Kawasaki disease: Studies on etiology, treatment and long-term follow-up
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Citation for published version (APA):
HEALTH RELATED QUALITY OF LIFE AND PERCEPTIONS OF CHILD VULNERABILITY AMONG PARENTS OF CHILDREN WITH A HISTORY OF KAWASAKI DISEASE

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Acta Paediatrica. 2014 March (Epub ahead of print)
ABSTRACT

Aim:
Kawasaki disease (KD) is an acute pediatric vasculitis. The psychosocial consequences of this sudden illness for parents are unknown. This study aimed to evaluate health related quality of life (HRQOL) and parental perceptions of child vulnerability (PPCV) in parents of children with KD, and to identify variables associated with PPCV.

Methods:
This cross-sectional study included 288 parents (83% mothers) of KD patients (mean age 8.7 years). HRQOL was assessed using the TNO-AZL Questionnaire for Adult’s HRQOL (TAAQOL) and PPCV using the Child Vulnerability Scale (CVS). Scores of KD parents were compared with reference groups of Dutch parents. Logistic regression analyses were performed to examine associated variables.

Results:
The HRQOL of KD parents was comparable to the HRQOL of parents of healthy children. However, KD parents showed significantly higher PPCV, regarding both the median CVS total score and the percentage in the clinical range. No differences were found in CVS outcomes between KD parents and parents of a chronically ill child. None of the studied parental, child and disease characteristics were significantly associated with PPCV.

Conclusion:
Parents perceived their KD child more vulnerable to illness than healthy children, while in reality the majority had fully recovered from KD.
INTRODUCTION

Kawasaki disease (KD) is an acute, systemic vasculitis of unknown etiology that predominantly occurs in children under the age of five. The disease is complicated by the development of coronary artery aneurysms (CAA) in up to 25% of untreated patients. Treatment with high-dose intravenous immunoglobulins reduces the rate of CAA to <5%\(^1\). KD is, however, the leading cause of acquired heart disease in childhood in developed countries\(^2\). The diagnosis of KD is based primarily on the presence of persistent fever and four out of five classical clinical features (bilateral nonexudative conjunctival injection, polymorphous rash, erythema of the lips and oral mucosa, cervical lymphadenopathy and swelling and redness of the extremities)\(^1,3\).

Prior studies have focused primarily on the etiology and the cardiac complications of the disease. Studies evaluating the long-term impact of KD on health related quality of life (HRQOL) and psychosocial functioning in children are limited\(^4-9\). Additionally, the long-term impact on parents of patients with KD is still being delineated. A pediatric illness like KD not only affects the child but the entire family, and especially the parents\(^10-12\). It has been described that parents of patients with KD experience a considerable amount of stress and anxiety resulting from the disease’s sudden onset, possible delay in diagnosis and the potentially severe complications of the disease\(^13\).

After the acute phase of KD, the majority of the patients recover fully and do not face long-term daily consequences of their disease. However, even if the patient did not develop cardiovascular sequelae, parents might continue to perceive their child as vulnerable to illness. A parent’s belief that a child is vulnerable or susceptible for harm or illness can potentially have an adverse effect on the child’s development\(^14\). High perceived vulnerability can lead to overprotective behavior in parents and psychological problems in children, such as psychosomatic complaints and school underachievement\(^15\). Increased understanding of possible HRQOL problems, parental perceptions of child vulnerability (PPCV) and associated variables will allow practitioners to provide the support and interventions these parents might need.

The aims of this study were (1) to evaluate the HRQOL and PPCV of parents of a child with a history of KD, and (2) to identify which parental, child and disease characteristics are associated with PPCV.

METHODS

Study population

This cross-sectional study was conducted between October 2010 and February 2011 at the multidisciplinary KD follow-up clinic of the Emma Children’s Hospital, a tertiary referral center. Parents were eligible to participate in the study if they had a child aged 0 to 18 years
with a history of KD according to the diagnostic criteria. Parents were excluded if they had an insufficient knowledge of the Dutch language or if their child had a history of a severe chronic illness unrelated to KD.

