

<b>Title</b>	<b>Hidden consequences of success in Pediatrics: parental Health Related Quality of Life. Results from the Care-project</b>	<b>A predictive model of Health Related Quality of life of parents of chronically ill children: the importance of care-dependency of their child and their support system</b>	<b>Back to a traditional breadwinner-homemaker model? Employment and leisure time of parents of children with a chronic disease</b>	<b>Subjective losses in well-being of parents of chronically ill children: a monetary evaluation</b>	<b>Quality of life of female caregivers of children with sickle cell disease: a survey</b>	<b>Predicting Health Related Quality of life of parents of children with inherited metabolic diseases</b>
<b>Aim</b>	Overview of caregiver HRQoL and comparison group	Exploring conceptual model of parental HRQoL	Employment and leisure activity time of parents and comparison group	Quantification of subjective loss of care	Disease specific HRQoL of mothers of children with sickle cell disease	Disease specific predictors of HRQoL of parents of children with metabolic disorders
<b>Inclusion</b>	N=533 parents of children with chronic disease <sup>1</sup> N=425 parents of school children <sup>2</sup>	N=543 parents of children with chronic disease	N=576 parents of children with chronic disease N=441 parents of schoolchildren	N=580 parents of children with chronic disease. N=443 parents of schoolchildren	N=54 mothers of children with SCD. N=700 reference population of TAAQoL. N=28 SES-matched comparison group.	N=121 parents of children with metabolic disorders
<b>Measurement</b>	Health related quality of life in the past month	Health related quality of life in the past month	Employment (hrs/week) Leisure activity time (hrs/week)	General wellbeing	Health Related Quality of Life in the past month	Health Related Quality of Life in the past month
<b>Outcome</b>	Parents of chronically ill children have a lower HRQoL. 50% at risk of HRQoL impairment	Social variables as mediator between disease characteristics, demographic background and HRQoL as outcome	Families with ill child work less hours a week: mothers work fewer hours. Also fewer hours leisure time when child is ill.	Costs of lower well-being described in household income: 4275-10925 euro.	Mothers of children with SCD lower socio-economic situation. SES comparison: lower HRQoL on depressive moods, daily activities, vitality.	These parents have lower HRQoL on majority of HRQoL scales
<b>Risk (-) and protective (+) factors</b>		Direct: female gender (-), parental age (+), chronic illness of parent (-), care dependency (-). Mediator: holiday (+) and emotional support (+)	Salient factors: Being parent of child with chronic disease (-), use of child care (+), care dependency (-), low educational level (-)			Low educational level (-), age parent (+), progressive disease development (-), tube feeding (+), loss of friendship (-), emotional support (+).
<b>Journal</b>	Pediatrics (2008), 122 (5)	Health and Quality of life outcomes (2009), 7(1)	Submitted	Submitted	Haematologica (2008), 93 (4)	Acta Paediatrica (2009), 98 (7)
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<sup>1</sup>Parents from children from 10 diagnosis groups (asthma, survivors of brain tumour, diabetes, Duchenne muscular dystrophy, Down syndrome, end stage renal disease, metabolic diseases, profound complex handicaps, sickle cell diseases, spina bifida)

<sup>2</sup>Parents from two elementary schools and one high school, whose children were not chronically ill (parent report)