Measuring physical fitness in persons with severe or profound intellectual and multiple disabilities
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Summary
Introduction

Physical fitness, physical activity and health are related in the sense that good physical fitness and a sufficient level of physical activity may improve both mental and physical health. In turn, good physical fitness and health may have a positive effect on wellbeing, participation, and quality of life.

Therefore, it is imperative to gain a comprehensive insight into physical fitness and physical activity levels of persons with severe or profound intellectual and visual (multiple) disabilities (SPIMD). These persons are at risk to develop health problems and are in danger of being excluded from many situations and opportunities usually available to people not suffering from intellectual disabilities (ID). However, due to limitations in intellectual functioning and adaptive behaviour on one hand, and visual and locomotor functioning on the other hand, the level of health-related physical fitness of persons with SPIMD is difficult to quantify in a feasible, valid and reliable manner. As a consequence, knowledge of the physical fitness levels and locomotor skills of persons with SPIMD is scarce.

Thus, the purpose of this thesis is to examine the feasibility, validity and reliability of physical fitness tests for persons with SPIMD.

Persons with intellectual disabilities

Four levels of ID can be distinguished: mild, moderate, severe or profound. Adults with severe ID have an intellectual age ranging from 3 to 6 years, which is likely to result in a continuous need for support. Adults with profound ID have an intellectual age below 3 years, which results in serious limitations in self-care, continence, communication and mobility.

When compared to the general population, persons with ID have twice as much health problems and significantly higher levels of co-morbidity such as epilepsy, neurological problems, visual or auditory impairment and locomotor disabilities. Moreover, the level of co-morbidity in persons with severe or profound ID is even higher than co-morbidity levels in persons with mild or moderate ID.

Research showed that persons with ID display inadequacies in perception, motor-reproduction and sensorimotor control. Furthermore, persons with ID are often not sufficiently active to achieve health benefits, and more than 50 % of the persons with ID of all age categories in Europe have a sedentary lifestyle. In addition, those classified with ID are more prone to experience lifestyle related diseases such as diabetes mellitus II or cardiovascular diseases. These persons often suffer from overweight or malnutrition. As a consequence, these persons may have poor physical fitness.

Physical fitness of persons with severe or profound intellectual and visual disabilities

Similar to individuals with ID, persons with visual impairments display poor performance on locomotor skills and have low levels of habitual activity, resulting in poor physical fitness when compared to the control group, in this case persons with normal eyesight.

Prevalence of visual impairment in persons with severe or profound ID is 92%. As the combination of ID and visual impairment is even more detrimental, thereby creating less opportunity for compensation, the combination of visual impairment with ID aggravates
problems in both locomotor skills as in daily functioning. These findings together put forward the suggestion that persons having SPIMD are likely to display insufficient physical fitness. However, the feasibility and reliability of physical fitness measurements and tests for participants with SPIMD have until now not been properly scrutinized, resulting in little reliable knowledge on the physical fitness levels and locomotor skills of persons with SPIMD. Due to the limitations related to SPIMD, the level of health-related physical fitness is difficult to quantify in a feasible, valid and reliable manner. Therefore, improving feasibility of physical fitness tests for individuals with SPIMD needs to be prioritized. Persons with SPIMD are not accustomed to assessments and have difficulty comprehending what is required of them. Furthermore, persons with visual disabilities cannot see how test tasks need to be performed, hence showing them how to perform the task at hand is useless. In general, if a participant does not understand the tasks within a certain test, the test will automatically fail to provide a realistic impression of the capabilities of the participant, rendering the test invalid. Thus, test instructions for persons with SPIMD require our special focus.

Another factor of influence when determining the feasibility, reliability and validity of physical fitness tests for participants with SPIMD is the prevalence of locomotor disabilities and motivational problems. As persons with SPIMD are not able to stand straight or to stand at all, adapted test procedures and specific inclusion criteria are required. Also, persons with SPIMD are often not motivated to exert themselves fully, which necessitates adjustments to and familiarization with test protocols.

The required attributes of physical fitness for persons with SPIMD described by caregivers, professionals and scientists in the field of SPIMD are: body composition, cardiorespiratory fitness, balance, muscle strength and muscle flexibility.

