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ReSpAct: Rehabilitation, Sports and Active Lifestyle

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Chapter *1*

General introduction

General introduction

Physical (in) activity: a public health issue

Physical inactivity is a global killer. It has been ranked as the fourth risk factor for global mortality, and is accountable for $\pm 6\%$ of the deaths worldwide [1]. A lack of physical activity has been associated with an increased risk for non-communicable diseases (NCDs) [2]. NCDs are slowly progressing chronic diseases, such as cardiovascular diseases, respiratory diseases (e.g. asthma), cancers and diabetes, and are together responsible for almost 70% of the deaths worldwide [1,3]. Besides the alarming health burden of physical inactivity, there is also a considerable economic burden. To illustrate, the global costs of physical inactivity have been estimated to be almost 54 billion dollar, in the year 2013 [4].

Fortunately, physical activity is a powerful medicine. Physical activity can be defined as “any bodily movement produced by the muscles that results in increased energy expenditure” [5]. Regular physical activity can minimize the risks on NCDs and is associated with a wide range of health benefits, both on the physical, cognitive and mental domain [6-8]. To achieve potential health benefits, the World Health Organization (WHO) recommends adults (18 – 64 years old) to be physically active at moderate intensity for at least 150 minutes per week or 75 minutes at vigorous intensity or a combination of both [8]. Despite of the potential health benefits of physical activity, many people around the world are still physically inactive according to these recommendations [9].

To conclude, physical (in)activity is a serious public health issue that needs to be addressed by global, national and local (governmental and healthcare) agencies [9-13].

People with physical disabilities and/or chronic diseases

For several reasons, there is a need to pay specific attention to people with disabilities or chronic diseases, when managing the physical (in)activity issue. Firstly, global estimations showed that more than one billion people live with some type of disability, which equals to more than 15% of the global population [14]. In the Netherlands, about 12% of the adult population (1.6 million persons) suffer from a moderate or severe physical disability [15]. This percentage increases to almost 40% when including people suffering from a mild physical disability [15]. Due to the aging population, it is expected that

the prevalence of disability will further increase over time [16], illustrating that people with disabilities and/or chronic diseases may include a substantial group of the whole population.

Secondly, people with disabilities are characterized as a heterogeneous population. The term disability is a complex and multidimensional term including impairments, activity limitations, and participation restrictions [14,17]. People can suffer from a physical disability as a result of a wide range of diseases or disorders, such as stroke, spinal cord injury, and rheumatic disorders. Furthermore, there is a large variation in the form and severity of each disability. As a result, the extent to which people experience limitations in performing daily activities and engaging in physical activities varies from person to person. This diversity in patients' characteristics and impairments makes it challenging to successfully target this group, when managing the physical (in)activity issue.

Lastly, a physically inactive lifestyle is more often reported among people with disabilities compared to people without disabilities [18-20]. To illustrate, people with disabilities are less likely to meet physical activity guidelines [15,21-23]. In addition, sport participation among people with disabilities tends to be lower [15,21,22]. These findings are worrisome, because it is believed that the aforementioned negative health risks of physical inactivity can be higher among people with disabilities compared to the people without disabilities. Simultaneously, potential health benefits of physical activity may be even more prominent for people with disabilities [20,24].

In sum, the importance to promote physical activity and sports among people with disabilities and/or chronic diseases is high [22,25,26].

Physical activity policies: are they targeting people with disabilities?

To date, physical activity has been acknowledged by many countries as an important public health topic [9,27-29]. To prevent NCDs on a global level, the WHO recommends national and local governments to embed physical activity promotion in their policies [30,31]. A recent publication showed that 91% of the countries (n=166), which participated in the WHO's Country Capacity Survey, had a physical activity policy [9,32]. Some countries have a separate policy focusing on physical activity promotion, while other countries integrate physical activity promotion within other existing health or sport policies [27,28,33].

1 Physical activity policies of national governments are often aimed at increasing physical activity levels on population-level, rather than focusing on specific sub-populations, such as people with disabilities. Since people with disabilities are often faced with different barriers to become and stay physically active [34,35], it is questionable whether these generally broad-formulated physical activity policies are successful in targeting people with disabilities.

