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Physical activity in hard-to-reach physically disabled people

Krops, Leonie

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General discussion



The aim of this thesis was to develop an intervention to stimulate physical activity in hard-to-reach physically disabled people, that can be applied in a community setting. The stepwise Intervention Mapping (IM) method was applied for the intervention development, to ensure application of theoretical behavioural change theories⁴⁴.

Main findings presented in this thesis

The first aim of this thesis was to study Health Related Quality of Life (HRQoL) and its association with physical activity in physically disabled people, in order to establish the need for intervention development (IM step 1). The RAND-36 questionnaire, measuring HRQoL, was found reliable for use at group level, and for research purposes in physically disabled people. The RAND-36 was not reliable enough for measuring HRQoL at an individual level, for instance for evaluation of individual progression over time (*chapter 2*). *Chapter 3* describes that HRQoL in physically disabled people was less compared to healthy individuals. A positive association was found between physical activity intensity (MET * hours/week) and all subscales of HRQoL, except for mental health. These results imply that physical activity intensity was positively associated to most components of bio-, psycho- and social health.

The second aim of this thesis was to investigate requirements of stakeholders (professionals and potential users) on an intervention to stimulate physical activity in hard-to-reach physically disabled people (IM step 2 and 3). *Chapter 4* describes that professionals expressed need for more collaboration between organisations from various backgrounds. According to professionals no new intervention to stimulate physical activity in hard-to-reach physically disabled people was needed. Instead, they indicated that an existing intervention should be adapted so that it also targets the hard-to-reach population. In *chapter 5* physically disabled people (potential users) strongly emphasised their own responsibility. They stressed the importance of intrinsic motivation for being physically active. Taking together the views of professionals and physically disabled people, an intervention should focus on stimulating organised physical activity, non-organised physical activity and physical activity during activities of daily living (ADL). An intervention should aim to raise awareness for the health effects of physical activity, stimulate intrinsic motivation, change attitude towards physical activity for physically disabled people of both the environment and the person itself, offer diverse possibilities and improve visibility of potential activities. Suggested intervention methods were for instance providing

individual coaching, connecting buddies, presenting role model stories, and using marketing. Hard-to-reach physically disabled people can be reached by means of networks of intermediate organisations from various background and different forms of media. Moreover, different persons and organisations are held responsible for stimulating physical activity in physically disabled people, and suggested for financing the intervention (*chapter 4 and 5*).

The third aim of this thesis was to develop and implement an intervention to stimulate physical activity in hard-to-reach physically disabled people, in a community setting (IM step 4-6). The existing intervention 'Activity Coach' (Dutch: Beweegcoach), was adapted into 'Activity Coach+' (Dutch: Beweegcoach+). Activity Coach+ reaches its target population by means of a network of organisations from healthcare-, social- and sports background, and by flyers and local newspaper articles. Participants receive a physiotherapeutic intake including history taking and physical assessment. An activity coach guides participants towards either participation in organised physical activity (by informing on possible activities), non-organised physical activity (by connecting buddies), or physical activity during ADL (by monitoring daily physical activity using a Fitbit Zip). Participants are coached during one year. *Chapter 6* describes the systematic development of Activity Coach+ following the method of IM. Moreover, plans for adoption, implementation and sustainability in a community setting were described. The design of a pilot study, evaluating the implementation process and effectiveness of Activity Coach+ on bio psychosocial health, was presented.

The last aim of this thesis was to evaluate feasibility and short-term health effects of an intervention to stimulate physical activity in hard-to-reach physically disabled people (IM: evaluation). *Chapter 7* describes that implementation of the adapted intervention Activity Coach+ was feasible in three municipalities in the province of Groningen (The Netherlands). Within the first four months after implementing Activity Coach+, physical activity behaviour did not change significantly. Body mass index, walking ability (10 metre walk test), exercise capacity (6 minute walk test), dynamic balance, and vitality increased over time after implementing Activity Coach+, and a clinically relevant trend was seen for the increase of hand grip force, within the first four months. The fact that functional outcomes improved without people spending more time active may be caused by an increase of intensity of the activities they perform, and by the curvilinear relationship between physical activity and health outcomes. The significant change of functional outcomes is underlined by the fact that in inactive people, even small increases of physical activity behaviour can lead to health benefits^{8,200}.

