Resolution of the diagnosis and maternal sensitivity among mothers of children with Intellectual Disability

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A B S T R A C T

We examined mothers’ resolution of their children’s diagnosis of Intellectual Disability (ID) and its link to maternal sensitivity, and we hypnotized that mothers’ who are “resolved” will show more sensitivity during their interactions with their children than “unresolved” mothers. We assessed maternal resolution using the Reaction to Diagnosis Interview and maternal sensitivity in three different play episodes using the Emotional Availability Scales. Our sample included 40 children between the ages of 2.5 and 5.5 with clinical diagnoses of non-syndromic ID and their mothers. Supporting our hypothesis we found that mothers who were resolved regarding the diagnosis of their children showed more maternal sensitivity to their children in two of the three play episodes. Another important finding was that resolution and sensitivity were associated even when we controlled for the child’s responsiveness to and involvement with the mother, suggesting that the link between resolution and sensitivity cannot be accounted by the impact of the child’s behavior on the mother.

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Parenting a child with Intellectual Disability (ID) presents unique challenges, among which are the adjustments of parental expectations and hopes for their child, and coming to terms with, or “resolving”, the feelings associated with the child’s diagnosis. From the perspective of attachment theory (Marvin & Pianta, 1996), parental resolution is not only important for the parent’s own wellbeing, but also has significant implications for the development of the child. This is because lack of resolution can interfere with the parent’s capacity to respond sensitively and appropriately to the child’s emotional signals. Therefore in this study we explored mothers’ resolution to their children’s diagnoses of ID and its associations with maternal sensitivity during interaction with the child, aiming to expand our understanding of parenting children with ID.

Most parents who receive a diagnosis of a serious developmental disability such as ID for their child experience strong emotional reactions, including shock, sadness, despair, and confusion (Fortier & Wanlass, 1984; Kanner, 1953). Receiving such diagnosis is a painful experience that shares many similarities with grief and mourning. Indeed, many have likened this experience to a metaphorical loss, as it were, of the hoped-for, typically developing child (Foley, 2006; Oppenheim et al., 2007).

Blacher (1984) reviewed research that investigated parental reactions to receiving diagnoses of various medical conditions for their children, including ID, Down Syndrome (DS), and heart defects. She described the patterns of parental emotional reactions to the diagnosis of their children as progressing through stages. The first stage involved shock, denial,
and a search for a reason. The second stage, emotional disorganization, was characterized primarily by feelings of guilt. The third stage, emotional adjustment, included adaptation and acceptance.

Blacher’s description of the different phases in parents’ reactions to their children’s diagnosis, shares some resemblances with Bowlby’s model of loss and mourning. Bowlby (1980) suggested four phases: numbing, yearning and searching for the lost figure, disorganization and despair, and reorganization. Bowlby regarded this sequence as a general pattern that includes many individual variations, possible oscillations from phase to phase, and possible overlapping of phases. Bowlby conceptualized the ultimate goal of the grief process as “reorganization”, which includes accepting the irreversible nature of the loss, working through and discarding old patterns of thinking, feeling, and acting, and a gradual acceptance that the loss is permanent and that life must be shaped anew. Similarly, the literature about the reaction to the diagnosis of a child’s handicap (Blacher, 1984) emphasizes the importance to the parental reorganization of the representation of the child.

Reorganization involves the parents adjusting their expectations of their child from those representing the healthy child originally anticipated to those representing a child with a serious diagnosis such as ID. Following Bowlby, Pianta, Marvin, & Morog (1999) defined resolution, in the context of having a child with a disability or a chronic illness, as the integration of the experience of the diagnosis into the parents’ representation of their child. This integration involves realignment of the parents’ expectations with the new reality of the diagnosis.

To assess resolution in the context of raising a child with a serious diagnosis, Marvin and Pianta (1996) developed the Reaction to Diagnosis Interview (RDI). The RDI includes five questions which ask parents to describe their feelings and thoughts about their child’s diagnosis. The patterns of thought and feeling revealed in the RDI are thought to be important not only because of what they reveal about the parents’ inner experience but also because of their associations with parental sensitivity.