The story is slightly different when focusing on national policies on disability sports instead of physical activity. In the last decades, the Paralympic games have increased towards one of the largest sport events worldwide. At the same time, there has been growing attention and recognition for disability sports [36], and several, mostly western countries established specific disability sport policies [37]. Moreover, on global level, the Convention on the Rights of Persons with Disabilities (CRPD) was established and is currently ratified by more than 170 countries [38]. The CRPD states that people with disabilities have the right to participate in sports and recreation activities indicating that facilities for sports and physical activities should be accessible to all.

Despite the growing attention for disability sports, research on national approaches to promote physical activity among disabled populations is lagging behind. Such research may help to develop effective national physical activity policies that successfully targeting disabled populations in order to improve physical activity levels in the whole population. Therefore, there is a need to develop and share 'good examples' of governmental approaches that not only promote disability sports, but also include the promotion of daily physical activities among disabled populations.

The Dutch governmental approach

A short historical overview is needed to understand the current Dutch governmental approach on sports and physical activity promotion among disabled populations. In the past decades, western countries have changed their policies and perceptions on disability from an individual-focused medical viewpoint (i.e. "medical-institutional model") towards a social participation viewpoint (i.e. "social model") [14,39]. Within a social model, the focus lies on enabling people with disabilities to participate in the society. Currently, the Dutch government aims at full integration of disabled individuals into all levels of society, including disability sports (i.e. "*inclusive society and equal treatment*") [40,41].

To realize an inclusive sports society, the Dutch government has raised attention on disability sports. From the year 2000, the Ministry of Health, Welfare and Sports (in Dutch: 'VWS') expressed its commitment to increase sports participation among disabled populations and to improve the disability sports infrastructure (e.g. accessibility of sports facilities). Between the years 2000 – 2008, the government provided funding to integrate disability sports federations and organizations into mainstream sports federations. Several institutional changes were established. For example, the Nederlands Olympisch Comité * Nederlandse Sport Federatie (NOC*NSF) is “*the main organization for organized sports in the Netherlands*”, which acts both as National Olympic Committee and National Paralympic Committee [42]. Moreover, national surveys with a 5-year interval (2008; 2013) were set up to monitor changes in sport participation and physical activity levels among disabled populations [15,43].

To further promote physical activity among Dutch disabled citizens and to strengthen the sports infrastructure, the Ministry of Health, Welfare and Sports provided funding to implement three national programs. These programs were all ‘setting-focused’ (in Dutch: ‘vindplaats’) indicating that they are implemented at places where groups of people with disabilities can be reached easily, such as specialized schools or rehabilitation centers [44,45].

The first program was called ‘An alternative way!’ (in Dutch ‘Zo kan het ook!’; 2009-2012) [46]. This program aimed to promote sports and physical activities among people with intellectual disabilities by integrating sports and physical activity promotion into daily routines of healthcare institutions for people with intellectual disabilities. In addition, the program contributed to more accessible sports facilities for this population.

The second program was called ‘Special Heroes’ (2009 – 2012) [47]. This program aimed to promote sports and physical activities among children and youth with disabilities by integrating sports and physical activities in educational settings (e.g. specialized primary and secondary schools).

The third program was called ‘Rehabilitation, Sports and Exercise’ (RSE) (in Dutch: ‘Revalidatie, Sport en Bewegen’; 2012 – 2015). This program aimed to promote sports and physical activities among people with physical disabilities and/or chronic diseases during and after rehabilitation. This thesis describes the nationwide implementation of the RSE program.

The 'Rehabilitation, Sports and Exercise' program

For several reasons, the RSE program is a promising national approach to increase physical activity levels among people with disabilities. The first reason is the setting and timing of physical activity promotion, namely during and after rehabilitation. As part of a rehabilitation treatment, patients are often engaged in some kind of sports or physical activities (e.g. fitness and swimming). Simultaneously, patients have the opportunity to experience, in supervised circumstances, to be physically active with their disability, thus learning to deal with potential barriers and limitations. Unfortunately, many patients perceive difficulties to maintain an active lifestyle after rehabilitation [26]. Therefore, rehabilitation seems to be an exemplary setting and timing to promote a behavior change and encourage patients to become and stay physically active at home [26,48]. The necessity to promote sports and daily physical activities not only during, but also in the period after rehabilitation was already demonstrated by van der Ploeg [49]. The authors conducted a randomized controlled trial and showed that physical activity counseling after rehabilitation was an effective approach to achieve improved physical activity levels, both on short and long term [50,51]. These encouraging findings of van der Ploeg *et al.* (2007) became the starting point for developing an evidence-informed program (i.e. RSE) that could be scaled up to more settings across the Netherlands.

