Consequences of care: Parents of children with a chronic disease
Hatzmann, J.

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Hidden consequences of success in pediatrics: parental Health Related Quality of Life. Results from the Care project.
ABSTRACT

Context The number of parents caring for a chronically ill child is increasing. Due to advances in medical care, parental caring tasks are changing. A detailed description of Parental Health Related Quality of Life (HRQOL) will add to the understanding of the impact of caring for a chronically ill child. This will contribute to pediatric family care.

Objective To determine the HRQOL of parents of chronically ill children compared to parents of healthy schoolchildren.

Design, setting, and participants A survey of 533 parents of children with chronic conditions (10 diagnosis groups, children aged 1-19 years, diagnosed >1 year ago, living at home) and 443 parents of schoolchildren was conducted between January 2006-September 2007. Parents were approached through the Emma Children’s Hospital, which has a tertiary referral and a regional function, and through parent associations. The comparison group included parents of healthy school children. HRQOL was assessed with the TNO-AZL Questionnaire for Adult’s Health Related Quality of Life.

Main outcome measure HRQOL measures gross and fine motor function, cognitive functioning, sleep, pain, social functioning, daily activities, sexuality, vitality, positive and depressive emotions, aggressiveness. HRQOL of the study group was compared with that of the comparison group (Univariate analysis of variance, p<0.004), effect sizes were estimated. The percentages of parents at risk for a low HRQOL were compared to the 25th percentile scores of the comparison group (Binomial test, p<0.008).

Results Parents of chronically ill children had a significantly lower HRQOL. Subgroup analysis showed lower HRQOL on sleep, social functioning, daily activities, vitality, positive emotions, and depressive emotions in disease specific groups. On average, 45% of parents were at risk for HRQOL impairment.

Conclusions Parents of chronically ill children report a seriously lower HRQOL, which should receive attention and supportive care if necessary. A family-centered approach in pediatrics is recommended.
INTRODUCTION

In The Netherlands, at least 14% (500,000 children) of all children grow up with a chronic illness.¹ Recent data from the United States show that at least 7% (5 million children) of all children have a limitation of activity due to a health condition, with the number of chronically ill children being even higher.² The number of children living with a chronic illness will likely further increase due to medical advancements and genetic, social, and behavioral changes.² For parents, learning that their child has a chronic and potentially life threatening disease is a very stressful and potentially traumatic event.³,⁴ Besides emotional impact, having a chronically ill child also influences family and social life, as parents provide most of the daily care for these children.⁵ This daily care involves management of the illness, which can be complex and is increasingly transferred from the hospital to the home (e.g. home dialysis, intravenous alimentation). The daily care also includes instructing others (e.g. teacher), combining care with family life, and managing the consequences of the illness on siblings.⁶-⁹ The caregiving role, combined with family life, an occupational career, and a social life, can be very stressful for parents.¹⁰-¹³ Parents report a lower quality of life and experience physical and emotional strain.¹⁴⁻¹⁸ Parental physical, emotional, and social health also influences the health and well-being of their children.⁴,¹⁹ This presents a conflicting situation, because as it becomes more difficult for parents to fulfill all tasks, their role in providing care becomes increasingly important for the health and well-being of their children.

In the literature, parental quality of life has been described in terms of emotional and physical health. However, we know that the daily life of parents of chronically ill children may also change; therefore, we were interested in a comprehensive view of Health Related Quality of Life (HRQOL) that also reflects these aspects of life.

We compared the HRQOL of parents of chronically ill children with a comparison group to assess possible differences in the specific aspects of HRQOL and if parents of chronically ill children are at risk for HRQOL impairment. We expected the HRQOL of parents of chronically ill children to be lower than that of a comparison group. This detailed information about the HRQOL of parents will give insight into specific problem areas and indicate which parents are at risk for an impaired HRQOL.

METHODS

Design

This study was conducted within the framework of a large retrospective study (the Care-project) examining HRQOL and social and financial consequences of parents caring for a chronically ill child. Participants were recruited between January 2006-September 2007 in the Emma Children’s Hospital, Amsterdam, The Netherlands and through patient organizations. A self report questionnaire was developed for this study, including an already existing
HRQOL questionnaire. The Care-questionnaire was also available in English, translated by a professional translator. The study was approved by the Medical Ethical Committee.

