

Resolution of diagnosis in mothers of infants with cerebral palsy

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Background

Cerebral palsy is a chronic condition that may have serious consequences for the child's physical, cognitive and social functioning, but also for his family. For parents, perhaps one of the most emotional experiences is receiving their child's diagnosis and the realisation that their child might always be different from other children. Rehabilitation professionals are less focussed on the grief reactions of the parents. Insight in the resolution of parents when their child has been diagnosed with cerebral palsy may help professionals in their provision of services for the families.



Aim

The present study aimed to describe the nature and prevalence of resolution of parents of young children with cerebral palsy.

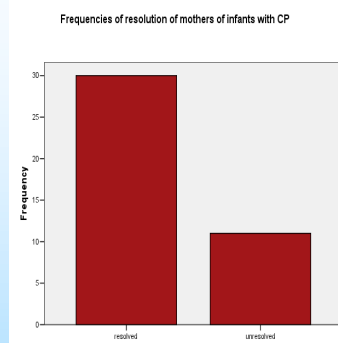
Methods

41 mothers of children with CP (mean age 20 months, sd= 2.9 months, GMFCS levels range I-V) completed the Reaction to Diagnosis Interview, a highly structured interview questioning the parent's beliefs, memories and emotional reactions to the news of their child having CP. Reactions were coded using the Reaction to Diagnosis Classification System which consist of a list of elements reflecting resolution or lack of resolution.

Results

Thirty mothers (73 %) were classified as **Resolved**, meaning that they have moved beyond the crisis of the diagnosis.

Eleven mothers (27 %) were classified as **Unresolved**, meaning that in some way they remain focused on that experience in an emotionally overwhelmed or angry stance, or use defensive exclusion, denial or deflection not to be confronted with the diagnosis.



Reaction to Diagnosis Classification System¹

Elements of Resolution

- Acknowledgement that the experience of the diagnosis was difficult
- Recognition of a change in feelings since the diagnosis
- Assertion of moving on in life
- Suspension of the search for an existential reason for the diagnosis
- Accurate representation of the child's abilities
- Balanced integrated statements regarding the benefits and drawbacks of the whole experience to the self.

Elements of Lack of Resolution

- Cognitive distortions about the child's condition (unrealistic beliefs, denial, wishes for realities)
- Continued active search for an existential reason for the diagnosis
- Grieving, anger or other affect strong and pervasive enough to suggest that the individual is 'stuck in the past' as if the diagnosis had just been given.
- Episodic memory and/or affect is sufficiently unavailable to indicate that the individual is cut off from the experience of the diagnosis.
- Incoherence and disorientation to indicate the lack of a strategy with which to communicate about the experience.

Conclusion

In this study 27 % of the mothers of infants with cerebral palsy are classified as Unresolved. Although reactions of grief are normal and most parents appear to get over their pain, learning of a child's diagnosis is often an emotional and painful experience for parents. When professionals are more aware of the parental burden and parental coping abilities, they are able to estimate the needs of the family and to identify families at risk for resolution problems. Examination of possible changes over time in the process of resolution is recommended. This study helps to shift the focus in rehabilitation practice from the child with cerebral palsy to their parents.

References

- ¹ Marvin RS, Pianta RC. Mothers' Reactions to Their Child's Diagnosis: Relation With Security of Attachment. *Journal of Clinical Child Psychology*. 1996. Vol 25, (4), 436-445.

This research has been performed as part of the PERRIN (Pediatric Rehabilitation Research in the Netherlands) research program and was funded by the Netherlands Organisation for Health Research and Development ZonMw, Johanna Kinderfonds and Stichting Bio Kinderrevalidatie.