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Health-related quality of life problems of children aged 8–11 years with a chronic disease

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Abstract
In paediatric research, Health-Related Quality-of-Life (HRQoL) has received increasing recognition as an important health outcome. This study aimed to investigate the nature and prevalence of HRQoL problems in children with different chronic diseases. Data were available on 318 children aged 8–11 years with different diseases: congenital heart disease ($n = 50$); coeliac disease ($n = 105$); asthma ($n = 32$); cancer ($n = 23$); juvenile chronic arthritis ($n = 45$); children with capillary haemangioma ($n = 25$) and severe meningococcal disease ($n = 38$). They all answered a validated generic instrument [TNO-AZL Children's Quality of life questionnaire] (TACQoL), in the outpatient clinic or at home. Analyses of variance were performed to investigate differences in mean scores for children with chronic conditions in comparison to healthy children. Prevalence of children at risk for substantial HRQoL problems was based on the 25th percentile in the norm population. In comparison to healthy children, only a small number of differences were found in mean scores of children studied. In contrast, prevalence of HRQoL problems in children with chronic diseases was higher in several domains. It is concluded that using an indicator variable of the norm 25th percentile seems important in identifying at-risk children with chronic disease.

Keywords: *Chronic disease, childhood, health-related quality-of-life, at-risk, consequences*

En la investigación pediátrica, la Health-Related Quality-of-Life (HRQoL) ha recibido un creciente reconocimiento como una forma importante de evaluación de resultados en aspectos de salud. Este estudio tenía como objeto investigar la naturaleza y prevalencia de los problemas HRQoL en niños con diferentes enfermedades crónicas. Los datos estuvieron disponibles en 318 niños con edades entre los 8 y 11 años, con diferentes enfermedades: enfermedad cardiaca congénita ($n = 50$), enfermedad celíaca ($n = 105$), asma ($n = 32$), cancer ($n = 23$), artritis juvenil crónica ($n = 45$), niños con hemangioma capilar ($n = 25$) y enfermedad meningocóccica severa ($n = 38$). Todos contestaron un instrumento genérico validado [TNO-AZL Children's Quality of Life Questionnaire] (TACQoL) en la clínica de consulta externa o en casa. Se realizó un análisis de variación para investigar las diferencias en las calificaciones promedio en los niños con afecciones crónicas en cornparación a los niños sanos. La prevalencia de niños en riesgo para tener problemas substánciales HRQoL se basó en la percentila 25 de la norma poblacional. En comparación a los niños sanos se encontró solamente un número pequeño de diferencias en las calificaciones de los niños estudiados. En contraste la prevalencia de los problemas del HRQoL en los niños con enfermedades crónicas fue más alta en varias áreas. Concluimos que el uso de un indicador variable de la norma de la percentila 25 parece ser importante en la identificación de niños en riesgo que cursan con una enfermedad crónica.

Palabras clave: *Enfermedad crónica, infancia, calidad de vida en relación a la salud, riesgo, consecuencias*

Introduction

Chronic illness refers to diseases with a protracted course for which no cure is available, but also to diseases for which treatment may be associated with long-term complications [1]. Approximately 10–40% of children suffer from chronic physical illness, depending on the definition of 'chronic illness' [2]. Advances in paediatrics and paediatric surgery have improved the medical course of many diseases. This success, however, has a down side and there is a need to evaluate the physical, psychological

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and social consequences of medical treatment in children with chronic diseases. From the 1980s, quality-of-life has been introduced in the study of the consequences of chronic illness in both adults and, more recently, in children. The current consensus on the assessment of quality of life (QoL) includes at least four domains: physical, cognitive, social and emotional functioning. Health-related quality of life (HRQoL) refers to the specific impact of an illness, injury or medical treatment on an individual's QoL. The effects of childhood disease and its treatment often increase the child's dependence on his/her parents and other adults and decrease the participation in peer- and school-based activities. This could have an adverse effect on the accomplishment of developmental tasks, resulting in an impaired QoL.

