Assessment of quality of life in children with asthma and developmental coordination disorder
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Summary

The aim of this thesis was to study the influence of two chronic disorders on the well-being of children.

The incentive for research on this subject was the observation that for most chronic childhood conditions medical treatment modalities seem to have reached their limits in the last ten years. In the last two decades, paediatricians have embraced the biomedical model of disease in most chronic conditions. Emphasis was put on the physical aspects and treatment. It was generally accepted that treatment of disease-specific symptoms or specific organ dysfunctions would lead to improvement of clinical status and as a consequence of quality-of-life. However, studies on quality-of-life showed a poor relation with clinical status. In line with this observation, quality-of-life was accepted as a distinct parameter that together with clinical parameters contribute to the understanding of final outcome. Nevertheless, application of quality-of-life-questionnaires in clinical practice remained limited.

In this thesis, we studied quality-of-life in paediatric practice of Asthma and Developmental Coordination Disorder (DCD). We evaluated the effects of the illness and of treatment on health related quality-of-life and on day-to-day performance. We validated two disease-specific instruments. We used both disease-specific and generic measures to broaden the insight into well being in these children.

In chapter 2.1 we addressed the question: How is health-related quality-of-life (HRQOL) in school-age children with mild, moderate and severe asthma compared with the reference population?

Considering that children with asthma treated in paediatric practice, are supposed to have received optimal treatment, the hypothesis was that disease-specific health-related-quality-of-life might be affected, but generic health-related-quality-of-life might not be affected. Few studies had been performed on generic-HRQOL that used self-assessment by school-age children with asthma. These studies showed differences with the general population, but only in a limited number of domains. Other studies showed differences especially in children with recent exacerbations or severe symptoms. Several authors assumed normal HRQOL in mild and moderate asthma. We used HRQOL-questionnaires that measure more than health status alone by incorporating perception of health status. We studied a population who had asthma for a prolonged period of time. We showed that children with mild asthma (intermittent) and the majority of children with moderate and severe asthma (persistent) have a normal quality-of-life. Normal quality-of-life may be attributed to correct prescription of medication steps. This might be due to the fact that maintenance
inhalation corticosteroids in more severe asthma led to reduction of symptoms causing identical prevalence of symptoms in mild, moderate and severe asthma. This symptom prevalence, however, was still high, as 40% of children have nightly complaints interfering with sleep, while 50-60% has daytime complaints of fatigue and trouble with strenuous activities. Aside from symptoms, 20-30% of children with moderate and severe asthma have generic scores below the normal range and two in three children rate their health as poor. These findings imply that regular care offered to these children leaves half of the children with regular complaints and a quarter with a severe loss of HRQOL.

In chapter 2.2 we addressed the question: *What is the prevalence of a number of distinct problems in children with asthma? How does prevalence compare with the general population?*

We studied the distinct problems in performance leading to diminished quality-of-life. We showed that day-to-day performance (in other studies evaluated as overall functional status) was affected in children with moderate and severe asthma. Functional status reflects to what extent children can carry out daily activities compared to healthy peers. As a group, children with asthma are hampered in physical and motor performance compared to healthy peers. These children did not report more social and school problems compared to healthy children.

These findings imply that a change of attitude from paediatricians may be required, towards measurement of functional status and subjective perception of illness, as well as to evaluation of health-related quality-of-life.

It is important to identify children with problems in performance and health at an early stage and to identify children at risk for dysfunction. We studied psychometric properties of the TACQOL-asthma.

In chapter 3 we addressed the question: *Is the TACQOL-asthma a reliable and valid instrument to be applied in combination with the TACQOL-generic, in clinical practice?*

The TACQOL-asthma ensures a measurement of health-status as well as appraisal of health-problems. Validity of the TACQOL-asthma was assessed using the Pediatric-quality-of-life-questionnaire (PAQLQ) as gold standard. The TACQOL-asthma has good reliability and validity properties to serve as an evaluative and discriminative disease-specific health-related-quality-of-life questionnaire.
The TACQOL-asthma and its generic counterpart, the TACQOL, cover all problems in functioning and general well being of children with asthma.