As stated before, the locomotor skills of persons with ID vary considerably and this may influence protocols for measuring physical fitness. Thus, next to the level of ID, persons with SPIMD are also grouped according to a motor function classification used to classify the locomotor skills in people with physical disabilities. In the studies examining a population consisting in majority of persons with severe intellectual disabilities, the term severe intellectual and multiple disabilities (SIMD) is used. In the studies examining a population consisting in majority of persons with profound intellectual disabilities, the term profound intellectual and multiple disabilities (PIMD) is used.
Aim and research questions of the thesis

The main aim of the research reported in this thesis is to examine the feasibility, validity and reliability of physical fitness tests for individuals with SPIMD. This research addresses the following research questions:

1. Are body composition measurements of participants with SIMD feasible and reliable [chapter 2]?
2. Are waist circumference measurements of participants with PIMD valid and reliable [chapter 3]?
3. Is cardiorespiratory fitness of persons with SIMD measured feasibly and reliably with either or both of two different walking tests? [chapter 4]?
4. Is a walking test performed on a treadmill feasible, valid and reliable for persons with SIMD [chapter 5]?
5. Is a balance test feasible and reliable for persons with SIMD [chapter 6]?
6. Are two tests to measure muscle tone and spasticity feasible and reliable when testing persons with PIMD [chapter 7]?
7. What is the level of physical activity of persons with PIMD based on heart rate patterns when compared to the American College of Sports Medicine guidelines of healthy physical activity? Is there a relation between heart rate patterns and observed level of activity in persons with PIMD? What is the influence of covariates such as gender, age, and common co-morbidity (motor disabilities, spasticity and sensory disabilities) on heart rate patterns [chapter 8]?

Body composition measurements

Anthropometric measurements are widely used to reliably quantify body composition and to estimate risks of overweight in both healthy subjects as in patients. However, information about the reliability of anthropometric measurements of persons with severe intellectual and visual disabilities is lacking. Chapter 2 addresses the feasibility and test-retest reliability of body composition measurements of persons with SIMD.

Test-retest reliability and feasibility for most measurements of persons with SIMD are acceptable. Skinfold measurements, however, could not be reliably performed with these participants. Therefore, assessing body fat composition in adults with SIMD through skinfold measurements is not recommended. Measuring tibia length and using the determined formula to calculate body height from tibia length is a reliable alternative for measuring body height. Although measuring body height of persons with SIMD as outlined in our protocol was feasible, the feasibility of performing tibia length measurements was much better.

Furthermore, our results indicate that according to Body Mass Index (ratio between body height and body weight, BMI) values, 10% of the female participants was obese while none of the male participants was obese. When waist circumference was used as a criterion, 39% of the female and 7% of the male participants was classified as obese.

Waist circumference measured in supine position

Waist circumference as an indicator of abdominal fat is an important predictor of health risks. In healthy participants, waist circumference is measured in standing position. It is unknown whether waist circumference can be measured validly and reliably when a participant is in a supine position. This assumption however is a critical one when international standards for healthy
subjects are to be applied to persons with profound intellectual, visual, and motor disabilities. Chapter 3 deals with the validity and reliability of measuring waist circumference of persons with PIMD.

The validity study performed with healthy participants, during which we compared waist circumference obtained in standing and supine positions, revealed significant differences between standing and supine waist circumference measurements. We found that the validity of supine waist circumference is biased towards higher values (1.5 cm) of standing waist circumference. However, standing waist circumference can be predicted from supine measurements using a simple prediction equation. This equation allows the comparison of supine measurements of disabled persons with international standards of waist circumference.

The test-retest study with PIMD participants, in which we measured the waist circumference of subjects in supine position, revealed no significant differences and showed good agreement between test and retest waist circumference values. It was concluded that supine waist circumference can be reliably measured in participants with PIMD.

**Functional exercise and aerobic capacity measured with over-ground tests**

Cardiorespiratory fitness can be divided into functional exercise and aerobic capacity. Timed walking tests are a valuable tool for assessing these components of physical fitness. However, feasibility, validity and reliability of walking tests for persons with SIMD are so far unknown. Chapter 4 seeks to address the issue of the cardiorespiratory component of physical fitness. Therefore, a study is put forward with the purpose of examining the feasibility and test-retest reliability of both the six-minute walking distance test (6MWD) as an adapted shuttle run test (aSRT) for participants with SIMD. SIMD participants performed the 6MWD and the aSRT twice while wearing a heart rate monitor.

The results show that the 6MWD is feasible and reliable for measuring functional exercise capacity of all participants with SIMD. The aSRT is feasible and reliable for measuring aerobic capacity of participants with the highest motor functioning level in the study population. In addition, we found that the participant’s motivational level can influence test outcomes, so we recommend to include both heart rate monitoring and motivational score into the protocols of the aSRT and 6MWD.

Furthermore, we compared the mean distance of the 6MWD as executed by our participants with values reported in other studies. This comparison indicated that persons with SIMD performed poorer on the 6MWD than those with other specific (chronic) health conditions including heart failure or COPD. The poor 6MWD results we observed suggest that a low functional exercise capacity of persons with severe multiple disabilities is a serious health problem, which in turn can burden their independence in day-to-day activities. Based on this result, further research should be aimed at developing, implementing and evaluating an appropriate intervention aimed at reducing health problems related to low functional exercise capacity and low aerobic capacity.
Aerobic capacity measured with a graded treadmill test

Exercise tests using treadmills are a valuable tool for assessing aerobic capacity. However, a treadmill protocol for persons with SIMD is not yet available. Chapter 5 examines the feasibility, validity and reliability of the adapted Shuttle Run Test performed on a treadmill by participants with SIMD.