Parental data were collected as part of a larger study about the long-term impact of the disease on families. Findings on HRQOL and behavioral functioning of the child have been reported before. The study design was also described in this prior report. In short, families were approached to participate in the study in an invitational letter or by telephone. After the families consented with participation, they received a password enabling them to complete online questionnaires on the study website (www.hetklikt.nu/twee/kawasaki). Apart from providing information about their child, parents (father or mother) were asked to complete questionnaires about their own functioning. This study was approved by the Medical Ethics Committee of our institute and was performed according to their regulations.

**Socio-demographics and clinical characteristics**

Socio-demographics of the participating parents were collected using an online questionnaire. Data were obtained on parental age, gender, country of birth, marital status, number of children and education level (low: no education, primary school or primary vocational education; middle: secondary school or secondary vocational education; high: higher vocational education or university). The following information was obtained about the child with KD: age, gender, age at KD onset, interval from KD onset to the study, duration of hospital admission, admission to the pediatric intensive care unit and CAA outcome (during acute phase and persistent CAA at follow-up). CAA were defined according to criteria established by the Japanese Ministry of Health in 1984. The clinical data were collected retrospectively by review of the medical records.

**Health Related Quality of Life (HRQOL)**

Parental HRQOL was assessed using the TNO-AZL Questionnaire for Adult’s Health Related Quality of Life (TAAQOL). This questionnaire measures health status problems weighted by the impact of problems on well-being on 12 multi-item scales: gross motor functioning, fine motor functioning, cognitive functioning, sleep, pain, social functioning, daily activities, sexuality, vitality, positive emotions, depressive emotions, and aggressiveness. Most items consist of two parts: the first part assesses the prevalence of a health problem or limitation in the past month, and the second part evaluates the emotional response to the health problem or limitation. 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 (range 0-100). The psychometric properties, validity and reliability of the TAAQOL were satisfactory. The Cronbach’s alpha values in the present study were good, ranging from 0.71 to 0.92.
Reference data are available of 424 parents of healthy children from two Dutch elementary schools and one high school, located near our hospital.10

Parental perceptions of child vulnerability (PPCV)

Parental perceptions of child vulnerability was assessed using the Child Vulnerability Scale (CVS)14. The CVS was translated into Dutch with permission from the author, and translated back and forth to check for validity of the translation18. The CVS consists of eight items (e.g. “I often have to keep my child indoors because of health reasons”, “In general my child seems less healthy than other children”) with a four-point response scale ranging from ‘definitely false’ to ‘definitely true’ scored from zero to three, resulting in a total score of zero to 24. A total score equal to or greater than 10 has been suggested by Forsyth et al as a cut-off for high vulnerability (defined as scores in the clinical range)14. The internal consistency of the Dutch scale (CVS total score) was good, with a Cronbach’s α value of 0.70. The Cronbach’s α in the present study sample was 0.84. Reference data are available of 519 parents of children from nine Dutch schools, aged 5-18 years. In the reference group, children with chronic health conditions were identified if the parents had reported that their child suffered from a chronic health condition. This group (n=69) included: asthma (36.2%), congenital defect (13.0%), skin disease (5.8%) and migraine (5.8%).

Statistical Analyses

IBM SPSS Statistics for Windows Version 20 was used to manage and analyze the data. First, the TAAQOL scale scores (HRQOL) were computed according to the manual. HRQOL differences between parents of a child with a history of KD and the reference group were analyzed using analysis of variance, corrected for the differences between the groups on socio-demographics (parental age). To adjust for multiple testing, we used a Bonferroni correction and adjusted the p-value to 0.004 (0.05/12).

Second, according to the manual, the CVS total score was computed (range 0-24). The answers on the individual CVS items were analyzed as dichotomous variables (“definitely true” and “mostly true” = one, “definitely false” and “mostly false” = zero). Since the age of the children in the reference group ranged from 5-18 years, parents in our study sample were not included in the CVS analyses if their child with a history of KD was aged <5 years at time of the study. CVS scores were analyzed in three age groups (5-7, 8-12 and 13-18) separately, according to the age groups in the reference group. CVS score of parents of a child with KD were compared to a reference group of parents of a healthy child and to a reference group of parents of a child with a chronic health condition. Mann Whitney tests were used for the median CVS total score, and Chi² tests for the analysis of the scores on the individual dichotomized items and for the number of parents with a CVS score in the clinical range (CVS total score ≥10). It was not necessary to correct the analyses for socio-demographic characteristics because the socio-demographic variables appeared not to be correlated
with the CVS scores. To adjust for multiple testing, we used a Bonferroni correction and adjusted the p-value to 0.006 (0.05/8).

