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Activity and participation among people with Late Effect of Polio admitted to comprehensive rehabilitation

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LICENTIATE DISSERTATION

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Abstract:
Late effects of polio (LEoP), a chronic progressive neuromuscular condition that affects people who have had polio earlier in life. LEoP manifests with new symptoms such as muscle weakness, fatigue, and pain, and can also have consequences for an individual's level of activity and participation. People with LEoP can benefit from comprehensive rehabilitation, with focus on enabling activity and participation, yet the understanding of the benefits of comprehensive rehabilitation remains limited. During comprehensive rehabilitation, outcome measures are often chosen based on the International Classification of Functioning, Disability, and Health (ICF), including measures of activity and participation. Common measures in these areas are the Canadian Occupational Performance Measure (COPM) and the Reintegration to Normal Living Index (RNL-I). Still, very few studies have focused on activity and participation in people with LEoP.

The overall aim of this licentiate thesis was to increase knowledge about activity and participation among people with LEoP who were admitted to and received comprehensive rehabilitation. That is, how activity and participation can be assessed and evaluated in relation to a comprehensive rehabilitation period, and how people with LEoP change their activity and participation after a comprehensive rehabilitation period.

Two quantitative studies were conducted using data from 102 participants with LEoP, collected retrospectively from a clinical database. The participants had been admitted to comprehensive rehabilitation between 2004-2015.
Study I, a cross-sectional study, aimed to explore the association between self-perceived performance (COPM performance), satisfaction (COPM satisfaction) in daily activities, and self-reported participation (RNL-I) among people with LEoP on admission to comprehensive rehabilitation. The data were analyzed with linear regression. The analysis was conducted in two steps, as an explorative analysis emerged during the analysis process.
In study II, the methodology involved a pre-post retrospective analysis of 102 LEoP participants, assessing changes in COPM performance and COPM satisfaction, using the COPM on admission and at discharge for people admitted to comprehensive rehabilitation. The analysis was conducted using descriptive statistics and a paired sample t-test.

Results showed that both COPM performance and COPM satisfaction were significantly associated with self-reported participation (RNL-I). Specifically, COPM performance in the subgroup COPM self-care correlated with RNL-I Daily Functioning. COPM satisfaction in the subgroup COPM leisure correlated with RNL-I Perception of Self. Results also indicated significant increases in mean COPM performance and mean COPM satisfaction scores from admission to discharge. However, a notable proportion of participants showed no change or even lower ratings at discharge, indicating a need for longer follow-ups.

In conclusion, COPM and RNL-I partly measure similar aspects of activity and participation, and both assessments are vital in comprehensive rehabilitation. Comprehensive rehabilitation can enhance self-rated performance and satisfaction with performance among people with LEoP. Additional assessments covering diverse activity and participation aspects may be necessary. To measure change in activity and participation, there is a need for longer follow-ups studies to capture the change. Such insights are crucial not only for occupational therapists but also for other rehabilitation professionals working with people with LEoP.

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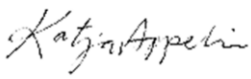
Signature  Date 2024-05-02

Activity and participation among people with Late Effects of Polio admitted to comprehensive rehabilitation

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Abstract

Late effects of polio (LEoP), a chronic progressive neuromuscular condition that affects people who have had polio earlier in life. LEoP manifests with new symptoms such as muscle weakness, fatigue, and pain, and can also have consequences for an individual's level of activity and participation. People with LEoP can benefit from comprehensive rehabilitation, with focus on enabling activity and participation, yet the understanding of the benefits of comprehensive rehabilitation remains limited. During comprehensive rehabilitation, outcome measures are often chosen based on the International Classification of Functioning, Disability, and Health (ICF), including measures of activity and participation. Common measures in these areas are the Canadian Occupational Performance Measure (COPM) and the Reintegration to Normal Living Index (RNL-I). Still, very few studies have focused on activity and participation in people with LEoP.

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discharge. However, a notable proportion of participants showed no change or even lower ratings at discharge, indicating a need for longer follow-ups.

In conclusion, COPM and RNL-I partly measure similar aspects of activity and participation, and both assessments are vital in comprehensive rehabilitation. Comprehensive rehabilitation can enhance self-rated performance and satisfaction with performance among people with LEoP. Additional assessments covering diverse activity and participation aspects may be necessary. To measure change in activity and participation, there is a need for longer follow-ups studies to capture the change. Such insights are crucial not only for occupational therapists but also for other rehabilitation professionals working with people with LEoP

Keywords: occupational performance, rehabilitation, post-poliomyelitis syndrome, outcome measures, change

Populärvetenskaplig sammanfattning

Sena effekter av polio (LEoP), ett kroniskt neuromuskulärt tillstånd, som drabbar personer som har haft polio tidigare i livet, och visar sig med nya symtom som muskelsvaghet, trötthet och smärta, och kan även få konsekvenser för en individs aktivitetsnivå och delaktighet. Personer med sena effekter av polio kan dra nytta av sammanhängande rehabilitering, med fokus på att möjliggöra aktivitet och delaktighet. Dock är kunskapen om effekterna av sammanhängande rehabilitering och dess olika interventioner för personer med sena effekter av polio fortfarande begränsade. I samband med sammanhängande rehabilitering, med fokus på att personen ska kunna vara så självständig som möjligt i aktivitet och uppleva hög delaktighet utifrån sina förutsättningar, används olika bedömningar för att mäta resultat enligt den internationella klassificeringen av funktion, funktionsnedsättning och hälsa (ICF). Bland dessa bedömningar finns Canadian Occupational Performance Measure (COPM) och Reintegration to Normal Living Index (RNL-I), som är standardiserade och väletablerade instrument för att bedöma aktivitet och delaktighet både inom kliniska verksamheter och i forskning.

Det övergripande syftet med denna licentiatuppsats var att öka kunskapen om aktivitet och delaktighet bland personer med sena effekter av polio som deltagit i sammanhängande rehabilitering. Mer specifikt ville vi undersöka hur aktivitet och delaktighet kan bedömas i samband med inskrivning till en sammanhängande rehabiliteringsperiod, samt om personer med sena effekter av polio förändrar sin aktivitet och delaktighet i samband med sammanhängande rehabiliteringsperiod.

Två kvantitativa studier genomfördes med hjälp av data från 102 deltagare med LEoP, insamlade retrospektivt från en klinisk databas. Deltagarna hade antagits till en sammanhängande, interdisciplinär rehabilitering mellan åren 2004–2015.

Studie I, en tvärsnittsstudie som syftade till att utforska sambandet mellan självupplevd aktivitet och delaktighet (COPM-utförande), självupplevd tillfredställelse med aktivitet och delaktighet (COPM-tillfredsställelse) i dagliga aktiviteter och självskattad delaktighet (RNL-I) bland personer med sena effekter av polio vid inskrivning till sammanhängande rehabilitering. Studie II genomfördes med en pre-post retrospektiv design av 102 deltagare med sena effekter av polio där analysen fokuserade på förändringar i COPM-utförande och COPM-tillfredsställelse efter att personer med LEoP deltagit i en sammanhängande rehabilitering.

Resultatet från studie I visade att både COPM utförande och COPM tillfredställelse, var signifikant associerade med självskattad delaktighet (RNL-I). Specifikt korrelerade COPM-utförande gällande personliga dagliga aktiviteter med RNL-I Daglig funktion och COPM tillfredsställelse gällande fritid korrelerade med RNL-I Självuppfattning. I studie II uppvisade deltagarna signifikanta, positiva förändringar både i genomsnittlig COPM-utförande och COPM-tillfredsställelse mellan

inskrivning och utskrivning. Flera deltagarna uppvisade dock inga förändringar eller till och med lägre poäng vid utskrivningen.

