Assessment of quality of life in children with asthma and developmental coordination disorder
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General Introduction
The application of quality-of-life measures in paediatric outpatient practice of chronic childhood conditions, to assess consequences in daily life and needs for care of the child.

General Introduction

Emphasis in health care has moved from treatment in acute illness to prevention and control of chronic conditions. Fifteen to twenty percent of children have a chronic illness or condition.¹,² Prevalence is rising and rates of longstanding illness doubled in the period 1975–1995 in children aged 5-15 years.¹,³ A chronic illness is defined as a "medically diagnosed condition" that affects children for extended periods of time and that can be "managed", but not cured.¹,⁵

Recent advances in medicine have resulted in improved survival and have changed the implications of a chronic physical illness in childhood. Life expectancy in cystic fibrosis improved from 14 years in 1970 to more than 30 years in 1995.⁶ Also individuals with disorders such as diabetes, cystic fibrosis, renal failure and cancer, who may previously have had a limited life-expectancy, are now surviving into adulthood.⁷ As treatment options of paediatric chronic diseases have improved and more and more children survive, the physical and psychosocial consequences and needs in day-to-day life have become increasingly relevant in paediatric health care.⁵,⁸ Recognition of this relevance has led to a shift from interest in treatment parameters related to survival and morbidity towards measurement of quality of the resulting life.

Chronic conditions cause a burden in day-to-day life, not only due to problems related to the underlying disease condition itself, but also due to "having to live with a chronic condition". One in two children with a chronic condition has to contend with daily "hassles" and one in four to five of these children can no longer keep up with the expected pace of development.¹,²,⁴ The impact on day-to-day performance and on quality-of-life is determined by the complications of the disease itself together with the burden of having to live with a chronic disease.⁵,⁹

Quality-of-life

There is consistent evidence that implications of a chronic condition have an impact on many aspects of life, such as physical, psychological, social and academic aspects of life. A measure that can encapsulate all these diverse experiences seems attractive.⁵,¹⁰,¹¹ Quality-of-life questionnaires are developed to investigate the impact of health problems on daily performance. Two types of questionnaires are used; the first contains questions about a
number of health problems reflecting common problems in daily functioning that are familiar to all persons, whether healthy or affected by an illness (generic measure of health-status). The second contains items that are related to a specific disease (disease-specific measure of health-status) and to patients. Daily performance is measured as a person’s functioning in different important domains of life, such as physical, psychological, emotional and social functioning. Several distinct health problems within a domain make up a scale. From responses a score is calculated and from the scale-scores a quality-of-life score is calculated. A score for prevalence or rather quantity of problems is expressed as health-status, while a score that includes emotional evaluation of health problems is expressed as health-related quality-of-life. The terms health status and health related quality-of-life are often used as if interchangeable, but they are not.

Perspectives on impact on day-to-day performance
Impact of a disorder on performance can be viewed from medical and disability perspectives. In working with children with a long term chronic disorder, much is to be gained from a more generic model, as opposed to a medical model. The medical perspective considers functioning as the “consequence of a disease or condition”. It measures burden of disease in disease-specific quality-of-life questionnaires. It uses overall quality-of-life score, primarily with the purpose to evaluate the effects of treatments, such as drug treatments or surgical interventions. The disability perspective considers functioning as an adaptation to disease (figure 1).

Figure 1 This framework of disability is according to the WHO International Classification of Functioning, Disability and Health (ICF).
This perspective considers daily functioning as influenced by both the condition and personal and contextual factors. It measures the burden of disease and its adaptation in a combination of disease-specific and generic questionnaires. In rehabilitation, not only the overall quality-of-life score, but also the presence of distinct problems that make up this score is important for treatment. The aim of treatment in chronic disorders is to improve quality-of-life, quality-of-life. However, quality-of-life measures are not routinely used in clinical practice or in clinical trials.\textsuperscript{3,5,10} Measurement is necessary as perception of the child’s well being among children, parents and their physician may differ considerably. Misunderstanding about quality-of-life may be the case both at the onset of a chronic disease and after a period if follow-up.\textsuperscript{14} As increasing emphasis is laid on the use of patient centred outcomes and on child perspectives, the assessment of quality-of-life in paediatric follow-up is becoming increasingly valued and mandatory.\textsuperscript{10}

The two most prevalent chronic conditions in childhood are asthma and developmental disorders. However, limited information is available on generic health related quality-of-life in asthma and Developmental Coordination Disorder.