Finally, logistic regression analyses were performed to examine which parental, child and disease characteristics were associated with PPCV, expressed as scores equal or above the cut-off score of 10. The logistic regression analyses were performed on parental gender, parental age, parental education (high versus middle/low), parental country of birth (foreign versus The Netherlands), marital status (married/living together versus not married/living together), child’s gender, interval disease onset-study, duration of hospital admission, CAA at follow-up and admission to the pediatric intensive care unit. The age of the child at study participation could not be included in the logistic regression model due to high correlation (0.83, p<0.000) with ‘interval disease to study participation’.

RESULTS
Of the 434 patients in our institutional database, 368 met the inclusion criteria for the study. Six parents were excluded from the study because of an insufficient knowledge of the Dutch language and two because of another severe chronic illness of their child, being chronic granulomatous disease and West syndrome. Ten letters of invitation were undeliverable. In total, 288 of the 350 eligible parents completed at least one of the questionnaires for this study (response rate 82%).

Socio-demographics and clinical characteristics
A total of 288 parents (83.3% mothers, mean age 40.20±6.28 years) completed the socio-demographic questionnaire. Characteristics of the participating parents and their children are shown in Table 1. The majority of the children with KD were male (61.1%) and the mean age of the children with KD was 8.73±4.35 years at time of the study.

Health Related Quality of Life (HRQOL)
The HRQOL of parents of children with a history of KD did not differ significantly from the HRQOL of parents of healthy children on eleven out of the twelve TAAQOL scales. Parents of children with KD scored significantly higher on the subscale ‘social functioning’ (p=0.003) (Table 2).

Parental perceptions of child vulnerability (PPCV)
PPCV are shown in Table 3. Parents of a child with KD had significantly higher scores compared to parents of healthy children, regarding both the median CVS total score and the percentage of subjects in the clinical range (scores ≥10). This was observed in the three age groups, with the exception of the age group 13-18. In that age-group, parents of a child with KD did not differ from parents of healthy children regarding the percentage with clinical CVS scores.
Parents of a child with KD also reported higher scores on most individual CVS items. In the age group 5-7 years, parents of a child with KD differed significantly from parents of healthy children on five out of eight items, in the age group 8-12 on seven out of eight items, and in the age group 13-18 on one out of eight items. Parents of a child with KD did not differ from parents with a chronically ill child on any CVS outcome.

* Date of birth was missing for 13 parents

Abbreviations: CAA=coronary artery aneurysms; KD=Kawasaki disease; PICU=pediatric intensive care unit.
Table 3. PPCV (according to the CVS) of parents of children with a history of Kawasaki disease (N=224), compared with both parents of healthy children (N=450) and parents of chronically ill children (N=69), divided into three age categories.

<table>
<thead>
<tr>
<th>5-7 years</th>
<th>KD parents (N=75)</th>
<th>Healthy child (N=85)</th>
<th>Chronically ill (N=14)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Median (25-75%)</td>
<td>Median (25-75%)</td>
<td>P</td>
<td>P</td>
</tr>
<tr>
<td>Total score (range 0-24) *</td>
<td>4 (2-7)</td>
<td>2 (1-3)</td>
<td>0.000</td>
<td>0.442</td>
</tr>
<tr>
<td>% (N)</td>
<td>% (N)</td>
<td>p</td>
<td>% (N)</td>
<td>P</td>
</tr>
<tr>
<td>Clinical total score (≥10)</td>
<td>20.0 (15)</td>
<td>1.2 (1)</td>
<td>0.000</td>
<td>1.00</td>
</tr>
</tbody>
</table>

Items **, (mostly) true:
1. Less healthy | 14.7 (11) | 1.2 (1) | 0.001 | 7.1 (1) | 0.682 |
2. Calling the doctor | 18.7 (14) | 3.5 (3) | 0.004 | 14.3 (2) | 1.00 |
3. Susceptible | 30.7 (23) | 11.8 (10) | 0.003 | 28.6 (4) | 1.00 |
4. Check at night | 24.0 (18) | 15.3 (13) | 0.164 | 21.4 (3) | 1.00 |
5. Look healthy | 17.3 (13) | 0 (0) | 0.000 | 7.1 (1) | 0.455 |
6. Keep indoors | 1.3 (1) | 0 (0) | 0.469 | 0 (0) | 1.00 |
7. Circles under eyes | 13.3 (10) | 3.5 (3) | 0.039 | 0 (0) | 0.352 |
8. More colds | 26.7 (20) | 9.4 (8) | 0.004 | 28.6 (4) | 1.00 |