Components for intervention effectiveness

Activity Coach+ is a multilevel intervention composed from different intervention methods. The intervention's effectiveness in reaching hard-to-reach physically disabled people seems to be caused by the different methods that were applied to reach the target population, including various intermediate organisations, and local newspapers. Individual tailoring seems to be one of the intervention methods that improved intervention effectiveness. In earlier research in the general population and people with lower socioeconomic status (SES), individual tailoring was found effective^{189,190,201-203}. Moreover, the appliance of Motivational Interviewing^{189,201}, self-monitoring of physical activity behaviour¹⁹⁰, goal setting¹⁹⁰, and a relatively long counselling period²⁰³, together with the theoretical basis of the intervention^{183,189,204}, were found to be effective in earlier research and seem to have improved effectiveness of Activity Coach+.

Research methods

Intervention Mapping; Developing interventions based on theory and evidence

One of the strengths of the research presented in this thesis is the application of IM⁴⁴. IM provided structure to the developmental process, and ensured the application of behavioural change theories. Activity Coach+ was composed from methods resulting from different behavioural change theories, as for instance the social cognitive theory and diffusion of innovations theory^{154,157}. Hereby, Activity Coach+ combines insights from different scientific disciplines. Generally, interventions that are developed based on a behavioural change theory are more likely to be effective compared to non-theory based interventions^{183,189}. A strength of IM is that it stimulates multilevel interventions, targeting both the individual- and environmental level²⁰⁵. Hence, Activity Coach+ was designed to include both individual (e.g. self-monitoring of daily physical activity) and environmental (e.g. mobilising social networks) intervention methods.

Co-creation; Bridging the science - practice gap

As an important step of the intervention development process described in this thesis, stakeholders (professionals and the target population) were asked for their demands

on an intervention. Involving the target population in intervention development is also referred to as co-creation. The guidelines for Health Enhancing Physical Activity (HEPA) recommended co-creation as a method to increase social validity. Social validity describes the target population's priority for intervening, and the degree to which the intervention is supported by the target population¹⁴⁸. Collaboration between policy, practice, and research, was found to increase transfer of knowledge and to achieve higher quality, improving public health²⁰⁶.

Applied research; Methodological concessions

The target population in this thesis were hard-to-reach physically disabled people. During the first steps of intervention development, no strategy for reaching these hard-to-reach people was available. The needs assessment (*chapter 2 and 3*), and the study on requirements of the target population (*chapter 5*) involved more general physically disabled people, instead of the targeted hard-to-reach physically disabled people. This discrepancy might have influenced findings on HRQoL and its association with physical activity (*chapter 3*) and demands towards an intervention (*chapter 5*).

For instance, physically disabled people who underwent rehabilitation in a rehabilitation centre, emphasised the influence of rehabilitation physicians and therapists. However, the hard-to-reach population had not been treated in a rehabilitation centre during the past year. Participants in *chapter 2* all underwent rehabilitation in a University Medical Centre rehabilitation centre, and might suffer from a more severe disability compared to physically disabled people living in community, targeted by the intervention. This difference might have influenced reference values for HRQoL, and association with physical activity, as presented in *chapter 2*. HRQoL is suggested to be poorer in people who suffer from a more severe disability. It might be that in people suffering from a more severe disability, participating in physical activity emphasises their disabilities, diminishing the association between physical activity and especially psycho- and social subscales of HRQoL. Part of the study population interviewed in *chapter 5* did not follow rehabilitation, and was considered hard-to-reach, however these people already participated in sports clubs, and are not part of the target population. Interviewing people who participated in sports clubs might have influenced the findings in this research. These active people might for instance focus more on participation in organised physical activity compared to non-organised physical activity. Moreover, these active people are suggested to be highly motivated, what might explain the emphasis on intrinsic motivation.