Many instruments that assess the HRQoL in adult populations have been developed over the years. Quality-of-life or adjustment measurement in children requires age-adjusted questionnaires because children need adequate language skills and the cognitive ability to interpret the questions. The time consuming nature of this process and the fact that large paediatric patient populations are often difficult to assemble is probably the reason why suitable, reliable and valid HRQoL instruments are still scarce in the paediatric field. Consequently, parents usually function as the major informants in paediatric assessments. In the Netherlands, a HRQoL instrument has been developed, the TACQoL [3]. This questionnaire assesses seven domains of HRQoL; i.e. physical complaints, motor functioning, autonomy, cognitive functioning, social functioning and positive as well as negative emotional functioning. In several studies of children with a chronic disease, in which the TACQoL was used, a similar HRQoL was found compared to healthy controls [4–8]. For adolescents with Inflammatory Bowel Disease (IBD), children with congenital heart disease and children with galactosemia, an impaired HRQoL measured with the TACQoL was found [9–11].

The finding that chronic paediatric disease populations do not always differ from healthy controls has been described in the literature. Lack of differences can be attributed to: insufficient sample sizes, possible selection bias of responding families, effects of successful coping processes and the discriminative validity of questionnaires [12]. It may also be possible that no differences are found due to the difference in distribution of scores between a disease and a healthy population. Ceiling effects concerning QoL measurements have been described in research with adults as well as children [13,14]. A possible solution is to divide the groups according to the number of individuals who score below or above the 25th percentile norms [14]. The question arises whether such a method would provide important information about impaired HRQoL in chronically ill children. This is of great importance for paediatricians working with children with chronic disease. It would give insight into the specific HRQoL of different populations. This could guide clinicians in addressing the specific domains in which children have their specific problems. The aim of the present study was to obtain more insight into the HRQoL of children with diverse chronic diseases and to identify chronically ill children who are at risk.

Methods

Patients and procedure

Data on children aged 8–11 years with a chronic condition were obtained from several ongoing studies at the Leiden University Medical Centre (LUMC) and the Emma Children's Hospital in the Academic Medical Centre Amsterdam (AMC). These children had the following conditions: congenital heart disease (CHD); coeliac disease; asthma; cancer; juvenile chronic arthritis (JCA); children with a capillary haemangiomas and survivors of severe meningococcal disease (SMD). Both hospitals serve as secondary care centres for the cities of Leiden and Amsterdam, respectively, and are tertiary referral centres for the central and western part of the Netherlands. The study was approved by the Medical Ethical Committee in both centres (AMC and LUMC). Inclusion criteria for the children in all studies were: the ability to read and understand Dutch and to fill out a questionnaire. For inclusion in this study patients were selected aged between 8–11 years from the databases of the CHD children [10] and children with coeliac disease [6]. Children with cancer were participating in a follow-up project after finishing treatment. Data on children with cancer were obtained at one of the first outpatient clinic visits after they successfully finished treatment in the AMC and were in remission. Children with SMD were participating in a follow-up project after admission and treatment on a PICU 1–7 years retrospectively in the AMC. Data from children with haemangiomas were obtained from a study in which all children seen at the plastic surgery or dermatology department of the AMC were invited to participate.

Additional data from children with asthma and JCA from ongoing studies at the LUMC were added to the database for this study. Most of the JCA patients included had an oligoarticular onset of their disease. Children visiting the outpatient clinic were invited to participate, at their convenience, in the studies. After giving their informed consent, most of the patients completed the questionnaire in the

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waiting room of the outpatient clinic. The children with celiac disease, however, were invited by the Dutch Coeliac Patients Society and were sent the questionnaire after informed consent had been obtained [6]. Children with haemangiomas and SMD were invited by the AMC and likewise sent the questionnaires after informed consent had been obtained.

