Prenatal and Postnatal Diagnosis of Infant Disability: Breaking the News to Mothers

Joyce A. Wright, DNSc, RN

ABSTRACT

The birth of an infant with a disability is often perceived as the loss of a “perfect” baby and is typically an unanticipated event for the mother and family. Mothers may experience self-blame for the disability; therefore, sensitive communication is crucial. A private setting is recommended, with a minimum of health-care professionals in attendance when the diagnosis is revealed. The perinatal educator can guide the mother through the early emotional phases of processing and accepting the new information by offering support and incorporating timely information and interventions. The perinatal educator can also inform and prepare other expectant couples in the childbirth class and encourage them to support the mother and father in celebrating the forthcoming birth. The objective of nursing care for a mother whose infant is newly diagnosed with a disability is to facilitate a positive outcome for her and to promote optimal infant bonding. In all communication and information, replacing the term “disabled infant” with “infant with a disability” is emphasized in order to recognize the infant first and the disability second.

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Shortly after her daughter’s birth, Sandra (not her real name) was surprised when the hospital’s director of neonatology visited her room and requested permission to administer a blood test on her newborn. The neonatologist said he was “99% sure” the baby had a chromosomal abnormality. Sandra looked up in disbelief and suddenly noticed a roomful of medical personnel silently hovering at her bedside and intently watching her after the physician delivered his news.

“What does this mean? Does my baby have Down syndrome?” Sandra cried. Inwardly panicking and realizing she needed to compose herself as she processed the new information, Sandra closed her eyes and told herself, “Hold on! Just...give yourself a minute of hope.”

Sandra later reflected, “I was in a medical center—a teaching hospital—and I always allowed residents and medical students before, but I couldn’t help wondering, ‘Did he have to bring in seven people that day to observe a mother’s reaction when she is told there is something wrong with her baby?’ He never asked my permission for this audience as my baby was taken away.”

As he left the room, the neonatologist said, “I want you to speak to the clergy. I think you’ll need this.”

Sandra replied, “Do you even have results, yet?” “No. But as I told you before, I am 99% sure.”

For Sandra, the celebration of her daughter’s birth would never be recaptured. Years later, she still describes the experience as feeling cheated.

Nothing in her life ever hurt as much. "I had a baby. I gave birth, and they took that joyous event away from me," she said. "I felt something was taken away from me because of her disability."

— Excerpted with permission from Wright (2002, p. 85), who conducted a qualitative study that explored the feelings and thoughts about loss and the personal views on infant disability among 12 mothers aged 30–44 years who had children with disabilities.

INTRODUCTION

The March of Dimes (2006) estimates that about 120,000 babies (1 in 33) are born with birth defects each year in the United States. A birth defect is an abnormality of structure, function, or metabolism that results in physical or mental disability or death (March of Dimes, 2006). Down syndrome, a chromosomal abnormality also known as "Trisomy 21," is one of the most common chromosomal birth defects, occurring at a rate of 1 in every 800 births (March of Dimes, 2007). Many diagnoses of infant disability are established prior to birth; therefore, the perinatal educator is in a key position to offer support and educate mothers, couples, families, and fellow attendees of the childbirth education classes. By guiding the parents from the moment the diagnosis is disclosed and throughout the pregnancy and postpartum periods, the perinatal educator can serve as a supportive presence and promote positive infant bonding between mother and baby.

The mother who experiences the news of an infant's disability needs a perinatal educator who will recognize the pain and feelings of loss associated with the diagnosis and who will tell her it is acceptable to express her feelings and to even "go ahead and cry." At some point, there is also a need for hope—hope that the couple and family will adapt; hope that the family will continue to function in a positive manner; and hope that the child will participate in many "normal" childhood activities, such as Little League or Scouts. Due to the overwhelming initial sense of loss, such future accomplishments may seem inconceivable; however, they are usually attainable.

Many questions and feelings arise for the perinatal educator and other health-care providers as the

diagnosis is confirmed: How should the diagnosis be disclosed? What are the appropriate interventions? How can this news be presented in the childbirth group setting? What is discussed with other expectant parents who have knowledge of this birth? This article aims to answer such challenging questions for perinatal educators and other health-care providers. It offers an outline on how to inform parents of the prenatal (or postnatal) diagnosis of infant disability, how to support and communicate with parents throughout the time it takes to process and accept the news, and how to share information on the sensitive topic of infant disability with other expectant couples in the childbirth education class. A positive approach by the health-care team can ultimately determine the mother's reaction to and perception of this unexpected event.