Moreover, due to the cross sectional design of *chapter 2* no causal relationships between physical activity and HRQoL can be established, meaning that it could be either that physical activity leads to higher HRQoL, or that people with higher HRQoL are more likely to be physically active. Due to the high number of participants *chapter 2*, it was not feasible to objectively measure physical activity. Physical activity was self-reported, using the Short Questionnaire for Assessing Health-enhancing physical activity (SQUASH), adapted for physically disabled people, who might be for instance wheelchair dependent. The adapted SQUASH was found to be moderately reliable and valid, and results should be interpreted with caution¹⁶⁸.

In *chapter 7*, describing short-term effectiveness of Activity Coach+, no matched control group was included, because of the heterogeneous study population regarding diagnoses, age and activity level. Randomised controlled trials are the most robust research designs for evaluating effectiveness of interventions, but are often not feasible in community research, and often lack external validity^{207,208}. Performing multiple baseline measures was not feasible for practical reasons. Moreover deciding to participate in a physical activity intervention might already influence baseline measures. By the lack of a control group, and multiple baseline measures, results of the effectiveness study can theoretically not only be assigned to the implementation of Activity Coach+. To prevent influences of other programmes, the intervention was pilot-tested in areas where no other physical activity or lifestyle interventions were implemented during the same period.

Implications of the findings

Generalisability of the findings

Research in this thesis involved physically disabled people (*chapter 2, 3, and 5-7*) and professionals (*chapter 4*). Throughout *chapter 2 and 3* former patients of a University Medical Centre rehabilitation centre in the Northern Netherlands were involved, limiting generalisability of findings to patients from other parts of the Netherlands, or elsewhere. In *chapter 4* professionals from the whole country were involved, where only physically disabled people from the Northern Netherlands were interviewed on their demands on an intervention (*chapter 5*). It was suggested that findings on intervention methods from both professionals and physically disabled people can be generalised nationally and internationally. However, findings on conditions (reach, funding and responsibility) are dependent on local organisational structures which differ between regions and countries¹⁴⁴.

Activity Coach+ was pilot-tested in three municipalities in the Northern Netherlands (Oldambt, Bellingwedde and Vlagtwedde) (*chapter 7*), a region with relatively low SES¹⁹⁷. People with lower SES are more likely to suffer from impaired health^{198,209}. It is unclear whether physical activity stimulating interventions should differ between people with and without lower SES, to be effective¹⁸³. Hereby it is unclear if effectiveness of Activity Coach+ can be generalised to regions with higher SES. Activity Coach+ is primarily based on individual coaching, whereby motivational skills of coaches might influence effectiveness. Although coaches were trained in Motivational Interviewing, as part of the intervention, results on effectiveness should be generalised with caution to other regions with other coaches.

Implications for future research

Research presented in this thesis fits in the research agenda on physical activity in physically disabled people²⁴. Since the RAND-36 was not reliable enough for individual use, future research should focus on further developing the RAND-36, or other questionnaires for evaluating HRQoL, to enable individual clinical use in rehabilitation. Currently, long term (up until one year after implementation) health effects of Activity Coach+ are being studied. Future research should evaluate the content and implementation process of Activity Coach+ in the current pilot-intervention, among professionals and participants. The iterative structure of IM encourages further development of Activity Coach+, based on the evaluations, until it matches all demands of stakeholders. Activity Coach+ can, for instance, be further developed by increasing focus on changing attitude of environment towards physical activity for physically disabled people. This attitude change was strongly emphasised by professionals (*chapter 4*), but included in Activity Coach+ only local newspaper articles. Moreover, cost-effectiveness of Activity Coach+ should be studied in a larger intervention sample.