<table>
<thead>
<tr>
<th>8-12 years</th>
<th>KD parents (N=95)</th>
<th>Healthy child (N=211)</th>
<th>Chronically ill (N=29)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Median (25-75%)</td>
<td>Median (25-75%)</td>
<td>P</td>
<td>P</td>
</tr>
<tr>
<td>Total score (range 0-24) *</td>
<td>3 (1-7)</td>
<td>1 (0-3)</td>
<td>0.000</td>
<td>0.750</td>
</tr>
<tr>
<td>% (N)</td>
<td>% (N)</td>
<td>p</td>
<td>% (N)</td>
<td>P</td>
</tr>
<tr>
<td>Clinical total score (≥10)</td>
<td>16.8 (16)</td>
<td>1.4 (3)</td>
<td>0.000</td>
<td>0.118</td>
</tr>
</tbody>
</table>

Items **, (mostly) true:
1. Less healthy | 12.6 (12) | 2.8 (6) | 0.001 | 13.8 (4) | 1.00 |
2. Calling the doctor | 8.4 (8) | 0.5 (1) | 0.000 | 13.8 (4) | 0.473 |
3. Susceptible | 20.0 (19) | 4.3 (9) | 0.000 | 3.4 (1) | 0.042 |
4. Check at night | 29.5 (28) | 8.5 (18) | 0.000 | 27.6 (8) | 0.845 |
5. Look healthy | 15.8 (15) | 4.7 (10) | 0.001 | 13.8 (4) | 1.00 |
6. Keep indoors | 4.2 (4) | 0 (0) | 0.009 | 10.3 (3) | 0.353 |
7. Circles under eyes | 15.8 (15) | 3.3 (7) | 0.000 | 17.2 (5) | 0.852 |
8. More colds | 17.9 (17) | 1.9 (4) | 0.000 | 10.3 (3) | 0.402 |

<table>
<thead>
<tr>
<th>13-18 years</th>
<th>KD parents (N=54)</th>
<th>Healthy child (N=154)</th>
<th>Chronically ill (N=26)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Median (25-75%)</td>
<td>Median (25-75%)</td>
<td>P</td>
<td>P</td>
</tr>
<tr>
<td>Total score (range 0-24) *</td>
<td>2 (0-5)</td>
<td>1 (0-2)</td>
<td>0.002</td>
<td>0.478</td>
</tr>
<tr>
<td>% (N)</td>
<td>% (N)</td>
<td>p</td>
<td>% (N)</td>
<td>P</td>
</tr>
<tr>
<td>Clinical total score (≥10)</td>
<td>7.4 (4)</td>
<td>0.6 (1)</td>
<td>0.017</td>
<td>7.7 (2)</td>
</tr>
</tbody>
</table>
### Table 3. (Continued)

Items **, (mostly) true:

<table>
<thead>
<tr>
<th>Item</th>
<th>Parental &amp; Child Characteristics</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less healthy</td>
<td>11.1 (6)</td>
<td>0.004</td>
</tr>
<tr>
<td>Calling the doctor</td>
<td>5.1 (3)</td>
<td>0.117</td>
</tr>
<tr>
<td>Susceptible</td>
<td>14.8 (8)</td>
<td>0.012</td>
</tr>
<tr>
<td>Check at night</td>
<td>9.3 (5)</td>
<td>0.130</td>
</tr>
<tr>
<td>Look healthy</td>
<td>11.1 (6)</td>
<td>0.026</td>
</tr>
<tr>
<td>Keep indoors</td>
<td>0 (0)</td>
<td>1.00</td>
</tr>
<tr>
<td>Circles under eyes</td>
<td>7.4 (4)</td>
<td>0.076</td>
</tr>
<tr>
<td>More colds</td>
<td>11.1 (6)</td>
<td>0.026</td>
</tr>
</tbody>
</table>

P-values according to Chi square test, Fisher’s exact test or Mann Whitney U test, where appropriate. To adjust for multiple testing in the comparison on item level, we used a Bonferroni correction and adjusted the p-value to .006

Abbreviations: CVS=Child Vulnerability Scale; KD=Kawasaki disease; PPCV=parental perceptions of child vulnerability.