The self-management of asthma is recognised as an effective strategy to reduce morbidity of the disease. We developed a self-management program for children with asthma. As a natural way of learning in school age is by experience through motor activity, we designed an education and exercise program. It aimed at “Secondary Prevention in Asthma by Self-Management and Exercise”, and was called “SPASME”. A high-risk group of children that had generic-scores below the normal range enrolled.

In chapter 4 we addressed the question: *What is the effect of the SPASME-program on health-related quality-of-life and morbidity in a high-risk group of children with asthma?*

We hypothesized that medical treatment might improve morbidity and asthma-specific quality-of-life, but that self-management directed at coping might influence generic quality-of-life. We showed that the SPASME-program led to improvements of HRQOL, as measured in both generic and asthma-specific measures. SPASME also led to improvement of morbidity. Improvements did not stem from change of medication, or from improvement of lung function or physical exercise capacity. The latter is consistent with studies of asthma education in adults that have shown improvement in quality of life after asthma education without changes in lung function.

In order to increase motivation to enrol in an education program, it should preferably be offered at a moment of optimal motivation, like the time of diagnosis or acute asthma attack leading to hospitalisation. Paediatricians have a role in motivating children and preparing those at risk to enrol as soon as they reach level 7 or 8 in elementary school and before high school. In-class education, peer education and summer camps should be considered as an alternative approach to improve recruitment for programs such as SPASME.

Reconsidering these findings one may ask why children with asthma have a lower generic quality-of-life. Some believe that generic physical complaints are a consequence of the pulmonary symptoms. On the other hand, problems in motor activities may also be secondary to drop out from sports or loss of exercise tolerance.

Some believe that the loss of quality-of-life is caused by asthma symptoms and side effects of medication. Only part of the losses of quality-of-life in generic motor and physical domains indeed will be directly related to asthma-symptoms, such as shortness of breath during
exercise. This is supported by the finding that correlation between asthma-specific and generic domains is poor. Generic well being in asthma may be affected by the combination of difficulties, like having to adapt to a chronic disorder and having to comply with treatment that constitute a burden to normal performance and quality-of-life. The better a child or its caretakers are capable of adaptations, the smaller the burden becomes. The improvements after the SPASME program may have come from better adaptation. SPASME led to improvement of well being that is most likely based on improved coping with day-to-day hassles in school and exercise. Improvement may be the result of a change towards a more positive view on health problems and may be related to a reduction of anxiety.

Considering the high prevalence of problems with physical fitness and problems with exercise, we feel that an education program, including an exercise module, should be offered to all school-age children with persistent asthma.

In the following chapters, problems experienced by children with DCD were evaluated. In chapter 5.1 we addressed the question: How is self-assessed HRQOL in children with DCD-ADHD compared to that in the reference population? How does HRQOL relate to behavioural problems?

It is not surprising that boys with DCD-ADHD in a child-rehabilitation setting have a significantly poorer quality-of-life than a control-group. The motor problems and attention problems that were confirmed by tests, also showed as impact on functioning in the TACQOL-domains relevant to these problems. Moreover, problems in the non-verbal tasks in school and the behavioural problems were expressed as impact on functioning in the cognitive TACQOL-domain. In one third of the boys, the teacher confirmed academic performance below the normal range despite normal intelligence.

Contrary to the other three criteria for the diagnosis of DCD that can be assessed by tests (M-ABC, physical exam and total-IQ), it was voiced that assessment of the third criterion lacked behind due to absence of a test to demonstrate substantial interference in daily life results. Our study shows that the generic measure may serve well to fill this gap.

In chapter 5.2 we addressed the question: What is the prevalence of problems in functioning in several developmental domains in children with DCD referred to the child rehabilitation clinic? How does prevalence compare with the norm in the general population?

Parents reported a wide range of associated behavioural problems, internalising behaviour (withdrawn, physical complaints, anxious), attention-problems and overall
problem-behaviour, of which prevalence is significantly higher than in the reference population.

