



# LUND UNIVERSITY

## Physical activity in persons with late effects of polio

Winberg, Cecilia

2014

[Link to publication](#)

*Citation for published version (APA):*

Winberg, C. (2014). *Physical activity in persons with late effects of polio*. [Doctoral Thesis (compilation), Rehabilitation medicine]. Rehabilitation medicine, Department of Health Sciences.

*Total number of authors:*

1

### General rights

Unless other specific re-use rights are stated the following general rights apply:

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal

Read more about Creative commons licenses: <https://creativecommons.org/licenses/>

### Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

LUND UNIVERSITY

PO Box 117  
221 00 Lund  
+46 46-222 00 00

# Physical activity in persons with late effects of polio

Cecilia Winberg



**LUND**  
UNIVERSITY

DOCTORAL DISSERTATION

by due permission of the Faculty of Medicine, Lund University, Sweden.

To be defended at the Health Sciences Center, Baravägen 3, Lund.

Thursday the 18th December, 2014 at 09.00.

*Faculty opponent*

Associate professor Maria Hagströmer

Karolinska institutet

Organization LUND UNIVERSITY Rehabilitation Medicine Research Group Department of Health Sciences Author(s) Cecilia Winberg	Document name DOCTORAL DISSERTATION	
	Date of issue November, 26, 2014	
	Sponsoring organization	
Title and subtitle: Physical activity in persons with late effects of polio		
<p>Abstract</p> <p>Physical activity is beneficial for the health of persons with disabilities but the levels of such activity are lower than for persons without disability. In addition the level of physical activity decreases with increasing age. For persons aging with a disability it may be a challenge to engage in physical activity, partly because of the disability and partly because of contextual barriers. One group of persons aging with a disability is those with late effects of polio. The latter are recommended being physically active with respect to their impairments and activity limitations but there is very limited knowledge regarding their engagement in physical activity and related factors.</p> <p>The overall aim of this thesis was to increase knowledge about PA in ambulatory persons with late effects of polio by describing PA, assessing the relationships between PA and impairments, activity limitations, participation restrictions and life satisfaction, and furthermore by exploring perceptions of PA. The 81 participants had a confirmed history of acute poliomyelitis affecting the lower limbs, and were between 50 and 80 years of age. In the first study physical activity was analysed by self-report (The Physical Activity and Disability Survey) and by a pedometer. In the second and third study impairments, activity limitations and participation restrictions common in this population were assessed. The fourth study was qualitative and 15 participants were individually interviewed regarding their perception of physical activity and the personal and environmental factors related to physical activity. The results showed that the participants were physically active on average three hours per day, mostly in low-level intensity activities and walked on average 6212 steps per day. The amount of PA varied considerably between the participants. There was a positive association between physical activity and life satisfaction. Physical activity was associated with impairments (knee muscle strength and self-reported impairments), activity limitations and participation restrictions (gait performance, self-reported limitations in walking and fear of falling). The variance in physical activity was moderately explained by the assessed impairments, activity limitations and participation restrictions. Overall the participants had a positive perception of physical activity but multiple factors affected them in their effort to perform PA. The participants described aspects that were closely related to the late effects of polio, such as specific impairments, changes in physical activity over time, past experiences, and contextual barriers. Persons with late effects of polio want to be physically active but may need assistance in order to be able to create suitable strategies for minimizing the impact of their impairments, to prioritize and to change aspects of performance. These results could assist health care professionals in guiding this group to achieve or maintain an active and healthy lifestyle.</p>		
Key words: exercise, gait, the International Classification of Functioning, Disability and Health (ICF), lifestyle, muscle strength, Post poliomyelitis syndrome, qualitative research, rehabilitation, self-report, walking		
Classification system and/or index terms (if any)		
Supplementary bibliographical information	Language English	
ISSN and key title 1652-8220 Lund University, Faculty of Medicine Doctoral Dissertation Series 2014:147	ISBN 978-91-7619-076-0	
Recipient's notes	Number of pages	Price
	Security classification	

I, the undersigned, being the copyright owner of the abstract of the above-mentioned dissertation, hereby grant to all reference sources permission to publish and disseminate the abstract of the above-mentioned dissertation.

Signature \_\_\_\_\_ Date \_\_\_\_\_

# Physical activity in persons with late effects of polio

Cecilia Winberg



**LUND**  
UNIVERSITY



Copyright Cecilia Winberg

Photo cover front, picture in thesis: Cecilia Winberg

Photo cover back: Kaoken Kõrm Cerenius

Faculty of Medicine and Department of Health Sciences

Division of Rehabilitation Medicine

ISBN 978-91-7619-076-0

ISSN 1652-8220

Printed in Sweden by Media-Tryck, Lund University

Lund 2014



# Contents

List of papers	1
Introduction	3
Living with a disability	3
Aging with a disability	5
Physical activity and aging	5
Defining physical activity	6
Health benefits of physical activity	6
Recommendations for physical activity	7
Measuring physical activity	8
Physical activity and aging with a disability	8
Late effects of polio	9
Polio in the 20 <sup>th</sup> Century	10
Rehabilitation and lifelong management of late effects of polio	11
Physical activity and late effects of polio	12
Rationale	15
Aims	17
Specific aims	17
Methods	19
Participants	20
Assessing Functioning and Disability	20
Physical activity assessments	21
Disability assessments	22
Life satisfaction assessment	25
Perceptions of physical activity	25
Procedure	26
Analyses	27
Statistical analyses	27
Qualitative analysis	28
Ethical considerations	29

Results	31
The participants' characteristics	31
Functioning and Disability	31
Physical activity among the participants	31
Disability among the participants	33
Life satisfaction among the participants	36
Perceptions of physical activity	36
Functioning and Disability	37
Contextual factors	38
Discussion	41
Physical activity	41
Participants	43
Disability, physical activity, and their associations	44
Perceptions of physical activity	45
Physical activity and life satisfaction	47
Methodological considerations	47
Data collection and data analyses	47
The ICF as a framework	50
Conclusions	53
Clinical implications	53
Suggestions for future research	54
Svensk sammanfattning	55
Acknowledgements	57
Fundings	58
References	59
Appendix	68
Paper I - IV	





# List of papers

This thesis is based on the following papers, which will be referred to in the text by Roman numerals (I-IV).

- I. Winberg C, Flansbjerg U-B, Carlsson G, Rimmer J, Lexell J. Physical activity in persons with late effects of polio: a descriptive study. *Disability and Health*, 2014; 7: 302-308
- II. Winberg C, Flansbjerg U-B, Rimmer J, Lexell J. Relationship between physical activity, knee muscle strength and gait performance in persons with late effects of polio. *PM R*. 2014 Sep 9. Epub ahead of print.
- III. Winberg C, Brogårdh C, Flansbjerg U-B, Carlsson G, Rimmer J, Lexell J. Physical activity and the association with self-reported impairments, walking limitations, fear of falling and incidence of falls in persons with late effects of polio. *Journal of Aging and Physical Activity*. 2014 Sep 30. Epub ahead of print.
- IV. Winberg C, Carlsson G, Brogårdh C, Lexell J. Using the ICF to explore the perception of physical activity in persons with late effects of polio. In manuscript.

Reprints were made with permission from the publishers.



# Introduction

## Living with a disability

A disability is a consequence of an injury or a disease and broadly describes a person's ability to function in everyday life (1). Disability is a complex phenomenon that reflects the interaction between features of a person's body and features of the society in which he or she lives.

It is estimated that 12% to 20% of the population worldwide have a disability (1). The proportion is similar in Sweden where approximately 13% of the Swedish population between 16 to 64 years have a disability (2). This proportion increases with age and approximately 45% of the Swedish population between 64 and 84 years of age is living with a disability (2). One fifth of these have a physical disability that affects mobility (2). The occurrence of disability does not, however, inform of its severity and its consequences. Persons with a disability do not constitute a homogenous group and they encompass a diversity of experiences. Their whole life situation may be affected and may include changes in their possibilities for engaging in everyday life and participating in society as well as for experiencing having a good life (1). Living with a disability does not necessarily entail deterioration in health but there are indications that the health of persons with disabilities is worse than it ought to be (2-5). Low self-rated health is more than ten times as common as in the general population, and obesity, inactivity and depression are more often reported (2-4, 6).

One framework that describes the complexity of disability and the interactions with the environment is the International Classification of Functioning, Disability and Health (ICF) (7). The ICF comprises two parts: Functioning and Disability and Contextual factors (Table 1). Functioning and Disability has two components: Body Functions and Structures, and Activities and Participation. Functioning is the umbrella term for the positive aspects of the components while disability is the umbrella term for the negative aspects: impairments, activity limitations, and participation restrictions. Impairment is a problem in body functions or structures, an activity limitation is a difficulty encountered by an individual in executing a task or action, while a participation restriction is a problem experienced by an individual in involvement in life situations. Activities and participation are defined

differently (Table 1) but it is difficult to distinguish between them as they share the same categories. In this thesis activities and participation are referred to as the same component.

Functioning and disability interacts with the second part of the ICF namely contextual factors, which include environmental and personal factors. The ICF framework aims to cover all human functioning and integrates the medical model and the social model into a bio-psycho-social approach. The concept of disability throughout this thesis is based on the ICF terminology.

Table 1. An overview of the parts, components, definitions and positive/negative aspects in the International Classification of Functioning, Disability and Health (7).

Parts	Functioning and Disability		Contextual factors	
Components	Body Functions and Structures	Activities and Participation	Environmental factors	Personal factors
Definitions	Body Functions are the physiological functions of the body systems  Body Structures are anatomical parts of the body	Activity is the execution of a task or action by an individual  Participation is involvement in a life situation	Environmental factors make up the physical, social and attitudinal environment in which persons live and conduct their lives	Personal factors are the particular background of an individual's life and living, and comprise features of the individual that are not part of a health condition or health states
Positive aspect	Functional and structural integrity  Functioning	Activities Participation	Facilitators	Not applicable
Negative aspect	Impairment  Disability	Activity limitation Participation restriction	Barriers	Not applicable

## Aging with a disability

The modern society with advances in medicine and in society has affected and increased life expectancy for the total population worldwide. The aging process is a dynamic and natural part of life that is described by different theories that include a number of aspects (8, 9). Gerontology utilizes multidisciplinary concepts and approaches in an attempt to understand all aspects of the aging process (9). The three main areas within gerontology are biological aging, psychological aging and social aging. Several theories focus on normal aging and have excluded persons with disabilities (10). Aging with a disability is mostly described in terms of the biological aging and includes the changes at the organ system level (9, 11). Persons who have acquired disabilities in their childhood or adolescence are said to age with a disability, e.g., cerebral palsy and poliomyelitis (12). The trajectory of aging is concurrent with the trajectory of disability for these persons. The persons who do not suffer from disability until late in life are said to experience disability with age (13). The life expectancy for persons living with disabilities has increased to about 80% to 90% of that of persons without disabilities during the last 30 years (8).

The aging process for persons aging with a disability obviously has an impact on functioning and disability (12). The decline in the organ systems appears to be quicker among persons aging with a disability and is more noticeable. One rationale for this is the reserve capacity theory (8, 14). Each organ creates excess or reserve capacity over and above what is needed for basic survival and a loss of this reserve capacity is a major age-related change in the body. When impairments occur during childhood the absolute level of capacity may never have been reached and the reserve capacity is lower (9). There is also evidence that the organ systems age quicker in these populations (8, 14). Another explanation is that persons living with disabilities put more stress on their bodies especially in the musculoskeletal systems (8). This “wear and tear” is most likely related to the duration of the impairment. These processes have a generally more rapid and severe impact on health conditions, perceived impairments, activity limitations, and other secondary conditions (8, 15). Persons aging with a disability need to find a balance between managing health conditions associated with the primary disability and the health effects associated with the aging process (16).

## Physical activity and aging

Physical activity (PA) is recommended for older adults as well as for the general population. There is a growing body of knowledge regarding the health benefits of PA in older adults (11, 17). Increasing PA in old age has a positive impact on

healthy aging, reducing the burden of chronic disease and disability and increasing longevity (18).

## **Defining physical activity**

The definition of PA is broad and includes "any bodily movement produced by skeletal muscles that result in energy expenditure" (19). Energy expenditure is the sum of the basal metabolic rate (the amount of energy expended while at complete rest), the thermic effect of food (the energy required to digest and absorb food) and the energy expended in physical activity (19). PA can be performed in several areas of life i.e. leisure activities, exercise, sports, activities during work, transportation, and household chores (19, 20). PA encompasses in this thesis all the areas described above.

Persons are physically active in different areas and these areas all need to be considered and are important to understand. Environmental and personal factors interplay with PA and are correlates of PA. For older adults the physical environment is particularly relevant in relation to PA (21). According to the ICF, physical environment includes nature and built environment (7). Personal factors such as age, sex, health status, self-efficacy, and motivation are associated with PA (22).

## **Health benefits of physical activity**

The health benefits of PA for older adults are numerous and even though no amount of PA can stop the biological aging it can minimize the negative physiological effects of an otherwise sedentary lifestyle and increase active life by limiting the development and progression of chronic disease and disabling conditions (11, 17). PA for older healthy adults has an impact on physiological aspects e.g. cardiovascular function and bone health, and psychological aspects e.g. improvements in overall psychological well-being and life satisfaction (11). According to the American College of Sports Medicine all older adults should avoid inactivity, some PA is better than none and adults who participate in any amount of PA gain some health benefits (11). The dose-response relationship between PA and health points towards greater health benefits with a higher intensity and increasing fitness (23). However, the greatest health benefits can be expected among the most sedentary and will occur if inactive persons become somewhat active (23). Recent data suggests that small amounts of PA, with a lower level of intensity and an increase in overall energy expenditure are associated with health benefits (24-26). A generally active life, regardless of exercising, is positively associated with cardiovascular health and longevity (25). These results are based on older healthy adults, but may be applicable for persons

aging with disabilities as well. It could be very difficult to increase the amount of PA or the intensity of it for some persons aging with a disability because of the latter (27). A feasible approach to increase PA in this population and to reduce sedentary time could be to promote an active daily life including non-exercise PA e.g. car maintenance, going fishing and gathering mushrooms or berries (25). Non-exercise PA is embedded into much of daily life and is mainly performed with low intensity (25). This approach may be especially suitable for persons aging with a disability as they tend to sit more. They spend a large proportion of the remaining day performing low-level intensity activities (25, 28). There is a need for further evidence of the beneficial effects of an active daily life on health and longevity in persons aging with a disability.

## **Recommendations for physical activity**

The World Health Organization's (WHO) international recommendations for persons 65 years or older include leisure time PA, transportation, occupational PA, household chores, and planned exercise (29). This group are recommended to do at least 150 minutes of moderate-intensity aerobic PA during the week, in bouts of at least 10 minutes duration (29), often interpreted as 30 minutes per day, five days per week (30). In addition they are recommended to perform muscle strengthening activities and activities to enhance balance and preventing falls. If a person is unable to do the recommended amounts of PA due to his/her health condition, the person should then be as physically active as his/her abilities and health condition permit.