* Higher scores represent more perceived vulnerability of the child

** Full-text items:

1. In general, my child seems less healthy than other children.
2. I often think about calling the doctor about my child.
3. When there is something going around my child usually catches it.
4. I often check on my child at night to make sure that s/he is okay.
5. Sometimes I get concerned that my child doesn’t look as healthy as s/he should.
6. I often have to keep my child indoors because of health reasons.
7. I get concerned about circles under my child’s eyes.
8. My child gets more colds than other children I know.

### Table 4. Logistic regression model of Parental Perceptions of Child Vulnerability (CVS total score ≥ 10) predicted by parental, child and disease variables (n=239).

<table>
<thead>
<tr>
<th>Parental characteristics</th>
<th>OR</th>
<th>95% CI</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (male)</td>
<td>1.48</td>
<td>[0.53-4.12]</td>
<td>0.450</td>
</tr>
<tr>
<td>Age</td>
<td>0.94</td>
<td>[0.87-1.02]</td>
<td>0.118</td>
</tr>
<tr>
<td>Education (high)</td>
<td>0.98</td>
<td>[0.43-2.27]</td>
<td>0.965</td>
</tr>
<tr>
<td>Country of birth (foreign countries)</td>
<td>1.42</td>
<td>[0.49-4.08]</td>
<td>0.517</td>
</tr>
<tr>
<td>Married/living together</td>
<td>0.81</td>
<td>[0.25-2.60]</td>
<td>0.724</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Child characteristics</th>
<th>OR</th>
<th>95% CI</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (male)</td>
<td>1.79</td>
<td>[0.77-4.15]</td>
<td>0.177</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Disease characteristics</th>
<th>OR</th>
<th>95% CI</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interval disease to study participation</td>
<td>1.00</td>
<td>[0.88-1.13]</td>
<td>0.988</td>
</tr>
<tr>
<td>Duration of hospital admission</td>
<td>0.98</td>
<td>[0.92-1.04]</td>
<td>0.457</td>
</tr>
<tr>
<td>Persistent CAA at follow-up</td>
<td>2.85</td>
<td>[0.76-10.63]</td>
<td>0.119</td>
</tr>
<tr>
<td>Admitted to PICU</td>
<td>3.83</td>
<td>[0.53-27.99]</td>
<td>0.185</td>
</tr>
</tbody>
</table>

Abbreviations: CAA=coronary artery aneurysms; CI=confidence interval; CVS=Child Vulnerability Scale; PICU=pediatric intensive care unit.
**Identifying variables associated with parental perceptions of child vulnerability**

The results of the logistic regression analysis are shown in Table 4. None of the parental, child or disease characteristics were significantly associated with PPCV.

**DISCUSSION**

Studies evaluating the long-term psychosocial consequences of KD on families are scarce. We reported previously on the HRQOL and behavioral functioning of children with a history of KD, and in the present study we provide more insight in the psychosocial functioning of their parents. The results show that the HRQOL of parents of a child with KD was comparable to the HRQOL of parents of healthy children, but evaluation of PPCV indicated that these parents perceived their child with a history of KD more vulnerable to illness than healthy children.

No significant differences were found between the HRQOL of parents of a child with KD and the HRQOL of the reference group. It is questionable whether the TAAQOL, a questionnaire focused at generic HRQOL, is sensitive enough to assess emotional well-being in parents of a child with KD. Anxiety, for example, is not being measured, while the focus-group study of Chahal et al has indicated that parents of a child with KD undergo a great deal of stress and anxiety associated with the diagnosis, disease severity, and the possible cardiovascular and long-term effects of this rare disease. In future studies, anxiety, stress reactions, and parental burden should be further investigated.

