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## The quality of primary relationships in families of children with spina bifida

Ignace PR Vermaes\*, Jan RM Gerris and Jan MAM Janssens

Address: Institute of Family and Child Care Studies, University of Nijmegen, Montessorilaan 3 – A06.30, 6525 H, The Netherlands

Email: Ignace PR Vermaes\* - i.vermaes@pwo.ru.nl

\* Corresponding author

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### Background

This study was part of the multidisciplinary research program "Prognosis of Spina Bifida" of the Radboud University Nijmegen, The Netherlands. Based on a family systems perspective, mothers and fathers of children with spina bifida were examined in comparison to non-clinical samples of parents across different levels of family functioning (individual, marital, parental, and familial). Two questions were addressed: (1) To what extent do families of children with spina bifida differ from regular families; and (2) Do child characteristics (severity of spina bifida, IQ, and/or behavioural problems) predict the divergent family characteristics?

### Materials and methods

Mothers and fathers of children with spina bifida ( $n = 70$ ; age Mean = 8.6, SD = 4.4; 43 girls) filled out questionnaires for which norm data were available including the Child Behaviour Check List, Coping Orientation of Problem Experience Inventory, Dyadic Adjustment Scales, Parenting Stress Index, and Family Environment Scales. Severity of Spina Bifida was assessed by a child neurologist and through parent reports. A neuropsychologist assessed the child's IQ by use of the WISC-III.

### Results

On individual level, index mothers and fathers did not diverge from parents of able-bodied children in their problem-focused coping efforts. However index mothers reported to seek significantly less social support and index fathers reported significantly less avoidant ways of coping than their counterparts. On dyadic level, both index parents reported to experience significantly less marital satisfaction in comparison to other parents. Within the parent-

child dyad, index parents reported to experience more child-rearing satisfaction than parents of able-bodied children, but at the same time they also reported significantly more parenting stress, i.e. more depression, less feelings of parenting competence, more role restrictions, more health problems, and more social isolation. On family level, index families scored significantly higher on the Family Relations Index than norm groups, indicative of more cohesion, expressiveness, and less conflicts. Preliminary linear regression analyses showed that the severity of spina bifida predicted avoidant coping negatively and family structure (organization and family norms) positively. The child's low IQ predicted less marital satisfaction, less child rearing satisfaction, and more family structure. Internalization problems of the child predicted less marital satisfaction and more parenting stress.

### Conclusion

The meaning of the current results will be discussed in the perspective of family systems and quality of life. The paradoxical results on the parenting dyad will be discussed along the parenting dimensions of affection, responsiveness, and control.