An evidence-based Physical Activity and Fitness Programme for Ageing Adults with Intellectual Disabilities

development, implementation and health effects

Marieke van Schijndel-Speet

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An evidence-based Physical Activity and Fitness Programme for Ageing Adults with Intellectual Disabilities

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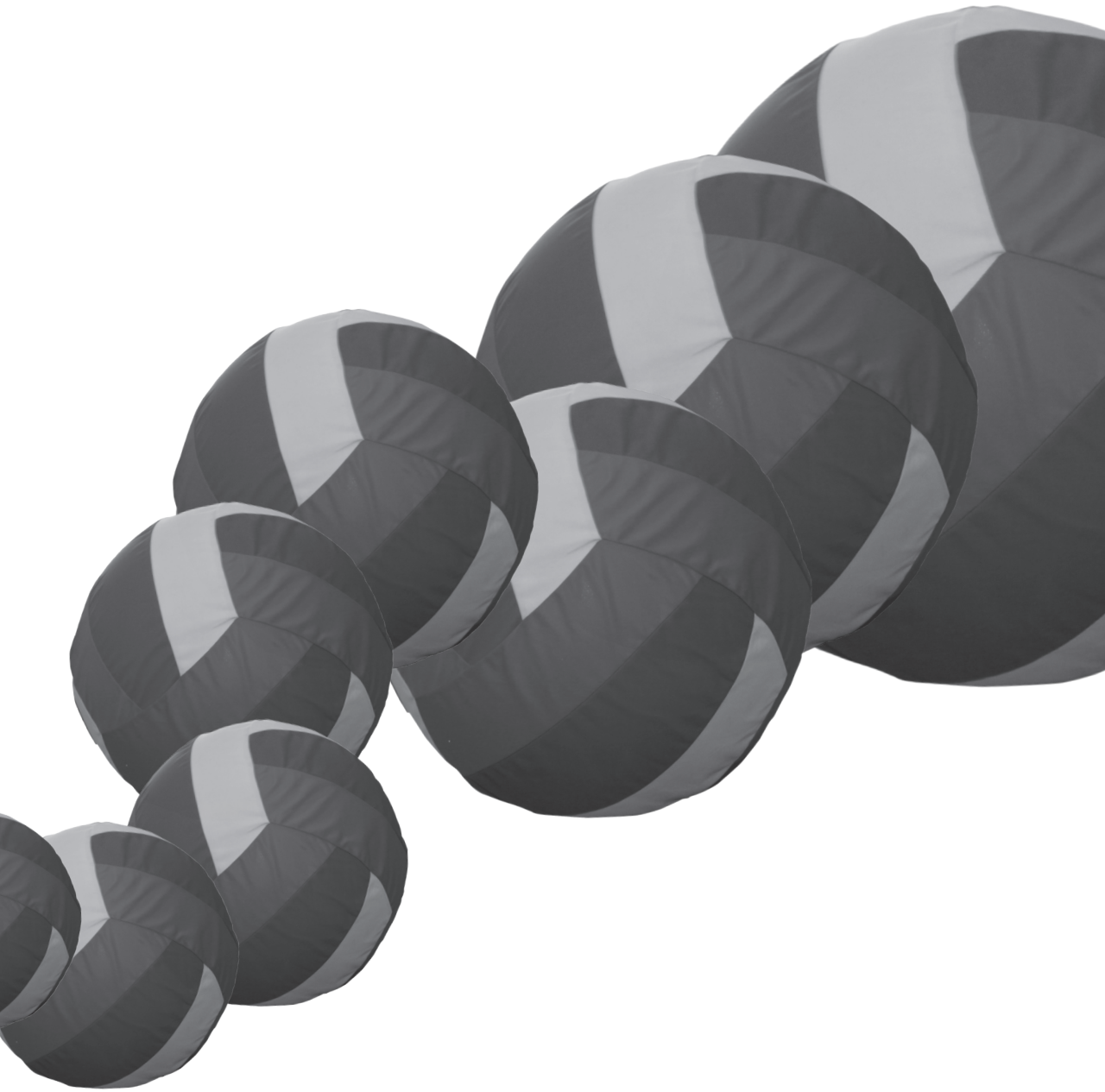
GENERAL INTRODUCTION



GENERAL INTRODUCTION

Regular physical activity is important to everyone. It is associated with enhanced health and reduced risk of all-cause mortality [1-5]. For older adults, physical activity plays a central role in the prevention and management of chronic disease and has potential to reduce physical decline, maintain functional ability and prevent injuries [6]. However, of Dutch older adults with intellectual disabilities, i.e. with IQ levels below 70 before the age of 18 and limitations in adaptive behaviour [7], a large majority has a sedentary lifestyle [8] and fitness levels comparable to those in the general population aged 80 years and over [9], contributing to increased prevalences of obesity, diabetes, metabolic syndrome and other health risks [10]. The aim of this study was to develop and evaluate a programme to increase physical activity and fitness among older adults with intellectual disabilities, taking their physical and mental disabilities into account.

AGEING PEOPLE WITH INTELLECTUAL DISABILITIES

The prolonged lifespan of people with mild intellectual disabilities (IQ <70-50), but also people with moderate (IQ 50-30) and severe intellectual disabilities (IQ<30) has led to an increasing number of older people in this group [11]. Results from the Healthy Ageing- with Intellectual Disabilities study (HA-ID) [12] demonstrate that this ageing mostly is not a healthy ageing. High prevalences of cardiovascular risk factors [13], sensory impairments and motor impairments [14-16], chronic multimorbidity [17], depression [18] and frailty [19, 20] do not only form a risk to their well-being and quality of life, but also have a major impact on healthcare costs.

PREVENTION THROUGH PHYSICAL ACTIVITY PROGRAMMES

Many studies in the general population focused on the effectiveness of physical activity for health, also specifically among older adults. Exercise training has the potential to develop and maintain strength, flexibility and cardiovascular fitness among older adults in the general population [21]. These fitness components are important for mobility and performing activities of daily living [22]. In addition, regular physical activity has proven to reduce the risk of cardiovascular disease [23], stroke [24], non-insuline-dependent diabetes (type 2)[25], colon cancer [26], osteoporosis [27] and depression [28]. The American College of Sports Medicine and the American Heart Association provided evidence- based recommendations for physical activity by older adults aged >65 yrs and by adults aged 50 to 64 years with clinically significant chronic conditions and/or

functional limitations, aimed at health maintenance [21, 29]. The importance of physical activity for health has also been recognised in the field of people with intellectual disabilities. Epidemiological research among this subgroup demonstrated very low levels of physical activity, despite of the fact that only a relatively fitter group could be included in the analysis [8, 30]. Nevertheless, only few well-designed studies with a substantial amount of participants have evaluated the health-related effectiveness of exercise training among people with intellectual disabilities [31, 32]. Most of these studies involved children and younger adults with mild intellectual disabilities; only few studies included older adults with intellectual disabilities [33, 34]. Results demonstrated that improvements in motor and cardiovascular fitness can be achieved. Guidelines evaluated for this group, regarding the frequency, duration and intensity of exercise, are lacking.

IMPLEMENTING REGULAR PHYSICAL ACTIVITY IN DAILY LIFE

The scientific evidence for the effectiveness of physical activity for health benefits has not resulted spontaneously in increased physical activity levels of (older) people with or without intellectual disabilities. Implementing physical activity in daily living has become a new research area, including the development of theoretical frameworks for behaviour change [35]. Beneficial effects of behaviour change techniques to increase physical activity and, which may even be more important, to maintain the new attained level of physical activity in daily living, is being investigated [36, 37]. Strategies implemented in physical activity interventions targeting older adults include health education, goal setting strategies, enhancing social support, improving self-efficacy, improving self-monitoring, stimulating active choices, health contracts, assurances of safety, positive reinforcement, relapse prevention, feedback, problem solving [38-40]. However, more research is needed to demonstrate the beneficial effects of such strategies [41]. Discussions address the need for specific techniques for specific subgroups: interventions including behavioural change techniques should be tailored to subgroups' or individuals' preferences and living situation.

THE NEED FOR A NEW PROGRAMME FOR AGEING PEOPLE WITH INTELLECTUAL DISABILITIES

Although increased knowledge and evidence are available about the content of physical activity programmes, including behaviour strategies for older adults in the general population, this information is not directly applicable to older adults with intellectual disabilities. We expected that within this target group, other determinants for physi-

cal inactivity than in older adults without intellectual disabilities could be important, because of physical problems (e.g. regarding balance, mobility or strength), cognitive limitations, different living situations and often limited experience with physical activity [9, 42]. In addition, the social networks of older adults with intellectual disabilities are often smaller than the network of their younger peers [43]. As such they may be less stimulated or supported to engage in physical activities. Knowledge about effective strategies that appropriately address the unique needs of older adults with intellectual disabilities, in order to promote regular physical activity, is lacking [30-32]. Therefore, the Intellectual Disability Medicine research group of the Erasmus University Medical Center Rotterdam and the Center for Human Movement Sciences of the University Medical Center Groningen, decided to develop and evaluate a new physical activity programme for older adults with intellectual disabilities, in a collaboration with three Dutch intellectual disabilities care provider services: Ipse de Bruggen (Zoetermeer), Amarant (Tilburg) and Abrona (Huis ter Heide).

STUDY AIMS AND CONTENTS OF THIS THESIS

The aim of this study was to systematically develop a day-activity programme for older adults with mild and moderate intellectual disabilities to improve their regular physical activity level and to improve or maintain their physical fitness and health. The programme's feasibility and effectiveness have been evaluated. For the development of the programme, we were inspired by the Intervention Mapping Protocol of Bartholomew et al [44] that distinguishes a six-step procedure for theory-based and evidence-based development of health promotion interventions. We first explored barriers and facilitators for physical activity among older adults with intellectual disabilities. Results of this qualitative study are described in Chapter 2. The development and final content of the programme are described in Chapter 3, including the plans for evaluation and implementation.

To gain insight in the programme's implementation, process evaluations were performed. In Chapter 4 we describe the compliance to programme's framework, and the programme's applicability and feasibility according to participants and programme leaders. The heart rate increase of people with intellectual disabilities in response to physical activity and exercise differs from the cardiac response of people without intellectual disabilities [45, 47]. In Chapter 5 we describe the heart rate of participants during the exercise sessions and explore its association with improvement on aerobic performance.

Physical activity was considered the primary outcome measure of the intervention and measured with pedometers. However, a substantial amount of participants

appeared to walk very slowly, so a specific measurement instrument was required to measure and evaluate their physical activity. To that end, we validated the StepWatch Activity Monitor for this group (Chapter 6).

The programme's effectiveness was evaluated using a cluster randomised clinical trial design. Chapter 7 describes the programme's effectiveness on physical activity, fitness and health.

Finally, Chapter 8 provides an overview of the main findings of this thesis. Implementation of the programme and the steps needed to achieve that goal will be discussed.

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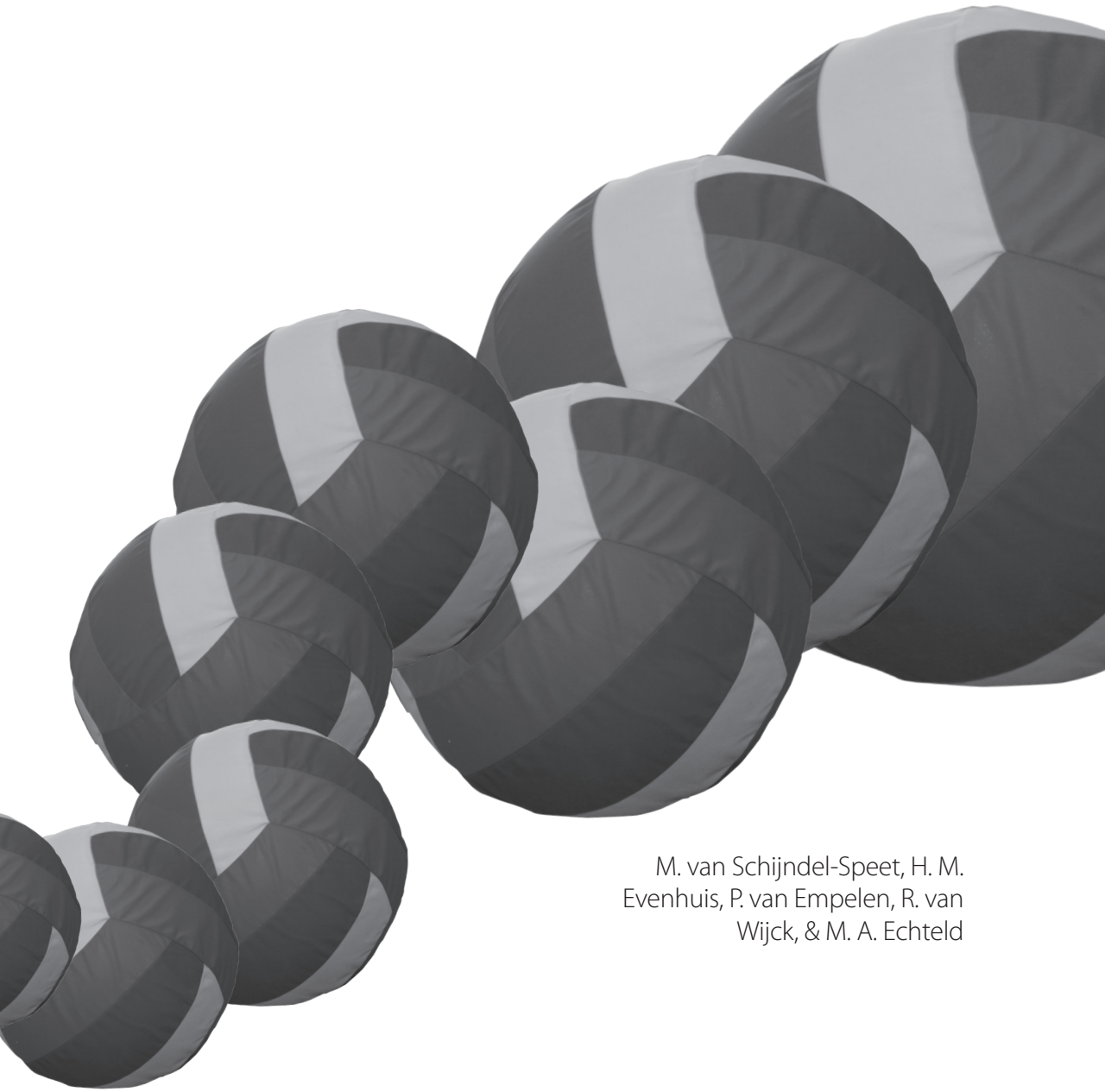
2

FACILITATORS AND BARRIERS TO PHYSICAL ACTIVITY AS PERCEIVED BY OLDER ADULTS WITH INTELLECTUAL DISABILITIES



M. van Schijndel-Speet, H. M. Evenhuis, P. van Empelen, R. van Wijck, & M. A. Echteld

ABSTRACT

Older people with intellectual disabilities (ID) are characterised by low physical activity (PA) levels. PA is important for reducing health risks and maintaining adequate fitness levels for performing activities of daily living. The aim of this study was to explore preferences of older adults with ID for specific physical activities, and to gain insight into facilitators and barriers to engageing into PA. Fourteen in-depth interviews and four focus groups were undertaken, with a total of 40 older adults with mild and moderate ID included in the analysis. NVivo software was used for analysing the transcribed verbatim interviews. In total, 30 codes for facilitators and barriers were identified. Themes concerning facilitators to PA were enjoyment, support from others, social contact and friendship, reward, and familiarity and routine of activities. Themes concerning barriers to PA were health and physiological factors, lack of self-confidence, lack of skills, lack of support, transportation problems, costs, and lack of appropriate PA options and materials. The results of the present study suggest that older adults with ID may benefit from specific PA programmes, adapted to their individual needs and limitations. Results can be used for developing feasible health promotion programmes for older adults with ID.

INTRODUCTION

Being physically active is universally acknowledged as an important factor for health and well-being. Regular moderately intensive physical activity has protective effects for several chronic diseases, including coronary heart disease, hypertension, non-insulin dependent diabetes mellitus, osteoporosis and colon cancer [1]. It is specifically important for the prevention and reduction of falls and functional limitations in older adults, and for maintaining muscle strength, independent living, mental and social well-being [2-4]. The World Health Organisation (WHO) recommends adults, including older adults, to be moderately physically active at least five days a week for a minimum of 30 minutes a day [5].

However, many individuals with intellectual disabilities (ID) are physically inactive [6, 7] and their fitness levels are low [8, 9]. The proportion of adults with ID who comply with the WHO guideline ranges from 17.5 to 33% [7]. In addition, at least 39% of older adults with ID walk less than 5000 steps per day [10], which can be categorised as having a sedentary lifestyle [11]. Immobility, sarcopenia and frailty form serious threats to this sedentary population as they negatively influence the older adults' health and quality of life [12]. Although the participation of people with ID in activities developed for the general population increased since the last decade, many people with ID still are not able to participate in such activities, as a result of physical and cognitive limitations, insufficient staff for assistance, and structural factors such as financial and transportation problems [13-16]. Although the importance of increasing the physical activity level of people with ID has been widely recognised, knowledge about effective strategies that appropriately address the unique needs of older adults with ID to accomplish this objective is lacking [17-19].

The development of such interventions requires insight into facilitators and barriers to physical activity for this group. Research has provided such information about younger adults with ID [8, 19] and about older people in the general population [20-24], but not about older people with ID. We expect that within this target group, other determinants for physical inactivity that differ from those for other groups will be emphasised, because of physical problems (e.g. regarding balance, mobility or strength), cognitive limitations, different living situations and often limited experiences with physical activity [9, 25]. In addition, the social networks of older adults with ID are often smaller than the network of their younger peers and include less relatives [26].

Therefore, our purpose was to explore preferences of older adults with ID for specific physical activities, facilitators, and barriers to physical activity. Research questions are: 1) In what kind of physical activities do older people with mild and moderate ID participate? and 2) What barriers and facilitators do older people with mild and moderate ID perceive with regard to participation in physical activities?

METHODS

This was a qualitative interview study based on interviews and focus groups. It was part of the development of the programme in the study: "Healthy Ageing- Physical Activity Programme" (HA-PAP), for which ethical approval was obtained (number NL29573.078.09) from the Ethics Committee of the Erasmus Medical Center at Rotterdam, The Netherlands.

Participants

Fourteen people aged 50 years and over with moderate or mild ID were selected for individual interviews in seven day-activity centers of three Dutch care provider services for people with ID. We expected this amount of interviews to be sufficient to achieve saturation of the data. If not, additional persons could be selected. Managers were asked to select persons aged 50 years and over who walked independently, who walked with aids or were dependent on a wheelchair, who liked being physically active or who disliked being physically active. Preference was given to persons who were likely to enjoy participating in interviews. The day-activity centers' staff explained the purpose of the interview to the potential respondents and invited them to participate. All 14 invited persons were willing to participate in the interviews. Information about the participant characteristics was provided by the managers.

In the interest of the Healthy Ageing study, four groups of older adults with ID were set to provide information about the research topics in focus groups. These groups, which were chosen from different geographical locations, consisted of members of client boards of the three participating organisations. Support workers who coached these client boards were also involved in the construction of the groups. They explained the purpose of the groups and invited the clients aged 50 years and over to participate. In total, 26 clients signed up to participate and were consulted for the current study in the focus groups to gain information about barriers and facilitators to physical activity. The four focus-group interviews were conducted with 5-11 participants per interview. Information about the participants' characteristics was provided by the support workers.

The 40 interview and focus group participants ranged in age from 50 to 80 years (see Table 1). Most participants (n=28) had mild ID. Seven used a walking aid, and four used a wheelchair. Participants received support in their living situation from ID-care organisations and mostly participated in activities organised by day-activity centers.

Materials

In both interviews and focus groups, the interviewer started with general questions about the respondents' physical activities. Subsequently, questions were asked about respondents' positive and negative experiences with their physical activities, in order

to gain insight in experienced facilitators and barriers. For example we asked what the respondents liked or disliked about the activities they performed. Because in earlier research the importance of social support and physical barriers for participation in physical activities was emphasised [13, 15, 16, 25, 27, 28], we specifically drafted questions about these concepts. For example, we asked whether the older adults received support from others to perform physical activities and whether they suffered from physical complaints when they performed physical activities. The support workers were asked to check terminology appropriateness of the questions using their professional experiences with the target group. The core questions and prompting questions used in the interviews are presented in Table 2.

Table 1: Characteristics of participants in the interviews (n=14) and focus groups (n=26).

Participants characteristics	**I**	**F total**	**F1**	**F2**	**F3**	**F4**
n	14	26	5	8	9	4
Age (mean)	60.6	61.5	64.4	59	59.3	67.5
Male Gender	5	9	3	5	0	1
Intellectual Disabilities						
Mild Intellectual Disabilities	6	22	5	8	9	0
Moderate Intellectual Disabilities	8	4	0	0	0	4
Mobility						
No walking aid	10	19	4	7	8	0
Walking aid	4	3	0	0	1	2
Wheelchair	0	4	1	1	0	2

I= Interviews; F= focus groups

Procedure

Fourteen individual semistandardised interviews and four semistandardized focus group interviews were undertaken. The individual interviews provided the opportunity to gain information about preferences for or barriers to physical activity. The advantage of focus groups is that participants can interact, which can lead to a broader range of information about the study's subject. In addition, this method makes it possible to explore related but unanticipated topics as they arise in the course of the groups' discussion [29].

The individual interviews were conducted onsite in the activity center by the first author, who is experienced in interviewing people with ID. If necessary, a staff member was present if the respondents' pronunciation was not clear for someone who did not know him or her well. The individual interviews lasted between 15 and 30 minutes; in two interviews a staff member was present. Most respondents were a little anxious about the interview but felt more at ease after a cup of coffee and a general 'warming up' talk about their living situation and daily activities. The researcher explained the purpose of the interview and asked permission to tape the conservation with an audio recorder.

Table 2: Key questions and prompts about physical activity asked in interviews and focus- group interviews with older adults with intellectual disabilities.

Key question	*In what physical activities do you participate?*
Prompts	How do you go to your work? What work do you do? What do you do in your free time in the evening and weekends? Do you help in housekeeping activities?
Key question	*What physical activities do you like most?*
Prompts	What do you like about…..?
Key question	*What physical activities do you dislike?*
Prompts	What do you dislike about .....
Key question	*Do you perform physical activities with others or alone?*
Prompts	Do you like to perform physical activities with others? Do you like to perform physical activities alone?
Key question	*Do people help you performing physical activities?*
Prompts	How do they help you? Would you like some (more) help with performing physical activities*?*
Key question	*Do people encourage you to be (more) physically active or not?*
Key question	*Do you have physical complaints when you are physically active?*
Prompts	Do these complaints make it difficult for you to perform physical activities or not?
Key question	*Would you like to be more physically active or not?*
Prompts	No: Why not? Yes: What activities would you like to do?
	Is there something else you would like to say about physical activity?

Not all questions were posed in each interview, and depending on the answers of the respondents, some subject was given more attention than others to gain more in-depth information about those subjects. Respondents received a little present to thank them for their participation.

The support workers participated in preparing and conducting the focus group interviews. They checked the appropriateness of the terminology of the questions using their professional experience with the target group and provided pictograms that were used to support the discussion. Before the start of the focus group discussions, the support workers communicated with the respondents about the content, time and location of the interviews. The support workers were trained by the researcher to participate as second mediators. The first author served as principal mediator and played a key role in ensuring that the core questions and prompts were covered. The second mediator supported the principal mediator to explain or rephrase the question to participants if needed and ensured that everyone was included in the discussion. The focus groups took place at the day-activity center. Because the support workers were familiar with the respondents, they could help them to feel at ease. The focus group discussions were video- and audio-recorded. A researcher, took field notes. The duration of the focus group interviews ranged from 70 to 95 minutes.

Analyses

The interviews and focus group discussions were transcribed verbatim by a researcher and two secretaries, who were well instructed by the researcher to write down literatim what was said in the interview by both the interviewer and respondents. If the quality of the audiotape was not sufficient for transcription of the focus groups, the videotapes were used. If a transcriber could not hear a sentence clearly enough, the transcriber placed a remark. The researcher checked these remarks by listening to the audiotape and/or the videotape again. Then the correct text was written down, or, if the sentence remained unclear, it was not transcribed and excluded from the analysis.

To indicate preferences for physical activities and the facilitators and barriers to physical activity, one researcher started the process of coding using Nvivo software (QSR NVivo software 8). Each text fragment- sometimes containing one sentence about one topic and sometimes five to six sentences- was given a code. The first author and two colleague researchers independently coded the text fragments of two interviews. A peer review was undertaken to compare the codes of the three coders. Subsequently, the first author coded the other interviews. New codes were defined until saturation of the data was achieved [29].

After open coding was completed, data were organised by the use of coding frames [29]. Following van Stralen et al. (2010), we clustered determinants of physical activity into four coding frames: 1) social and cultural determinants, 2) psychological determinants, 3) personal determinants, 4) physical environmental determinants. We applied these four coding frames, because they give direction to the nature of strategies that can be developed as part of a physical activity intervention [20]. In addition, a distinction was made between facilitators and barriers.

The interviewees were often not able to explain what they specifically liked or disliked about a certain activity, which made clustering of the codes not always easy. For example: 'coffee break' was one of the answers to the question about what the interviewees liked about a certain activity. Therefore we assigned this label to the coding frame: 'physical activity and preferences', although it could also have been clustered within the coding frames: 'psychological determinants' or 'social and cultural determinants'. Thus we chose the coding frame that was most directly linked to the context in which the determinant was described by the respondent.

Two medical students, a co-author and the first author clustered the codes independently and subsequently discussed the results and differences in cluster process.

Most of the codes appeared in both interviews and focus groups. Because the aim and the interview schedule used were comparable for both interviews and focus groups, we judged that possible differences in results from the two methods do not have an impact on the interpretation of the results. In favour of the readability of this manuscript, we

therefore made no distinction between codes revealed in interviews and codes revealed in focus groups when describing the results of this study.

RESULTS

Physical activities and preferences

The older adults participated in various physical activities. Walking was the most cited activity, but dancing, gymnastics for older adults, cycling, cycling on a home trainer, swimming and household activities were also frequently mentioned. Participants walked and cycleed to their work and for fun in their free time. Other activities were mostly part of the participants' day-activity programme, provided by the care provider services. Enjoying or disliking an activity were coded as separate facilitator and barriers for being physically active (see Table 3). It appeared that music made it fun to be active. Several interviewees liked dancing, individually or in a group. Disco dancing or folk-dancing were frequently cited as favorite activities. In addition, making music with others and singing appeared to motivate interviewees' participation in physical activity. Some examples of remarks about music:

Table 3: Facilitators and barriers to physical activity (PA), clustered by factor.

Code frame	Facilitators	n	Barriers	n
Personal factor			Being tired quickly	6
			Physical discomfort	16
			Physical limitations	14
			Pain	12
			Dependence on staff	11
			Road safety	6
Psychological factor	Enjoy activity	51	Dislike activity	23
	Body feels good and flexible	8	Fear of falling	16
	Relaxed, gives energy	6	Dislike feeling tired	14
	Good for health	2	Too difficult	16
	Useful activity	8	Useless activity	3
	Familiarity/routine	3	Retirement and relaxation	1
			Feeling insecure social context	5
Social and Cultural factor	Staff /family support PA	37	Staff members inhibit PA	2
	Pleasant atmosphere	2		
	Activity with others	32		
	Reward	3		
	Status of activity	4		
Physical environmental factor			Bad weather	5
			Transfer	1
			Money	5
			Transportation	2
			Lack of time staff	3

Participant 1: Music makes me happy.

Participant 2: I like to dance. If I know all the songs very well.

[When participant 3 is on a home trainer] I put on a CD. That is important. To put on the music when I cycle.

Walking, cycling and gardening were favorite activities, mostly because the participants enjoyed being outside. Some told us that these opportunities were limited, because they were not allowed to go outside without accompaniment. Also household activities, especially doing the groceries, were appreciated activities. The opinions about swimming and about gymnastic games for elderly varied. Some loved being in the warm water, others were afraid of drowning. Four older adults mentioned explicitly that they did not like throwing a ball because they found this difficult or stupid. Three participants did horseback riding and they loved the contact with the animals. The necessary change of clothes to perform an activity was not appreciated and could be a barrier to becoming physically active. Several older adults did not mention features of the activity itself, but the coffee and cigarette breaks in between as their favourite part of the activity.

FACILITATORS AND BARRIERS TO PHYSICAL ACTIVITY

In total, 30 labels for facilitators and barriers were identified (see Table 3). No new labels were indicated after analysing the ninth interview, which implies that saturation of the data was achieved. Several citations are added to provide insight into the level of the information that was provided by participants and to provide more detailed information about the described labels.

Psychological facilitators

Interviewees noted that they liked a certain activity, because they enjoyed participating in it. Three participants mentioned that they performed a certain activity simply because it was part of their day programme. Disruption of the programme, for example because staff is on vacation, is not appreciated.

Others performed so-called useful activities and liked them because it enabled them to help others, such as walking with someone in a wheelchair, cycling to the reception to get the mail or household activities.

Man, 58 years old, mild ID, walks independently. Works in neighborhood where mainly older people without ID live.

Interviewer: Does someone do activities in the garden*?*

Participant: I keep the neighborhood clean. I sweep and I pick up rubbish.

Interviewer : Do you like to do that?

Participant: Nahh like it…… that's not the word. I just want to keep it clean!

Interviewer: That's a nice task.

Participant: Yeah, the oldies like it. They like that I keep their neighborhood clean.

Four older adults said that they did physical activities because it was good for their body, their health and weight. Others were aware of the positive effects of physical activity on their body, such as feeling more flexible, relaxed, energetic and cheerful, and mentioned this with the context why they liked to be physically active.

Social and cultural facilitators

Support from staff or relatives who stimulate physical activity was considered an important facilitator for physical activity. Four older adults with ID noted that they liked walking or cycling together with family members in the weekend. Staff also supported physiotherapy exercises, which had to be executed at home. Two interviewees considered an activity to be fun because of a specific staff member who guided the activity.

Male, 52 years old, moderate ID, walks independently but with limitations.

Participant: In the morning I do exercises.

Interviewer: In the morning you do exercises. For physical therapy?.

Participant: Yes, for my back.

Interviewer: Do you have back complaints?

Participant: Now and then…..now and then it is. Don't carry things!!!! That's what …[physical therapist] says. Do your exercises!

Interviewer: Do you do your exercises with help from your staff*?*

Participant: I do them alone, but the staff is watching.

Receiving a reward for participating in physical activities (e.g. a medal), made older adults with ID proud of their performance and feeling valuable to others. Some physical activities were categorized as 'cool' activities such as Nintendo Wii, Bowling, and billiards. Performing physical activities with peers in a pleasant atmosphere also made it more fun to participate.

Personal barriers

Participants mentioned that they were confronted with physical discomfort, such as being tired quickly and having pain. Increasing physical limitations hampered them to perform certain physical activities they were used to, such as cycling and horseback riding. Risk of falling also played a role within this context (see next paragraph). Unfortunately, according to the interviewees, these activities were not always replaced by more appropriate activities. Participants who lived in the community spoke about their dependency on staff to go outside, because of the traffic or risk of falling.

Woman, 72 years old, mild intellectual disability, walks with aid

Interviewer : I used to walk very often. We went to the park.

Participant: Don't you walk anymore?
Interviewer: No. I have problems breathing. I can't walk far. It is such a shame I can't go walking anymore. Now staff members sometimes walk with me in the hallway.

Psychological barriers

Whereas participants liked certain activities, they disliked others, sometimes without being able to articulate why they did not like the activity. Three older adults did not want to participate in game-like activities that are specifically organised for older individuals with ID, such as passing a hoop around, because they did not see their usefulness or thought the activities rather dull. Also, cycling on a tricycle was not attractive for everyone: " I really would like to cycle again, but I am afraid to fall. And I don't want to cycle on a stupid tricycle".

Several older adults thought they were not able to perform certain activities because these were too difficult for them or because they were afraid to fall. They did not want to look stupid or being laughed at by others (see code in Table 3: feeling insecure social context).

Uncomfortable feelings that co-occur with being active, such as getting tired and sweaty, were not appreciated. "When I get tired, I quit the activity". One participant said she would retire soon and from that point onwards she would relax all day.

Social and cultural barriers

Staff members did not always seem to encourage older adults with ID to be physically active. Indeed, according to some older adults, they told their clients to relax and take it easy, because of their age.

Physical environmental barriers

Lastly, we identified some physical environmental determinants that hamper physical activity for older adults with ID. Like most of us, they did not like walking in bad weather. Moreover, they did not appreciate a transfer to another location where the activity took place.

When older adults were dependent on a taxi to go to an activity, taxis often arrived too late or too early, which caused a lot of stress and discomfort. Besides, transportation entailed costs, that most of the older adults could not afford. Lack of money sometimes forced older adults to stop an activity they enjoyed very much. Mentioned examples were activities, organised in the community -and thus more expensive- such as horseback riding, bowling and fitness. Three older adults told us they wanted to tandem bike, but the problem was that they had none. One participant noted: "I had a bike. But since I moved, I do not have a bike anymore. I had to leave my bike behind. I loved cycling. Now I have no hobby" .

As mentioned before, participants told us they were dependent on staff or their relatives to go outside or to take part in an activity. However, staff members did not always have enough time to support them in physical activities.

Woman, 72 years old, moderate intellectual disability, wheelchair dependent

Participant: You have to be patient.

Interviewer What do you mean?

Participant: You have to be patient. Staff members never have time to walk with you, to go outside. They always write and sit in their office.

DISCUSSION

This qualitative interview and focus group study provides insight into preferences as well as facilitators and barriers to physical activity among older adults with ID.

