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Stress and resolution in mothers of children with cerebral palsy



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ABSTRACT

Parental resolution of diagnosis represents coming to terms with and accepting the diagnosis of a serious condition in their child. As risk factors for achieving resolution, we investigated: a child's functional status, cumulative stress, and maternal depression. The current study tested the hypothesis that mothers who are unresolved to their child's diagnosis would have considerably higher levels of risk factors, compared to resolved mothers. We also examined whether the observed risk factors could predict the resolution status. Maternal resolution was assessed by means of the Reaction to Diagnosis Interview. The sample consisted of 100 mothers of children aged 2–7, diagnosed with cerebral palsy. The results showed that unresolved mothers had children with poorer functional status, experienced more stressful life events, and were more depressed compared to resolved ones. The functional status of a child and maternal depression were shown to be significant resolution predictors. Importantly, they were more successful in predicting the resolved than the unresolved status. Further research is needed in order to investigate more extensively the unresolved parental status.

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1. Introduction

Parents invest huge amounts of energy in childrearing, but at the same time enjoy their parenting role. When faced with caring for a child with developmental disability, families confront a number of additional challenges (emotional, physical, and financial) over a long period of time (DeMarle & le Roux, 2001; Lin, 2000). Parents can experience psychological stress and disappointment when their child fails to fulfill their hopes of having a healthy offspring, or a “perfect child” (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003). Thus, the stress involved in rearing a child with developmental disability can be understood as a combination of a greater need for care of a child with atypical development and the emotional reactions to the existence of disability within the family (McCubbin & Patterson, 1983).

Numerous studies have confirmed that remarkable emotional and physical demands of rearing a child with a chronic health condition or developmental disability cause stress in parents (e.g., Florian & Findler, 2001; Hauser-Cram et al., 2001). Increased demands for care of a child with developmental disability, such as cerebral palsy (CP), can have implications for psychological and physical wellbeing of the parents (Brehaut et al., 2004). The parents are uncertain about the outcome of their child's condition and the prognosis for his/her future development, they are burdened with frequent medical checkups

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and procedures as well as specific demands placed upon them by the child's condition. As the stressors brought on by increased childcare demands become more extensive, parents can feel increasingly depressed, helpless, or worthless (Crnic, Friedrich, & Greenberg, 1983). They must face the child's diagnosis, provide him/her with adequate care and adapt their lifestyle accordingly (Ketelaar, Volman, Gorter, & Vermeer, 2008; Sen & Yurtsever, 2007). Substantial variations have been proven to exist concerning the way that parents adapt to stressors and demands placed upon them (Raina et al., 2005). Research has pointed to a number of factors involving the parents, the children, and support systems, which are believed to underlie parental adaptation (Barnett et al., 2003; Rentinck, Ketelaar, Jomgmans, & Gorter, 2007).

This paper adopts the standpoint that parental adaptation is compatible with parental resolution of diagnosis status (Barnett et al., 2003). The resolution implies parental cognitive and emotional processing of the experience of learning the child's diagnosis. Cognitively, the parents are supposed to understand the meaning and implications of their child's diagnosis. Emotionally, they need to experience, accept and express their feelings of disappointment, grief, sorrow, anger and guilt in order to be able to comprehend the meaning of the information concerning their child having a serious impairment. Following the intense negative emotions, parents who are able to accept their child's condition can experience satisfaction, reward, enjoyment and a sense of being connected to their child. This does not imply that they would no longer feel distressed, but simply that those feelings would not be so strong or overwhelming as they used to be at the time of becoming informed of the child's health problems (Barnett et al., 2003).

The concept of resolution is based largely on the attachment theory and research, and represents a process during which parents change their working models of the anticipated perfect child into conceptions that are more aligned with the reality, representing a child with specific abilities and limitations. If parents are able to integrate the conflicting inner working models of the child, those present before and after becoming aware of the diagnosis, into a new, realistic model, and if they are able to direct their attention to present and future realities, they will find it easier to resolve their grief reactions. The phrase "grieving the loss of the perfect child" is used to describe the process during which parents change their models of a perfect child into those that represent a child with a chronic health condition (Marvin & Pianta, 1996).