With prenatal or postnatal diagnosis, it is also emphasized that the joy of the birth should not be diminished. Unfortunately, when diagnosis of an infant disability is suspected or confirmed, most health-care providers are uncomfortable and ill-prepared to talk to parents and tend to liken it to a tragedy. It is not uncommon for physicians to delay informing the parents of a confirmed diagnosis, and few birthing centers have an established protocol for relaying such information.

PRIVATE SETTING

The perinatal educator can foster a positive attitude and give parents hope by being present as the physician discloses the diagnosis. It is important to have both parents present, if possible, and to provide a private area for this discussion, with ample uninterrupted time for them to ask questions and express their feelings. The physician or perinatal educator can clearly explain how the diagnosis was established and present objective clinical data. It is also helpful if parents are informed together in a compassionate and caring manner. The perinatal educator and physician might offer to stay as long as possible to answer further questions. Similarly, if the parents prefer to return at a later time to further discuss the diagnosis, another meeting may be scheduled.

The physician and perinatal nurse educator might also consider limiting the number of health-care personnel, such as medical students and interns. For parents, this is an emotionally charged and seemingly unbearable moment, and it is not the appropriate time to have several "white-coated" team members in attendance (although it might be possible to include one person, for academic and support pur-

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poses, to observe the process). This has to be decided by the physician and perinatal nurse educator, and it must include the parents' permission.

If the diagnosis is established after birth, the mother can be offered the option to move to a private room, if possible, to allow her and the father more time for contemplation, reflection, and grieving of their loss. A private setting also prevents exposure to a roommate with a "perfect" newborn. It is recommended that the information be disclosed privately and exclusively to the parents. In Skotko's (2005) research, several mothers reported that their diagnosis was conveyed with other people in the room. As reported by one respondent:

The pediatric nurse practitioner came to my room and announced that our infant had Down syndrome. This was done in front of other family members and visitors, as well as my roommate and her guests. My mother-in-law was crying and took my older daughter into the hall. My daughter assumed that the infant had died, since everyone was upset. (Skotko, 2005, p. 70).

With postpartum parents, too, to help ensure a positive and warm presence, if the infant is present, the physician or perinatal educator might hold the baby. This shows compassion and acceptance of the baby.

TIMING

The timing of relaying a postnatal diagnosis is critical. In a retrospective survey of 1,250 mothers who gave birth to a child with Down syndrome, Skotko (2005) found that mothers who learned of the diagnosis after birth felt they would have preferred being informed earlier, as soon as the diagnosis was confirmed. Study respondents who reported a delay of more than 24 hours from diagnosis to disclosure stated that they had previously noticed the health-care team avoiding them or not having eye contact. These mothers, therefore, sensed that bad news was imminent. One participant reported that her obstetrician later told her he did not tell her the diagnosis because it was not his policy to give this type of information but, rather, that it was the pediatrician's responsibility. This mother stated, "I felt I was the last to know" (Skotko, 2005, p. 70).

THE RIGHT WORDS

Wright (2002) discourages use of the term "disabled infant," which unconsciously emphasizes

the disability first and the infant, or person, second. Instead, it is advisable to use the phrase "infant with a disability" or, better still, to refer to the infant by his or her name. If the child is unborn or unnamed, say "infant" or "baby" in discussions.

The perinatal educator will be a supportive presence for parents. There are no right or wrong responses for family members at the time of diagnosis (Shepard & Mahon, 2000). The parents are experiencing a life-altering event and will be acquiring new roles. For many mothers, having a child with a disability often means resigning from a job or career. In Wright's (2002) study, 9 out of 12 mothers were unable to continue their careers, thus creating a professional void and new financial concerns.

Shepard and Mahon (2000) recommend the following three interventions when the diagnosis is revealed:

1. Be concrete. Give the family as much information as is immediately necessary, but do not overwhelm them.
2. Provide resources to the primary-care provider and other members of the health-care team. Advise the family about what comes next.
3. Help the family put the diagnosis and treatment plan in perspective. This guidance can be accomplished by ascertaining what expectations the family has and by clarifying any misconceptions.