Participants frequently mentioned walking, dancing, gymnastics for older adults, cycling, cycling on a home trainer, swimming and household activities as preferred activities. They especially enjoyed activities with music and outside activities, and coffee breaks were also appreciated. Indentified psychological facilitators for participating in physical activity are a) enjoyment, b) perceived benefits for physical comfort, c) knowledge about benefits for health, d) physical activities as part of the daily routine, and e) being active for a useful purpose. Social support from relatives, staff and peers seems to be a prerequisite as well as a motivation for many older adults to perform physical activities. It was appreciated when staff members create a pleasant atmosphere in which people with ID feel at ease. For some older adults, activities with a certain status (activities that are popular in the group) were more appreciated, for example Nintendo Wii or Billiard. Receiving a reward and positive feedback from others may contribute to the participants feeling proud and appreciated.

Older adults reported physical complaints such as feeling tired more quickly, having less energy to become active, and sometimes being afraid to fall. Participants told us that they received support from others to perform physical activities. In addition, they often needed help to replace activities that became infeasible, such as horseback riding or cycling, by more appropriate ones, such as cycling on a tricycle or walking. However, some staff members seem to be concerned about their clients being active and, according to participants in our study, even discouraged them to be more active. Barriers such as a lack of self-confidence, fear of activities being too difficult, and fear of falling, prevented older adults with ID from engageing in activities. These psychological barriers seem to negatively influence the belief that they are able to perform the activities. Finally, physical environmental barriers, such as transportation problems and costs, seemed to influence participation in physical activities negatively. Older adults with ID

are often not able to use the road safely, have to deal with mobility problems, and have a high risk of falling [30]. Moreover, older people with ID in general have less contact with their relatives than younger adults with ID. Most of their parents have died, and brothers and sisters are not always committed to their relative with ID or do not live nearby [31-33].

In conclusion, factors that make older adults with ID happy, comfortable and self-confident, may positively contribute to their participation in physical activities. The lack of preconditions, such as support from others, transportation, suitable activities, and appropriate materials can prevent older adults from being physically active. Also, physical and psychological limitations were mentioned within the context of barriers to physical activity.

Comparison with younger adults with ID and older adults without intellectual disabilities

A substantial number of factors identified in this qualitative study correspond with facilitators and barriers found by research in (younger) adults with ID [9, 13, 15, 16, 25, 27, 28] and by research in older adults without ID [20, 22, 34, 35]. Facilitators to physical activity were support from others, social contact and friendship, positive feedback and reward, familiarity and routine of activities and having fun. Barriers to physical activity were health and physiological factors, lack of self-confidence, lack of skills, lack of support, transportation problems, costs of physical activity and lack of appropriate physical activities and materials. Factors that were identified in these populations, but not in the current study, involve factors concerning information-related barriers and knowledge and skills of the professional coaches [20, 35]. We hypothesised that these barriers may indeed be applicable to older adults with ID as well, but are beyond the scope of the target population.

However, the results of this study highlight some elements that are specifically important when promoting physical activity among older adults with ID, as compared to younger adults with ID and older adults without ID. Support by family of older adults with ID is often not available. More than younger adults with ID and older adults with normal intelligence, older adults with ID are dependent on professionals to stimulate or support them in being physically active. Staff members could receive training to increase their awareness of the importance of sufficient physical activity for older adults with ID and to consider support of physical activity as their responsibility [7, 25, 36]. Secondly, older adults with ID are in need of suitable activities, adapted to age-related decrease of physical functioning, which in this group starts at younger age compared to older adults without ID [12, 37]. Physical limitations such as balance and coordination problems, decrease in mobility and muscle strength [38] and pain, combined with limited understanding and often limited experiences with physical activity [25] indicate

a need for professional support to create a safe environment and to choose appropriate activities for the target group.

In conclusion, physical decline at younger age, life-long multi-morbidity [39] and dependence on staff to be physically active probably place older adults with ID at risk for low physical activity levels compared to younger people with ID and older adults without ID. The results of the present study suggests that older adults with ID may benefit from specific physical activity programmes, adapted to their individual needs and limitations.

Strengths and limitations of the study

The strength of this study was that a self-report paradigm was used, allowing clients' personal views to be obtained instead of proxies for clients' personal views. An elaborate qualitative design was used to capture these personal views. Relatively few people with ID are able to read and write and to fill in written questionnaires. Therefore the most appropriate method to gain subjective information from people with ID is interviewing [40]. Data about the clients' personal views were obtained, using a careful qualitative design. Participants with varying levels of mobility and in various age groups were included in the study, which supports the diversity of the findings. The comprehensiveness of the data was underlined by the fact that data saturation was achieved. Published studies of determinants of physical activity have involved younger adults with ID have not been based on interviews with the participants with ID [13, 15, 16, 25, 27, 28, 41].

On the other hand, restriction to the perspective of the older adults themselves is a limitation. Although we considered interviewing as the most appropriate method, interviewing people with ID also raises some significant and challenging methodological issues such as acquiescence and response bias [42, 43]. We acknowledge that these issues may have had impact on the answers of participants and thus on the study results. It appeared difficult to gain information about factors of a higher abstraction level without asking suggestive questions. This resulted in relatively superficial information and limited information about underlying factors. Triangulation, for example by interviewing staff and family members could provide more in-depth information about facilitators and barriers to physical activity among older adults with ID.

We included older adults who varied in age, mobility, motivation for physical activity and severity of ID. However, we did not register other biological, physiological or cognitive markers for ageing. Inherent to the methodology of the focus group itself, data gathered with this method are not representative of the larger population from which the sample is drawn. The 40 participants in this study were not representative for all older adults with mild and moderate ID; most participants had a mild ID, and participants who could not communicate were not included. Caution is needed when generalizing the results of this study to all older adults with mild and moderate ID. The

current study had an explorative nature; no conclusions can be drawn about the prevalence of barriers and facilitators indicated in this study.

Recommendations for physical activity promotion and research

Involving the target group itself when developing health promotion programmes and tailoring the activities to their needs, interests, and abilities, is of extreme importance for participation and adherence to the programme [21, 24]. Results from the current study can be used for developing effective programmes, aimed at promoting and improving physical activity among older adults with ID. Identified facilitators and barriers influencing physical activity among this target group can be translated into effective evidence-based strategies. It is recommended to tailor the physical activities, including appropriate materials, to the interests of the older adults in order for them to enjoy participating in them. Walking and activities with music seem to be popular activities, and coffee breaks were very appreciated by our participants. However, like everyone else, older adults with ID have their individual preferences for certain activities, which could be addressed in order to develop a successful programme. Support from experts, such as movement scientists and physical therapists, in specific activity games and create a safe environment is recommended. Positive experiences with simple physical activities may increase the older adults' confidence, reduce fear of falling and motivate them to continue. Education about physical activity and bodily reactions could also increase the motivation for participating more actively. The challenge will be to draft an effective programme that is suitable to older adults with ID that corresponds with their physical activity level, physical limitations and personal preferences, in order for them to participate actively over time. To increase the consciousness of the importance of physical activity, we recommend using strategies that address both older adults with ID and their staff. Further research about the staff's attitude towards promoting physical activity could additionally provide insight in which strategies should be used to implement physical activity programmes effectively.

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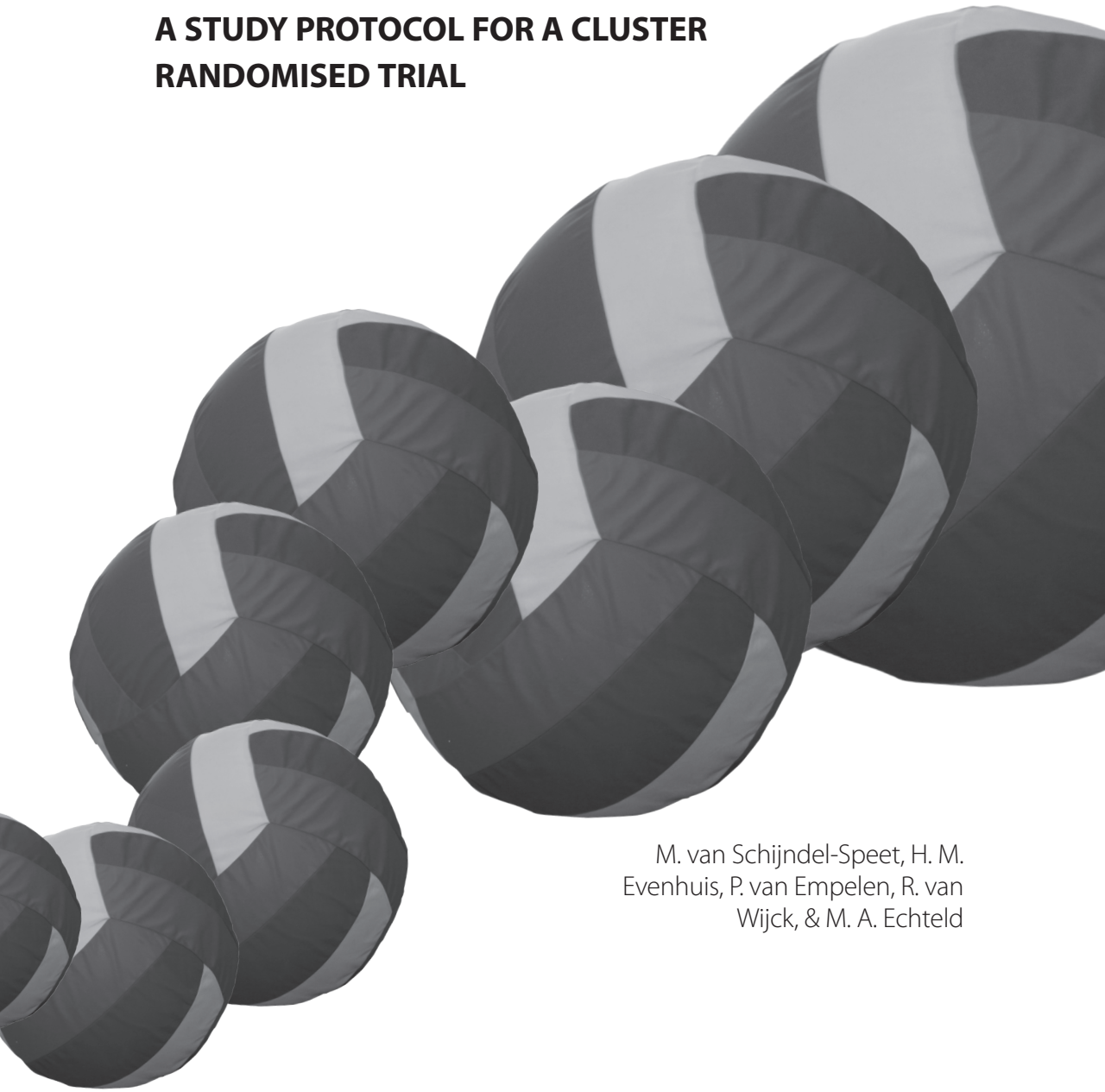
3

DEVELOPMENT AND EVALUATION OF A STRUCTURED PROGRAMME FOR PROMOTING PHYSICAL ACTIVITY AMONG SENIORS WITH INTELLECTUAL DISABILITIES: A STUDY PROTOCOL FOR A CLUSTER RANDOMISED TRIAL



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ABSTRACT

Background: Older people with intellectual disabilities have very low physical activity levels. Well designed, theory-driven and evidence-based health promotion programmes for the target population are lacking. This paper describes the design of a cluster-randomised trial for a systematically developed health promotion programme aimed at improving physical activity and increasing fitness among seniors with intellectual disabilities.

Methods and design: The Intervention Mapping protocol was used for programme development.

After defining the programme's objectives, the following behavioural techniques were selected to achieve them: Tailoring, Education, Modelling, Mirroring, Feedback, Reinforcement and Grading. With professionals and managers of provider services for people with intellectual disabilities, we translated these strategies into a structured day-activity programme, that consisted of a physical activity and an education programme. The programme will be executed in five day-activity centers in groups of eight to ten seniors during eight months, whereas seniors in five other centers receive care as usual. The physical activity level, as measured in number of steps a day, will be used as primary outcome measurement. Secondary outcome measurements include motor fitness, cardio respiratory fitness, morphological and metabolic fitness, ADL, functional deterioration and depressive symptoms. Differences in the primary and secondary outcome measures between participants and controls will be analysed using generalised estimation equations, correcting for day-activity center as cluster.

Discussion: This paper provides insight into the development and content of a theory-driven intervention aimed at behavioural change in a population with a low intellectual level. Its evaluation design is described. The programme's applicability to other populations is discussed.

Trial Number: ISRCTN82341588

BACKGROUND

It is a well-known fact that people with a low education level and socioeconomic status generally tend to have an unhealthy lifestyle, whereas community-based programmes aimed at improvement of healthy behaviour are insufficiently effective in reaching this population group [1]. This is even more so in adults with intellectual disabilities (ID), i.e. with IQ levels below 70 before the age of 18 and limitations in adaptive behaviour. In Dutch adults with ID aged 50 years and over, a large majority has a sedentary lifestyle and fitness levels comparable to the general population aged 80 years and over [2], leading to increased prevalences of obesity, diabetes, metabolic syndrome and other age-related health risks. [3]. Although in practice, several physical activity programmes have been developed for Dutch adults with ID, none of them have explicitly been designed using behavioural change theory or have been scientifically evaluated. To our knowledge, internationally, only one such programme has been set up for young adults with a mild ID and evaluated properly [4].

An approach based on theories and strategies for behavioural change is considered the initial step in the development and evaluation of complex interventions, increasing the likelihood of the interventions being effective [5, 6]. Although several theory- and evidence-based programmes to increase physical activity are available for older adults in the general population [7, 8], the applicability of such programmes to older people with ID is limited, because of their limited cognitive ability, frequent mobility and sensory limitations or other health problems, need of support, and limited financial means [9-11].

In the current report we describe the design of the evaluation study for a theory-based programme to promote physical activity and fitness in seniors with ID. Because persons with severe and profound ID (IQ lower than 35) cannot be verbally instructed and require a completely different approach, we decided to start with a programme for people with mild (IQ 55-70) and moderate (IQ 35-55) intellectual disabilities.

METHODS AND DESIGN

This study will evaluate the efficacy of the "Healthy Ageing- Physical Activity Programme (HA-PAP) for seniors with Intellectual Disabilities". More specifically, physical activity, fitness and health indices will be compared between older adults with mild-moderate intellectual disabilities (ID) who are assigned to the HA-PAP and who will be given usual care. The programme is developed to be executed in day-activity centers of care organisations for people with ID in the Netherlands, in groups of eight to ten seniors. Intervention Mapping (IM) was applied to systematically develop the programme [12].

The efficacy of the programme will be evaluated in a cluster-randomised clinical trial and to minimize contamination, the level of day centers is used as the randomisation level.

HA-PAP was approved by the Medical Ethics Committee of the Erasmus University Center Rotterdam (NL 29573.078.09).

Development of the programme

We applied Intervention Mapping (IM) to systematically develop the programme [12]. Intervention Mapping is a six-step protocol that facilitates a procedure for theory-based and evidence-based development of heath promotion interventions. In the first two steps, an assessment of needs and programme objectives, including a specification of necessary behavioural changes, are described. In step three, theory-based strategies are selected, which form the basis of the intervention programme, developed in step four. In this phase, we also selected and/or produced intervention materials. We will describe how the subsequent steps were addressed in the current study, resulting in our choices of goals, theories and strategies, applicable to this specific low IQ population.

Step 1: Needs assessment

Information on factors that may directly or indirectly influence participation in physical activity of this population was collected from the literature, by consultation of managers and movement experts of ID care provider services, and by 14 in-depth interviews and four focus-group discussions with seniors with mild and moderate ID. The interviews with the seniors themselves provided information regarding their preferences for specific physical activities and revealed 30 factors that promote or hamper participation in physical activity, the details of which have been published elsewhere [13]. The information obtained through these activities formed the basis for all further steps of the IM protocol.

When looking at the barriers for older adults with ID regarding physical activity, two important overarching barriers became apparent from the literature and were confirmed by managers and movement experts: a lack of social support [14-16] and the need of specific activities [17-20]. A third important barrier, mentioned by managers and movement experts, was the need for professional support. Enjoyment in physical activity in addition, was a recurrent theme in the interviews with seniors with ID themselves [13]. The facilitators they mentioned were also found in studies among younger adults with ID [14-16] and confirmed by movement experts of the ID care provider services. These needs for social support, specific activities, professional support and enjoyment in activities will be elucidated in this paragraph.

Social support is a robust stimulus for physical activity for everyone, but specifically for seniors with ID. They need to be supported in activities themselves, or in the transfer

to the activities, and they mostly do not think of the possibility or have the desire to become physically active themselves [14, 15]. Staff members in the residential setting however do not always have enough time or are insufficiently aware of the importance of regular physical activity for their clients [15]. Support by family may be limited after parents have died [17]. Aiming at increasing physical activity among the target group therefore means that we have to make sure that staff is motivated and sufficient staff is structurally available.

Managers and movement experts of the ID care provider services underlined that older adults with ID are in need of specific activities adapted to their age and physical limitations. As a result of childhood disabilities and multi morbidity, decline in physical functioning may start at a younger age when compared to seniors with normal intelligence [19]. Physical limitations such as balance and coordination problems, decrease in mobility and muscle strength [21], combined with limited understanding and often limited experiences with physical activities [16] require professional support to create a safe environment and to select appropriate activities for the group concerned. Such professional support can be provided by physical therapists or physical activity instructors, experienced in conducting physical activities with (older) adults with ID.

Seniors prefer activities they enjoy and feel comfortable with. Physical activities therefore should connect with their interests, should be part of their daily routine, should be well feasible for them (so they can become good at it and get rewarded), should include coffee breaks and should be conducted together with peers in a pleasant atmosphere. Furthermore, seniors with ID prefer to participate in activities close to their homes to avoid transportation problems and activities should be affordable [13].

In conclusion, seniors with ID have low physical activity and fitness levels and need to become more active for the benefit of their health and well being. There are specific needs that have to be fulfilled to develop an effective and successful physical activity programme as described in this paragraph. These needs were taken into account in steps three and four addressing the development of the programme.

Step 2: Programme objectives

In the second step of IM, we distinguished an overall health goal, performance objectives and change objectives.

Overall health goal

In accordance with the general health goal [22], our programme's goal was to increase the physical activity level of seniors with a mild or moderate ID who walk less than 7500 steps a day, and to maintain or increase the physical activity level of those who walk more than 7500 steps a day. In addition, the increased physical activity should lead to a delay of the decline of physical fitness, or even increase the physical fitness level.

Table 1: Objectives and determinants for increasing or maintaining the participants' PA level in the three phases of the study.

Performance objectives	Determinants		Change objectives
Phase 1 Seniors decide to participate in physical activities offered at the day -activity center	Attitude	+ enjoyment of activity	a) seniors think it is fun to participate in PA
	Self – confidence	- lack of self-confidence (lack of skills, fear of falling)	b) seniors think they are able to perform PA
		- physical complaints/ pain	c) seniors think it is physically safe and comfortable to perform PA
		- feeling tired	
	Social support	- lack of social support	d) seniors feel stimulated and supported by others to perform PA
		- feeling insecure social context	
		+ activity with familiar others	
		+ pleasant atmosphere	
Phase 2 Seniors participate actively in physical activities offered at the day-activity center and maintain participating in activities they were used to doing	Attitude	+ enjoyment of activity	a) seniors enjoy participating in PA
		+ familiarity/ routine	b) seniors experience PA as part of their daily activities/ routine
		+ aware of advantages of PA to their body	c) seniors become more consciousness of benefits of being PA
			d) seniors learn about normal bodily reactions to PA
	Self – confidence	+ self-confidence	e) seniors experience they are able to perform PA
		- physical complaints/ pain	f) seniors feel physically safe and comfortable to perform PA and explore their skills
		- feeling tired	
	Social support	+ social support	g) seniors feel stimulated and supported by others to perform PA
		+ status of physical activity	h) seniors are proud of their achievement
		+ activity with familiar others	
Phase 3 Seniors maintain participating in physical activities at the day-activity center and other activities they were used to doing	Attitude	+ enjoyment of activity	a)seniors enjoy participating in PA
		+ familiarity/ routine	b) seniors experience PA as part of their daily activities/ routine
	Self – confidence	+ self-confidence	c) seniors know they are able to perform PA
	Social support	+ social support	d) seniors feel stimulated and supported by others to perform PA

Performance objectives

Performance objectives are objectives that need to be addressed in order to achieve the overall programme goal. Based on theories suggesting that behavioural change can be differentiated into a pre-actional/intentional stage, an actional stage, and a maintenance stage [23, 24], we defined three specific performance objectives at an individual level: 1) Seniors *decide to* participate in physical activities offered at the day-activity center; 2) Seniors *participate actively* in physical activities offered at the day-activity center; 3) Seniors *maintain participating* in physical activities at the day-activity center and maintain other physical activities they were used to do.

Change objectives

Change objectives are changeable preconditions that have to be fulfilled in order to ensure active participation in a behavioural change programme. Information on personal and psychological barriers that had to be overcome and facilitators that could be used to ensure that seniors would participate actively were derived from the in-depth interviews and focus-group interviews with the target group [13]. According to the Theory of Planned Behaviour [25], we structured these factors according to attitude, self-confidence and social support (second column of Table 1). We subsequently translated each factor in change objectives that have to be achieved to ensure active participation in physical activities, such as feeling physically safe and comfortable to perform physical activities (shown in the third column of Table 1).

Step 3: Theory-driven strategies

In the third step of IM, theoretical models and practical strategies that have been identified in previous research to be likely to change the identified determinants, were selected for the design and execution of the programme. The selection was again based on behavioural change theory, such as Social Cognitive Theory [26] and the Theory of Planned Behaviour [25]. The following theoretical methods were selected: tailoring, education, grading, modelling, feedback, mirroring and reinforcement. Definitions and theories have been derived from an overview of behavioural change techniques used in interventions [27].

Tailoring [28]*:* adapting communication and activities to one specific person.

Provide information on consequences of behaviour in general (Theory of Planned Behaviour): providing information about health benefits of physical activity and immediate (negative) bodily reactions to physical activity.

Set graded tasks (*Social Cognitive Theory*): breaking down the target behaviour into smaller and easier to achieve tasks.

Provide instruction and model/demonstrate behaviour (*Social Cognitive Theory)*: a leader serves as an example to the client, provides instructions about the desired behaviour and shows how to correctly perform the behaviour.

Provide feedback on performance: (Control Theory): provide information about the behavioural performance of the person.

Mirroring (Social Cognitive Theory): copying the desired behaviour of the programme leader and peers.

Prompt rewards contingent on effort or progress towards behaviour and on successful behaviour (Operant Conditioning): praise, encouragement or material rewards that are explicitly linked to the achievement of the specific behaviours or for *attempts* at achieving a behavioural goal.

To ensure achievement of the overall health goal, we further studied evidence-based guidelines for physical activities designed to achieve health benefits. Because no specific guidelines exist for physical activity for people with ID, we adopted the guidelines of The American College of Sports Medicine (ACSM) and the American Heart Association (AHA) [29] [30] for the chronically ill and people aged over 65 years for our programme. Multi-component exercise programmes, including aerobic endurance, strength, balance and flexibility are recommended and optimal frequency, intensity and duration of the activities are specified.

Step 4: Development of programme and materials

Based on the identified needs of and objectives for seniors with ID, we decided to develop a structured physical activity programme to be integrated into the day-activity programme. In contrast to the home setting, staff in day-activity centers would be structurally available to support seniors participating in physical activities. Implementing the programme into the day-activity setting would provide structural physical activity integrated in their daily routine, in a familiar environment and transportation problems could also be mitigated.

We translated the selected behavioural change techniques and the physical activity guidelines into practical strategies (see Table 2, third column). With regard to the strategy 'to provide information about performing physical activity safely and about normal reactions' we decided with members of the project group (see step 5) to develop an education programme and a physical activity programme. Managers of day-activity centers and movement experts of ID-care provider services recommended an optimal group size of eight to ten seniors. To ensure the feasibility of the programme, we derived relevant information from the interviews with the target population, e.g. about preferences for physical activities, and developed the intervention in collaboration with professionals from the ID provider services.

Education programme

The education programme was inspired by the health promotion programme: "Health Matters", developed for adults with mild ID [31]. Like our education programme, the education curriculum of Marks et al. (2010) focuses on the increasing consciousness of normal bodily reactions to physical activity, the importance of physical activity for health and making healthy lifestyle choices. Because the content of the exercises was too difficult for our target group, we focused on the first two goals and developed exercises that relied on 'experiencing' the activity. For example, within the theme 'breathing' the participants will be asked to "blow a feather over the table" and in another activity

Table 2: Behaviour change techniques and strategies to promote physical activity used in the three phases of the study.

Change objectives	***Behaviour change techniques***	***Strategies***	***Phase 1***	***Phase 2***	***Phase 3***
Seniors enjoy participating in PA	Tailoring	Professionals select PA on preference target group	*X*	*X*	*X*
Seniors think it is physically safe and comfortable to perform PA activities	Provide information on consequences of behaviour in general	Day-activity centers' staff members apply several work forms and exercises in groups to provide information about performing PA safely and about normal bodily reactions to PA	*X*	*X*	
	Professional support	Support PA by *familiar* professionals	*X*	*X*	
Seniors experience PA as part of their daily activities/ routine	Repetition	Structured PA in the day-activity programme, three times a week		*X*	*X*
Seniors think they are able to perform PA	Set graded tasks	Select relatively easy, low intensive, short duration PA in Phase 1. Incremental increases follow.	*X*	*X*	
	Provide instruction on how to perform behaviour	Professionals tell seniors how to perform the PA	*X*	*X*	*X*
	Model/Demonstrate behaviour/ Mirroring	Professionals show seniors how to perform the PA through demonstrations. The PA takes place in a group setting, where other participants demonstrate PA.	*X*	*X*	
Seniors become more conscious of the benefits of being physically active	Provide information on consequences of behaviour in general	Day-activity centers' staff members apply several work forms and exercises in groups to provide information about benefits of PA		*X*	

Change objectives	Behaviour change techniques	Strategies	*Phase 1*	*Phase 2*	*Phase 3*
Seniors learn about normal bodily reactions to PA	Provide information on consequences of behaviour in general	Day-activity centers' staff members apply several work forms and exercises in groups to provide information about normal bodily reactions to PA	*X*	*X*	
Seniors feel physically safe and comfortable to explore their skills	Professional support	Support PA by familiar professionals	*X*	*X*	*X*
Seniors feel stimulated and supported by others to perform physical activity	Prompt rewards contingent on effort or progress towards behaviour	Using praise and rewards for attempts at performing PA.	*X*	*X*	
	Provide rewards contingent on successful behaviour	Professionals and day-activity centers' staff members reinforce successful performance of performance of PA. This includes praise, encouragement and material rewards.	*X*	*X*	*X*
	Provide feedback on performance	Providing information about participants' progress in performing the PA.	*X*	*X*	
	Plan social support/ change	The PA take place in a group setting, with peers familiar to the participant, in which social support can be encouraged.	*X*	*X*	*X*

we will ask them "to lay down on the floor and see your tummy going up and down". Information derived from the interviews was used for adaptations, e.g. resulting in a theme: 'Fear of falling'[13]. Our programme was developed with experts in educating people with ID and developing suitable educational materials. The final programme includes 13 themes, for example: "What is physical activity", "My body, the inside" ,"My body, the outside" ,"Fear of falling" and "My heart rate". Specific goals for each theme were described and four to eight activities per theme were developed to achieve the goals. Selected didactical methods are sorting/ranking, group discussion, games, creative activities and role-play.

The day-activity centers' staff members, the programme's executors, will choose activities and didactical methods that correspond to the groups' level of functioning. If necessary, they can adapt exercises to individuals' level of functioning. Discussion of the participants' experiences with the physical activities is part of the education programme. Materials such as pictograms and pictures are selected or specifically developed to support the communication about the themes and the explication of the activities. Written

information about the theme, including pictures, pictograms and exercise worksheets, can be included in the participants' individual portfolios.

Physical activity programme

Together with movement experts, physical activity-instructors and physical therapists who work with the population concerned, a physical activity framework was developed in accordance with the ACSM and AHA guideline. Although the guideline specifies exercise frequencies of at least five days a week, we chose a programme frequency of three times a week, taking the burden for the seniors and staff into account. In consultation with the movement experts, we selected feasible activities for each of the four fitness components: 14 exercises for endurance, 18 for strength, 17 for balance and 6 for flexibility. Each selected activity was structured, i.e.: goal, duration, required setting, materials, conduction and suggestions for safety.

Information about the feasibility of the ACSM and AHA guideline among seniors with ID is lacking, specifically concerning the duration and intensity of the physical activities. Therefore, we decided to start with simple activities and subsequently grade the activities step by step in duration and intensity (Table 3). We will start with a total programme duration of 15-20 minutes and subsequently expand the duration to 45 minutes. During each exercise period, intensity will be monitored by a heart rate monitor so that we are able to decide what intensity levels are feasible for each individual participant. If physical activity-instructors observe that seniors are not motivated to participate (more) actively, they can try to identify potential barriers that the seniors are experiencing and subsequently try to enlarge their self-confidence and enjoyment in participating, if necessary at a lower intensity.

Physical activity-instructors are responsible for the contents of the activity programme and its adjustment to the specific interests and needs of a group. They are also responsible for executing the programme correctly and safely, as well as for the application of the behavioural strategies selected in Step 3. Day-activity centers' staff members will be coached by the physical activity-instructors in conducting the physical activities. They also will serve as role models and supported and encourage the participants. Positive feedback and rewards such as medals and stickers will be provided to increase the participants' enjoyment in the activities and to motivate them. Because the physical activities are group-orientated, observing and learning from peers performing the physical activities is implicit part of the activities.

Table 3: Framework of the physical activity programme.

	day 1	**day 2**	**day 3**
	Endurance	*Endurance*	*Endurance*
Initiation (6 wks)	10 min HRR* 20-30%	15 min HRR 20-30%	10 min HRR 20-30%
Action/ Extension (14 wks)	15-20 min HRR 40-60%	20-30 min HRR 40-60%	15-20 min HRR 40-60%
Maintenance (12 wks)	15-20 min HRR 40-60%	20-30 min HRR 40-60%	15-20 min HRR 40-60%
	Strength	*Balance*	*Strength* *Balance*
Initiation (6 wks)	10 min	5 min	10 min 5 min
Action/ Extension (14 wks)	15 min	10 min	15 min 10 min
Maintenance (12 wks)	15 min	10 min	15 min 10 min
All phases	*Flexibility*	*Flexibility*	*Flexibility*
	5 min	5 min	5 min

* *Heart rate reserve* (HRR) the difference between a person's measured or predicted maximum heart rate and resting heart rate.

IMPLEMENTATION AND EVALUATION OF THE PROGRAMME

In the last two steps of the Intervention Mapping protocol, implementation and evaluation plans are developed.

Step 5: Implementation

Selection of day-activity centers and participants

This study is conducted by a Dutch consortium of three large ID care provider services and the Intellectual Disability Medicine research group of the Erasmus Medical Center at Rotterdam, in collaboration with the Center of Human Movement Sciences of the University Medical Center Groningen. HA-PAP is set in the three large ID care provider services, that include nineteen day-activity centers offering recreational activities to the target group. Two day-activity centers with reorganisation problems or substantial personnel problems are excluded. Based on earlier research, we expect to obtain informed consent for about 50% of the participants [32]. Because we planned to conduct the intervention in groups of eight to ten seniors (see Paragraph: development of the programme), 7 day-activity centers with less than 15 seniors with mild or moderate ID

are excluded. The ten remaining centers all have a large activity-room or a gymnasium facility in-house or nearby.

Our primary outcome measure is physical activity, defined as steps per day. We have data of seniors with a mild or moderate ID from the pilot of the study: "Healthy Ageing with Intellectual Disabilities" (HA-ID) [32] at our disposal (n=37), in which we found a mean physical activity level of 5480 steps per day (SD 2146). With a power of 80% to detect a difference of 1073 steps (effect size 0,5) and a type I error of 0.10, 60 seniors in both the control group and the participation group are required. We assume a drop out of 20% and planned to start therefore with 80 seniors in each group.

Seniors had to be aged 45 years and over and to be able to participate in groups. Clients who were dependent on a wheelchair in-house, who had dementia or had a medical contra-indication for participating in the physical activity programme would be excluded from the study. Managers of the selected ten day-activity centers provided anonymous information about their clients on date of birth, gender, level of intellectual disability, use of walking aid, presence of dementia and the ability to participate in group activities. Clients who satisfied the inclusion criteria are selected (n=237). Clients who are competent according to their behavioural therapist, will be informed about the project by the staff members who are familiar to them. The information will be structured using specific Patient Information Forms and subsequently written informed consent will be obtained. If older adults are not sufficiently competent to give informed consent themselves, Patient Information Forms and informed consent forms will be sent by mail to their legal representatives. Informed consent for blood sampling will be obtained separately and is no precondition for participation.

Randomisation

To help ensure comparability of the participants conducting the programme and the seniors in the control group, we looked for the best possible match with respect to sex, age, intellectual disability, the use of a walking aid and provider service. The matching procedure was conducted with the data of the potential 237 participants (see previous Paragraph) using chi-square and t-tests. The best match was found when the ten day-activity centers were divided into two specific groups of five centers each. We subsequently checked the comparability of important day-activity centers' characteristics in both groups, that is the availability of a gymnasium nearby and involvement of a physical-activity instructor in the day-activity centers' activities. These characteristics appeared to be comparable. The chairman of the steering group, in presence of the researcher and a senior staff member Public Relations, randomly selected one of the two groups of five day-activity centers who will conduct the programme. The remaining group of five day-activity centers will serve as the control group. Because the implementation of the programme has to be prepared and organised, the sequence is only concealed for the

clients and family, not to the day-activity centers' managers. After the informed consent procedure has ended, all participants and/or their family will receive a confirmation of participation in the study and information about the intervention allocation.

