Supporting Families: Lessons Learned from Parents' Narrative Experiences

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ABSTRACT

Support and guidance for parents of a newborn with newly diagnosed differences in sex differentiation (otherwise known as ambiguous genitalia or intersex) is important soon after birth. Often, parents do not immediately share this medical condition with many people in their family and social circle. The medical and psychosocial team can be helpful at the bedside by welcoming parents' beloved baby, normalizing this biological condition (1.7 percent of the population), providing the medical information that is known, supporting them through whatever emotions they may feel, and connecting them to peer support so they can talk openly with others who have kids with differences of development.

A first-year college student that I know has a t-shirt that reads "I am intersex. What is your superpower?" As a chaplain who works primarily in the neonatal intensive care unit (NICU), where infants are often first recognized to have intersex traits, it gives me great peace and joy when I hear of people who embrace being intersex. However, I do know that it can be hard for parents when they first learn of their baby's diagnosis. While the likelihood of being born with intersex traits is about the same as someone being born with red hair—1.7 percent—having a diagnosis that falls within the intersex umbrella is not one that is regularly known or shared. Prior to working in the NICU, I neither knew about intersex nor that it was common. Since then, many parents of intersex babies have shared their experiences with me. Their stories have provided insights into how to help parents navigate this space and guide them through this journey.

Parents of babies with intersex traits have shared with me that the first words after their baby was born were: "We don't know if your baby is a boy or a girl." For parents who anticipate greeting their beloved newborn, those are hard first words. Parents have said that the first words should be: "Here is your beautiful baby!" The gender discussion is bound to happen soon afterwards, but let the first words be positive, welcoming, and joyous.

Many parents look to the medical team to tell them if their baby is genetically more a boy or a girl, and rely on chromosome and blood tests. While these can be helpful, gender identification has more to do with which chemicals make it to the baby's brain during certain stages of development. Moreover, a child may not self-identify until older. Most parents have found it helpful to assign a gender at birth, but to be open to the possibility that in a few years their child may not identify with that gender.

One of the biggest struggles that I hear from parents is with the fear they feel for their baby's acceptance in society. Parents have reported to me that

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while they are personally okay with their baby's unknown gender and love their baby unconditionally, they worry that their child will struggle and be judged in society. Often parents wait days before sharing the announcement of their baby's birth, as they want to learn more about identifying factors about their baby's genetic makeup. This is a stark contrast to "normal" birth stories, when the moment a baby is born, parents share the joyful news of a new life.

I work with many families in the NICU who have a baby with other medical issues, and some have a poor prognosis. These families start a Caringbridge website, post on Facebook, have a GoFundMe page, and have entire communities around the world saying prayers for them, bringing them food, and telling the parents that they are thinking of them. Parents of intersex babies often feel isolated and alone, unsure with whom they can safely share their baby's medical condition. Many parents have even feared telling their spiritual/religious leader about the diagnosis, for fear of being judged.

This is a personal issue, and it is a respectful option for parents to keep it private and consider what their baby might want known in the community when the child is older. I have seen both extremes; parents who are pro-active in being interviewed by their small town newspaper, and parents who tell no one, not even grandparents. One thing is clear: the sooner parents can be connected to others and know that there is a supportive community out there for themselves and their child, either anonymously online or in person, the more helpful it will be. The intersex community is strong and supportive. Parents say that the sooner they can be connected to other parents, the better. They learn that their baby is not alone, that someday their child can be in a loving relationship, that their child can be accepted and loved in society, and that their child can be happy.

I have permission to share one family's story, and they prefer that I use their son's actual name. I was present with parents when they learned that their baby, Anna, was genetically a boy. These parents called in both sets of grandparents for an emergency meeting. As the grandparents arrived in the small NICU room, there was tension. The parents and grandparents alike were anxious and scared. The father explained that they had called the grandparents into the room to let them know that Anna was actually a boy, and they chose to name him Noah. One grandma said, "Is that all? We were worried that you were going to tell us that Anna wasn't going to live." All of the tension in the room melted into tears. The parents were relieved that their baby was so lovingly received by his grandparents, and the grandparents were relieved that this was not a terminal diagnosis.

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The emotion of shame is one that parents have tentatively shared with me. Shame is a very complicated emotion, and I want to be clear that the shame that parents say that they feel is not about a lack of love or acceptance of their baby's medical condition, but more about their fear of judgment from society, or about their own reaction of fear or being judged. I have learned that, in counseling parents, if I name shame as a possible reaction too soon, it is not helpful. It is almost too raw to name. Once I have a deeper and longer relationship with parents, I have been able to have a conversation about it. Shame and guilt are present for many parents with newborns that have medical diagnoses. Parents often intellectually know that it is not their fault, yet they still feel a sense of guilt. While it can be helpful to let parents know that this is biological, that they did not do anything to cause this, it is also important to let parents know that you hear their struggle. I often say to parents, "Many parents tell me that they know intellectually that it is not their fault, but inside they feel like it is." Normalizing this guilt and/or shame can be helpful, yet, as a medical team, we need to be careful not to name these emotions for parents too soon. Instead, we should follow parents' lead as they describe their feelings.

Listen to the words that they use to describe their feelings.

Often, I contrast for parents that if this were a heart condition they would let everyone know and receive prayers, well wishes, and even hot meals as their community reached out to help. While intersex traits do not often have a devastating medical prognosis, parents are reluctant to reach out for support from their community. What can be helpful, though, is to reach out and share with a smaller group of friends and family whom they trust and know will be supportive, nonjudgmental, and keep information confidential.

My hope is that one day all of society will see intersex variations as part of the wonderful diversity of human life. Yet, until that is true, I hope that we, as a members of medical teams who are the first to share this news and to support parents, can normalize this biological variation, celebrate this new life, and give guidance on how to connect with the greater intersex community. My hope is that someday these children will grow into adults who are comfortable and happy in their difference, and, if they choose, they will feel empowered to wear a t-shirt that says: “I am intersex. What’s your superpower?”