Participants
Parents of chronically ill children participated in this study. Chronic illness was defined according to Mokkink et al.\textsuperscript{1,20} using the following criteria: the disease occurs in children aged 0-18 years, the diagnosis is based on medical scientific knowledge, the disease is not (yet) curable and exists for at least three months, or will probably endure longer, or at least three disease episodes have occurred the last year. According to the definition, we selected ten different chronic diseases: asthma, diabetes, Down syndrome, Duchenne muscular dystrophy, end stage renal disease, metabolic diseases, profound multiple handicaps, sickle cell disease, spina bifida, and survivors of a brain tumor.

Inclusion criteria were:
1. the chronically ill children were aged between 1-19 years old,
2. diagnosed >1 year before inclusion in the study,
3. lived at home, and
4. the parents were able to fill out the questionnaire in Dutch or English.

Parents in the comparison group were eligible if their child:
1. was not chronically ill,
2. was aged between 1-19 years old,
3. lived at home, and
4. the parents were able to fill out the questionnaire in Dutch or English.

Procedure
Parents received an introductory letter explaining the aim of the study and asking for their participation. The letter was accompanied by the questionnaire, an informed consent form, and a stamped self-addressed envelope. Each family received one questionnaire, which was completed at home. The comparison group consisted of parents of healthy children from two elementary schools and one high school located within 50 kilometers of our hospital. The schoolchildren took an envelope with the information and the questionnaire home for their parents. The specific procedure for each disease group is described in the appendix.

Measurement
Demographic and HRQOL data were taken from the Care-questionnaire. HRQOL was assessed using the ‘TNO-AZL Questionnaire for Adult’s Health related Quality Of Life’ (TAAQOL).\textsuperscript{21} The questionnaire measures health status problems weighted by the impact
of problems on well-being on 12 multi-item scales: gross and fine motor functioning, cognitive functioning, sleep, pain, social functioning, daily activities, sexuality, vitality, positive emotions, depressive emotions, and aggressiveness.

Each item consists of two parts: the first part assesses the prevalence of a health problem or limitation in the past month, the second part evaluates the emotional response to the health problem or limitation. Answers were scored on 4 point scales. A single score is attributed to each combination of an item assessing the prevalence of a problem or limitation and the corresponding emotional response. The scales for vitality, positive emotions, depressive emotions, and aggressiveness only assess the occurrence of the feelings in the past month. Higher scores indicate a better HRQOL. The Cronbach’s alpha’s in the present study were mainly satisfactory to good, ranging from 0.60-0.96, with the exception of fine motor function in the Duchenne and Down syndrome group, sexuality in the multiple handicap group, and aggressiveness in the Duchenne, end stage renal disease, and spina bifida groups. These scales were excluded from analysis. The psychometric properties, validity, and reliability of the TAAQOL were satisfactory.21

**Statistical analysis**
First, scales were constructed and missing data were imputed based on the guidelines of the TAAQOL. In calculation of the scale scores, one missing combined-item score was allowed for. The missing score was replaced by the mean value of the non-missing item scores. Demographic data of the study and comparison group were compared using Chi-square tests for categorical data and t-tests for continuous data. The HRQOL of the total group of parents of chronically ill children was compared to the HRQOL of the comparison group by univariate analysis of variance for each scale, adjusted for parental age and education. Furthermore, a univariate analysis of variance was performed for each disease group, compared with the comparison group, with age and educational level as covariates. To adjust for multiple testing, we used a Bonferroni correction and adjusted the alpha to 0.004 (0.05/12). Effect sizes (d) were calculated by dividing the difference in mean scores between disease groups and the comparison group by the standard deviation of the comparison group. We considered effect sizes up to 0.2 to be small, around 0.5 to be moderate, and around 0.8 to be large.22 The distribution of gender between the disease population and the comparison group was equal, we considered mothers and fathers as one group for analysis.

