Chapter 8

General discussion
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In the present thesis physical activity (PA) and physical fitness (PF), expressed as aerobic and anaerobic exercise capacity, are studied in children and adolescents with juvenile idiopathic arthritis (JIA). The importance of PA and PF for healthy and sick children is increasingly brought to notice but still not fully recognised and understood. PA and PF are closely related but they should not be used as interchangeable concepts. PA and PF and their clinical relevance are discussed here in terms of “capacity” and “performance”. Capacity is the child’s ability to execute a task or action within a standardized environment and performance is defined as what a child does in his or her environment.

Capacity

Aerobic and anaerobic exercise capacity are two important elements of PF and they are necessary to meet the demands of daily living and they provide the basis for sport performance. In chapters 3 and 4 it is showed that aerobic as well as anaerobic exercise capacity are both significantly reduced in children and adolescents with JIA. Therefore measuring and improving aerobic and anaerobic exercise capacity in JIA should be essential parts of disease management.

Maximum or peak oxygen uptake (VO\textsubscript{2peak}) is the golden standard for measuring aerobic exercise capacity but its measurement through a maximal exercise capacity test with a metabolic cart to analyse respiratory gases is for clinical evaluations not feasible. Therefore there is a need for simple and inexpensive measurement tools. Chapter 2 showed that the 6-minute walking test (6-MWT) is not a valid measurement tool to measure aerobic exercise capacity but new evidence obliges us to reconsider this conclusion. In a cohort of 18 children with JIA, walking distance as measured with a 6-MWT and VO\textsubscript{2peak} was assessed and regression analysis showed that VO\textsubscript{2peak} could be predicted from the walking distance and the height of a patient. The researchers concluded that the accuracy of the prediction was low possibly due to the small number of participants and cross validation in another and larger sample of JIA patients might possibly reveal accurate predictive values which would make the 6-MWT a valid instrument to measure aerobic exercise capacity. Chuang et al and Hassan et al both argued that the work of walking during the 6-MWT can be expressed as walking distance times body weight (6Mwork) and that it seems to be a better outcome measure as walking distance alone. Chuang et al found in adult Chronic Obstructive Pulmonary...
Disease (COPD) patients that 6Mwork correlated significantly better with VO$_{2 \text{peak}}$ than did walking distance alone. An analysis of the correlation between 6Mwork and absolute VO$_{2 \text{peak}}$ in the sample described in chapter 2 showed a significant and high association. Therefore it might be worthwhile to explore the use of 6Mwork as a valid predictor of VO$_{2 \text{peak}}$ in JIA patients. In the pilot described in chapter 7, aerobic capacity was measured with a Bruce treadmill test. Endurance time on a treadmill test showed a high correlation with VO$_{2 \text{peak}}$ and for clinical purposes it is a satisfactory indicator of exercise capacity. Reference values for boys and girls, aged 4 to 18 years are available. Although one minor adverse incident was experienced of a boy falling at the end of the test, causing minor scrapes, the test was well tolerated and completed in 7 to 13 minutes by all patients. A Bruce treadmill test is therefore a suitable measurement tool for measuring aerobic capacity in the treatment of children with JIA.

While aerobic exercise capacity is needed to sustain physical activities for longer lasting periods of time, anaerobic exercise capacity is needed for more intensive, short burst type of physical activities. The anaerobic exercise capacity is usually measured by a Wingate anaerobic exercise test (WAnT). The degree in which both systems are diminished can be expressed with an “Anaerobic-to-aerobic Power Ratio”: maximal aerobic workload divided by mean anaerobic workload. Van Brussel et al showed that the anaerobic-to-aerobic power ratio in children with JIA is not significantly different from healthy peers suggesting that the deficits in exercise capacity both affect aerobic and anaerobic capacity to a similar degree. Aerobic as well as anaerobic exercise training are therefore equally important in training programs.