In the case of sending questionnaires at home, all parents and children received an introduction letter, in which the aim of the study was explained and participation was asked. With the letter a set of questionnaires and a pre-stamped envelope for returning the package was sent. In the written instructions children were asked to complete the questionnaire within 3 weeks. Instructions also included completing the entire questionnaire at the same time, to answer the questions without discussion with others.

Instrument

TACQol-CF. The TNO AZL Children's Quality of Life questionnaire (TACQoL) was recently developed and validated in a large sample ($n = 1122$ children) of Dutch school-going children aged 8–11 years, including children with or without a chronic medical condition [15]. Data were collected in 12 municipal health services located throughout the Netherlands. Two parallel questionnaires for children's HRQoL are available with identical items: a child's form (CF) and a parent's form (PF). The items are adjusted to the type of informant. The instrument contains seven domains of eight items each: physical functioning (e.g. the child is experiencing stomach-aches or abdominal pain, feeling sleepy); autonomy (e.g. is having difficulties going to school alone or doing hobbies independently); motor functioning (e.g. problems running or with balance); cognitive functioning (e.g. difficulties paying attention or concentrating, difficulty writing); social functioning (e.g. impaired ability to play or talk with other children or to feel at ease with other children); positive emotions (e.g. feelings of joy or contentedness) and negative emotions (e.g. sadness or aggression). A concretely and specifically formulated health-status problem, if reported, leads to a question about the child's emotional response. Figure 1 shows an example of such a question. On each item of the first five domains the respondent indicates the extent to which a specific problem occurred in the past few weeks (never (4), sometimes, often). If a problem occurred, the child can indicate how he/she felt about this problem on a 4-point Likert scale: (very) good (3), not so well (2), rather bad (1), bad (0). The emotional reaction to the complaints represents the 'health-related' component, which is reported here. Scores for these domains range from 0–32. On the domains regarding positive and negative emotions, respondents can indicate on a 3-point Likert scale whether the presented feelings were present in recent weeks (never (2), occasionally (1), often (0)). Scores on these two domains range from 0–16. The numbers in brackets refer to the scores presented in Figure 1. Numbers in brackets refer to the values resulting in the HRQoL scores. The instruments measure HRQoL on group level in a reliable and valid way [15]. The Cronbach's alphas in the study populations were moderate-to-good. The widely-accepted social science cut-off is that an alpha is moderate between 0.60–0.80 and good above 0.80. The Cronbach's alphas ranged from 0.60 (social functioning in cancer patients) to 0.90 (motor functioning in SMD population). Autonomy and social functioning for the population with haemangiomas failed to show adequate internal consistency and were, therefore, excluded from the analysis. In the calculation of the scale scores one or two missing combined-item scores are allowed for. They are replaced by the mean value of the non-missing (combined) item scores. For respondents with more missing combined item-scores per scale, the scale score is assumed to be missing. For all domains, high scores represent a high QoL.

Statistical analysis

Before conducting the final analyses several preparation analyses were conducted. First, scales were constructed and missing data imputed on the basis of the guidelines of the questionnaires used. Secondly, the reliability of the scales was

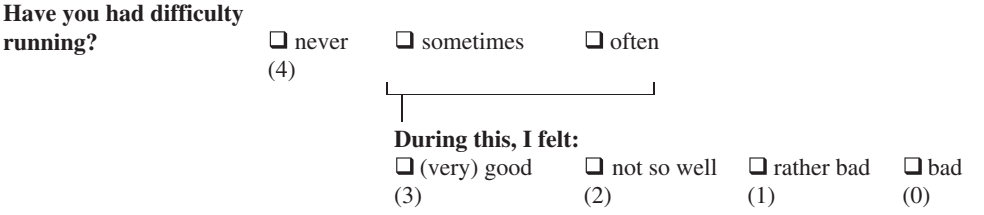

Figure 1. An example of a TACQoL-CF question translated from the Dutch original.