To further explore the scales on which most differences were found and effect sizes were moderate to high, we created a distinction between parents ‘at risk’ and those ‘not at risk’ for an impaired HRQOL, based on percentile norms of the healthy population.23 A parent in the comparison group who scores below the value of the 25th percentile is placed in the quarter of the most impaired population. We compared the percentage of parents in the disease samples scoring below the value of the 25th percentile of the norm population using binomial tests p<0.008 (0.05/6). We used the Statistical Package for Social Sciences (SPSS) version 12.0.
### Table 1 Demographics

<table>
<thead>
<tr>
<th></th>
<th>Comparison group n=425</th>
<th>Parents chronically ill children n=533</th>
<th>Asthma n=87</th>
<th>Survivors Brain tumor n=38</th>
<th>Diabetes n=24</th>
<th>Duchenne muscular dystrophy n=57</th>
<th>Down syndrome n=100</th>
<th>End stage renal disease n=18</th>
<th>Metabolic disease n=117</th>
<th>Profound complex handicaps n=12</th>
<th>Sickle cell disease n=59</th>
<th>Spina bifida n=21</th>
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<tbody>
<tr>
<td>Gender (Female)</td>
<td>354 (83%)</td>
<td>453 (85%)</td>
<td>75 (86%)</td>
<td>34 (90%)</td>
<td>21 (88%)</td>
<td>42 (74%)</td>
<td>87 (87%)</td>
<td>18 (100%)</td>
<td>89 (76%)</td>
<td>9 (69%)</td>
<td>53 (88%)</td>
<td>19 (91%)</td>
</tr>
<tr>
<td>Married/Partner</td>
<td>379 (89%)</td>
<td>470 (88%)</td>
<td>73 (84%)</td>
<td>32 (84%)</td>
<td>23 (96%)</td>
<td>56 (98%)^</td>
<td>98 (98%)^</td>
<td>13 (72%)</td>
<td>109 (93%)</td>
<td>12 (92%)</td>
<td>30 (51%)^</td>
<td>17 (81%)</td>
</tr>
<tr>
<td>Age Years (SD)</td>
<td>43.7 (5.5)</td>
<td>42.0 (6.4)^*</td>
<td>42.2 (6.7)</td>
<td>45.8 (5.5)^*</td>
<td>45.0 (6.6)</td>
<td>44.0 (5.6)</td>
<td>41.6 (4.9)^</td>
<td>42.9 (3.5)</td>
<td>41.3 (7.0)^</td>
<td>43.4 (5.2)</td>
<td>38.2 (7.3)^</td>
<td>41.0 (6.4)^*</td>
</tr>
<tr>
<td>Educational level</td>
<td></td>
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<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Lower</td>
<td>86 (20%)</td>
<td>140 (26%)^</td>
<td>15 (17%)</td>
<td>9 (24%)</td>
<td>7 (29%)</td>
<td>15 (26%)</td>
<td>20 (20%)</td>
<td>7 (39%)^</td>
<td>29 (25%)</td>
<td>3 (25%)</td>
<td>30 (50%)^</td>
<td>5 (24%)</td>
</tr>
<tr>
<td>Intermediate</td>
<td>163 (38%)</td>
<td>219 (41%)</td>
<td>40 (45%)</td>
<td>17 (45%)</td>
<td>8 (33%)</td>
<td>20 (35%)</td>
<td>40 (40%)</td>
<td>9 (50%)</td>
<td>50 (43%)</td>
<td>3 (25%)</td>
<td>3 (25%)</td>
<td>22 (37%)</td>
</tr>
<tr>
<td>Higher</td>
<td>176 (41%)</td>
<td>174 (33%)</td>
<td>32 (37%)</td>
<td>12 (31%)</td>
<td>9 (38%)</td>
<td>22 (39%)</td>
<td>40 (40%)</td>
<td>2 (11%)</td>
<td>38 (32%)</td>
<td>6 (50%)</td>
<td>8 (13%)</td>
<td>6 (28%)</td>
</tr>
<tr>
<td>Children per family</td>
<td>2.2 (0.8)</td>
<td>2.2 (0.9)</td>
<td>2.0 (1.0)</td>
<td>2.1 (0.7)</td>
<td>2.2 (1.0)</td>
<td>2.5 (0.9)^*</td>
<td>2.2 (0.7)</td>
<td>2.2 (0.9)</td>
<td>2.3 (1.0)</td>
<td>2.3 (1.2)</td>
<td>2.3 (1.2)</td>
<td>2.5 (0.8)</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Age chronically ill</td>
<td>-</td>
<td>10.0 (4.4)</td>
<td>10.7 (4.3)</td>
<td>14.6 (4.4)</td>
<td>12.6 (4.4)</td>
<td>11.6 (4.0)</td>
<td>7.3 (1.4)</td>
<td>13.0 (4.1)</td>
<td>8.7 (4.4)</td>
<td>9.7 (4.4)</td>
<td>9.2 (4.5)</td>
<td>9.9 (4.8)</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td>7.8 (4.3)</td>
<td>8.9 (5.0)</td>
<td>8.1 (3.8)</td>
<td>8.0 (5.5)</td>
<td>8.4 (4.3)</td>
<td>7.6 (1.3)</td>
<td>10.3 (5.3)</td>
<td>6.1 (4.0)</td>
<td>9.8 (3.9)</td>
<td>7.5 (4.4)</td>
<td>9.5 (5.1)</td>
<td></td>
</tr>
</tbody>
</table>

