

# **The dynamic nature of participation**

**Experiences, strategies and conditions for occupations in daily life amongst persons with late effects of polio**

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UNIVERSITY OF GOTHENBURG

Gothenburg 2016

Doctoral Dissertation in Medical sciences

University of Gothenburg, 2016

The dynamic nature of participation  
© Iolanda Santos Tavares Silva 2016  
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Cover illustration: artbyElsonRenato

ISBN 978-91-628-9734-5 (Hard copy)  
ISBN 978-91-628-9735-2 (e-pub)

Printed in Gothenburg, Sweden 2016  
By Ineko AB

*“Be the change that you wish to see in the world”*

— Mahatma Gandhi



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### ABSTRACT

**Aim:** The overall aim of this thesis was to explore the conditions for daily occupations, and how these are reflected in the daily lives of people with the late effects of polio. Four studies (studies I–IV) are included in this research: three follow a qualitative approach exploring the experiences, strategies, and conditions for daily occupations among immigrants with the late effects of polio, and one follows a quantitative approach to explore the possible factors associated with fatigue among persons with the late effects of polio in Sweden.

**Methods:** The Grounded Theory (GT) method was used to explore experiences, strategies, and participation in daily occupations and how participation is reflected and can be understood in daily life. Twelve immigrants from Eastern Africa with the late effects of polio were interviewed and the interviews were analyzed according to GT (studies I–III). For study III, a secondary analysis of the interviews was conducted to probe deeper into the complexity of participation. In study IV, an explorative and cross-sectional method was used to explore possible factors associated with fatigue.

**Results:** Study I showed that experiences in daily occupations were highly varied. Thoughts, feelings, and reasoning about capacities and opportunities to live and do things like everybody else resulted in the identification of participants' conceptions of occupational self, which in turn affected their view of the future. Experiences were dependent upon participation in daily occupations where the social environment had a salient role. The findings in study II showed how participants used 14 different strategies to find a balance between physical capacity, meaningful occupations, and the

conception of their own and others' norms and values and living conditions in Swedish society. This resulted in a struggle for occupational participation and normality. Occupations within different areas of life and social interaction appeared to be important. Based on the analysis in study III, participation proved to be an ongoing, dynamic, and interactive process influenced by five subprocesses that contributed to value and identity development. Different conditions in daily life shaped the participation process. The process could have different strengths and could lead to both a sense of participation and exclusion. Study IV showed that factors associated with fatigue such as age and the use of mobility assistive devices could partly explain fatigue among persons living with the late effects of polio in Sweden. Use of mobility assistive devices proved to be the factor most likely to explain fatigue among participants. Participants using mobility assistive devices reported less fatigue than non-users.

**Conclusions:** This thesis contributes to the understanding of conditions for daily occupations among immigrants with the late effects of polio. These conditions make participation an inconstant and changeable process. Attention must be paid to those conditions that create possibilities to perform daily occupations and opportunities for occupations, conditions that lead to engagement in occupations, and how the conception of occupations emerges in interactions with others and the environment. To provide interventions that support the management of physical capacity and increase knowledge about the late effects of polio and its consequences in daily life is essential. To prevent fatigue and enhance participation in daily occupations, it is important to provide and demonstrate the importance of assistive devices to ensure the management of fatigue. Understanding participation as an interactional process helps to clarify the social political aspects of participation, which advocates for the consideration of conditions that influence the participation process both politically and socially. The results call for a critical approach when addressing and enhancing participation. Additionally, the findings in this thesis reinforce the importance of occupations for those at risk of social exclusion.

**Keywords:** Activities of daily living, Cross-sectional study, Fatigue, Grounded Theory, Immigrants, Occupational science, Occupational therapy, Post-polio syndrome, Qualitative study.

**ISBN:** 978-91-628-9734-5 (Hard copy)

# SAMMANFATTNING PÅ SVENSKA

Debatten kring delaktighet har ökat i stora delar av världen och begreppet delaktighet har kommit att spela en central roll genom Världshälsoorganisationens (WHO) klassifikation av funktionstillstånd, funktionshinder och hälsa (ICF). Delaktighet är fundamentalt för hälsa och välbefinnande. Fokus på ojämlikheter i hälsa och delaktighet har ökat i världen. Delaktighetsfrågor har blivit betydelsefulla inom aktivitets- och vårdvetenskap.

Vi lever i en globaliserad värld där människor har olika förutsättningar. I Sverige råder det olika förutsättningar för hälsa och delaktighet i olika grupper. Immigranter och personer med funktionsnedsättningar har generellt sett sämre hälsa och sämre möjligheter till delaktighet i dagliga aktiviteter. Således finns behov av ökad kunskap om förutsättningar för delaktighet hos personer med funktionsnedsättningar och immigrant bakgrund.

Denna avhandling har haft som syfte att studera förutsättningar för delaktighet i dagliga aktiviteter samt hur delaktighet kommer till uttryck i dagliga livet hos personer med sena effekter efter polio.

Avhandlingen innefattar en ramberättelse och fyra delarbeten, där upplevelser, strategier, förutsättningar för dagliga aktiviteter däribland fatigue (trötthet) studeras hos personer med sena effekter efter polio. Resultat från de fyra olika delarbetena sammanbinds i ramberättelsen och sätts i relation till teoretiska perspektiv. Avhandlingen ger en förståelse för delaktighet som en process där olika förutsättningar i dagliga aktiviteter interagerar och påverkar känsla av delaktighet. Förutsättningar för delaktighet i dagliga aktiviteter visar sig vara på olika nivåer och därmed krävs olika typer av åtgärder. Behov av åtgärder går från individnivå till samhällsnivå. Det är viktigt med åtgärder som stödjer hantering av fysisk kapacitet och ger en ökad kunskap om de sena effekterna av polio och dess konsekvenser i det dagliga livet. Den socioemotionella betydelsen av delaktighet är framträdande. Det visar sig finnas ett behov av kritiskt förhållningssätt till normativa värden som skapar villkor för delaktighet hos olika personer samt i olika grupper i samhället. Politiska och sociala strukturer bör därmed beaktas för aktivitetsrättvisa i samhället genom en ökad jämlikhet i tillgång till dagliga aktiviteter.





## LIST OF PAPERS

This thesis is based on the following studies, referred to in the text by their Roman numerals. The published papers are reprinted with permission from the publisher<sup>1</sup>.

- I. Santos Tavares I, Thorén-Jönsson A-L. Confidence in the future and hopelessness: Experiences in daily occupations of immigrants with late effects of polio. *Scand J Occup Ther* 2013; 20:1, 9-20.
- II. Santos Tavares Silva I, Thorén-Jönsson A-L. Struggling to be part of Swedish society: Strategies used by immigrants with late effects of polio. *Scand J Occup Ther* 2015; 22:6, 450-61.
- III. Santos Tavares Silva I, Thorén-Jönsson A-L, Sunnerhagen KS, Dahlin-Ivanoff S. Processes influencing participation in daily lives of immigrants with late effects of polio in Sweden. *Submitted for publication*.
- IV. Santos Tavares Silva I, Ottenvall Hammar I, Willén C, Sunnerhagen KS. Fatigue among persons with late effects of polio is a common, but hard to explain phenomenon - a cross-sectional study in Sweden. *Submitted for publication*.

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<sup>1</sup> This is the authors' accepted manuscripts of two articles published as the version of record in Scandinavian Journal of Occupational Therapy <http://www.tandfonline.com>



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## **ABBREVIATIONS**

CNS	Central nervous system
EMG	Electromyogram
GT	Grounded Theory
ICF	International Classification of Functioning, Disability and Health
MFI	Multidimensional Fatigue Inventory
PPS	Post-Polio Syndrome
WFOT	World Federation of Occupational Therapists
WHO	World Health Organization

# PREFACE

The journey of a thousand miles begins with one step  
Lao Tse (600 b.c.)

My first step into this journey began without knowing that it would lead me to where I stand today. Somehow, it started during my last year of my Occupational Therapy training. Where I learned more about rehabilitation and realized that there were several groups that, for one reason or another, were not able to have the fully benefiting from their rehabilitation. My curiosity to find out why Occupational Therapy was not able to provide them with adequate resources started my journey.

It took several years and a great deal of learning, both at a professional and personal level, before I decided to become a PhD student. In the beginning, I did not have a clear intension of becoming a PhD student. However, my professional development at work, attending courses, teaching and meeting a lot of people led me to where I am today.

This research journey has led me closer to the statement that made me choose occupational therapy 15 years ago: “to value resources”. I have been focusing on understanding issues behind participation in daily life occupations. I have also been examining what enhances participation, in order to better make use of people’s resources and create conditions for equitable access to participation, regardless of differences that may exist among human beings.

At the personal level, I have learned so much about myself when trying to learn about other things. During this travel, I have grown as a person, as an occupational therapist and as a researcher. It took a while before I started reflecting about my own position in relationship with my research. At some point, I realized that being an immigrant is a parts of me and my everyday live. This awoke both advantages and disadvantages that caused me to be cautious as a researcher. Being a PhD student and researcher has been a stimulating, enlightening and a positive challenge to embrace. I have learned that it is not only about what is in front of us but also the things in our contextual background that creates the person we become.





# 1 INTRODUCTION

Debates about human participation have increased worldwide because of the concept's central role in the International Classification of Functioning, Disability and Health (ICF) since 2001 (1-4). An additional, and unfortunate, reason for this increase are global inequalities in health and participation (5, 6). Occupational and healthcare sciences have emphasized the importance of participation (3, 7); to participate and be part of communities and societies is considered fundamental for health, well-being and quality of life (8, 9). Within the fields of occupational science and occupational therapy, it is assumed that occupational engagement contributes positively to well-being (9-11). According to Hammell (12) this should encourage researchers to explore participation as it is perceived and subjectively experienced by people in their daily lives. Hence, there is a growing interest and awareness of the need to work and the need for an occupationally just society to support and enhance participation in occupations (13). However, there are inequalities related to access to participation (14, 15). According to the World Federation of Occupational Therapists (WFOT), there are several types of inequities related to the human right to occupation, such as economic, social or physical conditions in daily life. These conditions are shaped by barriers and by the control of access to occupations. Barriers can be attitudinal or physical, and/or related to access to necessary knowledge, skills and resources, or the location in which occupation takes place (13).

The current discussion about participation and equitable access to participation for all human beings, regardless of differences, is the starting point for this thesis. Different conditions may affect participation in daily occupations (2, 16). This thesis focuses on conditions related to migration and disability that shape daily occupations. The term 'condition' refers to factors and circumstances in individuals' lives that affect occupations and participation.