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calculated. Differences on all seven HRQoL mean domain scores between children with different chronic illnesses and healthy controls were examined using analyses of variance (ANOVA) and *post-hoc* procedures according to Scheffe. Children with a chronic disease in the healthy population were deleted from the available database from the original TACQoL study, maintaining $n = 913$ of healthy children. Finally, to be sure about the results, we also performed non-parametric Mann-Whitney U-tests. For these non-parametric multiple testings a significance level of $p < 0.01$ was used.

To create a clinically meaningful distinction between children that can be considered 'at risk' or 'not at risk', two groups were formed, based on percentile norms of the healthy population. If this is done for groups classified by age and gender, differences in the distributions between the study group and the norm group are accounted for and groups can be compared [14]. Definition of the children with QoL problems was based on the value of the 25th percentile for all seven domains in the norm population. An individual who scores below the 25th percentile is placed in the quarter of the most impaired population according to this QoL concept. To determine whether the disease samples were different from the general population, comparison of the percentages of groups were performed using Chi-square tests.

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Results

Patients

After selection of 8–11 year old patients from the different databases, 318 children divided into seven groups based on type of chronic illness were included: congenital heart disease ($n = 50$); coeliac disease ($n = 105$); asthma ($n = 32$); cancer ($n = 23$); juvenile chronic arthritis ($n = 45$); children with capillary haemangiomas ($n = 25$) and survivors of severe meningococcal disease ($n = 38$). Percentages of boys participating in the studies were: congenital heart disease 48%; coeliac disease 43%; asthma 66%; cancer 70%; juvenile chronic arthritis 51%; children with capillary haemangiomas 20% and survivors of severe meningococcal disease 55%. The percentage of missing scale scores was less than 2% in all groups.

Differences in HRQoL between healthy children and chronically ill children

No significant differences were found for the domains of physical functioning and negative emotions between the healthy children and the different illness groups according to one-way Anova. Significant differences were found for motor functioning ($F = 9.8$; df $= 1206$; $p < 0.0001$), autonomy ($F = 7.9$; df $= 1205$; $p < 0.0001$), cognitive functioning ($F = 2.8$; df $= 1201$; $p < 0.0001$), social functioning ($F = 3.4$; df $= 1199$; $p < 0.001$) and positive emotions ($F = 3.3$; df $= 1138$; $p < 0.01$). Table I shows the mean scores of the different groups. *Post-hoc* tests revealed the following differences: On motor functioning, children with CHD, asthma and cancer had a lower HRQoL than healthy controls. On the domain measuring autonomy, only children with cancer were found to have significantly lower scores. Children with coeliac disease had a lower HRQoL for social functioning. There were no differences for any domains comparing children with JCA, haemangiomas and SMD with healthy children. With non-parametric testing two more differences could be considered statistically significant. A difference was found for CHD patients on positive emotions and one for asthma patients on autonomy.

Prevalence of children with a chronic disease at risk

Table II shows the percentages of children at risk for all seven HRQoL domains. Chi-square tests comparing the diverse illnesses with healthy controls show the following significance for the seven HRQoL domains: Physical functioning was affected in 42% of children with asthma. Regarding motor functioning all sick children reported problems except those with JCA and haemangiomas. For the autonomy domain, problems were reported by 36% of the children with CHD, 46% of the children with asthma, 64% of the children with cancer and 40% of the children with SMD. Cognitive functioning was impaired in 36% of children with CHD, in 35% of children with coeliac disease and in 46% of children with cancer. Social functioning was affected in 39% of children with coeliac disease. Problems with emotional functioning were reported by 55% of the children with CHD and 48% of children with cancer.

Discussion

The aim of the present study was to investigate the nature and prevalence of HRQoL problems in children with different chronic diseases. The results of the study show that children have problems in varying HRQoL domains and, above all, the importance of looking beyond mean scores on HRQoL outcome measures alone.