* p<0.1 for disease group in comparison with the reference group (t-test)
^ p<0.1 for disease group in comparison with reference group (chi square)
RESULTS

Participants
In total, 533 of the 580 participating parents filled out the quality of life questionnaire. Overall, the groups had similar demographics (p< 0.1) except for educational level, with a larger proportion of highly educated parents in the comparison group (Table 1). Gender distribution in the Duchenne, sickle cell disease, and brain tumor survivor group statistically differed from the comparison group, with more women in the sickle cell and brain tumor group, and more men in the Duchenne group. Furthermore, parents of children with sickle cell disease and end stage renal disease were more often single and had a lower educational level than the comparison group. Parents of children with metabolic disease also had a lower educational level. Parents of children with Down syndrome had more children than the comparison group. Furthermore, the age of parents of children with asthma, sickle cell disease, and metabolic diseases was significantly lower than that of the comparison group.

Differences in HRQOL between parents of healthy children and parents of chronically ill children
The total group of parents of chronically ill children had significantly lower scores on all sub-scales (p<0.004) except fine motor functioning (Table 2). On the scales for cognitive functioning, sleep, social functioning, and positive emotions, significant differences were small to moderate as effect sizes ranged from 0.32-0.76. On the scales for daily activities, vitality, and depressive emotions, significant differences were moderate to large, with effect sizes from 0.47-1.16. On the scales for gross motor function, pain, sexuality, and aggressiveness, significant differences were small to moderate with effect sizes from 0.19-0.69.

Subgroup analysis revealed that the most salient differences occurred in the scales for sleep, daily activities, social functioning, vitality, positive emotions, and depressive emotions. Parents of children with metabolic diseases had a significantly lower score on all scales except fine motor function. These differences were all moderate to large, with effect sizes ranging from 0.44-1, except for gross motor function and aggressiveness. Furthermore, parents of children with asthma, Duchenne, and sickle cell disease had significantly lower scores on a relatively large number of scales. Parents of children with brain tumors, diabetes, end stage renal disease, and spina bifida had significantly lower scores on a small number of scales. However, despite the few differences found in the end stage renal disease group, the majority of effect sizes were moderate to large.

Proportion of parents of chronically ill children at risk for HRQOL impairment
Figure 1 shows the percentages of parents at risk for HRQOL impairment for the scales for sleep, social functioning, daily activities, vitality, positive and depressive emotions. The
Table 2 Mean HRQOL scale scores, 95% confidence intervals and effect sizes of caregivers of chronically ill children and the comparison group.