The description of a spectrum of problems in DCD is not new, but the severity of the motor and associated problems in children referred to a child-rehabilitation centre is worrisome. Findings showed very low motor performance in the Movement-ABC-test. Moreover, more children in the study (35%) had a writing disorder (dysgraphia) compared to children with DCD treated in primary settings (6%). Motor problems may also interfere with non-verbal tasks, leading to scores below the reference norm on the intelligence test. Fifty percent of the children with DCD had associated Attention Deficit and Hyperactivity Disorder (ADHD).

The explanation of the association of motor and attention problems may come from literature on information processing. Studies suggest that children with DCD have problems in regulation of impulses to execute motor activities, leading to less coordinated movements. In correspondence, children with ADHD have problems in the regulation of impulses related to attention. This impulse regulation is located in several (sub cortical) areas of the brain that regulate both motor and attention processes. A dysfunction in these impulse regulating areas can be expressed both in motor and attention impulse regulation.

As motor problems may serve as a symptom or signal of more complex developmental disorders they should be recognised at an early age. It is important to start early comprehensive intervention, as it has been shown that without intervention DCD problems persist. It has also been shown that an intervention may improve motor problems. With the purpose of screening for DCD-problems no Dutch questionnaire was available. Therefore we translated an English questionnaire, the DCD parent questionnaire (DCD-Q). We validated the Dutch DCD-questionnaire for screening of DCD-problems in the age group 4-8 and 8-12 years old.

In chapter 6 we addressed the question: Is the DCD-Q a reliable and valid instrument to detect DCD in children as early as in pre-school age? How is the agreement between DCD-Q and the “gold standard”, the movement-ABC-test?

We found that the DCD-Q is a reliable and valid instrument to assess daily life motor performance in the age range for which the questionnaire was developed (8-12 years), but also in a younger age range (4-8 years). To assess sensitivity and specificity of the DCD-Q, we used the Movement ABC as gold standard. We conclude that the DCD-Q is a sensitive instrument to detect DCD in children at risk for motor coordination problems. The DCD-Q meets standards for sensitivity in the clinic-referred sample, but not in the random sample. Specificity almost reaches the desired standard of 90% in both samples.
Considering the high prevalence of associated ADHD in children with DCD, we addressed the last two questions in chapter 7:

**How is fine motor performance in children with DCD-ADHD?**

Boys with DCD-ADHD performed poorer on the manual dexterity subtests, had poorer quality of handwriting, and drew faster, more fluently, but less accurately than controls on the graphomotor task. It seems impossible for these children with DCD to adapt in school with restrictions due to writing problems and perception problems. Problems in other domains of functioning, attention and of self-concept are even more frequent leading to loss of HRQOL. As a consequence, early assistance in school is needed.

**What is the effect of Methylphenidate on fine motor functioning?**

Fine motor performance in children with DCD-ADHD after administration of methylphenidate was better than before. These children have impairment in manual dexterity and poor quality of handwriting and drawing that improved after methylphenidate use, but performance on these tasks remained poorer than in the control group. In most cases clinical improvement of manual dexterity was attained and legibility of handwriting had improved in 50%. With methylphenidate use, children with DCD-ADHD are still affected by substantial fine motor problems warranting further treatment and support at school to overcome functional problems for handwriting and drawing. ADHD and DCD need to be identified as co-morbid conditions with distinct problems requiring complementary forms of intervention.

Reconsidering our findings, one may ask how we can apply assessment of generic quality-of-life in DCD. The problems in performance in boys with DCD-ADHD were reflected in lower scores not only in motor or concentration items, but also in almost all domains of generic quality-of-life-measures. This finding implies that the TACQOL may be of use as an instrument to measure interference in daily life, as one criterion of DCD (DSM-IV). The use of this combination of TACQOL and DCD-Q might be considered for use in clinical populations at risk for motor problems to assess impact of problems on quality-of-life in children with DCD.