Forums for implementation

Several forums are formed for the purpose of optimal motivation and support. Managers of the three ID care provider services regularly met with the research group to discuss the preconditions for implementation of the programme. Client boards were informed at the beginning of the study. A central *project group* is formed at the beginning of the study, to advise the researchers during every step of implementation of the programme. The project group consists of day-activity centers' managers and day-activity center's staff, movement experts and a behavioural therapist. During the programme's development phase, we already examined the potential fit with the participants and with the setting in which the programme needed to be carried out. A *linkage board i*s formed, responsible for the execution of the implementation plan. This linkage board consists of the researcher, a care director and a middle manager of the participating ID care provider services. Staff members in the homes of potential participants will be informed about the study and the importance of physical activity for their clients by their manager and researchers.

Materials and training

The programme will be implemented in five day-activity centers, the other five day-activity centers participate as control group. Together with the movement experts, a list of basic low-cost materials to perform the physical activities is drafted and purchased, including heart rate monitors. We developed a one-day training for physical activity-instructors, with the aim to teach them about the physical activity framework and how to design the physical activity programmes, that address the needs and interests of the target group, and is consistent with the underlying programme theories. They will also learn how to apply the heart rate monitors. The staff of the participating day-activity centers also will receive a one-day training, developed by a professional trainer, about the education programme. They receive information about why physical activity is important for their clients and about the goals and structure of the education programme. In addition, they will practice preparing and conducting the exercises and how to adapt exercises to the needs of their group.

Monitoring execution of the programme

A *workgroup* will be formed in each day-activity center that consists of the programme's leaders, a physical therapist, a behavioural therapist and the researcher. This working party will meet every five to six weeks to evaluate the execution of the programme

and establish solutions for the barriers that will be presented. Four months after the intervention has started, two evaluation meetings will be held to discuss barriers they met and exchange successful strategies for optimal participation of the seniors. One concerning the education programme with all staff members of the five participating day-activity centers and one with all the movement experts, involved with executing the physical activity programme.

Step 6: Evaluation

The evaluation includes an effect evaluation and a process evaluation. The main outcome variable in the effect evaluation is physical activity level, and will be measured with a pedometer that will be worn for at least 4 days [33]. The NL-1000 (New-Lifestyles, Missouri USA) is a hip-worn device that measures vertical acceleration, using a piezoelectric accelerometer mechanism. It measures reliably at a walking speed of 3.2 km/h or higher [34, 35]. Secondary outcome measurements include: muscle strength, balance, walking speed, blood pressure, aerobic capacity, weight, waist circumference, serum glucose, serum cholesterol, mobility, daily living skills, depressive symptoms and functional deterioration. Measurement instruments that are selected in the epidemiological study HA-ID and that were proven to be reliable among people with ID [32] are used for data collection.

All outcomes will be measured at baseline and after eight months, at the end of the intervention period. Health outcomes (motor fitness, cardio respiratory fitness and morphological fitness) will be assessed in or near the day-activity centers and performed by specially trained physical therapists and medical assistants, experienced in supporting seniors with ID [32]. Caregivers working at the homes of the participants and behavioural therapists will receive several checklists and/ or questionnaires by mail (about mobility, daily living skills, depressive symptoms and functional deterioration).

The process evaluation will entail analysis of data on the attendance, barriers, initial use, exposure and continued use after the intervention period. Physical activity-instructors will fill in registration forms during the intervention period about e.g. attendance and participation of each senior and the content and duration of each physical activity. Participants, programme leaders, and managers will be interviewed and/or receive a written questionnaire about barriers and continued use of the programme at the end of the intervention period.

Analyses

Generalised estimation equations will be used to identify significant differences in the primary and secondary outcome measures between participants and controls, correcting for day-activity center as cluster. The outcomes at the end of the intervention

for the control group and participation group will be compared, adjusted for outcome differences at baseline.

DISCUSSION

The development of a day-activity programme to increase physical activity among seniors with mild or moderate ID by following the six steps of Intervention Mapping has resulted in a novel, theory-driven intervention based on strategies proven to be effective in other populations. The programme will be evaluated using a cluster-randomised trial. Analyses will control for clusters and differences at baseline. The programme's five most important characteristics are 1) Structured multi-component physical activity programme based on the evidence-based guidelines, 2) Embedded in a routine day-activity programme, 3) Executed in peer groups, 4) Conducted by specifically trained movement experts and staff, 5) Supported by an education programme. Next to education, several behavioural change techniques are used to achieve the desired results, including: "Set graded tasks", "Provide instruction and model/demonstrate behaviour", Provide feedback on performance", "Mirroring" and "Prompt rewards contingent on effort or progress towards behaviour and on successful behaviour". The design of the programme is such that its contents can be tailored to the individual participant. An effect and process evaluation is being performed in a randomised clinical trial design.

Seniors with ID, experts in working with seniors with ID and managers involved with the implementation of the intervention, have had an important influence on the main concepts of the underlying programme. The experts who will conduct the programme played a central role in putting together a suitable programme and will offer the exercises using methods and strategies that fit best to the capacities, skills and needs of the participants with ID. By organising the intervention in the day-activity setting, there are no extra costs for the participants, the activities are nearby, and staff is available to support them in performing the activities. Although more health or fitness effects might be attained by individual fitness programmes with specific equipment, such a high-cost programme has no chance of being implemented on the long run. By selecting group activities and low-cost materials, we increased the feasibility and the likelihood of the programme's future implementation. Also the fact that the developed programme allows the programme leaders to tailor the programme to the abilities and interests of the target group, permits a broad implementation.

We found that Intervention Mapping is a useful tool to develop a theory-based programme, including strategies that appeared effective in other subgroups. To our knowledge, the used physical activity guidelines and behavioural change techniques have never been applied to and evaluated in older persons with ID. Therefore, the pro-

gramme's effectiveness still needs to be evaluated. Although health promotion research and practice projects have been expanding over the last few years in the field of people with ID, little research has focused on the development and evaluation of theory-based interventions and explicit behavioural change techniques [36, 37]. Using but also reporting the underlying theory and behaviour change techniques are valuable, because it contributes to the possibility of replicating effective interventions, synthesizing evidence and understanding causal mechanisms underlying behaviour change [27, 38]. Marks et al. (2010) developed a health promotion programme based on Social Cognitive Theory and the Transtheoretical model, targeted to adults with mild intellectual disabilities living in the community with limited support. The activity programme included activities in the gym, which were not applicable to our study group, because of lack of fitness equipment in day-activity centers and because these activities could not be conducted in groups of eight to ten older adults with ID.

In conclusion, the HA-PAP programme, is a day-activity programme consisting of a physical activity programme and an education programme. The effect evaluation of the study will provide insight into the programme's effects on physical activity and health. The process evaluation will provide more insight into the attitudes, facilitators and barriers to the implementation of the programme. If the intervention proves to be effective, a well-developed theory and evidence-based day-activity programme will become available for the promotion of physical activity among seniors with ID. Although this programme was developed explicitly for seniors with ID, we believe that the main programme elements may also be suitable for other subpopulations with similar characteristics, such as older people living in a residential setting and/or people with low-education levels.

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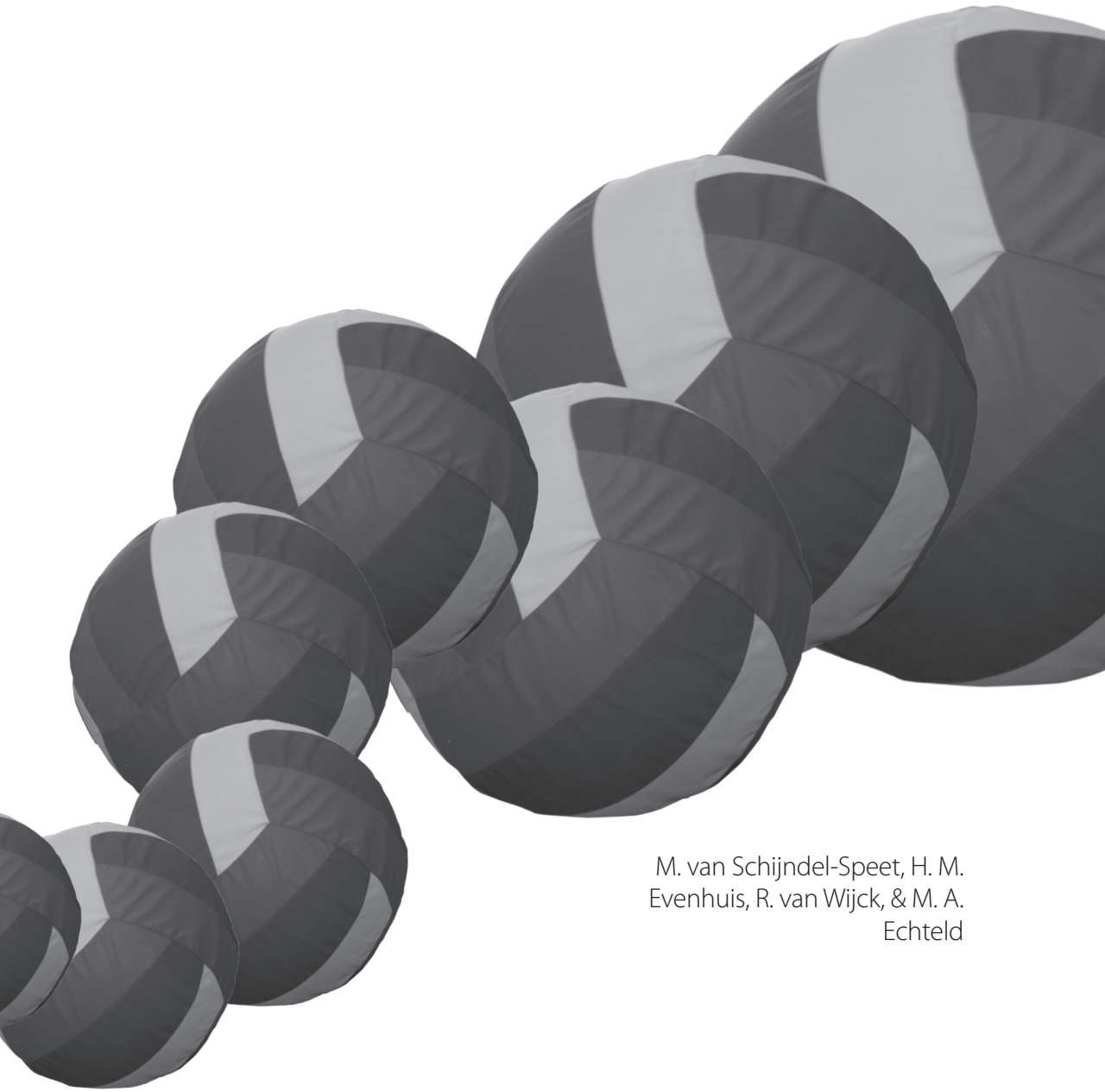
4

IMPLEMENTATION OF A GROUP-BASED PHYSICAL ACTIVITY PROGRAMME FOR AGEING ADULTS WITH ID: A PROCESS EVALUATION



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ABSTRACT

This paper describes the results of the process evaluation of a physical activity programme for people with intellectual disabilities (ID), including information about the concepts 'fidelity', 'dose delivered', 'satisfaction' and 'context'. Qualitative and quantitative methods among participants and programme leaders were used. The programme was well accepted, feasible and applicable to ageing people with ID. It was successfully implemented in terms of fidelity and dose delivered, although differences between day-activity centers were observed. The hampering factors that are revealed in this study and the facilitating activities that were part of the implementation plan may be used by care provider services for (ageing) people with intellectual disabilities and other groups of people with cognitive and/or physical deficits, such as frail elderly people or people with dementia when developing and or preparing implementation of health promotion programmes.

INTRODUCTION

As in the general population, health promotion among people with intellectual disabilities (ID) has become an important topic in the light of their unhealthy lifestyles [1-3], lower fitness and bad health conditions [4-8]. This unhealthy status is associated with immobility and higher dependence in performing activities in daily living [9]. Development and adequate evaluation of health promotion programmes are thus rapidly gaining in importance.

Several health promotion programmes have been developed, mainly addressing (younger) adults with mild ID [10-12]. Although the importance and utility of process evaluation have become more widely recognised [13], in most studies, emphasis is placed on the outcome evaluation to determine whether these programmes were successful; process evaluations remain scarce [10, 14-16]. Process evaluation is used to monitor and document programme implementation and can aid in understanding the relationship between specific programme elements and programme outcomes [13]. In addition, the process evaluation is about what was learnt about the programme's feasibility and prerequisites for implementation, and how that information can be fruitfully applied in the future [17].

Frameworks that guide the development and performance of process evaluation plans mostly include one or more of the following concepts [13, 18, 19]: 'Fidelity' (implementation of the intervention), 'Dose delivered' (provided elements of the intervention), 'Dose received' (extent to which participants actively engage), 'Satisfaction with the programme', 'Reach' (participation rate, attendence), 'Recruitment' (e.g. maintenance of participant involvement in intervention and measurements components in the study) and 'Context' (aspects of the environment that may have influenced intervention implementation or outcomes).

A physical activity (PA) programme was developed for older adults with ID and implemented in five day-activity centers in three Dutch ID care organisations. This paper describes the results of its process evaluation, including information about the concepts 'fidelity', 'dose delivered', 'satisfaction' and 'context'. Results of the other elements of the process evaluations ('reach', 'recruitment' and 'dose received') have been described elsewhere [20, 21]. Research questions of the current paper are:

1) To what extent was the new physical activity programme implemented as planned during the intervention period and performed compliant to the programme guidelines (fidelity and dose-delivered)?
2) To what extent was the programme feasible and applicable according to the programme leaders and participants (satisfaction)?
3) What aspects of the environment may have had impact on the implementation of the programme during the intervention period (context)?

METHODS

Participants

Physical-activity instructors together with staff of five day-activity centers executed the programme in eight groups of eight to ten participants.

81 participants and 70 controls (age 44 plus) with mild or moderate intellectual disabilities (IQ score respectively 50-70 and 35–50) were included after written informed consent was obtained [22]. The participants were judged to have the ability to function in a group. People with dementia or with a medical contra-indication for PA or dependent on a wheelchair in-house were excluded. Ethical approval for this study was obtained from the Medical Ethics Committee of the Erasmus University Medical Center (NL29573.078.09). The study adheres to the Declaration of Helsinki for research involving human subjects.

In total, 21 staff members of day-activity centers and 11 physical-activity instructors conducted the PA programme. The staff of day-activity centers knew the participants well and were experienced in conducting the target group in activities provided at the center (3 to 21 years experience). Most of them had some experience in conducting physical activities with the target group, such as walking, dancing or activities while sitting in a chair. The physical-activity instructors were experienced in drafting and conducting PA programmes for older adults with ID (two instructors had 1 year experience; the others 9 to 39 years experience). Most participants were unknown to the instructors. The physical-activity instructors received a one-day training, including exercises on how to put a training session together in accordance with the programme guidelines.

Physical activity programme

The guidelines of the American College of Sports Medicine and the American Heart Association [23] were used to develop the PA framework consisting of three PA sessions per week during eight months. In addition, information was provided about the fitness components that should be trained during each session (endurance, strength, balance and flexibility) as well as duration and intensity of activities during the initiation phase (first 6 weeks), extension (14 weeks) and maintenance phase (12 weeks) [22]. In collaboration with physical therapists and physical-activity instructors, feasible activities were selected and described for each of the selected components: 14 exercises for endurance, 18 for strength, 17 for balance and 6 for flexibility.

Next to education, several behavioural change techniques were used to achieve active participation, including: 'Set graded tasks', 'Provide instruction and model/demonstrate behaviour', 'Provide feedback on performance', 'Mirroring' and 'Prompt rewards contingent on effort or progress towards behaviour and on successful behaviour'. The

design of the programme was such that its contents could be tailored to the individual participant [22].

Measurements

A registration form was developed to gather data about the frequency of the PA sessions as well as the fitness components that were trained during each session and their duration (dose delivered). Physical-activity instructors reported directly to the researcher if a PA programme session was canceled (fidelity).

To gain more in-depth information about the feasibility and applicability of the programme, semi-structured interviews were performed with individual physical-activity instructors. Open-ended questions were formulated about the selection and implementation of feasible physical activities, the applicability of the PA framework such as the duration and intensity of activities and the applied behavioural change strategies to achieve active participation of the target group. At the end of the interview they could provide additional remarks about the programme and its implementation. In addition, short semi-structured interviews with participants were performed to gain insight in their opinion about the PA programme. Participants were asked if they enjoyed or did not enjoy the PA programme and if they would like to continue the programme in the future or if they would prefer to stop. Two open questions were asked about what they specifically liked and disliked about the PA programme.

A questionnaire was developed for the programme leaders (both physical activity-instructors and staff of day-activity centers) to gain quantitative information about factors that may have had impact on the programme's implementation. Relevant determinants for implementation of innovations described by Fleuren et al. [24] were selected and included characteristics of the programme leaders (including self-efficacy, attitude and support), characteristics of the organisation (including support of programme leaders by colleagues and superiors and the availability of prerequisites to perform the programme) and characteristics of the socio-political context (willingness of participants to cooperate with the programme) [24]. Subsequently, propositions were formulated and had to be answered on a 5 point-Likert-type rating scale: 1) totally disagree, 2) disagree 3) neither disagree nor agree 4) agree 5) totally agree. The questionnaire ended with an open question for additional comments regarding the programme's implementation.

Procedure

Physical-activity instructors were asked to register for each training session which fitness components were trained, which activities participants performed per fitness component and the duration of each activity. The written questionnaire was sent to all programme leaders in the sixth month of the intervention period.

Six months after the intervention had stopped, the physical-activity instructors were interviewed. The semi-structured interviews were performed by a PA instructor who has been involved with the programme's execution only at the very beginning of the intervention. She therefore knew the programme well, but was not involved in its performance. In total, seven physical-activity instructors participated in five interviews (one interview was with three physical- activity instructors) ; all five day-activity centers were represented. The interviewer took notes during the activities and made audio recordings of the interviews. She wrote reports of the interviews afterwards. These reports were sent to the interviewees for authorisation and they all agreed with the content of the reports.

The interviews with participants were performed by a psychologist or behavioural therapist, working at one of the involved ID-care organisations but who was not directly involved in the programme's execution. They were experienced in interviewing people with ID. At forehand, they received some tailored information about the programme and the context in which it was performed to understand the comments of participants. The interviews were part of the effect measurements of the study and thus performed recently after the programme had finished. Participants were considered to be capable of self-report if they used comprehensible speech and could oversee a timeframe of at least one week. The interviewers took notes during the interview.

Analyses

Data from programme registration forms, written questionnaires and interviews with participants were entered in a database by support workers working at the ID care organisations. Descriptive analyses were performed with SPSS version 20. The percentage of cardiovascular training for one group was calculated by dividing the amount of training sessions with cardiovascular activities by the amount of executed training sessions. Balance and strength activities in training sessions were calculated similarly.

The mean duration of cardiovascular, balance and strength activities was calculated by dividing the total duration of each of these activities by the amount of training sessions in which they were included. The researcher analysed the reports of the five interviews with physical-activity instructors by listing all comments about feasibility and applicability, including factors that, according to the interviewees, may have had an impact on the implementation of the programme.

RESULTS

Implementation and compliance

The PA programme guidelines entailed three times a week a PA session for the duration of eight months (100%) and 94%-97% of all planned sessions in each group was carried out accordingly. Holidays were the main reason for not carrying out the programme; in three cases a session was not performed because of illness of the physical-activity instructor.

The PA framework required cardiovascular endurance activities to be performed three times a week and both balance and strength training to be performed two times a week. Table 1a shows the percentage training of the three fitness components during the intervention period of eight months. None of the activity centers were completely compliant with the guidelines. Variation is seen between day-activity centers, especially in the performance of cardiovascular activities (26% to 95% compliance).

Physical-activity instructors were asked to start performing cardiovascular activities, balance activities and strength activities with a duration of 10, 5 and 10 minutes respectively. After the end of the initiation phase, the physical-activity instructors were asked to increase the duration of cardiovascular, balance and strength activities to 20-30, 10 and 15 minutes respectively. The mean training duration of the three fitness components of both the first four months and the last four months are presented in Table 1b. Regarding the last four months, all groups were compliant with the duration guidelines for cardiovascular, strength and balance activities. Specifically the duration of endurance activities increased the last four months compared to the first four months. Data on the intensity of training and compliance with the prescribed intensity in the PA framework will be presented elsewhere [21].

Table 1a: Frequency of cardiovascular (CV), strength en balance activities in each group.

Day-activity center	Group	Participants	CV[1] exercise %	Balance[2] exercise %	Strength[2] exercise %
1	A	9	95	58	47
	B	11	75	68	67
2	C	10	78	61	72
	D	9	94	58	70
3	E	7	92	42	52
	F	5	89	49	56
4	G	6	38	44	52
5	H	9	26	46	49

[1] framework: 100% (three times a week) [2] framework: 66% (two times a week)

Table 1b: Duration of cardiovascular (CV), strength en balance activities in each group in months 1-4 and months 5-8.

Day-activity center	Group	Partici-pants	Total duration per session (min)		Duration CV (min)		Duration Balance (min)		Duration Strength (min)	
			Months 1-4	Months 5-8	Months[1] 1-4	Months[2] 5-8	Months[3] 1-4	Months[1] 5-8	Months[1] 1-4	Months[4] 5-8
1	A	9	45	49	26	35	17	16	14	15
	B	11	45	48	26	22	16	22	17	25
2	C	10	37	41	19	23	11	10	14	14
	D	9	33	36	18	19	10	10	12	13
3	E	7	26	35	15	24	9	13	10	17
	F	5	23	31	13	23	8	10	8	12
4	G	6	23	33	15	22	18	21	16	23
5	H	9	22	33	13	33	16	19	15	20

[1] framework: 10 minutes per session
[2] framework: 20/30 minutes per session
[3] framework: 5 minutes per session
[4] framework: 15 minutes per session

Applicability and feasibility of the programme

Feasibility of activities

According to the physical-activity instructors, they succeeded to select feasible activities from the activity book that was developed specifically for this programme [22]. Activities were feasible for the whole group, despite the fact that the physical functioning of the participants within a group varied substantially. To increase feasibility, physical-activity instructors provided tailored instructions and activities, and sometimes split the group up into two subgroups. In collaboration with a staff member of the day-activity center, the physical-activity instructor ensured that each participant could participate at his or her own level and perform the activity as independently as possible.

Applicability of the PA framework

Physical-activity instructors were aware that often more than one fitness component was trained within one activity. This multi-functionality mostly occurred in cardiovascular activities, such as walking, for which (leg)strength and balance are required.

Physical-activity instructors succeeded in increasing the activities in duration and intensity, but not always in accordance with the guidelines. Sometimes participants´ attention span limited the extent to which the duration of activities could be increased. Physical-activity instructors experienced that with time, participants improved their skills, which facilitated more intensive participation. However, differences in functional abili-

ties limited the intensity of training; more intensive training could have been achieved with a more homogenous group, as noted by the physical-activity instructors. Materials like weights and heavy balls were used to increase intensity of strength exercises. The availability of a gymnasium increased the variability in choice of cardiovascular activities and facilitated active participation.

Important strategies for active participation of participants

Demonstration of behaviours, tailoring and positive encouragement were thought to be very effective strategies even prerequisites for active participation. Some remarks of physical-activity instructors: "You have to be very enthusiastic and participate in the activities as a role model to get the participants on their feet and willing to do their very best. Sometimes I could only motivate the participant to run if I gave him a hand and run together with him". "Using humor was also motivating. For example giving a 'wrong' demonstration of the activity; it provides a good atmosphere and a lot of fun". Challenging was not only to get participants started, but also to keep them active during the whole session. "Sometimes if you give your attention to an individual participant, the others become less active. Performing the activities together with a staff member of the day-activity centers really helped to get the participants active for a longer time".

Also the techniques 'mirroring', 'prompting rewards' and 'set graded tasks' were supportive according to the physical-activity instructors. "Seeing group mates being active stimulates being active yourself". "Participants were really proud of the badge and medals they received during the programme". Repetition of the activities improved recognition, so the participants knew what to do and improved their skills, which again was really motivating according to the physical-activity instructors. Also a fixed structure of the programme provided recognition and made participants feel secure; they knew what to expect. Sometimes physical-activity instructors made activities extra fun, for example by using a football during the walking activity, putting on music during specific activities, throwing a dice during strength activities to establish how many repetitions participants had to make, involving the participants in creating new exercises, offering the exercises in a relevant theme for example 'throwing snowballs' in de winter, etc.

Physical-activity instructors were not convinced about the added value of the information provided in the education programme about consequences of healthy behaviour in general. Not all participants had the ability to learn about this rather abstract concept, even though the exercises within the education programme were really practical and experience-based. They were more enthusiastic about the included exercises in the education programme aimed at body awareness and the physical reaction on activity, and discussion about barriers such as fear of falling. During the PA programme, the staff of day activity-centers repeated what was learned during the education programme.

To put what was discussed during the education programme into practice worked very well for participants.

Satisfaction of participants

Twenty of 66 participants who completed the intervention study, were able to be interviewed. Other participants did not have the cognitive ability to answer questions about the programme or were judged by their caregivers to be burdened by participating in the interview. Of the twenty participants who were interviewed after the intervention period ended, 19 mentioned they enjoyed the PA programme and 18 would be willing to continue the programme. In additional remarks they mentioned the positive atmosphere during the programme and the rewards they had received (medals, diploma). They also mentioned physical activities they liked, such as walking, dancing with the Nintendo WII and gamelike activities such as throwing the ball. In addition they enjoyed doing activities together with the PA instructor or staff of day-activity centers. Two participants mentioned that they did not enjoy putting on the heart rate monitor each session. One participant noted that she found the activities sometimes intensive and that she did not like to sweat. One participant with mild ID mentioned that she would prefer more variation in the programme: she got bored of the repetition of the activities.

Environmental factors that may have had impact on the programme's implementation

We received 8 out of 10 and 17 out of 20 completed questionnaires from the physical-activity instructors and staff of day-activity centers respectively (one PA-instructor and one staff member of a day-activity center did not work at the ID care provider services anymore). Both physical-activity instructors and staff of day-activity centers do have a positive attitude towards PA. However, staff of day-activity centers does sometimes feel that conducting physical activities conflicts with their other tasks (see Table 2). The Physical-activity instructors and staff of day-activity centers were self-confident about their knowledge, skills and competence in executing the PA programme. They also found the programme attractive to execute and were motivated to continue executing the programme after the intervention period would stop.

Physical-activity instructors were less satisfied with the requirements to conduct the programme well. Especially the setting was often not optimal. In two day-activity centers there was no gymnasium available and the available locations for the activities were not very suitable for this purpose, especially for performing cardiovascular activities. The other day-activity centers did not have a gymnasium at their disposal three times a week, but one or two times a week. Although a gymnasium is not a requirement to get participants physically active, it helps challenging participants to be more active according to the physical-activity instructors, especially for cardiovascular activities.

Table 2: Mean evaluation scores (1 to 5) of factors that may have had impact the programme's implementation, from the perspective of physical-activity (PA) instructors (n=8) and staff of day-activity centers (DC) (n=17).

	PA instructor	Staff DC
Attitude physical activity		
I enjoy being physically active	5.0	4.7
I think regular physical activity is important for my clients	4.9	4.8
Conducting physical activities is part of my job-responsibilities	4.3	3.9
Conducting physical activities is in conflict with my other duties	2.0	2.7
I am motivated to continue the physical activity programme at the day-activity center after the intervention period has ended	4.1	4.0
My colleagues think regular physical activity is important for my clients	4.6	4.4
Self-efficacy		
I have sufficient knowledge at my disposal to perform the programme well	4.5	4.0
I have sufficient skills at my disposal to perform the programme well	4.5	4.5
I feel confident about my competence to perform the programme well	4.5	4.2
Support		
My colleagues support me in performing the programme	4.0	na
Collaboration between PA instructors and staff of day-activity centers is good	4.4	4.5
My superior supports me in performing the programme	3.9	4.0
Characteristics of the organisation (context)		
The available PA materials are sufficient to perform the programme well	3.5	na
The available accommodations are feasible to conduct the activities	3.0	na
The available personnel is enough to prepare and perform the programme well	3.4	3.9
One or two involved programme leaders coordinate its implementation	3.4	na
Willingness participants cooperate		
Participants participate actively in the programme	3.9	4.3
Participants enjoy participating in the programme	4.3	4.4

Physical-activity instructors and staff of day-activity centers were positive about their collaboration and felt supported by their colleagues and superiors. According to them, clients participated rather actively in the programme and enjoyed participation.

In addition, we asked the programme's performers if there were other important factors that may have had impact on the implementation of the programme. Logistic problems limited available time for the PA programme. In two day-activity centers, physical-activity instructors had to travel a substantial time (half an hour) to the day-activity center within a very tight schedule. Furthermore, putting on the heart rate monitors was a time consuming activity, especially at the start of the programme. Later on, the staff of day-activity centers started putting on the heart rate monitors just before

the PA programme started. Finally, the composition of non-homogenous groups was mentioned as a barrier for (more) intensive participation.

We calculated the mean scores of factors that according to the programme leaders may have had a negative impact on the implementation per day-activity center (see Table 3). These include 1) the (non)availability of a gymnasium, 2) travel distances of physical-activity instructor , 3) materials, 4) available spaces for exercise, 5) available personnel, 6) coordination , 7) support of a superior and 8) active participation. Day-activity centers without a gymnasium nearby scored worse on available accomodations and had the lowest % of cardiovascular training (see Table 1a). In the day-activity centers in which the physical-activity instructor had to travel a substantial distance, leaders were more negative about the availability of personnel and the total duration per physical activity session was shorter (see Table 1b).

Table 3: Mean evaluation scores (1 to 5) per day-activity center of factors that, according to the physical-activity (PA) instructors and staff of day-activity centers, may have had impact on the programme's implementation.

Day-activity center	Materials	Available accomo-dations	Available personnel	Coordination	Support superior	Active partici-pation
1 Gymnasium Short travel time instructors	3	3	3.5	4.5	4.5	3
2 Gymnasium Longue travel time instructors	3.5	4.5	4.5	3.5	4.5	4.5
3 Gymnasium Short travel time instructors	4	2.7	3	3	3	4.3
4 No gymnasium Longue travel time instructors	3	1	2	2	4	3
5 No gymnasium Longue travel time instructors	3	1	2	2	4	3

DISCUSSION

In this study, the PA programme for older adults with ID was evaluated in terms of compliance (fidelity), implementation (dose/delivered), satisfaction with the programme´s content (feasibility and applicability) and environmental factors that may have had impact on the implementation of the programme (context). Overall, both leaders and participants were enthusiastic about the programme and were willing to continue performing it. Physical-activity instructors found the programme feasible for the target group and used all behavioural strategies to improve active participation, including: 'Set graded tasks', 'Provide instruction and model/demonstrate behaviour', 'Provide feedback on performance', 'Mirroring' and 'Prompt rewards contingent on effort or progress towards behaviour and on successful behaviour'. However, differences were observed in the extent to which the physical-activity instructors complied to the programme guidelines (dose-delivered). Specifically, a substantial variation was seen in inclusion of cardiovascular activities into the programme, which is also correlated with the attained heart rate levels of participants during the programme [21]. Programme leaders reported factors that may have influenced the programme´s compliance: 1) the absence of a gymnasium, 2) travel distances of physical-activity instructors and 3) the heterogeneity of the groups in terms of participants' physical functioning.

For this study we formulated a minimum of inclusion criteria, resulting in a heterogeneous study population that reflects clinical practice and thus permits generalisation of feasibility. Although the study is performed in The Netherlands, we have no reasons to assume that other results will be found for feasibility in other western countries. Regarding applicability, it is important that several prerequisites are fulfilled including the availability of a physical-activity expert to draft and conduct the physical activity programme in concordance with its guidelines and/or to coach staff of day-activity centers' work settings to conduct the programme safely. Secondly, materials and a gymnasium or at least a large accommodation with adequate safety precautions are needed to stimulate active participation and increased heart rates. Physical activities can also be performed outside, but uneven surfaces and bad weather conditions may pose safety threats. If these conditions are fulfilled, we assume that the results about the programme's applicability may be generalised internationally.

One of the strengths of this study was the multifaceted implementation plan [22]. For example, managers and professionals were involved with the development and preparation of the implementation from the very beginning, resulting in a good fidelity. Also the positive findings about the content and feasibility of the programme are a result of this careful developing process, using the concepts of Intervention Mapping [25]. Further strengths include the use of triangulation: programme leaders and participants were involved in the process evaluation and both qualitative and quantitative methods

have been used to gain valid information about the implementation of and satisfaction with the programme. The programme's execution has been monitored during the whole intervention period for each session, which means that detailed and valid information about the 'dose-delivered' was available.

Limitations of this study include the absence of detailed information about the implementation of behavioural strategies. For example, we are not able to draw conclusions about the extent to which the behavioural strategies are performed because we did not monitor it nor prescribe detailed guidelines. In addition, we do not know (yet) whether the indicated negative factors and/or non-compliance of the guidelines have indeed negatively influenced the programme's impact on the health outcomes. However, non-compliance may have contributed to the programme's success in terms of acceptance and client drop-out. We do not have data on this proposed relationship.

CONCLUSION

The importance of process evaluations is threefold: 1) it may indicate whether a programme's implementation will be successful and 2) it may show aspects that may lead to a programme's improvement and 3) it may reveal mechanisms of a programme's effectiveness. The current process evaluation contributed to all three aspects of knowledge. The programme was well accepted, feasible and applicable to ageing people with ID. It was successfully implemented in terms of fidelity and showed that behavioural change techniques may possibly improve the programme's effectiveness. Environmental factors may be important in successful implementation regarding the compliance with the framework. The hampering factors that are revealed in this study and the facilitating activities that were part of the implementation plan may be used by care provider services for (ageing) people with ID when developing and or preparing implementation of health promotion programmes. As O´Connor -Fleming put it: "The field of health promotion can only move forward when outcomes of comprehensive evaluations of what does work and what does not work are made available to practitioners" [17]. Further research is needed to evaluate the preconditions for embedding the physical-activity programme into daily practice.