Sammanfattningsvis mäter COPM och RNL-I delvis liknande aspekter av aktivitet och delaktighet vilket därför kan tolkas som att båda bedömningarna är viktiga att använda vid en sammanhängande rehabilitering. Samtidigt kan det vara nödvändigt att addera ytterligare bedömningar som täcker andra perspektiv av aktivitets- och delaktighet. Sammanhängande rehabilitering kan förbättra självskattad COPM utförande och COPM tillfredsställelse hos personer med sena effekter av polio men i framtida studier behöver deltagarna följas upp längre tid efter avslutad rehabilitering. Detta eftersom rehabiliteringen innebär en livsstilsförändring och som kräver längre tid att se resultat från. Sådana insikter är avgörande inte bara för arbetsterapeuter utan även för andra rehabiliteringspersonal som arbetar med personer med sena effekter av polio.

List of Papers

Paper I

Andersson N., Appelin K., Lexell J., Månsson Lexell E. (In manuscript). Associations between the Canadian Occupational Performance Measure and the Reintegration to Normal Living Index in people with Late Effects of Polio

Paper II

Appelin, K., Erlandsson, L. K., Lexell, J., & Lexell, E. M. (2024). Changes in self-perceived performance and satisfaction with performance of daily activities following interdisciplinary rehabilitation in people with late effects of polio. *NeuroRehabilitation, 54*(2), 331–342. https://doi.org/10.3233/NRE-230219

Author's contribution to the papers

Paper I

K Appelin gathered all data and was actively involved in the ethical proposal. She was also involved the study design, data analysis, and in manuscript preparation, with assistance from the co-authors.

Paper II

In this paper, K Appelin had an increased contribution. As in paper I, she gathered all data and was actively involved in the ethical proposal. She was also involved the study design, data analysis, and in manuscript preparation. In this paper, with less assistance (than in paper I) from the co-authors.

Abbreviations

COPM	Canadian Occupational Performance Measure
ICF	International Classification of Functioning, Disability and Health
LEoP	Late Effects of Polio
RNL-I	Reintegration to Normal Living Index
WHO	World Health Organization

Preface

I am an occupational therapist. For many years, I have worked as an occupational therapist in a rehabilitation medicine unit. Specifically, in an interdisciplinary rehabilitation program where I have had the opportunity to meet many people with late effects of polio (LEoP) who struggle to manage their daily activities due to new symptoms. Their efforts to stay as active and independent as possible in daily activities inspired me to gain more knowledge of how people with LEoP benefit from rehabilitation, especially regarding activity and participation.

I have also been inspired by working systematically with the rehabilitation process from a team-based perspective, which involves a team-based approach working towards a common goal and with a common language, including the occupational therapist's contribution to meaningful everyday activities.

Based on these thoughts, my master´s thesis identified which activities people with LEoP have found difficult to perform in their daily lives, showing a broad variety of problems. This work was also further explored during my training to become a specialist in occupational therapy. During both assignments, I have had the privilege to work together with docent Eva Månsson Lexell, who continued to be my supervisor during my licentiate studies.

As a clinical occupational therapist, I believe that every individual deserves an opportunity for a meaningful everyday life, regardless of the challenges they face. This is also true for people with LEoP, a group that is sometimes overlooked when it comes to health care services. I have met many people with LEoP who testify that there is a great lack of knowledge about LEoP within healthcare and that they therefore do not receive suitable interventions. I hope that this thesis can contribute to increasing knowledge about activity and participation in people with LEoP and how interdisciplinary rehabilitation can influence these aspects. By exploring and understanding the complex dynamics within the late effects of polio and the rehabilitation given, I hope to contribute to increased awareness and improved rehabilitation for people with LEoP.

Introduction

Late effects of polio (LEoP), a chronic progressive neuromuscular condition that affects people who have had polio earlier in life. LEoP manifests with new symptoms such as muscle weakness, fatigue, and pain and can also have consequences for an individual's level of activity and participation. Because there is no medical cure available, people with LEoP require team-based rehabilitation that focuses on enabling activity and participation. One of the team members is the occupational therapist, who specializes in activity and participation. However, there is a lack of research focusing on outcome measures regarding activity and participation, as well as how such tools are used to measure rehabilitation outcomes.

Occupational therapy and concepts of occupation

A main concept within occupational therapy is "occupation", which refers to "the things that people do in their everyday lives" (World Federation of Occupational therapists [WFOT], 2012). Through engagement in occupations, individuals achieve health, well-being, and participation in life (Townsend & Polatajko, 2007). The everyday things that people engage in can also be divided into specific categories, often self-care, productivity, or leisure (Townsend & Polatajko, 2007). Engagement in occupations includes not only the performance of occupations, which is the dynamic interaction between the person, the activity, and the environment but also the level of importance it holds and the degree of satisfaction it brings to the individual (Townsend & Polatajko, 2007). Thus, when occupational therapists assess engagement in occupations, all perspectives need to be addressed.

In clinical practice, a crucial emphasis is placed on client-centred care (Townsend & Polatajko, 2007), also known as person-centred care (Ekman, 2022). Occupational therapists utilize a process-driven approach and work systematically with each client during assessments, goal-setting, planning, and implementing different interventions, as well as with evaluation (Townsend & Polatajko, 2007).

One of the models that helps guide occupational therapists' clinical reasoning process, is the Occupational Therapy Intervention Process Model (OTIPM) (Fisher & Marterella, 2019). The model has a clear focus on clients' performance of occupations as well as their satisfaction with performance. Even though the concept

of "occupations" is well-known in occupational therapy, other professionals are less familiar with this terminology. Thus, when occupational therapists work with other professionals – as in a rehabilitation medicine setting – the term "occupation" is often replaced with "activity and/or participation", a terminology well known to all rehabilitation professionals.

Late effects of polio and consequences for activity and participation

Polio, short for poliomyelitis, is an infectious disease that can cause permanent paralysis. By the early 1980s, there were hundreds of thousands of cases annually across the world. In 1988 the World Health Organization (WHO) established the "Global Polio Eradication Initiative" and these massive international vaccination efforts have reduced the incidence of polio in the world by 99% (World Health Organization [WHO], 2023). In Sweden, the last epidemic year was 1953 when over 3000 people were affected by paralysis. Mass vaccination was introduced in the late 1950s, and since the 1960s, vaccination has been introduced into the general childhood vaccination program. As a result, the number of polio cases in Sweden subsequently decreased rapidly, and no cases have been reported in recent years (Public Health Agency of Sweden, 2024). Approximately 15-20 million polio survivors exist globally, with up to 80% of them likely to develop LEoP (J. Lexell, 2019). In Sweden, about 5000 people are living with LEoP (Carlsson & Stibrant Sunnerhagen, 2020).