<table>
<thead>
<tr>
<th>Condition</th>
<th>N</th>
<th>Gross Motor function</th>
<th>95% CI</th>
<th>Fire Motor function</th>
<th>95% CI</th>
<th>Cognitive functioning</th>
<th>95% CI</th>
<th>Sleep</th>
<th>95% CI</th>
<th>Pain</th>
<th>95% CI</th>
<th>Social Functioning</th>
<th>95% CI</th>
<th>ES*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents Healthy Children</td>
<td>425</td>
<td>88 (86-90)</td>
<td>0.17</td>
<td>97 (96-98)</td>
<td>0.11</td>
<td>79 (77-81)</td>
<td>0.32</td>
<td>70 (68-73)</td>
<td>0.36</td>
<td>72 (70-74)</td>
<td>0.27</td>
<td>76 (74-78)</td>
<td>0.4</td>
<td></td>
</tr>
<tr>
<td>Parents Chronically ill</td>
<td>533</td>
<td>84 (82-86)*</td>
<td>0.19</td>
<td>96 (95-97)</td>
<td>0.11</td>
<td>71 (69-73)*</td>
<td>0.32</td>
<td>61 (59-64)*</td>
<td>0.36</td>
<td>66 (64-69)*</td>
<td>0.27</td>
<td>76 (74-78)*</td>
<td>0.4</td>
<td></td>
</tr>
<tr>
<td>Asthma</td>
<td>87</td>
<td>80 (75-86)</td>
<td>0.38</td>
<td>83 (82-89)</td>
<td>0.44</td>
<td>73 (67-77)</td>
<td>0.32</td>
<td>58 (52-64)*</td>
<td>0.47</td>
<td>67 (61-72)</td>
<td>0.22</td>
<td>80 (75-84)</td>
<td>0.2</td>
<td></td>
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<tr>
<td>Survivors brain tumor</td>
<td>38</td>
<td>90 (84-97)</td>
<td>0.1</td>
<td>98 (71-100)</td>
<td>0.11</td>
<td>80 (71-89)</td>
<td>0.04</td>
<td>66 (58-75)</td>
<td>0.16</td>
<td>76 (69-84)</td>
<td>0.18</td>
<td>84 (78-89)</td>
<td>0.0</td>
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<tr>
<td>Diabetes</td>
<td>24</td>
<td>86 (74-97)</td>
<td>0.1</td>
<td>97 (92-100)</td>
<td>0.12</td>
<td>76 (65-87)</td>
<td>0.12</td>
<td>58 (47-68)</td>
<td>0.47</td>
<td>68 (59-78)</td>
<td>0.18</td>
<td>77 (69-85)</td>
<td>0.35</td>
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<tr>
<td>Duchenne muscular dystrophy</td>
<td>57</td>
<td>88 (84-92)</td>
<td>0.0</td>
<td>75 (68-81)</td>
<td>0.16</td>
<td>63 (56-70)</td>
<td>0.28</td>
<td>66 (60-72)</td>
<td>0.27</td>
<td>75 (71-80)*</td>
<td>0.45</td>
<td>75 (71-80)*</td>
<td>0.45</td>
<td></td>
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<tr>
<td>Down syndrome</td>
<td>100</td>
<td>87 (83-92)</td>
<td>0.05</td>
<td>66 (61-72)*</td>
<td>0.53</td>
<td>68 (62-74)</td>
<td>0.08</td>
<td>68 (63-73)</td>
<td>0.18</td>
<td>75 (70-80)*</td>
<td>0.45</td>
<td>75 (70-80)*</td>
<td>0.45</td>
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<tr>
<td>End stage renal disease</td>
<td>18</td>
<td>78 (67-90)</td>
<td>0.48</td>
<td>98 (96-100)</td>
<td>0.11</td>
<td>60 (43-78)</td>
<td>0.77</td>
<td>53 (39-67)</td>
<td>0.67</td>
<td>66 (53-78)</td>
<td>0.27</td>
<td>72 (63-80)</td>
<td>0.6</td>
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<td>Metabolic diseases</td>
<td>117</td>
<td>81 (76-85)</td>
<td>0.33</td>
<td>94 (91-97)</td>
<td>0.33</td>
<td>68 (63-73)*</td>
<td>0.45</td>
<td>58 (53-63)*</td>
<td>0.47</td>
<td>62 (56-67)*</td>
<td>0.45</td>
<td>71 (66-75)*</td>
<td>0.65</td>
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<tr>
<td>Profound complex handicap</td>
<td>12</td>
<td>87 (73-100)</td>
<td>0.05</td>
<td>97 (91-100)</td>
<td>0.20</td>
<td>74 (57-90)</td>
<td>0.20</td>
<td>57 (36-76)</td>
<td>0.51</td>
<td>66 (48-85)</td>
<td>0.27</td>
<td>70 (56-85)</td>
<td>0.70</td>
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<tr>
<td>Sickle cell disease</td>
<td>59</td>
<td>70 (62-77)*</td>
<td>0.86</td>
<td>95 (91-98)</td>
<td>0.22</td>
<td>70 (62-78)</td>
<td>0.36</td>
<td>51 (43-59)*</td>
<td>0.75</td>
<td>58 (51-66)*</td>
<td>0.63</td>
<td>73 (67-79)*</td>
<td>0.55</td>
<td></td>
</tr>
<tr>
<td>Spina bifida</td>
<td>21</td>
<td>85 (74-97)</td>
<td>0.14</td>
<td>94 (87-100)</td>
<td>0.33</td>
<td>68 (55-81)</td>
<td>0.45</td>
<td>62 (50-74)</td>
<td>0.32</td>
<td>65 (54-77)</td>
<td>0.31</td>
<td>75 (65-86)</td>
<td>0.45</td>
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</tr>
</tbody>
</table>