This introduction will begin by describing the consequences of migration for health and the occupational conditions for immigrants. The consequences of disability are then described and the health and daily life conditions of persons living with disability. Poliomyelitis and the late effects of polio are then addressed, and the most common symptom, fatigue, is highlighted. Finally, three related concepts within occupational science are introduced: occupation, health and participation.

## 1.1 Migration and Immigrant

International migration is a global issue; most countries are affected by immigration and emigration (17). Migration expansion results in an increased awareness of migration challenges and opportunities. The effects of migration have been studied particularly in the traditional immigration areas of North America and Western Europe (17). However, it is difficult to identify the precise point at which the effects of migration begin to be felt, or when a person becomes classed as an immigrant (18).

Terms to define individuals who have immigrated to Sweden have been drawn from both everyday language and population statistics (19, 20). The statistical Swedish definition of a population with a foreign background is persons born outside Sweden or with both parents born outside the country (21). Another definition of the concept of immigrant is a person who migrates into a country as a settler (22). There are several different definitions of the concept of immigrant. These definitions vary both within and between countries and are not necessarily interchangeable (23, 24). The purpose of this thesis was to study persons with experiences of migration and settlement in a new country. Therefore, the term 'immigrant' is used here to describe a person who was born outside Sweden to two foreign-born parents and has migrated to Sweden.

International changes in migration have resulted in an altered population composition in Sweden during the last decades. Sweden is currently a multicultural society (24). In this multicultural Sweden, 16% of the total population are immigrants (25). Migration to Sweden intensified in the middle of the 20th century as industrialization led to labour migration. At the beginning of the 1970s, there was a shift in labour migration as many immigrant people were granted asylum on humanitarian grounds because of wars and political and social unrest in many parts of the world (26).

Migration has consequences at individual, family and community levels in both the home and the host country. The migration process has been explained and described in different ways and has often been divided into different phases (27). When moving to another country, most people live through a so-called migration crisis (28). A migration crisis is a reaction to experiences of change. This crisis does not begin upon crossing the border, but is experienced later when the person passes a psychological limit. According to Franzén (28) this is a point at which individuals simultaneously feel at home but perceive themselves as a stranger. Immigrants' experiences during their first years in Sweden are characterized, according to Ehn (18) by the loss of everyday security and self-esteem.

Studies of the health of immigrants in Europe have produced contrasting findings. Health differences between immigrants and non-immigrants seem to be related to socioeconomic status. In general, immigrants have poorer health and occupy inferior positions in the labour market (29-31). The health and well-being of immigrants in Sweden are affected by their different life situations before and during migration and by their sociocultural position in Swedish society (32). Studies of health in immigrants in Sweden demonstrate the difficulty of establishing a link between poorer health and migration. There are many different social factors that affect immigrants, such as unemployment, low labour market status, social conditions, perceived security and social assistance, discrimination and insufficient knowledge of Swedish (29, 33-35).

A number of studies have addressed the health and living conditions of immigrants (27, 29, 31). However, there are few studies on the participation challenges related to immigration (36). Migration affects daily occupations in a complex and multifaceted way (29- 31, 37). Immigrants face challenges in their daily lives as they must reconstruct and integrate themselves into communities that may differ from what they are used to and in which they may not be welcome (38). Because of the process of reintegration into the new society, immigrants face life disruptions that lead to occupational disruption (38, 39). Research shows that all areas of occupational performance are affected by migration (36). The effect of migration on daily occupations is evident in role changes, which affect patterns of occupation, routines and habits. Immigrants usually face difficulties in searching for employment. They also face changes related to identity, such as the loss of their family role, but they may obtain new occupational opportunities by entering occupations that they were not able to pursue in their home country. Furthermore, health and well-being can be impaired through the challenges related to change, which may affect activities such as meal preparation, physical activity and education (37).

Migration is a major force that strains the health, education and welfare systems of more prosperous nations. Another such force is disability. Both migration and disability provoke debates about human rights (40).

## **1.2 Disability**

Debates about human rights are characterized by different perspectives. Within disability studies (the study of the experiences and lives of disabled people), there has been much discussion about the appropriate terms to describe disabled people. Debates about human rights often emphasize the

‘needs’ of disabled people rather than their ‘rights’. This distinction reflects the often negative or passive terms used to describe disabled people; who are often labelled by their impairment (41).

In this thesis, the concept of disability is used according to the ICF definition (4): as an umbrella term that includes impairment, activity limitations and participation restrictions. Disability is a multidimensional phenomenon created by the interaction between health conditions and contextual factors (environmental and personal factors) (4). The dynamic and complex interaction between physical, psychological and social aspects of disability affects individuals’ health and health-related conditions (4).

A variety of factors may explain the health vulnerability of persons living with a disability. The World Report on Disability (42) shows that people worldwide living with disabilities must focus on everyday survival and have fewer resources to pursue productive employment and personal fulfilment (42). In Sweden, health reports show that a substantial part of society’s collective illness can be found among people living with disabilities. Poor health is ten times more common in persons living with a disability than in the rest of the population (43). According to the Swedish National Institute of Public Health (43), improvements in the health of persons living with a disability require a focus on increasing social participation and physical activity, improving financial conditions and decreasing insulting treatment or discrimination (43). Within the field of disability studies, quality of life among persons living with disability has been related to equality of life. According to Hammell (44), the inequities in quality of life are related to factors such as prejudice, discrimination, inadequate service systems, lack of transportation and housing conditions and an inability to make choices about life (44).

Several studies have examined participation restrictions among persons living with disabilities (2, 45-47). For instance, research on perceptions of participation in persons with spinal cord injury shows that, despite participation being perceived as sufficient, in many areas access to social support was lacking. This led to perceived severe problems with participation in daily activities (48). Research on participation in persons living with disabilities indicates a range of perceptions, meanings and definitions of participation. The concept is complex and affects many aspects of daily life (2, 45-47).

Disabilities of various kinds place extra demands on participation in daily life when people experience inadequate environmental conditions. Additionally, disabilities with increased risk for health problems affect the ability to

manage normal daily life occupations and may lead to participation restrictions. This is the case for persons with late effects of polio (49).

### 1.3 Poliomyelitis

Poliomyelitis (polio) is an acute viral infectious disease that has been feared since ancient times. In most cases, acute infection causes fever and flu-like symptoms without any muscle weakness. However, in 2–3% of cases the virus affects the central nervous system, causing a deterioration of the anterior horn cells that results in paralysis or muscle weakness in one or more muscle groups (50). Although acute polio is a diminishing health challenge, research shows that over half of polio survivors are living with new health problems related to the original polio infection (51). Until the 1980s, polio was thought to be a stable condition after the acute phase, but clinical research on persons with late effects of polio shows that approximately 60–85% face recurrence of the original polio-related manifestations as well as experiencing new symptoms. This indicates the presence of a new health problem (51, 52). The symptoms may be a direct consequence of contracting polio and indirectly as a consequence of post-polio syndrome (PPS) (53). However, other terms have been used to describe these symptoms, such as ‘the late effects of polio’ and ‘post-polio sequelae’, regardless of whether there is evidence of new motor unit dysfunction or whether there is a progression of symptoms (51). In this thesis, the term ‘the late effects of polio’ is used.

There have been debates about the criteria for a PPS diagnosis. According to Gawne and Halstead (51), persons with a PPS diagnosis display symptoms of motor unit dysfunction and musculoskeletal overuse. The criteria for a PPS diagnosis are as follows: a prior episode of paralysis confirmed by history, physical exam, and findings on an electromyogram (EMG); a period of neurological recovery followed by an extended interval of neurological and functional stability, usually lasting 20 years or more; and a gradual or abrupt onset of new neurogenic, non-disuse weakness in previously affected and/or unaffected muscles. These symptoms may or may not be accompanied by other new health problems, such as excessive fatigue, muscle pain, joint pain, decreased endurance, decreased function, and atrophy. Finally, other medical, orthopaedic and neurologic conditions that might cause the health problems mentioned above must be excluded (51).

The eradication of polio is a global objective of the World Health Organization (WHO). This goal is yet to be reached, but 2015 has been described as a progress year in which fewer cases were reported before December compared with any other year on record (54). Today, the global

incidence of polio cases has decreased by 99% since 1988 (55). However, there are currently approximately 12 to 20 million polio survivors in the world (56) and about 700.000 people are estimated to be living in Europe (57). The total number of polio survivors in Sweden is estimated to be more than 15,000 (53). The last major polio epidemic in Sweden occurred in 1953; until 1960, Sweden had the highest infection rates in the world. Since the introduction of polio vaccination in Sweden at the end of the 1950s, few cases of polio have been encountered. Moreover, the number of young polio survivors in Sweden has increased as a result of immigration and adoption (53). About 20% of the 900 patients registered at the Polio Clinic in the Rehabilitation Department, Sahlgrenska University Hospital, Gothenburg, Sweden, are immigrants.

Some symptoms of the late effects of polio, particularly muscle weakness, pain and fatigue, increase during the lifetime (52, 58) and may affect participation in daily life. Research on participation in daily life among persons with late effects of polio shows that more restrictions are reported for occupations related to family role, work and education and autonomy outdoors (48). Moreover, dependence in occupations such as cleaning, transportation and shopping has also been associated with restrictions in daily life activities (49). Life satisfaction in persons living with late effects of polio is affected by perceived participation and problems with participation in different life situations (59). Nevertheless, one study on participation in educational and professional life among persons with late effects of polio showed that a history of polio did not affect individuals' levels of education compared with their siblings. Few individuals with late effects of polio were employed fulltime at the age of 40 years and males experienced reduced professional options (60). Regarding general health comparisons, individuals with late effects of polio reported lower health than their siblings, were less satisfied with their total life situation, reported less energy for leisure activities and reported more symptoms such as pain and tiredness.

## **1.4 Fatigue**

The physical and mental tiredness experienced by everyone at times can be related to fatigue (61, 62). Fatigue is one of the most common symptoms reported by persons living with late effects of polio (63-65) and a major problem for persons with PPS (66). By its nature, fatigue is a complex phenomenon that is experienced subjectively. There are many definitions and concepts of fatigue (58, 61, 62, 67). Fatigue may be either peripheral or central depending on where in the nervous system it originates (68). There

are different types of fatigue, such as general, physical or muscle fatigue, which relate to the way it is experienced (69). The definition of fatigue used in this thesis is an overwhelming sense of tiredness, a lack of energy and a feeling of exhaustion that may be associated with impaired physical and/or cognitive functioning (62). Fatigue affects health-related quality of life and is reported to be the most disabling symptom among persons with late effects of polio (52, 63, 64, 70); it impairs strength when performing occupations (63).