The RSE program is built upon the Physical Activity for people with a Disability (PAD) model [52] and the 'stage of change' part of the Transtheoretical model [53], illustrating its strong theoretical foundation. The PAD model focuses specifically on people with disabilities, and outlines the relationship between patients' physical activity behavior, relevant determinants of physical activity (environmental and personal), and patients' daily functioning [52]. The Transtheoretical model (i.e. 'stage of change' model) describes different steps that patients have to follow towards a behavioral change [53]. Although the effectiveness of the use of the 'stage of change' concept is still debatable, it is widely applied and experienced to be useful in general health promotion literature (e.g. smoking cessation, physical activity) (cf. [54-58]). Importantly, the 'stage of change' concept seems to be a practical and useful tool for counsellors to provide tailored counselling [49]. The strong theoretical and evidence-informed foundation of the RSE program is, therefore, another reason that makes the RSE program a promising national approach to increase physical activity levels among disabled populations.

Moreover, the RSE program uses a ‘disability-overarching’ approach, in which guidance is tailored on the individual patient [49]. Such an approach has the potential to be successful in targeting the heterogeneous group of people with disabilities.

Lastly, the RSE program includes the establishments of ‘sports counseling centers’¹ (in Dutch: ‘Sportloket’) [59]. A ‘sports counseling center’ is a room or department in the organization from which preventive consultations on active lifestyle are offered to patients. During these consultations, counselors use a behavioral change approach to promote sustainable physical activity behavior. Counselors help patients to make the step from physical activities in a familiar and supervised setting (i.e. rehabilitation) to physical activities in a new and self-initiated setting (i.e. community) [49]. The ‘sport counseling centers’ act, therefore, as a bridge between physical activities in rehabilitation care settings and physical activities in community settings [26,48,60].

In sum, the RSE program is a promising national approach to increase physical activity levels among people with disabilities. Therefore, the Dutch national government (i.e. Ministry of Health, Welfare and Sports) provided financial resources for scaling up this evidence-informed physical activity promotion program (i.e. RSE) to local rehabilitation settings.

The implementation challenge

The process of scaling up a national program to local settings is challenging [61-63]. Effective health promotion programs are rarely used by health professionals spontaneously [64,65]. Many effective programs are not continued after a funded research period indicating that research fails to have impact on policy or practice. Moreover, this results in an enormous research waste [66,67], especially in the area of health promotion research [68]. The existence of this ‘research-practice’ gap (i.e. ‘implementation gap’) is widely acknowledged (cf. [62-64,69-71]) and not unique for health promotion programs: it is described to occur with different kinds of innovations (e.g. guidelines, technologies) and in different settings (e.g. healthcare, education, community) (cf. [61,72-75]).

Besides the ‘research-practice’ gap, there is also a ‘policy-practice’ gap. Policy makers tend to be good in developing policies, but fail to implement

¹ In this thesis the ‘Sports counseling centers’ are also called ‘Physical activity counseling centers’. Both terms are interchangeable.

1

them. Recently, this ‘policy-practice’ gap was accentuated in national physical activity policies [9]. Although many countries (n=161) have a physical activity policy, only 114 countries (71%) have also a plan to implement the policy. This is worrisome, because a policy without a plan to implement it, does not make sense at all. On top of that, physical activity research on policy-related topics is lagging behind [76]. Therefore, we need more examples and better understanding of how national policy programs on physical activity promotion can be successfully implemented to local complex healthcare settings, such as rehabilitation care.

Another commonly mentioned challenge is implementing evidence-informed programs in a way that was intended by the program developers or designers [77]. This is an importance issue, because evidence-informed health promotion programs (e.g. RSE program) are only successful in changing patients’ behavior when they are “*well-implemented*” [77,78]. Generally speaking, better implementation results in better patient outcomes. However, in real-world settings, it is rarely possible to deliver an evidence-informed program, such as the RSE program, in exactly the same way as how it was proposed by the program developers due to different contexts and different patients [79]. In addition to that, adaptations seem necessary for long-term sustainability of a program in a local healthcare setting [80]. In literature, this phenomenon is also known as the ‘fidelity-adaptability’ balance [81-83]. It remains, however, unclear how to find the optimal balance between ‘fidelity’ and ‘adaptability’ in order to achieve the desirable patient outcomes, when implementing a physical activity promotion program in a multidisciplinary setting, as rehabilitation.