The objective of this thesis is to study the impact of having a long-standing chronic health condition on day-to-day performance and health-related quality-of-life (HRQOL) in comparison with healthy children. Studies are performed in two paediatric populations, children with asthma and with developmental coordination disorder. Two disease-specific questionnaires are validated for use in clinical populations. Effects of having the disorder and of a therapeutic intervention on day-to-day performance and health-related quality-of-life (HRQOL) are described.
Chapter 1

Asthma

Children with long-standing asthma have a chronic respiratory condition with "unpredictable" episodes of shortness of breath, but also episodes of normal functioning. To prevent attacks and permanent loss of lung function, maintenance medication to treat inflammation of airways needs to be taken. Thanks to the use maintenance inhalation of corticosteroids, children with more severe asthma may have a near normal lung function. Nevertheless, disease management demands constant adaptation.

Though asthma may not impress as a disabling condition, it may lead to considerable interference with daily life and school.¹ Prevalence in school-age children is 5-10%. Epidemiological studies demonstrated that the highest rate of disability in childhood is not caused by visible and severely handicapping conditions, but by asthma and developmental disorders.¹²⁴ An intervention aimed at reducing interference in day-to-day performance is needed to prevent limitations of activities, as disability may lead to developmental loss. The information on performance given by the child in quality-of-life questionnaires can be used to adapt the treatment plan.

Health related quality-of-life

In childhood asthma many studies of health-status have been performed in disease-specific questionnaires.¹³⁻²⁴ Generic HRQOL or rather general well being, is less well studied in asthma, as few studies evaluated quality-of-life in generic questionnaires.¹⁵⁻¹⁷ The comparison on well being between children, healthy and with asthma in these studies resulted in conflicting findings. As it is important to know how children with asthma perceive their quality-of-life, we defined research question 1.

| How is health-related quality-of-life in school-age children with mild, moderate and severe asthma as compared to that in the reference population? |

Prevalence of distinct health problems

In a large multi centre European study, parents reported a high prevalence of symptoms in their children with asthma, even when parents perceived good asthma-control.²⁵,²⁶ Less data are available on the prevalence of problems in day-to-day performance and of common complaints. Self-administered quality-of-life instruments may be used to evaluate such problems and complaints. Most studies use ratings in these questionnaires to calculate a health-status sum-score. Ratings of distinct problems can be studied to assess presence or rather prevalence of these distinct problems within the scales of the questionnaire. However, this evaluation is seldom used. As it is important to know the prevalence of distinct problems in day-to-day performance, we defined the second research question.
What is the prevalence of a number of distinct problems in children with asthma? How does this prevalence compare with the general population?

Instrument
To measure HRQOL, it has been recommended to use a combination of HRQOL-questionnaires. The combination would consist of a core generic-questionnaire supplemented with a disease-specific module. The combination can assess the total impact of a chronic disease on quality-of-life and day-to-day performance. At the time of this study no such combination of generic and disease-specific HRQOL-questionnaire was available for children with asthma. The current “gold standard” to measure health-status in childhood asthma is Juniper’s asthma-specific- Paediatric-Asthma-QOL-Questionnaire (PAQLQ), but the PAQLQ has no generic counterpart. The TACQOL (TNO-AZL-Child-QOL) is available as a measure of health and functional-status that incorporates appraisal of health-status. Its generic-TACQOL is validated for use in the general population and in chronic conditions, and is recommended for use in clinical populations. The asthma-specific-TACQOL was developed and awaiting validation. Our third research question was.

Is the TACQOL-asthma a reliable and valid instrument to be applied in combination with the TACQOL-generic in clinical practice?