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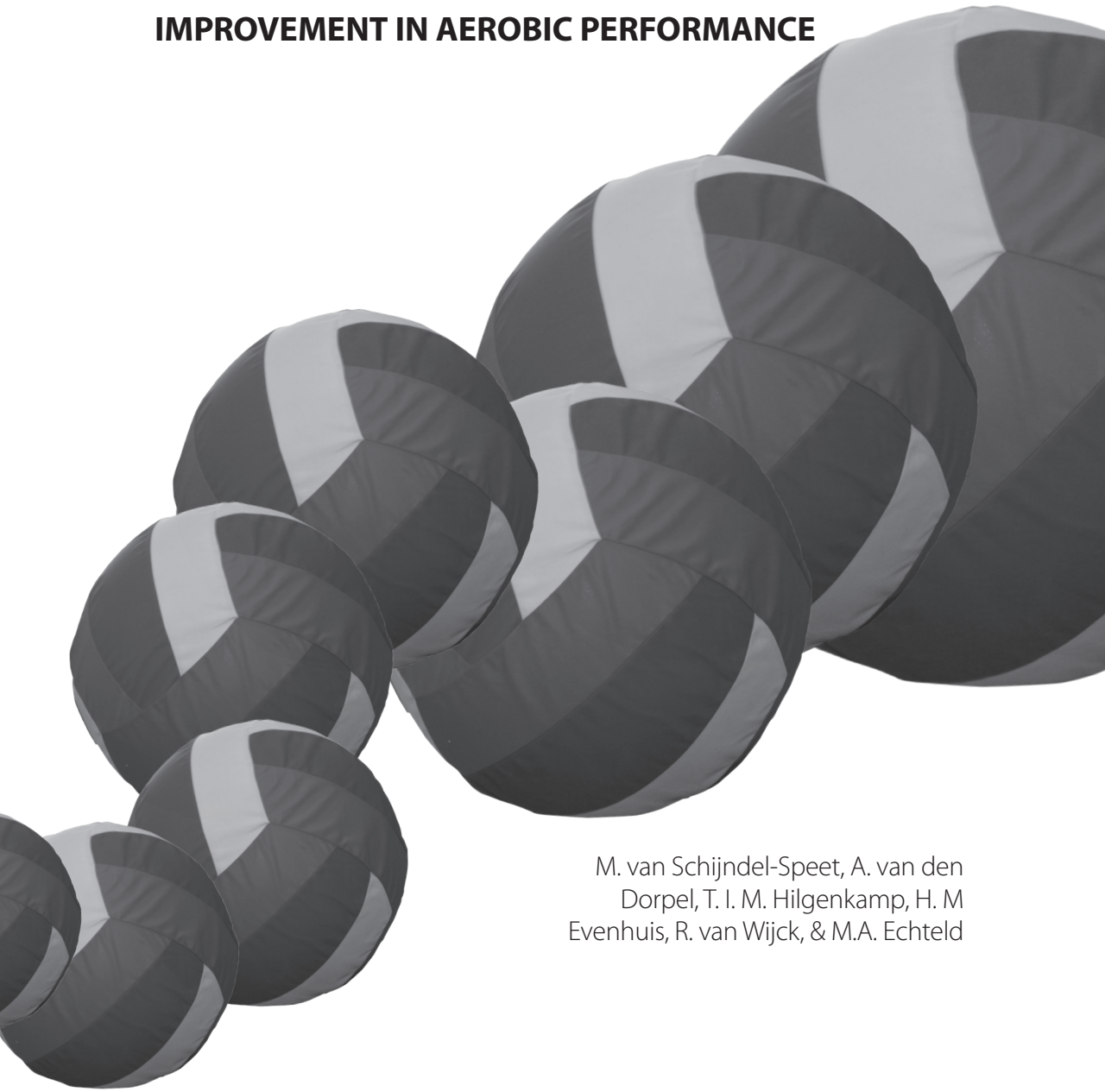
5

HEART RATE RESPONSE TO A PHYSICAL-ACTIVITY PROGRAMME AMONG PEOPLE WITH INTELLECTUAL DISABILITIES AND ITS ASSOCIATION WITH IMPROVEMENT IN AEROBIC PERFORMANCE



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ABSTRACT

Background

In this study we investigated the heart rate response to a physical activity and fitness programme among older adults with intellectual disabilities (ID) and its association with improvement in aerobic performance.

Method

The physical activity programme was executed in five day-activity centers in groups of eight to ten participants three times a week during eight months. In total 66 ageing adults with ID completed the programme; data of 63 participants with ID were included in the analysis. Heart rate was assessed with heart rate monitors. Aerobic performance was assessed pre and post-intervention with the Incremental Shuttle Walking Test.

Results

Participants mostly exercised at low-intensity levels. Positive associations were found between heart rate increase and being younger, having Down syndrome and having severe behavioural problems. Notable were the high heart rate levels of participants with autism. Exercising in a gymnasium was associated with heart rate increase and more minutes training at at least 90 heart beats per minute. Improvement in aerobic performance was positively associated with severe behavioural problems and negatively associated with Down syndrome.

Conclusion

Characteristics of ageing adults with intellectual disabilities seem to be important predictors for attained heart rate levels during exercise. Low levels of weekly energy expenditure might be sufficient to establish positive health effects among ageing adults with intellectual disabilities.

INTRODUCTION

The need to increase physical activity and fitness levels among older people with intellectual disabilities (ID) with suitable physical activity programmes is high. The cardiorespiratory fitness of older adults with ID (50+) is similar to that of older adults (75+) in the general population [1]. Low cardiorespiratory levels increase the risk of cardiovascular diseases and may limit functioning in activities of daily life [2]. Only few studies investigated the influence of physical activity programmes on cardiorespiratory levels of people with Down syndrome and other causes of ID [3-8]. Although these studies were often executed with low participant numbers and/or performed among children or younger adults with mild ID only, results so far are promising. We recently developed and implemented a physical activity and fitness programme for ageing adults with ID, that improved physical activity and other health outcomes. The current paper describes the heart rate responses of the participants during the physical activity programme and their association with improvements in aerobic performance.

The heart rate increase of people with ID in response to physical activity and exercise appears to differ from the cardiac response of people without ID [7, 9]. There is evidence of autonomic dysfunction in people with Down Syndrome (DS), resulting in lower maximum oxygen uptake (VO_2max), lower peak heart rates and an attenuated absolute change in heart rates from rest to exercise [7, 9-12]. Chronotropic incompetence, explained by a blunted adrenergic responsiveness to exercise, could be the cause, but the exact underlying mechanism is not yet (completely) understood [10]. Research among individuals with other causes of ID demonstrate low cardiorespiratory fitness levels of children and adolescents, with further decline with increasing age [8], although research has been focusing mostly on younger adults with ID with and without DS. Only few intervention studies measured and /or reported on the heart rates of these adults during exercise sessions [6, 7]. These studies included aerobic exercise on treadmills and mostly younger adults with DS and other causes of ID; no data are available for ageing adults with ID. When attempting to establish a physical activity programme that is optimal for improvement or maintenance of health in this group, more insight is needed into factors that impact their heart rate during physical activity and improvements in aerobic performance.

The research questions in this study were:

1) What is the peak heart rate, heart rate increase, and the amount of minutes exercised at different heart rate levels of ageing adults with ID during a physical activity and fitness programme?
2) Are peak heart rate, heart rate increase and the amount of minutes exercised at different heart rate levels, associated with participant characteristics, health parameters, and programme characteristics?

3) Can improvement in aerobic performance be predicted by participant characteristics, baseline health, programme characteristics and attained heart rate levels?

METHODS

This paper describes data from the study "Healthy Ageing- Physical Activity Programme (HA-PAP) for older adults with Intellectual Disabilities". The programme was evaluated in a cluster-randomised clinical trial (Trial Number: ISRCTN82341588) [13]. Ethical approval for this study was obtained from the Medical Ethics Committee of the Erasmus University Medical Center Rotterdam (NL29573.078.09). The study adheres to the Declaration of Helsinki for research involving human subjects.

Participants

In total, 81 and 70 older adults with ID were included as participants and controls respectively, selected from ten day-activity centers that provide activities to older adults with disabilities in the Netherlands [14]. Participants older than 40 years with the ability to function in a group were included. People with dementia, people with a medical contra-indication for physical activity or who were dependent on a wheelchair in-house were excluded. More detailed information about the inclusion criteria have been published elsewhere [14]. In total, fifteen out of 81 participants dropped out, mostly because of chronic illness or distress caused by participation in a group. For the current analysis, data of participants who had a cardiac pacemaker were excluded.

The physical activity and fitness programme

The programme was based on guidelines for maintaining or increasing the physical fitness level, proven to be effective among chronically ill people and people older than 65 years [15]. In accordance with these guidelines, a physical activity framework was developed to address the fitness components strength, endurance, balance and flexibility [14].

The programme was performed three times a week from October 2010 until June 2011 (eight months). Together with physical therapists and physical-activity instructors, feasible activities were selected and described for each of the selected components: 14 exercises for endurance, 18 for strength, 17 for balance and 6 for flexibility. The programme was performed by physical-activity instructors in five day-activity centers in groups of eight to ten participants; staff of day-activity centers worked together with the physical-activity instructors in motivating the participants and performing the activities. The programme guidelines prescribed endurance activities for three times a week. The first six weeks (the initial phase) allowed the participants to get used to their new activity

programme and to increase their self-confidence in and enjoyment of participating in the physical activities. Physical-activity instructors were asked to start with low-intensity activities with a duration of 10 to 20 minutes per session. After six weeks, the physical-activity instructors were asked to increase the duration to 30-40 minutes per session and to increase the intensity step by step, depending on participants' individual abilities and motivation. Activities focusing on strength, balance and flexibility were also included in the exercise sessions, but these were not explicitely analysed in this paper.

Instruments

Monitoring heart rate during exercise

The Polar RS400, a wrist-worn device in combination with a chest belt for the sensor, was used to monitor the heart rate during all activities of the physical activity programme. The software automatically records the amount of seconds that a person trains in 6 heart rate zones: 0-89 heart beats per minute, 90-107, 108-127, 128-145, 146-168 and >168 heart beats per minute. The software also monitors the peak and minimum heart rate during each exercise session. Data of the month November was excluded because it was part of the initial phase in which only low intensity activities were performed. Data of the month June was excluded because the programme stopped in this month. Variables regarding the intensity of training were calculated as follows:

- The duration (amount of seconds) that was exercised in each heart rate zone was assessed per session. Subsequently the mean duration exercised in each intensity zone was calculated including data from December 2010-May 2011.
- The minimum heart rate was defined as the mean of the minimum heart rate of all sessions.
- The mean peak heart rate was defined as the mean of the maximum heart rate in all sessions.
- The mean maximum increase of the heart rate during exercise was calculated by the mean peak heart rate minus the mean minimum heart rate.
- The predicted maximal heart rate was calculated with the formula of Fernhall et al, 2001: 210-(0.56*age) - 15.5 - 15.5 (if the participant had Down Syndrome).
- The heart rate peak as percentage of the maximum predicted heart rate is defined as the mean peak heart rate/ predicted maximum heart rate * 100%.

Attendance of participants and programme administration

Physical-activity instructors registered per session which fitness components they trained, which activities they executed, the duration of each activity and the presence of participants. Attendance was defined as the percentage of exercise sessions in which the participants participated during the intervention period of eight months. Physical-

activity instructors informed the researcher about the exercise frequency in a gymnasium, as opposed to other rooms.

Participant characteristics

Sex and age were collected from the records of the care provider services. General practitioners and specialised physicians for people with ID recorded etiology (e.g. Down syndrome, Rett syndrome, Prader-Willi). Information about the level of intellectual disability (mild, moderate, severe), severe behavioural problems (yes/no) and autism (yes/no) was provided by behavioural therapists (psychologists) working for the care provider services.

Health at baseline

Physical activity was measured with pedometers (NL-1000) during at least 4 days [16].

Weight was measured using a digital floor scale (Seca robusta type 813), with participants wearing light clothes and no shoes.

Aerobic performance was assessed with the Incremental Shuttle Walking Test (ISWT) [17]. The participant started walking a 10-m section at 0.50 m/s together with the test instructor. Every minute, the test instructor increased walking speed by 0.17 m/s in accordance with the test procedure; the participant continued walking until he or she could no longer keep up with the pace. The test was executed twice for each participant with at least one hour in between. The best result was used for analyses; i.e. the longest time that the participant was able to keep up with the pace. The test-retest reliability in older adults with ID is good [18].

Walking aid: professional staff in day-activity centers registered for each participant if he or she walked with or without support in-house (cane, walker or walking frame).

Cardiovascular problems were assessed with a checklist administered by general practitioners and ID physicians and included: heart failure, the use of a pacemaker, peripheral arterial disease, valve abnormalities/congenital heart defects, stroke, coronary artery disease, cardiac arrhythmias.

Use of medication was noted by general practitioners and specialised physicians for people with ID.

Procedure

Measuring heart rate

Participants were asked to wear a heart rate monitor during each exercise session. The physical-activity instructor and/or staff of day activity centers helped the participants to put the heart rate monitors and sensor on and off. They also pushed the buttons to start and end recording. Once per 6-8 weeks the researcher downloaded the data to a

computer. Invalid data with 'flat lines' for at least two minutes were excluded from the analyses. If more than 50% of the programme duration had to be excluded because of invalid data, all data of that particular exercise session were excluded.

Effect measurements of aerobic performance

The ISWT was assessed two times: at baseline and after eight months at the end of the intervention period. The test was performed in or nearby the day-activity centers by specially trained physical therapists and medical assistants, experienced in supporting older adults with ID, but not involved in the execution of the intervention, thus adopting the procedure followed by Hilgenkamp et al [19]. Participants with a medical contra-indication for intensive physical activity were excluded from the ISWT. In addition, if professional caregivers indicated that a participant would be burdened because of the measurements or if the participants indicated verbally or non-verbally that they did not want to participate, the measurements were not performed or were stopped immediately.

Statistical analyses

Descriptive analyses were performed to describe participant characteristics and heart rate levels. Pearson's correlation coefficients were calculated to test the association between participants' heart rate levels with participant characteristics, health at baseline and programme characteristics. Pearson's correlations were also calculated between improvement of aerobic performance with participant characteristics, health at baseline, and programme characteristics and active participation (attendance rate, attained heart rate levels, duration of activities and frequency of endurance exercise).

Because the intervention was performed in clustered groups, cluster effects may have had impact on the significance of the correlations between outcome measures. Therefore, not linear regression models, but generalised linear models (GLM) with random effects were used to test the significance of the correlations, correcting for day-activity center as cluster.

Results are presented of data from the final models. These include all participant characteristics that were associated univariately with one or more outcomes on heart rate or change in aerobic performance ($p<0.05$). Variables concerning health at baseline, programme characteristics and (in the analysis of aerobic change) heart rate levels during the programme were only included in the final model, if they were significant ($pwald<0.05$). Analyses were performed with SPSS statistics 20.

RESULTS

Participant characteristics

Data of three participants with pacemaker were excluded. Mean age of the 63 remaining participants was 58 years (range 44 to 83 years). Most of them had a moderate ID (Table 1). In total, 23 participants were overweight (BMI between 25 and 30) and 16 were obese (BMI>30). Physical activity measurements at baseline were available for 26 participants; 21 walked less than 7500 steps per day necessary for health benefits ([20] and 13 walked less than 5000 steps per day (sedentary). In total, 23 participants received medication that may have influenced their heart rate during physical activities.

For 58 of the 63 participants, data were available from the ISWT at baseline and for 49 of these 58 participants post intervention data were also available. Causes for missing data were medical contra-indication (n=4), technical problems with the cardiac monitor (n=10), unwillingness to participate (n=2) and participant burden according to a caregiver (n=1). The 49 older adults who participated in both pre- and post intervention measurements of the ISWT, improved their aerobic performance with 26 seconds,

Table 1: Participant characteristics at baseline (n=63).

Participant characteristics	n	mean	range
Age	63	58.2	(44-83)
Sex (Men)	27/63	43%	-
Intellectual disabilities			-
Mild	14/63	22%	
Moderate	35/63	56%	
Severe	13/63	21%	
Unknown	1/63	2%	
Down syndrome	9/61	15%	-
Autism	10/58	16%	-
Severe behavioural problems	14/58	24%	-
Health			
Use of a walking aid	14/63	22%	-
Body Mass Index	56	30.0	(20.1 - 47.9)
Physical activity (steps per day)	25	5634	(1198 - 15156)
Aerobic performance (minutes:sec ISWT[1]) pre-intervention	55	5:20	(1:00 - 9:26)
Aerobic performance (minutes:sec ISWT) post-intervention	49	5:44	(1:12 - 12.09)
Cardiovascular conditions	11/57	22%	-
Medication which may affect cardiovascular reactions			
Beta-blockers	4/57	10%	-
Betasympaticomimetics	5/57	8%	-
Antipsychotics	19/57	32%	-
Antidepressants	10/57	17%	-

[1] *ISWT:Incremental Shuttle Walking Test*

whereas a decline of 17 seconds among controls (n=37) was observed (pwald=0.085) [13].

Attendance to and execution of the physical activity programme

On average, the 63 participants who completed the programme were present during 78% of all the exercise sessions, provided three times a week during eight months (SD = 16). In 81% of all provided sessions, aerobic activities were executed, whereas 100% (three times a week during eight months) was prescribed in the programme guidelines. The duration of the aerobic activities ranged from 5 minutes to 80 minutes per session; the average duration was 22 minutes (SD 12.4). The executed aerobic activities included walking, dancing and game-like activities such as tag along and running track.

Heart rate during the physical activity programme

The total amount of sessions per participant that provided valid data about the heart rate ranged from 15 to 73 sessions (out of a maximum of 78 sessions for each participant executed in the period from December until June), data of 42,5 sessions on average. The lowest heart rate during the physical-activity sessions (minimum heart rate) ranged from 46 to 110 beats per minute (Table 2). Sixty-one of 63 participants reached the intensity level of 90 beats per minute at least once during the intervention period. The average time they trained at a level higher than 90 beats per minute was almost 20 minutes per session (Table 2). The average heart peak during exercise ranged from 49% of the predicted maximum heart rate to 92% (see Table 2). The average maximum heart rate increase during exercise ranged from 18 to 72 beats per minute. Fifty-three participants did reach the intensity level of 108 beats per minute and trained for almost 7 minutes on average at this intensity level or higher. Twenty-four participants trained one minute and 18 seconds on average with at least 126 beats per minute.

Table 2: Average heart rate of participants during exercise (n=63).

		mean	SD	Range
Mean minimum heart rate (bpm*)		72	11.9	(46-110)
Maximum heart rate increase during exercise (heart bpm)		35	11.5	(18-72)
Peak heart rate as % of maximum predicted heart rate (bpm)		67	9.9	(49-92)
Average duration (min:sec)	≥90 bpm per session	19:26	16:08	(0:0-55:11)
Average duration (min:sec)	≥108 bpm per session	6:56	10:27	(0:0-51:48)
Average duration (min:sec)	≥126 bpm per session	1:18	2:56	(0:0-14:33)

*Beats per minute

Correlates of heart rate

In this paragraph is described to what extent peak heart rate, heart rate increase and the amount of time exercised at different heart rate levels are associated with participant characteristics, health parameters, and programme characteristics. In Table 3, univariate correlations with heart rate during physical activity are presented; Table 5 shows the results of the final generalised linear models. Multicollinearity did not occur in any of the regression analyses; variance inflation factors were between 1.2 and 4.3, thus below the cut off score of 10.

Table 3: Pearson correlations between the heart rate during physical activity and participant characteristics, baseline health and program characteristics.

	n	Minimum HR[1]	Minutes ≥90 bpm[3]	Minutes ≥108 bpm	Minutes ≥126 bpm	Maximal HR Increase	Peak HR as % max HR
Participant characteristics							
Age	63	-.15	-.24	**-.33****	**-.25***	**-.45****	**-.33****
Male	63	-.06	-.02	-.16	-.15	-.05	-.05
Level ID	62	.09	.13	.11	.22	.17	.19
Down syndrome	63	**-.36****	-.18	-.11	-.08	**.40****	.20
Autism	58	**.30***	.24	**.40****	**.37****	-.09	.13
Severe behavioural problems	58	**.31***	**.39****	**.40****	**.53***	**.40***	**.48****
Baseline Health							
Body Mass Index	56	-.11	-.04	-.10	-.03	.23	.15
Walking aid	63	**-.34****	**-.32***	-.24	-.02	-.12	**-.28***
Physical activity	25	-.22	-.08	-.02	.06	.22	-.08
Aerobic performance	55	.07	.15	.23	.15	.25	.17
Heart failure	57	-.14	-.15	-.11	-.11	-.01	-.09
Medication							
Antipsychotics	57	.17	.09	.19	.05	.03	.09
Antidepressants	57	.25	.14	.18	.01	**-.28***	-.07
Betablockers	57	-.07	-.10	-.09	-.06	-.13	-.12
Betasympaticomimetics	57	.00	-.03	-.03	-.07	-.10	-.08
Program characteristics							
Exercise gymnasium	63	-	**.42****	**.37****	**.29***	**.25***	**.31****
% CV[2] in sessions	63	-	**.45****	**.29***	.19	.13	**.35****
Duration CV	63	-	-.06	.18	.20	-.09	-.15

*=p<0.05 **=p<0.01 [1]HR: heart rate [2]cardiovascular activities [3]bpm: beats per minute

Participant characteristics

Participant characteristics were independently associated with heart rate during exercise (Table 5), including age, severe behavioural problems, Down syndrome and autism. Higher age correlated negatively with the intensity of exercise. Severe behavioural problems ware associated with longer exercise at relatively higher heart rate levels, higher heart rate increase and peak heart rate. Down syndrome was associated with lower heart rates at start, and higher increase of their heart rate. Autism was associated with more minutes exercise on higher intensity heart rate levels (>108bpm).

Health at baseline

The use of a walking aid was independently associated with minimum heart rate (Table 3 and Table 5). The use of antidepressants was univariately but not independently associated with less heart rate increase. No other significant correlations were found between the heart rate during exercise and the use of heart rate increasing/suppressing drugs or other baseline health measurements.

Table 4: Pearson correlations between the change in aerobic performance and participant characteristics, measures of health, programme characteristics and participants' cardiac response.

	n	Change in aerobic performance pre-post intervention
Participant Characteristics		
Age	49	-.06
Sex (Male)	49	.11
Level intellectual disability	48	.05
Down syndrome	49	-.30
Autism	45	-.02
Severe behavioural problems	45	.37*
Baseline Health		
Body Mass Index	46	.17
Walking aid	49	-.05
Physical activity	19	.29
Aerobic performance	49	-.24
Heart failure	45	-.13
Programme characteristics		
Exercise in gymnasium	48	.11
% cardiovascular exercise	49	.23
Duration cardiovascular activities	49	.11
Heart rate during programme		
Minutes HR[1] ≥56	48	.09
Minutes HR ≥ 90	48	.32*
Minutes HR ≥108	48	.33*
Minutes HR ≥126	48	.27
Maximum HR increase	48	.17
Peak HR % of maximum predicted HR	48	.27

*=$p<0.05$ [1] HR: heart rate

Programme characteristics

More frequent exercise in a gymnasium was independently correlated with more minutes exercise at higher intensity levels and higher maximum heart rate increase (Table 3 and Table 5). Including aerobic activities in the exercise sessions was associated with more minutes exercising at intensity levels of at least 90 and 108 beats per minute and higher peak heart rates (see Table 3). However, this association was not confirmed by GLM analysis (Table 5) .

Predictors for change in aerobic performance

Down syndrome was negatively and severe behavioural problems were positively associated with improvement on aerobic performance (Table 4 and 5). Training more minutes at an intensity level of at least 90 beats per minute or at least 108 beats per minute are univariately correlated with better aerobic improvements (see Table 4), but no independent associations were found (Table 5).

Table 5: Standardised coefficients of predictors for heart rate during physical activity and change in aerobic performance.

	Minimum HR[1]	**Minutes ≥90 bpm**	**Minutes ≥108 bpm**	**Maximal HR Increase**	**Peak HR as % max HR**	**Change aerobic performance**
	Adjusted R square .30** **Beta**	Adjusted R square .29** **Beta**	Adjusted R square .36** **Beta**	Adjusted R square .46** **Beta**	Adjusted R square .29** **Beta**	Adjusted R square .16* **Beta**
Participant characteristics						
Age	-.26**	-.23**	-.36**	-.20**	-.24**	.-10
Down syndrome	-.40**	-.20**	-.16**	.34**	.15*	-.37*
Autism	.19**	.05	.30**	-.28**	-.02	-.14
Severe behavioural problems	.12	.28*	.15**	.47**	.46**	.36**
Baseline Health						
Walking aid	-.20*	nf	-	-	nf	nf
Antidepressants	-	-	-	nf	-	-
Programme characteristics						
Exercise in gymnasium	-	.31**	.22	.22**	nf	-
% CV[2] in sessions	-	nf	nf	-	nf	-
Heart rate during programme						
Minutes HR ≥ 90 bpm	-	-	-	-	-	nf
Minutes HR ≥ 108 bpm	-	-	-	-	-	nf

*=pwald<0.05 **pwald=p<0.01 [1]HR: heart rate [2]CV: cardiovascular activities; -: not included in analyses; nf: included in analyses, but not included in final model.

DISCUSSION

Main findings

To our best knowledge, this is the first study that reports on heart rates of ageing adults with intellectual disabilities (ID) in response to an eight month physical activity and fitness programme. In addition, we looked at predictors for higher heart rate levels and changes in aerobic performance. Our main conclusion is that there is a large variation among the participants in attained peak heart rate and heart rate increase during the programme and that participant characteristics seem to be important predictors for attained heart rate levels. Heart rate increase in response to physical activity was positively associated with being younger, Down syndrome, having severe behavioural problems, and negatively associated with autism. Participants exercised more minutes at an intensity level of at least 90 or 108 heart beats per minute if activities were performed in a gymnasium. Improvement in aerobic change was positively associated with severe behavioural problems and negatively associated with having Down syndrome, although explained variance was small.

Within this study, the participants mostly exercised at low intensity levels (lower than 108 heart beats per minute) with a few minutes at moderate intensity levels (more than 108 heart beats per minute). Down syndrome was associated with low minimum heart rates, but with higher heart rate increase. This last finding is in contradiction with findings from other studies [11, 12, 21, 22]. However, despite the relatively high heart rate increase, Down syndrome was negatively associated with aerobic improvement.

Notable were (continuous) high heart rate levels of participants with autism during the physical activities; these may have been a result of reduced cardiac parasympathetic activity as demonstrated among children with autism [23]. Severe behavioural problems were associated with a higher heart rate increase, higher maximal peak heart rate and more improvement in aerobic performance. Regarding this appropriate cardiac response to physical activity, combined with improvement on aerobic performance, we assume that the heart rate increase of these participants was not (only) caused by arousal.

Only small univariate correlations were found between heart rate and the use of beta- blockers or betasympaticomimetics. However, only few participants used these drugs. The univariate association between the use of antipsychotics and heart rate was positive, as was to be expected (www.whocc.no/ATC/DD), but small.

Although participants mainly participated at low intensity levels in the programme, on average they improved their aerobic performance, whereas a decline was seen among controls [13]. Furthermore, significant changes in health parameters were found. Regarding the low physical activity of older people with ID in general [24], as well as their low physical fitness levels [1] and high levels of frailty [25, 26], we expect that lower levels of weekly energy expenditure might be sufficient to establish positive health

effects [27]. With lower levels we mean lower than the recommendations of the American College of Sports Medicine and the American Heart Association for older adults, including the need for moderately intensive aerobic physical activity for a minimum of 30 minutes on five days each week [15].

Strengths and limitations of the study

The strengths of the study include the content and duration of the programme, broad variability of participants, and monitoring of performance and active participation (heart rate).

The physical activity and fitness programme was based on available evidence and accepted standards and conducted by experienced physical-activity instructors, working at the participating care provider services. Moreover, participants with different levels of intellectual disability, people with autism, people with severe behaviour problems and people with Down syndrome, obese people and people using a walking aid. The presence of these aspects add to the ecological validity of the intervention. External validity, however, may be limited because of the low participant numbers. Different from other studies [28], in this study data about the frequency, duration and intensity of activities were gathered and reported. These extensive evaluations enabled studying key elements in this intervention, that contribute to its effectiveness.

Limitations of this study concern the variation in physical functioning (e.g. mobility, baseline health), incomplete data of heart rate due to exclusion of invalid data and the limited sample size. The participants of this study were divided into eight different groups. The physical-activity instructors chose physical activities that were suitable for the whole group. A (lower) level of physical functioning of group-mates may have limited the possibility of more intensive participation by others. A random part of the heart rate data had to be excluded, because they were invalid (flat lines etc). This implies that the calculated amount of minutes exercised at different intensity levels are an underestimation of the minutes exercised at that levels. This includes an important bias in the data presented in this paper, although we do not have a reason to assume that the invalid data were associated with any specific intensity level.

The formula of Fernhall to predict the maximal heart rate for people with ID with and without Down syndrome was developed based on findings of a study among participants in the age of 8-46 years [9]. No older adults with ID were included. We do not know to what extent the formula is applicable to 45+ adults with ID, but we expect that it overrates the predicted maximal heart rate. This would affect the results about the attained percentage of maximal heart rate (it would be higher) and the association with change in aerobic performance (it is not sure how this would affect the presented results).

The limited power of the study has impact on the reliability of the described results and may have led to underreporting of predictive factors. Therefore, this study provides preliminary data about the heart rate response to physical activity executed in clinical practice.

Recommendations for practice and further research

Aerobic activities should be part of any physical activity programmes for (ageing) adults with ID. Including moderately intensive activities may be enough to improve aerobic performance. Regarding the physical frailty of ageing people with ID, it is recommended that experts on physical activity with this subgroups such as physical therapists and physical-activity instructors, put the programme together and remain involved in supervising the activities as leader or as coach for staff. Exercise in a gymnasium better allows active participation than exercise in other rooms and facilitates heart rate increase. Large empty rooms may also be used to exercise, if the rooms are adequately equipped and safety precautions are taken. Although a large variation is found between participants' heart rates, the variation within participants was small, indicating that monitoring heart rates can be done periodically instead of during each exercise session.

Further research among people with ID and ageing adults with ID in particular, could provide more insight into the mechanism of cardiac response to low- to medium-intensive physical activities and improvements in aerobic performance. Heart rate measurements during physical activities among a larger amount of participants could provide more insight into factors contributing to or hampering heart rate increase. It would also be interesting to investigate if other positive health outcomes than change in aerobic performance, such as blood lipids and blood pressure, can be attained by exercising at low to moderate intensity levels. When evaluating the heart rate levels of people with Down syndrome, researchers and or physical activity experts should take their low minimum heart rate into account. High heart rate levels during physical activity among people with autism and the impact of these high levels on their health could be a new topic of fundamental and clinical research.

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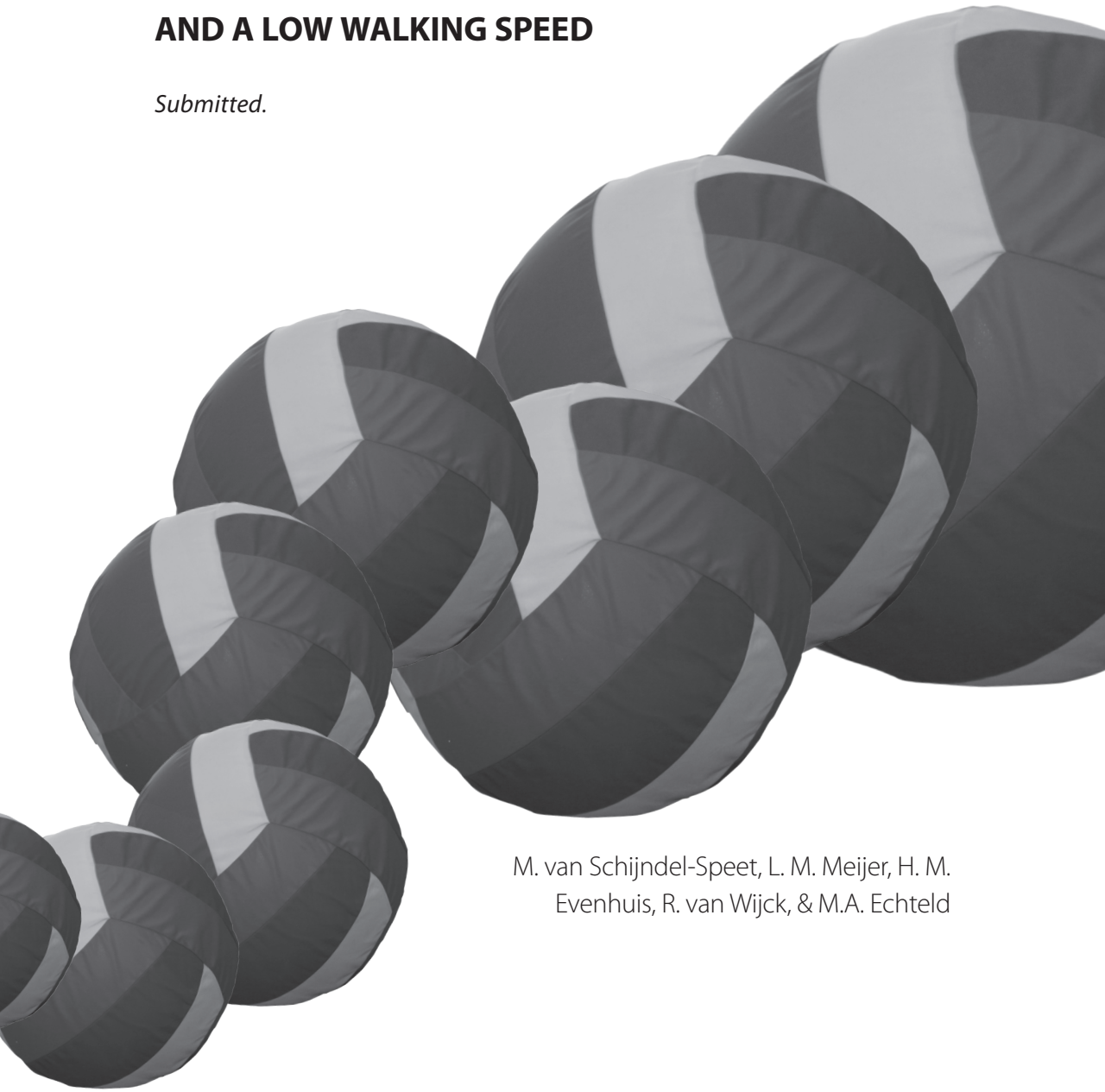
6

APPLICABLE AND VALID MEASUREMENTS OF PHYSICAL ACTIVITY AMONG PEOPLE WITH INTELLECTUAL DISABILITIES AND A LOW WALKING SPEED

Submitted.