LEoP is a chronic progressive neuromuscular condition that develops in people who have previously contracted polio. Typical symptoms in people with LEoP are muscle weakness, fatigue, and pain (J. Lexell, 2019). Other reported symptoms can be cold intolerance, breathing difficulties, problems swallowing, sleeping difficulties, concentration difficulties, and mood swings (Li Hi Sing et al., 2019). People who live with LEoP can have a range of different symptoms that can impact activity and participation (Ahlström & Karlsson, 2000; Appelin et al., 2014; Atwal et al., 2013; Burger & Marincek, 2000; Hammarlund et al., 2020; Kling et al., 2002; Thorén-Jönsson et al., 2001). Many people with LEoP are independent in their personal daily activities, but more than 50% are dependent on cleaning, shopping, and transportation (Thorén-Jönsson & Grimby, 2001). But despite being independent, many report difficulties with the performance of activities (Thorén-Jönsson et al.; 2001), such as, dressing, cooking, and housework, as well as walking and climbing stairs (Burger & Marincek, 2000; Brogårdh & Lexell, 2014; Kling et al., 2002). Further, studies have also shown that people with LEoP have difficulties with employment and participating in leisure and social activities (Thorén-Jönsson et al., 2001; Lund & Lexell, 2008). These problems in daily activities can lead to

restrictions on participation (Lund & Lexell, 2008) and, in turn, affect health related quality of life (Kling et al., 2000) and life satisfaction (Burger & Marincek, 2000; J. Lexell & Brogårdh, 2012). The wide range of problems with the performance of activities has also been verified previously (Appelin et al., 2014). Thus, many people with LEoP need to find new ways to compensate for remaining impairments and learn to adapt to their daily activities (Thorén-Jönsson, 2001).

Comprehensive rehabilitation for people with LEoP

Since there is no effective medical treatment for LEoP, access to individualized, comprehensive rehabilitation is essential (Lo & Robinson, 2018; J. Lexell, 2019; Trojan & Cashman, 2005). This type of rehabilitation is client-centered and follows an intervention process designed to address the unique challenges and symptoms associated with LEoP (Lo & Robinson, 2018; J. Lexell, 2019). Within the rehabilitation community, rehabilitation is a problem-solving educational process that requires professionals to work multi- or interdisciplinary, providing the individual the opportunity to take an active role during the whole rehabilitation process (Wade, 2020; J. Lexell, 2019).

The International Classification of Functioning, Disability, and Health (ICF) (WHO, 2001) is often used as a framework and common terminology during the rehabilitation process (J. Lexell & Brogårdh, 2015). Central to the ICF model are the concepts of activity and participation, which offer insights into peoples' engagement in life situations and their ability to carry out activities and roles. Participation and activity are emphasized in the ICF as important elements of health, functioning, and disability. The ICF also provides a framework for choosing assessments and outcome measures. That is, different tools are often chosen to cover different ICF concepts. For instance, in rehabilitation for people with LEoP, the Self-Reported Impairments in Persons with Late Effects of Polio Rating Scale (SIPP) (Brogårdh & Lexell, 2016) is often used to measure impairments. To measure activity and participation, the Canadian Occupational Performance Measure (COPM) (Law et al., 2019), and the Reintegration to Normal Living Index (RNL-I) (Wood-Dauphine & Williams, 1987) are often used. Among occupational therapists, the COPM is known to capture activities that the individual perceives as difficult to perform in terms of two different aspects: "self-perceived performance" (COPM performance) and "satisfaction with performance" (COPM satisfaction). The COPM has been described as an assessment tool for activity and participation (Townsend & Polatajko, 2007). At the same time, other studies have described the COPM as a psychosocial measure (Chenq et al, 2002) or a measure of well-being (Curtis et al, 2020). The RNL-I, on the other hand, is described as a measure of activity and participation (Wood-Dauphine & Williams, 1987). Although they seem

to measure similar constructs, both tools are often used simultaneously in rehabilitation settings.

The ICF is also used as a guide through the rehabilitation process. This process is fundamentally structured around four key steps: assessment, goal setting, interventions, and outcome measures (J. Lexell, 2012). The overall goal is to empower individuals with LEoP to maintain their independence, manage symptoms effectively, and achieve the highest possible quality of life. The rehabilitation process is ongoing, recognizing that the needs of people with LEoP may evolve over time (Lo & Robinson, 2018). The multidisciplinary team is at the core of managing individuals living with LEoP and consists of different professionals such as physiotherapists, occupational therapists, physicians, and social workers (J. Lexell, 2019).

Occupational therapy within comprehensive rehabilitation for people with LEoP

Occupational therapists are a common profession in rehabilitation teams for people with LEoP (Atwal et al., 2019; J. Lexell, 2019). With their specific expertise in assessments and interventions that focus on activity and participation, they contribute important knowledge to the individuals' rehabilitation process and the team (WFOT, 2012).

In rehabilitation, occupational therapists may utilize the Occupational Therapy Intervention Process Model (OTIPM) (Fisher & Marterella, 2019), which is based on a client-centred reasoning, and focus on activity and participation. The occupational therapist begins by gathering information about individual's activity and participation in everyday life, where the focus is on personal conditions, e.g., physical, cognitive, and environmental aspects, e.g., physical, societal, and cultural environment, and which activities are meaningful for the individual. Both subjective and objective assessments are used in this phase.

The intervention phase often includes compensatory strategies and techniques, which means that the occupational therapist and the individual together try to find new and adapted ways of performing activities, for example recommend assistive devices, teach new alternative or compensatory strategies, and adaptation in the environment (Atwal et al., 2019; Foley & Nolan, 2007; Kling et al., 2002; Young, 1989). These interventions are developed in collaboration with the individual, considering his/her specific challenges, needs, and expectations. Occupational therapy interventions also include acquisitional training, where the individual is allowed to practice the performance of an activity. During the practice sessions, the therapist gradually adapts the activity until the individual can perform the activity in a more effective, safe, and less energy-consuming way. The occupational therapist must ensure that the learned and recommended strategies and techniques

can be applied at home and in the individual's daily life. Identifying alternative activities and guiding the individual to find a good balance between different daily activities are also part of the therapist's work. Further, offering individuals the possibility to be involved in educational programmes, such as the Packer Fatigue Management program, can also contribute with knowledge related to how, in this case, fatigue can be managed to increase or maintain activity and participation (Fisher & Marterella, 2019).

Rehabilitation outcomes for people with LEoP

Research on rehabilitation outcomes for people with LEoP has predominantly focused on the effectiveness of various single interventions, exploring the impact on overall physical function (Ramachandran et al., 2021). Very few studies have investigated the effects of rehabilitation for people with LEoP (Atwal et al., 2019).

There are several qualitative studies that, in different ways, have described how people with LEoP experience comprehensive rehabilitation. Two qualitative studies (E.M. Lexell et al., 2016; Larsson Lund & Lexell, 2010) have shown that people with LEoP who participated in an individualized, goal-oriented, comprehensive rehabilitation reached long-term positive benefits. Atwal et al. (2019) also concluded that the client's preferences and views must be evaluated when measuring outcomes.

Three studies (Bertelsen et al., 2009; Davidson et al., 2009; Curtis et al., 2020) have evaluated the benefits of comprehensive rehabilitation for individuals with LEoP. Bertelsen et al. (2009) evaluated a physiotherapy intervention performed within a multidisciplinary rehabilitation context, including 50 participants, and reporting better functional capacity measured by standing and walking tests. Improvements were seen in general health (Short Form 36). However, aspects of activity and participation were not their targeted outcomes.

Davidson et al., (2009) and Curtis et al., (2020) assessed activity and participation in terms of performance and satisfaction, according to the COPM (Law et al., 2019). Davidson et al., (2009), performed a pilot study evaluating a nine-day multidisciplinary rehabilitation period among 27 people with LEoP, and reported significant improvements for exercise endurance, depression, and levels of fatigue. Out of the 27 participants, 24 participants had completed the COPM on admission and at a six-month follow-up, showing significant improvements in 25% of the reported activities for COPM performance, and 28% regarding COPM satisfaction. Five of 24 of the participants reported improvements in both COPM areas.