Fatigue may also have a substantial negative effect on different areas of life for persons with late effects of polio (63, 65, 71). Fatigue affects the daily lives of such individuals, particularly those with PPS, as it affects physical and psychosocial functioning (65). Health conditions related to PPS have been associated with the dimensions of physical mobility, energy, pain and emotional reactions (65, 70). Reduced physical capacity sets off a chain reaction because it leads to increased effort to perform daily activities, such as walking and climbing stairs, which in turn leads to increased fatigue (72, 73). Research on the impact of fatigue on performance and participation in daily occupations shows that fatigue can influence motivation and the capacity for occupations (74).

## **1.5 Occupation, health and participation**

### **1.5.1 Occupation**

The concept of ‘occupation’ has been used within different fields of science. How occupation is defined within a community or field of science depends on the different goals and purposes assigned to it (75). Usually, occupation is defined as work; this perception of occupation is conveyed to humans during childhood. The common view of occupation as work or a job might conflict with the definition of occupation within occupational science (75).

In this thesis, the concept of daily occupations is defined as all human ‘doing’ and comprises broad areas of doing occurring in the context of time, space, society and culture (76). The concept of daily occupations refers to all human occupations occurring in the context of daily life. The environment is the context in which occupations take place (76). An occupation is located in, influenced and given meaning by the physical, social, cultural and institutional contexts and situations outside individuals (76, 77).

By attending to the meaning of occupations and the way human beings occupy their time and space, occupational science moves beyond the common sense interpretation of occupation as related to work. Occupations are seen as improving health and well-being in daily life; what people do is remarkably important to their well-being. Involvement in meaningful occupations contributes to maintaining and regaining health (75). ‘Occupations is not just something that is done, nor is it just a category of work. Instead, occupation involves a series of thoughts, actions and interactions in particular places and times. To understand this, the observer must analyse the components of daily human engagement’ (75) (page 85). Studies of occupation enable connections to be drawn between occupations and the societies in which they occur (78). Occupation is central to the understanding of human experiences and should be understood within the framework of human lives (78). A consideration of the specific aspects of human occupation can enhance an understanding of the complexity of daily life (75).

## 1.5.2 Health

The relationship between occupation and health is a basic assumption in occupational science (11, 79, 80), and can be traced back to the origins of occupational therapy, which emphasized the health-promoting benefits of engagement in occupations (11, 80). However, an adequate definition of health requires a multidimensional perspective, because ideas about health can be influenced by many factors, such as social or individual perspectives, cultural and spiritual philosophies, geographical location, economy and accessible health technology (11). In an attempt to approach a universally accepted definition of health, the WHO defined health in 1946 as ‘a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity’ (81). In occupational science, the definition of health relates not only to the absence of disease and infirmity but also to the ability to do what you want to do, to participate in work and leisure activities, to realize ideas and values and meet the challenges you face (11, 80). This approach to health is consistent with the view of Nordenfelt (82), who defined health in terms of the ability to reach vital goals. He emphasized the dynamic nature of health and defined it as an individual’s ability to reach all his or her vital goals in standard circumstances; this ability ranges across a continuum from a state of complete health to a state of maximal illness (82). Consequently, to experience health requires concordance between an individual’s ability, the goals she has in life and the environment she lives in.



### 1.5.3 Participation

The assumptions in occupational science about how occupations affect health and well-being share conceptual similarities with the ICF's definition of participation (3). The ICF's definition of participation as involvement in a life situation (4) shows, according to Hemmingsson (3), an understanding of health as related to people's daily lives (3). Individuals are involved in various areas of life and participation is seen as actual conducted activity in these areas (4). However, the ICF's conceptualization of participation is considered problematic and has been criticized. The criticisms relate to several aspects, such as the exclusion of subjective experiences of meaning in the coding of participation, the charge that the ICF does not pay enough attention to relevant aspects of participation like volition, choice and agency, and the allegation that professionals' perspectives are privileged over those of disabled people (12). Research on participation indicates that the concept of participation is complex and, which makes it difficult to conceptualize, define and measure (2, 8, 47, 83-86).

Hence, participation is multidimensional and researchers from several fields have discussed the ambiguities of this concept (1, 3, 87). According to Gustavsson (1), one important aspect of participation essential for its understanding is that participation makes a society a society, because people's experiences and feelings of participation provide a united community in relation to various aspects of life. To participate and be part of communities and societies is fundamental for health, well-being and quality of life (8, 9). Additionally, to understand participation in occupation is a means of understanding social inclusion and occupational justice (88). Occupational justice is supported by the beliefs that individuals and groups have the right to participate in diverse and meaningful occupations as a way to meet their needs and develop their potential (89).



## 2 THEORETICAL AND METHODOLOGICAL FRAMEWORK

### 2.1 Theoretical framework

This thesis is based on the theoretical understanding of humans as occupational beings, an idea that has its roots in the discipline of occupational science.

Occupational science is an interdisciplinary research field that aims to study occupation to create an understanding of its nature, meaning and sociocultural structure. The discipline was established in the late 1980s (75). Originally, the purpose of occupational science was to advise and support occupational therapy. The aim was to create a body of knowledge in occupational therapy that would increase occupational-based practice (90).

The philosophical movement underlying occupational science began in 1809 with the development of the occupational therapy profession, which was originally named ‘moral treatment’. The physician and philosopher Pinel developed a more humane treatment approach that perceived all humans as individuals who were able to reason and who should be treated with compassion (91). Together with the work of Tuke in England, this approach laid the foundations for the work of Meyer (1922), the father of occupational therapy. According to Meyer, mental problems were seen as ‘problems of living’. At this time, occupational therapy was about ‘opportunities rather than prescriptions. There must be opportunities to work, opportunities to do and to plan and create, and to learn to use material’ (92) (page 641).

The concept of occupation is fundamental and occupational participation has been identified as the most representative value in occupational science (93). Within occupational science, the ‘occupational perspective’ is ‘a way of looking at or thinking about human doing’ (94). This thesis is based on an occupational perspective because it focuses on occupations in which persons are engaged in their daily lives, on conditions for these occupations and on how occupational participation is reflected in daily life.

The investigation of what any occupation means for an individual, family, group or community must be conducted with respect for the conditions of the person, the environment and what the occupation itself requires from the person performing the occupation (11, 75, 80). There is a current discussion about different levels of focus in understanding occupational experiences.

These occupational experiences can be perceived from an individual level or from a social level that embodies generalized cultural ideas of occupation (90). This discussion is evident in the practice of occupational therapy, which may focus on either individual-based or social-based interventions. There is a growing tension related to whether focus should be placed on individual agency or collective action (95). However, both views of occupation are valued in occupational science (96). This thesis focuses on both levels of understanding occupation: the unique and subjective experiences that individuals have in their own lives and the social perspective of occupation, which highlights the importance of the context in ordinary occupations.

## **2.2 Methodological framework**

A distinction has often been made between qualitative and quantitative research methods. These two approaches are supported by different assumptions (97). Despite the differences between qualitative and quantitative methods, a dichotomization of these two broad research traditions might obscure the potential relationships between them (98). One of the many terms used to describe the combination of qualitative and quantitative methods is ‘mixed methods’ (98). This thesis uses the lowest level of mixed methods because the integration of qualitative and quantitative data occurs outside of the studies that produced them. Both qualitative and quantitative methods have been used to study daily occupations and conditions influencing participation in daily life. The use of mixed methods is supported by a pragmatic philosophical view, which permits the combination of research methods, techniques and procedures to meet the needs and overall aim of a study or thesis (99).

Quantitative research tests theories using the deductive logical approach. In contrast, qualitative research uses an inductive approach (100). Qualitative research is based on an empirical, holistic, epistemological perspective and studies unknown phenomena by identifying characteristics and meanings related to variability, structures and processes (97, 100, 101). Qualitative research study individuals in their societal and cultural contexts, contexts that shape meaning, behaviour, experiences and understanding of the world (100). Qualitative research is informed by the assumption that there are multiple realities, not just one single human reality. These multiple realities reflect the

different meaning structures of different groups (97). Qualitative research allows researchers to understand the phenomena under investigation by finding patterns in the data that illuminate the actual state of reality. The fact that all perspectives are valued as equal in qualitative research makes it possible for those whom society ignores to describe their experiences openly (102). The grounded theory (GT) qualitative method has been used to explore the experiences, strategies and conditions for participation related to occupations in daily life. In contrast, quantitative research is based upon an empirical, reductionist, epistemological perspective. Consequently, the aim in quantitative analysis is to study previously defined phenomena and the characteristics and distributions of this phenomenon in a population or a sample (97, 100, 101). In this thesis, quantitative analysis using statistical methods was used to explore associations between a set of factors (gender, age, country of birth, occupation/employment level, and the use of mobility assistive devices) and common and recognized symptom (fatigue) among persons with late effects of polio.



### 3 AIM

The overall aim of this thesis was to explore the conditions for daily occupations and how these are reflected in the daily lives of persons with late effects of polio. This thesis comprises four papers, three with a qualitative approach and one with a quantitative approach. The overall aim of the thesis was met by developing four separate studies with the following aims:

Study I aimed to explore and describe how immigrants with late effects of polio experience their daily occupations.

Study II aimed to explore and describe strategies in daily occupations among immigrants with late effects of polio.

Study III aimed to explore and describe conditions influencing participation in daily occupations and how these conditions interact with each other.

Study IV aimed to explore possible factors associated with fatigue among persons with late effects of polio in Sweden.





## 4 METHODS

### 4.1 Design

In this thesis, both qualitative and quantitative methods were used to study different aspects of conditions for daily occupations of persons with late effects of polio. The qualitative method of GT (103) was used in studies I–III. In studies I and II, an analysis of the primary data set was carried out to explore and describe how immigrants with late effects of polio experience daily occupations and to explore strategies in daily occupations. In study III, a secondary analysis of the same data set was conducted and the interviews were re-examined to explore conditions that influence participation in daily occupations. A quantitative research method was used in study IV. A cross-sectional multiple linear regression was conducted to explore possible factors associated with fatigue among persons with late effects of polio. An overview of the samples and methodological approaches can be found in Table I.