**From capacity to performance**

Aerobic and anaerobic exercise capacity are pre-requisites for and reflect a child’s PA potential. However, actual child performance or PA is not only determined by exercise potential. Chapter 5 showed that there is a moderate positive and significant association between absolute VO$_{2 \text{peak}}$ and PA in adolescents with JIA. Chapter 4 showed a poor to moderate significant association between functional ability, expressing the ability to perform daily activities of life and assessed with the Childhood Health Assessment Questionnaire (CHAQ), and aerobic and anaerobic exercise capacity. Takken et al found a moderate significant association between anaerobic exercise capacity and functional ability and suggested a kind of threshold for PF. Once PF tumbles under such a threshold, PA levels
and functional ability can significantly decline due to low exercise capacity. This is what happens in the elderly whereby the age related decline in PF reaches a critical threshold causing disability\textsuperscript{17, 18}. However, most light to moderate intense daily activities normally require only a fraction of a child’s exercise capacity and we can therefore assume that PA is not solely determined by exercise capacity\textsuperscript{19}. In children with chronic fatigue syndrome exercise capacity seems to be only mildly affected while disability is high and PA levels are low\textsuperscript{20, 21}. What than makes a child inactive while the potential is there? To answer this question we must look at and consider PA as a type of behaviour which can be influenced and controlled by internal and external means\textsuperscript{22}. An example of strict control and strong influence by external means is bed rest as prescribed by a physician. Bed rest as a therapeutic measure and as an opposite of physical activity, was invented in the 18\textsuperscript{th} century and somehow it was interpreted “that most patients should be put to bed, in many cases for an indefinite length of time”\textsuperscript{23}. Such regimens were widely used for arthritis patients but only in the 1970’s, less than four decades ago, questions arose about its efficacy\textsuperscript{24}. With or without bed rest, arthritis was often a crippling disease. Since the mid-1980s more effective drug therapies have become available for the treatment of arthritis and JIA and the understanding of their effect on the immune system has grown\textsuperscript{25}. We now know that the crippling effect is caused by ongoing inflammation and arthritis\textsuperscript{26}. As a result, bed rest as a treatment modality for JIA has (gradually) disappeared\textsuperscript{27}. However, it is our experience that up till now, many JIA patients are still forbidden by teachers, parents and even health care providers, to engage in more vigorous activities, although there is no evidence to do this. Once a myth is created it is hard work to abolish its influence. Therefore, to successfully improve PA one must successfully identify those influencable internal and external determinants of PA and incorporate them into an intervention which is safe, feasible and applicable to larger groups of patients. Chapter 7 describes and tested such an intervention aimed at improving PA in daily life in children with JIA and, in particular, aimed at improving moderate to vigorous PA. With the help of the Health Promotion Model of Pender mouldable determinants of PA behavior were identified and used to design an intervention. The basic assumption is that children with JIA are social actors, actively involved in dealing with a chronic disease. The active involvement is demonstrated in chapter 6 which showed that adolescents with JIA form dynamic and explicit illness perceptions towards their JIA. Chapter 6 also showed that some of the determinants of illness perceptions are related to functional status. Subsequently, chapter 7 showed that in those children with low PA levels, such an intervention can effectively improve PA levels.
Can performance improve capacity?
What is more important for gaining health benefits: PA or PF? What is the dose-response relationship between PA and health? What is the dose-response relationship between PF and health? What is the dose-response relationship between PA and PF? These are all important questions and most probably no definite answers can be given due to genetic individuality. The HERITAGE Family Study indicates that there are large individual differences in the magnitude of the effect of PA on the components of PF and that these differences are strongly influenced by genetic factors. The VO\textsubscript{2max} response to a standardized and controlled training program in a group of 481 adult sedentary individuals ranged from no gain to increases of more than 1.000 ml O\textsubscript{2}/minute whereby the individual differences where characterised by family aggregation. Teran-Garcia et al state that the proportion of people who do not show clinically meaningful improvements in response to regular exercise ranges from 10 to 40%. This heterogeneity in exercise response implies that non responders are always present in any training group. Besides this, the trainability of 8 to 12 year old children is far less compared to adults. Taking this in mind it is an important finding that as described in chapter 7 endurance time can significantly improve through a program aimed at improving PA. Normally a training program designed to improve aerobic fitness is closely structured, supervised and consists of a certain amount of workload during a minimal period of time. The disadvantage of such a program is that non responders (we assume 10 to 40%) will get frustrated and will fall out. Such a negative experience for a child might install sedentary behavior for the rest of their lives. We therefore advocate an approach based on self-efficacy whereby the child is in control and learns from positive experiences. Children with positive attitude and high self-efficacy towards PA are more likely to form intentions to participate in PA. A child with JIA must realise that PA and PF is important for his or her health and a program to achieve this can give direction and support. To encourage the public awareness of the importance of PA and PF, PA guidelines are launched all over the world. In 2005, an evidence-based PA guideline for school-aged youth was published in the USA, under the authority of the Centers for Disease Control and Prevention: “School-aged youth should participate daily in 60 minutes or more of moderate to vigorous PA that is developmentally appropriate, enjoyable, and involves a variety of activities”. This guideline recognises the necessity to take into account age, development, individual likings and the essential role of experience in PA. It may be therefore that the program, “Rheumates@work”, as described in chapter 7, has scored high on satisfaction by the participant patients.
Considering all the aforementioned, children with JIA (and children with chronic disease) should be encouraged to engage daily and in sufficient quantities, in a variety of developmentally appropriate physical activities which are enjoyable and sustainable. The skills and the attitudes to perform such a behavior can possibly be developed through internet-based programs. In addition, training programs, to improve exercise capacity, are needed for a selected group of patients.