Worldwide 79% of the adult population performed PA with moderate intensity at least 30 minutes per day five days per week (30). In a Swedish sample 65% of the population above 15 years of age were physically active at least 30 minutes per day (31). Inactivity increases with age and worldwide 50% of adults above 60 years of age performed PA with moderate intensity at least 30 minutes per day and five days per week (30). In the Swedish National Public Health Survey, the participants were asked to report how much time they spent performing PA and 61% of adults aged between 65 and 84 years reported being physically active at least 30 minutes per day (31).

PA can also be calculated in terms of the number of steps and the recommendation amounts to 8 000 to 10 000 steps per day (32). It has been suggested that 3 000 to 4 000 steps are needed for daily activities and that less than 5 000 steps per day is considered sedentary in healthy adults (32). Normative data indicate that healthy adults typically take between 4 000 and 18 000 steps per day (33), and for older adults (above 60 years of age) the number of steps ranges from 2 749 to 4 490 (34).



## Measuring physical activity

Describing and capturing all aspects of PA is considered a challenge since PA can be performed in several areas of life. There is thus no “golden” standard for measuring PA (35). One way to provide valid and reliable data for the different aspects of PA is to measure and describe PA by using multiple methods (36). PA can be assessed with subjective measures e.g. questionnaires, activity logs and diaries, and/or with objective measures e.g. energy expenditure, pedometers, accelerometers and heart rate monitoring (36-38).

Questionnaires or self-reports are commonly used as they are inexpensive and easy to administer (37). The accuracy of these tends to be low as PA is often overestimated in self-reports (39), but can be improved if the self-reports include PA in occupation, transport and household, especially in women and older adults (40).

Pedometers are used in an attempt to objectify the behaviour and are direct measures of body movement. A pedometer is a motion detector that measures the number of steps using different techniques and they are convenient and simple to use (37). The accuracy of pedometer counts decreases at a low walking speed (<0.8 meters per second) and with a shuffling gait (41, 42).

There are few validated measures for persons aging with a disability. Measurements for this population need to capture low level intensity activity and include use of mobility devices (43). Measuring PA in persons with disability is further complicated because the disability changes the nature of PA itself. The energy cost may be higher, major muscles are used differently and the use of mobility devices reduces the energy cost when walking (36).

## Physical activity and aging with a disability

The level of PA decreases with increasing age and is lower in persons with disabilities than in the general population. Adults with a disability are twice as likely to be physically inactive than are those with no disability (44). In a Swedish survey, 23% of the persons with disabilities had a sedentary leisure time in comparison to the rest of the population's 10% (2). In persons 65 years of age and older, only 15% of those with a disability met the WHO recommendations for PA, of at least 30 minutes per day five days per week with at least moderate intensity, compared to 26% of those without a disability (45). Little is known about the prevalence of PA in persons aging with a physical disability and no specific population based information exists on the percentage of persons who meet the recommendations (43). PA may reduce secondary conditions and decrease the level of disability and impact on quality of life and overall well-being for persons

aging with a disability but there is a limited body of research (45, 46). It may be more urgent to address PA needs in these populations than in the general population, as they are more sedentary and have a reduced physical fitness due to their disability (44). Their functioning and physical independence is negatively affected by even small reductions in strength and endurance (16).

It may be a challenge to increase engagement in PA in this population and more PA may not always be suitable due to their disability (27, 47). Persons aging with multiple sclerosis and late effects of polio most likely benefit from PA but since most studies have been conducted on persons under 65 years of age the effect of PA on older adults is not known (46). In other physical disabilities, such as stroke and Parkinson's disease, that occur mostly in middle-aged and in older adults PA is recommended to minimize the effects of impairments, to prevent secondary conditions and to increase quality of life (48, 49).

The key to an effective PA plan is to understand the multitude of factors that are associated with successful participation in PA. It is important to consider the physical environment for persons with physical disabilities where the mobility is affected. Limited access to the physical environment and exercise facilities is a commonly reported barrier for persons with disabilities (27, 50). Absence of support in the social environment is perceived as being a barrier while the opposite can be a facilitator (27, 50, 51). Barriers and facilitators need to be considered when promoting health in these populations. Health promotion is defined as a process that aims to increase an individual's possibility of improving and taking control over his/her own health (20). Health promotion for persons aging with a disability needs to take a healthy and accessible environment into consideration (6). Health promotion should also include preparation for self-management of health and promotion of opportunities for participating in non-exercise PA (6, 52).

## Late effects of polio

One group of persons aging with a disability is those with prior polio who as they enter their middle age is of risk to develop new symptoms or impairments, referred to as late effects of polio. The term, late effects of polio, will be used throughout this thesis. Late effects of polio refer to all the new symptoms that persons with polio may have after a period of stability i.e. not only the symptoms described in post-polio syndrome but also symptoms from secondary medical conditions related to the polio, comorbidity or aging (53). It may be difficult to separate impairments such as muscle weakness and fatigue from impairments related to comorbidity or aging (54).

## Polio in the 20<sup>th</sup> Century

Many children became ill in acute poliomyelitis, a generalized viral illness, in the beginning of the 20<sup>th</sup> century (53). Paralysis occurred in 1/100 of infected persons and many had minimal or transient weakness. Paralysis was more prominent in the legs than in the arms and was randomly distributed. The recovery period usually lasted from months to years. The majority of the children who became ill in polio recovered and has lived their lives with only some degree of disability or no disability at all. They are experienced in using coping strategies and the majority are well adjusted to society and have lived a good life (55-57).

As these persons enter their middle age there is a risk to them of developing late effects of polio (58). It is estimated that 12-20 million persons worldwide have late effects of polio and in Sweden about 15 000 to 20 000 persons are expected to be diagnosed with this condition (53, 59). An increasing number of persons with late effects of polio in Sweden are immigrants and younger. Although the number of persons with polio is decreasing in the western world the number will remain high in developing countries for the next decades (53). The knowledge related to this population will thus be needed for many years ahead.

The cause of these new impairments is not entirely clear, but it is a general consensus that the new symptoms (muscle weakness and fatigue) are due to a distal degeneration of axons in enlarged motor units. Enlarged motor units are developed during recovery after the acute poliomyelitis and at the age of around 50 years persons start to suffer from the “normal” age-related loss of motor neurons (53, 60). The most common impairments, muscle weakness, muscle fatigue, general fatigue, and musculoskeletal pain (61-63), cause increasing difficulties with physical functioning and increasing difficulties with gait and mobility. Difficulties in physical functioning can, in turn, affect their performance of everyday activities and restrict their participation. Persons with late effects of polio are often functioning independently by use of technical aids and by living in an adapted environment (64). Life satisfaction is reduced compared with non-disabled persons especially in relation to physical health (65, 66). The progression rate is slow (67) but persons with late effects of polio can be deconditioned due to their impairments and their prior polio (60). The prevalence of coronary heart disease risk factors is increased (68) and the energy cost, which is strongly related to the extent of muscle weakness, is higher when performing PA (69). The new impairments change the life situation for these persons and they need to create and adopt new coping strategies (60).

## **Rehabilitation and lifelong management of late effects of polio**

Persons with late effects of polio in Sweden are mostly treated within a rehabilitation setting. According to the WHO, rehabilitation of persons with disabilities is defined as a “process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels” (20). All aspects of the rehabilitation process are based on the ICF (7).

Individualized, goal oriented, comprehensive and interdisciplinary rehabilitation has been described as a process of change in persons with late effects of polio. In addition they described themselves that taking part in a rehabilitation programme had a positive impact on their sense of control and their acceptance of their condition (70).

The person with late effects of polio participates actively in all parts of the rehabilitation programme together with the members of the interdisciplinary team. The person is assessed by the individual team members and these assessments combined with his/her own perception of disability form the base for setting goals during the rehabilitation programme. The team members work in close collaboration with the person in order to achieve his or her goals (71). The emphasis for persons with late effects of polio is on education and self-management with the aim of enhancing participation and the experience of living a good life (Table 2). Life style changes and health promotion aims to reduce secondary conditions, to maintain functional independence and to enhance quality of life and life satisfaction (72).

Enhancing life satisfaction is a common and overarching goal of rehabilitation and in the management of lifelong disabilities (56, 73). Life satisfaction is commonly referred to as a person’ subjective contentment with his/her life (74) and reflects the degree to which an individual perceives that his or her aspirations (or goals) and achievements have been met (66). Life satisfaction is not defined in the ICF, but strongly associated with perceived participation in persons with late effects of polio (73).

Table 2. Rehabilitation and life-long management of persons with late effects of polio.

---

Examples of interventions
Prescription of mobility aids and orthotic devices
Teaching of compensatory techniques
Medical and nonmedical interventions aimed at reducing pain, fatigue and sleep disturbances
Ergonomics and vocational interventions to maintain workability
Therapeutic home exercises
Life style changes including education, recommendations about PA and weight management.
Home visits to assist in environmental adaptations

---

## Physical activity and late effects of polio

Lifestyle changes include advice on PA and persons with late effects of polio are encouraged to be physically active. However, due to their impairments they may be unable to increase the amount of PA or to achieve the desired level of PA intensity to be beneficial for health. There are generally no restrictions for PA when the body parts and muscles are not affected or only mildly affected. When body parts and muscles are significantly affected the intensity needs to be individually tailored and they may have to engage in low-level intensity PA. There is an overall need for longer recovery after PA and due to the random distribution of muscle weakness PA may be increased for certain parts of the body and decreased for other parts. These persons might be physically active closer to their maximal capacity and with an increased energy cost (69, 75). The latter is strongly related to the extent of muscle weakness in the lower extremities (69). Advice about PA should also include information regarding energy conservation, which includes pacing of daily activities with rest periods, eliminating unnecessary energy-consuming activities and decreasing standing time when feasible (76).

These persons have in the past been recommended not to exercise as it was supposed to cause more harm than good. According to the European guidelines (62), however, no prospective studies have shown that increased muscle activity or training has led to a loss of muscular strength compared with the absence of training or less muscular activity. Muscle training and aerobic exercise have positive effects on muscle strength (62, 77, 78) and cardiorespiratory functions (79). Persons who reported regular PA had fewer impairments such as pain, fatigue and reduced muscle strength and a higher functional level than physically

inactive persons (62, 75, 80, 81), while persons who perform PA at a higher intensity level are more likely to have moderate to severe pain (75).

Only a few studies have reported on levels of PA in this population. In a Norwegian and Estonian sample nearly 50% reported no physical exercise (80). The participants were asked to report whether they exercised regularly, at least weekly, and in the Estonian sample 5% exercised regularly while in the Norwegian sample 19% exercised regularly (80). In a Swedish study, overall PA was described in 32 persons with late effects of polio (mean age 56 years). The majority scored high on household activities and 50% of the participants performed strenuous sports activities involving muscle strength and endurance (81). In another study, Klein compared perceived and actual activity levels in 65 persons with late effects of polio during a 3-year period. The perceived activity level decreased over time but the daily walking activity did not change statistically (75).

Late effects of polio is characterized by different impairments and activity limitations. Commonly reported impairments such as muscle weakness, pain and fatigue are associated with lower rates of daily PA (75, 81) and can lead to activity limitations (82), many of which are related to gait performance (83). This, in turn, can impact on perceived participation (73) and life satisfaction (65).

The impairments but also inaccessible environments and lack of understanding among health care providers are reported as barriers for PA in persons with late effects of polio (84-86). The adapted and individualized health promotion programmes that this population need require an understanding of how their impairments and activity limitations mediate and affect their rates of PA participation. It is also necessary to include the interplay with environmental and personal factors as they are correlates for PA (22).



# Rationale

Persons with late effects of polio are recommended to be physically active and pursue an active and healthy lifestyle. It may be a challenge to pursue an active and healthy lifestyle due to the condition and due to contextual factors that are associated with PA. It can be very difficult for persons with late effects of polio to comply with the recommendations for PA. Due to their impairments they may not be able to increase the amount of time spent in PA or the intensity of the PA. In order to individualise health promotion and lifestyle changes more knowledge is needed on the amount of PA and on the type of PA in this population. There is a need to assess which factors mediate daily PA among persons with late effects of polio. In persons with disabilities environmental and personal factors are associated with PA. The interplay between functioning and disability and environmental and personal needs to be described and further explored in relation to PA.





# Aims

The overall aim of this thesis was to increase knowledge about PA in ambulatory persons with late effects of polio by describing PA, assessing the relationships between PA and impairments, activity limitations, participation restrictions and life satisfaction, and furthermore by exploring perceptions of PA.

## Specific aims

In ambulatory persons with late effects of polio:

- describe their level of PA;
- assess the relationship between PA, life satisfaction and various contextual factors (e.g., age, sex, Body Mass Index (BMI), marital status, living condition);
- assess the relationship between PA, impairments (knee muscle strength), and activity limitations (gait performance);
- examine the association between PA, self-reported impairments, and activity limitations and participation restrictions (walking limitations, fear of falling and incidence of falls);
- explore the perception of PA and factors that could be perceived as facilitators of and barriers to PA.



# Methods

This thesis is based on three descriptive cross-sectional studies (Papers I, II, and III) and one qualitative study (Paper IV). In Table 3, an overview of design, participants, outcome measures and data analyses is presented.

Table 3. Overview of the study design, participants, outcome measures and data analyses for studies I-IV.

	Study I	Study II	Study III	Study IV
Design	Descriptive, cross-sectional	Descriptive, cross-sectional	Descriptive, cross-sectional	Qualitative study
Participants	N=81 (43 men/ 38 women)	N=77 (42 men/ 35 women)	N=81 (43 men/ 38 women)	N=15 (8 men/ 7 women)
Age, mean (SD)	67 years (6)	67 years (6)	67 years (6)	68 years (6)
Outcome measures	Physical Activity and Disability Survey (PADS), pedometer, Life satisfaction questionnaire (LiSat-11), study specific questionnaire	Physical Activity and Disability Survey (PADS), pedometer, isokinetic knee muscle strength, Timed “Up & Go” test (TUG), 10 m comfortable and fast gait speed tests (CGS and FGS), 6-Minute Walk test (6MWT)	Physical Activity and Disability Survey (PADS), pedometer, Self-reported Impairments in persons with late effects of polio (SIPP), Walking Impact Scale (Walk-12), Falls Efficacy Scale-International (FES-I)	Data collected through qualitative individual semi-structured interviews
Data analyses	Students T-test, Pearson’s correlation coefficient, Spearman’s correlation coefficient, Mann-Whitney U-test	Students T-test, Pearson’s correlation coefficient, Spearman’s correlation coefficient, multiple linear regression	Students T-test, Pearson’s correlation coefficient, Spearman’s correlation coefficient, multiple linear regression	Directed content analysis

## Participants

The participants in these studies were recruited from a database at a post-polio rehabilitation clinic in a university hospital in Southern Sweden. The database has existed since 2003 and included at the time of recruitment 609 persons with late effects of polio. An electromyogram had been recorded in the lower limbs for all participants as part of the initial routine clinical examination and verification of prior polio.

The inclusion criteria were based on the overall aims of this thesis and were for the studies: 50 to 80 years of age; a confirmed history of acute poliomyelitis affecting the lower limbs with new symptoms after a period of functional stability; no other conditions such as severe joint problems, cardiovascular or pulmonary diseases that could affect mobility and PA; being ambulatory with or without mobility devices and not using a wheelchair as their main mode of transportation; living in ordinary housing; being able to understand spoken and written Swedish.