Parents of a child with a history of KD perceived their child as significantly more vulnerable than did parents of healthy children, but comparable to the extent to which parents of chronically ill children perceived their child as vulnerable. The previous study by Chahal et al also noted that parents of a child with KD felt they were overprotective and reported profound changes in themselves after the KD episode of their child. These are interesting findings. With a mean of almost 6 years after the acute phase of KD, the majority of the children with KD in the current study have recovered fully and do not face daily consequences of their disease, in contrast to children with a chronic illness. Based on our clinical experience, it is not likely that the children with a history of KD are ‘truly medically vulnerable’ in general terms. It is known that parents who perceive their child as more vulnerable are more likely to overprotect their child, and that higher PPCV is associated with worse developmental outcome. Overprotection may interfere with the development of personal skills in children needed to cope with the challenges of growing up. Therefore, pediatricians should take away parental worries about their child’s health and should encourage parents to stimulate the independence of their child. In addition, it would be interesting to study the parenting styles of parents of a child with KD to get more insight in the perceived vulnerability, we aimed to identify variables that were associated with PPCV. Results showed that none of the studied parental, child or disease variables was associated with the perceived vulnerability. This is in line with other stud-
ies, in which illness-related characteristics of the child were shown not to influence parental functioning\textsuperscript{20,21}. In a study on parents of neonatal intensive care unit graduates, no correlations were found between PPCV and parental demographic variables (maternal education, age and socioeconomic status) and severity of the neonatal problems\textsuperscript{22}. The same results were found in a population of mothers of healthy infants; none of the socio-demographic variables (child gender, parental age and education) were associated with PPCV scores\textsuperscript{23}. However, in a study of Perrin et al, higher maternal education was found to predict any increase in the perceived vulnerability, and married mothers reported less sense of vulnerability\textsuperscript{24}. In our study, education and marital status were not correlated with PPCV.

As parents indicate that the period around the KD diagnosis of their child is characterized by an overwhelming range of emotions (‘emotional roller coaster’), this intensive period might be regarded as a potentially traumatic event\textsuperscript{13}. KD can be life-threatening and a small percentage of the patients need to be admitted to the pediatric intensive care unit (PICU). Previous studies showed that an unexpected admission to the PICU is a stressful event for parents\textsuperscript{25}. In the current study, symptoms of pediatric medical traumatic stress\textsuperscript{26} were not measured, nor were feelings of anxiety. From clinical experience, we know that the acute KD phase can be considered as traumatic for parents. Therefore, studying medical traumatic stress symptoms in parents of a child with a history of KD would be a suggestion for future research, both shortly after the acute phase and during the long-term follow-up.

Certain limitations of the current study should be taken into account. First, mainly mothers participated in this study. It would be interesting to examine psychosocial functioning in both the father and mother of the patient. The second limitation is the cross-sectional study design. For this reason, no information was available about the course of HRQOL and perceived vulnerability over time. Furthermore, regarding the parental reference group of the TAAQOL (HRQOL), it should be mentioned that gender and age of the children were unknown. Therefore, it was not possible to control the analyses for these variables, while it might have had an effect on the outcomes. Finally, the questionnaires used in this study might not be sensitive enough to capture emotional problems that the parents could experience. For example, anxiety and medical traumatic stress are not measured.

In conclusion, our study contributes to the limited existing literature on psychosocial functioning of parents of a child with KD. Parents perceived their child with a history of KD more vulnerable to illness than healthy children, while in reality the vast majority of the children have fully recovered from their disease. Our study had a relatively large study sample and included two important outcomes of parental functioning, i.e. HRQOL and PPCV. However, there is a need for further research on these domains, as well as on psychosocial functioning and medical traumatic stress symptoms in parents of a child with KD to gain knowledge on the starting points for developing interventions. To improve the care for children with KD, more research should be focused on the parents. The potential burden of the parents should be identified, as well as their stress levels and reactions to the uncontrollable aspects of this rare pediatric illness.
ACKNOWLEDGEMENTS
The authors thank all the parents who participated in this study. In addition, they thank Birgit Berk for her assistance in the data collection and BioMedia/Artsen voor Kinderen for the web design.

KEY NOTES
• Little is known about the psychosocial consequences of Kawasaki Disease (KD) for parents.
• Parents of children with a history of KD did not differ from parents of healthy children regarding health related quality of life, but they did perceive their child as more vulnerable to illness, even though most had fully recovered from KD.
• Healthcare providers should be aware that parental perceptions of child vulnerability may induce overprotective parenting.
REFERENCES