Curtis et al. (2020) evaluated a rehabilitation program focused on self-management with individually tailored support on physical exercise and fatigue management for 217 people with LEoP. The COPM was used to evaluate activity and participation, but from 217 individuals there were only available COPM data for 153 participants

at baseline and at 6 months follow-up. The result shows a significant improvement in COPM satisfaction, but COPM performance did not change. The authors concluded that the programme led to improvement in symptoms, knowledge, and walking speed, but not quality of life.

In summary, few studies have evaluated the benefits of comprehensive rehabilitation in terms of activity and participation. Thus, there is a need to further study this area.

Rationale

Different assessment tools are used to measure outcomes after LEoP rehabilitation, covering different concepts according to the ICF. Regarding activity and participation, the COPM and the RNL-I are frequently used, although it is unclear whether they measure similar or overlapping concepts. Thus, their relationship is unclear. Research on the association between activity and participation measures and their impact on rehabilitation outcomes is limited, especially regarding outcome measures used among people with LEoP who participated in comprehensive, interdisciplinary rehabilitation.

Despite being a rehabilitation process that not only includes physical exercise interventions, comprehensive, interdisciplinary rehabilitation for people with LEoP also encompasses lifestyle adjustments and compensatory strategies. Still, most of the research on rehabilitation outcomes has focused on aspects of function or mobility. That is, perspectives on activity and participation have been scarcely investigated. Improving knowledge of assessment tools that measure activity and participation can improve the tools that are chosen to measure outcomes after comprehensive rehabilitation. Such understanding can also help design outcome studies and build evidence-based knowledge regarding comprehensive rehabilitation for people with LEoP.

Aims

The overall aim of this licentiate thesis was to increase our knowledge about activity and participation among people with LEoP who were admitted to and received comprehensive rehabilitation. That is, how activity and participation can be assessed and evaluated in relation to an interdisciplinary rehabilitation period, and how people with LEoP change activity and participation after an interdisciplinary rehabilitation period.

Study specific aims

Study I: to investigate the association between self-perceived performance and satisfaction with performance in everyday activities and self-reported participation for people with LEoP.

Study II: to evaluate changes in performance and satisfaction with performance in daily activities among people with LEoP following comprehensive rehabilitation.

Overview of this thesis

This thesis comprises two quantitative studies, and an overview are presented in table 1.

Table 1. Overview of this thesis

Study	**I**	**II**
Aims	To investigate the association between self-perceived performance and satisfaction with performance in everyday activities and self-reported participation for people with LEoP.	To evaluate changes in performance and satisfaction with performance in daily activities among people with LEoP following comprehensive rehabilitation.
Design	Ouantitative Crosss sectional	Quantitavie Pre-post design
Number of participants	102	
Data collection	Retrospective, clinical database medical records	
Outcome	RNL-I COPM	COPM
Analyses	Descriptive Linear regression	Descriptive Pearson's correlation coefficients Paired-sample t-test

COPM= Canadian Occupational Performance Measure; RNL-I= Reintegration to Normal Living Index

Methods

Study I and Study II are based on retrospective data from a clinical database at a rehabilitation unit at a University Hospital in Sweden. Study I is a cross-sectional study and study II has a pre-post design without a control group. These studies are part of a larger project focusing on activity and participation among people with LEoP who underwent an individualized, comprehensive, interdisciplinary rehabilitation program 10-20 years ago.

The research design was shaped by the retrospective data available from the database. Both studies were conducted to provide a deeper understanding of activity and participation among people with LEoP admitted to comprehensive rehabilitation.

Participants

Eligible participants for this thesis were selected from the clinical database including 712 people over 18 years of age, and with LEoP who received rehabilitation at a university hospital in Sweden during 2004 and 2015. To be included in this project, participants had to be admitted to the comprehensive, interdisciplinary rehabilitation program, have a confirmed history of polio and LEoP diagnosis, have completed assessments on admission and at discharge to the rehabilitation program with the COPM (Law et al., 2019), and the Reintegration to Normal Living Index (RNL-I) (Wood-Dauphine& Williams, 1987). The final sample included 102 participants and a flowchart of the participants included in the studies are presented in Figure 1.

