Assessment of quality of life in children with asthma and developmental coordination disorder
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Document Version
Publisher's PDF, also known as Version of record

Publication date:
2005

Link to publication in University of Groningen/UMCG research database

Citation for published version (APA):

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General Discussion
Discussion

The studies in this thesis show that children with common chronic disorders experience more limitations in functioning in daily life than healthy children. Children with asthma and developmental coordination disorders (DCD) have problems in functioning that are disease-related and concern restrictions due to symptoms and treatment. They also have generic problems that cause restrictions in general physical, social and personal functioning. These problems do negatively affect their quality-of-life.

To optimise health care in childhood chronic disorders, it is important that the paediatrician evaluates the impact of a chronic disorder on all aspects of a child’s functioning in daily life. The assessment should pay attention to limitations that are relevant to the child because these interfere in his daily life. The child is able to report about the impact of health problems in quality-of-life questionnaires.

In order to adapt to the consequences of a chronic disorder the child needs mechanisms to cope with these health problems. A child’s dealing with a long-term health condition can benefit from self-management techniques in addition to optimal medical care.

For the paediatrician caring for children with a chronic disorder, it is a challenge to treat the child and not his disorder. It is difficult to assess how well a child with a chronic disorder performs in daily life using the paediatric tools available. Even an extensive interview and physical examination and additional clinical tests may not be sufficient to appraise the impact a chronic disorder has on the child’s well being. The humanistic or holistic approach is hard to perform in the office. This may explain the need for multi disciplinary teams to assist in the care of the child and family. The various disciplines within the team are able to assess consequences in the areas of their expertise. However, a multi disciplinary approach does not guarantee to address all aspects of functioning in physical, social and personal domains that are relevant to the child.

The studies in this thesis show that many children with asthma experience more common health problems and limitations in daily life than was expected. Also when optimal care is given by paediatricians, often supported by asthma nurses, and when correct medication steps (Dutch guideline) are applied, a loss of health related quality-of-life (HRQOL) couldn’t be prevented in patients with persistent asthma. That optimal asthma control in our children with asthma was achieved was supported by the findings of adequate symptom reduction in children with severe asthma, of regular follow-up visits, of adequate maintenance medication prescription and of normal lung function. Nevertheless, more than 50% of the children with asthma report symptoms during the day and night causing daily restrictions.
Chapter 8

The question is why the limitations revealed in our studies remained underexposed in the paediatric interview. Is the doctor, the patient or the method to blame?

First, it is understandable that physicians focus their follow up assessment at symptoms and physical consequences of asthma and at the dysfunction of the respiratory system (chapter 1). They perform an interview and physical examination, and order laboratory tests, with or without disease specific guidelines. The information exchanged between paediatrician and parents may concern topics in which the doctor is interested with respect to the treatment and home care provided by parents. In this exchange, both parents and doctors may not realize that their perceptions about the well being of the child differ and that the topics important to well being change over time. The perception of the child may not show to full advantage until he is old enough to express himself in an interview.

A method to have children self-assess their limitations in daily functioning is the use of questionnaires on quality-of-life. These questionnaires may have several advantages over interviews.

A questionnaire can be completed at home and allows for some reflection time, which may be more suitable and less confronting, especially in school-age children than a direct question posed in the office. A possible disadvantage of filling in a questionnaire at home is the introduction of a bias. Generic-HRQOL-questionnaires are developed to assess all problems relevant to a child’s daily functioning in the domains physical, social and personal functioning, and as such reflect a holistic approach.

A generic questionnaire that is validated in healthy children can reveal differences in well being between children with a disorder and healthy children. Its use can improve the precision and comparability of health assessments.

School-age children are reliable respondents, and responses of children and of parents about their children are said to be complementary.

As has been shown in other studies, our study confirms also that HRQOL is lower with more severe asthma. HRQOL in children with moderate and severe asthma is lower than in healthy children. HRQOL in children with mild asthma might be normal, but our mild asthma group was too small to draw conclusions.