Implications for rehabilitation practice

Although Activity Coach+ is implemented in community rather than in clinical rehabilitation setting, this research also presents relevant findings for professionals in rehabilitation practice. Rehabilitation medicine, being one of the more multidisciplinary medical specialisms, adheres much to the bio psychosocial health approach. HRQoL,

a bio psychosocial construct, is often used as an outcome measure in rehabilitation research⁴⁶. Research in neurology has shown that clinicians only focussed on physical components of HRQoL, when evaluating their patients' functional status. When patients reported on their functional status, both physical and mental components of HRQoL were addressed⁷¹. To evaluate both physical and mental components of functional status, asking patients to self-report HRQoL was suggested to be beneficial for clinical purposes⁷¹. As described in *chapter 2*, the RAND-36 was reliable for research and group comparisons. However, individual progression of HRQoL measured using the RAND-36 should be interpreted with caution.

The positive association between physical activity and HRQoL, as described in *chapter 3*, endorses the importance of stimulating physical activity during rehabilitation. As found in *chapter 5* stimulation of physical activity by rehabilitation professionals is needed. During inpatient rehabilitation, physical activity is stimulated, for instance, by physiotherapeutic treatment, exercise therapy and advices from rehabilitation professionals. The physical activity stimulating intervention Rehabilitation, Sports and Exercise (RSE) aims to stimulate a physically active lifestyle in people with a physical disability and/or a chronic disease during and after their rehabilitation period. RSE is theoretically based on the physical activity for people with a disability (PAD) model. It bridges the gap between inpatient rehabilitation and the community situation in the Netherlands³⁶. Within RSE, inpatient rehabilitation patients are referred to a sports counselling centre (Dutch: Sportloket), and receive one face-to-face consultation. Patients receive telephone-based counselling sessions at 2, 5, 8 and 13 weeks after the end of inpatient rehabilitation³⁵. All consultations are based on Motivational Interviewing^{163,210}.

RSE and Activity Coach+ have many similarities, for instance the individual coaching sessions based on Motivational Interviewing and coaching towards existing local activities. Moreover, RSE and Activity Coach+ are both theoretically based on the PAD model. A difference between RSE and Activity Coach+ is that RSE operates central (from the hospital) and Activity Coach+ operates locally (in the municipality). Especially in more sparsely populated areas, as in the north of the Netherlands, RSE can collaborate with Activity Coach+, since hospitals and rehabilitation centres cover a larger service area, in which employees of sport counselling centres might not know all activities. Moreover, in patients who need longer counselling after finishing RSE, Activity Coach+ can continue counselling. Activity Coach+ has a higher intensity compared to RSE, by the application more face-to-face consultations, and the use of an activity tracker. RSE and Activity Coach+ are complementary and therefore it is suggested to collaborate for the consultation of rehabilitation patients who are

in need of a more intensive programme. Rehabilitation professionals from smaller, regional hospitals, that have not implemented RSE, are suggested to join the local multidisciplinary networks of Activity Coach+, so that they can refer their patients to Activity Coach+.

Implications for health policy

International level

At international level, the United Nations Convention on the rights of persons with a disability aims to promote inclusion and participation of disabled people²¹¹. One of the key points of this convention is the aim for an inclusive society, in which disabled people can participate in mainstream, able-bodied, activities. Activity Coach+, and the research described in this thesis, complement to this convention, by stimulating physically disabled people to participate in organised physical activity, which are often non-adapted, mainstream activities.

National level

In the Netherlands, three different policies are related to the promotion of health enhancing physical activity in physically disabled people. All three are initiated by the Dutch Ministry of Health, Welfare and Sport (Dutch: Ministerie van Volksgezondheid, Welzijn en Sport).

First, the general health policy 'Health nearby' (Dutch: Gezondheid dichtbij) partly focusses on secondary prevention in people with chronic diseases^{212,213}. This general health policy recommends an integral approach, applied in the nearby environment of people. In this general health policy, physical activity is recommended as one of the important methods for prevention. The importance of applying health care and prevention programmes in the nearby environment of people was confirmed by the target population who suggested that activities should be performed nearby (*chapter 5*). Moreover, the focus of the general health policy complies with forming networks of local healthcare and social organisations for reaching the target population, and by involving local physiotherapists for pre interventional physiotherapeutic assessment (*chapter 6*).