It is important to emphasize that resolution does not imply a complete cessation of grieving, allowing for grief to become reactivated. Therefore, the cyclic process of grieving in parents of children with developmental disabilities has been termed chronic sorrow (Olshansky, 1962). Nevertheless, the key issue for achieving parental resolution is that the intensity of grief is not so overwhelming, as it was at the beginning of the adaptation process, when the parents first learned about the child's diagnosis. Grief symptoms are intensified and thus resolution becomes harder to achieve when parents re-experience the disparity between their actual child and the idealized, perfect child they wished for. One of the processes contributing to increased symptoms of grief is experiential avoidance, defined as an attempt to avoid the form, frequency or situational sensitivity of cognition, memories or emotions associated with grief (Whittingham, Wee, Sanders, & Boyd, 2013).

Marvin and Pianta (1996) made an enormous breakthrough in assessing parents' success in resolving their child's diagnosis. They developed a standardized, reliable procedure in a form of a semi-structured interview known as the Reaction to Diagnosis Interview (RDI; Pianta & Marvin, 1993). The RDI assesses whether a parent has succeeded in overcoming the trauma caused by becoming aware of their child's chronic health problems and reorienting to the reality of the child's condition. The RDI has been proven to be a valid procedure for predicting the affective attachment status in a child. As an indication of validity, children of parents classified as resolved were significantly more often securely attached to their parents than children of unresolved parents (Barnett et al., 2006; Marvin & Pianta, 1996).

The research has shown the resolution percentages to vary between 33.3% and 81.6% in parents of children with different health conditions (Barnett et al., 2006; Kearney, Britner, Farrell, & Robinson, 2011; Lord, Ungerer, & Wastell, 2008; Oppenheim, Koren-Karie, Dolev, & Yirmiya, 2009; Pianta, Marvin, Britner, & Borowitz, 1996; Rentinck, Ketelaar, Jongmans, Lindeman, & Gorter, 2009; Schuengel et al., 2009). This variability can suggest that certain health conditions are more challenging for parental resolution. Nevertheless, in addition to the diagnosis itself, it is not entirely clear which particular factors lead to the increase in parental stress and thus hinder resolution. The researchers in this area have emphasized the need for additional research in order to recognize risk and resilience factors that affect the parental resolution (Barak-Levy & Atzaba-Poria, 2013).

The present research adopts Wallander and Varni's Disability-Stress-Coping model of factors influencing parental adaptation, as the guiding theoretical framework (Wallander & Varni (1998)). This model attempts to identify major risk and resistance factors that directly or indirectly affect adaptation of parents raising children with developmental disabilities. It includes three categories of the risk factors: (1) disease/disability parameters (e.g., severity), (2) functional dependence, and (3) psychosocial stressors (disability-related problems, major life events, daily hassles), as well as three categories of resistance factors: (1) intrapersonal factors, (2) socioecological factors, and (3) stress processing factors. The model is complex and comprehensive and is therefore difficult to test the full model in a single research. We relied on Wallander and Varni's model to address specific risk factors (functional status of the child and the accumulation of stressful life events in the family). However, in contrast to this model which regards maternal mental health as an outcome, we considered maternal depression an additional risk factor affecting adaptation. This is in line with previous research showing parental depression to be a contributing factor to parenting stress (Rodenburg, Meijer, Deković, & Aldenkamp, 2007; Webster Stratton & Hammond, 1988). Hence, given our intention to cover variables from the three important domains – child-, mother-, and family-related – we were interested in three specific risk factors: the child's functional status, maternal depression, and the accumulation of stressful life events in the family.

Although the Disability-Stress-Coping model includes condition severity as an important risk factor, it is quite difficult to operationalize it in children with CP. CP represents a condition primarily defined through its motor deficit, but it is strongly

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