**Table I. Overview of the samples and methodological approaches**

	<b>Sample</b>	<b>Study design</b>	<b>Data collection</b>	<b>Data Analysis</b>
<b>Study I - II</b>	Persons (20-65 years) living with late effects of polio, migrated to Sweden from Eastern Africa ( $n=12$ )	Inductive/ descriptive Qualitative Grounded Theory	Individual interviews	Grounded Theory, Corbin and Strauss
<b>Study III</b>	Persons (20-65 years) living with late effects of polio, migrated to Sweden from Eastern Africa ( $n=12$ )	Inductive/ descriptive Qualitative Grounded Theory	Individual interviews	Secondary data analysis Grounded Theory, Corbin and Strauss
<b>Study IV</b>	Persons (19-93 years) living with late effects of polio, recruited from a clinical database ( $n= 89$ )	Explorative/ descriptive Quantitative Cross-sectional	Face-to-face interviews with Multidimensional Fatigue Inventory (MFI-20) and questionnaires measuring/ assessing a set of relevant factors*	Pearson's correlation coefficient and multiple linear regression

\*Factors: gender, age, country of birth, occupation/employment level and the use of mobility assistive devices.

### **4.1.1 Grounded Theory: methodological choice and assumptions**

The GT method aims to generate theoretical explanations by comparing data. GT is appropriate for building a theoretical understanding of complex social processes (104). This method focuses on the meaning assigned to events, and on the actions, interactions and emotions produced in response. According to Corbin (103) this type of study makes it possible for researchers to identify patterns of action–interaction that enable the establishment and maintenance of stability and social order (103). It is also important to consider the context in which the events and responses take place. Descriptive qualitative research, such as GT, is appropriate for the development of knowledge (105), which can then be used to explore little-known issues. Therefore, this method is suitable for the study of persons with chronic illness (103). Thus, GT was chosen to identify how immigrants with late effects of polio in studies I, II, and III experience, manage, reason about and perceive their participation in daily occupations. These were interview studies in which the data consisted of the participants' own words.

### **4.1.2 Cross-sectional multiple linear regression**

Study IV was a cross-sectional study. Cross-sectional studies are observational studies in which no interventions are carried out; the researcher simply observes. The method is usually used when the research objective is to establish prevalence; it is not used to study cause and effect. Cross-sectional studies are suitable to identify associations between variables (108), which was the aim of study IV. This study investigated the possible factors associated with fatigue; therefore, an explorative multiple linear regression analysis was used. This is an appropriate technique to examine associations between variables. Multiple linear regression analysis is a very flexible method that can examine relationships between both quantitative independent variables (e.g., personality traits) and categorical independent variables (e.g., ethnic groups) (109).

## **4.2 Settings**

The four studies (I–IV) were conducted in the western part of Sweden. Participants in studies I to III were selected from a polio clinic at the Sahlgrenska University Hospital, Gothenburg, Sweden. Study IV used patient data from the clinical database of persons with late effects of polio. Data from more than 900 persons with polio has been collected since the clinic opened in 1994 and different questionnaires have been used during this time.

## 4.3 Recruitment and participants

### 4.3.1 Study I - III

The following inclusion criteria were applied: diagnosis of polio, immigrant from East Africa (refugee, labour migrant or family reunion), ability to speak and understand Swedish, and aged between 18 and 65 years (the Swedish working age population). The participants were selected from the patient register using a GT theoretical sampling process; that is, the participants were selected step by step (103). This resulted in a sample with heterogeneity according to the participants' degree of disability, marital status, family, work conditions and country of origin (Table II).

**Table II. Characteristics of the participants in study I-III**

Characteristics	<i>n</i> (%)
<b>Gender</b>	
Female	7
Male	5
<b>Country of birth</b>	
Somalia	5
Eritrea	4
Ethiopia	1
Kenya	1
Uganda	1
<b>Migration</b>	
Alone	10
With family	2
Refugee	10
Family reunion	2
<b>Living conditions</b>	
Single	7
Single, cohabiting with children	2
Cohabiting with partner and children	2
Cohabiting with parents/sibling	1
<b>Occupational conditions</b>	
Full-time employment	2
Part-time employment	3
Education	3
Unemployment	3
Full disability pension	1

The participants were born in East Africa and had migrated to Sweden between 1978 and 2001 because of conflicts such as war, insecurity and/or economic reasons. They had lived in Sweden for 5–25 years (mean = 14 years). With the exception of one man, all participants experienced the onset of polio during the first 5 years of life. The most frequently experienced symptoms of the late effects of polio were muscular weakness (mainly in the lower limbs and spine), fatigue and pain (mainly joint pain in the knees and spine). For all participants, walking and balance capacity were affected as a

result of decreased function in the lower limbs. Walking devices were therefore required for 10 of the 12 participants, and six of them also occasionally used a wheelchair. All participants had access to transportation services for disabled persons and eight had their own cars.

### 4.3.2 Study IV

The participants in study IV were identified from the clinical database. The following two inclusion criteria were used: (i) persons aged 18 years or older, and (ii) with late effects of polio. In a total, 89 persons were included in study IV those that had answered the fatigue questionnaire. Due to internal dropouts in different items the calculations were based on slightly samples size (see notes table III-IV).

**Table III. Characteristics of participants (n=89)**

<b>Participants</b>	<b>n (%)</b>
<b>Gender</b>	
Female	48 (53.9)
<b>Age (years)</b>	19-93
<b>Range</b>	
19-29	5 (5.6)
30-49	12 (13.5)
50-69	40 (44.9)
70 ≥	32 (36.0)
<b>Country of birth</b>	
Nordic countries	65 (73.0)
Outside the Nordic countries	24 (27.0)
<b>Post-polio syndrome (PPS)</b>	88 (98.9)
<b>Occupation/employment level</b>	
Unemployed	6 (6.7)
Working ≤ 50 %	5 (5.6)
Working 100 %	28 (31.5)
Early retirement	7 (7.9)
Retired	43 (48.3)
<b>Use of assistive devices</b>	
No walking devices	59 (66.3)
Crutches, cane and/or walker	20 (22.5)
Wheelchair occasionally	5 (5.6)
Wheelchair	5 (5.6)

Data from 89 persons were used in this study; 73% were born in the Nordic countries and 27% were born outside the Nordic countries. Approximately 54% of the participants were female. A majority of the participants had PPS (99%). The occupation/employment levels were working fulltime (31%), early retirement (8%) and retired (48%) (For more information see Table III.)

## **4.4 Data collection and procedures**

### **4.4.1 Individual in depth interviews and questionnaire (study I-III)**

Data for studies I, II and III were collected through face-to-face interviews; all interviews were tape-recorded. The interviews were carried out in Swedish in an informal, conversational manner. All interviews were conducted by the author (ISTS). The interview guide was designed to address the research questions of studies I and II, but as the primary data set for these studies also included data about conditions for participation, the same data set was used again to address the research question of study III. The primary data set was collected through interviews focused on the participants' descriptions of their daily occupations, views of disability, life histories, their life conditions in Sweden, the environment and their thoughts about the future. As an introduction, the participants were asked to describe an ordinary day. Detailed memos were written during the research process, which lasted from interviews to analysis. The participants were visited once for a total of 1–3 hours. Eight participants were interviewed in their own home, two at the rehabilitation unit, one at work and one at school. When the qualitative interview was completed, a questionnaire was used to collect supplementary data on sociodemographics, housing conditions and assistive devices. All interviews were transcribed verbatim immediately after the interview.

### **4.4.2 Assessments (study IV)**

For study IV, all data were collected between 2008 and 2011. All clinical examinations were performed by a rehabilitation team (rehabilitation medicine physician, physiotherapist and occupational therapist). All EMG analyses were performed by a clinical neurophysiologist.

#### **4.4.2.1 Dependent variable**

The Swedish version of the Multidimensional Fatigue Inventory (MFI-20) was used to assess fatigue. The MFI-20 is a 20-item self-administered questionnaire. It assesses self-rated fatigue with five subscales: General Fatigue (GF), Physical Fatigue (PF), Mental Fatigue (MF), Reduced Motivation (RM) and Reduced Activity (RA) (67) (for more information see study IV). The Swedish version of the MFI-20 shows good psychometric

properties in different settings (persons with post-polio, cancer, fibromyalgia, chronic widespread pain and in a healthy population) (67, 71, 108).

#### 4.4.2.2 Independent variables

The independent variables were *gender* and *age*, which were used to describe the basic demographics of the participants. Age was divided into four categories: 18–29 years, 30–49 years, 50–69 years, and  $\geq 70$  years. The factors country of birth, occupational/employment level and the use of mobility assistive devices were chosen because previous research indicates that they affect daily life among persons with late effects of polio (109–112). Regarding *country of birth* the participants were divided into two groups: persons born in the Nordic countries (Sweden, Denmark, Finland and Norway) and persons born outside the Nordic countries (Afghanistan, Bolivia, Chile, Ethiopia, countries of the former Yugoslavia, the Philippines, Gambia, Iraq, Iran, Lebanon, Nigeria, Peru, Sierra Leone, Somalia, Syria, Tunisia and Turkey). The participants' *occupation/employment level* was explored by forming two groups: working (working fulltime, working halftime or less) and not working (unemployed, early retirement [pension before 65 years of age], and retired [pension at 65 years of age, or older]). To explore *the use of mobility assistive devices* participants were divided into two groups: those who did not use mobility assistive devices and those who used mobility assistive devices (crutches, cane and/or walker, wheelchair occasionally, and wheelchair).

## 4.5 Data analysis

### 4.5.1 Grounded theory comparative analysis (studies I– III)

The transcribed interviews and memos were analysed according to the GT method (113). The data analysis started directly after each interview had been transcribed for studies I and II. In the primary analysis (studies I and II), the focus was the participants, conditions and context and how these affected participants' experiences and strategies in daily occupations. Data were coded line by line, each phenomenon was given a code name and a systematic comparison was performed to group similar phenomena under the same name (concept). In the next step, these concepts were further compared and grouped into categories. Each category was analysed to identify its

characteristics; this process resulted in a large number of descriptive categories. The next step of the analysis was to perform a natural separation of the categories related to different aspects of daily occupations. Based on the relationship between the categories and subcategories that emerged from the data, statements about the participants' experiences in daily occupations were formulated (113). Because of the scope of the data, not all categories could be described in a single paper. Consequently, the study I analysis focused on categories describing the participants' experiences in daily occupations, and the study II analysis focused on the strategies that were interpreted through the participants' doing and reasoning in daily occupations.