Among children with moderate and severe asthma, some have HRQOL in the normal range and others below the normal range. We studied the subgroup with a total generic HRQOL-score below reference P10. Parents as proxy report such a score below P10 in 20% of children with moderate asthma (GINA equivalent is mild persistent), and in 30% of children with severe asthma (GINA equivalent moderate and severe persistent asthma). Children
themselves report such a low level in 26% of children with severe asthma only, while in moderate and mild asthma prevalence is not increased compared to healthy subjects. A comparison between those with a HRQOL-score below reference P_{10} and those with a HRQOL-score above reference P_{10} shows that the former “high risk” group is more often bothered by asthma attacks, needs more oral prednisone courses and more often has smoking parents. These children also have more problems in motor activities and school functioning and are more often absent from school as a possible sign of trouble with coping. These findings imply a relation between loss of HRQOL and unfavourable environmental factors (i.e. smoking). Problems in school may also be a sign of trouble with coping.\textsuperscript{10} On the other hand, the study showed that the majority of children with asthma have a HRQOL in the normal range. Psychosocial factors may protect against loss of HRQOL in children with persistent asthma that have a normal HRQOL. Future studies should assess the protective factors that may be promoted in children with persistent asthma.

Additional care was offered to children who had a HRQOL-score below reference P_{10}. The treatment offered to these children consisted of an education program to which an exercise program was added. The program aimed at coping with health problems and with the treatment regimen. About 60% of potential candidates for the program actually enrolled. The intake examination of participants showed that the inhalation technique could be improved in 60% and that optimalisation of medication was possible in 32%. The aim of the educational program was to recognize physical symptoms, to avoid adverse situations, to learn to deal with exercise and nocturnal symptoms, and to cope with uncertainties and fears.

Our study shows similar positive effects of our program on morbidity as has been described by the original education program.\textsuperscript{11} Moreover, our study shows an improvement of HRQOL for several months. (Chapter 4) While no changes in HRQOL are found in the control group, changes in HRQOL are consistently seen in participants. Changes reach the level of significance and are of clinical importance. In accordance with studies of asthma education in adults\textsuperscript{12}, we show an improvement in quality of life after asthma education without changes in lung function or physical exercise capacity. Changes could not be attributed to optimalisation of medication alone, as groups with and without medication change show similar improvements of HRQOL and morbidity.

We choose to add an exercise module to the education module for several reasons. First, to improve participation in activities, as participants had developed a fear for motor activities and activity limitations. During the program children could practice and train under supervision. Second, practice by way of movement activities has been shown to be an
effective natural way to learn for children.\textsuperscript{13} The movement part may have improved attractiveness of our program.

In our studies, impact of the disorder in daily life is evaluated by translating the responses in HRQOL-questionnaires not only as a HRQOL-score (Chapter 2.1), but also as prevalence of distinct health problems (Chapter 2.2). In contrast to the wide spread use of responses in behavioural questionnaires to provide us with epidemiological data on prevalence of psychosocial and behavioural problems, HRQOL-questionnaires have seldom been used to proved epidemiological data on generic health problems in children with and without asthma.\textsuperscript{10,14,15,10,26}

The evaluation of distinct problems in the TACQOL-questionnaires of our study shows the existence of more health problems and limitations in activities in children with asthma than in healthy children. It gives insight into the rather high prevalence of daily problems caused by asthma symptoms, provoking factors, medication use and doctors' visits, which are the asthma-specific consequences in daily life. It shows the presence of a difference between children with asthma and healthy children in general physical, motor, autonomic functioning, but also an absence of a difference in social relations with peers and parents, in school functioning and in moods.

The reference data from the healthy population are needed to determine disability in a clinical population. Disability is a long term lack of ability to participate and perform activities of play, sports and school in the way that healthy children of similar age and gender would do".\textsuperscript{16,17} From other studies we know that activity disability is increased in asthma.\textsuperscript{19} In our study, a higher prevalence of problems in physical fitness and activity in children with asthma was found than in healthy children. This does not necessarily mean that children with problems in physical activity had a disability, but it implies that this group of children is at risk of activity disability.