M. van Schijndel-Speet, L. M. Meijer, H. M. Evenhuis, R. van Wijck, & M.A. Echteld

ABSTRACT

The applicability and validity of the StepWatch Activity Monitor™, an accurate device to detect steps among people with deviant walking patterns, were assessed in ageing people with ID and a low walking speed (<3.2 km/h). Applicability was evaluated by registration of the drop-out during measurements with the StepWatch in daily life. Of total 36 participants, 19 dropped out because they refused (8 participants) or because their caregivers indicated potential burden (11 participants). On average, physical activity data of the required minimal 4 days were available after 6 days of which the participants had the monitor in their possession (range 4 to 12 days).

Validity was evaluated against a gold standard, defined as the number of steps counted during video-observation. Participants walked 150 meters, in five rounds of 30 meters at their own comfortable walking speed indoors. Measurements of the much cheaper NL-1000 were also evaluated, to explore the magnitude of its deviation from the gold standard. Data of 25 participants were included in the analyses. The StepWatch underestimated 0.5% of the steps on average, with a range of 30% to -17 %. The Intraclass Correlation Coefficient (ICC*)* for steps recorded by the StepWatch and the gold standard was .93 (lower bound .84, upper bound .97, $p<0.01$). The average underestimation of steps detected by the NL-1000 was -55% to the gold standard with a range of -99% to 6%. The *ICC* for steps counted by the NL-1000 and the gold standard was .08 (lower bound -.32, upper bound .45; $p=.36$). Bland-Altman plots confirmed that the range of discrepancies between NL-1000 scores and Gold standard was wider than the discrepancies between StepWatch scores and Gold standard.

The StepWatch Activity Monitor™ provides valid measures of physical activity among people with intellectual disabilities (ID) with low walking speeds; the NL-1000 largely underestimated the steps taken. However, comparable to the NL-1000, the StepWatch's applicability in daily circumstances is impaired by anticipated burden or carelessness with the expensive device.

INTRODUCTION

In a recent large-scale study of physical activity in older adults with intellectual disabilities (ID), it was found that at least a quarter of the study population had a walking speed lower than 3.2 km/h [1], which is the threshold for valid measurements with the applied pedometer (NL-1000) [2]. Because self-report data on physical activity or information by observants appear to be unreliable [3], more sensitive and thus more expensive monitors are required to reliably measure the physical activity levels of subgroups with a low walking speed, such as frail elderly [4-7]. In this study, the validity and applicability of such a device is tested in slow-walking older people with ID.

The StepWatch Activity Monitor™ (Orthocare Innovations, Seattle, Washington) is a device that accurately detects steps in people with a low walking speed, with a high BMI, who use walking aids, and in other populations with divergent walking patterns [7-9]. People with ID often have a divergent walking pattern due to neurological and physical impairments, and differences of validity of pedometer measurements have been demonstrated earlier between adults with Down syndrome and non-handicapped people [10]. In addition, information about the applicability of devices such as the StepWatch for older people with ID and a low walking speed is lacking.

Therefore, applicability and criterion validity of the StepWatch were assessed in ageing people with ID and a low walking speed. Because the StepWatch is a rather expensive instrument, we also evaluated measurements of the much cheaper NL-1000, to explore the magnitude of its deviation from a gold standard. In addition, we evaluated the extent to which deviation from the gold standard was correlated with BMI and the use of a walking aid, because these variables may impact the validity, specifically of (accelerometer based) pedometers [11].

METHODS

This was a cross-sectional validation study, using video-assisted step counts as the gold standard against steps registered by the StepWatch en NL-1000. Applicability was evaluated by measuring the drop-out when using the StepWatch in daily life.

Study population

All participants with walking speeds below 3.2 km/h included into a Dutch physical activity programme (Healthy Ageing- Physical Activity Programme for ageing adults with Intellectual Disabilities HA-PAP) for ageing adults with ID, were included. Ethical approval for this study was obtained from the Ethics Committee of the Erasmus University Medical Center Rotterdam (number NL29573.078.09) and the ethical committees of

the three Dutch care providers participating in the study. In total, 36 out of 40 eligible people consented to participate.

Sixteen out of the 36 participants participated in the applicability study in daily life. Eight participants refused to participate specifically in this part of the study. Eleven participants were excluded, because the caregiver expected that the participant would be burdened by wearing the StepWatch during the day and/or would take the StepWatch off and throw it away. One person was ill. The average walking speed was 2.1 km/h (SD:0.6 km/h) with a range of 1.0 to 3.0 km/h, and the median was 2.0 km/h.

Data of 25 out of 36 participants were included for the validation study; two participants did not participate in the validity measurements because they had other appointments and or activities, two refused and two were ill (2). The data of five participants could not be used, because of one malfunctioning instrument and four cases of violations of the StepWatch protocol instructions. The mean age of the 25 participants was 61 years and most of them had a moderate intellectual disability (Table 1). The average walking speed was 2.1 km/h (SD:0.6 km/h) with a range of 1.2 to 3.2 km/h, and the median was 2.1 km/h.

Table 1: Characteristics of participants.

	Validation measurements n=25			*Measurements in daily life n=16*		
	n	Mean	SD (Range)	n	Mean	SD (Range)
Sex *(men)*	8/25	-	-	5/16	-	-
ID *(mild)*	2/25	-	-	2/16	-	-
(moderate)	19/25	-	-	13/16	-	-
(severe)	4/25	-	-	1/16	-	-
Walking frame *(yes)*	13/25	-	-	5/16	-	-
Age *(years)*	25	61	9.0 (49-83)	16	61	9.0 (50-77)
Height *(cm)*	25	156	11 (135-177)	16	157	12 (135-177)
Weight *(kg)*	25	70.5	20.1 (45-138)	16	73	20.4 (47-138)
BMI	25	29.0	7.9 (21-61)	16	29.9	8.9 (24-62)
Gait speed *(km/h)*	25	2.1	0.6 (1.0-3.2)	16	2.1	0.6 (1.2-3.0)

Instruments

StepWatch™ . The StepWatch™ 3.1 is an accelerometer-based pedometer that measures vertical and horizontal acceleration [5,7,12,13]. The device can be adjusted to personal characteristics such as body height, walking speed, leg movement, quick stepping and range of speed. The StepWatch is attached at the ankle using an elastic strap. Step counting data can be stored for 30 days in various length epochs and information about time spent in different categories of intensity is also provided. StepWatch analysis software

version 3.1 was used for the analysis. Besides the number of steps per day, the StepWatch also measured the intensity of steps taken at three intensity levels: 1) less than 30 steps a minute; 2) between 30 and 80 steps a minute and 3) more than 80 steps a minute.

NL-1000. The NL-1000 (NEW-LIFESTYLES, Missouri USA) is a hip-worn device that measures vertical acceleration [5, 11]. Registration of the acceleration in relation to gravitation is used to record steps. The number of steps can be read directly from the display. The NL-1000 has the capacity to store the data over seven days, in 1-day segments. Moreover, data about the duration of intensive physical activity are given [14].

Gold standard. Criterion-validity is the degree to which the scores of an instrument are an adequate reflection of a 'gold standard' [15]. The gold standard was defined as the number of steps counted during video-observation. A step was defined as a clearance of the foot and shift of bodyweight to that foot.

Walking speed. Walking speed has been determined by recording the time a participant needed to walk 5 meters at their own comfortable walking speed in a standardised indoor setting. The average of three walking times was calculated [16, 17].

Anthropometric characteristics and walking aid. Anthropometric characteristics were measured during the baseline measurements of the trial. Participants' height and weight were collected according to the methods used in the: "Healthy Ageing with Intellectual Disabilities" study (HA-ID) [16, 18]. The use of walking frames was registered by the researchers.

Procedure

Data for the current study were collected in the period that the effect measurements of the clinical trial took place.

Applicability

Applicability was evaluated by measuring the drop-out when using the StepWatch in daily life. In addition, the amount of days the participants had the monitor in their possession until physical activity data for a minimum of 4 days were available, was calculated. Data of the required minimum of 4 days is necessary to achieve a reliable measure of the mean physical activity level of older adults with ID [19]. Participants were asked to take the StepWatch to their homes and to attach the monitor in the morning and remove it when they went to sleep, if necessary with help from caregivers. A written instruction was provided. The researchers stored the data of the monitor after 7 to 10 days. If physical data of less than 4 days were available, these participants were asked to wear the StepWatch another week.

Validation

Validation measurements took place indoors, mostly in a sports hall or community room. The researcher or medical student explained the purpose and procedure of the study to the participant and asked if he or she was willing to cooperate. Prior to the collection of data, a calibration procedure was undertaken according to the instructions provided by StepWatch. The height of each participant, the walking speed (slow) and walking type ('gentle' or 'geriatric') were entered. For each participant, the first steps taken whilst wearing the device were observed to ensure that the device was detecting the steps, as indicated by a flashing light by each step. If the light did not flash, the StepWatch was adjusted to be more sensitive. Participants wore a StepWatch and a NL-1000 on the same side of the body. They were asked to walk 150 meters, in five rounds of 30 meters at their own comfortable walking speed. Walking aids were allowed. The walking activity was video-recorded. The duration of the test was about 15 minutes in total. After walking the five rounds, the registered steps were read from both instruments. Afterwards, two observers independently counted the steps on the video with a manual counter, blinded from the outcomes of the devices. Any differences in counted steps between the observers were resolved by a third observer, who counted the video-taped steps as well.

Analyses

Reasons for dropping out before or during the measurements in daily life were described. Data from the StepWatch were analysed to determine the amount of days the participants had the StepWatch in their possession until four days with data were available.

Instrument performance was calculated as mean percent error, based on the difference between detected steps and video-observed steps: (detected – observed steps) / (observed steps). Intra-Class Correlation Coefficients were calculated to examine the level of agreement between the gold standard and the steps measured with the StepWatch and NL-1000 respectively. In addition, Bland-Altman plots were prepared to explore the distribution of the discrepancies between the measurements of both devices and the gold standard, and overall gold standard values. [18]. Pearson correlation coefficients were calculated between the instrument performance's and BMI, walking speed and the use of a walking frame. SPSS 20.0 for Windows was used for the statistical analyses.

RESULTS

Applicability

As indicated in the methods section, eight participants refused to participate specific in this part of the study and eleven participants were excluded, because the caregiver

indicated potential burden or carelessness with the expensive device. No participants dropped-out during the physical activity measurements in free-living settings. On average, data of minimal 4 days were available after 6.4 days the participants had the monitor in their possession (range 4 to 12 days). Five participants were asked to wear the StepWatch another week because of too many missing data. Except for one participant, all participants wore the StepWatch at least one weekend day (22% of the measured days were weekend days).

Participants walked on average 4844 steps per day (Table 2) in about 180 minutes in total; mostly at low intensity (<80 steps per minute). Participants walked on average 10 minutes a day at an intensity level of more than 80 steps per minute.

Table 2: Number of steps taken in daily life and intensity of taken steps (n=16).

	Mean number of steps			Mean duration (minutes)		
Intensity levels	Min	Max	Mean (SD)	Lowest	Highest	Mean (SD)
Overall	1858	9862	4844 (2645)	81	397	186 (90)
<30 steps per minute	492	2486	1294 (585)	61	289	125 (62)
30-80 steps per minute	782	6562	2551 (1589)	14	131	51 (31)
>80 steps per minute	66	3802	999 (967)	1	37	10 (9)

Validation measurements

In two cases, the steps counted by the two observers watching the video-tape to define the gold standard differed (a difference of one step and two steps respectively). In both cases, the third observer counted the steps as well and her result was taken as the gold standard for both cases.

Table 3 presents the numbers of steps and percentages error of the StepWatch and the NL-1000 with reference to the gold standard. The StepWatch underestimated 0.5% of the steps on average, with a range of 30% to -17 % (Table 3). The *ICC* for steps recorded by the StepWatch and the gold standard was .93 (lower bound .84, upper bound .97, $p<0.01$). The Bland-Altman plot showed that differences between measurements with the StepWatch and gold standard were mostly small over all values of the gold standard. Only one outlier was detected (Figure 1). Error was neither correlated with walking speed ($r=0.06$), nor with the use of a walking frame ($r= -0.05$) or BMI ($r= -0.04$).

The average underestimation of steps detected by the NL-1000 was 55% to the gold standard, with a range of -99% to 6% (Table 3). The *ICC* for steps counted by the NL-1000 and the gold standard was .08 (lower bound -.32, upper bound .45; $p=.36$). The Bland-Altman plot demonstrated that a substantial amount of measurements underestimated the steps truly taken (Figure 2). Error was correlated with lower walking speed ($r=.37$; $p=.06$); no correlations were found between error of NL-1000 and the use of a walking frame ($r=.03$) or BMI ($r=.17$).

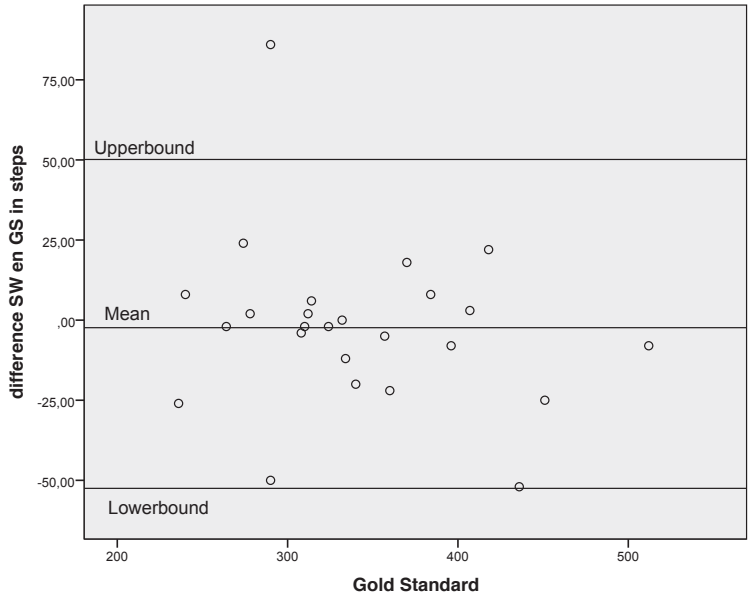


Figure 1: Bland-Altman plot of the measurements with the StepWatch and the gold standard.

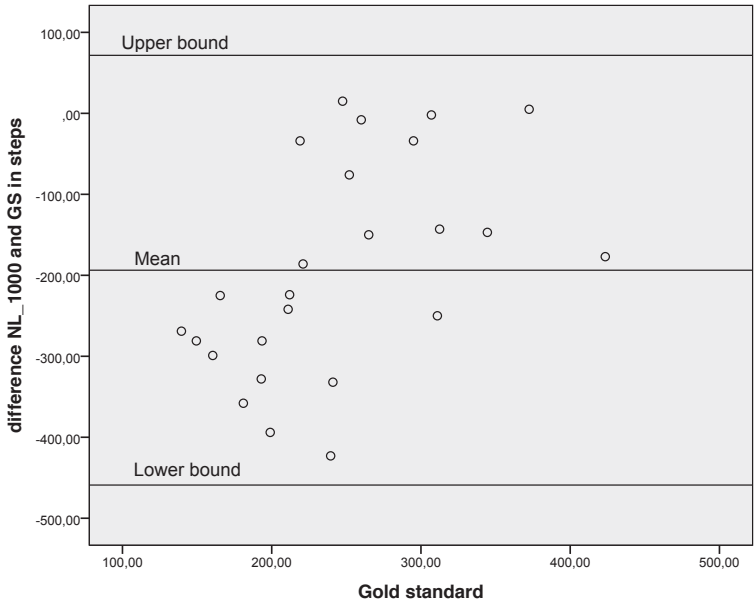


Figure 2: Bland-Altman plot of the measurements with the NL-1000 and the gold standard.

Table 3: Difference gold standard and steps measured by StepWatch and NL-1000 (n=25).

	Difference in steps			Difference in percentage		
	Min	Max	Mean (SD)	Min	Max	Mean (SD)
Stepwatch against gold standard	-52	86	-2.4(26)	-17.2	29.7	-.47 (8.4)
NL-1000 against gold standard	-423	15	-193.7 (133)	-99.5	6.25	-55.2 (37.2)

DISCUSSION

The results of this study demonstrate that the StepWatch Activity Monitor™ provides valid measures of physical activity among people with intellectual disabilities (ID) with low walking speeds. BMI, walking speed, and the use of a walking frame are not correlated to deviation from the gold standard. Applicability in daily circumstances is primarily impaired by refusal, anticipated burden or carelessness with the expensive device. We confirmed that the NL-1000 largely underestimate the steps taken. Valid physical activity data (≥ 4 days) can mostly be stored after a week. However, a check is needed because some people (or their caregivers) forget some days to put the StepWatch on.

The results of this validation study are generally consistent with studies in other populations. Earlier research showed valid measurements of the StepWatch under controlled conditions with an average undercounting or overcounting of maximally 1% of the observed steps under controlled settings [2,21,22]. In studies where several accelerometers were compared within a controlled setting, devices that measure both horizontal and vertical acceleration such as the StepWatch, scored superior in people with low walking speed compared to devices that measure acceleration only on one axis, regardless of the study population (adults, community-dwelling older adults, patients with COPD) [5,7,23-25]. In daily life, the StepWatch counts more steps than other devices, which indicates a superior accuracy [2, 5, 6, 7].

In contrast with most previous studies, the participants did not walk on a treadmill, but walked a trajectory in their comfortable walking speed, if necessary with a walking aid. Another strength of this study is that the StepWatch was tested in free-living conditions, permitting conclusions about the StepWatch's applicability. Only few studies using (accelerometer-based) pedometers in people with ID reported about the drop-out of participants [21, 28]), while this information is very important when using these devices to measure physical activity levels, for example to evaluate the effectiveness of physical activity programmes.

The StepWatch appeared to be a valuable instrument for the measurement of physical activity among ageing adults with ID and a low walking speed. People with a low walking speed are likely to be more prone to lower levels of physical activity, which stresses the importance of adequate physical activity assessment. With its capacity to

be adapted to personal characteristics, divergent gait patterns or gait pattern variability between persons seem to have no impact on the StepWatch's validity. Participants in this study demonstrated a low number of steps on average, mostly taken at low intensity as measured in steps per minute [29]. Physical activity measurements in a larger group are warranted to gain insight in specific subgroups at risk for an inactive lifestyle. The use of the valid StepWatch is recommended if participants accept to wear them. A search for smaller valid devices that can be worn on a place where the participant does not notice it (for example attached to the shoelaces) could enhance the participation rate.

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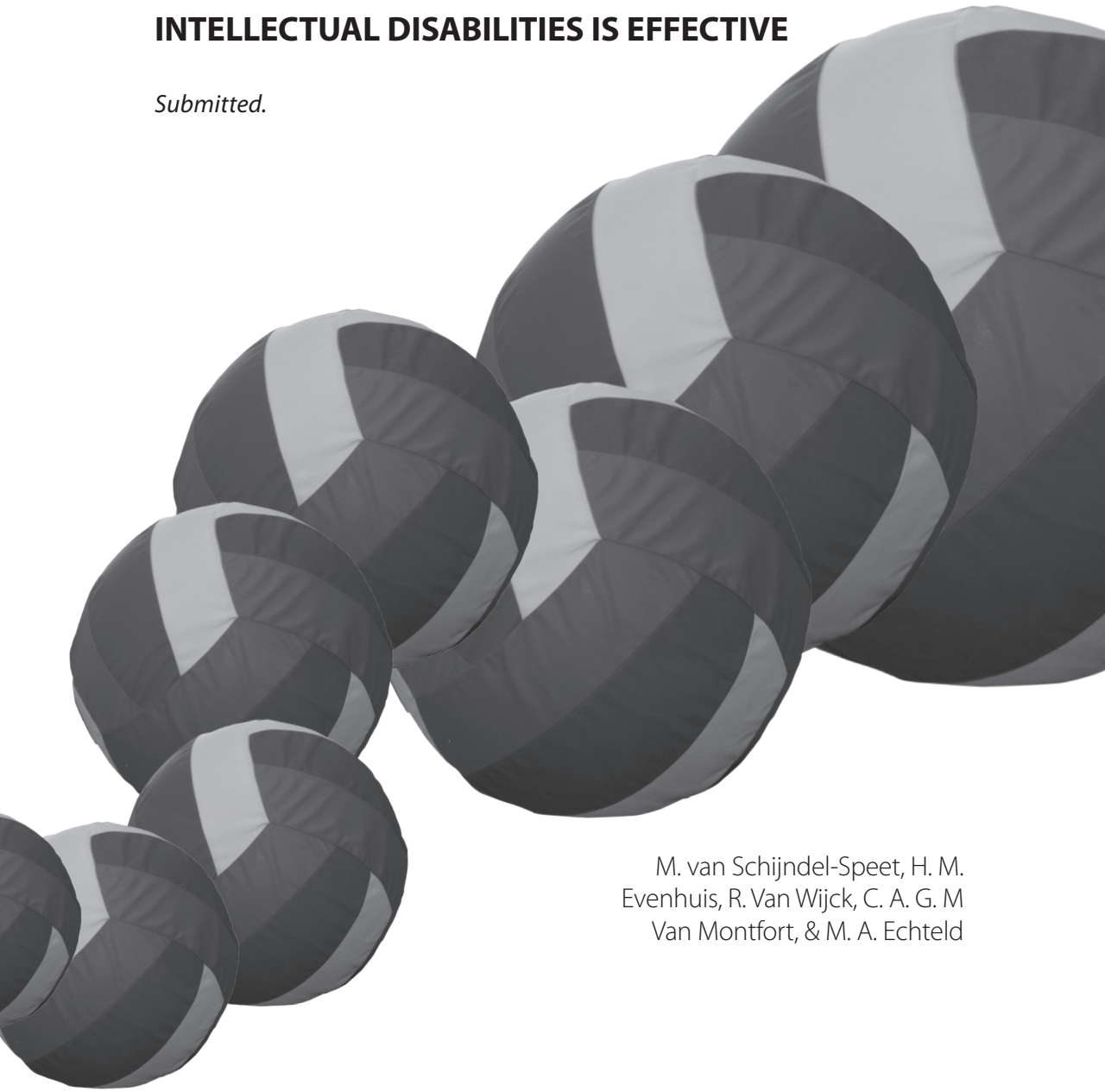
7

RESULTS OF A CLUSTER RANDOMISED CLINICAL TRIAL SHOW THAT A PHYSICAL ACTIVITY PROGRAMME FOR AGEING ADULTS WITH INTELLECTUAL DISABILITIES IS EFFECTIVE

Submitted.



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ABSTRACT

Background The physical activity level of older adults with intellectual disabilities (ID) is extremely low and their fitness levels are far beneath accepted norms for older people with normal intelligence and comparable to frail older people. A physical activity programme, including an education programme was developed for older adults with ID using behaviour change techniques. The programme aimed at improving or maintaining adequate levels of steps per day (primary outcome measure) and motor fitness, cardiorespiratory fitness, morphologic and metabolic fitness, activities of daily living (ADL), cognitive functioning and depressive symptoms (secondary outcome measures).
Method The programme's efficacy was evaluated in a cluster randomised clinical trial among people aged 43 years and over with mild-moderate levels of ID. Five day-activity centers were randomised to the participation group. In these centers, 81 older adults participated in groups of eight to ten in the programme, three times a week during eight months. The programme was executed by physical activity instructors and staff of day-activity centers. Five other day-activity centers were randomised to the control group; 70 older adults in these centers received care as usual. The generalised linear model with mixed effects was used to test the programme's effectiveness.
Results Significant effects were found on steps per day, muscle strength, systolic and diastolic blood pressure, serum cholesterol level and cognitive functioning, in favor of the programme's participants. No significant improvements were found on balance, serum glucose, weight, waist circumference, aerobic performance, walking speed, mobility, depression or (I)ADL.
Conclusions The physical activity programme proved to be effective in increasing physical activity and preventing or delaying deterioration in physical fitness among older adults with ID. In addition, it has positive effects on important risk factors for the development of cardiovascular disease. Implementation of evidence-based physical activity programmes among older adults with ID is recommended. Further research is needed to investigate the effectiveness of physical activity on daily life functioning and the development on chronic diseases in the long run.

INTRODUCTION

The importance of structured physical activity (PA) for older people to delay deterioration of their physical fitness and the development of chronic diseases has been internationally acknowledged [1, 2]. Associations were found between low PA and low physical fitness levels on the one hand and larger ADL dependence on the other hand [3]. It is to be expected that in the long run, low PA and low physical fitness levels will lead to higher frailty levels, poorer quality of life and higher costs of care [4-6].

Older adults with intellectual disabilities have extremely low PA levels [7], whereas their fitness levels are far beneath generally accepted norms for older people with normal intelligence and comparable to those of frail older people [8, 9]. Several studies have been performed to gain insight into barriers to and facilitators for PA in this group [10-12]. However, well-designed and evaluated PA programmes for this population are lacking [13-15].

Therefore, the Intellectual Disability Medicine research group of the Erasmus University Medical Center Rotterdam and the Center for Human Movement Sciences of the University Medical Center Groningen, together with three Dutch ID care provider services, have developed a PA programme, including an education programme, to be executed in day-activity centers for older adults with mild and moderate ID. The programme was based on international guidelines to increase physical fitness or prevent further deterioration in physical fitness and health, proven to be effective among the chronically ill and people over 65 years [16]. Its design was inspired by information collected from clients and other stakeholders, whereas specific behavioural change techniques were systematically applied. Detailed information on the programme's development has been published elsewhere [17].

We performed a randomised clinical trial to study effects of this daycare programme on PA and health parameters of older adults, based on the following study questions:

1. What are the programme effects on the physical activity level (number of steps per day)?
2. What are its effects on physical fitness, cardiorespiratory fitness, morphologic and metabolic fitness, (i)ADL, cognitive functioning and depressive symptoms?

METHODS

We evaluated the efficacy of the "Healthy Ageing- Physical Activity Programme (HAPAP) for older adults with Intellectual Disabilities". The programme was evaluated in a cluster-randomised clinical trial with a follow-up of eight months (Trial Number: ISRCTN82341588). Ethical approval for this study was obtained from the Medical Eth-

ics Committee of the Erasmus University Medical Center (NL29573.078.09). The study adheres to the Declaration of Helsinki for research involving human subjects.

Selection of day-activity centers and participants

In the three participating ID provider services, nineteen day-activity centers offered recreational activities to the target group. Two day-activity centers with reorganisation problems or substantial staffing problems were excluded. Based on earlier research, we expected to obtain informed consent for about 50% of the participants [18]. Because we planned to conduct the intervention in groups of 8 to 10 older adults, 7 day-activity centers with less than 15 older adults with mild or moderate ID were excluded (see Figure 1).

Participants had to be aged 45 years and over and to be able to participate in group activities. Clients who were dependent on a wheelchair in-house, had dementia or a medical contra-indication for participating in the PA programme, were excluded from the study. Managers of the selected ten day-activity centers provided anonymous information about their clients on date of birth, sex, level of ID, use of walking aid, presence of dementia and the ability to participate in group activities. Clients who satisfied the inclusion criteria were selected. In two day-activity centers, relatively many clients could not be included, because they did not have the ability to participate in groups. To limit a power problem, we decreased the inclusion criteria of age to 40 years for these two day-activity centers. In total, 237 older adults met the inclusion criteria and were invited for the study. If older adults were not sufficiently competent to give informed consent themselves, legal representatives were asked to provide informed consent. Informed consent for blood sampling was obtained separately and was no precondition for participation.

Randomisation

To help ensure comparability of the participants included in the programme and those in the control group, we looked for the best possible match with respect to sex, age, intellectual disability, walking aid use and health care provider. Adequate comparability was tested with chi-square and t-tests. The matching procedure was conducted with the data of the potential 237 participants, invited to the study (see previous paragraph). The best match was found when the ten day-activity centers were divided into two specific groups of five centers each. We subsequently checked the comparability of important day-activity centers' characteristics in both groups, i.e. the availability of a gymnasium nearby and involvement of a physical-activity instructor in the day-activity centers' activities (see Table 1). The chairman of the steering committee, in presence of the researcher and a senior staff member Public Relations, randomly selected one of the two groups of five day-activity centers that would execute the programme. The other group of five day-activity centers would serve as the control group. Because the

implementation of the programme had to be prepared and organised, the sequence was only concealed for the clients and family, not to the day-activity centers' managers. After the informed consent procedure had ended, all participants and/or their families received a confirmation notice of participation in the study and information about the intervention allocation by mail.

Because of the nature of the intervention it was not possible to blind the participants nor the intervention's conductors for allocation. The executors of the baseline and effect measurements were not blinded for allocation, but neither involved in the programme's execution. Study data were entered in the computer by supportive staff members, blind for allocation.

Intervention

In co-operation with managers and professionals of the provider services, we systematically developed a structured PA programme, using the Intervention Mapping protocol [19]. Information from the literature, interviews with older adults with ID and consultancy of movement professionals was applied to develop a feasible and, where applicable, a theory-based programme. In this paragraph the programme is described concisely. A detailed description of the development and content of the programme has been published elsewhere [17].

The intervention programme includes two components: a PA programme and an education programme. The *education programme* was developed to increase participants' knowledge about PA and its benefits to health and well-being. Discussions about experiences with PA and perceived barriers were combined with information about normal bodily reactions to exercise (such as increased heart rate and sweating). The education programme was inspired by the health promotion programme: "Health Matters" for adults with mild ID [20] and developed with experts in educating people with ID and developing suitable educational materials. The *physical activity programme* was based on the guidelines of the American College of Sports Medicine and the American Heart Association [16]. A PA framework was developed [17] to address the fitness components muscle strength, endurance, balance and flexibility, in accordance with the aforementioned guidelines. Although the guideline specifies exercise frequencies of at least five days a week, we chose a programme frequency of three times a week, taking the burden for the older adults and staff into account. Together with physical therapists and PA-instructors, feasible activities were selected and described for each of the selected components: 14 exercises for endurance, 18 for strength, 17 for balance and 6 for flexibility. Older adults in the control group received care as usual; no placebo intervention was used.

Outcome measures and instruments

A wide range of outcomes were measured to evaluate the effectiveness of the day-activity programme. The measurement of flexibility was excluded from this study, because data from a recent study demonstrated that the selected instrument Extended Modified Back Saver Sit and Reach was not reliable for ageing people with ID.

Physical activity

PA, the primary outcome, was measured by wearing a pedometer for at least 4 days [21]. Two different pedometers were used. The NL-1000 (New-Lifestyles, Missouri USA) is a hip-worn device that measures vertical acceleration. It measures reliably at a walking speed of 3.2 km/h or higher [22, 23]. Older adults with a low walking speed (<3.2 km/h) were measured with the StepWatch™ (Orthocareinnovations, Oklahoma City United States), of which we have established a good validity in our target population [24]. The StepWatch™ is an accelerometer attached to the ankle with an elastic strap, and measures vertical and horizontal acceleration [25-27].

Motor fitness

Muscle strength. Grip strength was used as a proxy for muscle strength and was measured with the Jamar Hand Dynamometer (Sammons Preston Rolyan, USA) [28]. The best result of three attempts for both the left and the right hand (with a 1-min-pause between attempts) was recorded.

Balance. The Berg Balance Test is a performance based measure of balance, consisting of 14 observational tasks [29, 30].

Walking speed. Comfortable and maximum walking speed were measured over a distance of 5 m (after 3 m for acceleration) without someone walking alongside. The results of three attempts were averaged to determine the comfortable walking speed; de maximum result of three attempts walking at maximum pace was analysed. The test-retest reliability and feasibility of the three measurements for motor fitness in older adults with ID are good [31, 32].

Cardiorespiratory fitness

Blood pressure was measured twice using an electronic manometer (Omron M7), after at least 2 min of rest in seated position. Older adults using anti-hypertensives C02, beta-blockers C07, ACE-inhibitors C09, diuretics C03 or selective angiotensin II antagonists C09 were excluded from analysis of programme's efficacy on systolic and diastolic blood pressure.

Aerobic performance was assessed with the Incremental Shuttle Walking Test [33]. The participant started walking a 10-m section at 0.50 m/s together with the test instructor. Every minute, the test instructor increased walking speed by 0.17 m/s in accordance

with the test procedure; the participant continued walking until he or she could no longer keep up with the pace. The test was executed twice for each participant with at least one hour in between. The best result was used for analysis. The test-retest reliability in older adults with ID is good [31].

Heart rate The Polar RS400 was used to monitor the heart rate during this test, but also during the PA programme.

Morphologic and metabolic fitness

Weight was measured using a digital floor scale (Seca robusta type 813), with participants wearing light clothes and no shoes.

Waist circumference was measured over the unclothed abdomen at the narrowest point between the costal margin and iliac [8, 18, 34].