Second, the national programme on health prevention, named 'Everything is health' (Dutch: Alles is gezondheid) is a ministry overarching policy, aiming to increase vitality of inhabitants, in order to prevent diseases²¹⁴. As part of this prevention programme, the subprogramme 'Sports and exercise in the neighbourhood' (Dutch: Sport en bewegen in de buurt) stimulates physical activity participation in the environment of inhabitants, by facilitating sport coaches in the neighbourhood. The association between physical activity and HRQoL, as described in *chapter 3*, endorses the effects of physical activity on health prevention. Neighbourhood sport coaches who are focussed on vulnerable populations, can act as activity coach, whereby implementation of Activity Coach+ (*chapter 6*) can accomplish the national prevention programme.

Third, the national policy on disability sports, named 'Active without boundaries' (Dutch: Grenzeloos actief) focusses on stimulating physical activity participation of disabled people²¹⁵. This policy facilitates education of neighbourhood sport coaches to coach disabled people. Moreover, this policy aims for improving insight in activities suitable for disabled people, and providing sufficient activities covering the whole country. Increasing visibility of activities fits requirements professionals and physically disabled people pose, as described in *chapter 4 and 5*. However, not only organised physical activity, but also non organised physical activity was required, what might be a discrepancy between this national policy and requirements users pose. The national policy on disability sports aims to organise local partnerships in which organisations collaborate that focus on physical activity for disabled people. This aim agrees with the need for increased collaboration, as suggested by professionals (*chapter 4*). Activity Coach+ can be a method to effectuate the national policy on disability sports.

Municipality level

The positive association between physical activity and bio psychosocial health as found in *Chapter 3* indicated the importance for stimulating physical activity in disabled people to effectuate municipality level health policy. Activity Coach+, as developed and tested in this thesis, could be implemented to stimulate physical activity in physically disabled people at municipality level. Activity Coach+ is mainly based on individual coaching, which is time intensive, and relatively expensive. However, only people who are inactive and need to increase physical activity will be included in the intervention. Hereby no money is spend to people who are not in need of an intervention. Health benefits in this very inactive population can be large⁸.

For future practice, ideally, every municipality has appointed a person (for instance a neighbourhood sport coach) who focusses on physical activity stimulation in vulnerable populations (amongst others physically disabled people). This intermediate person organises different physical activity stimulating interventions for vulnerable populations, and participates in local partnerships including organisations from healthcare, social background and sports (as aimed for by the national policy on disability sports 'Active without boundaries'). This person can inform and redirect inhabitants to the intervention that might be most suitable for them. From an organisational perspective, these intermediate people from numerous municipalities should be coordinated centrally, so that innovations on interventions, as for instance Activity Coach+, could be efficiently implemented. Central organisation and local implementation are also suggested by professionals in *chapter 4*.

General conclusion

This thesis described the systematic development of an intervention to stimulate physical activity in hard-to-reach physically disabled people. In physically disabled people, physical activity behaviour is positively related to bio psychosocial health, measured as HRQoL. Professionals working in the field of adapted physical activity suggested increased collaboration between organisations, and adaptation of an existing intervention to stimulate physical activity in hard-to-reach physically disabled people. According to these professionals, and physically disabled people, an intervention should stimulate both organised and non-organised physical activity, and improve physical activity during activities of daily living. Several intervention methods were suggested, for instance individual coaching, providing role model stories and self-monitoring of daily physical activity. The intervention Activity Coach+ was adapted from the existing intervention Activity Coach, to fulfil the demands posed by professionals and physically disabled people. Implementation of Activity Coach+ in community was found feasible. Physical activity behaviour did not change within the first four months after implementation of Activity Coach+. However, first results for effects of Activity Coach+ on health outcomes were promising, given the increase of walking ability, exercise capacity, dynamic balance and vitality, during the first four months after implementation. Aims and methods of Activity Coach+ in general correspond to international and national health policy, enhancing possibilities for implementation of Activity Coach+ at municipality level.