Sensitivity in communication is paramount. Do not impart personal, negative feelings to the parents as the diagnosis is revealed; always keep the approach in a positive light. Many mothers in Skotko's (2005) study reported that their health-care professionals intimated that the birth of a child with Down syndrome was a "regrettable happening" (p. 68).

CURRENT INFORMATION AND WRITTEN MATERIALS

As the diagnosis is confirmed and disclosed, parents will need timely information—written and verbal (Prezant & Marshak, 2006; Rahi, Manaras, Tuomainen, & Hundt, 2004; Skotko, 2005; Wright, 2002). The information can incorporate the disability, medical treatments, and available support groups, and must be up-to-date—even up-to-the-minute—and positive in tone. As reported by mothers in Wright's (2002) research, nothing was more distressing than outdated information, which often insensitively portrayed an antiquated or stereotypical image of the infant or child with a disability.

Printed materials are effective when they are objective and encouraging, presenting all aspects of the diagnosis. Mothers in Wright's (2002) study also found it very disturbing when statistics were inaccurate or when members of the health-care team prematurely predicted their child's future cognitive and physical abilities.

Many of the most current resources can be found on the Internet. Also, numerous hardcopy resources and references are available in the retail market, and most chain bookstores offer special sections that target parents of children with disabilities (see Box 1).

COMMUNICATION WITH PARENTS

Communication is essential, and Prezant and Marshak (2006) emphasize that there has been a departure from the historical image of parents as passive recipients of information and services. The perinatal educator can encourage the mother's and father's active participation in discussions and ensure that they understand the plan of care and treatment options. Simple and direct explanations usually work best. In Prezant and Marshak's (2006) qualitative study, parents of infants with disabilities reported that they wanted health-care professionals to listen and respect parental input, to be

knowledgeable, to provide information, and to collaborate and communicate with them. The perinatal educator must acknowledge and integrate the mother's valuable input because she will know her infant best. This will also give the mother a sense of control and empowerment.

SELF-BLAME

The perinatal educator must be aware and recognize that mothers may experience certain feelings such as self-blame and guilt when an infant is newly diagnosed. The perinatal educator can openly discuss these feelings and help the mother work through them, emphasizing that self-blame may potentially affect infant bonding. Research provides evidence that many mothers have varying degrees of self-blame in regard to the infant's disability, particularly if the disability resulted from a genetic transference (Wright, 2002). Consequently, mothers may have the dual emotional circumstance of having a child who is disabled and the realization that their child's disability was the direct effect of their genetic heredity that transferred with conception (Landsman, 1998; Wright, 2002). In Wright's study (2002), many mothers expressed self-blame for passing on "inferior" genes. This may also reflect a common female tendency of mothers to center their lives on the well-being of their child and to take complete responsibility for the child's welfare, even prior to the birth.

DISCUSSIONS OF LOSS WITH OTHER EXPECTANT AND NEW PARENTS

A significant challenge for the perinatal educator is to inform other Lamaze class participants that another couple from their class has given birth, or will give birth, to an infant with a disability. This is initially perceived by most people as the loss of the illusion of the "perfect baby." An open discussion setting is recommended, whereby the couples can talk about the disability and their own reactions, feelings, and fears. A common fear among most expectant parents is that this will also happen to them. The perinatal educator can be a "sounding board" and help them understand the situation.

The perinatal educator might introduce the topic of loss, which is defined as an event perceived to be negative by the individuals involved and one that results in long-term changes to one's social situation, relationships, or cognition (Miller & Omarzu, 1998). This definition can be a framework for discussion. The perinatal educator can encour-

BOX 1

Suggested Resources for Parents of Children With Disabilities

The following Web sites are recommended resources that provide book lists and information on a variety of disabilities:

- Woodbine House – A trusted source for books on disabilities (www.woodbinehouse.com)
- The Family Village – A global community of disability-related resources (www.familyvillage.wisc.edu)
- The Arc – The world's largest community-based organization of and for people with intellectual and developmental disabilities (www.thearc.org)

The following books are recommended:

- *Breakthrough Parenting for Children with Special Needs: Raising the Bar of Expectations*, by Judi Winter
- *Raising a Handicapped Child*, by Charlotte Thompson
- *Special Children, Challenged Parents*, by Robert A. Naseef (offers information and strategies for the mother and family)

age the group to talk about their own feelings of loss, and then help them understand how the affected couple might be experiencing loss.