Three hundred persons, 130 men and 170 women (mean age 69 years) met the inclusion criteria and 102 persons were consecutively invited to participate by two physiotherapists at the rehabilitation clinic. The participants were invited by mail or in conjunction with a visit to the clinic and 81 persons accepted the invitation. Four persons did not want to participate in Study II as they found it inconvenient to travel to the rehabilitation clinic for the assessments.

Recruitment of the participants in the fourth study was made from the 81 persons in the Study I-III. A wide range of experiences were sought by selecting participants in terms of varying gender, age, functional level, PA level and vocational situation. Twenty persons were invited to participate and 15 persons accepted the invitation.

## Assessing Functioning and Disability

In Study I data on personal and environmental factors, such as age, sex, self-reported height and weight (to calculate their BMI), marital status, housing, living condition and vocational situation, were obtained by a study-specific questionnaire. Data regarding the age at onset of poliomyelitis and the duration of late effects of polio were retrieved from the database at the rehabilitation clinic.

## Physical activity assessments

PA is part of the Activities/Participation component in the ICF, but is presented as an own entity in the following section. PA is recommended to be measured with multiple methods that were taken into account in the studies. PA was measured by a self-report – the Physical Activity and Disability Survey (PADS) – and by an objective measure – a pedometer. The data derived from the PADS and the pedometer was used in Study I-III.

### *Physical activity and Disability Survey (PADS)*

The PADS is a self-report questionnaire developed to provide a measure of the day-to-day level of PA in persons with disabilities (87). The PADS consists of three parts, the first focusing on demographic data, the second comprising four subscales focusing on exercise, leisure, household and work/school, and the third part describing therapy or use of a wheelchair. In the second part the participants were asked about their PA behaviour in the four subscales which covered the following four areas: 1) structured exercise (exercising at specific time of day on a regular basis with an emphasis on improving fitness; 2) leisure time PA (unstructured PA performed on an infrequent basis, such as bowling, going for an occasional walk, and not focused on fitness; 3) indoor and outdoor household activities (indoor activities, such as dusting, mopping floor, doing laundry, and outdoor activities such as gardening and maintenance); 4) work-related activity (activities during work). The participants were informed of the definitions of the different subscales as described above during the interview. The participants were asked to report the amount of time spent performing PA within each area during the last year (Table 4). Data were then converted into minutes per day for each subscale.

Table 4. An example of how PA was described in terms of type, frequency and duration in the Physical Activity and Disability Survey (PADS).

Type of Activity	Days per week	Minutes per day	Weeks per years
walking	3	30	40
gardening	2	60	16

The PADS has displayed good psychometric properties and good test-retest reliability in persons with disabilities and chronic health conditions such as stroke, multiple sclerosis and diabetes (87, 88). The PADS is significantly correlated with

peak oxygen uptake (87) and is sensitive to pre and post changes in PA levels after specific interventions (89). Internal consistency reliability (Cronbach's alpha) ranged from 0.67 (exercise) to 0.77 (household activities) and test-retest reliability (intra-class correlation coefficient, ICC) with one week interval, ranged from 0.83 (exercise) to 0.95 (leisure). The inter-rater reliability ranged from 0.92 (household activities) to 0.99 (exercise, leisure and total) (87). PADS was translated and adapted into Swedish in collaboration with its developer (J.H. Rimmer) using a forward-backward translation and monolingual test (90).

### *Pedometer*

A pedometer (Yamax SW 200, Tokyo, Japan) was used to measure the number of steps during three ordinary days (weekdays as well as weekends) (Figure 1). The Yamax pedometer is considered to have good validity and reliability (91, 92). It has been tested for test-retest reliability in ambulatory persons with stroke and ICC ranged from 0.66 and 0.98 (93). Pedometers are strongly correlated with other motion detectors as accelerometers ( $r=0,86$ ), moderately with energy expenditure ( $r=0.68$ ) and weakly with self-reported PA ( $r=0.33$ ) (36). Although no study has validated the use of a pedometer for persons with late effects of polio, available evidence suggests that pedometers are valid for use for persons with physical disabilities in clinical and research settings (41, 42).



Figure 1.  
The pedometer (Yamax SW 200) used for measuring the number of steps in Study I-III.

## **Disability assessments**

Disability is the interaction between impairments, activity limitations and participation restrictions (7). The assessments and measures described below illustrate common impairments, activity limitations and participation restrictions in persons with late effects of polio. Activities and participation are, as previously

mentioned, referred to as the same component. Participation restrictions are to some extent considered in items in the Falls Efficacy Scale-International (FES-I).

### *Knee muscle strength*

Isokinetic knee extensor and flexor muscle strength were measured at 60°/s with a Biodex ® Multi-Joint System 3 PRO dynamometer using a standard protocol applied in our research group. Knee muscle strength measurements are reliable in persons with late effects of polio with high test-retest agreement and intra-class correlation coefficients (ICC; 0.93-0.98), and low standard error of measurement (SEM %; 4%-14%) (94). The participants were seated in the adjustable chair of the dynamometer, without shoes or orthotics. They were firmly stabilized with straps across the shoulders, waist and thigh, and sat with folded arms throughout the test. The ankle cuff of the lever arm was strapped 3 cm proximal to the malleoli of the tested leg. After a structured warm-up, each participant performed, in successions, three maximal concentric knee extensor and flexor contractions at 60°/s and the highest peak torques were recorded (Newton meter; Nm). The range of motion was set prior to each measurement and the Biodex software applied the gravity correction. Consistent verbal encouragement was given throughout. Following the National Rehabilitation Hospital Post-polio Limb classification (95) and the individuals' own perception of their late effects of polio, one lower limb was defined as the "more affected" and the other as the "less affected". All measurements started with the less affected lower limb followed by the more affected lower limb. Due to weakness, 5 participants were unable to perform the knee flexion measurements in their more affected lower limb; muscle strength for these measurements was therefore scored as "0" in the statistical analyses.

### *Self-reported impairments*

The participants reported their impairments in the Self-reported Impairments in Persons with Late Effects of Polio (SIPP), which is a 13-item scale (96). The participants rated how much they have been bothered during the past two weeks by various impairments, directly (e.g. muscle weakness, pain, fatigue) or indirectly (e.g. sensory disturbances, mood swings) related to late effects of polio. There are four response options, ranging from 1 (not at all) to 4 (extremely). The sum score is calculated by adding the score for each item and ranges from 13 to 52 points. A higher score indicates that the participant is more bothered by the impairments related to late effects of polio. SIPP has been Rasch analysed and is unidimensional, which allows total sum scores and the use of parametric analyses (96).

### *Gait performance tests*

The following gait performance tests were used: the Timed "Up & Go" test (TUG) (97), the 10 meter Comfortable Gait Speed and the 10 meter Fast Gait Speed tests (CGS and FGS) (98), and the 6-Minute Walk test (6MWT) (99). The gait



performance tests are reliable in persons with late effects of polio with high test-retest agreement, (ICC; 0.82-0.97) and low SEM% (4%-7%) (100).

For the TUG, each participant sat in an armchair placed at the end of a marked 3-m walkway. Participants were instructed to sit with their back against the chair and on the word “go”, stand up, walk at a comfortable speed past the 3-m mark, turn around, walk back and sit down in the chair. They were allowed to use the armrests for support if needed. The TUG was carried out twice, with a 1-minute rest between each trial, and the mean of the two tests were recorded (seconds).

For the CGS and FGS, a 14-m walkway was marked on the floor, and the participants were timed over the middle 10 meters. For the CGS, the participants were told to walk at a self-selected comfortable pace, whereas for the FGS, the participants were told to walk as fast and safely as possible without running. The CGS and FGS were performed 3 times with 30 seconds between each trial. The time (in seconds) taken to walk 10 meters was recorded for each trial and the mean value for CGS and FGS were calculated and converted to gait speed (m/s).

For the 6MWT, the participants were instructed to walk 30 m between two marks on the floor. After passing either mark, they were told to turn and walk back. They were instructed to cover as much ground as possible and to walk as far as possible for six minutes. The 6MWT was performed once and the number of 30 m-lengths was counted. On the wall every meter was marked so the distance could be measured to the nearest meter. The participants were informed when 3 minutes of the test remained. They were allowed to rest and then continue walking, but no participant needed to rest during the test.

No verbal encouragement was given during the gait performance tests. A digital stopwatch with an accuracy of one decimal figure in units of 1 second was used to measure time. All participants were independent walkers but were allowed to use, if needed, their mobility device and/or orthotic. All 77 participants completed the 4 gait performance tests.

#### *Self-reported activity limitations and participation restrictions*

Walking limitations were assessed with the Walking Impact Scale (Walk-12), which consists of 12 items and asks about limitations during the past two weeks in activities related to walking, running, climbing stairs, balance, distance and efforts, need for support indoors and outdoors, gait quality aspects and concentration when walking (101). There are five response options, ranging from 1 (not at all) to 5 (extremely). The sum score of the Walk-12 is generated and reported on a 0-100 scale, in which 0 indicates no limitation and 100 indicates maximum limitation. The score, in percentage, is obtained by using the following equation:  $100 \times (\text{mean value of 12 items} - 1) / (5 - 1)$ . Walk-12 has been used in persons with late effects of polio and the psychometric properties are good (102, 103).

Fear of falling was assessed with the Falls Efficacy Scale-International (FES-I) (104). The FES-I focuses on the participants' level of concern about falling when performing 16 daily activities. The FES-I consists of the following items: cleaning the house, getting dressed/undressed, preparing simple meals, taking a bath or a shower, going to the shop, getting in or out of a chair, going up or down stairs, walking around outside, reaching up or bending down, answering the telephone, walking on slippery surface, visiting a friend/relative, going to a place with crowds, walking on uneven surface, walking up or down a slope and going to a social event. There are four response options, ranging from 1 (not at all concerned) to 4 (very concerned). The sum score is calculated by adding the scores for each item and ranges from 16 to 64 points. It has been shown to have good psychometric properties in older adults (104). The FES-I has been recently used for persons with late effects of polio (105).

### *Incidence of falls*

The participants reported the incidence of falls by responding to a question regarding the occurrence of falls during the past year. A fall was defined as an event which results in a person coming to rest inadvertently on the ground or floor or other lower level (20). Fall incidence was subsequently dichotomized as 'yes' (one or more falls during the past year) or 'no' (no falls during the past year).

### **Life satisfaction assessment**

Life satisfaction was assessed by use of the Life Satisfaction Questionnaire (LiSat-11). LiSat-11 is a generic self-report checklist that assesses the level of global satisfaction with life in one item and the level of domain-specific satisfaction in 10 items (106). The item assessing level of global satisfaction with life was only used here (Study I). There are six response options ranging from 1 (very dissatisfied) to 6 (very satisfied). Higher scores indicated a higher level of global satisfaction with life. LiSat-11 has a stable construct and is pragmatically sound (106), and has been used to assess life satisfaction in persons with late effects of polio (65, 66, 73).

## Perceptions of physical activity

In Study IV data were collected in semi-structured qualitative individual interviews. An interview guide with semi-structured open-ended questions was developed, based on the parts (and components) in the ICF – Functioning and Disability (Body Functions and Structures; Activities and Participation) and Contextual Factors (Environmental factors; Personal factors) (7). The interviews

focused on themes such as perception of PA, the impact of PA, and environmental and personal factors perceived as facilitators of and barriers to PA.

## Procedure

In Study I all the participants were interviewed by the author. The interview started with a study-specific questionnaire, followed by Li-Sat-11, and ended with the PADS. The interview took 30 to 45 minutes. After the interview, each participant received information about the pedometer, how to use it and how to record their daily counts. They were carefully instructed on how to wear the pedometer, clipped to their clothing (either side) and close to the anterior iliac spine, from the time they woke up in the morning to the time they went to bed at night. The participants recorded their daily counts and then reset the pedometer every morning. The pedometers were returned in a prepaid envelope, together with the records of the daily counts. Fifty participants were interviewed at the rehabilitation clinic and 31 participants were interviewed in their home.

In Study II knee muscle strength measurements and gait performance tests were performed at the rehabilitation clinic. Knee muscle strength was measured and gait performance assessed at the rehabilitation clinic by skilled physiotherapists. The order of the assessments was fixed. Knee muscle strength was measured first in a Biodex dynamometer, then the participants had a 20 minutes rest, and thereafter, their gait performance was assessed by four tests in the following order: the TUG, then the CGS and FGS, and finally the 6MWT. The total time for the tests was 2 hours.

In Study III the participants responded individually to the self-reports assessing impairments, activity limitations and participation restrictions: the SIPP, the Walk-12, the FES-I, and fall incidence. Data in Study I-III were collected throughout the year and started in March 2011 and ended in December 2012.

In Study IV the data collection consisted of one individual interview with each participant. All the interviews were undertaken during the period from October to November 2013 and conducted by the author. The interviews lasted between 30 and 60 minutes (mean 39 minutes) and were performed at a place chosen by the participants. Eleven participants were interviewed in their own home and four at the author's workplace.

# Analyses

## Statistical analyses

Descriptive statistics (mean  $\pm$  SD) were calculated for the characteristics of the participants. Associations between PA, contextual factors, impairments, activity limitations, participation restrictions and life satisfaction were analysed with Pearson's correlation coefficient ( $r$ ) for continuous data and with the Spearman rank correlation coefficient ( $\rho$ ) for ordinal data. Independent samples t-test was used to determine differences between groups for continuous data and Mann-Whitney for ordinal data. In Study II and III multiple linear regression analyses were performed.

For the multiple regression analyses, the dependent variables in Study II were the PADS leisure subscale and the number of steps as they were significantly associated with the knee muscle strength measurements and gait performance tests. In the first step of the analysis the strength measurements and the gait performance tests were the independent variables. They were analysed separately as there were significant correlations between the knee extensor and flexor muscle strength measurements as well as between the different gait performance tests. In the second step of the analyses the other independent variables (age, sex and BMI) were added.

The sum of PADS and the number of steps were the dependent variables in Study III and the outcomes of the SIPP, the Walk-12 and the FES-I were the independent variables. Age, sex and BMI were also included in the analyses. All the independent variables were checked for multicollinearity and only small to moderate correlations were found ( $r= 0.25$  to  $0.44$ ,  $p<0.05$ ). From the full models, variables were omitted one by one starting with the variable with the greatest p-value, until all remaining variables had a p-value less than 0.05.

In both studies the suitability of this approach – the aptness of the linear model and the normality of the residuals – were addressed in scatterplots of the residuals and predicted values, in normal probability plots and in Q-Q plots. The aptness of these models was not rejected, confirming that a linear model could be applied to this sample.

All calculations were performed using IBM SPSS Statistics version 20 and 21 (IBM Corporation, Armonk, New York, United States). Significance levels less than 5% represented statistical significance.

## **Qualitative analysis**

In Study IV, a qualitative content analysis with a directed approach was performed (107) by using the ICF components as preliminary categories (7). The analysis included several steps. First, all interviews were read several times to acquire a sense of the essence (108). Second, the text was divided into meaningful units consisting of a communicative act where the participants talked about their perception of PA and of environmental and personal factors related to PA. Each meaningful unit was coded into a preliminary code, describing the perception of PA and the facilitators of and barriers to PA. The preliminary codes were studied and pooled into subcategories. The subcategories were then sorted according to which parts and components they mainly belonged to in the ICF. All subcategories emerging from the transcripts could be fitted into the ICF parts and components.

