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# RECEIVING A PRENATAL OR POSTNATAL DIAGNOSIS OF (DIS)ABILITY: THE ROLE AND IMPORTANCE OF THE NURSE

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## Abstract

The phenomenon of carrying and birthing an infant with a (dis)ability is complex and emotionally driven for parents. Infants with (dis)abilities are at risk for long-term health and developmental challenges, which may cause fear and stress in families. Parents report dissatisfaction with their experience of learning of their infant's (dis)ability diagnosis. After unexpected news is given to expecting or new parents prenatally or postnatally, it is the nurse who is often left with parents during an extremely emotional and vulnerable time. Although nurses play a pivotal role in supporting parents through this vulnerable time, their specific role is not well defined. This narrative synthesis reviews the role of the nurse during complex family situations and applies findings to their role in supporting families through receiving the diagnosis of a (dis)ability

for their infant either prenatally or postnatally. Nurses can assist parents through this process of adaptation by using a compassionate and empathetic approach in their care, facilitating opportunities for parent–infant bonding, speaking with person-first language, clarifying complex information, and assisting with allocation of various internal and external resources. Future research dedicated to the creation of best practice clinical guidelines on communicating with families during the diagnosis of (dis)ability would assist nurses and other health care professionals in meeting the multifaceted and sensitive needs of parents and families, ultimately contributing to improved health outcomes for the parents, family, and infant.

**Key words:** Disability; Infant; Nursing care; Parent; Patient satisfaction.

**P**regnancy and childbirth are complex phenomena that are generally filled with hope, excitement, and anticipation, as couples prepare for the arrival of their newborn and for parenthood (Riley & Rubarth, 2015). Soon-to-be-parents often have preconceived ideas of the qualities their newborn will have, the bond they will share, and the journey they will have as a new family. The experience of carrying an infant with a known (dis)ability, or receiving this diagnosis postnatally, may shatter these preconceived ideas, as an unfamiliar wave of emotions surfaces during the perinatal process, superimposed on an already emotionally driven time (Grane et al., 2022; Waxler et al., 2013).

We use the term (dis)ability, with an intentional use of parentheses. This language uses a strengths-based and person-first approach, and incorporates the principles of equity, diversity, and inclusion (Crocker & Smith, 2019; Gottlieb & Gottlieb, 2017; Government of Canada, 2023).

After unexpected news is given to parents prenatally or postnatally, it is the nurse who is often left with parents (Warnock, 2014). The supportive role of the nurse is viewed as an essential element of high-quality care and in achieving patients' satisfaction. However, there is scant literature to inform clinical guidelines on the specific role of the nurse during complex situations; thus, their role is unclear (Atienza-Carrasco et al., 2018). The purpose of this review is to provide a narrative synthesis of the literature about the nurse's role during complex family situations and apply these findings to their role in supporting families through receiving the diagnosis of a (dis)ability for their infant prenatally or during the immediate postnatal period (the period beginning immediately after the birth of the infant and extending up to 6 weeks; World Health Organization [WHO] & Special Programme of Research Development, 2022).

## (Dis)ability Diagnosis and Its Implications

(Dis)abilities can be the result of conditions that are present at birth (e.g., disorders in single genes and chromosomes), maternal exposure to illnesses and environment, and injury. The most common types of (dis)abilities are heart defects, neural tube defects, and Down syndrome (Centers for Disease Control and Prevention, 2020). (Dis)abilities affect approximately 6% of newborns globally, with 240,000 newborns dying annually within 28 days of birth due to severe (dis)abilities (WHO, 2022). Infants with (dis)abilities may experience lifelong challenges with infections, mobility, pain, learning, socialization, and speech development (WHO, 2022).

In a study analyzing birth stories of mothers of infants with Down syndrome, 66% reported having increased anxiety about health concerns for themselves and their unborn infant when received the diagnosis (Kammes et al., 2022). (Dis)abilities often require mothers to have a cesarean birth, the infant to be admitted to the neonatal intensive care unit (NICU), and a prolonged stay in hospital (Riley & Rubarth, 2015). These factors may have negative implications on the parent–infant dyad, as it has been reported that the attachment of parents to their

child with a (dis)ability is typically established later than usual when compared to attachment with neurotypical infants (Veleminsky et al., 2019). These implications may also affect the existing relationship between parents and their children at home, as well as the future relationship between the infant and their siblings (Riley & Rubarth, 2015).