Glucose and cholesterol. Venipuncture was performed after an overnight fast. Serum was captured and analysed at the laboratory of the Erasmus Medical Center, which is a reference laboratory, with specific expertise in serum lipid analysis. Analyses were performed all at once after the effect measurements were completed, to prevent differences in the test-reliability. Older adults using glucose lowering drugs A10 or lipid lowering drugs C10 were excluded from the analysis of programme's efficacy on respectively serum glucose levels and serum cholesterol levels.

Functioning in daily life

Mobility was assessed with a questionnaire, asking caregivers about the use of mobility devices and the use of assistance in 6 situations: 1) walking inside in house, 2) walking inside, at school or at work, 3) walking the stairs, 4) walking outside within 50 mtrs, 5) walking outside, more than 50 mrts, and 6) walking outside in the community.

Daily living skills were assessed with the Barthel Index (for Activities of Daily Living) [35] and the Lawton IADL scale (for Instrumental Activities of Daily Living) [36].

Depressive symptoms were assessed with the Dutch informant-report Signalizing Depression List for people with Intellectual Disabilities (SDL-ID) [37].

Cognitive functioning was measured with the Dementia Questionnaire for Persons with Mental Retardation (DMR) [38]; score changes on the subscale for cognitive functioning were used.

Participant characteristics

Gender and *age* data were collected from the records of the care provider services. Participant characteristics were obtained from medical files and files of the behavioural therapists. General practitioners and specialised physicians for people with ID recorded *Down syndrome.* Information about the *level of intellectual disability*, *behavioural problems* and *autism* was provided by the behavioural therapists.

Use of medication: Medication use was noted by general practitioners and specialised physicians for people with ID.

Active participation

Attendance was defined as the percentage that the participant participated in the training sessions.

The intensity of training was measured with the heart rate monitor Polar RS 400. The mean of minutes per session that was exercised with a heart rate of minimum of 108 was calculated. When estimating the maximum heart rate for our subgroup with the formula of Fernhall and colleagues [39], this level of intensity can be classified as moderate intensive activity.

Procedure

Measurements

In September and October 2010 (T=0), the baseline measurements were performed. Participants were asked to wear the NL-1000 on the hip for two weeks. The results were registered by a movement expert or the researcher. The other subject-centered health outcomes (motor fitness, cardio respiratory fitness and morphological fitness) were assessed in or nearby the day-activity centers and performed by specially trained physical therapists and medical assistants, experienced in supporting older adults with ID but not involved in the execution of the intervention [18]. If professional caregivers indicated that a participant would be burdened by the measurements or if the participant expressed him or herself verbally or non-verbally that he or she did not want to participate, the measurements were not performed or were stopped immediately. Participants underwent a venipuncture at home after an overnight fast. Medical assistants handled the serum in accordance with a specific protocol of the Erasmus MC Laboratory, and then sent the serum in a special envelope to the Erasmus Laboratory, where it was stored at -20 degrees Celsius. Caregivers working at the homes of the participants received checklists and/ or questionnaires by mail (Barthel-Index, Lawton-IADL, mobility, SDL-ID, DMR). After three weeks, a reminder was sent to caregivers who had not filled in the questionnaires at that moment.

Four months after the intervention started (T=1), the primary outcome measure: 'PA' was measured again with the NL-1000. After noticing a substantial amount of participants with a walking speed < 3.2 km/h after baseline measurements, StepWatches were used among these participants.

Eight months after the intervention started (T=2) the intervention period ended and all outcome measurements were performed again following the same procedures as at the baseline measurements, including StepWatch measurements.

Six months after the programme had stopped (T=3), the primary outcome: 'PA' was measured with the NL-1000 or the StepWatch.

Intervention

Both PA-instructors and staff of day-activity centers received in September 2010 a one-day training about how to execute the PA programme and the education programme. In October 2010, after the baseline measurements, the programme started in five day-activity centers. The education programme was conducted two times a week, 45 minutes per session and took place just before or just after the PA training. The PA programme was executed three times a week. PA-instructors were asked to start with a duration of 15-20 minutes per training and subsequently expand the duration of the PA to 45 minutes. PA-instructors were responsible for the contents of the activity programme, for adjusting it to the specific interests and needs of their group and for executing the programme correctly and safely, with support from day-activity centers' staff members. PA-instructors registered per training which fitness components they trained, which activities they executed, the duration of each activity and the presence of participants.

Statistical analyses

Descriptive analyses were performed to describe participant characteristics of both control and participation group and PA levels at different moments during the study. We introduced the StepWatch at T=1 (four months after the intervention began), which means that baseline measurements of PA for people walking less than 3.2 km/h were not available. Therefore we compared the PA level measured with the StepWatch during the programme (T=1), with follow-up data collected six months after the intervention had stopped (T=3).

Because the intervention was performed in clustered groups, cluster effects may have had impact on the significance of the outcome measures. Therefore, not linear regression models, but generalised linear models with random effects were used to identify significant programme effects on the primary and secondary outcome measures at the end of the intervention (T=2), correcting for day-activity center as cluster and the outcome measure at baseline. Potential covariates were identified by significant Pearson's correlation coefficients with the outcome variables at baseline. Covariates included age, sex, level of ID, Down syndrome and severe behavioural problems. Only significant covariates were included in the final models. Analyses were performed with SPSS statistics 20.

RESULTS

Participants

In total, informed consent was obtained for 151 of the 237 older adults invited to the study (65%). 81 older adults were included in the five day-activity centers that were randomised in the participation group; 70 older adults started in the control group. In total, 66/81 participants in the intervention group and 65/70 older adults of the control group completed the study. The reasons for drop out are presented in Figure 1. Chronic illness (7) and behavioural problems (7) were the most frequent reasons for stopping. Almost all participants who stopped had a moderate ID; one of them had autism. The age of participants and controls ranged from 42 to 83 years (see Table 1). Most had a moderate ID (80/131), some had a severe ID (20/131). Although we planned to exclude this last mentioned subgroup, we only had the correct information about the level of ID at our disposal after the intervention had started, at which point some people with severe ID appeared to have been included in both the control group and the participation group. For ethical reasons, we decided not to exclude these older adults who did not appear to be burdened by participating in the activities. Of all participants, 69 were overweight (BMI>25) and 36 obese (BMI>30). Baseline PA measurements were available for 64 of the131 participants; 52 walked less than 7500 steps per day necessary for health benefits [40]; of whom 25 walked less than 5000 steps per day.

Participation in the intervention and outcome measurements

Participation, execution and adverse events

The 66 participants who completed the programme were actually present at 78% of all training sessions, provided three times a week during eight months (sd 16%). On average, they trained 6 minutes and 50 seconds (sd: 10:24 min:sec) at moderate intensity (with a heart rate of minimally 108 beats a minute) [41].

During the eight months that the programme was executed, four adverse events occurred. Three participants fell during the physical activities. One participant with diabetes had a hypoglycemic episode at the beginning of the programme. The adverse events did not cause any serious injuries.

Incomplete measurements

Although 66 participants and 65 controls completed the study, not all baseline and/or effect measurements of primary and secondary outcomes were available for each of them. In this paragraph most important reasons for incomplete outcome data are described; detailed information for the primary outcome measure is presented in Figure 1. Potential burden was the most important reason for incomplete data collected by

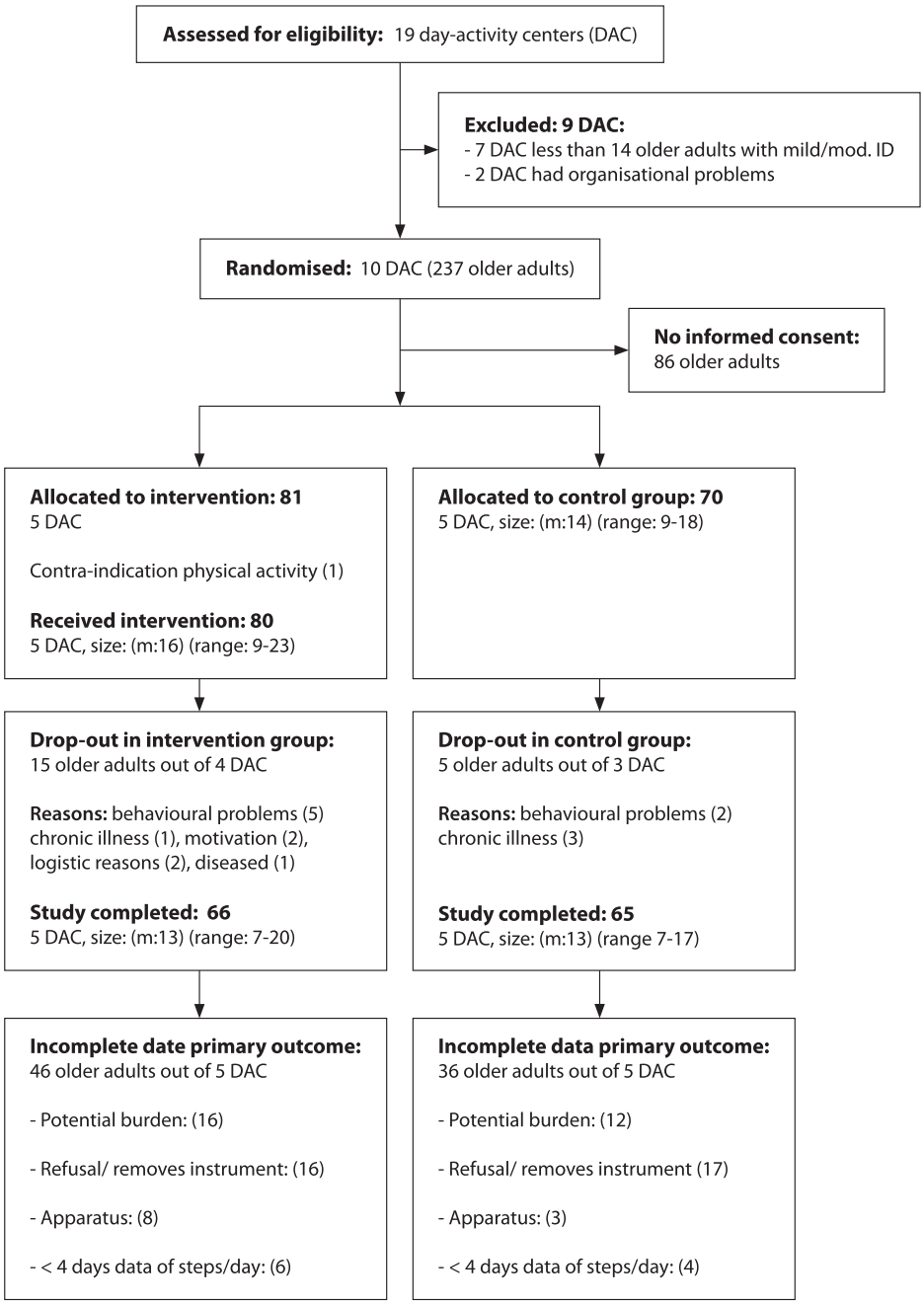

Figure 1: Chart flow day-activity centers (DAC) and participants.

physical measurements, such as PA, physical examination, physical fitness (20-50% of incomplete data). Some older adults were physically unable to participate in all measurements, for example because of mobility problems or cardiac problems (10-40% of the missing data). Problems with the heart rate monitors were the most common reason for missing data concerning aerobic performance (40%). At baseline, PA measurements of people walking < 3.2 km/h were missing because the StepWatch monitors were not available at T=0). Informed consent was obtained separately for blood sampling and obtained for 75% of the participants. In a few cases, blood sampling failed (not enough serum was taken) or deviation from the protocol after blood sampling was noticed. Lastly, logistic problems or illness of participants during the period of measurements caused some of the missing data (about 5%). Causes of incomplete data among older adults in the participation group and the control group were comparable.

Programme's effectiveness

Effects on physical activity level

Table 2 shows the programme's effectiveness on PA (mean steps per day for participants with a walking speed of more than 3.2 km/h). Because of missing data (see Figure 1), numbers of participants are different for T2 and T3. When comparing the PA level of

Table 1: Baseline characteristics of day-activity centers and participants.

Day-activity centers characteristics at baseline	***Intervention group***			***Control group***		
	n			**n**		
Total	5			5		
Gymnasium	3			3		
Activities provided by activity instructor	3			4		
Intramural setting	2			1		
Participant characteristics at baseline	**n**	**mean**	**range**	**n**	**mean**	**range**
Total	66			65		
Age	66	58.2	(44-83)	65	57.9	(42-78)
Sex (Men)	28/66		-	31/65		-
Intellectual Disabilities						
Mild	14/66		-	9/65		-
Moderate	38/66			42/65		
Severe	13/66			7/65		
Unknown	1/66			7/65		
Down syndrome	10/61		-	17/65		-
Autism	10/61		-	3/40		-
Behavioural problems	15/61		-	10/44		-
Walking aid	14/66		-	16/65		-
Body Mass Index	59	27.9	(20.1-47.9)	58	27.5	(20.6-38.9)
Physical Activity	26	5838	(1198-15156)	33	5850	(1173-12210)

Table 2: Changes in steps per day between baseline (T0) and post intervention (T2) and 6 months after the intervention had stopped (T3).

	Intervention group			***Control group***			***Intervention group***			***Control group***		
walking speed>3.2km/h NL-1000		**Difference steps/day (T2-T0)**			**Difference steps/day (T2-T0)**			**Difference steps/day (T3-T0)**			**Difference steps/day (T3-T0)**	
	n	**mean**	**sd**	**n**	**mean**	**sd**	**n**	**mean**	**sd**	**n**	**mean**	**sd**
<5000 steps/day baseline	4	1697	1219	6	207	1333	7	126	1341	2	-347	136
5000-7500 steps/day baseline	5	960	3319	14	-305	1005	5	560	1787	13	-800	1950
>7500 steps/day baseline	5	102	2257	4	-1444	563	4	-607	3107	4	-1305	1201
Total	14	836	2386	24	-368	1135	16	78	1924	19	-859	1689

Table 3: Descriptives of the outcome measures pre-intervention (T=0) and post-intervention (T=2) in the participation and control group.

	Participation			Control		
Outcome	N	pre-intervention (sd)	post- intervention (sd)	N	pre-intervention (sd)	post- intervention (sd)
Physical activity						
NL-1000 *steps /day*	14	7215 (2732)	8051 (3743)	24	5830 (2444)	5462 (2152)
StepWatch steps/ day*	6	5300 (1696)	4008 (2168)	5	4404 (2904)	3934 (3086)
Motor fitness						
Strength *kg/m*	53	21.0 (8.0)	21.8 (9.0)	43	24.35 (7.5)	23.6 (8.2)
Balance *BBS (0-58)*	58	39.9 (12.4)	40.6 (11.8)	51	44.2 (10.9)	43.0 (12.1)
Walk Speed comf *m/sec*	50	0.87 (0.32)	0.87 (0.27)	44	1.02 (0.33)	0.91 (0.28)
Walk. Speed fast *m/sec*	42	1.41 (0.69)	1.36 (0.74)	41	1.65 (0.63)	1.43 (0.63)
Cardio respiratory fitness						
Diastolic blood pressure	33	79.4 (11.2)	75.7 (10.2)	29	78.3 (8.6)	78.6 (11.4)
Systolic blood pressure	33	124.3 (19.1)	120.1 (14.4)	29	123.1 (13.6)	123.6 (17.9)
Aerob. perf. *min:sec ISWT*	49	5:18 (1:59)	5:44 (2:20)	37	5:57 (2:09)	5:40 (2:12)
Morphological fitness						
Weight *kg*	54	72.2 (14.3)	72.3 (14.0)	47	72.3 (13.2)	72.2 (14.3)
Waist circumference *cm*	55	95.3 (14.0)	94.6 (13.7)	47	89.8 (11.0)	91.1 (10.8)
Metabolic fitness						
Glucose *mmol/l*	26	5.05 (0.7)	5.13 (2.1)	26	4.78 (0.8)	4.95 (1.8)
Cholesterol *mmol/l*	23	5.80 (0.9)	5.60 (1.2)	25	5.19 (1.1)	5.41 (1.1)
Functioning daily life						
Mobility *(0-72)*	38	8.9 (11.5)	10.8 (12.0)	50	8.8 (11.3)	10.7 (12.3)
ADL *Barthel index (0-20)*	37	15.2 (3.6)	15.0 (3.6)	50	16.2 (3.4)	15.8 (3.7)
IADL *Lawton scale (0-33)*	37	7.1 (5.6)	7.0 (5.9)	49	11.1 (8.7)	11.1 (8.9)
Depressive sympt. *SDL-ID (0-54)*	37	27.3 (5.7)	27.4 (5.6)	49	27.0 (6.2)	27.0 (6.4)
Cognitive functioning						
DMR Cognitive subscale (0-50)	35	12.5 (8.7)	12.6 (9.3)	49	8.1 (9.0)	9.6 (9.7)

* StepWatch data of T1 and T3 were compared

participants with a walking speed > 3.2 km/h at baseline (T=0) and at the end of the intervention (T=2), the programme's participants significantly improved their PA level with 836 steps per day on average, compared to the participants in the control group, whose PA level decreased with 368 steps on average (p<0.001). The lower the PA level of the participants at baseline, the more they improved their PA level (see Table 2). When comparing PA levels at baseline (T=0) and six months after the intervention period had ended (T=3), results demonstrate that controls declined whereas participants improved their PA level (B= 930 steps per day, p<0.05).

When comparing PA levels during the intervention (T=1) and six months after the intervention period had ended (T=3), the PA level of participants with a lower walking speed in the participant group decreased more than that of the control group, but not significantly (see Table 5).

Table 4: Pearson correlations between outcome measurements and participant characteristics, including baseline measurements of the particular outcome, age, sex, level of ID, Down Syndrome and severe behavioural problems.

Outcome (T=2)	Baseline (T=0)	Age	Sex (Male)	Level ID	Down syndrome	Severe behavioural problems
Physical activity						
NL-1000 *steps /day*	**.83****	-.26	-.01	-.19	.12	-.10
StepWatch *steps/ day****	**.82****	.56	.15	-.21	-.25	-.38
Motor fitness						
Strength *kg/m*	**.88****	-.07	**-.46****	**-.25***	-.07	.04
Balance *BBS (0-58)*	**.85****	-.06	-.16	**-.28****	-.01	.03
Walk Speed comfortable *m/sec*	**.64****	-.16	-.13	-.04	-.06	.18
Walk. Speed fast *m/sec*	**.71****	-.15	-.07	-.06	-.03	**.23***
Cardio respiratory fitness						
Diastolic blood pressure	**.61****	**.36****	.10	-.13	**-.32***	-.18
Systolic blood pressure	**.61****	**.39****	.12	-.05	-.15	-.14
Aerobic performance *min:sec ISWT*	**.74****	**-.22***	-.10	-.08	-.16	.17
Morphological fitness						
Weight *kg*	**.98****	.02	**-.20***	**-.30****	**-.30****	.08
Waist circumference *cm*	**.87****	.11	-.05	**-.32****	**-.22***	.13
Metabolic fitness						
Glucose *mmol/l*	.16	**.30***	.21	.07	-.01	-.14
Cholesterol *mmol/l*	**.87****	.01	-.02	-.20	-.13	.08
Functioning daily life						
Mobility (*0-72*)	**.91****	**.28****	.15	.10	-.02	-.06
ADL *Barthel index (0-20)*	**.77****	-.11	-.10	**-.33****	-.02	-.15
IADL *Lawton scale (0-33)*	**.90****	-.05	-.14	**-.48****	-.05	-.02
Depressive symptoms *SDL- ID (0-54)*	**.66****	-.01	-.01	-.16	-.03	.12
Cognitive functioning						
DMR Cognitive subscale *(0-50)*	**.90****	-.01	.08	**.52****	.14	.11

*p<0.05

**p<0.01

***StepWatch data of T1 and T3 were included in analysis

Table 5: General linear model parameter estimates of the prediction of outcome measures at T2 using intervention participation, the outcome's baseline measure and covariates.

	Outcome measure	Number of programme's participants	Number of controls	Mean*	SD*	Predictor	Parameter (B)	P (Wald)
Physical activity	NL-1000 *steps /day*	14	24	6416	3066	Intervention	1493	**<.001**
						Baseline	.79	**<.001**
	StepWatch *steps/ day****	6	5	1987	1241	Intervention	-392	.33
						Baseline	.94	**<.001**
Motor fitness	Strength *kg/m*	53	43	22.6	8.7	Intervention	1.5	**.004**
						Baseline	.98	**<.001**
	Balance *BBS (0-58)*	58	51	41.7	11.9	Intervention	1.2	.41
						Baseline	.87	**<.001**
	Walking speed comf *m/sec*	50	44	.89	.27	Intervention	.04	.54
						Baseline	.54	**<.001**
	Walking speed fast *m/sec*	42	41	1.32	.69	Intervention	.10	.40
						Baseline	.74	**<.001**
Cardio respiratory fitness	Diastolic bloodpressure	33	29	77.1	10.4	Intervention	-3.8	**.001**
						Baseline	.58	**.002**
						Age	.28	**0.04**
	Systolic bloodpressure	33	29	121.7	16.2	Intervention	-4.8	**.008**
						Baseline	.47	**<.001**
						Age	.48	**.050**
	Aerobic performance *min:sec* ISWT**	49	37	5.42	2.2	Intervention	36.7	.085
						Baseline	.83	**<.001**
Morphological fitness	Weight *kg*	54	47	72.2	13.7	Intervention	.05	.26
						Baseline	1.02	**<.001**
						Male	1.1	**.048**
	Waist circumference *cm*	55	47	92.9	12.8	Intervention	-2.0	.13
						Baseline	.84	**<.001**
Metabolic fitness	Glucose *mmol/l*	26	26	5.04	1.60	Intervention	-.13	.76
						Age	.08	**.035**
	Cholesterol *mmol/l*	23	25	5.50	1.08	Intervention	-.41	**.002**
						Baseline	.97	**<.001**

*Mean and SD of total group including participants and controls

** Incremental Shuttle Walking Test

***StepWatch Data of T1 and T3 were included in analylis

	Outcome measure	Number of programme's participants	Number of controls	Mean*	SD*	Predictor	Parameter (B)	P (Wald)
Functioning daily life	Mobility (*0-72*)	38	50	10.8	12.1	Intervention	-.04	.97
						Baseline	.97	**<.001**
	ADL *Barthel index (0-20)*	36	44	15.3	3.7	Intervention	-.04	.90
						Baseline	.76	**<.001**
						Level ID	-.75	**.008**
	IADL *Lawton scale (0-33)*	37	49	9.4	8.0	Intervention	-.48	.53
						Baseline	.92	**<.001**
	Depressive symptoms *SDL- ID (0-54)*	37	49	27.2	6.1	Intervention	-.07	.92
						Baseline	.67	**<.001**
Cognitive functioning	*DMR* Cognitive subscale *(0-50)*	35	49	10.9	9.6	Intervention	-1.1	**.011**
						Baseline	.96	**<.001**

*Mean and SD of total group including participants and controls

Effects on secondary outcome measures

Table 3 shows descriptives of the outcome measures pre-intervention (T=0) and post-intervention (T=2) in the participation and control group. Table 4 shows associations between the outcome measurements (T=2) and potential covariates, including baseline measurements, age, sex, level of ID, Down syndrome and severe behavioural problems. Next to baseline measurements, significant covariates ($p<0.05$) were entered in the final models: *age* in the analyses of diastolic and systolic blood pressure and glucose; *sex* in the analysis of weight; and *level of ID* in the analysis of the ADL Barthel index.

Table 5 shows that the intervention has a significant effect ($p<0.001$) on steps per day measured with the NL1000 (controlling for baseline steps). The intervention's effectiveness was not demonstrated in the participants wearing a StepWatch. Positive significant effects were demonstrated on the following secondary outcome measures in favor of the participants, again controlling for baseline and covariates: strength, diastolic blood pressure, systolic blood pressure, serum cholesterol level, and cognitive functioning. The relative improvement of aerobic performance as shown in Table 3 did not reach significance ($p=.085$).

DISCUSSION

Findings of the study

Eight months Healthy Ageing Physical Activity Programme has proven to be effective among older adults with intellectual disabilities (ID). Results demonstrated a significant

improvement of 836 steps per day among participants with a walking speed of >3.2 km/h, whereas the steps in the control group decreased with an average of 368. Participants with lower baseline PA increased their PA level relatively more. In addition to PA, significant positive effects were found on muscle strength, serum cholesterol level, systolic and diastolic blood pressure and cognitive functioning. While participants improved, a decline in PA and fitness was observed among controls. These results were controlled for differences in baseline fitness between participants and controls and when relevant, other significant covariates such as age, sex and level of ID. No significant improvements were found on balance, serum glucose, weight, aerobic performance, waist circumference, walking speed, mobility, depression or (I)ADL.

Generalisability and clinical relevance of the programme effects

For this study we formulated a minimum of inclusion criteria, resulting in a heterogeneous study population that reflects clinical practice. People with behavioural problems, autism, Down syndrome, chronic obstructive pulmonary disease, mobility problems, obesity and even some older adults with severe intellectual disabilities participated in the study.

No similar studies were found to compare the programme effects on the physical activity level and to our best knowledge, no data are available about cut-off scores to determine the clinical relevance of increased PA levels for physical health and daily functioning. In addition, we faced large dropout rates on this outcome. We therefore do not permit ourselves to draw conclusions about the clinical relevance nor generalisability of the study results concerning PA level.

The overall health goal of the intervention was, besides increasing the PA level of participants, to delay the decline or to improve physical fitness. In this study, significant effects were found for serum cholesterol level, systolic and diastolic blood pressure, which are important risk factors for the development of diabetes and coronary heart diseases [42, 43]. In the light of the low baseline fitness of participants, the attained change in fitness and health in combination with the importance of these parameters for health, we conclude that the current programme effects concerning secondary outcome measures are clinically relevant. Generalisability of the programme's efficacy is less evident, partly due to the substantial amount of missing outcome measurements. However, considering results of our process evaluations, demonstrating that participants who could not participate in effect measurements did participate actively in the programme, considering their attendance rate, their heart rate increase and attained heart rate levels during exercise [44], we do not see any reasons to assume that the programme is less effective for participants whose effect measurements are missing.

Strengths and limitations of the study

The programme was tested with the gold standard for evaluating the effectiveness of interventions: the randomised controlled trial. Furthermore, the programme's success can be attributed to its development based on The Intervention Mapping protocol and the use of staff and target population views in its development. The activities and behaviour change techniques were carefully chosen to match the needs and characteristics of the target population. In addition, the programme was embedded in excisting structures and familiar settings. Managers and programme leaders were committed from the start of the project and an infrastructure was developed to support implementation of the programme [17].

An important limitation of this study was the substantial amount of missing data, particularly on the primary outcome measure. In future studies, one should find new ways of collecting data on PA that are less prone to drop-out. With regard to the missing data of the primary outcome measure PA, we assume that the presented results in the current study are an underestimation of the programme's effectiveness, because data for participants with lower PA levels at baseline were missing, and lower PA levels at baseline were associated with more improvement of PA.

Blinding the programme leaders for allocation was not possible, due to the nature of the intervention. Blinding the executors of the baseline and effect measurements for allocation was practically nor financially possible. To minimize bias, the measurements' executors were well trained and not involved in the programme's execution.

Future research and recommendations for implementation

The PA programme has proven to be an effective intervention for many outcome measures that are related to health and functional deterioration [46, 47]. Further research with longer follow-up is needed to evaluate the preventive effect of this programme regarding the development of mobility impairment, chronic diseases and frailty on the long run. Although evidence-based guidelines of the American College of Sports Medicine recommend a minimum frequency of five times a week [16], this study demonstrates that a lower frequency can already lead to first positive health effects. More insight into frequency, intensity and duration that are required for health improvement could lead to specific physical activity guidelines for this subpopulation. Commitment of stakeholders to the programme and the development of an infrastructure to support implementation of the programme into routine care are recommended.

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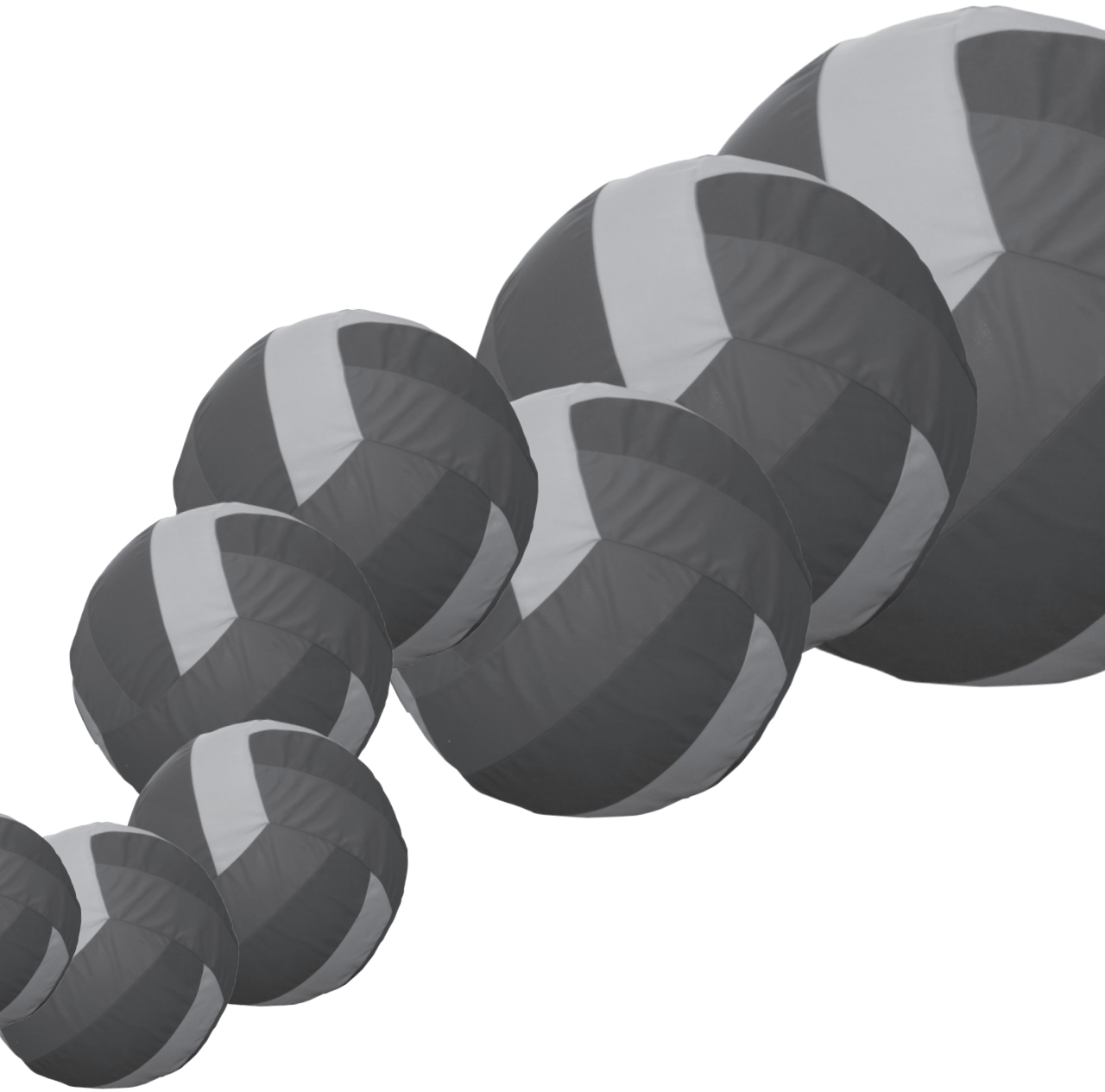
8

GENERAL DISCUSSION



PRINCIPAL FINDINGS

Several studies showed that 50 plus people ageing people with intellectual disabilities (ID) have extremely low physical activity and physical fitness levels [1, 2] however, no systematically evaluated suitable programmes were available for this specific frail subgroup. We developed a physical activity programme for 40-plus people with mild to moderate intellectual disabilities. The concept of Intervention Mapping [3] appeared to be a useful tool for creating a feasible and effective programme, including available evidence-based knowledge.

The principal programme's framework was focused on training the fitness components muscle strength, balance, cardiovascular endurance and flexibility. This is in compliance with the recommended guidelines for physical activity for people 65+ and for adults aged 50-65 years with clinically significant chronic conditions and/or functional limitations [4]. Within this framework, the physical activity instructors selected physical activities that could be tailored to the capabilities and interests of their specific group. As a result, the physical activity sessions were feasible to all participants, despite the fact that the mobility levels and exercise skills of the participants within a group varied substantially. Programme leaders and participants cooperated well and were enthusiastic about the programme, resulting in low drop-out rates due to a lack of motivation. Results of the process evaluations demonstrated that the programme leaders indeed included activities addressing the four fitness components into the sessions. Variation in compliance with the framework mainly appeared to be a result of logistic problems and the lack of a suitable large room or gymnasium to perform cardiovascular activities optimally.

Programme effects were systematically evaluated. After eight months, significant effects were found on physical activity indicated as mean steps per day, despite the substantial missing data on this primary outcome measure and despite the fact that the programme's framework was primarily focused on fitness components instead of on increase of steps. The overall health goal of the intervention was, apart from increasing the physical activity level of participants, to delay decline or to improve the physical fitness. During eight months significant although mainly small effects were achieved on serum cholesterol, muscle strength, blood pressure and cognitive functioning. Notable is the fact that health effects were achieved while participants mainly trained at mild intensity levels and participated in the programme 2 to 3 times a week. Whereas the guidelines of the American College of Sports Medicine and American Heart Association recommend performing physical activities at least 5 times a week at moderate intensity levels. These attained heath effects were probably related to participants' low baseline fitness levels. Improvement of fitness of persons with the lowest levels of physical activity or fitness, is associated with the greatest health benefits [5-7]. We conclude that the

current programme effects are clinically relevant, also in light of the importance of the increased parameters for health, although norms for clinically relevant improvement of measured health parameters for ageing people are lacking.