For study III, a second stage analysis was conducted. The primary data set was re-examined and a secondary analysis was carried out according to the GT method (113). This involved analysing the interview data from studies I and II according to the same analysis procedure described above, but from a new perspective. Thus, the focus of the secondary analysis was the participants' involvement in, and performance of, daily occupations and how they reasoned about and perceived their participation in daily occupations. Consequently, the transcribed interviews and memos were re-read and analysed to identify the signs of the phenomena participation, such as the participants' involvement in, and performance of, daily occupations. By this close re-examination, the participation process was identified as the core category and the central phenomena of the study (113).

To illustrate and support the categories, subcategories, processes and subprocesses in studies I, II and III, quotations from the interviews are used. Unspoken but implied words are written in square brackets; omitted words and sentences are indicated by an ellipsis (...).

## **4.5.2 Statistical analysis (study IV)**

Study IV explored and analysed the dependent variable, fatigue, in relation to the following factors: gender, age, country of birth, occupation/employment level, and the use of mobility assistive devices. The participants' characteristics and fatigue were described with descriptive statistics. Pearson's correlation coefficient was used to analyse the strength of the correlation between variables. A multiple linear regression was used to explore factors associated with fatigue. Statistical analyses were performed using IBM SPSS Statistics, version 22.0 (IBM Corp., Armonk, NY, 2013).





## 5 ETHICAL CONSIDERATIONS

Before the research began, the four studies included in this thesis were approved by the Regional Ethical Review Board, Gothenburg University, Sweden (Dnr. S 014-03 & Dnr. 123-09).

Before inclusion in the data collection reported in studies I–III, all the participants were informed orally and in writing about the nature and aims of the studies. They were also informed about confidentiality procedures and it was explained that their participation was voluntary and that they could withdraw from the study at any time. Thereafter, each participant signed an informed consent form. In addition, two important aspects of confidentiality were addressed in this research project. First, participants were informed that the information and data would be used decoded. Hence, names and specific information were avoided in the written reports to ensure that no participant was recognized. Second, participants were informed that only the researchers had access to the coded information and could identify the participants.

In studies I–III, we had to consider how to prevent the reinforcement of stigma. Another issue was how much knowledge of the Swedish language the study group had; we had to ensure that participants had understood the study information and their rights, such as the voluntary nature of participation. During the interviews, the questions were adapted so that participants could understand them and could feel that their responses were understood.

As the studies included persons from groups that are usually treated as vulnerable, such as immigrants and disabled people, there may have been a risk of stigmatization. Although we mentioned issues related to group differences, our intention was not to accentuate those differences, but rather to address how vulnerability is created. We attempted to counteract invisibility and the negative visibility of the group by describing inequities in health, participation and access to human rights. The intention was to prevent reinforcement of stigma by addressing the needs, desires and rights of the group as individual protagonists, in a way in which they are seldom heard.



## 6 RESULTS

### 6.1 Experiences in daily occupations (study I)

The daily occupational experiences of Swedish immigrants with late effects of polio were highly varied and complex, with experiences within the group varying between situations and people. To better evaluate these experiences, they were described in the terms of six categories. These six categories of experience were described as a continuum with two opposite endpoints. The experiences were viewed as a result of the dynamic interaction between the person and the environment (Figure 1).

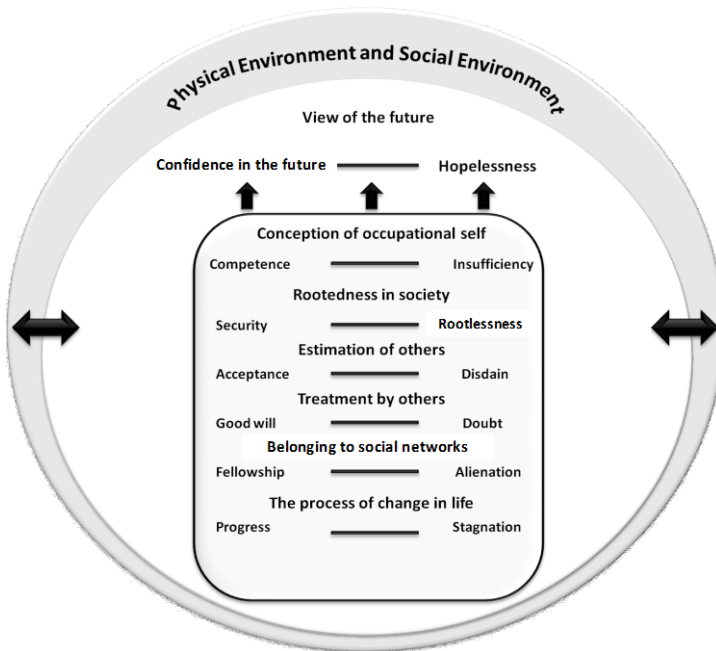


Figure 1. The participants' experiences in daily occupations in interaction with the physical and social environment. There are six categories of experiences that influence the core category, view of the future, which is characterized by experiences between confidence in the future and hopelessness<sup>2</sup>.

<sup>2</sup> Originally published in Santos-Tavares I, Thorén-Jönsson A-L. Confidence in the future and hopelessness: Experiences in daily occupations of immigrants with late effects of polio. *Scand J Occup Ther* 2013;20:9-20

Immigrants' experiences depended upon participation in daily occupations, with the social environment having a salient role. Thoughts, feelings, and reasonings on the capacity and opportunity to live and do things like everybody else, resulted in conception of the occupational self, and affected a person's view of the future. Experiences could be either positive or negative, implying either a feeling of confidence in the future or hopelessness. Confidence in the future occurred when secure living conditions, acceptance and kind treatment were experienced; these supported participation in daily occupations and installed a feeling of competence in daily life. Conversely, some of the persons felt various degrees of hopelessness, which was related to a lack of progress in life, and a lack of orientation in society, combined with disdain and doubt from others.

## **6.2 Strategies for occupational participation and normality (study II)**

The study showed a struggle for occupational participation and normality, as a person's conditions in daily life required a willingness to struggle in different situations. Furthermore, to be like everybody else was a prerequisite for occupational participation, and for being part of Swedish society. Fourteen strategies were identified and divided into the following four categories; managing physical capacity, promoting occupational performance, strategies for gaining respect, and preparing ground for one's existence. The strategies supported the participants' struggle for occupational participation and normality, and were related to their efforts to participate in, and be part of, Swedish society. Furthermore, the strategies employed in daily occupations showed a desire to maintain dignity and normality, regardless of any obstacles. Participants demonstrated a willingness to find a balance between physical capacity and meaningful occupation, conception of their own and others' norms and values, and occupational conditions in daily life in Swedish society. The strategy category, managing physical capacity, was composed of four strategies aimed at achieving control over the body and overcoming daily occupational limitations. The second strategy category, promoting occupational performance, consisted of two strategies intended to increase independence and participation in daily occupations. The third category was termed strategies for gaining respect, and was concerned with gaining respect and convincing others of one's value; this category contained two strategies. The fourth category, preparing a ground for one's existence,

was composed of five strategies aimed at participation in society and fulfilment of roles. These strategies were intended to create occupational opportunities, allow the making of contacts and establishment of relationships, and allow participants to increase their knowledge base (Figure 2).



Figure 2. The core category “Struggling for occupational participation and normality” and four categories of strategies used by immigrants with late effects of polio created a ground for existence and participation in daily occupations<sup>3</sup>.

### 6.3 Complex and dynamic process of participation (study III)

Participation in daily occupations was shown to occur through a process influenced by an ongoing, dynamic interaction of sub-processes, which contributed to value and identity development. The sub-processes consisted of the actions and interactions used by the participants to reach the goal of participation, or to resolve problems preventing their participation. The sub-

<sup>3</sup> Originally published in Silva-Tavares I, Thorén-Jönsson A-L. Struggling to be part of Swedish society: Strategies used by immigrants with late effects of polio. Scan J Occup Ther.2015;22: 6,450-461

processes both enabled and restricted participants' mastery of daily life. They were concerned with creating meaningfulness, connections with others, installing a sense of belonging and gaining trust from others (Figure 3).

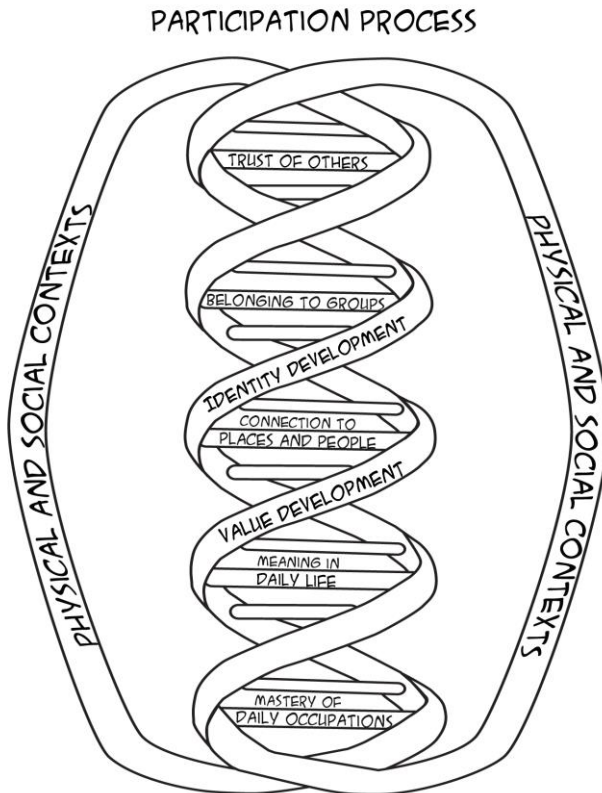


Figure 3: The process consisted of five subprocesses; mastery of daily occupations, meaning in everyday life, connection to places and people, belonging to groups and trust of others. The interaction between the subprocesses shaped the participation process and contributed to value and identity development.

Different conditions related to the daily occupational life of immigrants with late effects of polio were detailed in the sub-processes. The conditions could be specifically related to late effects of polio; such as the ability to perform occupations that could be affected by muscular weakness and fatigue. The conditions could also be specifically related to the immigrant situation, such as understanding occupations and their context, and the ability to communicate in Swedish. Thus, the conditions could be related to both immigrant situation and late effects of polio, and affected the available choices regarding daily occupation, access to places and opportunities, and

connections with others. The position and roles within a group were also conditions affecting the sub-process of belonging. Understanding and acceptance created conditions that helped shape trust in others.