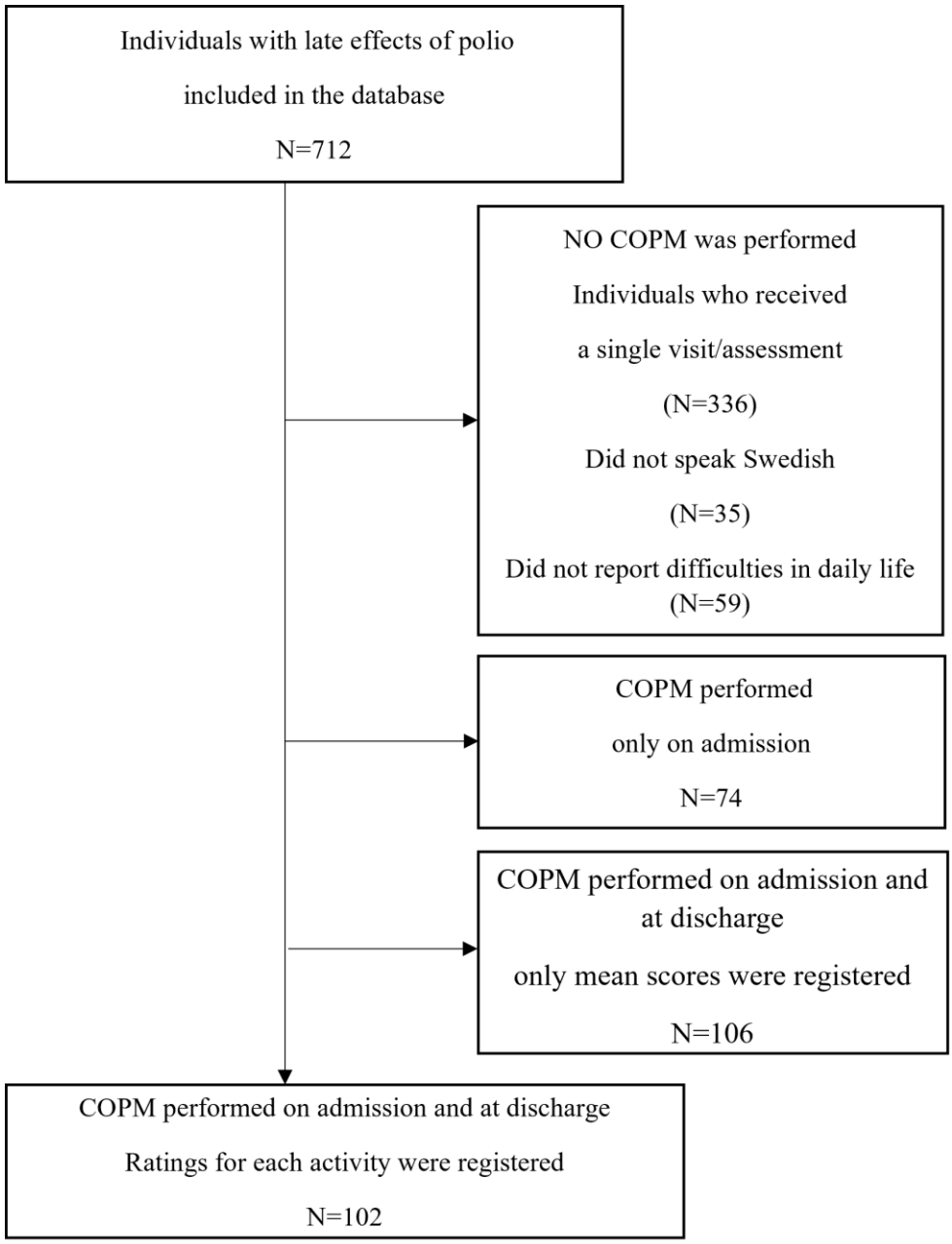


Figure1. Flowchart showing how the particpants were selected

The comprehensive interdisciplinary rehabilitation program

The primary objective of the comprehensive rehabilitation program was to decrease self-perceived disability through individually tailored interventions grounded in the principles of self-management theory (Larsson Lund & Lexell, 2010; Lorig & Holman, 2003). The rehabilitation program was successively accredited according to the Commission on Accreditation of Rehabilitation Facilities (CARF) standards (CARF international, 2024), internationally recognized standards regarding the quality of rehabilitation services. The interdisciplinary rehabilitation team consisted of a rehabilitation medicine physician, a physiotherapist, an occupational therapist, and a social worker, all of whom had experience working in interdisciplinary teams with people with LEoP. The program followed a four-step structured process that included assessment, goal setting and planning, intervention implementation, and evaluation (J. Lexell, 2012). A rehabilitation plan, structured according to the ICF, documented the process. The different assessments and outcome measures were chosen to cover different aspects of the ICF (J. Lexell & Brogårdh, 2015).

The rehabilitation process started with the first visit to the clinic. The physician assessed clinical symptoms, reviewed the medical history, and performed a neurological examination. An EMG evaluation was an important part of this process to confirm the extent of polio. This information was also used as a guide to plan and implement the correct interventions during the rehabilitation process. The other team members carried out general assessments according to an interdisciplinary checklist. The results were discussed with the individual and summarized in a document, which also included information about further planned rehabilitation interventions. The document was given to the individual and registered in the medical journal. For individuals who were motivated to participate in the interdisciplinary rehabilitation program, extended assessments were conducted by each profession.

Based on previous research (E.M. Lexell et al., 2016; Larsson Lund & Lexell, 2010), the ICF rehabilitation plan was used as a mutual tool shared by the individual and the team members together. Specifically, the results of the extended assessments were discussed with each individual and merged into an ICF rehabilitation plan. The assessments also served the purpose of increasing everyone's awareness of his/her problems and facilitating a process of change, a necessary step in the rehabilitation process. Thereafter, professionals and the individual formulated and negotiated goals relevant to and tailored to each individual. As a result of the individualized, yet standardized procedure with individually set goals that took different time to achieve, the length of the rehabilitation for everyone also varied in time, lasting approximately three months. However, not all this time was spent at the rehabilitation facility.

During the interdisciplinary rehabilitation period, various interventions were implemented tailored to the individual's goals in the rehabilitation plan. Group

lectures were offered to all participants. Lectures and discussions included information about LEoP, rehabilitation methodology (including how to manage an ICF-based rehabilitation plan), and self-management strategies.

The occupational therapist started the process with an interview with a focus on the individual's conditions for activity and participation in daily activities, according to the COPM. Observational assessments were also conducted, where the individual's performance was evaluated based on safety, independence, effort, and need of assistance. Personal characteristics and abilities, the significance of the environment, and activities that were important and meaningful for the individual but difficult to perform, were also considered. Based on this analysis, goals and interventions were set and planned together with the individual and coordinated with other team members. Interventions were based on general recommendations for people with LEoP when it comes to energy-saving strategies, such as pacing, energy management, and work simplification in order to find an appropriate level of activity for each individual (Atwal et al., 2019; Foley & Nolan, 2007; Young, 1989). The intervention also included mapping the individual's activity repertoire and activity patterns, to identify opportunities for adapting energy and time to perform various daily activities. Finding new routines, prioritizing, and using activity schedules were also important parts of the interventions, as this type of rehabilitation focused on lifestyle alterations. At the end of the rehabilitation period, goals were evaluated, and each individual received a discharge plan and was offered a one-year follow-up.

Data collection

Sociodemographic data were collected from the clinical database and medical journals, and covered aspects such as age, sex, diagnosis, accommodation, assistive devices, living and vocational situation.

Canadian Occupation Performance Measure (COPM)

The COPM is an individualized, client-centred assessment tool, designed to capture an individual's self-perceived performance (COPM performance) and satisfaction with performance (COPM satisfaction) in daily activities (Law et al., 2019). The COPM covers three areas that each comprise three subgroups of activities: i) self-care (personal care, functional mobility, and community management), ii) productivity (paid/unpaid work, household management, and play/school), and iii) leisure (quiet recreation, active recreation, and socialization). The COPM interview starts with an open question where the individual identifies daily activities that he or she finds difficult to perform. Thereafter, the individual rates the importance of

each of the identified activities on a 10-point Visual Analogue Scale (VAS), ranging from 1 (not at all important) to 10 (extremely important). Finally, the most important activities are prioritized. For these, performance and satisfaction are rated on a similar VAS-scale (ranging from "not able to do" to "able to do extremely well" and "not satisfied" to "extremely satisfied"); higher ratings indicate greater importance, better performance, and more satisfaction.

The COPM is administered by the occupational therapist together with the individual, on admission and at discharge from the program. Thereafter, the ratings for performance and satisfaction are summarized into a mean score for performance and satisfaction, retrospectively. When the COPM is used as an outcome measure, the difference between the mean scores at discharge and on admission for each individual constitutes a change score for performance and for satisfaction. The COPM ratings are ordinal data, but according to the manual and in general practice, they are treated as continuous variables and therefore mean scores are calculated (Law et al., 2019).

The Reintegration to Normal Living Index (RNL-I)

The Reintegration to Normal Living Index (RNL-I) is a widely used assessment tool designed to measure self-perceived activity and participation in daily life following illness or trauma (Wood-Dauphine & Williams, 1987). It has been utilized in various studies (Hitzig et al., 2012; Johansson et al., 2007; Lui et al., 2017), including those involving individuals with LEoP (Nolvi et al., 2020). The assessment comprises 11 items, each rated on a scale from 1 to 4, reflecting the individual´s perceived level of description of their situation. 1= does not describe my situation; 2= somehow describe my situation; 3= partly describe my situation; and 4=fully describe my situation. These ratings can be summed to yield a total score ranging from 1 to 100, with two sub-scales focusing on daily functioning (DF) and perception of self (PoS).

That is, item 1-8 regarding daily functioning (DF) has a total score ranging between 8-32 points, and item 9-11 regarding perception of self (PoS) has a total score range between 3-12 points. Higher scores indicate greater levels of reintegration. The RNL-I has been psychometrically evaluated for reliability among individuals with LEoP, yielding satisfactory results in test-retest reliability (Andersson et al., 2020; Bourget et al., 2018).

Procedure

All data included in study I and II were retrieved retrospectively from the database. All assessments were undertaken during each individual's rehabilitation period. The RNL-I were administered and explained to the individual within the first day at rehabilitation. If there were any questions about the self-reported assessment, the

different team members could answer and help the individual to understand the questions and the rating scale. The COPM were conducted by different occupational therapist in the team. The individual identified activities, that they perceived difficult to perform due to consequences of LEoP. According to the individual´s preference the different activities were placed according to appropriate COPM subgroup. The individual could choose as many activities as they wished, without being limited to five as stated in the manual of COPM. This aside, the administration followed the ordinary procedures according to the COPM manual (Law et al., 2019).

Analyses

Sociodemographic data were analysed descriptively, with mean scores (standard deviation) and medians (interquartile range) utilized for numerical variables, and numbers (percentages) for categorical variables.