# Ethical considerations

Ethical considerations have been addressed and reflected upon throughout the studies. For all studies the presumptive participants were contacted by post with information explaining the study, an invitation to participate, an option to receive additional verbal information and an informed consent form. They were also informed about the right to withdraw from the study at any time without giving any reason and that eventual withdrawal would not affect their possibilities for future care. After the participants had signed the informed consent they were given the opportunity to receive additional verbal information regarding the study.

In Study IV the participants were individually interviewed. The participants were given the opportunity to choose the place for the interview. It was important to perform the interviews at a place where the participants felt comfortable. The majority of the participants chose to perform the interviews at home. Visiting persons in their own home requires respect for personal integrity, which the interviewer took into account. An interview may cause discomfort and sense of privacy violation, which was taken in consideration during the planning of the interview questions. The participants decided themselves what they wanted to share. The transcripts from the interviews were anonymized before the analysis process started.

The results are presented on a group level in Study I-III; in the qualitative study (IV) the results are presented in such a way that individuals cannot be identified. The foreseeable benefits of each study were considered to outweigh any foreseeable discomfort for the participants. The research on PA in persons with late effects of polio is very limited which makes these results important. The results call attention to this population and their special needs in relation to PA. This knowledge is valuable in terms of further recommendations about PA for persons with late effects of polio.

The principles of the Helsinki declaration (109) have been followed throughout this thesis. All studies were approved by the Regional Ethical Review Board, Lund, Sweden (Study I-III Dnr 2013/427, Study IV Dnr 2013/403).



# Results

The results are presented thematically and start with a description of the participants, followed by a description of PA, functioning and disability, and the associations between PA and disability. These results are based on Study I-III, where the participants are the same apart from the four persons who did not participate in Study II. Finally, the perceptions of PA and perceived facilitators and barriers in relation to PA will be presented (Study IV).

## The participants' characteristics

The participants were all diagnosed with late effects of polio and the mean duration of new symptoms was 16 years (Study I-III) to 18 years (Study IV). The mean age at onset of poliomyelitis was 4 years. Sixty-three percent of the participants had a BMI above 25 and were considered overweight. Seventy-five percent of the participants were married or cohabiting and 35% worked full-time or part-time. Almost 70% lived in a single family house and 85% of the participants lived in a city or a small town. Twenty-six percent of the participants used mobility devices i.e. canes, crutches and wheeled walkers for ambulation and 26% used an ankle foot orthotics or knee-ankle foot orthotics. Five participants used an electric scooter for ambulation outdoors.

## Functioning and Disability

### **Physical activity among the participants**

The results showed large variations in PA level between the participants, both in their self-reported PA and in the pedometer counts. According to the PADS, the participants were active 158 minutes per day (range 17 to 438) in the four subscales (exercise, leisure, household and work). Seventy-three percent of the self-reported PA was performed in the household subscale, on average 116



minutes per day (range 17 to 397). All participants performed household activities such as household chores and gardening.

Leisure PA was performed by 68% of the participants and the average time spent on these activities was 26 minutes per day (range 2 to 169). Leisure PA is defined as more unstructured than exercise and performed on an infrequent basis. The most common activities were walking and cycling. Regular exercise was performed by 60% of the participants but less than 10% of the total amount of PA was performed in exercise (mean 9 minutes per day, range 2 to 120). Structured and planned exercise was mostly performed once a week and most often as aquatics. In the exercise subscale the participants rated the intensity of PA. Exercise was rated as low-level intensity by 15 participants, 24 participants rated their exercise to be moderate-level intensity and the remainder (9 participants) considered their exercise to be high-level intensity. Among the 28 participants who worked, 15 reported being physically active at work, on average 8 minutes per day.

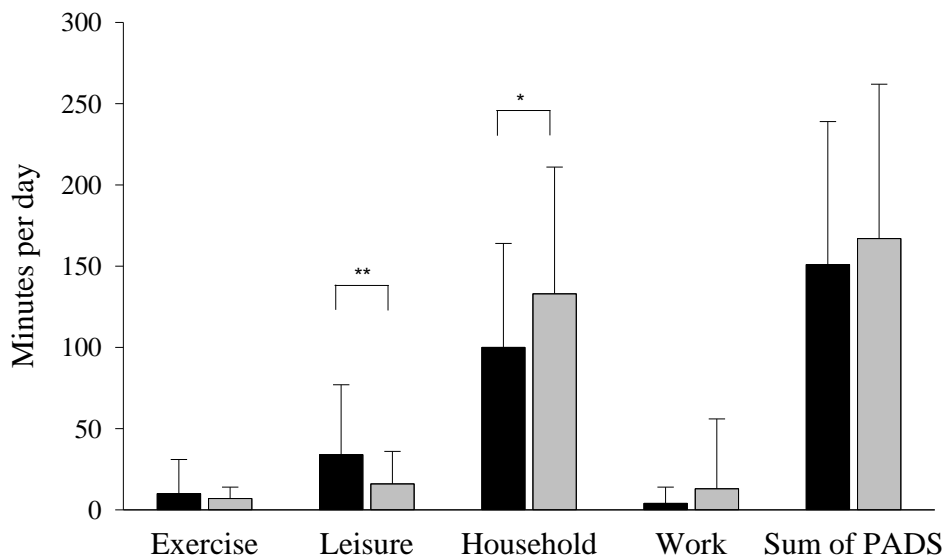


Figure 2. The self-reported levels of PA (the four subscales and the total sum of the Physical Activity and Disability Survey (PADS) in 81 persons with late effects of polio. Men, black bars; Women, grey bars. \*\*  $P < .01$ , \*  $P < .05$ .

The participants walked on average 6212 steps per day (range 122 to 16 016) (Study I). A majority (86%) walked less than 10 000 steps per day and 37% walked less than 5000 steps per day. The total score of PADS was significantly and positively associated with the number of steps ( $r=0.39$ ,  $p<0.001$ ).

### *Physical activity and contextual factors*

There was no significant difference between men and women in the total score of PADS and in the number of steps. However, women spent significantly more time in household activities ( $p<0.05$ ), whereas the men spent significantly more time performing leisure activities ( $p<0.01$ ) (Figure 2). The sum of PADS as well as all the subscales were positively associated with age and the level of self-reported PA was higher in the older participants ( $r=0.22$  to  $0.40$ ,  $p<0.05$ ). The number of steps was not significantly related to age. In addition, participants living in a single family house spent significantly ( $p<0.05$ ) more time in household activities than participants living in an apartment. There was a significant difference in the number of steps between persons who used or did not use a mobility device ( $p<0.05$ ); persons who did not use a mobility device walked more than those who used a mobility device.

## **Disability among the participants**

### *Impairments*

Knee muscle strength in the 77 participants in Study II is presented in Table 5. Men and women are presented together even though knee muscle strength was significantly lower for the women ( $p<0.01$ ).

Table 5. Knee muscle strength in 77 persons with late effects of polio (Study II)

	Knee extension MA (Nm)	Knee extension LA (Nm)	Knee flexion MA (Nm)	Knee flexion LA (Nm)
Mean, SD (range)	69, 43 (0-169)	104, 43 (15-211)	36, 24 (0-99)	59, 25 (3-131)

MA, more affected lower limb; LA, less affected lower limb; Nm, Newton meter; SD, Standard deviation

Knee muscle strength was significantly and positively associated with the PADS leisure subscale ( $r=0.25$  to  $0.31$ ,  $p<0.05$ ) and with the number of steps ( $r=0.29$  to  $0.42$ ,  $p<0.05$ ), (Figure 3).

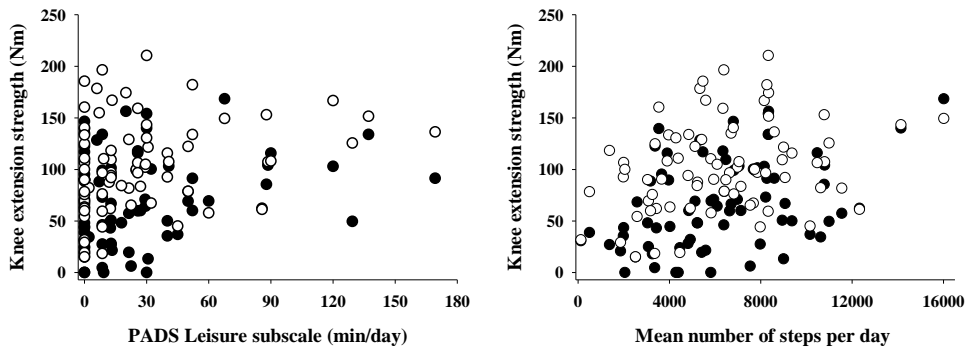


Figure 3.

The relationship between isokinetic knee extensor muscle strength in the more affected lower limbs (filled circles) and the less affected lower limbs (open circles), and the PADS leisure subscale and the number of steps.

Participants with increased muscle weakness performed fewer leisure activities and walked fewer steps. The multiple linear regression analyses showed that 5% to 16% ( $p < 0.05$ ) of the variation in leisure and number of steps was explained by knee muscle strength. When age, sex and BMI were added to the analysis they explained up to 13% (leisure) and 19% (number of steps) of the variance in PA.

Self-perceived impairments were rated by the SIPP (Study III) and the mean score was 26 out of 52 (SD 7, range 13 to 41). The most difficult impairments (rated as ‘quite a bit’ or ‘extremely’) that the participants reported were: muscle and/or joint pain during PA (61%), muscle weakness (53%), muscle fatigue (51%) and general fatigue (47%). The sum score of SIPP was significantly and negatively associated with the number of steps ( $r = -0.23$ ,  $p < 0.05$ ), indicating that participants who were less bothered by impairments walked more. The sum score of the SIPP was not associated with self-reported PA and was not part of the final model in the linear regression analysis.

#### *Activity limitations and participation restrictions*

In Table 6 the results of the gait performance tests are presented; there were no significant differences between the men and the women.

Table 6. Gait performance in 77 persons with late effects of polio (Study II)

	Timed “Up & Go” test (s)	Comfortable gait speed (m/s)	Fast gait speed (m/s)	6-Minute walk test (m)
Mean, SD (range)	10, 3 (7-23)	1.2, 0.2 (0.6-1.6)	1.6, 0.3 (0.8-2.7)	436, 99 (210-720)

s, seconds; m/s, meter per second; m, meters; SD, Standard deviation

Two gait performance tests, CGS and 6MWT, were significantly associated with the PADS leisure subscale ( $r=-0.25$  to  $0.30$ ,  $p<0.05$ ) whereas all gait performance tests were significantly associated with the number of steps ( $r=-0.40$  to  $-0.57$ ,  $p<0.01$ ); an example of these associations are shown in Figure 4.

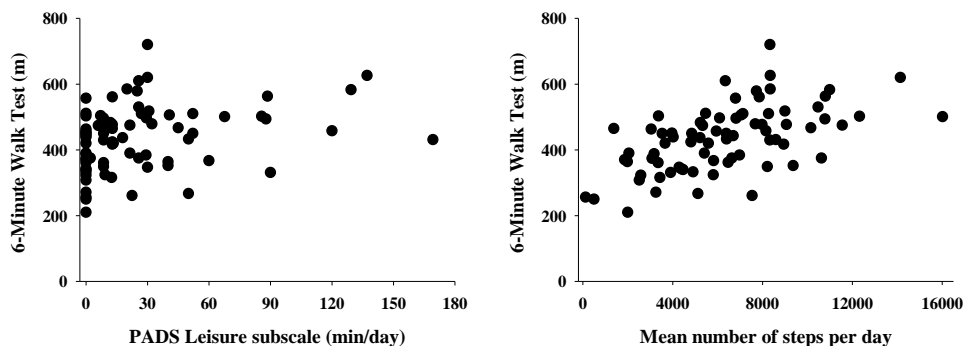


Figure 4. The relationship between the 6-Minute Walk Test (6MWT) and the PADS leisure subscale and the number of steps.

Participants who walked slower and had less endurance performed less PA within the leisure subscale and walked fewer steps. The multiple linear regression analyses showed that 5% to 8% ( $p<0.05$ ) of the variation in leisure was explained by CGS and 6MWT. The four gait performance tests explained 15% to 31% ( $p<0.01$ ) of the variance in the number of steps. When age, sex and BMI were added to the analysis they explained up to 14% in leisure whereas they reduced the explanation of the variance in the number of steps with at most 3%.

Walking limitations were assessed by the Walk-12 and the mean score was 48% out of 100% (SD 28, range 0 to 100). A majority (75%) of the participants reported limitations (‘quite a bit’ or ‘extremely’) in running and over 40% reported limitations in their ability to climb stairs, in their walking speed and walking distance, in their ability to walk smoothly, and in increased concentration and effort when walking.

Fear of falling was assessed by the FES-I and the mean score was 28 out of 64 (SD 9, range 16 to 54). The most difficult activities (reported as ‘fairly concerned’ or ‘very concerned’) were walking on slippery surface (69%), walking on uneven surface (60%), and walking up or down a slope (52%) and going up or down stairs (35%). The participants reported the incidence of falls during the last year and fifty participants (62%) reported at least one fall in this period.

Perceived limitations in walking was significantly and negatively associated with the sum score of PADS, the leisure subscale and with the number of steps ( $r=-0.22$  to  $-0.31$ ,  $p<0.05$ ). The total score of FES-I was significantly and negatively associated with the leisure subscale and with the number of steps ( $r=-0.26$  to  $-0.32$ ,  $p<0.05$ ). Participants who perceived more walking limitations and fear of falling performed less PA. The falls incidence was not significantly correlated with PADS or with the number of steps, indicating that the occurrence of one or more falls during the past years did not influence on the participants’ level of PA.

The results from the final model in the multivariate linear regression analyses showed that Walk-12 ( $p=0.01$ , B -1, 95% CI -1.68 to -0.33) and age ( $p=0.02$ , B 4.1, 95% CI 0.82 to 7.28) were significantly associated with the sum of PADS and explained 14% of the variance. FES-I ( $p=0.01$ , B -109.6, 95% CI -183.98 to -35.17) was significantly associated with the number of steps and explained 9% of the variance.

## **Life satisfaction among the participants**

Fifty-six participants (69%) rated themselves as satisfied (satisfied or very satisfied) with life as a whole. Life satisfaction was positively and significantly associated with the sum of PADS ( $\rho=0.23$ ,  $p<0.05$ ) and the number of steps ( $\rho=0.37$ ,  $p<0.001$ ). The participants who performed more PA rated higher life satisfaction.

## **Perceptions of physical activity**

The results of the qualitative analysis are schematically presented in Table 7 and further described below. The ICF is multidimensional and includes both positive and negative aspects of a person’s Functioning and Disability. The ICF describes Contextual factors (Environmental and Personal factors) that impact on a person positively (facilitator) and/or negatively (barrier). In these results we applied facilitators and barriers for all components. Overall, five subcategories were categorized within the ICF part Functioning and Disability and six subcategories within the ICF part Contextual factors. The results describe both the positive and

the negative aspects of the components (Body Functions and Structures, Activities and Participation, and Personal and Environmental factors).