Intervention
Self-management programs aim at education about management of health problems. Relevant health problems will be endorsed as distinct problems in the HRQOL-questionnaire. Education programs teach coping techniques to overcome these problems. We designed an outpatient group-education program, which is a combination of not only an education module as proposed by Colland, but also an exercise module. Within the exercise module, educational themes are incorporated. The purpose of the program lies in its name, SPASME-Secondary-Prevention of Asthma by Movement and Education. The SPASME-program was offered if children had long-standing asthma and adequate symptom reduction, but still had a low generic quality-of-life (defined as a total generic-HRQOL-score <reference P10). We selected this cohort as we assumed that children with long-standing asthma that have a substantial loss of general well being form a high-risk group. Educational training was also offered to parents and teachers. In research question 4 we analysed

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?
Chapter 1

Developmental Coordination Disorder

Children with Developmental Coordination Disorder (DCD) have a problem with motor coordination resulting in clumsy motor performance and considerable interference in daily life and school. Clumsiness becomes more obvious with complex motor activities in school age. DCD is one of the mild specific developmental disorders with normal intelligence. DCD may not impress as a disabling condition, but is often associated with other developmental disorders, and may lead to serious learning and social problems. To prevent loss of academic and social performance, special education services, as well as psychological and educational support may be needed. Motor intervention should focus on the difficulties in the execution of tasks or actions relevant to the child. The child’s perspective on performance can be assessed in quality-of-life measures.

Health related quality-of-life has scarcely been studied in developmental disorders. HRQOL has not been studied in DCD. Fifty percent of children referred to Dutch child rehabilitation centres may also have Attention Deficit and Hyperactivity Disorder (ADHD). HRQOL has been studied in ADHD and significant impact on the social and behavioural domains of the generic child health questionnaire (CHQ) are described. It is important to know what aspects of quality-of-life are affected in children who have not only DCD, but also ADHD. In question 5 we analysed.

How are health-related quality-of-life and behavioural performance in boys with DCD-ADHD in comparison with the reference population?

Prevalence of health problems

Many studies describe motor, behavioural, learning and social problems in children with developmental disorders from the perspective of parents and teachers. In these studies, the association of DCD with ADHD (attention deficit/hyperactivity disorder) is reported in approximately half of children referred to psychiatric and rehabilitation institutions. While in children referred to clinical psychiatric institutions, ADHD is predominant and motor-functioning may be less well studied, in children referred to rehabilitation institutions, DCD is predominant and ADHD problems are less well studied. For purposes of treatment and prognosis it is important to know the extent of the motor problems and co morbidity in children with DCD referred to a child rehabilitation centre. Research question 6 was.

What is the prevalence of problems in performance in children with DCD referred to a child rehabilitation centre?
Instrument
Considering the spectrum of problems children with DCD may encounter, an early intervention is warranted. Preferably detection should be as early as during pre-school age when problems in motor functioning are just becoming evident. Screening would be suitable at the start of elementary school. At that time, many children are tested on language skills and orientation to tasks, but not on motor skills. As high demands are posed on motor skills in school, early detection of motor problems is warranted.
A Dutch questionnaire for DCD screening was not available yet. Recently a questionnaire was developed in Canada to identify children with movement difficulties; the parental developmental coordination disorder questionnaire (DCD-Q). Research concerning the psychometric properties is still limited. We translated the DCD-Q for use in Dutch children. We tested the DCD-Q not only in the age group of the original questionnaire (8 years onward), but also in children of 4-8 years. This DCD-Q was applied in a multi-school survey among the school age population 4-12 years to evaluate reliability and validity and examine the agreement between motor problems in the DCD-Q and the “gold standard”, the Movement-ABC-test. Research question 7 is:

Is the DCD-Q a reliable and valid instrument to detect DCD in children in pre-school age?
How is the agreement between DCD-Q and the “gold standard”, the movement-ABC-test?

Intervention
The findings on individual problems in day-to-day performance, activities and participation in DCD may be used to guide an intervention directed at reducing limitations in day-to-day performance and health. To offer a program based on the motor and behavioural problems confirmed in the diagnostic protocol, we use a multi-disciplinary approach that consists of education and counselling to parents, while motor therapy and behaviour therapy are offered to the child, either alone or in a group. In the case of the combination of DCD with ADHD a double blind placebo controlled trial may show positive effects of psycho-pharmacological therapy on ADHD-symptoms. Methylphenidate (MPH) is the most widely used drug in ADHD. Studies have shown has positive effects of Methylphenidate on ADHD-symptoms, and have described positive effects on motor functions. The effects of MPH on motor functioning have not been studied in children with DCD-ADHD. Fine motor functioning is most important to execute relevant motor tasks in school. In research question 8 we studied

How is fine motor performance in children with DCD-ADHD?
What is the effect of Methylphenidate on fine motor functioning?
References


General introduction