In the case of the RSE program, the abovementioned implementation challenges emphasize the importance to monitor the process on both organization and patient level. Fortunately, the importance to monitor and evaluate national programs is also acknowledged by the Dutch Ministry. They provided, therefore, not only funding for the implementation of the RSE program, but also to monitor and evaluate the program on organization and patient level.

Terminology and the guiding framework

Since terminology in implementation science literature varies substantially, it is important to provide definitions of key terms used in this thesis [84]. The following definitions are adapted from the glossary of Rabin *et al.* (2008) [85]:

- *Dissemination* is “an active approach of spreading evidence-based² interventions to the target audience via determined channels using planned strategies”.
- *Adoption* is “the decision of an organization or a community to commit to and initiate an evidence-based intervention”.
- *Implementation* is “the process of putting to use or integrating evidence-based or evidence-informed interventions within a setting”.
- *Sustainability/continuation*³ “describes to what extent an evidence-based or evidence-informed intervention can deliver its intended benefits over an extended period of time after external support from the donor agency is terminated”.

The following definition is adapted from Milat *et al.* [86] and based on [87]:

- *Scaling up*: “is the process by which health interventions, shown to be efficacious on a small scale and or under controlled conditions, are expanded under real world conditions into broader policy and practice”.

To date, many frameworks exist to guide evaluations of implementation processes [89,90]. This thesis uses the framework described by Wierenga *et al.* [88] as a guiding tool to systematically monitor and evaluate the nationwide implementation of the RSE program (see figure 1.1). This framework is built upon different frameworks, models, and theories that are widely known and commonly used in implementation studies (e.g. RE-AIM, Diffusion theory) [72,91-94].

The right-side of the framework depicts the three main phases of an innovation process: *adoption*, *implementation* and *continuation* (see above-mentioned definitions). The process outcomes (e.g. fidelity, dosage, reach, satisfaction) [91,94,95] are used to describe and evaluate the innovation process on different levels (e.g. organization, professional, participant). A further operationalization of the process outcomes used in this thesis (e.g. fidelity, reach, satisfaction) is described in chapters two through six.

The left-side of the framework depicts the *innovation determinants*, which are factors that facilitate or hamper the innovation process. The identification of the

² This includes evidence-informed interventions.

³ Continuation and sustainability are exchangeable.

potential facilitating and hampering factors provides insights into the *context* of the innovation process. The determinants are grouped into characteristics of socio-political context, organization, innovation (i.e. program), professional (i.e. user) and participant. This grouping system is built upon the work of Fleuren *et al.* [72] and commonly used in the (inter)national literature on implementation determinants.

The middle of the framework depicts the *implementation strategy*. The implementation strategy includes one or more activities aiming to support the adoption, implementation and/or continuation of a program [96,97], such as financial incentives, educational meetings, and audits. Implementation strategies can consist of a single activity ('single component') or a combination of activities ('multifaceted component') [98]. Ultimately, the implementation strategy aims to minimize hampering factors and/or to strengthen facilitating factors [63,74,99].