Table 7. An overview of the perception of physical activity (PA), and factors that could be perceived as facilitators of and barriers to PA in 15 participants with late effects of polio. The International Classification of Functioning, Disability and Health (ICF) was used as a framework when data were analysed.

ICF parts	Functioning and Disability		Contextual factors	
ICF components	Body Functions and Structures	Activities and Participation	Personal factors	Environmental factors
Subcategories	My impairments are the main barrier to PA	PA makes me feel in control of my disability	My personality keeps me active	Support from others keep me active
		Wanting to fit in	Past experiences have shaped me	Accessible physical environment promotes PA
		Change in PA over time		Season and climate impact on PA
		Finding time for PA		Mobility devices support PA

## Functioning and Disability

In the subcategory “My impairments are the main barriers” the participants described the difficulty of staying physically active because of the progression of their condition and the impairments they experienced. The participants described less endurance, less flexibility, fatigue and pain and the impact these impairments had on their possibility to perform PA. One participant described it like this:

*“I am reluctant to walk, I like doing it but starting and getting going is difficult... suddenly I feel pain and then I have to sit down and rest somewhere.”*

The participants spoke of PA making them feel in control of their disability and how PA was used to maintain health, both physical and mental. PA made them feel more content with themselves and they were afraid if they stopped being physically active they had to face the consequences of being sedentary as referred to in this quotation:

*“Of course I move, if not then I’ll stay sedentary and feel even more pain.”*

Some participants described the feeling of not fitting in and the struggle about where to belong as a barrier to PA. Being physically active was acknowledged as something “normal” persons do. PA had changed over time and they described how they had changed their PA over time as consequences of increasing age and with their onset of late effects of polio. They had stopped doing the PA they had done before and now preferred other activities such as aquatics and walking, and in addition they were less physically active. The increasing impairments had made them change performance. Finding time for PA was an issue for several participants; those who worked described being too tired after work to perform PA. Several had busy schedules, regardless of whether they were working or not. They tried to plan for and fit in PA, as they did not want to have too much planned but still prioritized PA.

## **Contextual factors**

Personality and past experiences were described as facilitators of PA by the participants. They described that their past experiences had shaped their attitudes and perceptions of PA. They had been brought up to be physically active and they were certain that this had shaped them to consider PA as a normal part of life. On the other hand, many participants had been advised later on in life not to exercise as it was thought to exacerbate their impairments.

Support and relationships were important for being physically active. Family and friends coached the participants; one married woman described it like this:

*“As long as we are two everything works but if I was alone...nothing would work because then I’d not have the same discipline. “*

Support from knowledgeable health care professionals was important and could facilitate PA while lack of knowledge raised uncertainty and was a barrier to PA. The physical environment was considered both as a facilitator of and a barrier to PA. Being outdoors and having the opportunity to be physically active outdoors and closeness to an accessible nature was considered as facilitators. One man described it like this:

*“The forest near to our house is a fantastic opportunity with cycle tracks and paths for walking, it is an advantage. Even in our neighborhood we have good opportunities to move around freely. “*

The inaccessible physical environment and seasonal changes were barriers to PA; the participants described being less physically active during the winter because of the temperature and because on the ice on the ground. Mobility devices are part of

the physical environment and were described as facilitators since they enabled PA and made the participants feel safe and supported.





# Discussion

The studies in this thesis have focused on PA in ambulatory persons with late effects of polio and the overall aim was to increase the knowledge about PA and to explore associations between PA and disability and furthermore to explore perceptions of PA. The main findings were that PA was performed on average almost three hours per day, mostly in household activities, and that the participants walked 6 212 steps per day. The amount of PA was positively associated with age and life satisfaction. Impairments, activity limitations and participation restrictions were associated with PA but the variance in PA was only moderately explained by these variables. The perception of PA was positive and facilitators of and barriers to PA were identified in the Activities/Participation component of the ICF and in Personal and Environmental factors, but in Body Functions/Structures only barriers were identified. In this section the main findings will be discussed and finally some methodological aspects of this thesis will be considered.

## Physical activity

The amount of self-reported PA varied considerably among the participants but they were on average physically active 158 minutes per day, which is almost 3 hours. The majority of PA was spent performing household activities (e.g. doing the laundry, cleaning, gardening and maintaining a house), which are considered to have a low level of intensity. Intensity refers to the difficulty of an activity and is often presented as the Metabolic Equivalent (MET), which is a calculation of the energy cost in specific activities. Intensity can be rated as light (1.6-2.9 METs), moderate (3-5.9 METs) and vigorous (>6 METs) (23, 110). The compendium of MET does not include MET values for older adults or persons with disabilities (110) and it has been suggested that a specific METs algorithm has to be developed for these persons (36). Household activities are estimated as light to moderate intensity in the compendium but for persons with disabilities domestic activities can be as strenuous as walking (111). The energy cost is higher in persons with late effects of polio (69) and they walk at a level that is closer to their maximal capacity (75). The intensity and the amount of PA need to be appropriate to a person's capacity and a person with low exercise capacity i.e. low physical fitness can achieve health benefits with lower intensity and less duration

of PA than persons with a higher capacity (29). PA with low-level intensity spread across the day can have substantial health benefits in healthy adults (24-26) and most likely the health benefits are similar in persons with late effects of polio. It is thus reasonable to assume that for many of the participants, especially those with more pronounced disability, the intensity is higher when engaging in assumed low-level intensity activities as household activities. Energy expenditure and the appropriate intensity of activities for persons with disabilities warrant further research attention.

It may be difficult to remember the time spent in activities that occur incidentally throughout the day (36) but even so it is recommended to include household activities in self-reports especially for older adults and women (40). It is more easy to remember self-chosen PA that occurs at a particular time such as exercise and leisure (36). The majority of the participants performed leisure activities and most frequently walking for leisure and recreation. Walking leisurely, e.g. walking the dog or walking to the store, is different from walking for moderate to vigorous exercise that is more planned and structured. It was more common among the participants to perform leisure activities than exercise, which concurs with other studies on healthy older adults, who preferred leisure activities where the intensity is lower as opposed to exercise (112, 113). The participants spent less than ten minutes per day exercising and the most common activity was aquatics, which were performed once a week. Aquatic exercise is commonly recommended in persons with late effects of polio because the water provides resistance but minimizes biomechanical stress on muscles and joints (114).

The PADS has been used to assess PA in persons with other disabilities and the amount of PA has varied greatly between participants. Persons with osteoarthritis (115) reported a mean total of PA time of 186 minutes per day compared to only 27 minutes per day in persons with mobility disabilities (89). One reason for the differences in the amount of PA may be that leisure activities are defined differently. In this thesis, leisure was defined as unstructured PA performed on an infrequent basis, while the study on persons with osteoarthritis included all recreational and leisure activities such as going to church and visiting friends (115). In the study including persons with mobility disabilities, the participants were severely obese and had a mean BMI on 49 (89).

The positive association between level of self-reported PA and age, persons who were older were more physically active, is noteworthy. A generally held notion is the opposite view that PA decreases with increasing age (30). One possible explanation for the higher amount of PA reported by our sample is the transition from work to retirement. Persons with late effects of polio need to balance their activities and when they are working their effort and energy is put into work (116). The participants in Study IV described being too tired after work to perform PA. Increased levels of PA especially in leisure activities have been shown in healthy older adults as they experience the transition to retirement (112, 113).

The number of steps recorded by the pedometer varied considerably and ranged from 122 to 16 016. The mean value of 6 212 steps per day indicates that the participants were “low active” according to Tudor-Locke et al (32). These authors suggested that 3 000 to 4 000 steps are needed for daily activities and that less than 5 000 steps are considered sedentary in healthy adults. Thirty seven percent of the participants in Study I walked less than 5 000 steps per day. The mean value is similar to the findings in a previous study of persons with late effects of polio (mean age 62 years) with a reported mean value of 6 450 steps per day (75) but higher than the normative values as presented by Tudor-Locke et al, for persons aged 65 to 69 years the values ranged from 3 302 to 5 269 (34). One reason for the difference may be the context in which the studies have been performed. Our study was performed in a Swedish context where walking is common both for leisure and transport.

## **Participants**

These studies are among the first to describe PA in detail for persons with late effects of polio. The participants were recruited from a database at a rehabilitation clinic and had all participated in a rehabilitation programme. This may have impacted on their engagement in PA as well as their perception of PA. However, in a Swedish context most persons with late effects of polio have experiences of rehabilitation.

The studies included ambulatory persons with mild to moderate late effects of polio. In studies reporting on disability in persons with late effects of polio the majority of the participants are ambulatory, with or without mobility devices (55, 64, 117). The participants in our studies represented a wide range of functioning; some had very weak muscles but were still able to perform the gait performance tests. The obtained result on PA ranged from those who were marginally active (less than half an hour a day) to those who were very active (more than 7 hours each day) which indicates a heterogeneous sample. Even though the results can only be generalized to ambulatory persons with mild to moderate late effects of polio, this group represents the majority of persons with late effect of polio. Persons with more severe disability perceive more barriers in the environment when performing PA (43) and the results would most likely have been different if these persons had been included in the studies. Future research ought to include persons with severe late effects of polio and further describe their possibilities of performing PA.

Today it is estimated worldwide that 12 to 20 million persons have late effects of polio. Polio has not yet been eradicated even though the number of new cases has decreased drastically since 1988 when the eradication programme started (118). The large number of children and young persons that has been infected by polio

worldwide will, as they reach their middle age, face the consequences of late effects of polio. The results from this thesis will therefore be valuable in the management of these persons.

## Disability, physical activity, and their associations

Disability was assessed in several ways and focused on common impairments and activity limitations in persons with late effects of polio. Reduced muscle strength especially in the lower limbs is commonly reported (53) and was reported by the majority of the participants. Objectively measured knee muscle strength was lower than normative data for healthy adults aged 60 to 69 years (119). Other common impairments were pain and fatigue as reported in the SIPP. Gait performance was assessed and the participants' gait speed was similar to persons aged 60 to 69 years (120) whereas the TUG and the 6MWT were below predicted performance compared to healthy adults aged 60 to 69 years (121, 122). The participants reported limitations in walking, mostly in running, walking up and down stairs, and walking distance. Increased difficulties in walking are common in persons with late effects of polio (100, 117) and is also reported in persons with other neurological conditions such as Parkinson's disease (123), stroke (102) and multiple sclerosis (124). The participants were not particularly concerned about falling when performing daily activities (the mean value of FES-I was 28 points out of 64 points) even though a majority (62%) had fallen at least once during the past year. The incidence of fall is the same as in a study on falls and fear of falling in 325 persons with late effects of polio (mean age 69 years) (105). In the study by Brogårdh and Lexell, the mean value of FES-I were 29 points for non-fallers and 36 points for fallers (105).

The associations between PA and disability (impairments, activity limitations and participation restrictions) were low to moderate and the variance in PA was explained in a low to moderate degree by the level of disability. The associations were higher for the number of steps than in self-reported PA, which may be due to the impairments and activity limitations chosen as they are all related to mobility. Reduced knee muscle strength in the lower limbs is a predictor for gait performance (125) and impedes walking (126, 127). Gait performance and Walk-12 describe different aspects of walking (103) and several of the items in FES-I are related to mobility (128).

Walking is an important aspect of daily activities for most persons. The leisure subscale, where the most occurring type of activity was walking, was the only subscale associated with knee muscle strength, gait performance, Walk-12 and FES-I. Walking is reported to be a predictor for PA in persons with multiple sclerosis and stroke (43) and seems important for persons with late effects of polio

as well. To the best of our knowledge this is the first attempt to describe the associations between PA and gait performance for persons with late effects of polio.

The other subscales in the PADS (exercise, household and work) were not associated with knee muscle strength, the total score of SIPP, gait performance, the total score of Walk-12 and FES-I. It may be that since the participants mostly performed PA in household activities they only walked for short distances and/or performed these activities either standing up or sitting down. It is possible that we did not detect an association with exercise and PA during work due to the low amount of time spent performing these activities.

Even though a majority of the participants reported being bothered by pain, muscle weakness and fatigue in the SIPP, only muscle weakness was associated with the number of steps. This is different from other studies where pain and fatigue are associated with PA (75, 81). It has also been shown that more sedentary persons with late effects of polio perceive greater pain and fatigue (80). The participants in our studies were physically active but mostly in activities with a low level of intensity and they may have found a balance between impairments and PA and thus limited the impact of pain and fatigue.

The variance in PA was explained to a moderate degree by self-reported walking limitations and fear of falling. Both walking limitations and fear of falling are predictors to PA in persons with Parkinson's disease (51) and multiple sclerosis (43). These activity limitations need to be addressed in health promotion and in rehabilitation. Walking limitations and fear of falling can be addressed by different interventions e.g. by prescribing suitable mobility devices, teaching compensatory techniques, exercise and environmental adaptations.

The level of the associations strengthens the notion of PA as a complex behaviour that is affected by numerous factors (22). It may very well be that the variance in PA can be explained to a higher degree by other outcome measures of disability and activity limitations. In future research muscle strength in other muscle groups can be addressed, as well as physical fitness and more specific measures on pain and fatigue. Participation was not specifically assessed in these studies and may be a factor associated with PA. Most likely there are several factors, which together describe the variance in PA.

## Perceptions of physical activity

The participants in the qualitative study had a positive perception of PA but multiple factors affected them in their effort to perform PA. Facilitators and barriers were often described as opposites of each other and they were described in

close relation to their late effects of polio. Impairments were considered a barrier and the participants described the changes they had made over time to enable PA. Their past experiences had impacted two-fold on their PA participation. The participants also described general aspects that are of importance for the PA of many people, such as personality and support from others.

The impairments and the progression of the condition was as expected a barrier to PA. Impairments and the levels of disability are described as barriers to PA both for persons with late effects of polio (84) and for persons with other disabilities (27, 129). Impairments have been reported to be life limiting and impact upon engagement in activities among persons with late effects of polio (116). PA was described by the participants as a way of staying in control of the disability and a way of managing one's health. All of the participants were physically active on their own and not within the health care system. Preparing for self-management of health is an important part of health promotion (6).

The participants described the changes in PA over time and the strategies they had developed in order to enable PA despite increasing impairments. Persons living with late effects of polio are experienced in using coping strategies (56, 57, 130). Successful ones are acknowledged as an important part of quality of life and influence happiness (56). The participants have also described a longing to fit in and an uncertainty about where to belong. This longing and uncertainty can be sign of inadequate coping (130) but it may also be an effect of past experiences. The participants were influenced by their past experiences that had shaped their perception of PA. On the other hand they had been advised by health care professionals later on in life not to exercise as it may worsen their impairments. The onset of late effects polio and the changes of the disability increase the importance of advice on how to manage the condition. More PA is not always recommended (76, 81) and health care professionals and fitness instructors are needed to provide opportunities and to help creating strategies to cope with an altered life situation. It is likely that support from health care professionals is more important among persons with disabilities than in the general population (47). Knowledgeable health care professionals and support from close relations were acknowledged as facilitators of PA. Support from others facilitates PA in persons with neurological disability (22, 131, 132), whereas the opposite i.e. lack of support and lack of knowledge, is a barrier to PA in persons with late effects of polio (133).