In children with asthma, the higher prevalence of health problems led to the perception of poor health and of substantial loss of HRQOL in two to three times as many children as in the healthy population.
DCD

Developmental Coordination Disorder (DCD) is a rather new entity and the name is not very familiar to paediatricians. DCD is defined as a disorder of coordination of motor performance not explained by a neurological illness that causes considerable interference in daily functioning.\textsuperscript{20} Paediatrician's interest in this disorder, formerly also called MBD (minimal brain dysfunction) and DAMP (disorder of attention and motor performance), was lost in the late 80's, possibly because no organic cause could be demonstrated.\textsuperscript{21,22}

Other specialists continued their interest and formulated classifying criteria for the term DCD. We do not know the natural course of mild, moderate and severe DCD. The children with DCD included in our study showed more severe motor and behaviour problems than children with mild and moderate DCD in other studies.\textsuperscript{23} Children with DCD may benefit from a short course of functional physiotherapy.\textsuperscript{24,25}

Motor coordination problems may be the first sign of difficulties in processing of information to perform complex tasks.\textsuperscript{27} In children with more severe DCD, such difficulties might extent to processing beyond motor tasks, such as complex attentive, learning or social tasks, and this might explain the overlap with attention deficit and hyperactivity disorder (ADHD).\textsuperscript{26} Paediatricians may not often see children referred for DCD, but may look for DCD among children referred for ADHD. Studies have shown that 50\% of children referred to centres of developmental paediatrics or child psychiatry with ADHD may have DCD.\textsuperscript{26} We do not know how often DCD occurs in children referred to the general paediatrician.

Our study gives information about children with more severe DCD referred to a child rehabilitation centre. They show the number of problems the children encounter in daily life and what impact these problems have on HRQOL. (Chapter 5) One in two to three children with DCD in our centre have confirmed disorders in several domains outside the motor functioning domain. We show that using strict criteria, ADHD and internalising behaviour disorder can be confirmed in half of these children, and problems with social skills and learning in a third of the children. Similar findings are described in other studies.\textsuperscript{23,26}

Identification of associated problems in DCD is needed, as child psychiatric treatment and special education services must be offered to these children. Identification of behaviour problems is possible using behaviour questionnaires. Most studies use questionnaires completed by parents or teachers, and these studies suggest associated problems related to attention, cognition or behaviour, in 50\% of DCD referrals to tertiary centres. This is similar to our findings in parental and teacher reports.\textsuperscript{23,26}
Our study shows that Identification of motor, social and school problems is also possible in HRQOL-questionnaires completed by children themselves. The group of boys who had both DCD and ADHD were able to endorse their problems in the domains of the HRQOL-questionnaire. (Chapter 5.1) As expected, HRQOL was decreased compared to controls as an expression of problems in the motor domain, as well as in social and cognitive domains in these children. Abnormal scores on developmental tests that assess performance level in each domain could objectively verify these problems endorsed in the different domains of the HRQOL-questionnaires.

If we compare HRQOL between children with DCD-ADHD and asthma, we must compare the groups with severe grades, as our DCD-ADHD consists of the severe DCD group only. In children with DCD-ADHD, HRQOL seems to be more affected than in children with severe asthma, mainly in the domains cognitive and possibly in the social domains of functioning and in moods, but not in the physical, motor or autonomic domains. However, a reliable comparison between children with DCD and asthma on HRQOL-level would require a larger DCD population containing all severity grades of DCD, similar to the asthma population.

Identification of DCD problems at an early age seems warranted. In populations with developmental problems of motor and attention performance, prognosis has not been favourable without therapy. We know that 70-80 % of children do not outgrow severe motor problems.26,28 We know that children with severe motor problems often have associated developmental disorders with a poor prognosis for adult functioning in motor and social domains.28 It is known that children with DCD benefit from motor therapy.24 Early screening for DCD is necessary, because in confirmed cases of DCD, motor therapy, educational therapy and special services in school may be needed. Our study on reliability of the parental DCDQ shows that an instrument has become available that can be used as a first screening for DCD to identify children with motor coordination disorder in clinical practice.