The participation process could have different strengths and could lead to both a sense of participation and a sense of exclusion, depending on how each sub-process unfolded, and the interactions between the sub-processes. There was a dynamic interaction between the different daily occupational conditions shaping sub-processes; these created both barriers and opportunities for the persons to participate in daily occupations and life in general.

## 6.4 Fatigue is a common, but hard to explain phenomenon (study IV)

The dependent variable of fatigue was explored and analysed in relation to the following factors; gender, age, country of birth, occupation/employment level, and the use of mobility assistive devices. Two factors, the use of mobility assistive devices and age, partly explained self-rated fatigue in people living with late effects of polio. However, the factors within the regression model explained 14% of the variation in fatigue, with the use of mobility assistive devices being the factor with the strongest contribution (Table IV).

**Table IV. Multiple linear regression for fatigue and the factors ( $n = 85$ )**

Independent variables	$\beta$	95% CI	$p$ -value
Age	0.304	0.38 – 4.04	<b>0.019</b>
Gender	-0.009	-2.70 – 2.28	0.032
Occupation/employment level	0.086	-2.20 - 4.36	0.514
Mobility assistive devices	0.262	0.63 – 6.22	<b>0.017</b>

$R^2 = 14\%$

The statistically significant correlations showed that fatigue was positively and weakly correlated with age ( $r = 0.234$ ,  $p < 0.05$ ) and that participants using mobility assistive devices reported less fatigue ( $r = 0.255$ ,  $p < 0.05$ ). Besides the correlation between fatigue and the different factors, statistically

significant correlations also occurred between the factors. The use of mobility assistive devices correlated positively and weakly with occupational employment level ( $r = 0.238$ ,  $p < 0.05$ ), indicating that non-working participants used mobility assistive devices to a lesser extent. There was also a weak and positive correlation between country of birth and occupational/employment level ( $r = 0.278$ ,  $p < 0.01$ ). This was influenced by the fact that persons born in the Nordic countries were older, and so therefore were more often retired (see Table V).

**Table V. Correlation between fatigue and the factors ( $n=85$ )**

Variables	Fatigue	Gender	Age	Country of birth	Occupation/employment level
Fatigue	1				
Gender	-0.046	1			
Age	0.234*	-0.073	1		
Country of birth	-0.189	0.211	-0.729**	1	
Occupation/employment level	-0.017	-0.158	-0.548**	0.278*	1
Mobility assistive devices	0.255*	-0.004	-0.090	-0.74	0.238*

The participants rated fatigue highly in three of the five sub-scales of the MFI-20: physical fatigue (90%), general fatigue (89%) and reduced activity (84%). Variation in the distribution of fatigue within the five subscales related to gender, age, country of birth, occupational/employment level, and the use of mobility assistive devices. Nevertheless, it was not possible to evaluate significant differences within the factors.



## 7 DISCUSSION

### 7.1 Conditions for participation in daily occupations

The conditions of daily occupations resulted in participation being an inconsistent and changeable process. Participation was identified as a process with no given starting point, which could change from situation to situation. In this study, the process of participation in daily occupations occurred at different levels (personal, contextual, meaning, and value) and conditions in these levels either enabled or restrained the participation process to different degrees. Four conditions represented in the findings of this study are discussed in detail. The conditions shaped occupational participation in different ways; personal conditions led to the possibility to perform occupations, contextual conditions led to the opportunity for occupations, conditions related to meaning led to engagement in occupations, and conditions related to values led to conception of occupations (see Figure 4).

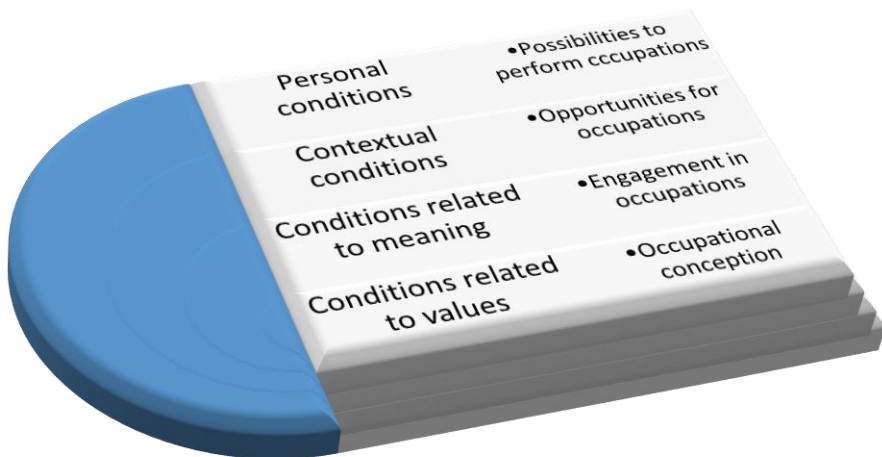


Figure 4. Four conditions influencing the participation in daily occupations were identified: the possibility to perform occupations, opportunity for occupations, engagement in occupations, and conception of occupations.

The contexts and situations where the occupations in the qualitative studies I, II, and III occurred have been described in this thesis as physical and social environments. However, in occupational therapy literature, the environment is more specifically defined as the context in which occupations take place (76). Occupation is considered to be influenced and given meaning, by the physical, social, cultural and institutional contexts and situations external to the individual (76, 77). When social contexts are described in this thesis, the cultural and institutional environment has been incorporated into the social context.

## **7.2 Personal conditions and possibilities to perform occupations**

Personal conditions have both positive and negative effects on the potential to perform occupations. These conditions are closely related to the capacity to adequately deal with daily occupations. This was expressed in study I, in the category, conception of occupational self, where participants were found to experience feelings of both competence and insufficiency. Strategies for managing physical capacity and promoting occupational performance (study II) are also related to personal conditions. The strategies used for performing occupations attempted to enhance the achievement of competence. In turn, the true competence was shaped by both physical and social context.

In study III, the sub-process of mastery of daily occupations was shaped by the ability to perform occupations, and the performance requirements. A perception of ability was created, both in the person themselves, and in others, which depended on the mastery of daily occupations. This affected development of an individual's value and identity in different directions. The effects of occupational performance on a person's value and identity can lead to action. One explanation for mobilisation of actions may be that people attempt to make an impression on others. When an individual is in the presence of others, they will tend to mobilise actions that make an impression on others, for the purpose of furthering their own interests (114). Mobilisation of actions and impression making, appeared in several of the strategies identified in study II. For example, by numbing body signals with the help of medication, participants were able to perform their daily

occupations without showing disability and weakness. When they stretched the limits of their capability, participants were able to live up to their self-image and social requirements.

An earlier study of people living with late effects of polio showed that participants tried to make an impression on others by adopting a strategy which focused on other peoples' preconceived notions of people with disabilities (115). The matter of living with illness and disability has shown to lead to underestimations in existing abilities, which in turn leads to devaluation of the whole person. The possibility to engage in personally meaningful occupations contributes to self-worth and the perception of being competent, capable and valuable (16). In study III, conditions such as muscular weakness and fatigue were shown to affect a person's ability to perform occupations, and had negative influences on the sub-process of mastery of daily occupations. The conditions could be either invisible (e.g. fatigue), or visible (e.g. muscle atrophy). The findings on the effects of fatigue on the sub-process of mastery of daily occupations enhance the understanding of how one invisible condition creates disadvantages for daily participation in occupations for people living with late effects of polio. Previous research on people with late effects of polio has shown that fatigue has a substantial negative impact on different areas of life (63, 65, 71). Additionally, research on the impact of fatigue on the performance and participation in daily occupations, shows that fatigue can be a condition influencing motivation, as well as capacity, for those occupations (74). In study IV, the associations between fatigue and the use of mobility assistive devices showed that people using mobility assistive devices reported less fatigue, demonstrating that healthcare professionals should provide and demonstrate the importance of assistive devices to ensure management of fatigue in persons living with late effects of polio. This can be seen as an important intervention to enhance the possibility of performing occupations.

### **7.3 Contextual conditions and opportunities for occupations**

The importance of equitable occupational opportunities has been highlighted as a human right (6, 13). Focus has been put on access to meaningful occupations as a matter of justice. Occupational justice is supported by the belief in the right of individuals and groups to participate in diverse and

meaningful occupations, as a way to meet people's needs and develop people's potential (89). Hence, the findings in this study relate to people's opportunities to participate in daily occupations, and can be related to the occupational injustice that occurs when participation in occupations is restricted, segregated, prohibited or underdeveloped (88).

Both physical and social contextual conditions created opportunities for people to participate in daily occupations. In study II, two groups of strategies showed how people handle physical and social conditions that influence their opportunities to participate in occupations. The participants had strategies for gaining respect in interactions with others, and strategies aimed at preparing a ground for existence. These strategies aimed to create opportunities to take part in occupations, make contacts and establish relationships. The connection to places and people (study III) showed that opportunities for occupation could lead to both connections and disjunctions. The findings in studies I, II and III showed that participants tend to strive to be like everybody else, a striving that can be related to a lack of equitable opportunity for occupations in daily life.

The findings in study I showed how people's experiences of rootedness in society ranged from security to rootlessness. The conditions that lead to experiences of security were related to basic conditions in Swedish society. These are governed by laws protecting human rights that ensure equity, justice, democracy, and peace. These were seen to provide a platform for daily occupations. According to Kronenberg, Algado, and Pollard (116), human occupations can be facilitated by political influences operating in the social and economic environment. The restriction or denial of access to dignified and meaningful participation in occupation is described to be occasioned by political forces, which are seen to be systematic and pervasive, and to have social, cultural, and economic consequences that put health and wellbeing in danger. This is termed as occupational apartheid and is considered as a complementary term to occupational justice (116).

Consideration of how occupational apartheid (116) affects human occupational participation may present a tool for seeing new ways to facilitate human occupations. This could be a way to counter arguments that have described migration and disability as major forces putting strains on the health, education and welfare systems of more prosperous nations (40). The need for critical occupational therapy has been raised, with occupational

therapy being challenged with the responsibilities of regarding humans' occupational rights (117, 118). Occupational therapists should practice on the basis of an understanding of the impact of historic and social inequities, and their effects on opportunities and human well-being (118). Hammell (118) suggested an aspiration to structural competency, which has been defined by Metzger and Hansen (119) as the ability to discern the impact of institutional and social conditions on health inequality.