Significant differences in mean scores were shown in all domains except for physical functioning and negative emotions. Comparing the study group's

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Table I. Mean health-related QoL scores and 95% confidence-intervals for healthy children and children with chronic diseases.

Condition	*n*	Physical functioning	Motor functioning	Autonomy	Cognitive functioning	Social functioning	Positive emotions	Negative emotions
Healthy children	913	25.2 (24.9–25.6)	30.0 (29.8–30.2)	31.3 (31.2–31.4)	28.5 (28.3–28.7)	29.8 (29.6–30.0)	13.6 (13.4–13.8)	11.7 (11.6–11.9)
CHD	50	24.6 (22.9–26.4)	27.8 (26.3–29.3)**	30.4 (29.6–31.2)	26.9 (25.4–28.4)	29.0 (28.1–29.9)	12.2 (11.5–13.0)^	11.1 (10.4–11.8)
Coeliac disease	104	25.0 (24.0–25.9)	29.3 (28.6–30.0)	31.1 (30.7–31.5)	27.3 (26.4–28.3)	28.7 (28.0–29.3)*	13.2 (12.6–13.7)	11.3 (10.7–11.8)
Asthma	26	23.0 (20.5–25.5)	27.1 (25.0–29.1)*	30.1 (28.9–31.2)^	28.1 (26.3–29.8)	28.5 (26.8–30.1)	12.8 (11.5–14.1)	11.1 (9.9–12.2)
Cancer	23	25.5 (23.1–27.8)	26.6 (24.8–28.4)**	28.8 (27.2–30.4)***	27.1 (24.7–28.7)	29.5 (28.6–30.7)	12.2 (10.7–13.7)	11.5 (10.3–12.7)
JCA	37	25.0 (23.3–26.7)	28.5 (26.7–30.2)	30.4 (29.2–31.7)	28.1 (26.7–29.5)	29.6 (28.2–30.8)	13.6 (12.7–14.4)	11.3 (10.3–12.3)
Haemangiomas	25	26.8 (24.9–27.3)	30.5 (29.5–31.6)	–	27.0 (24.6–29.4)	–	14.0 (13.1–15.0)	12.5 (11.4–13.6)
SMD	38	25.7 (24.1–27.3)	28.3 (26.5–30.0)	30.7 (29.7–31.7)	27.7 (26.4–29.0)	29.3 (28.3–30.3)	13.4 (12.6–14.3)	11.4 (10.4–12.4)

Range domains 0–32; range positive and negative emotions 0–16.
*$p<0.05$; **$p<0.01$; ***$p<0.001$ for disease group in comparison to healthy children; ^$p<0.01$ for disease group in comparison to healthy children (Mann-Whitney U-tests).
CHD = Congenital Heart Disease; JCA = Juvenile Chronic Arthritis; SMD = Severe Meningococcal Disease.

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Table II. Percentage of chronically ill children at risk for HRQoL problems.

	n	Physical functioning	Motor functioning	Autonomy	Cognitive functioning	Social functioning	Positive emotions	Negative emotions
CHD	50	20%	48%**	36%*	36%*	35%	55%***	29%
Coeliac disease	104	23%	35%*	25%	35%**	41%**	33%	29%
Asthma	26	42%*	54%**	46%*	23%	39%	35%	35%
Cancer	23	35%	70%***	64%***	46%*	32%	48%*	33%
JCA	37	22%	35%	27%	24%	27%	24%	29%
Haemangiomas	25	16%	20%	–	32%	–	20%	12%
SMD	38	18%	45%**	40%*	34%	38%	24%	22%

*$p<0.05$; **$p<0.01$; ***$p<0.001$ Chi-square test in comparison with healthy children.
CHD = Congenital Heart Disease; JCA = Juvenile Chronic Arthritis; SMD = Severe Meningococcal Disease.

