanding in the quality of care for my daughter. Demanding? Maybe, but it is because really great nurses – great in communication skills and quality of care – have empowered me to provide excellent complex care for my daughter, and I know what that looks like.

When we brought Justice home after two months in the NICU, her brother held her for the first time. It was a pivotal point in the life of our family. Because of Justice’s fragility, we had experienced doubt over whether the siblings should touch. However, because of NICU nurses empowering us to make accommodations, we were able to value the importance of relationships and love over the fear that disability and medical complexity can often foster. In the many years since, our family rolls with Justice’s care. In fact, all of our kids have learned to participate in daily routines of her care. For example, they know the names of procedures, how to push meds, and how to spike TPN. Although some people express sorrow for our children and worry they are burdened, I choose to see the situation differently. It is true that our family has had many very challenging times; however, I have no doubt that my children are forever blessed by their sister Justice. This is their life, and although I may wish to take away their pain and pro-

10 Things I Wish Nurses Would Do When Interacting with My Child with a Disability

1. **Relax!! Leave any labels at the door.**
Take a deep breath! Interacting with a child who has a disability is not rocket science. Treat my daughter as you would want to be treated.
2. **Don’t play peekaboo!**
Make eye contact and connect with my daughter, and any child, regardless of their ability or diagnosis.
3. **Get to know *my* child, not a stereotype.**
Meeting one patient with a specific diagnosis is meeting one patient with a specific diagnosis. My daughter is not a “they” or one of “those kids.” Her name is Justice. She loves music, dancing, and lots of bling.
4. **Talk with my child, not at or in front of her.**
My daughter may have cognitive disabilities, but she is a young lady who has feelings, hopes, and dreams. Don’t belittle her by talking loudly, in a baby voice, or by addressing only her parents.
5. **Assess my child, not a vital sign.**
Vitals are great indicators of what is going on with my daughter, but they do not paint the whole picture. Trust yourself and my daughter to go beyond the vitals. Ask her, look at her facial expressions, watch her body movements: she is telling you how she feels. If you are unsure, ask us, her parents.
6. **Don’t interpret everything as negative.**
A loud vocalization is not necessarily pain. It might be laughter. Closing her eyes or turning her head away does not mean my daughter is sleepy or having a seizure. Maybe she is just fed up with all the medical talk!
7. **Ask before you touch.**
My daughter is not a pincushion. She pulls away when you rub an alcohol wipe on her forearm because she knows what is coming – not because she is “so tight.” Respect for a child’s body is the same, regardless of ability!
8. **My child is not a routine.**
You may have changed hundreds of ostomy bags, but you haven’t yet had the opportunity to care for my daughter. Although she may not talk to or interact with you in the same way as your other patients, please give her respect and provide care with the same enthusiasm, quality, detail, and compassion.
9. **Share the love!**
Please comfort my daughter the same way you comfort your other patients. She feels scared and hurt, and needs the same comfort, even though she may communicate it differently.
10. **Nothing about her without her!**
Don’t talk about my daughter as if she isn’t in the room or as if she isn’t a person. Be an advocate for her – she needs high-quality care and also someone to ensure that she is not disregarded just because she has a disability.

Source: Adapted from Coleman, 2015.

tect them, I can only love them, teach them how to cope and to be flexible, and empower them to weather any storm – just as our best nurses have taught us to do.

Empower to Advocate

Advocacy means ensuring those who are not always seen or heard have a voice, and for their voices to join other voices in making decisions and effecting change. Although most see me as the voice for Justice, it is Justice, in fact, who has given me a voice. My professional life has taken many unexpected turns – from domestic abuse advocate, to immigration lawyer, to author of a children's book entitled *I am Justice, Hear Me Roar* (Coleman, 2010), and now instructor of pediatrics at a medical school, teaching about patient-centered medical homes and humanism. I have to thank the many nurses who have each talked with me for hours, have helped me focus on the good in the midst of challenge, have supported me as I made sense of heartache, and have given me the courage, especially when I didn't think I had it, to advocate for hope and change.

Nurses are uniquely situated to model advocacy for care by getting to know each child by his or her name, not by a diagnosis. Too many times, I have heard people standing outside of Justice's room call her the "MRCP kid" or a "short gut kid," before I hear a knock, and they enter the room. As a parent, I am reluctant to allow someone to care for my child if they do not value her as a child first. I understand HIPAA may make it difficult to refer to a patient in all settings by name. However, thinking about a child *as a child* first, before a label or diagnosis, is about so much more than HIPAA. It is about empowering children – and their parents – to believe and find value in themselves and feel loved. Any child who spends so much time in hospitals and visits more doctors' offices than playgrounds desperately needs to see him or herself as more than a patient.

Although Justice may be labeled "non-verbal," she does communicate in many ways. I love to sit back and watch her interact with the nurses and other health professionals who have taken the time to get to know her. Justice often expects – and even demands – a greeting far beyond hello. Being a true diva, she requires you to compliment her accessories for the day (hair style, bows, bangles, and outfit). One of my favorite memories of watching this interaction between Justice and her providers was when one of her male GI doctors failed to "greet" Justice properly and jumped right into rounds. Justice grunted negatively at him, to which he asked if she was in pain. Her nurse and the PA laughed and gently explained that he had not com-

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plimented her hair and bracelets. He looked at them as though they were crazy, but he has properly greeted Justice ever since and seems to enjoy doing so. I hope he has learned from Justice to extend the courtesy of a personalized greeting to all children.

Parents and families need this acknowledgement as well. Many of us find acceptance of a diagnosis difficult. Most of us get so caught up in managing and providing care that we may forget to be parents and just love our children. We, too, sometimes need to be taught or reminded that we are all here first and foremost to love a child. In fact, our best nurse advocates have not only empowered us to communicate and provide care, they have spent time emphasizing

that our most important job is to be parents and love Justice unconditionally. The impact of this advocacy for not only care, but human caring, is *huge*. It teaches us all acceptance and tolerance, and it breeds a community in which not a single person is excluded because of "differences" or medical conditions. Real caring is infectious, not only for all members of Justice's – or another child's – family and care team. It extends far beyond the four walls of the consult or hospital room.

Conclusion

As I reflect on all that nurses have given our family, I am struck that they have each done this as singular human beings. One by one, they have built us up. These nurses equipped us to be our best selves; infused us with confidence, hope, and love; and walked along side of us as we have learned and grown. While I am not a mathematically inclined person, it doesn't take much math ability to see the factorial power of each nurse multiplied out far beyond the Coleman Chaos.

Sometimes, a day at work for a nurse may be overwhelming or disheartening, and may even leave a nurse questioning whether he or she even made a difference. Please do not ever doubt your ability to empower your patients and families. One step at a time. One patient at a time. Even if you don't see the end results, know that your care multiplies! ■

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