The physical environment is often described as a barrier to PA for persons with disabilities as well as for those with late effects of polio (27, 84, 129) which was acknowledged in this study. Inaccessible environments were described in relation to the participants' disability; fear of falling and cold intolerance impacted on how PA was performed and during which season PA was performed. On the other hand the environment was also described as a facilitator, which to the best of our knowledge, has not been shown before in persons with late effects of polio. The

participants preferred performing PA outdoors and enjoyed the experience of nature and its diversity. Our results are in line with a previous study where engaging in PA outdoors promoted well-being and self-perceived health in a healthy population (134).

## Physical activity and life satisfaction

The majority (69%) of the participants rated that they were satisfied with their life as a whole, which is higher than in previous studies where 46% to 55% have been satisfied with life as a whole (65, 66). There are studies suggesting that persons with late effects of polio feel that they have lived a satisfactory life despite problems associated with their condition (57, 65). These have described life satisfaction as being able to do what you want do (56). Life satisfaction was associated with PA among our participants but it is not possible to say anything about causality because of the nature of the study. It may be that persons who performed more PA were more satisfied with life. But, it could also be that persons who were more satisfied with life performed more PA. Our results are in line with a previous study where psychological aspects impacted on participation in leisure activities (55).

## Methodological considerations

Some methodological considerations need to be addressed to evaluate the strengths and weaknesses of this thesis. In order to describe PA, the relationships and perceptions of PA, both quantitative and qualitative research approaches were used, which are reflected upon in this section.

### **Data collection and data analyses**

In this section the outcome measures and the process of data collection and analyses will be further discussed in relation to validity, reliability and trustworthiness. The PADS, which was the self-report chosen for this thesis, has not been used by persons with late effects of polio previously but is considered generic since it is developed for persons with chronic conditions and sedentary behaviour (87). Validity has several aspects but mainly concerns whether the construct that was intended was actually measured, whereas reliability assesses whether a test is measuring something in a reproducible fashion (135). Data were



collected using standardized protocols and well established measures in order to reduce the risk of instrumentation (136).

### *The Physical Activity and Disability Survey*

The PADS was chosen as it covers low levels of PA and gives the participants the opportunity to describe any type of PA. Given the absence of a “golden standard” for measuring PA, validity in relation to PA is usually referred to as face validity, criterion validity and indirect validity (137). The PADS was developed with the assistance of persons with physical disabilities and two experts in PA and survey design methodology and the final version was examined for clarity by persons with disability (87). This indicates good face validity, meaning that the instrument assess the desired qualities and seems reasonable (135). Criterion validity describes the level of agreement with other measures of PA, which was found to be low in persons with multiple sclerosis (88) where the score of PADS did not predict accelerometer counts. This could be due to limitations in PADS but also to limitations in accelerometers as they have been reported to underestimate lower levels of PA and overestimate vigorous activities (88). The significant association between PADS and the number of steps ( $r=0.39$ ,  $p<0.001$ ) in Study I is acceptable (36) even though interviewer-administered measures are expected to have greater associations ( $r=0.5$ ) (138). Indirect validity refers to expected associations with characteristics known to be related to PA. This was described in the original paper where PADS correlated significantly with peak oxygen uptake (87). The PADS has shown good reliability as reported in the methods section. The PADS can be calculated with an algorithm and the results presented in points (87, 88). However, recent research calculates minutes per day (52, 115), which is recommended by the developer of the PADS (J.H. Rimmer, personal communication). In our studies we have calculated the amount of PA in minutes per day, which makes it easier to compare the results with other studies and with the recommendations for PA.

The overestimation of PA needs to be considered in the PADS as well as in other self-reports (36, 37). In the PADS, the intensity is only rated in the exercise subscale which makes it difficult to compare the score of PADS with the recommendations for PA. Another issue concerning the PADS is the recall period of one year, which affects the accuracy of data. Long-time recall is often designed to elicit more of an estimate of usual activity rather than recalling specific episodes of activity (137). The recall period, nevertheless, makes it possible to describe seasonal differences in PA which is an advantage, since seasonality in PA engagement has been described for persons with late effect of polio (75).

### *The pedometer*

Self-reports are known to overestimate PA, while on the other hand pedometers may undercount PA, especially in persons with neurological disabilities. This is due to a changed gait pattern (41), which implies that the participants' daily

number of steps could have been somewhat higher. The pedometer used, the Yamax SW 200, is considered to have good validity and reliability (91, 92) and is associated with accelerometers in healthy adults, both during laboratory and free-living conditions ( $r=0.80-0.93$ ) (92). Pedometer counts are associated with the observed number of steps in persons with physical disabilities ( $r=0.52-0.87$ ) (42). The validity of pedometers is affected by slow walking ( $\leq 0.8$  meter per second) and a shuffling gait (42, 91). None of the participants in the studies had a shuffling gait and only five participants walked slower than 0.8 meter per second when comfortable gait speed was assessed. The pedometers were used for three consecutive days, which is considered sufficient to capture habitual pedometer-determined physical activity in healthy adults. Even fewer days (two) have been shown to be sufficient to obtain a stable estimate of habitual PA in sedentary populations with chronic illnesses (139).

#### *Assessments of functioning and disability*

Disability was assessed by measurements of impairments, activity limitations and participant restrictions. The measurements were chosen, based on common impairments and activity limitations in persons with late effects of polio. They have been used for this group previously and have good psychometric properties. They are also commonly used by physiotherapists within rehabilitation to assess impairments and activity limitations. Since disability affects a person's entire life situation it was important to measure it in more than one way in order to achieve a more complete picture of the disability. It was also important to take the person's own experiences and perceptions into account. As the relationships between disability and PA were low to moderate and the variance in PA was only explained to a low degree there are most likely other factors to consider in the future. In Study IV motivation was a facilitator of PA, which is in line with previous research where motivation together with self-efficacy and intention are associated with PA (43). They were not addressed in this thesis but should be considered for future research as they are important personal determinants of PA (47).

#### *Reflections on the qualitative analysis*

The results from Study I-III confirm the complexity of PA and the multitude of factors impacting on it. Based on these results and on the knowledge that environmental and personal factors are associated with PA in healthy populations (22) we chose a model, the ICF, that aims to cover aspects of both the person and the environment for the framework of the directed content analysis in Study IV. When using qualitative designs there is a need to address issues of trustworthiness, which can be assessed by means of credibility, confirmability, transferability and dependability (140). In directed content analysis it is especially important to address neutrality as the researcher enters the process with an informed but nevertheless strong bias (107). Credibility refers to the true value of a study and the ability to capture realities (140), and was increased by triangulation and peer

debriefing. Triangulation was achieved by having co-authors with several professional backgrounds (PTs, OT and rehabilitation medicine specialist). Peer debriefing was achieved when the study was presented and discussed at a seminar with doctoral students and senior researchers. In addition, credibility can be assured by choosing participants with various experiences of the phenomena, to get an appropriate amount of data and to illuminate the analysis process (107, 140). The purposeful selection of participants enhanced the possibility for variations. There were differences in sex (eight men and seven women), in age (ranging from 60 to 78 years), and in PA level (in type of PA and in the amount of time spent being physically active). The 15 interviews lasted between 30 and 60 minutes (mean time 39 minutes) and yielded rich and extensive data. The sample size was found adequate for the purpose of the study (141). The analysis process was thoroughly described in Study IV and the results were presented with quotations. The thorough description of the process and the discussion regarding the ICF helped to assure neutrality and an unbiased result. The researchers' objectivity and neutrality regarding their data is referred to as confirmability (140), which was increased by triangulation between authors and by use of quotations. The author acknowledged her pre-understanding, based on physiotherapy and the positive effects of movement, and this was considered during the interviews and in the analysis process. Transferability relates to the possibility of transferring the result to other settings or groups (140). Efforts were made to facilitate the assessment of transferability by providing a clear description of the context, the participants, data collection and analysis process. Dependability, which is closely linked to credibility, relates to changes in data over time and includes changes in the researchers' perceptions and experiences during data collection and in the interpretation of the data during the analysis process (140). All the interviews were based on the same themes and covered different aspects. The involvement of the co-authors throughout the process increased the possibility of discovering change over time.

## The ICF as a framework

This thesis is based on the framework and the nomenclature of the ICF, which has been evident throughout the studies where different aspects of disability have been assessed. In order to fully comprehend the complexity of PA and the multiple factors affecting it an ecological approach is necessary (22, 142). The ICF provides definitions for impairments, activity limitations and participation restrictions and takes the interplay with contextual factors into consideration. In Study IV, the directed content analysis was guided by the ICF, which has previously been used for describing facilitators of and barriers to PA in persons with various neurological conditions (27, 132, 143). During the analysis process in

Study IV, the ICF was valuable in structuring and elucidating the complexity of PA, even though the interplay between the parts and components were challenging. The components are not independent of the content in the other components and in fact share proxy, or counterpart information in one or more other components. The content of the personal factors Fitness and Lifestyle has similarities to that in the chapter Self-care, which includes ensuring health, and physical and mental well-being and an appropriate level of PA. This raises questions about the uniqueness of the identified content and about the overlap. In our findings one example of this is the subcategory “PA makes me feel in control of my disability”, which at first glance concerns impairments but was categorized as activities and participation since it was a way to manage one’s health as defined in the chapter Self-care. In addition, there is a lack of categorization of the personal factors in the ICF. They are not clearly defined and there are no guidelines as to how they should be documented (144). Furthermore, time is not clearly defined in the ICF framework but can be considered as past experiences in the component personal factor. The ICF describes functioning and disability at a given time and do not intend to describe e.g. longitudinal relationships and change over time (145). The participants in Study IV referred to change in PA over time and finding time for PA, which was categorized as activities and participation. Finding time can be related to carrying out daily routines and budgeting time, while change over time deals with looking after one’s health and staying physically active. In further development of the ICF a time aspect could be considered but it has to be comprehensive and included in all parts and components of the framework.



# Conclusions

- Despite a progressive physical disability, persons with late effects of polio are physically active, but many of the activities are performed as part of household activities and not as traditional exercise.
- The relationship between PA, age and life satisfaction further supports the general contention that an active lifestyle is an important factor for perceived life satisfaction among persons with late effects of polio.
- Knee muscle strength, self-perceived impairments, gait performance, walking limitations, and fear of falling are weak to moderate predictors of PA and the strength of the relationships indicates that there are other factors that could be of importance for PA in this population.
- Facilitators of and barriers to PA emerged in Activities/Participation, Environmental and Personal factors but in Body Functions/Structures only barriers were identified. The impairments were the main barriers to PA while it was facilitated by support from close relations, knowledgeable health care professionals and accessible environments.
- Persons with late effects of polio want to be physically active but they may need assistance to create suitable strategies for minimizing the impact of their impairments, prioritizing and for changing aspects of performance.

## Clinical implications

- There is a need to broaden the perspective of PA from only exercise to include all activities that increase energy expenditure and are performed throughout the day. All areas in which PA can be performed need to be acknowledged. By demonstrating different possibilities for performing PA it may be easier to promote it among persons with late effects of polio.
- When promoting PA in persons with late effects of polio it is important to consider functioning and disability and advice on PA based on this knowledge. Past experiences and social support can be facilitators of PA and need to be acknowledged in a health promotion plan.

- Walking limitations and fear of falling need attention in the clinical setting as they are associated with PA. By assessing these activity limitations and by minimizing the effects of them persons with late effects of polio may be more confident in performing PA.
- Environmental and personal factors facilitate PA and/or are barriers to PA. The facilitators and barriers need to be explored and acknowledged in order to gain a more complete picture of PA behaviour. This knowledge may be valuable for creating individualized PA recommendations.
- Persons with late effects of polio need assistance in order to create suitable strategies for minimizing the impact of their impairments, for prioritizing and for changing aspects of performance.
- An adjusted and individualized health promotion plan can form the foundation for persons with late effects of polio and allow them to manage their own health and perform PA on their own.

### **Suggestions for future research**

- To describe and explore the specific health benefits of PA in persons with late effects of polio.
- To describe PA and associated factors for persons with more severe late effects of polio.
- To develop a health promotion programme with multilevel approach, including personal and environmental factors, directed to persons with late effects of polio.
- To further explore valid and reliable instruments for measuring PA in persons aging with disabilities.
- To describe and explore PA-related aspects such as energy expenditure, endurance and VO<sub>2</sub>max function in persons with late effects of polio.

# Svensk sammanfattning

Fysisk aktivitet har positiva hälsoeffekter och kan användas både förebyggande och behandlande. Det är idag väl känt när det gäller normalbefolkningen men för personer med funktionsnedsättningar är dock kunskapen begränsad. Människor med funktionsnedsättningar är fysiskt aktiva i mindre utsträckning än människor utan funktionsnedsättningar och aktivitetsnivån minskar med stigande ålder.

En grupp som åldras med funktionsnedsättning är de som har sena effekter av polio (postpolio). Idag finns det ungefär 15 000 till 20 000 personer med sena effekter av polio i Sverige. Det är en grupp som har levt större delen av sitt liv med någon form av funktionsnedsättning till följd av polio i barndomen. När de åldras kan de få utökade eller förnyade symtom. Fokus för avhandlingen har varit att beskriva fysisk aktivitet hos personer med postpolio, vilka faktorer som påverkar fysisk aktivitet samt hur denna grupp uppfattar fysisk aktivitet.

I avhandlingen ingick personer med postpolio som är mellan 50 och 80 år gamla. I den första studien deltog 81 personer. Deltagarna intervjuades om fysisk aktivitet och använde en stegräknare under tre dagar. Aktivitetsnivån skiftade mycket mellan personerna men i genomsnitt var de fysiskt aktiva ca tre timmar per dag. Aktiviteterna var främst i anslutning till hemmet, t.ex. hushållsarbete och trädgårdsarbete. Den vanligaste fritidsaktiviteten var promenader. Deltagarna gick i genomsnitt 6212 steg per dag vilket betyder att majoriteten inte var stillasittande. Det fanns ett positivt samband mellan fysisk aktivitet och livstillfredsställelse. De som var mer fysiskt aktiva skattade en högre livstillfredsställelse.

I studie två (77 deltagare) undersöktes vanliga funktionsnedsättningar och aktivitetsbegränsningar (lårmuskelstyrka och gångförmåga) hos personer med postpolio. Målet var att utvärdera om det fanns ett samband mellan dessa och fysisk aktivitet. Både lårmuskelstyrka och gångförmåga visade sig ha ett samband med fysisk aktivitet. De personer, som var starkare, gick snabbare och orkade gå längre, var mer fysiskt aktiva på sin fritid och gick fler steg under en dag.

I studie tre (81 deltagare) fick deltagarna skatta upplevda funktionsnedsättningar, upplevd gångförmåga och rädsla för att falla. Begränsningar i gångförmåga och rädsla för att falla visade sig ha ett samband med fysisk aktivitet. Generellt var den som var svagare i låren, gick långsammare, upplevde fler begränsningar i sin gångförmåga och kände en oro för att falla mindre fysiskt aktiv.



I den fjärde studien intervjuades 15 personer om sin uppfattning om fysisk aktivitet. De ombads också att beskriva personfaktorer och omgivningsfaktorer som uppfattas som hindrande respektive stödjande i relation till fysisk aktivitet. Fysisk aktivitet uppfattades som något positivt och nyttigt och underlättades av stöd från andra personer och tidigare positiva erfarenheter av fysisk aktivitet. Den fysiska omgivningen kunde vara stimulerande men också ett hinder. Flera deltagare uppskattade att vara fysiskt aktiva utomhus och att bo nära naturen. De blev dock begränsade av kyla och när det var halt ute vilket kunde göra det svårare att ta sig fram. Ett annat hinder var funktionsnedsättningarna som gjorde det svårt att vara så aktiv som man ville.