The question is whether screening for DCD should be restricted to children referred to a specialist for motor problems, or that screening should be extended to pre-school children in the general population. An argument against general screening is that too many children might be identified that do not experience trouble in daily life. An argument in favour is that up to half of the children that develop learning and behaviour problems in school age might have had motor problems already at pre-school age. In our opinion, the DCD-Q has potential value for community-wide screening of DCD.
Before we decide in favour of DCD screening in the general population at the age of school entry, one must agree on what has to be done once the screening shows an abnormal result. Further research is needed to make procedures evidence based.

How could the procedure be for screening of DCD and referral to paediatricians? If the DCDQ score is lower than the cut-off score and a low generic HRQOL suggests interference in daily life, a motor test is indicated. Motor problems have to be confirmed with the M-ABC test. If the M-ABC total score is also lower than the cut-off score, referral should follow. DCD has to be confirmed by a physical examination performed by a paediatric specialist trained in developmental disorders. After confirmation of DCD, motor therapy is indicated that can be offered by primary care therapists in cases of mild and moderate DCD. However in cases of very low motor scores and signs of problems in school, also screening of associated cognitive, learning and behaviour problems in parent and teacher questionnaires is advocated. If low scores in these questionnaires confirm such problems, more extensive developmental tests must be performed to complete the picture and place motor performance within the context of total developmental performance. In confirmed cases of severe DCD, referral to child rehabilitation teams of children with motor problems and ADHD may improve outcome.

The physical examination of children with DCD is a challenge, as findings may seem mild. The paediatrician may have to apply specific tests to assess coordination problems and minor neurological signs (MNS). It has been shown that even paediatricians with interest in motor problems were not able to assess the loss of motor performance well enough in the office. Verification with the M-ABC test was needed. The paediatrician might need more training in both the identification and treatment of DCD and of other developmental disorders, as well as on possibilities to influence information processes with functional and psycho-pharmacological treatment.

The therapy of DCD is a multi disciplinary one. Instructions in therapy sessions have a much better chance of being used by the child with DCD-ADHD if he enjoys the effect of Methylphenidate on control of attention problems. The presence of ADHD in our group with DCD-ADHD offered the possibility of a trial treatment with Methylphenidate (MPH of Ritalin®). Currently, Ritalin® is the most prescribed drug in ADHD. We recommend using a double blind placebo controlled method to confirm effects on ADHD and DCD symptoms.
Our children with DCD-ADHD did profit from the effects of Ritalin®, both on ADHD symptoms, and on fine motor performance (chapter 7). Though normalisation of fine motor performance was not always the case, improvement of performance led to better options to improve handwriting. Considering the importance of written communication in current society this is an important result. Our study population was small and though findings are similar to the few other studies performed\textsuperscript{32,33}, they must be reproduced.

The purpose of paediatric follow-up of children with long term chronic conditions must be to establish a picture of the course of the illness, but also of the consequences for daily functioning and well being. Our findings show that the application of HRQOL-questionnaires in paediatric practice is feasible, not only for research, but also for practical purposes to assess limitations in individual patients. Generic quality-of-life questionnaires can help paediatricians to assess and evaluate impact of disorders on functioning and health of the child. Though parents and children agree rather well on report of problems, they may report differences when perception of subjective items is concerned.

All research findings in this thesis can only be applied to two selected populations referred to paediatricians or to other paediatric specialists. However, the implementation in paediatric practice of self-report by children could be effective for children with other long-term health conditions too. The diagnostic interventions described may be especially relevant for high-risk subgroups.

The communication between doctors, parents and children about responses in the questionnaires is the first step towards self-management, and might lead to better atonement of relevant issues that concern physical functioning and disability, personal perception and evaluation of the child and functioning in a social context. In treatment it is important the relevant health problems are determined and solutions are sought within both the medical framework and the rehabilitative or rather functioning framework. We hope that our studies can serve as a standard of comparison for quality-of-life studies in children with different chronic health conditions.
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