## **7.4 Conditions related to meaning and engagement in occupations**

The sub-process of meaning in daily occupations influenced the participation process; meaning was shaped by the occupations performed in daily life, and the values assigned to these occupations. This is not surprising; according to the Value and Meaning in Occupations model, the perceived meaning in life is related to the values people experience when they perform daily occupations (120). One important aspect of perceived meaning in daily life of the participants (study III), was the opportunity to choose different occupations, which in turn led to engagement in occupations. Opportunities in choice and control have been described as one dimension of meaning in daily occupations (16). A feeling of control is important in relation to the experience of a life worth living. In turn, a sense of control is gained by choosing, shaping and orchestrating daily occupations (16). Another aspect related to conditions for meaningful engagement in occupations was described in the category belonging to social networks (study I), and the sub-process belonging to groups (study III). The importance of the opportunity to be with others for meaningful experiences and the motivation to engage in daily occupations was evident.

## **7.5 Conditions related to values and conception of occupations**

According to the findings (study III), the interaction between being an immigrant and having a disability reinforces the importance of both value and identity. Occupational participation has previously been highlighted as a contributor to identity, and when an identity is accepted and consistent with

other people's views, it contributes to coherence and well-being (121). Feelings of personal value have also been related to performance in daily occupations, and have been shown to be important to the sense of self-worth (76, 120). This has been previously noted in a study on disabled immigrants living in Belgian society, where both the immigrants' citizenship and disability status, which might affect perceived identity and value, had to be negotiated (40). Thus, the importance of value and identity development as part of the participation process was not an entirely surprising finding in study III. However, the value leading to a conception of occupations in daily life, was shown to be important for the socioemotional dimension of the participation process. Trust in others was the sub-process shaped by both the credibility given by others, and the level of trust perceived by a person. The findings in this thesis have shown that the conception of occupations was shaped by individual values, group values and/or values of society in general.

According to Kronenberg et al (116), we interact with others and the environment via our occupations. The findings in this thesis regarding the importance of trust of others (study III), treatment by others, and estimation of others (study I), show how interactions in daily life via occupations can affect the socioemotional meaning of participation. Occupational scientists aspire for social sensitivity where everyone is seen to have responsibility in their interactions in daily life (7, 116). Attention should be given to the values creating social, cultural, and political conditions, and those shaping experiences and opportunities for participation in occupations and social contexts. Some occupations are socially understood as having more value than others. This understanding can be related to the structures of social inequality present in most societies (75). In the subprocess of trust (study III), it becomes clear how values in society can affect self-image: when people are trusted with occupations that give them responsibility, their feelings of importance are enhanced.

## **8 METHODOLOGICAL CONSIDERATIONS**

### **8.1 Integration of quantitative and qualitative methods**

This thesis applied both a qualitative and a quantitative approach to investigate different aspects of the main research question, the conditions for daily occupations of persons with late effects of polio. This thesis aimed to fill a gap in the existing knowledge regarding immigrants who live with the late effects of polio and their participation in daily occupations. Given that this thesis had an explorative design, mixed methods with quantitative and qualitative research techniques were used.

According to Mortenson (98) when qualitative and quantitative methods are combined, a term such as mixed design, mixed method, mixed methods, or multi-methods can be used. In addition, three different levels of mixed methods were described. A low level of integration occurs when qualitative and quantitative methods are combined outside of the individual studies, e.g. in a thesis. A middle level of integration occurs when both qualitative and quantitative methods are used in the same study, although the extent of integration is not specified. Finally, a high level of integration occurs when qualitative and quantitative methods are incorporated through the research process, by taking into consideration the conceptual framework in relation to study questions, sampling, data collection, analysis, and discussion. In the high level of integration, the process is guided by the research paradigm (98). In this thesis a low level of integration was used.

Questions have been raised over the use of mixed methods if they have not been linked to the purpose of the research (122). In this study, the use of both kinds of data was supported by the separate aims of each study. Studies I, II, and III were inductive and aimed to explore and understand experiences, strategies and conditions of daily occupation. Therefore, GT was considered suitable for these qualitative methods. Study IV was deductive, with the knowledge on the influence of fatigue on persons with late effects of polio obtained from previous research (63, 65, 69, 123) and studies (I to III). The aim was to explore the association of fatigue symptoms with other factors;

consequently, a quantitative method was appropriate. There is added strength when mixed methods are used in tandem to reach the overall aim, especially when the researcher address multifaceted phenomena such as health, illness and occupation (99, 122). Mixed methods allow the weaknesses of each individual method to be reduced. As the limited possibilities to generalisation of qualitative results, as well as limited possibilities for depth understanding when using quantitative methods (99). In this thesis, the use of qualitative methods enabled a deeper understanding of experiences, meanings, and conditions for participation. By using quantitative method fatigue could be explored as a single condition influencing persons with late effects of polio. This allowed a stronger understanding of its role in the complex dynamical process of participation.

With regard to philosophical assumptions, a pragmatic worldview can be found, both in the use of mixed methods, and the theoretical assumptions related to occupational science. Pragmatists and mixed methods researchers focus on many approaches to allow different perspectives and freedom of choice, without subscribing to one single method, qualitative or quantitative (99, 122). Occupational sciences have a background in the new American philosophy of pragmatism where the relationships between person, environment and occupations are emphasized to maximize the opportunities to balance the relationship (124). The pragmatic view concerns the context in which the research was performed; pragmatists have the opinion that research occurs in a context (e.g., social, historical, political). Consequently, mixed method research might have a theoretical lens where reflections of social justice and political aims can take place (122). As a matter of fact, the pragmatic attitude and the corresponding theory of action (transationalism) are considered to be relevant to occupational sciences in regard to social justice, inclusion and participation (124). On the basis of this reasoning, the combination in this thesis of mixed methods and a theoretical framework from occupational science, can be seen as an attempt to approach the issue of participation in daily occupations using mixed methods and a framework stemming from the same philosophical base. Aside from the benefits ensuing from approaching the research question by choices following the same philosophical view, there was an additional benefit of using the two different methods in this study; this was related to the researcher's methodological training. Training in both kinds of methods was possible. When conducting mixed method research, it is important to ensure that the researchers have experience of the methods applied (99), which was the case in this thesis. All



researchers involved in studies I-IV had a broad experiences of qualitative and quantitative methods. In fact, the researchers had a mixture of experiences related to polio, rehabilitation, occupational therapy and occupational science.

## **8.2 Grounded theory as used in studies I, II and III**

GT was chosen to identify how immigrants with late effects of polio in (studies I-II) experienced, managed, reasoned and perceived participation in their daily occupations. The studies were designed as interview studies with data consisting of the participants' own words. Strategies described in the literature were used (103, 113), to increase the credibility and trustworthiness of the findings. With regard to data quality, the interviews were tape-recorded, transcribed verbatim, and detailed memos were written during the whole process. This increased the credibility of the data used in the primary data set in study I and II, and in the secondary data analysis for study III. To ensure understanding of the data during the interviews, confirmation of the interpretation was performed, and the interview questions were often repeated. Even though there was an inclusion criteria to speak and understand Swedish, the participants' levels of language ability differed. Because of this, it was important to confirm interpretations and repeat questions. In relation to the language issue, questions can be raised about the use of an interpreter. The use of an interpreter was considered, but we chose to reduce external influences that might disrupt the dialogue between the researcher and the participants. According to previous research (125), there may be challenges related to openness and immediacy when interpreters are used in qualitative interviews. The principle of openness is fundamental when the aim is to gain a new understanding of an unknown phenomenon. This was the case in the qualitative studies I to III conducted in this study. However, this is not an argument against using interpreters in the research situation, but the inclusion of interpreters means a three-way construction of data, where the interview includes the different experiences and horizons of understanding of three people (125). In relation to the quality of the findings when using interpreter, the interpreter's role, involvement, competence, style of interpreting and impact on the findings have to be considered before commencing the interviews (125, 126).

The researcher and all other people involved in the research have to follow strategies to enhance trustworthiness of the findings. Reflexivity and sensitivity are two important concerns on the role of the researcher (103). In relation to reflexivity, one has to be aware that the first step is to ask oneself how to go about studying the problem, checking for signs of biases and assumptions (103). In this study, critical considerations regarding both the researchers' experience and the research findings were made throughout the whole process. With reference to personal experiences, the researchers involved discussed the author's immigrant background and experiences, and made note of these when writing about the research, as is recommended in GT (103). It is essential for the researcher to reflect on moving from being an insider, to being an outsider with a more neutral perspective. However, in this process it is important to maintain sensitivity to the participants and data, to avoid losing the richness and depth of the data. Sensitivity towards the participants means finding a balance between being distant, and developing enough sensitivity to capture the participants' viewpoint (103). To increase the credibility of the findings, the findings were discussed in seminars and discussion groups involving co-workers (103) with different perspectives.

The different perspectives that participants bring to the data are also of importance concerning two key terms in GT, theoretical sampling and saturation. In theoretical sampling, the researcher does not collect all the data before beginning the analysis. Instead, the ongoing analysis leads to concepts, which in turn generate new questions, and from these new questions more data is collected to improve clarity about the concepts (103, 113). The use of theoretical sampling in the primary dataset for studies I and II led to a heterogeneous group of participants with regard to their degree of disability, marital status, family, work conditions and country of origin. This provided a broad sample of the area of concern, and even the possibility of approaching saturation, with data showing dimensional variation allowing development and integration of the categories. This even allowed a secondary analysis to be performed on the primary dataset in study III (103, 113). Although the heterogeneity allowed a larger range of perspectives, there were limitations related to the selection of inclusion criteria based on language skills, such as the ability to speak and understand Swedish. This resulted in a group of immigrants being excluded from the study, as they were unable to communicate in Swedish. The results were based on only one empirical area; young immigrants with late effects of polio living in Sweden. Additionally, all the participants had contact with the polio clinic and may have obtained satisfactory assistance with managing late effects of polio. The findings may

have differed in a group of immigrants with similar disabilities, who had received no contact with health care and rehabilitation.

Due to the quantity of data in studies with qualitative analysis, the theory must be developed step by step. Theories may be substantive, when they have been developed for one empirical area (103). In studies I and II, an understanding of the importance of participation in daily occupations emerged. The findings in study III allowed a deeper understanding of conditions for daily occupations of immigrants with late effects of polio from eastern Africa. Thus, the findings in this thesis belong to a substantive theory, which means that it has been developed for one empirical area. To reach a middle range theory, the concepts need to be further developed by studying other groups and raising the level of abstraction. For a formal theory, the obtained understandings should be used for a wider range of social concerns and problems (103).

