

Clinical Determinants of Parents' Emotional Reactions to the Disclosure of a Diagnosis of Congenital Anomaly

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ABSTRACT

Objective: To examine parents' emotional reactions (high intensity vs. low intensity) and the intensity of each emotion when a prenatal or postnatal diagnosis of a congenital anomaly is disclosed

Design: Cross-sectional study.

Setting: Two urban Portuguese hospitals.

Participants: The parents (60 mothers and 50 fathers) of 60 infants prenatally or postnatally diagnosed with a congenital anomaly.

Methods: One month after the disclosure of the diagnosis, the parents answered questionnaires regarding sociodemographic and clinical variables and their emotional experiences at the disclosure.

Results: Gender differences in the parents' emotional reactions were not found, and intracouple congruence was frequent. When there was uncertainty regarding the diagnosis, no prior knowledge about the diagnosis (for fathers only), and no history of pregnancy loss (for mothers only), parents presented significantly more frequently with a pattern of high-intensity negative emotional reactions to the disclosure. Type of congenital anomaly, timing of diagnosis, and parity were not found to be significantly associated with the patterns of emotional reactions, but differences in the intensity of specific emotions were found for all variables.

Conclusion: Both parents' emotional experiences should be acknowledged at the disclosure. Clinical variables were found to define the stressful situation (the diagnosis). When the diagnosis was perceived as more threatening (i.e., more unexpected, less controllable, and predictable), parents presented a pattern of high-intensity emotional reactions.

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AWHONN

Congenital anomalies are the leading cause of infant mortality and morbidity (Milunsky & Milunsky, 2010). In Portugal, 119 cases of live births with an identifiable congenital anomaly per 10,000 live births were reported in 2009 (European Surveillance of Congenital Anomalies [EUROCAT], 2012), with only 50.7% being identified during the prenatal period (Instituto Nacional de Saúde Doutor Ricardo Jorge, 2011). The disclosure of a diagnosis of a congenital anomaly (DCA) is frequently shocking and disrupts the existing perception of parents of a perfect and healthy infant (Aite, Zaccara, Nahomm, et al., 2006), triggering a set of mostly negative emotional reactions in both parents (Statham, Solomou, & Chitty, 2000).

Most existing research has identified a pattern of acute grief reaction in response to the DCA (Statham et al., 2000) characterized by highly in-

tense negative emotions, including shock, anxiety, sadness, anger, guilt, despair, and frustration (Chaplin, Schwitzer, & Perkoulidis, 2005; Drotar, Baskiewicz, Irvin, Kennell, & Klaus, 1975). Few studies mention the presence of positive emotions such as relief (Petrucci, Walker, & Schorry, 1998) and hope (Sommerseth & Sundby, 2010). Research shows that mothers and fathers feel the same emotions at the disclosure, although fathers presented less intense negative emotional reactions than mothers in some studies (Kerr & McIntosh, 1998; Schuth, Karck, Wilhelm, & Reisch, 1994). Other researchers found no gender differences (Fonseca, Nazaré, & Canavarro, 2011a).

Despite the description of a common pattern of acute grief reactions to the disclosure of DCA, some researchers have also highlighted the variability of parents' emotional reactions, that is, the

possibility that different parents experience distinct emotional reactions (Statham et al., 2000). In fact, previous authors identified two distinct patterns of parental emotional reactions to the disclosure of DCA: a pattern of high-intensity negative emotional reactions, which fits the pattern of acute grief reactions described in the literature, and a pattern characterized by low-intensity negative emotional reactions. These two patterns differed with respect to the intensity of negative emotions but were similar with regard to the intensity of positive emotions (Fonseca et al., 2011a). As the pattern of high-intensity negative emotional reactions at the disclosure of DCA was found to be predictive of both parents' psychopathological symptoms 6 months after the infant's birth (Fonseca et al., 2011b), it is important to examine the variability of the parents' emotional reactions to the disclosure.

Research on this topic has been primarily descriptive, so knowledge is scarce about the factors underlying the variability of parents' emotional reactions to the disclosure of a DCA. In this study, we focused on the variability of these reactions as a function of several clinical variables (DCA characteristics and obstetric history) because these variables are important in defining the stressful situation (Boss, 2002; Rolland, 1999), that is the occurrence of a DCA.

When considering the characteristics of the DCA, results suggest that parents' emotional reactions do not vary as a function of type of congenital anomaly. Although the researchers did not specifically aim to examine this question, the emotions described were similar whether the samples included several types of congenital anomaly (Drotar et al., 1975; Lalor, Begley, & Galavan, 2009; Mitchell, 2004) or just a single specific congenital anomaly (e.g., sex chromosome abnormalities, Petrucelli et al., 1998; cleft lip and palate, Beaumont, 2006). Aite, Zaccara, Nahom, et al. (2006) found that the type of congenital anomaly was not related to the presence of negative emotions (sadness, anxiety, and anger) in mothers following the disclosure of the diagnosis. However, other researchers found that parents of infants with congenital heart disease felt higher anxiety, whereas parents of infants with Down syndrome reacted primarily with shock, suggesting that some variability may occur as a function of type of congenital anomaly (Garwick, Patterson, Bennett, & Blum, 1995).

Moreover, the parental emotional reactions to the DCA were similar whether the DCA was disclosed

Parents' emotional reactions at the disclosure of a diagnosis of a congenital anomaly were found to be predictive of their subsequent adjustment.

during pregnancy or after the infant's birth (Aite, Zaccara, Nahom, et al., 2006; Beaumont, 2006; Nusbaum et al., 2008). However, when the diagnosis is prenatal, parents may receive less information (e.g., treatment options, often available only after the infant's birth; Statham et al., 2000), which may intensify their anxiety, despair, and frustration when the diagnosis is disclosed. On the other hand, as parents may feel reassured about the infant's health due to normal prenatal examinations (Aite et al., 2003), the postnatal DCA may be perceived as more unexpected for parents, leading to more intense reactions of shock.

Often, when parents first learn of their infant's DCA, they have no prior knowledge about the diagnosis. When the DCA is disclosed, they are faced with a great deal of new and sometimes difficult-to-understand information, which can intensify their reactions of anxiety and shock (Aite et al., 2004; Aite, Zaccara, Trucchi, et al., 2006).

Furthermore, the degree of uncertainty associated with the DCA and its prognosis is also an important DCA characteristic, because it is associated with the inability to determine the meaning of illness-related events and can influence the individual's psychological adaptation (Mishel, 1988, 1990). Research has shown that when great diagnostic uncertainty is perceived, mothers tend to report more difficulties in attaching meaning to the diagnosis (Lalor, Begley, & Galavan, 2008; Lalor et al., 2009) and manifest greater levels of anxiety (Kemp, Davenport, & Pernet, 1998). Aite et al. (2009) found that maternal anxiety after a prenatal DCA was associated more strongly with the uncertainty regarding the clinical development and prognosis rather than with the objective medical severity of the DCA, suggesting that a great degree of uncertainty may be related to high-intensity negative emotional reactions.

Finally, obstetric history can also be considered an important factor in the variability of emotional reactions. To our knowledge, the effect of parity has not been investigated. However, women with a previous healthy pregnancy may be more confident about the infant's health, leading to greater unexpectedness of the DCA (Lalor & Begley, 2006) and thus more intense negative emotional reactions.

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