Wright (2002) recommends that other Lamaze class couples acknowledge the infant: The baby's life is to be valued and celebrated, not viewed as a disaster or tragedy. They, and the parents of the infant with a disability, need to see a beautiful infant first, and the disability second. The perinatal educator can also encourage other parents to support and stay in touch with the couple and to convey congratulations—with cards, flowers, or visits—after the birth.

FOSTERING SUPPORT

The perinatal educator can encourage the mother to seek support from positive, loving family and friends who can help her through this experience. With the mother's permission, a visit from another mother of a child with the same disability can be arranged, because great comfort is often derived from speaking with another who has had the same experience. Wright (2002) found a unique and unspoken bond and a psychological, intuitive connection among mothers of children with disabilities. One mother stated, "We are bonded by our children forever" (Wright, 2002, p. 127).

Mothers of children with disabilities seem to gravitate toward each other, and they share a special common bond that creates interdependence, a common unity, and a connection. As another participant in Wright's (2002) study stated:

I feel like the other mothers I met are like my sorority that I was a member of. I have made genuine friends now for life. . . . We are in another world. . . . We are in a separate world that other mothers, with typically developing children, have no sense or appreciation of. (p. 126)

Emily Perl Kingsley, a writer and mother of a child with a disability, composed an eloquent, brief essay, titled "Welcome to Holland" (see Box 2). Kingsley's article provides a glimpse of the experience of having a child with a disability and presents it in a positive light for those who have not had this experience.

FUTURE PREGNANCIES

It is suggested that discussion of future pregnancies and genetic testing be objective, empathetic, and carefully approached. Parents need to know their

BOX 2

Welcome to Holland **By Emily Perl Kingsley**

I am often asked to describe the experience of raising a child with a disability—to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this. . .

When you're going to have a baby, it's like planning a fabulous vacation trip—to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a *different* place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around. . . and you begin to notice that Holland has windmills. . . and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy. . . and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, *ever* go away. . . because the loss of that dream is a very, very significant loss.

But. . . if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things. . . about Holland.

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options, and mothers will feel comfortable talking about any concerns for future pregnancies if the perinatal educator and other health-care members are supportive and nonjudgmental. In parent discussions, the health-care team can avoid talking about the disability as if it were a disaster or "heartbreak." In Wright's (2002) study, the mother of a child with Down syndrome reported that her

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obstetrician advised an amniocentesis in any subsequent pregnancies. He told her, "Another child with a disability would be a heartache, and there is no reason in this world why you should have a child with a disability when testing and termination are options for you" (p. 87). Although prenatal testing is advisable, the clinician should not pass judgment or personal opinions if the parent declines it.

TRANSCENDENCE

Wright (2002) reported that most mothers in her study required a minimum of 6 months to 1 year to integrate and fully process their infant's disability. This was a period of self-transcendence. As time passed, the mothers became assertive, possessed authoritative knowledge, and became the single most important advocates for their children. Wright (2002) also noted that the mothers had a deeper appreciation of life in general. For them, life improved and became happier. Final statements from two other participants in Wright's (2002) study exemplify appreciation:

You appreciate life; you understand it a little bit better. You understand you know that life is not perfect. . . . What if he was a normal 5-year-old? How much easier would life be for me? But then. . . you wouldn't appreciate it, though. (p. 122)

I have a fuller life because of my child. You know, it's hard to believe—but I'm thinking this has made me maybe a better mother than I could ever be. And I feel like this has added a whole dimension to my life, to my whole being. (p. 129)

There may even be a beautiful paradox to having an infant with a disability. As the disability is accepted, the mother will transcend the experience and may even interpret it as enriching her life. Landsman's (1998) qualitative research revealed that mothers caring for a child with a disability redefined *quality* and what was meaningful and most important in life. These mothers even redefined motherhood itself.

CONCLUSION

The perinatal educator plays an integral role in supporting an expectant mother, or one who has just given birth, when she first learns her baby has a disability. A private setting and a compassionate and caring manner are crucial as parents are informed of the diagnosis of the disability and begin to assimilate and accept the news. The importance of the timing of the news, with the "right words" and up-to-date information, cannot be emphasized enough. With careful intervention and genuine and compassionate support from family, friends, and health-care providers, the mother of a child with a disability can develop and maintain an adaptive perspective to a lifelong journey.

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JOYCE WRIGHT is an associate professor in the College of Nursing at Seton Hall University in South Orange, New Jersey.