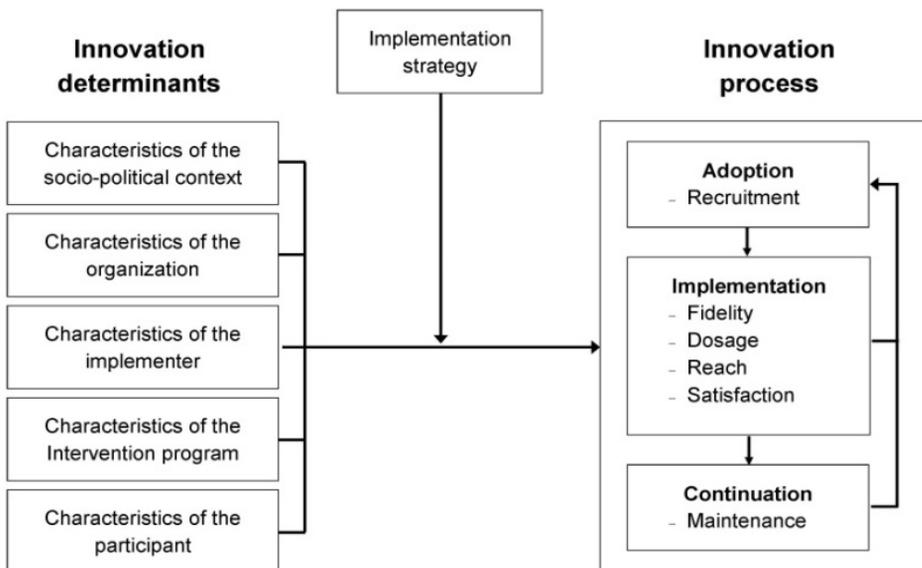


Figure 1.1

The theoretical framework [88] used to guide the monitoring and evaluation of the implementation of the 'Rehabilitation, Sports and Exercise' program.

The ReSpAct-study

The Rehabilitation, Sports and Active Lifestyle (ReSpAct) study is a multicenter longitudinal cohort study designed to evaluate the RSE program on organization and patient level. On organization level, the ReSpAct study aimed to monitor and evaluate the implementation of the RSE program in Dutch rehabilitation care. This thesis provides insight into the processes of adoption, implementation and continuation of the RSE program in 18 rehabilitation centers and rehabilitation departments of hospitals during a three-year period.

On patient level, the ReSpAct-study aimed to recruit ± 2000 adults suffering from a physical disability and/or chronic disease and participating in the RSE program [100]. Program outcomes (e.g. physical activity levels, quality of life, health care utilization) were assessed at different moments in time, up to one year after discharge from rehabilitation. This thesis also includes short term outcomes on patients' physical activity levels. The ReSpAct research group is currently working on analyzing the long term patient level outcomes. These insights will be available in the near future.

Aims of this thesis

This thesis describes the adoption, implementation and continuation of a national physical activity promotion program (i.e. RSE) in Dutch rehabilitation care. More specifically, the aim of this thesis was to monitor and evaluate the implementation of the RSE program in 18 rehabilitation centers and hospitals over a three-year period (2013 – 2015). This thesis provides, therefore, insight on how sports and physical activity promotion can be a structural and integrated component of a rehabilitation treatment, including potentially facilitating and hampering factors to the implementation and continuation. Moreover, the study provides insight into the process of scaling up national physical activity promotion programs (e.g. governmental programs) to local multidisciplinary healthcare settings (e.g. rehabilitation care). Lastly, this thesis provides examples of different governmental approaches to promote sports and physical activity among adults with disabilities.

Outline of this thesis

Chapters 2 till 6 report on the dissemination of the RSE program. These findings have theoretical and practical contributions, both from a rehabilitation science perspective as well as from an implementation science perspective. *Chapter 7*

describes different governmental approaches to promote disability sports. The findings are discussed from a policy perspective.

Chapter 2 describes the rationale and design of the study on the dissemination of the RSE program in Dutch rehabilitation care.

Chapter 3 describes the status of the integration of sports and physical activity in rehabilitation care at the start of the implementation period. This chapter gives an overview of the situation in seventeen organizations that adopted the RSE program in the first year of the program period. Two process outcomes (fidelity and satisfaction) are used to describe the starting positions of the involved organizations.

Chapter 4 describes professionals' perceptions on barriers and facilitators to the implementation and continuation of a physical activity promotion program in rehabilitation care. This chapter focuses, therefore, mainly on perceived 'innovation determinants' as illustrated on the left-side of the theoretical framework (figure 1.1).

Chapter 5 describes the results of the process evaluation of the nationwide implementation of the physical activity promotion program in Dutch rehabilitation care using four process outcomes (dosage, reach, satisfaction, maintenance). In addition, this chapter presents different profiles of received counseling and shows how these profiles are associated with changes in patients' physical activity behavior on the short term.

Chapter 6 describes the heterogeneity of implementation fidelity trajectories of a health promotion program (i.e. physical activity promotion) in a multidisciplinary setting (i.e. rehabilitation care) and its association with changes in patients' physical activity behavior.

Chapter 7 puts the current Dutch governmental approach to promote physical activity in an international perspective: it describes how the Dutch and Canadian governments promote sports and physical activities among adults with disabilities. In addition, key similarities and differences between both governmental approaches are identified. In addition, this chapter outlines how the Dutch government continues with investments in physical activity promotion after the RSE program (2016).

Chapter 8 includes a summary of the main findings, a general discussion and conclusion of this thesis.

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