### **8.3 Quantitative method, used in study IV**

Research supports the validity of the MFI-20 as an instrument with psychometric qualities to assess fatigue (127). The Swedish version of the MFI-20 used in this thesis has been shown to be a valid and reliable instrument to measure fatigue in persons with and without a diagnosis (67). Moreover, in a study aimed to assess the validity and reliability of the Swedish version of the MFI-20 in persons with post-polio syndrome (PPS), both the MFI-20 total scale and subscale scores were shown to be valid and reliable (71). Thereby, the Swedish version of the MFI-20 was considered a suitable questionnaire to capture fatigue in study IV. The fact that the Swedish version of the MFI-20 has been shown to be valid and reliable for persons with PPS increases the credibility of the measure of fatigue in study IV, whereby the majority of those in the sample had PPS.

Fatigue is a widely experienced symptom (67), with a wide variation of degree (128). Furthermore, fatigue can be difficult to quantify (62), and because of its subjective nature, it can be challenging to define (58, 61, 62, 67). Thus, fatigue is difficult to measure, and further research is required to improve the understanding and measure of fatigue. Multidimensional fatigue instruments are recommended to capture its complexity; however, the choice of measure should preponderate the detail required for an optimal

measurement of fatigue and the issues of achievement (128). Consequently, the use of the MFI-20 is appropriate when the questionnaire comprises 20 items that can be answered by participants while attending their clinic, which was the case when collecting data for study IV.

This thesis focuses on the conditions regarding daily occupations to explore and create an understanding of how these conditions reflect daily life and affect participation. Thereby, previous findings (109-112) that captured the diverse factors creating the conditions of daily life among people with the late effects of polio guided the choice of factors used as independent variables (country of birth, occupational/employment level, and the use of mobility assistive devices) in study IV.

Before the analysis of data (study IV), fatigue was dichotomized as ‘no reported fatigue’ (level one to two on the scale) and ‘reported fatigue’ (level three to five on the scale) on a subscale level when analyzing the percentage distribution of participants rating fatigue. Another possible dichotomization method could be to include level three as no reported fatigue. However, that method could result in those reporting low levels of fatigue to be included in the ‘no reported fatigue’ category. To capture participants’ perceptions of fatigue, the former dichotomization method seemed most appropriate.

## 9 CONCLUSION

This thesis highlights the complexity behind the experiences, strategies, and conditions related to daily occupations and how these affect the participation of immigrants with the late effects of polio. Participation was identified as a process shaped by four levels of conditions: personal, contextual, related to meaning, and related to values. This implies the focus must be on the different levels when concerning conditions relating to participation. Thus, when considering participation, attention must be paid to those conditions that create possibilities to perform daily occupations and opportunities for occupations, conditions that lead to engagement in occupations, and how the conception of occupations emerges in interactions with others and the environment.

To target conditions enabling the possibility to perform daily occupations, awareness of how to deal with fatigue is necessary for people living with the late effects of polio. Healthcare professionals should provide and demonstrate the importance of strategies promoting occupational performance, such as assistive devices to ensure the management of fatigue for such individuals. Thus, it is essential to provide interventions that support the management of physical capacity and increase knowledge about the late effects of polio and its consequences in daily life. Because of the challenges associated with disability and migration, there is a need for support that focuses on enhancing the possibility finding occupations as well as role balance in daily occupations. Occupation should be seen as a tool to cope with changes, adaptation, and enable participation. It is clear that employment provides central meeting places for immigrants living with disability. Occupational therapy and rehabilitation in general should support people to find occupations and role balance in daily occupations.

Because of the complexity and interaction of conditions, strategies for daily occupations span many different areas of daily life, creating an extensive need for support in different areas. Thus, interventions require a rehabilitation team including various professionals as well as coordination between different sectors of society (e.g., the healthcare system, job centers, national insurance offices, and municipal services). Thus, it is necessary to implement interventions that promote opportunities to move toward daily occupation,

social interaction, and a feeling of having something in common with other members of society. It is of vital importance to be aware of the underlying social conditions and needs for social support. It is also necessary to consider the social, cultural, and political demands affecting perceptions of occupation and participation.

These findings call for a critical approach when addressing the inequalities of opportunities for participation in daily life by immigrants with the late effects of polio. With a deeper understanding of participation as an interactional process, with a socioemotional meaning, the sociopolitical aspect of participation becomes evident. There is a dynamic interaction, creating barriers for participation in daily occupations, and life in general, for immigrants living with the late effects of polio. The conditions for occupations in daily life should be considered on individual, political, and social levels. On a political level, structures that prevent and enable participation must be considered, and those that promote participation must be created. On a social level, acceptance must prevail in everyday interactions to ensure that all people, regardless of their differences, are given opportunities to be trusted, to be connected, and to belong.

## 10 FUTURE PERSPECTIVES

This thesis explores the participation process for primarily, immigrants with late effects of polio from Eastern Africa. As a stepping stone for an understanding of conditions for occupational participation the findings could encourage researchers to engage in research in the context of people with diverse backgrounds. The conditions for occupational participation may be different among immigrants from other countries, with other disabilities and who have no contact with health care and rehabilitation.

Since the findings provide a foundation for an understanding of participation as a process, it calls for a need of future research, carried out with a longitudinal perspective where levels of participation and factors creating conditions for participation can be considered over time.

For a better understanding of how to prevent fatigue among persons with late effects of polio further research is needed to explore other factors of relevance for fatigue. Furthermore, the findings indicate a need to explore fatigue in larger samples.

Moreover, although this thesis proposes interventions that support the management of physical capacity and increased knowledge about late effects of polio and its consequences in daily life there is a need of further investigations of intervention studies. Additionally, to obtain an understanding of participation as an interactional process where social political aspects should be consider, future research should use study designs that facilitate individual experiences of participation against the prevailing political and social conditions. The findings, highlight the social political aspects of participation. However, questions remain about characteristics of social and political aspects in the context of disability and migration; what are they? How can they be used to enhance participation in daily occupations and reduce participation inequities in society?





# ACKNOWLEDGEMENT

This thesis was performed at the Department of Health and Rehabilitation, Institute of Neuroscience and Physiology, Sahlgrenska Academy at University of Gothenburg, Sweden. I would like to express my gratitude to the University for giving me this opportunity.

The efforts and work with completing this thesis was made possible through the cooperation and support of many people. I wish to express my gratitude and appreciation to all those people. In particular I am grateful to:

All the persons living with late effects of polio who participated in the studies, especially the 12 women and men that welcomed me into their homes, thank you for sharing your experiences and thoughts.

*Synneve Dahlin Ivanoff*, my main supervisor for all the support and for believing in me from the beginning and wished me welcoming back to the institution as a graduate from the Occupational Therapy program. Thank you for agreeing to jump in this voyage with a strong aspiration to make my journey possible to be completed.

*Anna-Lisa Thorén-Jönsson*, my co-supervisor and devoted companion. Thank you for motivating me for research early on my Occupational Therapy education. You have been with me and supported me in every step of this journey with enthusiasm, dedication and patience. I am thankful for so many hours of interesting discussions.

*Katharina Stibrant Sunnerhagen*, my co-supervisor for all support and for opening the door for me to start, with the belief that those who want something can achieve it.

*Isabelle Ottenvall Hammar*, my co-author and friend for your enthusiasm and incredible willingness to work with good planning and good cooperation. Specially, for all the fun together.

*Carin Willén*, my co-author, for your support, kindness and wise contribution to our work.

*Lisa Åkesson*, my mentor, thank you for being a friend and discussion partner.

**Lena Mårtensson** for following me and giving appreciated comments during my process of development as a researcher, and for being opponent for my half-time and pre-dissertation seminars.

**Joakim Öhlén**, and **Elisabeth Björk Brämberg** for generously helping me with constructive critical questions at the half-time seminar.

**Anders Möller** for generously helping me with constructive critical questions at the pre-dissertation seminar.

**Gunilla Gosman-Hedström** and **Ulla Svantesson** for organizing the doctoral seminars at the Institution, and for supporting and encouraging me.

**Kajsa Eklund** for the opportunity to teach at Occupational Therapy program.

**All my colleagues at the Institution** for your good collaboration, great support, friendship in all the moments of laughter and joy, frustration and learning. In special I am sincerely thankful to my colleagues doctoral students **Qarin Lood** for being so energetic and crazy, **Daniela Castro** for incredible IT support, and togetherness in the last part of this journey, **Emmelie Barenfeld** for sharing my office and being my soul mate, **Christina Ekelund** for bringing tranquillity, **Therese Mybeck** for positive spirit, **Theresa Westgård** for language support, **Anna Kurkinen** for introducing me to a valuable friend, SPSS, **Hadeel Halaweh** for your support. **Git Lidman**, **Lena Bergqvist**, and **Margret Buchholz** for reading and giving valued comments.

**All my colleagues at the Sahlgrenska University Hospital** and **former and current bosses**, especially my former boss, **Helga Hjort** for supporting and encouraging me, and **Pernilla Siavashi** for all administrative support.

**Polio team** for collaboration and friendly support.

**Elson Ferreira** for your dedication, enthusiasm and good will when creating the illustration for my thesis.

My lovely **breakfast family**, for support encouragement, friendship and really good time together, in special **Claudia Spencer** and **Sandro Almeida** for helping me with my figures, and **Karina Delgado** for reading and for discussing everything between heaven and earth.

To my parents *Luizete* and *Antonio*, I would like to thank you for the love, simplicity and humility you have passed on to me, teaching me to find the wonder and the marvel of an ordinary life, where I got the strength to find the extraordinary things. My sister *Susete*, and brother *Luis* and their families, for love and support. My parents-in-law, *Gregoria & Hilário*, and family for their love and support.

There are so many *family members, friends, and colleagues*, who have contributed to this journey in different ways during the years, a special thanks to all of you, although not mentioned here, still remembered in my heart and mind.

Last but not least, thank you to my husband *Humberto* for supporting and encouraging me, and being there for me always with so much love and spontaneity and to my wonderful son *Giovanni* and daughter *Kiara*, for making life worth to living, and remind me of what's important.

### **Financial support**

The studies were supported by grants from the local Research and Development Council of Gothenburg and southern Bohuslän, by the Norrbacka-Eugenia Foundation, and by the Committee for Mental and Physical Disabilities of the Region Västra Götaland.



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