Participants with SIMD performed the aSRT on a treadmill twice and a validity test was performed afterwards. Our results show that the feasibility, validity and test-retest reliability were sufficient for the aSRT on the treadmill when testing participants with SIMD. For determining peak heart rate of SIMD individuals, the validity of the aSRT on the treadmill was better than that of the aSRT performed over ground.

An equation used for estimating peak heart rate for people with ID systematically overestimates peak heart rate for people with SIMD. Therefore, it is recommended to adjust this equation in future research so as to enable a better prediction of the peak heart rate of this specific group.

Balance Scale

Sufficient balance is necessary to perform daily activities. Since the feasibility and reliability of balance tests are so far unknown for persons with SIMD, chapter 6 describes a study with the purpose of determining the feasibility and reliability of the modified Berg Balance Scale (mBBS) for this specific group.

Participants with SIMD performed the mBBS twice with a one week interval. The results show that the test-retest reliability of 10 out of 12 mBBS tasks is acceptable. The mBBS is thus a reliable test for evaluating the functional balance of persons with SIMD. Furthermore, the mBBS is a feasible instrument for the tested target group.

Tests to measure muscle tone and level of spasticity

The quality of daily movement depends partly on muscle tone or level of spasticity, which can be measured by the Modified Ashworth Scale (MAS) and the Modified Tardieu Scale (MTS). However, no research has been performed to determine the psychometric properties of the MTS and the MAS for persons with PIMD. The purpose of the study described in Chapter 7 was to determine the feasibility, the test-retest and interrater reliability of the MAS and the MTS in persons with PIMD.

Participants with PIMD were measured twice using both the MAS and the MTS, with a one-week interval between test and retest. Two observers performed the measurements.

The data indicated that the feasibility of the MAS and MTS for measuring muscle tone in persons with PIMD was good. For both test-retest and interrater reliability, measurements of the MAS revealed acceptable agreement. However, for both test-retest and interrater reliability, the measurements of the MTS showed insufficient agreement. The MAS may be a good method to evaluate the quality of daily movements of individuals with PIMD. A good instruction may contribute to a better reliability.

Heart rate patterns

Assessing physical activity levels of persons with PIMD is important, but these levels are difficult to reliably quantify when dealing with participants who are not able to walk. Heart rate monitoring
may be an indicator of activity levels, however, both the method of dating heart rate patterns as the correlation between heart rate and activity level for this specific group had so far not been subject to research.

Chapter 8 describes heart rate monitoring and heart rate patterns of persons PIMD. Furthermore, this chapter examines the relative activity of persons with profound intellectual and multiple disabilities when compared to the American College of Sports Medicine guidelines of healthy physical activity. It also looks at the correlation between heart rate patterns and level of activity of this specific target group. Finally, the influence of covariates such as gender, age, and common co-morbidity on heart rate height are examined and participants are classified according to heart rate height during physical activity.

Using a heart rate monitor, heart rate patterns were measured 8 hours during 6 days. Heart rate intensity was calculated using heart rate reserves. Physical activity levels were also measured with questionnaires filled out by the caregivers of the participants.

Our study shows that persons with PIMD are not sufficiently physically active based on the guidelines of American College of Sports Medicine. Time of day and age have considerable influence on heart rate patterns. We observed four classes in heart rate patterns of persons with PIMD.

**Discussion**

Chapter 9 summarizes the main findings of this research and puts them in perspective. The most important results are mentioned and discussed against the background of other research. The main products of this thesis are feasible, valid and reliable tests of physical fitness for persons with SPIMD, which can directly be implemented into daily practice. The main conclusion is that persons with SPIMD are able to learn and become accustomed to test and measurement situations if an optimal test environment is created. Various tested ways to enhance test environment are described, and suggestions for further possible enhancement of test conditions are put forward. Furthermore, this thesis has brought forth a couple of important findings regarding formulas or equations applicable to research on this specific target group.

The benefit of combining both severity of ID and GMFCS level to classify the abilities of persons with severe or profound ID is once more underscored. Moreover, the steps necessary to explore the concept of participation for persons with SPIMD as well as the relation between participation and physical fitness, activity and health are described.

Finally, methodological issues are discussed, followed by the implications for clinical practice and recommendations for further research. The main recommendation of this research is to develop, perform and evaluate tailored interventions with the aim of promoting components of physical fitness and participation for individuals with SPIMD.