

Psychosocial adjustment in families with rare skin diseases

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Introduction

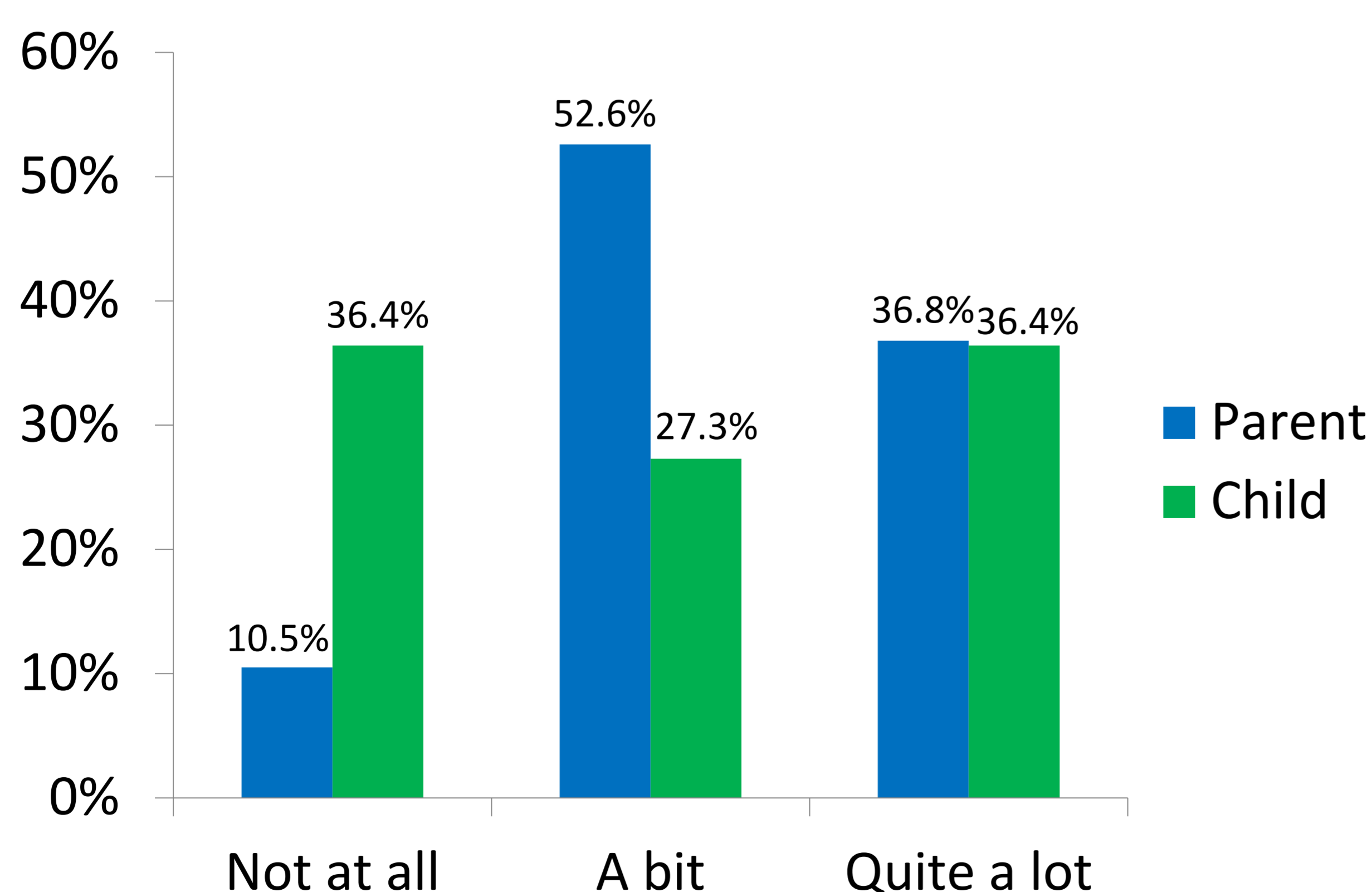
- Rare skin diseases do not only physically affect the patient, but can also impact his/her psychosocial adjustment, as well as the entire family's functioning.
- The current study investigated the quality of life of parents of children with rare skin diseases, in addition to the parents' perceptions of their child's adjustment and coping.



Sample and method

- The sample consisted of 28 parents (18 mothers, 10 fathers) of 19 children (11 girls, 8 boys) with rare skin diseases: epidermolysis bullosa ($N = 7$), ichthyosis ($N = 5$), ectodermal dysplasia ($N = 6$) and incontinentia pigmenti ($N = 1$).
- All children were in primary school age (age range 5-12).
- Parents filled out questionnaires where they were asked to report about themselves (World Health Organization Quality of Life questionnaire, WHOQOL-BREF) and their children (Strengths and Difficulties Questionnaire, SDQ).
- Supplementary questions were added.