Parental sensitivity is the main mechanism thought to account for individual differences in children’s attachment (Ainsworth, Blehar, Waters, & Wall, 1978). Parental sensitivity involves accurate reading of the child’s emotional signals and prompt, flexible and appropriate responses, all within the context of a positive emotional climate (Ainsworth et al., 1978; Biringen & Robinson, 1991/1998). Marvin and Pianta (1996) claimed that resolved parents, whose representations of the child are aligned with the child’s functioning, are likely to be sensitive to the child’s signals and to match their behavior to the child’s strengths as well as the child’s vulnerabilities (Marvin & Pianta, 1996). Conversely, unresolved parents’ difficulties in revising their representations of the child in light of the diagnosis may limit their capacity to respond in a way that is appropriate to the child, hence, to be sensitive to their child. The mismatch between the perception of the child in the mind of the parent and the child in reality can interfere with the parents’ capacity to read the child’s signals correctly and respond appropriately. For example, the parent may respond to the “whished-for” child rather than to the actual child, attributing to the child capabilities that are far beyond his or her actual abilities, resulting in frustration and confusing for both the child and the parent. Alternatively, parents may see the child only through the lens of his disability, and have difficulties seeing the child’s broader needs that are beyond the diagnosis, such as the need to play, and to have joyful, unstructured time. Therefore resolution is thought to have an important role in fostering parental sensitivity.

Marvin and Pianta conducted the first study that evaluated mothers’ resolution regarding the diagnosis of their children (Marvin & Pianta, 1996). In their pioneering study they looked at children with cerebral palsy and their mothers and found that 82% of mothers who were classified as resolved with regard to their child’s diagnosis had securely attached children, and 81% of mothers classified as unresolved had insecurely attached children. Barnett et al. (2006) provided additional support to Marvin and Pianta’s results in a study of children with congenital anomalies involving either neurological impairment (including ID) or physical malformation. They found that maternal resolution regarding the child’s diagnosis was associated with the child’s secure attachment. Note that resolution, in the above studies, was not associated with the severity of the child’s diagnosis, suggesting that resolution is not merely a reflection of milder impairment in the child.

According to attachment theory, the main mechanism thought to account for individual differences in children’s attachment is the caregiver’s sensitivity (Ainsworth et al., 1978). Therefore the question raised is whether the link between parents’ resolution of the diagnosis and children’s security of attachment is due to the enhanced sensitivity of mothers classified as resolved. Dolev (2006) examined the association between maternal resolution and maternal sensitivity in a study of preschoolers diagnosed with Autism Spectrum Disorder (ASD), many of whom also had ID. Dolev (2006) found that mothers classified as resolved based on the RDI showed greater sensitivity to their children during interactions with the child, and structured the interaction better than did mothers classified as unresolved. Similarly to Barnett et al. (2006) and Marvin and Pianta (1996), Dolev reported that resolution was not associated with the children’s level of functioning, lending further support to the notion that the RDI captures how parents manage the emotions and thoughts related to the child’s diagnosis and not merely the severity of the child’s condition. In a recent study, Wachtel and Carter (2008) also used the RDI with mothers of children with ASD and found that resolved mothers were rated higher in cognitive and supportive engagement during play interactions than were unresolved mothers. Wachtel and Carter (2008) suggested that parent’s resolution had an important effect on maternal interaction style.

Up to this point we discussed the impact of maternal resolution on maternal sensitivity, but children’s behavior can also affect maternal sensitivity and maternal resolution. The cognitive deficits and other difficulties characterizing children with ID may be manifested in their behavior during interaction with their mothers. For example, children with ID were found to be less reactive and cooperative, and less clear in their signaling behavior than typically developing children (Dunst, 1985; Marfo, 1984) which may make it more difficult for parents to find interactions with their children to be appealing or
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