Support services are often required to meet or prepare for the multifaceted needs of both the infant with a (dis)ability and parents. For example, infants born with Down syndrome often have difficulty breastfeeding due to tongue protrusion or neuromotor coordination deficiency, which may lead to the health care team consult-

ing a lactation consultant or occupational therapist (Barros da Silva et al., 2019). Although breastfeeding is often a rewarding and intimate experience that mothers share with their infants, the stress of dealing with the emotions that accompany breastfeeding an infant with anatomical and physiological challenges can lead to a certain discontent with breastfeeding (Barros da Silva et al., 2019). Increased stress associated with breastfeeding, along with feelings of hopelessness, anxiety, grief, shock, and disappointment that often accompany a (dis)ability diagnosis, may require consultation for professional psychological support to provide parents the opportunity to work through their emotions (Davey et al., 2023; Douglas et al., 2017; Mugweni et al., 2021).

Generally, parents are dissatisfied with the experience of learning about their infant's (dis)ability, whether it is given prenatally or postnatally (Davey et al., 2023; Kammes et al., 2022; Kritikos & Holmbeck, 2020; Nes et al., 2014; Waxler et al., 2013). Dissatisfaction is related to health care providers approaching the infant's diagnosis in a negative way, providing a lack of opportunities for parents to bond with their infant, use of insensitive language, lack of clear information provided, and limited assistance with acquiring the appropriate resources to assist with caring for the infant (Douglas et al., 2017; Grane et al., 2022; Kammes et al., 2022; Mugweni et al., 2021). Waxler et al. (2013) found nearly 60% of parents who had an infant diagnosed with Williams syndrome reported that they were told something inappropriate, unhelpful, or insensitive during the time of diagnosis,

Nurses caring for parents before, during, or after the birth of an infant with a (dis)ability have a tremendous impact on parental coping, parental psychological distress, parent-infant-family bonding, and infant development.

whereas 34.4% denied recalling anything positive about their diagnostic experience.

## The Role of the Nurse

Nurses, who are responsible for meeting the physical, emotional, and psychosocial needs of their patients, have an integral role to play in meeting the family's needs during the time of receiving a diagnosis of (dis)ability for their newborn (Riley & Rubarth, 2015). The nurse is in an influential position as their words and caring actions have a great impact on parental coping, bonding, and future decision making (Phillips & Boyd, 2015; Riley & Rubarth, 2015).

### Compassion and Empathy

Parents express the need for health care providers to display compassion and empathy following the birth of an infant with a (dis)ability, and parents report that this quality is often lacking in health care providers (Grane et al., 2022; Waxler et al., 2013). Empathy can be demonstrated by entering the parents' experience with them to share their burden in solidarity; leading the way for parents to retain their independence, dignity, and hope for the future of their infant (Atienza-Carrasco et al., 2018; Crawford et al., 2013; Warnock, 2014). Nurses can practice compassionately and empathetically by being physically present with parents, which provides consolation and support (Grane et al., 2022; Warnock, 2014).

It is important for nurses to assist parents through the process of adaptation during the birth and hospitalization process by validating the stress and fear that is present and addressing the family's newfound expectations (Riley & Rubarth, 2015). Nurses can use a strengths-based approach with parents, where the nurse recognizes the existing strengths within the family and builds upon those strengths to facilitate empowerment, support, and care practices to limit uncertainty (Gottlieb & Gottlieb, 2017).

At the center of a compassionate nursing approach is the appropriate and thoughtful use of language to support the parents. Using phrases that promote a sense of pity such as "this is devastating news" and "I am so sorry for this loss" leads parents to link negative emotions and feelings to their newborn with a (dis)ability (Kammes et al., 2022; Waxler et al., 2013). This negative connotation by health care providers can have long-lasting effects on parent–infant bonding, family development, and coping (Riley & Rubarth, 2015). Nurses should encourage parents to see their infant and situation through an open lens while using positive, inclusive language (Phillips & Boyd, 2015; Riley & Rubarth, 2015). For example, nurses should normalize congratulating parents on the birth of their infant with a (dis)ability. Parents report that when the diagnosis of their infant is reframed in a positive way rather than a negative way, they can view the diagnosis as a new "challenge" as opposed to a "burden" (Kammes et al., 2022; Waxler et al., 2013).

### Parent–Infant Bonding

Lack of parent–infant bonding opportunities in the NICU poses an emotional dilemma for parents who are already

struggling to connect with and bond with their infant who has a (dis)ability, as parents stay in an unfamiliar environment. Although parent-led interventions have been strongly supported in the literature in neonatal settings, the importance of the nurse's role in facilitating bonding cannot be understated. Nurses can promote parent–infant bonding and parental confidence by allowing them to be directly involved in the care (Riley & Rubarth, 2015).