Limitations of the thesis

It is assumed that PA and PF are beneficial for youth. However, benefits of PA and PF in youth are not easily tested by direct studies since the effect depends on life-long pathological processes that become only clinically apparent in (late) adult years\(^3\). Most evidence so far is based on prospective observational studies and it is not possible to conclude whether PA or PF is more important for health\(^3, 59\). Another limitation is the low number of included patients in some of the studies. In chapter 4, in which aerobic and anaerobic exercise capacity in adolescents with JIA is assessed, only 22 adolescents were included and therefore it was not possible to make strong assumptions regarding possible indicators of (lowered) aerobic and anaerobic exercise capacity. The study described in chapter 7, assessing the effect of an internet-based program to improve PA in children with JIA, has a small sample size of patients with low PA levels and therefore care should be taken to generalise its results. Therefore a larger study is needed. Another limitation is the method of assessing PA. PA is a complex behavior and it can be expressed and measured in different terms, all having their limitations. In this thesis a 3- and 7-day activity diary were used but in future studies additional methods such as activity monitors should be considered\(^40, 41\).

What have we learned: key findings

- Children and adolescents with JIA have reduced aerobic and anaerobic exercise capacity as compared with healthy controls

- Adolescents with JIA have reduced PA levels as compared with healthy controls

- The explicit views of adolescents with JIA are related to functional status
- “Rheumates@work”: an internet-based program, combined with four group sessions, is a feasible and promising intervention to improve physical activity in children with JIA with low PA levels.

**Recommendations**

Measuring aerobic and anaerobic exercise capacity and measuring physical activity should be part of standard care in the disease management of JIA patients. Training programs should be designed for those patients who fall under a critical threshold. Research is needed to determine such a threshold. The effectiveness of “Rheumates@work” has to be tested in a large multi-center trial and similar programs have to be developed for adolescent age groups. The effect of physical activity and physical fitness has to be studied in the long term, in particular in relation with work capacity, social participation, health and quality of life. Means of enhancing self-efficacy should be further explored and developed.

**References**