Figure 1: Experience with the diagnosis made me (/my child) stronger



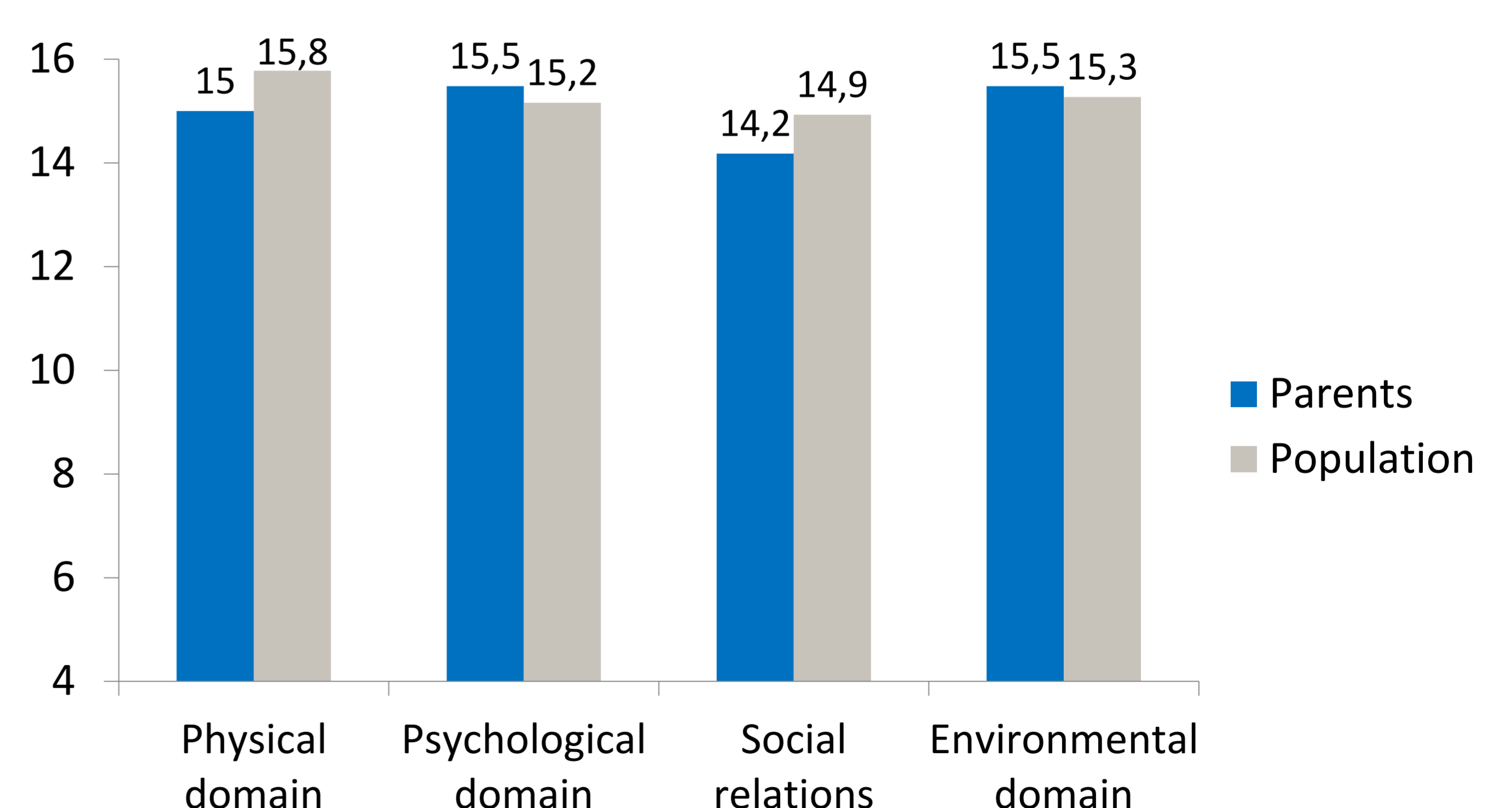
Results

- There were no significant differences in responses of parents of children with EB and other rare skin diseases.
- The vast majority of parents (91%) reported that their child's diagnosis affected their daily life.
- Almost half of the parents admitted that the diagnosis led to conflicts within the couple.
- Mothers had more difficulties accepting their child's diagnosis (82%) than fathers (41%).
- Parents of children with skin diseases had the same quality of life as the general Norwegian population.
- Children with rare skin diseases were reported to have more adjustment problems than the general Norwegian population of children in the same age group.

Table 1: Strengths and difficulties (evaluation by parents)

	Total difficulties M (SD)	Emotional M (SD)	Conduct M (SD)	Hyperactivity M (SD)	Peer problems M (SD)	Prosocial M (SD)
Girls with skin diseases	13.4 (7.9)	3.1 (2.1)	2.4 (2.3)	5.5 (2.8)	2.5 (2.5)	8.5 (2.5)
Boys with skin diseases	13.5 (8.5)	3.9 (3.3)	2.3 (1.9)	5.3 (2.2)	2.2 (2.9)	8.0 (1.6)
General population of girls (10-13)	5.7 (4.8)	1.4 (1.8)	1.0 (1.2)	2.2 (2.0)	1.1 (1.6)	8.5 (1.5)
General population of boys (10-13)	6.6 (5.2)	1.2 (1.7)	1.1 (1.4)	3.0 (2.4)	1.3 (1.7)	8.0 (1.7)

Figure 2: Parents' quality of life (range 4-20; 20 = highest QoL)



For further information

- Supplemental handouts are available.
- For more details please contact krifer@ous-hf.no.