Sammanfattningsvis visade studierna att trots sina funktionsnedsättningar var personer med sena effekter av polio fysiskt aktiva, huvudsakligen i aktiviteter i anslutning till hemmet (inomhus och utomhus) och inte i traditionell träning. De hade en generell positiv inställning till fysisk aktivitet. Resultaten bekräftade också att det finns ett samband mellan fysisk aktivitet och livstillfredsställelse hos personer med postpolio. Mängden fysisk aktivitet förklarades till en måttlig del av de funktionsnedsättningar och aktivitetsbegränsningar som deltagarna hade. Det behövs fler studier för att förklara vad det är som påverkar hur fysiskt aktiv man är om man har sena effekter av polio. Fysisk aktivitet stimuleras av stöd från andra, kunnig sjukvårdspersonal och god tillgänglighet i omgivningen. För att bli fysiskt aktiv kan man behöva hjälp för att prioritera och att utveckla strategier för att anpassa den fysiska aktiviteten till sina funktionsnedsättningar och aktivitetsbegränsningar.

# Acknowledgements

This work was carried out at the Department of Health Sciences, Lund University, the Centre for Ageing and Supportive Environments (CASE) and the Department of Rehabilitation Medicine, Skåne University Hospital. I would like to express my sincere gratitude to all those who in various ways have contributed to this thesis, and particularly to:

All the persons with late effect of polio who participated in the studies, without you, your knowledge and your experience this thesis would not have been possible.

Jan Lexell, my main supervisor and co-author. You have been a support in many ways, first of all for accepting me as a PhD-student. While working on this thesis you have taught me the necessity to focus, showed me how to write in a structured and understandable way and forced me to argue for my case. For that I am grateful.

Ulla-Britt Flansbjerg, my co-supervisor and co-author. Without you there would have been no figures, no nice tables and no fun. Thank you for always being encouraging, challenging and supporting.

Gunilla Carlsson, my co-supervisor and co-author. Throughout this work you have contributed with your perspective and also made me focus on the unity of this thesis. Your knowledge in qualitative methods was invaluable.

James Rimmer, my co-author. You are a precursor in the field of PA and disability and I have really enjoyed entering this field of knowledge. Your help in designing the studies and while writing the papers have been valuable and made considerable improvements to the work.

Christina Brogårdh, my co-author. Thank you for being a part in my thesis work, I have truly appreciated your support, your patience and your wise reflections.

I have enjoyed being a part of CASE; it has stimulated and broadened my mind. I would like to thank everyone in CASE for support, different perspectives and stimulating discussions.

Susanne Iwarsson, director of CASE, you run CASE with an open mind and a firm hand. I admire your strategic work and you are indeed a great role-model as a researcher.

Charlotte Löfquist, for being an engaging study director at the graduate school. You are generous and allowing, which have helped in creating a stimulating and engaging environment.

Mia Nilsson, thank you being my coach and my friend.

Ingrid Hilborn, for all the help with practical arrangements.

Thanks to all the PhD-students within Rehabilitation Medicine and within CASE; without you no shrimp sandwiches and no fun. Keep calm and carry on.

A special thanks to the three musketeers, Marianne, Marianne and Cecilia. We have walked this path together and I have appreciated you, your support, our discussions and the reality checks.

Ingrid Lindgren, for bringing me chocolate and for being supportive throughout this work.

Eva Bramell-Risberg, my colleague, who has taught me the importance to be generous with knowledge and the importance of being thorough.

Christina Espelund and Håkan Carlsson, physiotherapists at the Department of Rehabilitation Medicine, thank you for helping out in the real world with recruiting and assessing.

All my physio-friends in the Swedish Association for Physiotherapists and in the section for Neurology. Pia, you told me to enjoy my last year as a PhD-student; and I have really tried. Mari, you helped me find my voice. Thank you all for your support, strategic talks, and commitment. I am looking forward to continue working with you.

My parents Ingrid and Tore for being supportive, loving and helping out with family matters when time has been limited. Without you no PhD.

My husband Magnus for your love, support and perspective. We have made this journey together and you have grounded me.

My children Ebbe, Tor and Signe for being you and for not really caring about how and where I spend my days.

## Fundings

This study was supported by grants from: the Centre for Ageing and Supportive Environments (CASE), The Swedish Research council for Health, Working Life and Welfare (Forte), The Swedish Association for Survivors of Accident and Injury (RTP), Stiftelsen för bistånd åt rörelsehindrade i Skåne, Norrbacka-Eugenia stiftelsen and Skane county council's research and development foundation.

# References

1. World Health Organization. World Bank. *World report on disability*. Geneva, Switzerland: World Health Organization; 2011.
2. Boström G. Hälsa på lika villkor? Hälsa och livsvillkor bland personer med funktionsnedsättning (Health On Equal Terms? Health and Life Conditions among Persons with Disabilities). Statens folkhälsoinstitut (Swedish National Institute of Public Health). Stockholm 2008.
3. *The Future of Disability in America*. Field MJ, Jette A, editors. The National Academies Press; 2007.
4. Iezzoni LI. Public health goals for persons with disabilities: looking ahead to 2020. *Disabil Health J*. 2009;2:111-115
5. Rimmer JH, Chen MD, Hsieh K. A conceptual model for identifying, preventing, and managing secondary conditions in people with disabilities. *Phys Ther*. 2011;91:1728-1739
6. Rimmer J, Rowland JL. Health promotion for people with disabilities: implications for empowering the person and promoting disability-friendly environments. *Am J Lifestyle Med*. 2008;2:409-420
7. World Health Organization. *International Classification of Functioning, Disability and Health: ICF*. Geneva: World Health Organization; 2001.
8. Kemp BJ. What the rehabilitation professional and the consumer need to know. *Phys Med Rehabil Clin N Am*. 2005;16:1-18
9. Saxon S, Etten MJ, Perkins E. *Physical Change and Aging, A guide for the helping professions* New York: Springer Publishing Company; 2010.
10. Putnam M. Linking aging theory and disability models: increasing the potential to explore aging with physical impairment. *Gerontologist*. 2002;42:799-806
11. Chodzko-Zajko WJ, Proctor DN, Fiatarone Singh MA, et al. American College of Sports Medicine position stand. Exercise and physical activity for older adults. *Med Sci Sports Exerc*. 2009;41:1510-1530
12. Klingbeil H, Baer HR, Wilson PE. Aging with a disability. *Arc Phys Med Rehabil*. 2004;85:S68-73
13. Verbrugge L, Yang L. Aging with disability and disability with aging. *J Disabil Policy Stud*. 2002;12:253-267
14. Kemp B, Adkins R, Thompson L. Aging with a spinal cord injury: What recent research shows. *Top Spinal Cord Inj Rehabil*. 2004;10:175-197
15. Molton IR, Jensen MP. Aging and disability: biopsychosocial perspectives. *Phys Med Rehabil Clin N Am*. 2010;21:253-265
16. Rimmer JH. Exercise and physical activity in persons aging with a physical disability. *Phys Med Rehabil Clin N Am*. 2005;16:41-56

17. Manini TM, Pahor M. Physical activity and maintaining physical function in older adults. *Br J Sports Med.* 2009;43:28-31
18. Batt ME, Tanji J, Börjesson M. Exercise at 65 and beyond. *Sports Med.* 2013;43:525-530
19. Caspersen CJ, Powell KE, Christenson GM. Physical activity, exercise, and physical fitness: definitions and distinctions for health-related research. *Public Health Rep.* 1985;100:126-131
20. World Health Organization. New York; 2014 [cited 12<sup>th</sup> of Aug 2014]. Available from: <http://www.who.int>.
21. Moran M, Van Cauwenberg J, Hercky-Linnewiel R, et al. Understanding the relationships between the physical environment and physical activity in older adults: a systematic review of qualitative studies. *Int J Behav Nutr Phys Act.* 2014;11:79
22. Bauman AE, Reis RS, Sallis JF, et al. Correlates of physical activity: why are some people physically active and others not? *Lancet.* 2012;380:258-271
23. Powell KE, Paluch AE, Blair SN. Physical activity for health: What kind? How much? How intense? On top of what? *Annu Rev Public Health.* 2011;32:349-365
24. Dunstan DW, Healy GN, Sugiyama T, Owen N. "Too Much Sitting" and Metabolic Risk- Has Modern Technology Caught Up with Us? *European Endocrinology.* 2010;6:19-23
25. Ekblom-Bak E, Ekblom B, Vikström M, de Faire U, Hellenius ML. The importance of non-exercise physical activity for cardiovascular health and longevity. *Br J Sports Med.* 2014;48:233-238
26. Owen N, Healy GN, Matthews CE, Dunstan DW. Too much sitting: the population health science of sedentary behavior. *Exerc Sport Sci Rev.* 2010;38:105-113
27. Mulligan HF, Hale LA, Whitehead L, Baxter GD. Barriers to physical activity for people with long-term neurological conditions: a review study. *Adapt Phys Activ Q.* 2012;29:243-265
28. Motl RW. Lifestyle physical activity in persons with multiple sclerosis: the new kid on the MS block. *Mult Scler.* 2014;20:1025-1029
29. World Health Organization. Physical activity guidelines. 2014 [cited 12<sup>th</sup> Sept 2014]. Available from: <http://www.who.int>.
30. Hallal PC, Andersen LB, Bull FC, et al. Global physical activity levels: surveillance progress, pitfalls, and prospects. *Lancet.* 2012;380:247-257
31. Swedish National Institute of Public Health. Nationella folkhälsoenkäten - Hälsa på lika villkor (National public health survey). Stockholm: 2014. [cited 15<sup>th</sup> Sept 2014]. Available from: [www.folkhalsomyndigheten.se](http://www.folkhalsomyndigheten.se).
32. Tudor-Locke C, Hatano Y, Pangrazi RP, Kang M. Revisiting "how many steps are enough?". *Med Sci Sports Exerc.* 2008;40:537-543
33. Tudor-Locke C, Craig CL, Brown WJ, et al. How many steps/day are enough? For adults. *Int J Behav Nutr Phys Act.* 2011;8:79
34. Tudor-Locke C, Schuna JM, Jr., Barreira TV, et al. Normative steps/day values for older adults: NHANES 2005-2006. *J Gerontol A Biol Sci Med Sci.* 2013;68:1426-1432
35. Pettee Gabriel KK, Morrow J, Woolsey A-L. Framework for physical activity as a complex and multidimensional behavior. *J Phys Act Health.* 2012; 9:S11-18

36. Warme C. Physical activity measurement in persons with chronic and disabling conditions - methods, strategies, and issues. *Fam Community Health*. 2006;29:78-88
37. Ainsworth BE. How do I measure physical activity in my patients? Questionnaires and objective methods. *Br J Sports Med*. 2009;43:6-9
38. Hagströmer M, Hassmén P. Bedöma och styra fysisk aktivitet (Assessing and controlling physical activity. FYSS (Physical activity in the prevention and treatment of disease). Swedish National Institute of Public Health, editor. Östersund 2008. p. 93-111
39. Masse LC, de Niet JE. Sources of validity evidence needed with self-report measures of physical activity. *J Phys Act Health*. 2012;9:S44-55
40. Frändin K. Physical activity and functional performance in a population studied longitudinally from 70 to 76 years of age. Gothenburg: Gothenburg University; 1995.
41. Elsworth C, Dawes H, Winward C, et al. Pedometer step counts in individuals with neurological conditions. *Clin Rehabil*. 2009;23:171-175
42. Kenyon A, McEvoy M, Sprod J, Maher C. Validity of pedometers in people with physical disabilities: A systematic review. *Arch Phys Med Rehabil*. 2013;94:1161-1170
43. Rosenberg DE, Bombardier CH, Hoffman JM, Belza B. Physical activity among persons aging with mobility disabilities: shaping a research agenda. *J Aging Research*. 2011;2011:708510
44. Rimmer JH, Marques AC. Physical activity for people with disabilities. *Lancet*. 2012;380:193-195
45. Motl RW, McAuley E. Physical activity, disability, and quality of life in older adults. *Phys Med Rehabil Clin N Am*. 2010;21:299-308
46. Eldar R, Marincek C. Physical activity for elderly persons with neurological impairment: a review. *Scand J Rehabil Med*. 2000;32:99-103
47. van der Ploeg HP, van der Beek AJ, van der Woude LH, van Mechelen W. Physical activity for people with a disability: a conceptual model. *Sports Med*. 2004;34:639-649
48. Billinger SA, Arena R, Bernhardt J, et al. Physical activity and exercise recommendations for stroke survivors: a statement for healthcare professionals from the American Heart Association/American Stroke Association. *Stroke*. 2014;45:2532-2553
49. van der Kolk NM, King LA. Effects of exercise on mobility in people with Parkinson's disease. *Mov Disord*. 2013;28:1587-1596
50. Rimmer JH, Wang E, Smith D. Barriers associated with exercise and community access for individuals with stroke. *J Rehabil Res Dev*. 2008;45:315-322
51. Ellis T, Boudreau JK, Deangelis TR, et al. Barriers to exercise in people with Parkinson disease. *Phys Ther*. 2013;93:628-636
52. Rimmer JH, Chen M-D, McCubbin JA, Drum C, Peterson J. Exercise intervention research on persons with disabilities: what we know and where we need to go. *Am J Phys Med Rehabil*. 2010;89:249-263
53. Lexell J. Postpoliomyelitis Syndrome. In: Frontera W, Silver J, Rizzo J, T., eds. *Essentials of physical medicine and rehabilitation*. Philadelphia: Elsevier Saunders; 2014:p. 775-781.