Study I

In this study, associations between the COPM and the RNL-I were examined through a two-step linear regression analysis. Firstly, linear regression analyses were conducted with COPM performance and COPM satisfaction as dependent variables in two separate analyses, and with self-perceived RNL-I total score as the independent variable. Assumptions for linear regressions were graphically evaluated and met (Tabachnick & Fidell, 2013). The regression models were initially unadjusted and then in the next step adjusted for age and sex. Secondly, a more exploratory analysis was conducted. This analysis was made to explore potential associations between all COPM subgroups (self-care, productivity, and leisure) for performance and satisfaction, and for the RNL-I sub-scales, daily functioning (DF) and perception of self (PoS). Linear regression analyses were performed with each COPM subgroup as dependent variables, and with each RNL-I sub-scale as independent variables, resulting in a total of 12 analyses. Age and sex were controlled for in all regression models.

Because there were missing answers in some RNL-I data (8,6%), item mean substitution imputation was made to calculate a total sum score for those participants (Huisman, 2000). The level of statistical significance was set to $p<0.05$. The analyses were conducted using IBM SPSS Statistics 28 software (IBM Corporation, Armonk, New York, United States).

Study II

In study II, the participants' number of prioritized activities within each COPM occupational area and subgroup were initially summarized. Mean scores for COPM performance and COPM satisfaction were calculated for all participants and paired-sample t-tests were used to analyse change scores at a group level. Cohen's d was utilized as an effect size measure to determine the magnitude of change between admission and discharge scores. Thresholds for clinically relevant change scores in the COPM were applied, where change scores greater than 1.4 points indicated a significant change in COPM performance and change scores greater than 1.9 points indicated a significant change in COPM satisfaction (Eyssen et al., 2011). These thresholds have also been suggested in other studies (Karhula et al., 2022; Kos et al., 2016). These thresholds were used to identify participants change scores, following the rehabilitation program. Additionally, the number of activities showing improvement based on these thresholds was calculated.

Pearson´s correlation coefficients were employed to assess relationships between change scores for COPM performance and COPM satisfaction with performance at admission and discharge. Statistical significance was determined at levels less than 5%. The analyses were conducted using IBM SPSS Statistics 25 software (IBM Corporation, Armonk, New York, United States).

Ethics

The two studies in this thesis constitutes the first part of a long-term follow-up project. In the first part of the project, data was collected retrospectively from a data base including people with LEoP who received comprehensive interdisciplinary rehabilitation 10-15 years ago. In the second part of the project, people identified in the first part were contacted again and invited to participate in a new data collection. The current thesis only comprises data obtained in the first part of the project.

Both parts of the project have been approved by the Swedish Ethical Review Authority (2020-05313). The project complies with the principles of the Helsinki Declaration's (World Medical Association, 2013) and were performed in accordance with principles of informed consent. At the time of the data collection in the first part of the project, each individual gave their consent to have their data included in the database.

In a retrospective study, it is important to be clear that there may be various biases, such as misclassification of outcome variables, missing information, inconsistent documentation, uncontrolled confounders may distort associations. Thus, the result must be interpreted accordingly.

Results

Participants characteristics

The 102 included participants had a mean age of 61 years (range 29 to 81 years). Their mean age at polio onset was 5,5 years and around 39 years (range 1 to 70 years) had passed before new symptom occurred. More than 50% of the participants reported muscle weakness, muscle fatigue, and general fatigue, according to the assessment Self-reported impairment in persons with LEoP (SIPP) (Brogårdh & Lexell, 2016). Half of the male participants and 22% of the female participants were employed. The majority used some type of assistive device for walking, and some participants used several assistive devices. Additionally, 91% of the participants relied on some form of orthotic device. (See Table 2).

Tabel 2. Characteristics of the participants included (N=102).

Variables	Value	Missing (n)
Age, mean (SD) min - max	60.8 (9.7) 29-81	-
Sex, (men/women), n (%)	28/74 (27.5/72.5)	-
Age at acute polio, mean (SD) min-max	5.5 (4.6) 1-20	-
Years before onset of late effects of polio, mean (SD) min-max	38.8 (11.1) 1-70	-
SIPP, mean (SD)	44.5 (14.7)	21
Vocational situation, n (%)		1
Work	30 (29.4)	
Health insurance	34 (33.3)	
Old-age pension	35 (34.3)	
Other	2 (2)	
Living situation, n (%)		1
Living with another person (partner, spouse, children)	67 (66.3)	
Living alone	34 (33.7)	
Accommodation, n (%)		1
House	52 (51)	
Apartment	49 (48)	
Assistive devices, n (%)*		2
Wheelchair (manual)	16 (15.7)	
Wheelchair (powered)	19 (18.6)	
Walker	32 (31.4)	
Crutches	34 (33.3)	
Orthopaedic technical aids	93 (91.2)	
Personal care	40 (39)	
Household	25 (24.5)	

*Some participants used several assistive devices. SIPP= The Self-reported Impairments in Person with late effects of Polio, possible sum score 13-52 points (higher scores=more impairments)

Study I

COPM performance, COPM satisfaction and self-perceived RNL-I participation

The participants had a mean score of COPM performance of 5.2 points, and 4.9 points for COPM satisfaction. For self-perceived participation (RNL-I), the participants' total sum score was 71.6 points. (See Table 3).

Table 3. Characteristics of the participants COPM and RNL-I (N=102).

Variables	Value	Missing (n)
COPM		
COPM performance, mean (SD)	5.2 (1.9)	
COPM satisfaction with performance, mean (SD)	4.9 (2.2)	
RNL-I (total sum score), mean (SD)	71.6 (21.6)	21
RNL-I, Daily function, mean (SD)	25 (5.2)	21
RNL-I, Perception of self, mean (SD)	10 (2)	21

COPM= Canadian Occupational Performance Measure, performance rated on a ten point scale (1= not able to do; 10=able to do extremely well)/satisfaction (1=not satisfied; 10=extremely satisfied); RNL-I=The Reintegration to Normal Living Index, possible sum score ranging between 1-100 point, subscale DF= Daliy functioning, total sum score range between 8-32 points; subscale PoS=Perception of Self, total sum score ranging between 3-12 points, at all higher scores=greater re-integration

Associations between COPM performance, COPM satisfaction and RNL-I participation

The univariate linear regression analysis between COPM performance as well as for COPM satisfaction were significantly associated with RNL-I participation. When the analyses were controlled for sex and age, COPM performance was still significantly associated with RNL-I participation (β=0.024, p=0.015). That is, the higher COPM performance, the higher RNL-I participation. The associations between COPM satisfaction and RNL-I participation were also significant (β=0.024, p=0.029), when controlling for sex and age, indicating the higher COPM satisfaction the higher RNL-I participation. (See Table 4).

Table 4. Linear regression analysis exploring the association between COPM performance and COPM satisfaction, and RNL-I participation, for people with LEoP.

Multivariate linear regression analyses Dependent variable: COPM Performance and COPM satisfaction				
Dependent variable	Independent variable	*B* (95% CI)	*p* value	N
COPM Performance	RNL-I	0.020 (0.001-0.039)	0.041	80
COPM Performance †	RNL-I	0.024 (0.005-0.430)	0.015	80
COPM satisfaction	RNL-I	0.018 (-0.004-0.040)	0.109	80
COPM satisfaction †	RNL-I	0.024 (0.003-0.046)	0.029	80

COPM=Canadian Occupational Performance Measure, COPM performance, rated on a 10-point scale (1=not able to do - 10=able to do extremely well)/COPM satisfaction (1=not satisfied –10=extremely satisfied); RNL-I=The Reintegration to Normal Living Index, total sum score range between 1-100 points, higher scores=greater re-integration; †Analysis adjusted for sex and age.