Although systematic evaluation of the programme's efficacy appeared feasible, we had to deal with incomplete follow-up data in both the participation and control groups, due to supposed burden. That is, if caregivers indicated that their clients would get negatively aroused by the scientific measurements, they were excluded from the measurements. We carefully selected the most feasible and reliable measurement instruments to evaluate physical activity, physical fitness and other health parameters in people with ID, available when our study started. Because proxy data are not reliable and thus do not provide valid information about the measured health parameters [8] other instruments or methods are needed to include people with ID who are expected to get negatively aroused by measurements of physical activity and other health parameters.

GENERALISATION

In this study we aimed at developing a programme feasible to and effective for a broad population of individuals with mild or moderate intellectual disabilities, applicable in various day-activity or work settings for this group. We formulated a minimum of inclusion criteria, resulting in a heterogeneous study population, adding to the ecological validity of the intervention.

Generalisation of the programme's feasibility results

Implementation of the programme in various care settings will be possible. Within the evidence-based framework, the programme allows programme leaders to tailor the activities and behavioural change strategies to the abilities and interests of the target group. Composition of more homogeneous groups according to participants' physical and cognitive functioning would allow optimal tailoring of activities. The programme could also be implemented in clubs for activities in leisure time. Implementation in the day-activity or working setting however, has the advantage of no extra transportation costs for participants and will most probably yields high adherence rates. In the programme, not individual but group activities are included and no high cost materials are needed. Although larger health or fitness effects might be attained by individual fitness programmes, we assumed that such a high-cost programme has less chance of being implemented on the long run. The availability of a physical-activity expert to put the physical-activity programme together congruent with the framework, and to coach staff of day-activity centers or work settings in conducting the programme adequately and safely is an important prerequisite. A physical-activity expert can be a physical therapist

or a physical-activity instructor, educated in conducting physical activities among specific target groups with special care needs. Limited availability of these experts in care settings impede the programme's implementation.

To increase the likelihood of our programme being effective, behavioural change techniques were included [9, 10] and were allowed to be tailored to the participants' level of cognitive en socio-emotional functioning. It is a well-known fact that people with a low education and low socioeconomic status often tend to have an unhealthy lifestyle, whereas community-based programmes aimed at healthy lifestyle are insufficiently effective in reaching this population group [11]. This is even more so in adults with ID. Programme leaders in our study estimated the applied behaviour change strategies as effective and thus important programme elements.

In view of the heterogeneous group of participants in our study, we conclude that the feasibility data found in our study apply to all people with mild to moderate intellectual disabilities and maybe also to other people with low education and socioeconomic status. For people with complex physical and or mental problems, the programme is expected to be less feasible; smaller groups and/or more intensive support are needed.

Generalisability of the programme's efficacy

Generalisability of the programme's efficacy is less evident, partly due to the substantial amount of missing outcome measurements. Data of the process evaluation were available for almost all participants and demonstrated that most participants who could not participate in effect measurements, did participate actively in the programme, considering their attendance rate, their heart rate increase and attained heart rate levels during exercise. In fact, some of them were even more active than their peers, for example participants with severe behavioural problems who attained relatively high heart rate levels during the sessions [12]. We therefore do not see any reasons to assume that the programme is less effective for participants whose effect measurements are missing. Another point is that data from process evaluations demonstrated that programme leaders did not always follow the framework guidelines and that participants did not always participate at the desired frequency and intensity levels. This non-compliance may have had a negative impact on the programme effects. However, from a realistic point of view we consider it as a reflection of daily practice, which has to be taken into account when implementing a physical activity programme.

In conclusion, with caution we assume the programme's efficacy can be generalised to 40-plus people with mild and moderate intellectual disabilities. In light of the low baseline fitness of participants in our study, we assume that for people with intellectual disabilities with higher baseline fitness more intensive participation is needed to achieve comparable health effects.

IMPLICATIONS FOR POLICY AND PRACTICE

Physical activity should be available to all (older) adults with intellectual disabilities. By agreement of the convention of the rights of persons with disabilities, that include equality of opportunity and accessibility [13], people with disabilities have the right of full participation. Many people with ID are not able to participate in regular physical activities and are mostly dependent on others to become physically active. Professional support to create a safe environment and to select appropriate activities is required because of multimorbidity, physical limitations such as balance and coordination problems, decrease in mobility and muscle strength [2], combined with limited understanding and often limited experiences with physical activities [14]. Such professional support can be provided by physical therapists or physical-activity instructors, experienced in conducting physical activities with (older) adults with ID. Policymakers, municipalities, care provider services and health insurers all have a responsibility in the availability of suitable physical activity programmes including professional support for this population.

Another reason why physical activity should be available to all (older) adults is the proven positive effect of structured physical activity on health and wellbeing [6, 15-17]. Compared to the general population, relatively few well-designed studies have been performed among (older) adults people with ID, however results are promising and the body of evidence is growing [18, 19]. In addition, the current study was the first well-designed physical fitness programme for ageing adults with ID, demonstrating positive health effects. Regarding the overall low fitness levels and frailty of older adults with ID [20, 21], it is recommended to include all (older) adults with ID in health promotion programmes and not only the people with the lowest fitness levels. As Franco cited Pickering: "shifting the whole population into a lower risk category benefits more individuals than shifting the high risk individuals into a lower risk category" [22].

As indicated earlier, management of care provider services and in the municipalities must recognise the importance of physical activity for people with ID and facilitate implementation. Partly as a result of a large physical activity project in the Netherlands financed by the Dutch government (Zo kan het ook, Gehandicaptensport Nederland), many care providers in the Netherlands developed and performed (practice based) physical activities suitable for people with ID. However, effect evaluations were not performed. It would be recommended that physical activity experts systematically evaluate the effects of their physical activity programmes with a standardised set of suitable instruments. The Netherlands Institute for Sport and Physical Activity (NISB) may play an initiating and coordinating role in cooperation with the Dutch association for physical therapists for people with intellectual disabilities (NVFVG). Systematic evaluation is important to gather additional evidence concerning the health effects of structured

physical activity and to further explore effective strategies to promote physical activity and active participation among people with ID.

The implementation costs of the current physical activity programme mainly concern the involvement of physical activity experts, for whom structural budget is needed. Because the unfavourable economic situation, however, care provider services are forced to take financial measures that affect staff availability, and a negative influence on physical activity levels of individuals with ID is to be expected. Family and significant others should become more actively involved in supporting their family member with ID in daily life activities. However, ageing people with ID have fewer family contacts and fewer other significant contacts [23], and it is rather unrealistic to assume that most family members themselves are conscious of the importance of physical activity for their family member with ID. Care providers services and policy makers should be aware of the consequences of organisational measures for the clients' fitness levels and health, which in the longer run are to be expected to have an impact on health care costs. The other way around: broad implementation of physical activity may be cost-effective regarding its contribution to the prevention and management of chronic disease and potential to reduce physical decline, maintain functional ability and prevent injuries [24]. According to Vuori et al. (2013), exercise should be seen and dealt with in the same ways as drugs and other medical interventions regarding the basic and continuing education and training of personnel, the reimbursement of the services related to it and the funding of research on its efficacy and feasibility [25]. In other words: physical activity should be seen as a necessary continuous preventive health measure, and not as an optional activity for pleasure only. Future research on the cost-effectiveness of physical activity among people with ID is warranted, in order to motivate all stakeholders to invest in the performance of evidence-based physical activity programmes, organised by care provider services of municipalities.

DIRECTIONS FOR FUTURE RESEARCH

This study provides relevant information about programme elements that facilitate effective health promotion among people with ID. Description of the programme's development and results from the process evaluations can be used by other researchers and care provider services developing and implementing health promotion programmes; in the field for people with ID but maybe also in field of geriatric patients and people with low-economic status.

The current study demonstrated significant effects of structured physical activity on physical fitness and health parameters; among controls deterioration was observed. Although effects were small, they were detected after only eight months. Longitudinal

studies are needed to demonstrate if structured physical activity can prevent not only a decline in physical fitness and other health parameters, but also prevent functional decline and the development of chronic diseases and thus frailty, directing cost-effectiveness and cost-benefits as well.

Further research among people with ID and older adults with ID in particular could provide more insight into the mechanism of cardiac response to mild- and moderate-intensive physical activities among specific subgroups, such as people with Down syndrome and people with autism, related to health improvements. Researchers and or physical activity experts should take the low starting heart rate of people with Down syndrome into account. High heart rate levels among people with autism and the impact of these high levels on their health could be a new topic of fundamental and clinical research.

In this study significant health effects were attained while participants participated in physical activities mostly at mild intensity levels, and some minutes at moderate intensity levels, 2 to 3 times a week. This may suggest that physical activity at moderate intensity levels with a frequency of 5 times a week, as recommended by the American College of Sports Medicine and American Heart Association, may not be a prerequisite for achieving health benefits for ageing people with ID. Further research on health effects of mild intensity activities is warranted, because these activities are much easier to implement in daily life than activities at moderate intensity, with less involvement of physical activity experts. In addition, reducing sitting time among sedentary people, as an independent risk-factor for the development of chronic diseases [26, 27] could also be a new research topic among people with ID.

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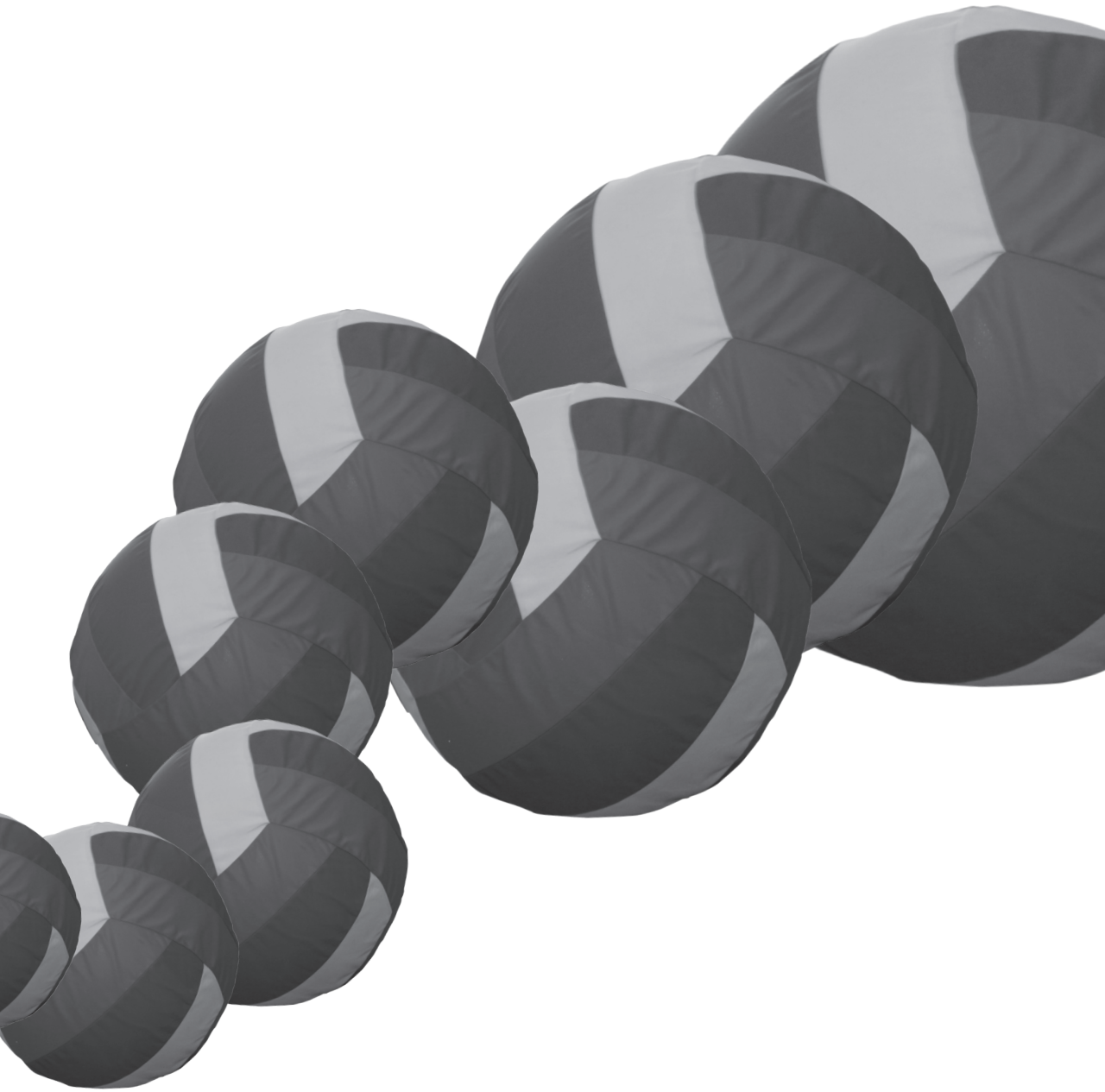
SUMMARY



CHAPTER 1

General introduction

The current study aimed at improving the physical activity level and improving or maintaining fitness levels of ageing adults with ID. Three Dutch ID care provider services (Abrona, Amarant and Ipse de Bruggen) and two academic centers (Intellectual Disability Medicine, Erasmus Medical Center of Rotterdam and Human Movement Sciences, University Medical Center Groningen) founded a consortium and started the study 'Healthy Ageing and Intellectual Disability (HA-ID). Physical activity and Fitness, Nutrition and Nutritional state and Mood and Anxiety were investigated from a perspective of prevention. In this study, extremely low physical activity and fitness levels among older adults with intellectual disabilities were demonstrated. Although the importance of physical activity for health has been recognised in the field of people with ID, only few well-designed studies with a substantial amount of participants evaluated the health-related effectiveness of physical activity programmes among people with ID, mostly children or adults with mild ID. The development of a physical activity and fitness programme for ageing people with ID, results of implementation and execution, and programme's effects are described in this thesis.

CHAPTER 2

Barriers and facilitators as perceived by older adults with ID

For the development of the programme, we were inspired by the Intervention Mapping Protocol of Bartholomew that distinguishes a six-step procedure for theory-based and evidence-based development of health promotion interventions. A qualitative study was performed to explore preferences of older adults with ID for specific physical activities, and to gain insight into facilitators and barriers to engage into physical activity. Fourteen in-depth interviews and four focus groups were undertaken, with a total of 40 older adults with mild or moderate ID included in the analysis. Identified facilitators to physical activity were: enjoyment, support from others, social contact and friendship, reward, and familiarity and routine of activities. Barriers to physical activity were health and physiological factors, lack of self-confidence, lack of skills, lack of support, transportation problems, costs, and lack of appropriate physical activity options and materials. The results of this qualitative study highlight elements that are specifically important when promoting physical activity among older adults with ID.

CHAPTER 3

Development of a structured physical activity programme

Results of the qualitative study aimed at identifying barriers and facilitators were used for the development of the day-activity programme. Theory-based strategies were selected that formed the basis of the intervention programme. The following behavioural change techniques were selected to improve physical activity and to maintain or improve physical fitness levels of the target group: Tailoring, Education, Modelling, Mirroring, Feedback, Reinforcement and Grading. With professionals and managers of provider services for people with ID, we translated these techniques into a structured day-activity programme that consisted of two components: a physical activity programme and an education programme. To ensure achievement of the overall health goal, we studied evidence-based guidelines for physical activities designed to achieve health benefits. Because no specific guidelines exist for physical activity for people with ID, we adapted the guidelines of The American College of Sports Medicine (ACSM) and the American Heart Association (AHA) for chronically ill and people aged over 65 years for our programme. In these guidelines, multi-component exercise programmes, including aerobic endurance, strength, balance and flexibility are recommended and optimal frequency, intensity and duration of the activities are specified. Our education programme was inspired by the health promotion programme: "Health Matters", developed for adults with mild ID. Our education programme focused on the increasing consciousness of normal bodily reactions to physical activity, the importance of physical activity for health and experienced barriers to physical activity. The education programme was developed with experts in educating people with ID and in developing suitable educational materials. Specific goals for each of thirteen programme themes were described and four to eight activities per theme were developed to achieve the goals. Selected didactical methods were sorting/ranking, group discussion, games, creative activities and role-play. The physical activity and education programme were embedded in a routine day-activity programme and conducted by specifically trained movement experts and staff of day-activity centers in groups of eight to ten ageing adults. The design of the programme was such that its contents could be tailored to the individual participant.

CHAPTER 4

Programme's implementation and execution

In this study, much attention has been paid to the preparation of the implementation of the programme. We evaluated to what extent the physical activity programme was successfully implemented during the intervention period and performed in compliance

with the programme guidelines. In addition, we evaluated to what extent the programme was feasible according to the programme leaders and participants and which environmental factors may have had impact on the implementation of the programme during the intervention period. Overall, both leaders and participants were enthusiastic about the programme and were willing to continue. Physical-activity instructors found the programme feasible for the target group and used all previous described behavioural strategies to improve active participation. As planned, the programme was implemented three times a week during eight months in the five participating day-activity centers. Furthermore, it was successfully implemented in compliance with the programme guidelines, although variation between day-activity centers was observed, in particular in the frequency of performed cardiovascular activities. Factors that may have influenced the programme´s compliance were: 1) the presence of a gymnasium, 2) travel distances of physical-activity instructors and 3) the heterogeneity of the groups in terms of participants' physical functioning.

CHAPTER 5

Heart rate response to the physical activity programme

In chapter 5, we described the heart rate response to the physical activity and fitness programme and its association with improvement in aerobic performance. Heart rate was assessed with heart rate monitors. Aerobic performance was assessed pre and post-intervention with the Incremental Shuttle Walking Test.

Evaluations of the heart rate data demonstrated that participants mostly exercised at low intensity levels and on average several minutes at moderate intensity levels. Positive associations were found between heart rate increase and being younger, having Down syndrome and having severe behavioural problems. Notable were the high heart rate levels of participants with autism.

Exercising in a gymnasium instead of at the day-activity center facilitates heart rate increase. Improvement in aerobic change was positively associated with severe behavioural problems and negatively associated with Down syndrome. In light of the on average low heart rate levels during exercise and the attained improvements in aerobic performance, low levels of weekly energy expenditure might be sufficient to establish positive health effects among ageing adults with ID.

CHAPTER 6

Applicability and validity of the StepWatch™

The applicability and validity of the StepWatch Activity Monitor™, a device that accurately detects steps in people with deviant walking patterns, were assessed in ageing people with ID and a low walking speed (<3.2 km/h). Applicability was evaluated by registration of the drop-out during measurements with the StepWatch in daily life. Of total 36 participants, 19 dropped out because they refused (8 participants) or because their caregivers indicated potential burden (11 participants). On average, physical activity data of the required minimal 4 days were available after 6 days of which the participants had the monitor in their possession (range 4 to 12 days). Validity was evaluated against a gold standard, defined as the number of steps counted during video-observation. Participants walked 150 meters, in five rounds of 30 meters at their own comfortable walking speed indoors. Measurements of the much cheaper NL-1000 were also evaluated, to explore the magnitude of its deviation from the gold standard. Data of 25 participants were included in the analyses. The StepWatch provides valid measures of physical activity among people with ID with low walking speeds (ICC=.93); the NL-1000 largely underestimated the steps taken (ICC= .08). Bland-Altman plots confirmed that the range of discrepancies between NL-1000 scores and Gold standard was wider than the discrepancies between StepWatch scores and Gold standard. However, comparable to the NL-1000, the StepWatch's applicability in daily circumstances is impaired by anticipated burden or carelessness with the expensive device.

CHAPTER 7

Programme's efficacy

The programme's efficacy was evaluated in a cluster randomised clinical trial among people with ID older than 45 years. Five day-activity centers were randomised to the participation group. In these centers, 81 older adults participated in groups of eight to ten in the programme, three times a week during eight months. The programme was executed by physical activity instructors and staff of day-activity centers. Five other day-activity centers were randomised to the control group; 70 older adults in these centers received care as usual. Generalised linear models with random effects were used to test the programme's effectiveness.

In favour of programme participants, significant effects were found on steps per day, muscle strength, systolic and diastolic blood pressure, serum cholesterol level and cognitive functioning. No significant improvements were found on balance, serum glucose, weight, waist circumference, walking speed, mobility, depression or (I)ADL.

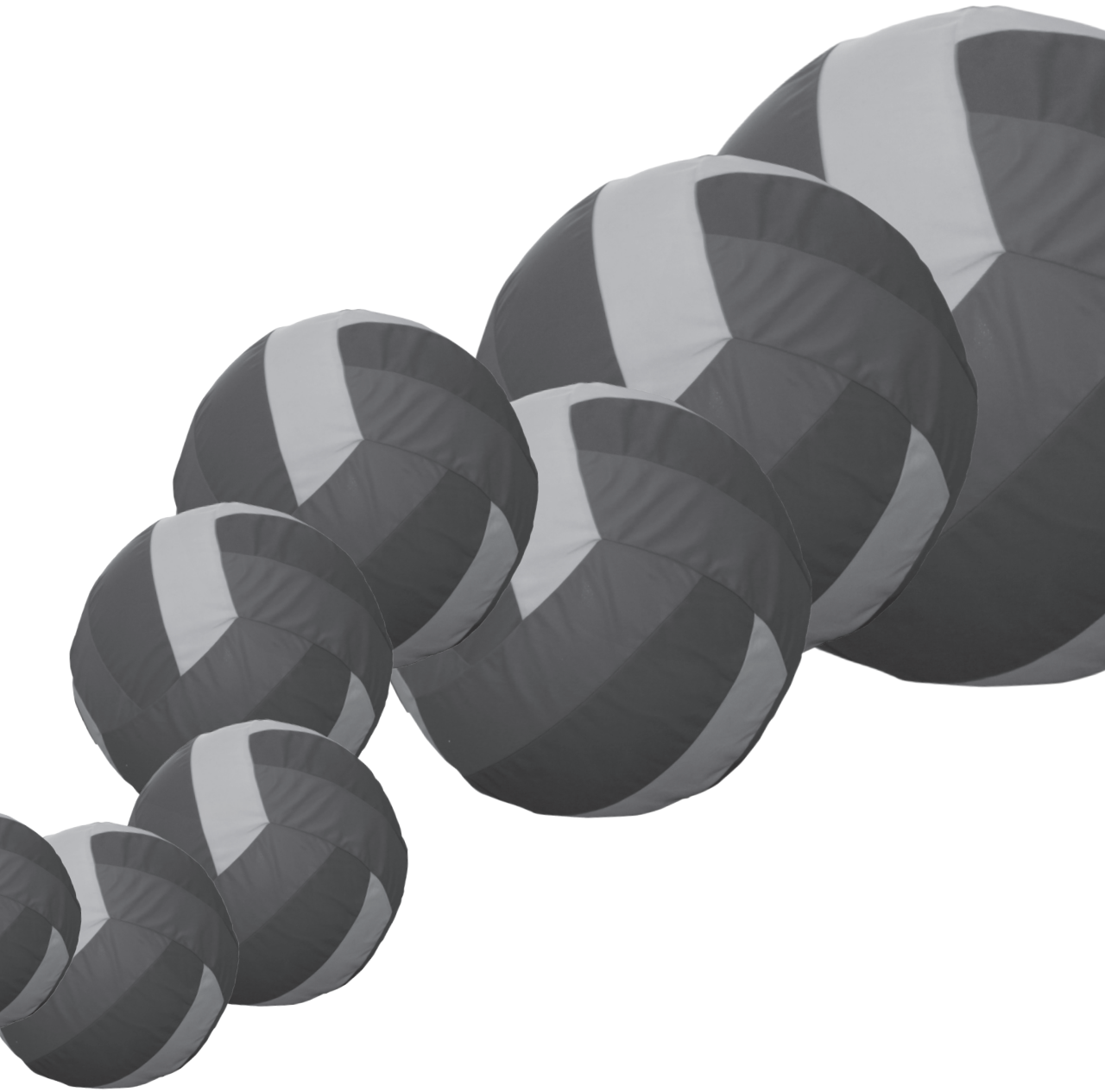
CHAPTER 8

General discussion

This study demonstrated that the developed physical-activity and fitness programme is effective to improve physical activity and to maintain or improve physical fitness among ageing adults with intellectual disabilities. Process evaluations demonstrated that the programme was successfully implemented and feasible to the target group. Many people with ID are not able to participate in regular physical activities and are mostly dependent on others to become physically active. In light of the agreement of the convention of the rights of persons with disabilities, policymakers, municipalities, care provider services and health insurers all have a responsibility in the availability of suitable physical activity programmes for this population, also including professional support. Such support can be provided by physical therapists or physical-activity instructors, experienced in conducting physical activities with (older) adults with ID. Implementing our programme, including structured multidimensional physical activity and carefully selected behavioural change techniques, in day-activity centers or work settings is recommended. Broad implementation of physical activity may be cost-effective regarding its contribution to the prevention and management of chronic disease and the potential to reduce physical decline, maintain functional ability and prevent injuries.

Description of the programme's development and results from the process evaluations can be used by other researchers and care provider services developing and implementing health promotion programmes; in the field of people with ID but maybe also in the field of geriatric patients and people with low-economic status. Longitudinal studies are needed to demonstrate if structured physical activity could prevent functional decline and the development of chronic diseases and frailty, adressing cost-effectiveness and cost-benefits as well.

SAMENVATTING



HOOFDSTUK 1

Inleiding

De voorliggende studie had als doel om de lichamelijke activiteit van oudere mensen met een verstandelijke beperking te verhogen en hun lichamelijke fitheid te handhaven of te verbeteren. Drie Nederlandse zorgorganisaties (Abrona, Amarant en Ipse de Bruggen) en twee academische centra (Leerstoel voor geneeskunde voor verstandelijk gehandicapten van het Erasmus Medisch Centrum en de afdeling bewegingswetenschappen van het Universitair Medisch Centrum van de Rijksuniversiteit Groningen) startten de studie: Gezond OUDer met een Verstandelijke beperking (GOUD). Lichamelijke activiteit en fitheid, voeding en voedingstoestand en depressie en angst zijn onderzocht. Aangetoond is dat oudere mensen met een verstandelijk beperking zeer beperkt lichamelijk actief zijn en een relatief laag fitheidsniveau hebben. Hoewel het belang van lichamelijke activiteit voor mensen met een verstandelijke beperking door de sector wordt erkend, zijn er slechts enkele methodologisch goede studies uitgevoerd met een redelijk aantal deelnemers (meestal jongeren of volwassenen met een lichte verstandelijke beperking), die de gezondheids- gerelateerde effectiviteit van beweegprogramma's evalueerden. De ontwikkeling, de implementatie en de effectiviteit van een programma gericht op de lichamelijke activiteit en fitheid van ouderen met een verstandelijke beperking zijn beschreven in dit proefschrift. Deze interventiestudie maakt onderdeel uit van de GOUD-studie.

HOOFDSTUK 2

Barrières en bevorderende factoren voor bewegen zoals ervaren door ouderen met een verstandelijke beperking

Geïnspireerd door het Intervention Mapping protocol van Bartholomew dat zes stappen onderscheidt in de ontwikkeling en implementatie van theoretisch en wetenschappelijk onderbouwde gezondheidsbevorderende programma's, ontwikkelden we ons programma. Een kwalitatieve studie is uitgevoerd om voorkeuren van ouderen met een verstandelijke beperking voor specifieke beweegactiviteiten te exploreren en om inzicht te krijgen in ervaren barrières en stimulerende factoren om te bewegen. Veertien interviews en vier focusgroepen zijn gehouden met in totaal 40 ouderen met een lichte of matige verstandelijke beperking. Geïdentificeerde stimulerende factoren voor lichamelijke activiteit waren: plezier, ondersteuning van anderen, sociale contacten en vriendschap, beloning, bekendheid met activiteiten en routine. Barrières voor lichamelijke activiteiten waren fysieke factoren, gebrek aan zelfvertrouwen, gebrek aan

ondersteuning, vervoersproblemen, kosten en gebrek aan voor de doelgroep geschikte beweegactiviteiten en materialen.

HOOFDSTUK 3

Ontwikkeling van een gestructureerd beweegprogramma

Resultaten van de kwalitatieve studie naar ervaren barrières en stimulerende factoren zijn gebruikt voor de ontwikkeling van het dagprogramma. Theoretisch gefundeerde strategieën vormden de basis van het programma, gericht op het verhogen van plezier in deelname. Om de lichamelijke activiteit van ouderen met een verstandelijke beperking te verhogen en de fitheid te onderhouden of te verhogen werden de volgende gedragstechnieken geselecteerd: tailoring, educatie, modelling, feedback, beloning, en grading (stap voor stap opbouwen). In samenwerking met bewegingsdeskundigen en managers van de zorgorganisaties, vertaalden we deze technieken in een gestructureerd dagprogramma dat bestond uit twee onderdelen: een beweegprogramma en een educatief programma. We bestudeerden evidence-based richtlijnen voor het behalen van beoogde gezondheidseffecten via lichamelijke activiteit. Omdat er geen richtlijnen bestaan specifiek voor mensen met een verstandelijke beperking, hebben we de richtlijnen van The American College of Sports Medicine (ACSM) en the American Heart Association (AHA) voor chronisch zieken en mensen van 65 jaar en ouder als uitgangspunt genomen voor ons programma. In deze richtlijnen worden multidimensionale beweegactiviteiten aanbevolen, namelijk gericht uithoudingsvermogen, kracht, balans en flexibiliteit. Aanbevolen frequentie, intensiteit en duur van activiteiten zijn gespecificeerd in deze richtlijnen. Het educatief programma is geïnspireerd door het gezondheidsbevorderend programma "Health Matters", ontwikkeld voor volwassenen met een lichte verstandelijke beperking. Het educatief programma richtte zich op het verhogen van het bewustzijn van normale lichamelijke reacties op bewegen, het belang van bewegen voor de gezondheid en ervaren barrières om (actief) te bewegen. Het educatief programma is ontwikkeld door deskundigen in het ontwikkelen en aanbieden van educatie aan mensen met een verstandelijke beperking. Per thema werden vier tot acht oefeningen ontwikkeld om de specifieke doelen binnen elk van de dertien thema's te behalen. Didactische methodieken waren sorteren, ordenen, groepsdiscussie, spellen, creatieve activiteiten en rollenspellen. Het beweegprogramma en educatief programma waren ingebed in een dagactiviteiten programma en uitgevoerd in groepen van acht tot tien deelnemers door specifiek voor dit programma getrainde bewegingsdeskundigen en activiteitenbegeleiders. Het programma was dusdanig opgezet dat indien wenselijk activiteiten per individuele deelnemer konden worden aangepast.

HOOFDSTUK 4

Implementatie en uitvoering van het dagprogramma

In dit onderzoek is veel aandacht besteed aan de voorbereiding en implementatie van het programma. We evalueerden in welke mate het beweegprogramma succesvol was geïmplementeerd gedurende de interventieperiode. Daarnaast evalueerden we in welke mate het programma volgens de uitvoerders en de deelnemers goed toepasbaar was en welke omgevingsfactoren mogelijk van invloed zijn geweest op de implementatie.

Over het algemeen waren zowel de programmaleiders als de deelnemers enthousiast over het programma. Bewegingsagogen vonden het programma voor de doelgroep toepasbaar en hebben alle eerder beschreven gedragstrategieën toegepast om actieve deelname te bevorderen. Het programma werd drie keer per week gedurende acht maanden ingebed in het dagactiviteiten programma in de vijf participerende dagcentra. Het programma werd over het algemeen geïmplementeerd volgens de richtlijnen, hoewel er vooral wat betreft het uitvoeren van cardiovasculaire activiteiten verschillen waren te zien tussen dagcentra. Factoren die mogelijk van invloed zijn geweest op het (niet) volgen van de richtlijnen zijn: de beschikbaarheid van een gymzaal, de reisafstand van de bewegingsagogen tot de dagcentra en de heterogeniteit in het lichamelijk functioneren van de deelnemers.

HOOFDSTUK 5

Hartslag van deelnemers tijdens het beweegprogramma

In hoofdstuk 5 beschreven we de hartslag van de deelnemers tijdens het beweeg- en fitheidsprogramma en de relatie hiervan met de verbetering in aerobe capaciteit. Aerobe capaciteit werd gemeten voor en na de interventie met behulp van de Incremental Shuttle Walking Test (piepjes test).

Evaluaties van de hartslagdata lieten zien dat deelnemers vooral trainden in lage intensiteit en gemiddeld enkele minuten in matige intensiteit. Een positieve samenhang is aangetoond tussen de hartslag toename en jongere leeftijd, het hebben van Down syndroom en de aanwezigheid van ernstige gedragsproblemen. Opvallend waren de hogere hartslagniveaus gedurende het hele programma bij mensen met autisme. Het bewegen in een gymzaal in plaats van in een ruimte op het dagcentrum zorgde voor extra verhoging van de hartslag. Verbetering in aerobe capaciteit was positief geassocieerd met ernstige gedragsproblemen en negatief geassocieerd met het hebben van Down syndroom. Met het oog op de behaalde verbeteringen op aerobe werkcapaciteit is het trainen in relatief lagere intensiteit mogelijk voldoende om gezondheidseffecten te bewerkstelligen bij ouder wordende mensen met een verstandelijke beperking.

HOOFDSTUK 6

Toepasbaarheid en validiteit van de StepWatch™

De toepasbaarheid en validiteit van de StepWatch Activity Monitor™, een instrument dat het aantal stappen gelopen door mensen met afwijkende looppatronen zeer accuraat kan meten, zijn geëvalueerd bij oudere mensen met een verstandelijke beperking en een lage wandelsnelheid (<3.2 km/h). De toepasbaarheid is geëvalueerd door het registreren van uitval gedurende de metingen met de StepWatch in het dagelijks leven. Van de in totaal 36 participanten vielen er 19 uit omdat ze (verdere) deelname weigerden (8 deelnemers) of omdat hun begeleiders inschatten dat de deelnemers gestrest zouden kunnen raken van het dragen van de StepWatch en/of het apparaat zouden weggooien (11 deelnemers). Data over de benodigde 4 dagen lichamelijke activiteit waren gemiddeld beschikbaar na 6 dagen vanaf het moment dat de deelnemers het instrument in hun bezit hadden (range van 4 tot 12 dagen). De validiteit is geëvalueerd met behulp van een Gouden standaard, die was gedefinieerd als het aantal stappen dat op basis van video observatie was geteld. Deelnemers liepen 150 meter in vijf ronden van 30 meter in hun eigen comfortabele wandelsnelheid. Metingen met de veel goedkopere NL-1000 zijn ook geëvalueerd, om ook bij dit instrument de afwijking van de Gouden standaard na te gaan.