Parents report struggling to connect with their newborn due to the shock and grief they are internalizing after receiving the (dis)ability diagnosis (March, 2017). Parents report that these feelings could have been mitigated if health care providers created opportunities for parents to bond with their newborn (Kammes et al., 2022; March, 2017; Waxler et al., 2013). While facilitating bonding, nurses can educate parents on the importance of establishing positive experiences with their newborn in the early days of life, as positive interactions between parents and infants are crucial for future infant development, parental coping, quality of life, and self-efficacy (Riley & Rubarth, 2015).

### Person-First Language

The language and phrases that nurses use, especially during complex situations, have a major influence on parental adaptation, coping, how parents feel about their infant, and how the infant is perceived by others (Kammes et al., 2022; Phillips & Boyd, 2015; Riley & Rubarth, 2015). Nurses must encourage parents to acknowledge and recognize the person (i.e., the infant) before the (dis)ability.

Person-first language emphasizes the person before the (dis)ability; for example, "infant with a (dis)ability" in contrast to identity-first language, which places the identifier before the person, such as saying "(dis)abled infant" (Crocker & Smith, 2019; Ladau, 2021). Identity-first language may objectify a person by his or her disabling condition, which can create stigma, disparities, and discrimination (Crocker & Smith, 2019). When nurses speak with parents about their infant using person-first language, they are leading the way for parents to recognize that they are parenting a person who has dignity, feelings, and rights, not parenting a (dis)ability or a disease. This paradigm shift in thinking and language execution is subtle but extremely powerful, as person-first language can facilitate family connection, bonding, and feelings of positivity (Kammes et al., 2022).

Person-first language can also have implications on future health outcomes of persons with (dis)abilities across the lifespan (Whiteley et al., 2016). Stigma and disparities that can develop from the use of identity-first language in health care can lead to persons with (dis)abilities avoiding professional guidance for their health issues, leading to poor health outcomes (Whiteley et al., 2016). Using person-first language in the early days of life can create a ripple effect into the future life of the infant with a (dis)ability.

As infants with (dis)abilities age and develop their own preferences for identity formation, they may choose



## Nurses can assist in creating a supportive experience for parents through a compassionate approach, using positive, person-oriented language, and collaborating with parents to navigate resources.

to use identity-first language to describe themselves, as opposed to person-first language. This preference stems from persons with (dis)abilities honouring and recognizing that their (dis)ability is part of their overall identity and should not be hidden behind the recognition of humanity first (Ladau, 2021). However, when these persons with (dis)abilities are infants who do not have the conceptual ability to have a preference for one use of language over the other, nurses must make an effort to use person-first language when speaking with the parents.

### Reinforcing and Clarifying Information

Written material, such as pamphlets and books or evidence-based online sites, offers valuable information for parents following the delivery of unexpected news (Phillips & Boyd, 2015). Some parents report dissatisfaction with the limited amount of supplemental written information they received on their infant's diagnosis, and state that these additional pieces of written material would have been useful in navigating the emotions and questions following the diagnosis of the (dis)ability (Kammes et al., 2022; Waxler et al., 2013). Nurses can provide parents with these resources following the (dis)ability diagnosis; however, these materials should be used in collaboration with the nurse as a primary source of emotional support. When written materials are provided as the sole means to clarify information, parents feel overwhelmed, unsupported, and alone in their grief; instead, parents prefer for nurses to talk to them therapeutically first to offer their support (Waxler et al., 2013).

It is important for the nurse to offer parents the opportunity to reflect and debrief following the diagnosis, such as asking the parents questions about how they are feeling and what they understand about their situation.

This may also encompass offering a moment of silence to let the parents organize their thoughts and feelings, while the nurse reaffirms that they are present to support the parents and have discussion when they are ready (Crawford et al., 2013).

### Resource Allocation

Nurses can assist in removing added stress on the parents by offering them resources on where to get specialty equipment (Phillips & Boyd, 2015). Nurses can also provide information on educational resources parents can access upon leaving the hospital, such as online resources to support initiating tube feedings for infants with hypoplastic left heart syndrome (March, 2017).