Mean scale scores and 95% Confidence interval. Range domains 0-100. Empty box indicates exclusion due to Cronbach’s alpha <0.60; * p < 0.004 for parents of children in disease group in comparison to parents of healthy children (Mann-Whitney U-tests). °ES: Effect size, Cohen’s d
Figure 1 HRQoL impairment based on percentages of parents scoring below the 25th percentile of the comparison group

* p<0.008 for parents in disease group in comparison with parents of healthy children, binomial test

The black line equals the 25 percent of parents in the comparison group below the 25th percentile. Due to distribution of scale scores percentiles approach 25th, ranging from 18th-31st percentile.
total group of parents of chronically ill children showed significantly higher percentages, ranging from 35%-54%, than the comparison group. In the disease groups, parents of children with asthma, metabolic disease, and sickle cell disease had significantly higher percentages than the comparison group on a majority of scales and were therefore considered at risk for an impaired HRQOL.

**DISCUSSION**

The aim of the present study was to identify differences in HRQOL between parents of chronically ill children and parents of healthy children. The results show that parents of chronically ill children have a lower HRQOL than parents of healthy children. In order to add clinical meaning to these differences, we divided parents into two groups, one at risk for an impaired HRQOL and one not at risk. This division shows that parents of chronically ill children have a seriously low HRQOL almost twice as often as parents of healthy children and are at risk for HRQOL impairment. These serious problems related to many aspects of daily life underline the importance of parental support in clinical practice.

More specifically, parents of chronically ill children in disease specific groups report a significantly lower HRQOL due to problems with three clusters: social and daily functioning, vitality and sleep, and having less positive and more negative emotions. Furthermore, 40-50% of these parents are at risk for HRQOL impairment. Although not all differences are statistically significant, they indicate a trend towards HRQOL impairment across disease groups. Most problems are reported with social functioning and depressive emotions. Our results are in line with other studies describing more problems with depression and social and emotional functioning in parents of chronically ill children.10;14-17 These studies also found impaired physical functioning, which is not fully confirmed by our study, since little problems with pain, gross and fine motor function were reported. Nevertheless, parents reported that they were less vital and had difficulties sleeping. It should be noted that despite the above-mentioned difficulties, there are also parents who seem to cope well with their child’s disease. Both positive and negative determinants of HRQOL need to be estimated in future research.