Associations between the subgroups of COPM performance, COPM satisfaction and the sub-scales of RNL-I participation

There were significant associations between the subgroup self-care of COPM performance and the sub-scale DF of RNL-I (β=0.102 (0.011-0.193), p=0.028, n=74). There was also a significant association between the subgroup leisure of COPM satisfaction and the sub-scale PoS of RNL-I (β=0. 0.471 (0.063-0.879), p=0.025, n=47). No other significant associations were found for the other subgroups.

Study II

On admission to interdisciplinary rehabilitation

The 102 participants prioritized 506 activities (mean 5; mean (SD) 9.7, range 1 to 22) that they found difficult to perform. Of the prioritized activities, 49% were in the area self-care, followed by 29% for productivity, and 22% for leisure. None of the participants prioritized activities in the subgroup play/school (COPM productivity).

In Table 5, data for COPM performance and COPM satisfaction on admission are presented. The highest mean COPM performance scores for all participants were in the subgroup socialization (5.9), followed by paid/unpaid work (5.8), whereas the lowest mean COPM performance scores were found in the subgroup functional mobility (4.9). The highest mean scores of COPM satisfaction were found in socialization (6.0), and quiet recreation as the lowest (4.4).

Table 5. The number of prioritized activities (N=506) that the 102 individuals with LEoP perceived as difficult to perform according to the COPM, including COPM performance and COPM satisfaction on admission and at discharge

	Prioritized occupations	**COPM Performance**			**COPM Satisfaction**		
	N (%)	**On admission[a]**	**At discharge[a]**	**Number of activities that improved at least ≥1.4 points N (%)**	**On admission[a]**	**At discharge[a]**	**Number of activities that improved at least ≥1.9 points N (%)**
Self-care	**246 (49)**			**58 (24)**			**68 (28)**
Personal care	67 (13)	5.0 (SD 2.2, 1-10)	5.7 (SD 2.3, 1-10)	16 (24)	4.6 (SD 2.9, 1-10)	5.3 (SD 2.7, 1-10)	21 (31)
Functional mobility	133 (26)	4.9 (SD 2.3, 1-10)	5.5 (SD 2.2, 1-10)	33 (25)	4.5 (SD 2.9, 1-10)	5.1 (SD 2.8, 1-10)	37 (28)
Community management	46 (9)	5.0 (SD 2.5, 1-10)	5.2 (SD 2.3, 1-10)	9 (20)	4.5 (SD 2.9, 1-10)	5.1 (SD 2.6, 1-10)	10 (22)
Productivity	**147 (29)**			**31 (21)**			**40 (27)**
Paid/ unpaid work	24 (5)	5.8 (SD 3.2, 1-10)	6.5 (SD 3.3, 1-10)	7 (29)	4.8 (SD3.0, 1-10)	5.3 (SD 3.5, 1-10)	8 (33)
Household management	123 (24)	5.6 (SD 2.5, 1-10)	6.0 (SD 2.4, 1-10)	24 (20)	5.3 (SD 3.0, 1-10)	5.9 (SD 2.9,1-10)	32 (26)
Play/school	0	0	0	0	0	0	0
Leisure	**113 (22)**			**20 (18)**			**23 (20)**
Quiet recreation	31 (6)	5.2 (SD 3.2, 1-10)	5.3 (SD 2.7, 1-10)	8 (26)	4.4 (SD 3.4, 1-10)	5.6 (SD 2.8, 1-10)	10 (32)
Active recreation	66 (13)	5.0 (SD 2.7, 1-10)	5.5 (SD 2.6, 1-10)	11 (17)	5.3 (SD 3.2, 1-10)	5.7 (SD 3.2, 1-10)	10 (15)
Socialization	16 (3)	5.9 (SD 2.2, 1-10)	5.9 (SD 2.0, 1-9)	1 (6)	6.0 (SD 3.3, 1-10)	6.6 (SD 2.8, 2-10)	3 (19)

[a]Values are presented as mean score, SD and range; Note: Canadian Occupational Performance Measure COPM)

At discharge from interdisciplinary rehabilitation

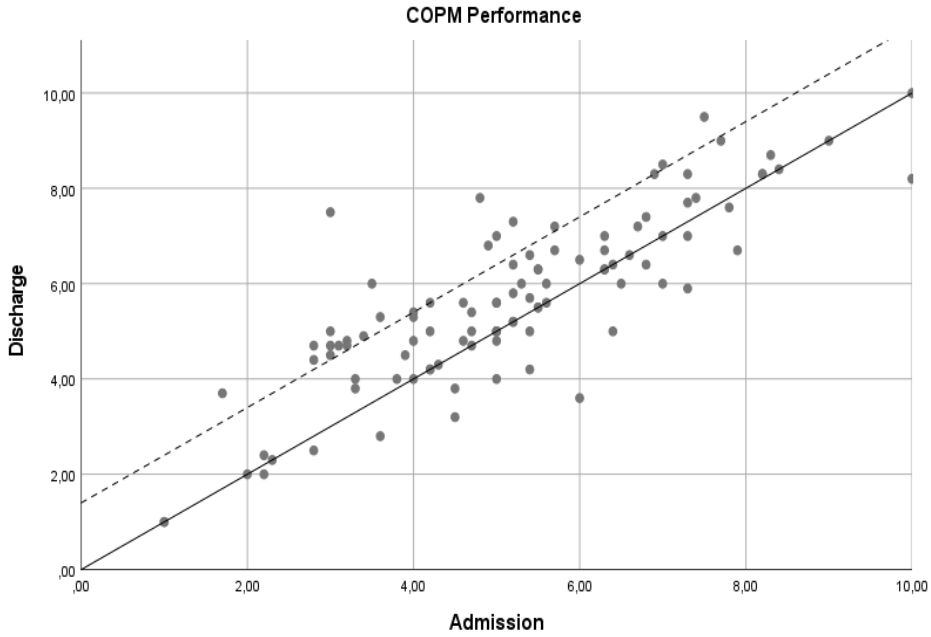
The highest mean COPM performance scores were found in the subgroup unpaid/paid work (6.5), and the lowest in the subgroup community management (5.2). For COPM satisfaction, the highest mean scores were found in socialization (6.6), and functional mobility and community management as the lowest (5.1). (See table 5).

There was a statistically significant increase in the mean COPM performance scores between admission (5.18; SD = 1.9) and discharge (5.66; SD=1.8) ($p < 0.001$). For

COPM performance, the mean increase in change scores were 0.48 with a 95% confidence interval ranging from 0.28 to 0.68. For COPM satisfaction, there was a statistically significant increase between mean scores from admission (mean = 4.90; SD =2.2) to discharge (mean=5.40; SD=2.1) ($p < 0.001$). The mean increase in COPM satisfaction change scores was 0.50 with a 95% confidence interval ranging from 0.20 to 0.80. The effect size between the change scores was 0.20 (COPM performance) and 0.22 (COPM satisfaction).

In Figure 2, plots for the mean scores for COPM performance and COPM satisfaction on admission and at discharge for each participant are presented. The dotted line indicates the cut-off for change scores of 1.4 or above for COPM performance, and change scores of 1.9 or above for COPM satisfaction (Eyssen et al., 2011). There was a statistically significant correlation between the change in COPM performance and in COPM satisfaction from admission to discharge ($r=0.43$; $p<0.00$). No statistically significant correlation was found between COPM performance on admission and the differences at discharge, or between COPM satisfaction on admission and the differences at discharge.