Peer support provides parents of children with (dis)abilities validation of their thoughts and feelings, as well as insight on how to manage psychological stress (Carlsson et al., 2020). Peer support groups offers parents hope for a healthy, positive, and fulfilling future with their infant with a (dis)ability (Riley & Rubarth, 2015). Parents often express the need to be connected with individuals navigating similar situations following the birth of an infant with a (dis)ability (Carlsson et al., 2020; Davey et al., 2023; Riley & Rubarth, 2015). Provision of peer support relies heavily on networking internally within the health care setting; therefore, nurses play an important role in initiating these opportunities (Carlsson et al., 2020).

## Implications for Nursing Practice, Education, and Research

Key points on the supportive role of the nurse during complex patient situations can be applied to the advancement of clinical practice, education, and research.

### Clinical Practice

The way in which nurses practice while caring for parents receiving a prenatal or postnatal (dis)ability diagnosis for their infant has a tremendous impact on parental coping, parental psychological distress, parent-infant-family bonding, and infant development (Phillips & Boyd, 2015; Riley & Rubarth, 2015). Nurses and other health care providers must be cognizant of their professional role as an advocate, educator, and supporter, when interacting with parents, to facilitate positive health outcomes and experiences for the parents, family members, and infants (Kammes et al., 2022). Nurses working in the clinical setting can assist in creating a more supportive experience for parents, through a thoughtful caring approach, using positive, person-first language, and working with parents to clarify information and available resources (Crawford et al., 2013; Crocker & Smith, 2019; Jalali et al., 2023; Sinclair et al., 2016).

### Education

Education and information on best practices for interacting with and caring for the parents and infants with (dis)abilities should be implemented in clinical settings and degree curricula, as nurses report feeling underprepared

## CLINICAL IMPLICATIONS

- Nurses should validate the stress and fear that may be present in the parents, while addressing the family's newfound expectations of having an infant with a (dis)ability. To achieve this, nurses can use a strengths-based approach with parents, where the nurse recognizes the existing strengths within the family and builds upon those strengths to facilitate empowerment, support, and care practices to limit uncertainty.
- Nurses should encourage parents to see their infant and situation through an open lens while using positive, inclusive language, which will allow the parents to view the diagnosis as a new "challenge" as opposed to a "burden." For example, nurses should normalize congratulating parents on the birth of their infant with a (dis)ability.
- Nurses should make every effort to initiate bonding activities to guide parents through a vulnerable and unfamiliar time, as they commonly struggle to connect with their newborn due to the shock and grief they are internalizing after receiving the (dis)ability diagnosis.
- When nurses speak with parents about their infant, it is important that they use person-first language to facilitate family connection, bonding, and feelings of positivity. This leads the way for parents to recognize that they are parenting a person who has dignity, feelings, and rights, not parenting a (dis)ability or a disease.
- Nurses can offer parents information on educational resources they can retrieve after leaving the hospital. For example, online resources facilitating specialty techniques on how to breastfeed an infant with Down syndrome. By allocating this type of resource to the parents, nurses are facilitating the increased maintenance of breastfeeding, which would provide benefits for both the parents and their infant.

to care for persons with (dis)abilities (Crawford et al., 2013; Doody et al., 2023; Edwards et al., 2022; Ilkhani et al., 2016). This may include communication skills workshops guiding clinicians through various complex patient and family situations within the clinical setting (Dale, 2015; Jalali et al., 2023; Phillips & Boyd, 2015). Having sensitivity training built into curriculums would facilitate the creation of a health care team that is equipped to meet the needs of parents during the infant diagnosis of (dis)ability, as well as other complex patient and family situations (Jalali et al., 2023). Educational sessions dedicated to assisting health care providers to manage their emotional well-being following the conveyance of bad news to patients and families should be implemented, as these complex situations take a psychological toll on health care providers (Nate & Nashwan, 2023).

### Future Research

The role of the nurse during these complex situations can be incorporated into clinical practice through the formation of specific best practice guidelines (Crawford et al., 2013; Warnock, 2014). More research must be conduct-

ed exploring both the perspective of the parent(s) and the health care provider. Exploring the perspective of nurses and other health care providers would offer in-depth insight into their experiences with these complex situations, and where they feel they require additional education. Research should be directed toward understanding the effect of the positive attitude of nurses and other health care providers on parent coping, wellbeing, parent-infant bonding, and infant health outcomes (Riley & Rubarth, 2015). Future research should be dedicated to analyzing what the current best practices are on giving unexpected news to parents, supporting parents, and educational opportunities that exist in hospitals and degree curricula to ensure that health care professionals are receiving adequate education and information before entering these complex situations. ❖

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