Data van 25 deelnemers zijn geanalyseerd. De StepWatch leverde valide metingen van lichamelijke activiteit bij mensen met een verstandelijke beperking en een lage wandelsnelheid (ICC=.93); de NL-1000 onderschatte het aantal stappen ruim (ICC= .08). Bland-Altman plots bevestigden de grotere afwijkingen van de NL-1000 tot de Gouden standaard in vergelijking met de StepWatch. Echter, net als de NL-1000 is de toepasbaarheid van de StepWatch in het dagelijks leven bij ouderen met een verstandelijke beperking beperkt doordat, volgens begeleiders, een aanzienlijk aantal gestrest zal raken door het dragen ervan of de kans aanzienlijk is dat het dure instrument wordt weggegooid.

HOOFDSTUK 7

Effectiviteit van het programma

De effectiviteit van het programma is geëvalueerd aan de hand van een cluster randomised clinical trial bij mensen met een verstandelijke beperking ouder dan 45 jaar. Vijf dagcentra waren gerandomiseerd in de participatiegroep. In deze centra participeerden 81 ouderen in groepen van acht tot tien in het programma, drie keer per week gedurende acht maanden. Het programma werd uitgevoerd door bewegingsagogen en activiteitenbegeleiders. Vijf andere dagcentra waren gerandomiseerd tot de controle

groep. 70 ouderen in deze centra kregen de activiteiten aangeboden zoals ze waren gewend. Gegeneraliseerde lineaire modellen met random effecten zijn toegepast om de effectiviteit van het programma te testen. Ten gunste van de deelnemers aan het programma werden significante effecten gevonden op het aantal stappen per dag, kracht, systolische en diastolische bloeddruk, cholesterol en cognitief functioneren. Geen significante effecten zijn gevonden voor aerobe werkcapaciteit, balans, glucose, gewicht, middelomtrek, wandelsnelheid, mobiliteit, depressie en (I)ADL.

HOOFDSTUK 8

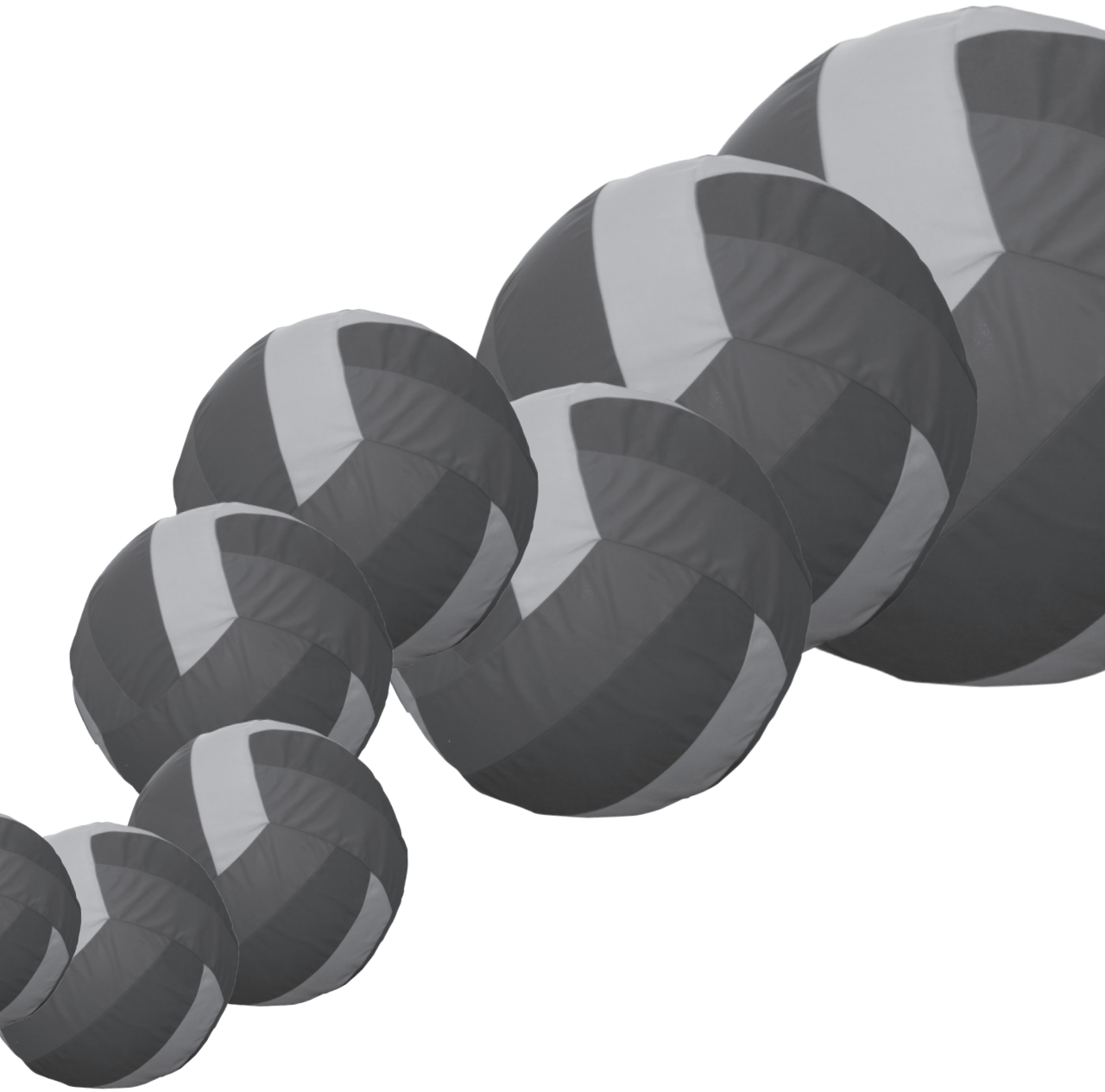
Discussie

Deze studie heeft aangetoond dat het ontwikkelde dagprogramma effectief is voor het verbeteren van lichamelijke activiteit en het verbeteren of onderhouden van fitheid van ouder wordende mensen met een verstandelijke beperking. Procesevaluaties hebben aangetoond dat het programma succesvol was geïmplementeerd en goed toepasbaar was voor de doelgroep. Veel mensen met een verstandelijke beperking hebben niet de mogelijkheid om te participeren in reguliere beweegactiviteiten en zijn meestal afhankelijk van anderen om actief te bewegen.

Met het oog op de conventie voor gelijke rechten van mensen met beperkingen hebben politici, gemeenten, zorgorganisaties, zorgkantoren en zorgverzekeraars allen een verantwoordelijkheid in het beschikbaar stellen van toepasbare beweegprogramma's voor deze doelgroep, inclusief professionele ondersteuning. Dergelijke ondersteuning kan worden geboden door fysiotherapeuten of bewegingsagogen, ervaren in het begeleiden van (oudere) mensen met een verstandelijke beperking. Het is aan te bevelen om ons dagprogramma, inclusief multidimensionale gestructureerde lichamelijke activiteit en zorgvuldig geselecteerde technieken voor gedragsverandering in te bedden in dagactiviteiten of werksituaties. Het breed implementeren van lichamelijke activiteit zou kosten-effectief kunnen zijn gezien de bijdrage aan de preventie van (verernstiging van) chronische ziekte en de potentie om achteruitgang te vertragen en functionaliteit te behouden.

De beschrijving van de ontwikkeling van het programma en de resultaten van de implementatie kunnen worden gebruikt door andere onderzoekers en zorgorganisaties die gezondheidsbevorderende programma's ontwikkelen: in de verstandelijk gehandicapten sector en mogelijk ook in de geriatrie en bij mensen met een lage sociaal economische status. Langdurige studies zijn nodig om aan te tonen dat gestructureerde lichamelijke activiteit functionele achteruitgang, de ontwikkeling of verergering van chronische ziektes en toename in kwetsbaarheid kan voorkomen, waarbij ook de kosten-effectiviteit in beeld gebracht zou moeten worden.

DANKWOORD



DANKWOORD

Graag wil ik iedereen bedanken die een bijdrage heeft geleverd aan het mogelijk maken van het onderzoek en de totstandkoming van mijn proefschrift.

In de eerste plaats gaat mijn dank uit naar de deelnemers aan het dagprogramma: bedankt voor jullie (doorgaans) enthousiaste deelname aan het educatief programma en het beweegprogramma! Enkelen van jullie droegen gedurende het gehele programma de button van GOUD op een trainingspak; een deelnemer was zelfs assistent van de bewegingsagoog en deed groepsgenoten de oefeningen voor. Iedereen deed op zijn eigen manier en niveau mee; echt top! Speciale dank gaat uit naar deelnemers in de controlegroep, want zij kregen niet het leuke programma, maar wel de metingen die nodig waren voor de evaluatie ervan. Jullie zijn ontzettend belangrijk geweest voor dit onderzoek! De wettelijk vertegenwoordigers die toestemming hebben gegeven voor deelname wil ik hartelijk bedanken voor het vertrouwen.

Vele medewerkers van Ipse de Bruggen, Abrona en Amarant zijn betrokken geweest bij de ontwikkeling, implementatie en evaluatie van het dagprogramma.

Het beweegprogramma en het educatief programma getest in dit onderzoek zijn nieuw ontwikkeld; daarvoor was relatief weinig tijd beschikbaar. Sigrid en Marjolein: wat hebben jullie hard gewerkt aan het educatief programma en wat zijn jullie creatief en deskundig op dit terrein! Samen hebben we onze schouders eronder gezet en dat resulteerde in een uitgebreid programma, met vele oefeningen en ondersteunend materiaal. Het was ontzettend leuk toen we na de interventieperiode subsidie kregen van ZonMW om naar aanleiding van de ervaringen in het onderzoek het programma door te ontwikkelen, inclusief fotomateriaal, onder begeleiding van Vilans. Het prachtige resultaat waar ik oprecht trots op ben is gratis te downloaden en dat is reeds vele keren gebeurd (www.kennispleingehandicaptensector.nl/bewegen). Hilair Balsters; hartelijk dank voor de prettige samenwerking tijdens deze werkplaats. Peter, de ontwikkeling van het educatie programma was nog in volle gang toen jij werd gevraagd een training te ontwikkelen voor de activiteitenbegeleiders, die met het educatief programma aan de slag zouden gaan. Hartelijk dank voor je flexibele opstelling; ik hoop dat nog vele activiteitenbegeleiders jouw ontwikkelde training zullen gaan volgen (www.leer-en-begeleidingstrajecten.nl).

Bijzondere dank gaat uit naar de bewegingsdeskundigen die betrokken zijn geweest bij de (door)ontwikkeling en uitvoering van het beweegprogramma. Arnold, Diet, Idske, Karin M, Karin van A, Karin S, Lilian, Rick, Ria, Ron van D, Ron D, Sander, Stefan, Stijn en Viola: jullie namen de activiteitenbegeleiders mee in jullie enthousiasme en maakten dat de cliënten met plezier en naar vermogen fanatiek deelnamen in het programma! Daarnaast registreerden jullie ook nog keurig elk programma de aanwezigheid van cliënten en de activiteiten die jullie uitvoerden; enorm bedankt daarvoor. Diet: bedankt voor de

keren dat je samen met mij tijdens een symposium de tips en trics hebt gedeeld met je collega's binnen het consortium maar ook daarbuiten. De interesse van buitenaf in het beweegprogramma en de downloads bevestigen de behoefte hieraan in de praktijk!

Het aanbieden van educatie aan groepen cliënten was geen gemeengoed voor de meeste activiteitenbegeleiders. Desondanks gingen zij na een korte training dapper aan de slag. Ageeth, Anne, Anja, Arjan, Carla, Caroline, Jeanne, Lies, Marlies, Neeltje, Nel, Ria, Petra, Pea, Wilma, Mireille, Jacqueline, Judith, Karen en Karin: elk op jullie eigen manier hebben jullie invulling gegeven aan het educatief programma. Veel aanspraak werd gedaan op jullie deskundigheid en creativiteit: het programma was nooit eerder uitgetest en bevatte de gebruikelijke kinderziektes. Bij de ene groep cliënten werden de thema's en oefeningen enthousiaster ontvangen dan bij de andere; jullie zochten dan naar manieren waarop de oefeningen wel aansloegen bij de cliënten op hun eigen niveau. Arjan ontwikkelde zelfs een powerpoint om de thema's te bespreken en Neeltje heeft het programma nu verder doorontwikkeld voor cliënten met een meer ernstige verstandelijke beperking: echt fantastisch!

Een speciale plek in dit dankwoord gaat uit naar de managers, die de implementatie van het programma mogelijk hebben gemaakt in de praktijk en vaak ook in de voorbereiding daarvan een rol hebben gespeeld, maar evenwel naar de managers en activiteitenbegeleiders van dagcentra in de controlegroep, die zeer bereidwillig hun ondersteuning hebben verleend aan het organiseren van de metingen. Adrie, Ageeth, Arnold, Brigette, Carmen, Emilie, Frans, Gini, Maria, Marleen, Marike, Marlies, Mariette, Minke, Monique, Nynke, Patricia, Peter, Ria, Sacha, Sylvia en Willy: mijn dank is groot.

En ja, dan zijn de metingen van de GOUD-studie in een afrondende fase en wordt er gevraagd of je ook nog voor de interventiestudie gezondheidsmetingen wilt uitvoeren. Even gemopper, maar dan met alle deskundigheid, serieusheid en volledige inzet is de klus zorgvuldig geklaard: chapeau! In totaal hebben meer dan 100 (para) medici een bijdrage geleverd aan de baseline- en effectmetingen: fysiotherapeuten, bewegingsagogen, verpleegkundigen, doktersassistenten, artsen, gedragsdeskundigen, test-assistenten: zonder jullie professionele inzet waren de onderzoeksresultaten waardeloos geweest; enorm bedankt! Ook de woonbegeleiders van de deelnemers wil ik bedanken voor het (voor de tweede keer) invullen van de vragenlijsten en ik weet dat meerderen dat in hun vrije tijd hebben gedaan. Nagenoeg alle in dit onderzoek verzamelde data (en dat zijn er enorm veel) zijn handmatig ingevoerd. Anne, Elly, Jeannette, Lenneke, Marion, Marijn, Marianne, Marjolein, Rian, Sunny, Thijs: hartelijk dank voor jullie praktische ondersteuning en de accuraatheid waarmee jullie de gegevens hebben ingevoerd: jullie hebben een enorme berg werk verzet. Door de gigantische organisatie van de epidemiologische metingen GOUD waren Erwin, Ineke, Arjen, Stephan, Anemone en Joris inmiddels door de wol geverfde interne coördinatoren; het creëren van randvoorwaarden voor het uitvoeren van de interventiestudie was appeltje eitje voor

jullie. Voor het organiseren van het dagprogramma en de gezondheidsmetingen kreeg ik alle medewerking die ik wensen kon: enorm bedankt voor jullie inzet en steun. Gilles: jij toverde mijn data om in professioneel opgezette posters voor de congressen; dat heb je mooi gedaan.

Dit onderzoek was niet mogelijk geweest zonder het vertrouwen en de overtuiging van de bestuurders in de opbrengst van de GOUD-studie, uitgevoerd in consortium verband. Jan Fidder, opgevolgd door Jan van Hoek en Eric Zwennis (Ipse de Bruggen), Nico Peelen, opgevolgd door Jan Duenk (Abrona) en Ronald van Helder (Amarant) wil ik hartelijk danken voor hun tijdsinvestering en vertrouwen, als ook de directeuren Marcel Schellart, Ankie Lubbers, Ditte van Vliet en Frank Brouwers en de bestuurssecretarissen Henriette Bandringa en Rianne Verweij. Gedurende het onderzoek en nu nog steeds in het vervolgonderzoek van GOUD, wordt periodiek overlegd om met elkaar organisatorisch haalbare grenzen af te tasten waarbinnen het onderzoek kan worden uitgevoerd en de benodigde randvoorwaarden te creëeren. Ik vind het fantastisch om te zien hoe bewegen in alle drie de organisaties een prominente plek heeft gekregen in de zorg.

Heleen, tijdens een interview voor Markant tijdens het 5 jarig jubileum van de leerstoel vroeg de journalist ons typerende kenmerken van je te benoemen, en ik antwoordde 'lef'. Je hebt de leerstoel, die je inmiddels formeel hebt overgedragen, tot een succes gemaakt en met je onderzoek een belangrijke bijdrage geleverd aan voor de praktijk waardevolle wetenschappelijke kennis over mensen met een verstandelijke beperking. Ik heb veel geleerd en dankbaar gebruik gemaakt van je kritische blik en constructieve feedback.

Ruud, ik ben je enorm dankbaar voor je steun tijdens mijn zoektocht aan het begin van mijn promotietraject waarin ik mijn onderzoeksprotocol en de interventie ontwikkelde. Met jou sparde ik over stakeholders in het project en belangrijke elementen in het implementatie plan. Vanuit Groningen kwam je speciaal voor bijeenkomsten met werkgroepen en projectgroepen die we hadden opgericht voor de ontwikkeling van de interventie en de voorbereiding van implementatie ervan in de praktijk. Hiervoor ben ik je zeer erkentelijk; je bent een trouwe steun geweest van begin tot eind.

Michael, jij kwam op de afdeling geneeskunde voor verstandelijk gehandicapten toen de interventiestudie nagenoeg was afgerond en ik in de startfase zat van het schrijven van mijn artikelen. Het was een voorrecht om door jou hierbij begeleid te worden; ik heb veel van je systematische aanpak en schrijfkwaliteiten geleerd. Je gaf me alle vrijheid om zelf aan de slag te gaan, en als ik aan de bel trok stond jij klaar met feedback of tips. Je social media kennis en netwerkkwaliteiten kwamen niet alleen mij maar de gehele afdeling ten goede.

Pepijn, jij introduceerde me in de wereld van gedragsverandering in de gezondheidszorg: zowel je netwerk als kennis hebben een belangrijke invloed gehad op de onderzoeksopzet en interventieontwikkeling. Hartelijk dank, ook voor de fijne samenwerking.

Luc, Thessa en Heidi: jullie zijn echt toppers! Het opstarten van het GOUD onderzoek was een grote uitdaging en niet altijd even gemakkelijk, ik ben oprecht trots op wat jullie hebben gepresteerd! Ieder had z'n eigen expertise en kwaliteiten en we vulden elkaar perfect aan als multidisciplinair onderzoeksteam. Er was altijd iemand om inhoudelijk mee te sparren als ik even vastliep. De sfeer was goed, professioneel, maar ook vertrouwd en wat vond ik het gezellig samen met jullie tijdens de congressen of andere uitjes. Luc, ik heb veel respect voor de manier waarop jij je als onderzoeker hebt ontwikkeld en als arts bij Ipse de Bruggen in je werk staat; je bent een toffe collega en ik kon altijd bij je terecht in moeilijke tijden. Ik vind het dan ook fijn dat je mijn paranimf wilt zijn. Ook de andere collega's van de afdeling geneeskunde voor verstandelijk gehandicapten wil ik bedanken voor de gezellige sfeer en waardevolle inhoudelijke feedback tijdens ons wekelijks overleg: Alyt, Cis, Channa, Corine, Ellen, Fleur, Josje, Marieke, Sandra, Sonja, Rob en Ymie. Dank ook aan de onderzoekers van Huisartsgeneeskunde voor de kritische vragen bij de werkbesprekingen.

De leden van de promotiecommissie dank ik hartelijk voor hun bereidheid om tijd vrij te maken voor het beoordelen van mijn proefschrift.

Anne, Marjolein en Thijs; als geneeskunde studenten selecteerden jullie mijn project voor jullie keuzeonderzoek; het was ontzettend leuk en leerzaam om jullie te begeleiden in elk jullie eigen leertraject. Dankbaar maakte ik gebruik van de gegevens die jullie met enorm veel inzet hebben verzameld en/of ingevoerd en geanalyseerd. Ook Steffie en Lotte, stagiaires fysiotherapie superbedankt: niet alleen hebben jullie de toepasbaarheid van Wii spellen uitgetest bij onze doelgroep, maar ook meegeholpen met het uitvoeren van de metingen!

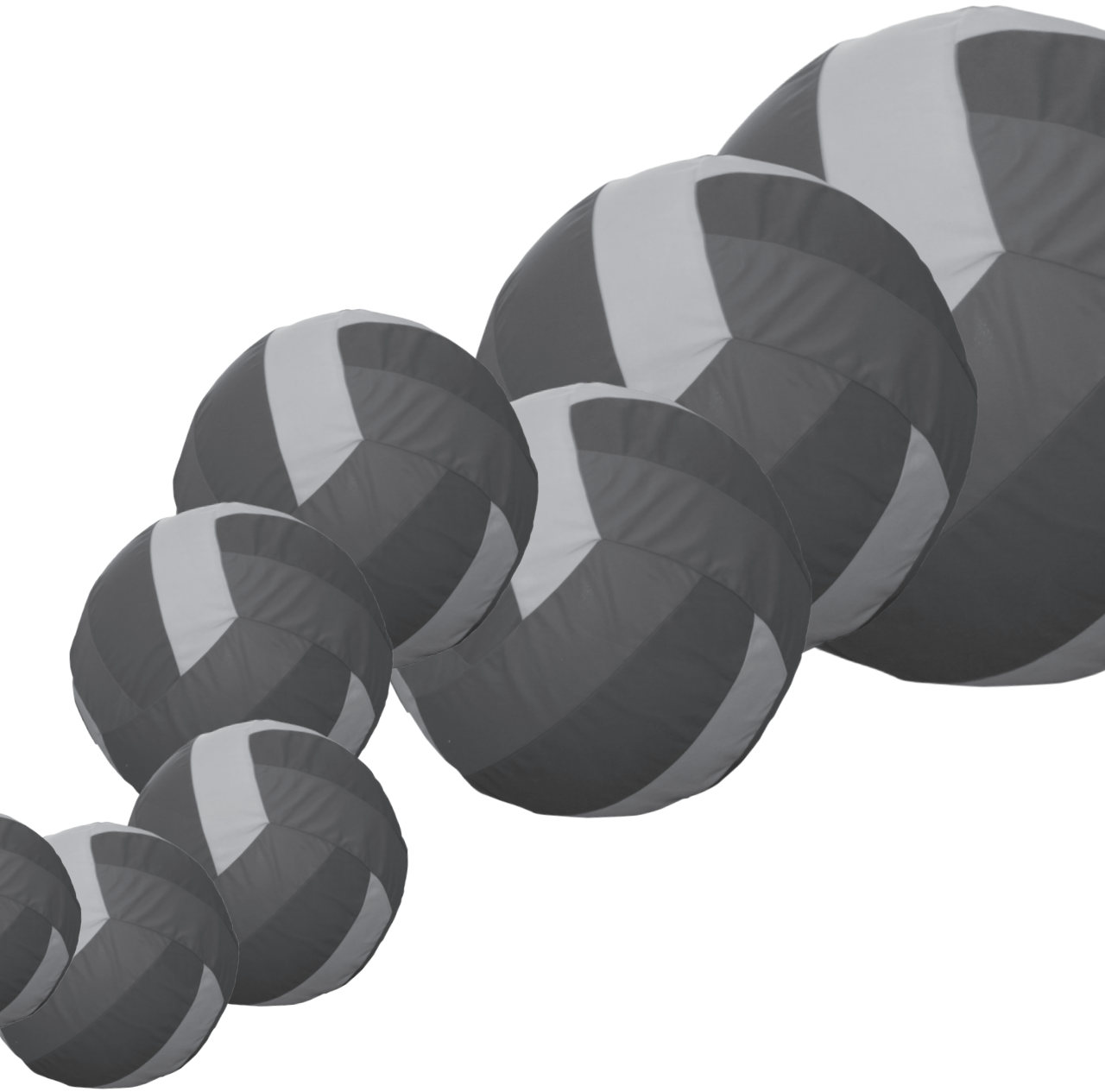
Marjolijn op de foto kan je zien dat jij met plezier deelnam aan het beweegprogramma onder begeleiding van Idske; Monique Weijers, bedankt voor het maken van deze vrolijke omslag. Fotograaf Walter Planije dank ik voor zijn toestemming om deze foto te gebruiken voor mijn kaft.

Mijn (schoon)familie en vrienden wil ik bedanken voor hun steun, vriendschap en gezelligheid. Opa's en oma's en tante Willie: hartelijk bedankt voor alle extra oppasdagen. Dames Master VSTS: wat is het toch lekker om tegen een volleybal aan te kunnen slaan, juist als je moe bent of in een dip zit. Na een training of wedstrijd met jullie gezelligheid zit ik weer vol energie. Bedankt voor het begrip voor mijn vele afzeggingen afgelopen jaren wanneer ik toch prioriteit gaf aan het onderzoek, waardoor ik zelfs ons Augurkje afgelopen voorjaar in Parijs heb misgelopen……

Pappa en Mamma, jullie hebben me altijd de vrijheid gegeven om te doen wat ik graag wilde doen en me gesteund daar waar het nodig was en dat doen jullie nog steeds. Dat vond ik vanzelfsprekend, maar dat is het niet en dat besef ik des te meer sinds Liam en Julie in mijn leven zijn gekomen. Ik ben jullie daarvoor zeer dankbaar en vind het speciaal dat pappa namens jullie beiden mijn paranimf wil zijn.

Lieve Bart, zonder jou had ik dit traject nooit kunnen afronden; jij stond voor me klaar. Of het nou ging om een goed gesprek als ik het even niet meer zag zitten, praktische hulp bij het ophalen van verpakkingsmateriaal voor de bloedmonsters, het maken van materiaal voor de fitheidstesten of het een paar dagen op stap gaan met Liam en Julie zodat ik rustig aan mijn proefschrift kon schrijven: op jou kon ik rekenen. Ik hoop dat ik je net zo zal kunnen steunen bij het opzetten van je eigen sportmarketing bedrijf: Sport Stories.

ABOUT THE AUTHOR



CURRICULUM VITAE

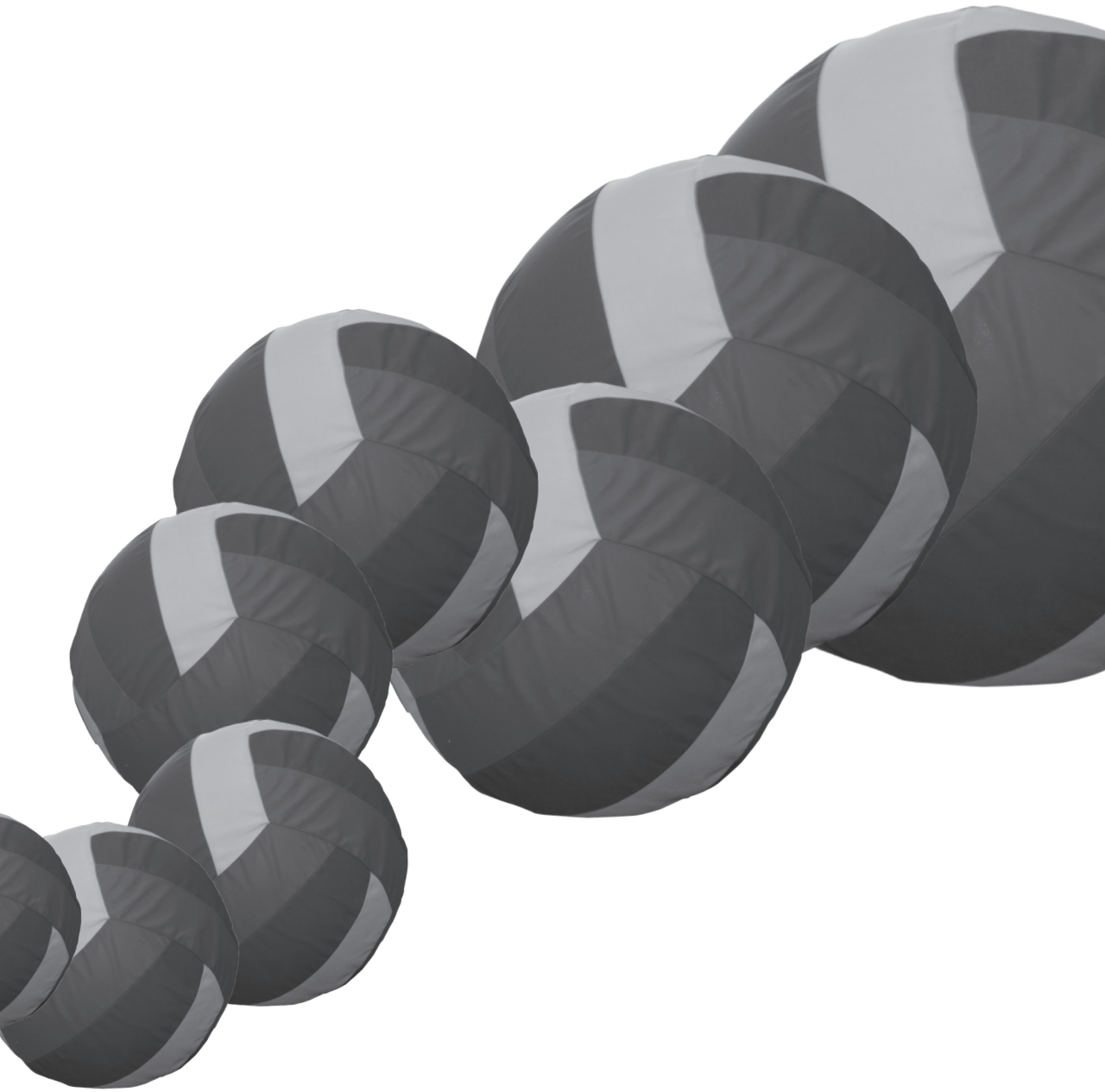
Marieke van Schijndel-Speet is geboren op 23 maart 1976 in Eindhoven. In 1994 haalde zij haar VWO diploma Strabrechtcollege te Geldrop. Na de middelbare school heeft zij haar studie Sociaal Pedagogische Hulpverlening gevolgd in Eindhoven, waar zij tijdens het derde studiejaar in Frankrijk stage liep op een dagcentrum voor jongeren met een verstandelijke beperking in Versaille. Na het behalen van haar SPH diploma in 1998 is zij Gezondheidswetenschappen gaan studeren in Maastricht, met als afstudeerrichting Geestelijke Gezondheidskunde. Parallel werkte zij bij Lunetzorg (Meare) te Eindhoven als groepsleidster op een woning met volwassen met een verstandelijke beperking en psychiatrische problematiek. Zowel bij Lunetzorg als bij Prezzent (Stichting Woonvormen) te Zaltbommel heeft zij onderzoek gedaan naar ervaringen van cliënten met de zorg die zij ontvangen. In oktober 2001 is zij begonnen als junior onderzoeker bij het NIVEL (Nederlands instituut voor onderzoek van de gezondheidszorg) in Utrecht. Hier heeft zij diverse onderzoeken uitgevoerd waaronder onderzoek naar palliatieve zorg in de verstandelijk gehandicaptensector en onderzoek naar de kwaliteit van zorg vanuit het perspectief van vertegenwoordigers van cliënten met een verstandelijke beperking van de 's Heeren Loo Zorggroep. Vanaf maart 2008 is zij gestart als onderzoeker bij het project "Gezond ouder met een verstandelijke beperking" (GOUD). Het promotieonderzoek dat resulteerde in dit proefschrift werd opgezet vanuit een consortium met de Leerstoel Geneeskunde van verstandelijk gehandicapten van het Erasmus MC in Rotterdam, drie zorgaanbieders (Ipse de Bruggen, Amarant en Abrona) en een samenwerkingsverband met de afdeling bewegingswetenschappen van de Rijksuniversiteit Groningen. Sinds september 2013 werkt zij als beleidsmedewerker zorg voor de Raad van Bestuur van Ipse de Bruggen, te Zoetermeer.

Marieke is getrouwd met Bart en met hun twee kinderen Liam (8) en Julie (5) wonen zij in Vleuten.

Marieke van Schijndel-Speet was born on March 23, 1976 in Eindhoven, the Netherlands. She finished her pre-university-education at the Strabrecht College in Geldrop in 1994. After completing secondary school she studied social work for residential institutions, community development and child and youth welfare in Eindhoven and attained her Bachelor's degree. In her third year she lived in France and worked with adolescents with intellectual disabilities at a day-activity centre in Versaille. After graduating in 1998, she studied Health Promotion Sciences at the University of Maastricht, specializing in mental health sciences. At the same time, she worked at Lunet zorg (Meare) and supported adults with intellectual disabilities and phychiatric problems in their daily activities. At Lunet zorg and at Prezzent (Stichting Woonvormen) in Zaltbommel, she conducted studies regarding the quality of life from the perspective of people with intellectual

disabilities. In October 2001, she started working as a junior researcher at NIVEL (Netherlands Institute for Health Services Research) in Utrecht. At NIVEL she conducted various studies, including studies regarding palliative care in the field of intellectual disabilities and the quality of care from the perspective of legal representatives of clients with intellectual disabilities of the 's Heeren Loo Zorggroep. From march 2008 she was employed by Ipse de Bruggen as a researcher at the project of 'Healthy Ageing with Intellectual Disabilities'. Under supervision of the Department of General Practices, Intellectual Disability Medicine at the Erasmus Medical Centre in Rotterdam and the University of Groningen and in cooperation with two other care organisations, she carried out the research, presented in this theses. Since Septembre 2013 she has worked as policy officer for the Board of Ipse de Bruggen at Zoetermeer.

LIST OF PULICATIONS



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