Consequences of care: Parents of children with a chronic disease
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Summary of this thesis
SUMMARY OF THIS THESIS

In the Netherlands approximately 14% of all children grow up with a chronic disease. The treatment of several diseases has improved enormously in recent decades. Diseases that used to be life-threatening and life-limiting have now become chronic diseases, resulting in an increasing number of children growing up with special health care needs. Children may experience physical, emotional and cognitive consequences of their illness or treatment. This not only affects the lives of these children themselves, but also has consequences for their families. The present thesis focuses on the consequences for parents. Parents increasingly have extended care responsibilities related to the illness of their child and may experience emotional consequences. Caring for a child with a chronic disease can be seen as an additional role for parents, which poses a burden on other roles. Besides the regular care every child needs, parents have to manage the illness, instruct others about the care, incorporate the care in family life, manage the consequences for siblings and keep these tasks in balance with personal needs.

This thesis presents the results from the Care-project, a cross-sectional retrospective study that was conducted among 580 parents of children with a chronic disease (10 different diagnoses – see Appendix A) and 443 parents of healthy schoolchildren. All parents completed a survey including questions about their Health Related Quality of Life (HRQoL), employment and leisure activity time and several demographic and disease related questions.

The main aims of the present thesis were:
1 to compare parental HRQoL, employment and leisure time between parents of children with a chronic disease and parents of healthy children,
2 to identify factors associated with HRQoL, employment and leisure time
3 to quantify the association of being a parent of a child with a chronic disease on well-being in a monetary value. The results for each chapter are summarized below.

In the general introduction, chapter 1, the context of the Care-project is illustrated and a description of the study design is given. Previous studies addressing consequences for parents in terms of quality of life, employment and leisure activity time were described. Finally, a conceptual model explaining parental HRQoL by demographic and social factors is presented.

The Care-project adds to the current knowledge by providing information about how parents evaluate their physical, social and emotional functioning. Also, in the Netherlands, little is known about how these families combine care with employment and leisure time. The majority of studies lack a good definition of chronic illness, have small sample sizes, and have no comparison group. In addition, most studies have been done within disease groups, impeding comparability between studies and diseases.
In the generic part of this thesis, a generic approach was followed to describe consequences experienced by parents. Chapter 2 focuses on parental HRQoL, by providing a comparison between all parents of children with a chronic disease in our sample and parents of healthy schoolchildren. Parents of chronically ill children had lower HRQoL scores than parents of healthy children, on the following domains: gross motor functioning, cognitive functioning, sleep, pain, social functioning, daily activities, sexuality, vitality, positive emotions, and depressive emotions. Comparison of disease specific groups and the comparison group revealed most differences for parents of children with metabolic disorders, followed by parents of children with sickle cell disease, Duchenne muscular disease, and asthma. In general, parents in disease specific groups reported a significantly lower HRQoL because of problems with social and daily functioning, vitality, and sleep, and having less positive and more negative emotions. To add clinical meaning to these differences, we divided parents into 2 groups, one at risk for an impaired HRQoL and one not at risk, based on the 25th percentile of the comparison group. This division showed that on average 40% - 50% of the parents of chronically ill children were at risk for HRQoL impairment. These problems concern several aspects of daily life, which underlines the importance of parental support in clinical practice. Although within disease groups not all differences were statistically significant, they indicate a trend towards HRQoL impairment across disease groups.

In our conceptual model (chapter 3), parental HRQoL was directly negatively associated with female gender, lower parental age, lower educational level, higher care-dependency of the child, having a chronic illness as a parent, less emotional support, and number of days parents went on holiday in the past year. In addition to these direct effects, the effect of educational level, having a partner, being born in the Netherlands, being chronically ill, having a chronically ill partner and care-dependency on HRQoL was mediated by holiday and emotional support. Mediation means that the background characteristics were associated with HRQoL indirectly through emotional support and holiday. Taking the size of the (significant) effects into account, care-dependency of the child, chronic illness of the parent, limited number of days on holiday, and less emotional support seem to be the main factors associated with lower parental HRQoL.

Chapter 4 shows that parents of chronically ill children worked fewer hours a week, mothers less often participated in the labor force, and it shows that parents spent less time doing leisure activities than parents of healthy children. Dependency on daily care of the child was negatively associated with family employment and maternal labor force participation, but not with leisure activity time. Parents making use of child care had a higher probability of working more hours a week. In addition, the effect of child care on employment was stronger for mothers than on a family level. A low educational level was a risk factor for family and maternal employment and for leisure activity time.

Chapter 5 focuses on parental subjective well-being and gives an estimation of these losses described in a monetary value. This study showed that having a chronically ill child was negatively associated with parental subjective well-being. This association was stronger for parents that had a child with a progressive illness followed by parents
whose child had a relapsing course of disease. For the specific disease groups, the association with well-being was strongest for parents of children with Duchenne and multiple complex handicaps. The monetary value equating this loss in well-being indicated that parents with a chronically ill child would need 4275 euro a month to report the same well-being level as parents without a chronically ill child. For parents of children with a progressive illness (e.g. Duchenne and several metabolic disorders) the monetary value is about 4.5 times their monthly income (10925 euro). The values for each disease group range from 6959 to 10629 euro.

In the disease specific part of this thesis, two groups of parents are highlighted: parents of children with sickle cell disease and with metabolic diseases, who both had a remarkable lower HRQoL as shown in chapter 2. In chapter 6, a comparison was made of mothers of children with a sickle cell disease with a Dutch population and a group with a similar socio-economic status. Compared to the Dutch population, caregivers of children with sickle cell disease had lower HRQoL scores on all domains. To test whether these results were distorted by the lower socioeconomic situation of these caregivers, a comparison of HRQoL with mothers of children with a similar socio-economic status was made. This revealed lower scores on the domains depressive moods, daily activities and vitality for caregivers of children with sickle cell disease, indicating an effect of the disease on mothers’ HRQoL.

In chapter 7 we studied associated factors with parental HRQoL, for parents of children with metabolic diseases. Psychosocial factors appeared to be more related with the low HRQOL of parents of children with metabolic disorders than socio-demographic and medical variables. Emotional support and friendship were positively associated with HRQoL, while loss of friends negatively related to parental HRQoL. Medical variables related to aspects of HRQoL were reported progression of illness, tube feeding and when the child had difficulties making contact.

Chapter 8, the general discussion, provides a reflection on the main findings and a description of implications of the Care-project for clinical practice and future research. Parents of children with a chronic disease are relatively young and experience a multitude of consequences in daily life. Most salient risk factors were a lower socio-demographic status and a child that needs more care, while emotional support was an important protective factor. Limitations of the present study were, among others, the response rate of 52%, the fact that mainly mothers participated and the use of a single informant. Due to the cross-sectional design, inferences about causality of the associations were not possible. It would be interesting to investigate family functioning more comprehensively by performing a longitudinal study including mothers, fathers and all children, in order to get a more complete picture of the consequences of the chronic disease.

For parents, chronic illness in their child suddenly or gradually influences their career, income and social activities, resulting in a decline in the growth curve of their societal development. Minimizing this decline should become one of the aims of pediatric health
care. This implicates screening of parents ‘at risk’ in clinical practise, and more attention for family functioning in both research and clinical practice. Interventions aimed at empowerment of parents will help parents gain self-awareness and self-efficacy and will benefit their chronically ill child. In conclusion, parental functioning should become an additional parameter of pediatric treatment outcome.