54. Stolwijk-Swuste JM, Tersteeg I, Beelen A, Lankhorst GJ, Nollet F. The impact of age and comorbidity on the progression of disability in late-onset sequelae of poliomyelitis. *Arch Phys Med Rehabil.* 2010;91:523-528
55. Ahlström G, Karlsson U. Disability and quality of life in individuals with postpolio syndrome. *Disabil Rehabil.* 2000;22:416-422
56. Atwal A, Spiliotopoulou G, Coleman C, et al. Polio survivors' perceptions of the meaning of quality of life and strategies used to promote participation in everyday activities. *Health Expect.* 2014, E-pub ahead of print:Accessed 15<sup>th</sup> Oct
57. Wenneberg S, Ahlström G. Illness narratives of persons with post-polio syndrome. *J Adv Nurs.* 2000;31:354-361
58. Laffont I, Julia M, Tiffreau V, et al. Aging and sequelae of poliomyelitis. *Ann Phys Rehabil Med.* 2010;53:24-33
59. Lexell J. *Everything you need to know about post-polio syndrome (PPS). A guide for people who have had polio or who work in the health service.* Stockholm, Sweden: Personskadeförbundet RTP (The Swedish Association for Survivors of Accident and Injury); 2009.
60. Bartels MN, Omura A. Aging in polio. *Phys Med Rehabil Clin N Am.* 2005;16:197-218
61. Boyer FC, Tiffreau V, Rapin A, et al. Post-polio syndrome: Pathophysiological hypotheses, diagnosis criteria, drug therapy. *Ann Phys Rehabil Med.* 2010;53:34-41
62. Farbu E, Gilhus NE, Barnes MP, et al. EFNS guideline on diagnosis and management of post-polio syndrome. Report of an EFNS task force. *Eur J Neurol.* 2006;13:795-801
63. Trojan DA, Cashman NR. Post-poliomyelitis syndrome. *Muscle Nerve.* 2005;31:6-19
64. Kling C, Persson A, Gardulf A. The ADL ability and use of technical aids in persons with late effects of polio. *Am J Occup Ther.* 2002;56:457-461
65. Lund ML, Lexell J. Life satisfaction in persons with late effects of polio. *Appl Res Qual Life.* 2011;6:71-80
66. Lexell J, Brogårdh C. Life satisfaction and self-reported impairments in persons with late effects of polio. *Ann Phys Rehabil Med.* 2012;55:577-589
67. Stolwijk-Swuste JM, Beelen A, Lankhorst GJ, Nollet F. The course of functional status and muscle strength in patients with late-onset sequelae of poliomyelitis: a systematic review. *Arch Phys Med Rehabil.* 2005;86:1693-1701
68. Gawne AC, Wells KR, Wilson KS. Cardiac risk factors in polio survivors. *Arch Phys Med Rehabil.* 2003;84:694-696
69. Brehm MA, Nollet F, Harlaar J. Energy demands of walking in persons with postpoliomyelitis syndrome: relationship with muscle strength and reproducibility. *Arch Phys Med Rehabil.* 2006;87:136-140
70. Larsson Lund M, Lexell J. A positive turning point in life--how persons with late effects of polio experience the influence of an interdisciplinary rehabilitation programme. *J Rehabil Med.* 2010;42:559-565
71. Leach E, Cornwell P, Fleming J, Haines T. Patient centered goal-setting in a subacute rehabilitation setting. *Disabil Rehabil.* 2010;32:159-172

72. Rimmer JH. Health promotion for people with disabilities: the emerging paradigm shift from disability prevention to prevention of secondary conditions. *Phys Ther.* 1999;79:495-502
73. Lund ML, Lexell J. Relationship between participation in life situations and life satisfaction in persons with late effects of polio. *Disabil Rehabil.* 2009;31:1592-1597
74. Fugl-Meyer AR. Rehabilitation in Europe: biostatistical or holistic? *Trop Geogr Med.* 1993;45:235-237
75. Klein MG, Braitman LE, Costello R, Keenan MA, Esquenazi A. Actual and perceived activity levels in polio survivors and older controls: a longitudinal study. *Arch Phys Med Rehabil.* 2008;89:297-303
76. Tiffreau V, Rapin A, Serafi R, et al. Post-polio syndrome and rehabilitation. *Ann Phys Rehabil Med.* 2010;53:42-50
77. Chan KM, Amirjani N, Sumrain M, Clarke A, Strohschein FJ. Randomized controlled trial of strength training in post-polio patients. *Muscle Nerve.* 2003;27:332-338
78. Oncu J, Durmaz B, Karapolat H. Short-term effects of aerobic exercise on functional capacity, fatigue, and quality of life in patients with post-polio syndrome. *Clin Rehabil.* 2009;23:155-163
79. Jones DR, Speier J, Canine K, Owen R, Stull GA. Cardiorespiratory responses to aerobic training by patients with postpoliomyelitis sequelae. *Jama.* 1989;261:3255-3258
80. Rekand T, Kõrv J, Farbu E, et al. Lifestyle and late effects after poliomyelitis. A risk factor study of two populations. *Acta Neurol Scand.* 2004;109:120-125
81. Willen C, Grimby G. Pain, physical activity, and disability in individuals with late effects of polio. *Arch Phys Med Rehabil.* 1998;79:915-919
82. Thoren-Jönsson AL, Grimby G. Ability and perceived difficulty in daily activities in people with poliomyelitis sequelae. *J Rehabil Med.* 2001;33:4-11
83. Appelin K, Lexell J, Mansson Lexell E. Occupations that People with Late Effects of Polio Perceive Difficult to Perform. *Occup Ther Int.* 2014;21:98-107
84. Becker H, Stuijbergen A. What makes it so hard? Barriers to health promotion experienced by people with multiple sclerosis and polio. *Fam Community Health.* 2004;27:75-85
85. Harrison T, Stuijbergen A. Barriers that further disablement: a study of survivors of polio. *J Neurosci Nurs.* 2001;33:160-166
86. Stuijbergen AK. Secondary conditions and life satisfaction among polio survivors. *Rehabil Nurs.* 2005;30:173-179
87. Rimmer JH, Riley BB, Rubin SS. A new measure for assessing the physical activity behaviors of persons with disabilities and chronic health conditions: The Physical Activity and Disability Survey. *Am J Health Promot.* 2001;16:34-45
88. Kayes NM, McPherson KM, Taylor D, et al. The Physical Activity and Disability Survey (PADS): reliability, validity and acceptability in people with multiple sclerosis. *Clin Rehabil.* 2007;21:628-639
89. Rimmer JH, Hsieh K, Graham BC, Gerber BS, Gray-Stanley JA. Barrier removal in increasing physical activity levels in obese African American women with disabilities. *J Womens Health.* 2010;19:1869-1876



90. Maneesriwongul W, Dixon JK. Instrument translation process: a methods review. *J Adv Nurs*. 2004;48:175-186
91. Tudor-Locke C, Williams JE, Reis JP, Pluto D. Utility of pedometers for assessing physical activity: convergent validity. *Sports Med*. 2002;32:795-808
92. Bergman RJ, Bassett DR, Jr., Muthukrishnan S, Klein DA. Validity of 2 devices for measuring steps taken by older adults in assisted-living facilities. *J Phys Act Health*. 2008;5:S166-175
93. Vanroy C, Vissers D, Cras P, et al. Physical activity monitoring in stroke: SenseWear Pro2 Activity accelerometer versus Yamax Digi-Walker SW-200 Pedometer. *Disabil Rehabil*. 2014;36:1695-1703
94. Flansbjerg UB, Lexell J. Reliability of knee extensor and flexor muscle strength measurements in persons with late effects of polio. *J Rehabil Med*. 2010;42:588-592
95. Halstead LS, Gawne AC, Pham BT. National rehabilitation hospital limb classification for exercise, research, and clinical trials in post-polio patients. *Ann N Y Acad Sci*. 1995;753:343-353
96. Brogårdh C, Lexell J, Lundgren-Nilsson A. Construct validity of a new rating scale for self-reported impairments in persons with late effects of polio. *PM R*. 2013;5:176-181
97. Podsiadlo D, Richardson S. The timed "Up & Go": a test of basic functional mobility for frail elderly persons. *J Am Geriatr Soc*. 1991;39:142-148
98. Bohannon RW. Comfortable and maximum walking speed of adults aged 20-79 years: reference values and determinants. *Age Ageing*. 1997;26:15-19
99. Bittner V, Weiner DH, Yusuf S, et al. Prediction of mortality and morbidity with a 6-minute walk test in patients with left ventricular dysfunction. SOLVD Investigators. *JAMA*. 1993;270:1702-1707
100. Flansbjerg UB, Lexell J. Reliability of gait performance tests in individuals with late effects of polio. *PM R*. 2010;2:125-131
101. Holland A, O'Connor RJ, Thompson AJ, Playford ED, Hobart JC. Talking the talk on walking the walk: a 12-item generic walking scale suitable for neurological conditions? *J Neurol*. 2006;253:1594-1602
102. Brogårdh C, Flansbjerg UB, Lexell J. Self-reported walking ability in persons with chronic stroke and the relationship with gait performance tests. *PM R*. 2012;4:734-738
103. Brogårdh C, Flansbjerg UB, Espelund C, Lexell J. Relationship between self-reported walking ability and objectively assessed gait performance in persons with late effects of polio. *NeuroRehabilitation*. 2013;33:127-132
104. Yardley L, Beyer N, Hauer K, et al. Development and initial validation of the Falls Efficacy Scale-International (FES-I). *Age Ageing*. 2005;34:614-619
105. Brogårdh C, Lexell J. Falls, fear of falling, self-reported impairments and walking limitations in persons with late effects of polio. *PM R*. 2014;E-pub ahead of print:Accessed 15<sup>th</sup> Oct
106. Fugl-Meyer AR, Melin R, Fugl-Meyer KS. Life satisfaction in 18- to 64-year-old Swedes: in relation to gender, age, partner and immigrant status. *J Rehabil Med*. 2002;34:239-246
107. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15:1277-1288

108. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*. 2004;24:105-112
109. World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. *Jama*. 2013;310:2191-2194
110. Ainsworth BE, Haskell WL, Herrmann SD, et al. 2011 Compendium of Physical Activities: A Second Update of Codes and MET Values. *Med Sci Sports Exerc*. 2011;43:1575-1581
111. Mattiasson-Nilo I, Sonn U, Johannesson K, et al. Domestic activities and walking in the elderly: evaluation from a 30-hour heart rate recording. *Aging (Milano)*. 1990;2:191-198
112. Barnett I, van Sluijs E, Ogilvie D, Wareham NJ. Changes in household, transport and recreational physical activity and television viewing time across the transition to retirement: longitudinal evidence from the EPIC-Norfolk cohort. *J Epidemiol Community Health*. 2014;68:747-753
113. Barnett I, van Sluijs EM, Ogilvie D. Physical activity and transitioning to retirement: a systematic review. *Am J Prev Med*. 2012;43:329-336
114. Willen C, Scherman MH. Group training in a pool causes ripples on the water: experiences by persons with late effects of polio. *J Rehabil Med*. 2002;34:191-197
115. Greene B, Haldeman G, Kaminski A, et al. Factors affecting physical activity behavior in urban adults with arthritis who are predominantly African-American and female. *Phys Ther*. 2006;86:510-519
116. Atwal A, Giles A, Spiliotopoulou G, Plastow N, Wilson L. Living with polio and postpolio syndrome in the United Kingdom. *Scand J Caring Sci*. 2013;27:238-245
117. Nollet F, Beelen A, Twisk JW, Lankhorst GJ, De Visser M. Perceived health and physical functioning in postpoliomyelitis syndrome: a 6-year prospective follow-up study. *Arch Phys Med Rehabil*. 2003;84:1048-1056
118. Global Polio Eradication Initiative. 2014 [cited 5<sup>th</sup> Nov 2014]. Available from <http://www.polioeradication.org>.
119. Harbo T, Brincks J, Andersen H. Maximal isokinetic and isometric muscle strength of major muscle groups related to age, body mass, height, and sex in 178 healthy subjects. *Eur J Appl Physiol*. 2012;112:267-275
120. Bohannon RW, Williams Andrews A. Normal walking speed: a descriptive meta-analysis. *Physiotherapy*. 2011;97:182-189
121. Bohannon RW. Reference values for the timed up and go test: a descriptive meta-analysis. *J Geriatr Phys Ther*. 2006;29:64-68
122. Bohannon RW. Six-minute walk test. A meta-analysis of data from apparently healthy adults. *Top Geriatr Rehabil*. 2007;23:155-160
123. Bladh S, Nilsson MH, Hariz GM, et al. Psychometric performance of a generic walking scale (Walk-12G) in multiple sclerosis and Parkinson's disease. *J Neurol*. 2012;259:729-738
124. Nilsagård Y, Gunnarsson LG, Denison E. Self-perceived gait limitations in persons with multiple sclerosis. *Adv Physiother*. 2007:136-143

125. Flansbjerg UB, Brogårdh C, Lexell J. Muscle strength is only a weak to moderate predictor of gait performance in persons with late effects of polio. *NeuroRehabilitation*. 2013;33:457-464
126. Horemans HL, Bussmann JB, Beelen A, Stam HJ, Nollet F. Walking in postpoliomyelitis syndrome: the relationships between time-scored tests, walking in daily life and perceived mobility problems. *J Rehabil Med*. 2005;37:142-146
127. Willen C, Sunnerhagen KS, Ekman C, Grimby G. How is walking speed related to muscle strength? A study of healthy persons and persons with late effects of polio. *Arch Phys Med Rehabil*. 2004;85:1923-1928
128. Bladh S, Nilsson MH, Carlsson G, Lexell J. Content analysis of four fear of falling rating scales by linking to the International Classification of Functioning, Disability and Health. *PM R*. 2013;5:573-582
129. Phillips M, Flemming N, Tsintzas K. An exploratory study of physical activity and perceived barriers to exercise in ambulant people with neuromuscular disease compared with unaffected controls. *Clin Rehabil*. 2009;23:746-755
130. Hollingsworth L, Didelot MJ, Levington C. Post-polio syndrome: psychological adjustment to disability. *Issues Ment Health Nurs*. 2002;23:135-156
131. Fuller BG, Stewart Williams JA, Byles JE. Active living - the perception of older people with chronic conditions. *Chronic Illn*. 2010;6:294-305
132. Vissers M, van den Berg-Emons R, Sluis T, et al. Barriers to and facilitators of everyday physical activity in persons with a spinal cord injury after discharge from the rehabilitation centre. *J Rehabil Med*. 2008;40:461-467
133. Stuifbergen AK, Seraphine A, Harrison T, Adachi E. An explanatory model of health promotion and quality of life for persons with post-polio syndrome. *Soc Sci Med*. 2005;60:383-393
134. Bowler DE, Buyung-Ali LM, Knight TM, Pullin AS. A systematic review of evidence for the added benefits to health of exposure to natural environments. *BMC public health*. 2010;10:456
135. Streiner D, Norman G. *Health measurements scales*. Oxford University Press; 2008.
136. Kazdin A. *Research design in clinical psychology*. Boston: Pearson; 2010.
137. Sternfeld B, Goldman-Rosas L. A systematic approach to selecting an appropriate measure of self-reported physical activity or sedentary behavior. *J Phys Act Health*. 2012;9:S19-28
138. Sallis JF, Saelens BE. Assessment of physical activity by self-report: status, limitations, and future directions. *Res Q Exerc Sport*. 2000;71:S1-14
139. Tudor-Locke C, Hart TL, Washington TL. Expected values for pedometer-determined physical activity in older populations. *Int J Behav Nutr Phys Act*. 2009;6:59
140. Lincoln Y, Guba E. *Naturalistic inquiry*. USA: Sage Publications; 1985.
141. Patton M, Q. *Qualitative Research & Evaluation Methods*. USA: Sage Publications; 2002.
142. Sallis JF, Cervero RB, Ascher W, et al. An ecological approach to creating active living communities. *Annu Rev Public Health*. 2006;27:297-322
143. Ravenek MJ, Schneider MA. Social support for physical activity and perceptions of control in early Parkinson's disease. *Disabil Rehabil*. 2009;31:1925-1936

144. Simeonsson RJ, Lollar D, Björck-Åkesson E, et al. ICF and ICF-CY lessons learned: Pandora's box of personal factors. *Disabil Rehabil.* 2014;E-pub ahead of print, Accessed 15<sup>th</sup> Oct
145. Davis AM, Perruccio AV, Ibrahim S, et al. Understanding recovery: changes in the relationships of the International Classification of Functioning (ICF) components over time. *Soc Sci Med.* 2012;75:1999-2006

# Appendix