The definition of parents being at risk for an impaired HRQOL was based on the value of the 25th percentile of all scales of the comparison group. There is no gold standard for a good or bad HRQOL; however, this definition is considered to be an appropriate way to differentiate between individuals with higher scale scores and individuals with lower scale scores.25

A salient result is that parents of children with metabolic disease reported a low HRQOL on almost all subscales. This might be explained by the hereditary and progressive nature of these diseases (lysosomal storage diseases, organic acidurias, mitochondrial respiratory chain defects), in addition to the uncertain health status of some of the children, which leads to growing strain and increasing caregiver burden over time.7,24
Parents of children with sickle cell disease also report a significantly lower HRQOL on most subscales. This could also be explained by their demographics, which differ most from the comparison group; they are more often single parents, have a lower educational level, and are younger than the comparison group. In addition, parents of children with sickle cell disease in The Netherlands often are from migrant families, which generally are known to have a lower socioeconomic status (SES). To account for SES, we have previously compared this group of parents to a SES-matched control group, which showed that parents of children with sickle cell disease have a lower HRQOL on the scales for daily activities, vitality, and depressive emotions. This is in line with our results.

A third group showing significantly lower HRQOL is comprised of parents of children with asthma. The literature shows ambiguous results, with parenting stress being found in one study and good quality of life in another, except for a small group describing a negative emotional effect. A possible explanation for our findings could be that we included a relatively severe asthma group, as the hospital serves as a secondary care centre for parts of the city of Amsterdam and is a tertiary referral centre for the central and western part of the Netherlands.

Parents of children with profound complex handicaps do not report a significantly lower HRQOL. Nevertheless, the small sample size and the low response rate hamper the interpretation of the results, and future research is needed.

Some limitations of this study should be addressed. First, although we describe ten different groups of parents of chronically ill children, we cannot easily generalize the results to all parents of chronically ill children, as more than 280 ICD-10 diagnoses meet the criteria of chronic childhood disease. However, the rather consistent outcome of this study indicates an overall burden for parents across disease groups. Second, respondents in this study were mainly mothers; a more thorough exploration of the HRQOL of fathers is desirable. Third, parents in this study had a higher educational level than the average Dutch population (Lower: 33%, Intermediate 41%, Higher 25%); however, we have taken these differences into account when comparing the data. The percentage of parents born in the Netherlands is also higher than in the average Dutch population. Our expectation is that participants in this study had a better SES than is average in The Netherlands. A lower individual and neighborhood level SES is associated with worse health status. Therefore, in our study we have probably demonstrated the HRQOL of parents with a relatively good SES and health status and have presumably given an underestimation of the HRQOL impairment. A fourth limitation is the average response rate of 54% in the disease groups. We have little information regarding non responders, although the higher educational level in comparison to the Dutch average indicates a selection bias towards parents with higher educational levels. Perhaps these parents more easily respond to a questionnaire. At last, we must note that several sample sizes were small; these data do, however, support the hypothesis of more parents being at risk for HRQOL impairment in these groups.
Clinical and future implications

Parents in our study group report a seriously lower HRQOL than the comparison group, and on average, 45% of parents are at risk for HRQOL impairment. As the emphasis on informal care is expected to continue to grow, the number of parents caring for their children will consequently increase. Besides the fact that this is a stressful situation for parents themselves, it can also have negative consequences for the chronically ill child, and their siblings. Children depend on their parents, and chronically ill children probably even more so than healthy children. Parental mental functioning is known to influence their children’s health and adjustment, both for chronically ill and healthy children. Since parents of chronically ill children report higher stress levels than parents of healthy children, chronically ill children and their siblings are at higher risk for additional health and adjustment problems.

In our opinion, pediatricians as well as GP’s should be aware of the impact of caring for a chronically ill child on parental HRQOL and of the multitude of problems parents report. Parental functioning should be part of clinical practice in pediatrics. Moreover, attention should be paid to parental functioning, as parents’ resilience may be impaired due to problems sleeping and problems with vitality and depressive emotions. Family-oriented programs that have been developed in e.g. psycho-oncology should be introduced in other disease populations as well. Professionals working with parents of chronically ill children should pay attention to the difficulties parents experience and provide supportive care if necessary.
REFERENCES LIST


29 Central Bureau of Statistics.Voorburg/Heerlen TN. Available from. 2007. Ref Type: Generic