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mean scores with those of healthy children revealed that most differences were found in *post-hoc* analysis for motor functioning, particularly in children with CHD, asthma and cancer, while there was no difference in physical functioning. The advances in the medical treatment of side-effects may explain this finding.

The definition of children as being 'at risk' for a HRQoL problem was based on the value of the 25th percentile on all seven domains in the norm population. Because there is no gold standard comparison, the cut-off point may seem quite arbitrary. This method, compared to contrasting means, reveals more differences between the children with a chronic condition and healthy controls, particularly with children who have congenital heart disease, coeliac disease, asthma and survivors of SMD. While the mean scores revealed no differences in the physical domain, this second statistical method revealed problems for 42% of children with asthma. Furthermore, these children also report difficulties in the domain of motor functioning. The same is true for children with SMD. For children with congenital heart disease, one can now see that they are at risk for problems with motor functioning, which was not significant if comparing the mean score alone. For children with coeliac disease, problems in motor functioning and cognitive functioning become apparent.

The results show that difficulties can be diagnosis specific and paediatricians should pay attention to disease-specific problems. Although social problems were only found for children with coeliac disease, it is still believed that for children with a chronic disease it is important to pay attention to possible problems in this area. A study by Meijer et al. [16] showed that, compared to healthy norms, chronically ill children reported less aggressive behaviour. With regard to illness characteristics, both physical restrictions and pain were associated with restricted social activities, but not with other measures of social peer-interaction. Meyer et al. conclude that children who display submissive behaviour and children who are restricted in their social activities should receive extra attention because they are especially vulnerable to problems in their social development.

Children with JCA and children with haemangiomas do not report difficulties on any of the investigated domains of QoL. For children with JCA this is not in line with a previous study [17]. However, considering the fact that many of the JCA patients who participated had an oligoarticular onset of their disease (a small number of joints involved) this might have influenced the positive outcome. Most of the haemangiomas of the children in this study were no longer in the growth phase. It has been found that disfiguring facial haemangiomas were associated with parental reactions of disbelief, fear and mourning, particularly during the growth phase [18], but this relates to the psychosocial adjustment of younger children.

Some limitations of the study should be discussed. The whole sample, although relatively large for children with diverse chronic condition diseases, nevertheless contains only small samples of children per disease. Consequently, the results should be interpreted with caution. Furthermore, it was not the aim of the study to focus on clinical differences between illness groups in relation to HRQoL. It should be taken into account, however, that all illness groups include children with varying severity of their illness. Every diagnostic group has a wide variability in health status at any point in time [19]. Children with cancer who have just finished treatment appear to have considerable limitations in motor functioning, autonomy, cognitive functioning and positive emotions. In view of the time of their inclusion in the study, this is to be expected. Similar findings about QoL in children with cancer have been found, especially during treatment [20]. For children with CHD, the timing of inclusion is different. Most children have been operated on a long time ago. Although severity may be a factor predicting HRQoL, it is known from previous research that this is not the case [10]. Apparently these children continue to experience HRQoL

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problems long after surgical correction of their anomaly. Another limitation which needs consideration concerns the context of completion of the questionnaires either in the clinic or at home. It is imaginable that the context of completion of the questionnaires could influence the responses, but the authors believe this has not happened. Most important, the questions concern complaints and functioning in the past weeks, so not the respondents' feelings during completion of the questionnaires. Furthermore, patients who filled in the questionnaires at home were carefully instructed by letter.

Quality of life determination may be of potential value in comparing outcomes of interventions or simply to aid understanding of the child's point of view [1]. The results of this study have shown that with the TACQoL it is possible to discriminate between groups and, most importantly, to identify children with problems using a cut-off score. Although previous research showed little differences for child population with a chronic disease compared to healthy controls, with this method one finds considerable children at risk for problems. Consequently, paediatricians should monitor these problems. Future research with larger populations is recommended to confirm the present results.

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