Twenty-three participants (22%) had change scores for COPM performance that were equal to or greater than 1.4 points, whereas for 25 participants, no change had occurred between discharge and admission, and 19 participants had change scores that had decreased at discharge. For COPM satisfaction, 19 participants (19%) had change scores that were equal to or greater than 1.9 points at discharge. For 27 participants, no change had occurred between discharge and admission for COPM satisfaction, and 22 participants had change scores that had decreased at discharge. Six participants had change scores above the cut-off for both COPM performance and COPM satisfaction.



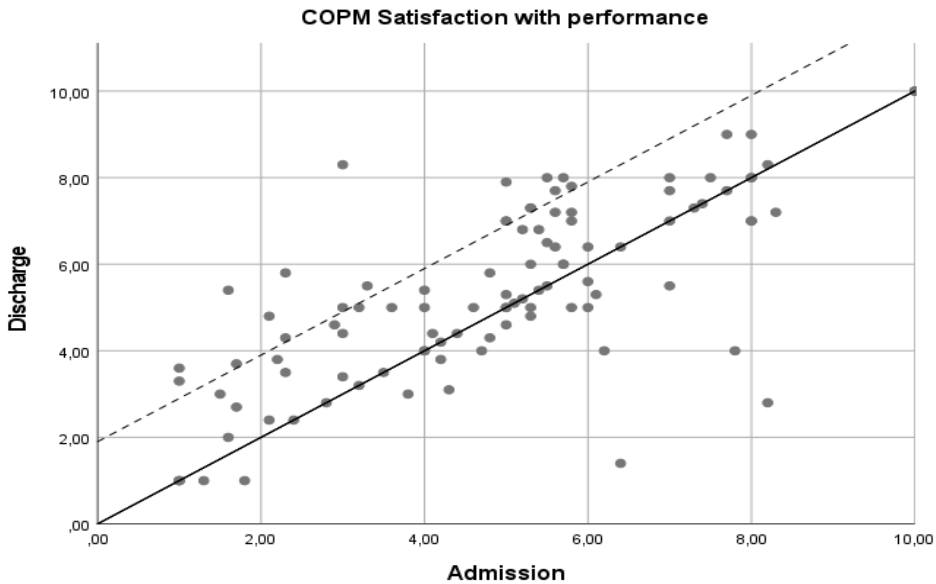


Figure 2. Each participant´s individual mean score on admission and at discharge

At discharge, 174 (35%) of the 506 prioritized activities had increased COPM performance scores, 250 (49%) were unchanged, and 74 (14%) had decreased scores compared to on admission. For COPM satisfaction, 131 (26%) activities had increased scores at discharge, 250 (49%) activities were unchanged, and 57 (11%) activities had decreased. Most of the activities with increased mean scores for COPM performance were related to the subgroups paid/unpaid work (29 %), quiet recreation (26 %), and functional mobility (25 %) (see table 5). Thirty-three percent of activities related to paid/unpaid work had improved mean scores of COPM satisfaction, 32% for quiet recreation, and 31% for personal care.

Discussion

The aim of this licentiate thesis was to increase our knowledge about activity and participation among people with LEoP who were admitted to and received comprehensive rehabilitation. Such knowledge is important because improvements in these areas can also lead to a better life satisfaction and health, despite remaining impairments (J. Lexell & Brogårdh, 2012; Gocheva et al., 2020).

In study I, the results show that there were only week associations between COPM performance, COPM satisfaction and RNL-I. This can be interpreted as if they measure similar constructs but also provide separate information regarding activity and participation. This suggests that both tools are important when measuring outcome after comprehensive rehabilitation. There is also a difference regarding how the tools are administered which may explain why they are only partially associated. For instance, the COPM is administered as a semi-structured interview, where each individual can identify unique problems relevant for her/him whereas the RNL-I has predefined fixed statements with four response alternatives.

Significant associations were found between COPM performance self-care subgroup and RNL-I daily functioning sub-scale ($p=0.028$). This is rather logical since the interview guide regarding the subgroup self-care in COPM comprises not only personal care activities but also mobility and community management, including transportation. These activities are also addressed in several of the items in RNL-I sub-scale daily functioning. Furthermore, a significant association ($p=0.025$) was found between COPM satisfaction for the subgroup leisure and RNL-I sub-scale perception of self. This may be explained by the fact that leisure activities often are performed together with others, which also are the focus in the perception of self-items in RNL-I. The findings contribute with some clarity to understanding the relation between the COPM and RNL-I. Still, more studies are needed with larger samples sizes to confirm these results.

From another perspective, the COPM provides information about how the individual perceive and reflect upon their activity and participation in all aspects of daily life, an important part in the first step of the rehabilitation process (Wressle et al., 2002). When individuals become aware of their problems in activity and participation, they are also able to start a process of change (E. M. Lexell et al., 2016; Sturkenboom et al., 2014; Wressle et al., 2002). Conversely, the RNL-I covers broader areas of activities, and no single activities are described. On the other hand,

because the RNL-I has predefined fixed statements it may be easier to use as an outcome measure than the COPM. Still, aligning with occupational therapy models, for example the Transactional Model of Occupation (Fisher & Marterella, 2019), activity and participation includes also other aspects not covered by the COPM or the RNL-I. For instance, both subjective and objective elements need to be covered, using interviews, questionnaires along with observations. Assessments tools that target other areas of activity and participation can therefore be beneficial. For instance, the Occupational Gaps Questionnaire (Eriksson, 2020) that covers aspects of which activities an individual wants to perform compared to which activities he or she actually do perform in everyday life. The Occupational Balance Questionnaire -11 (Håkansson et al., 2020) is another tool that measures aspects of an individual's perception of balance and satisfaction across different areas of daily life activities that may be relevant. However, none of them have been utilized specifically in studies regarding activity and participation among people with LEoP.

In study II, the COPM was used to measure change in activity and participation after a comprehensive rehabilitation period and showed a statistically significant increase in mean scores for both COPM performance and COPM satisfaction. These results align with previous studies evaluating rehabilitation interventions in people with LEoP (Davidson et al., 2009; Curtis et al., 2020) as well as for other diagnostic groups (Kos et al., 2016; E.M. Lexell et al., 2014; Persson et al., 2004).

The overall aim of rehabilitation is for the individual to be as independent as possible in everyday activities and enable participation in different life situations (WHO, 2024). When it comes to comprehensive rehabilitation for individuals with LEoP, it often involves interventions that require the individual to perform lifestyle changes. The lifestyle changes often involve compensatory strategies and learning new ways to perform daily activities that may involve learning new ways to use an assistive device, for instance mobility devices. Different individuals have different ways of managing and learning how to use assistive devices (Lund & Nygård, 2003). When an individual change his or her activity performance, it is not only the physical doing that change. It is also affecting the individual's habits, roles, and identity (Kielhofner, 2008). E.M. Lexell et al. (2016) described that individuals with LEoP often struggle to adapt to the consequences of their condition when participating in interdisciplinary self-management rehabilitation programme. The process of change is complex, and often take more time than the rehabilitation period itself, sometimes up to one year in total (Larsson Lund & Lexell, 2010). Similar results have been found for other diagnostic groups, indicating self-management interventions require longer implementation periods (Hagelskjaer et al., 2021; Kos et al., 2016). It is therefore reasonable to assume that if study II had conducted additional follow-up assessments six to twelve months after program completion, our participants might have shown greater improvements in their self-perceived activity and participation.

The COPM change scores in study II, comprised participants with not only increased scores, but also decreased as well as scores that never changed. This may be interpreted as a reflection of the change process that rehabilitation participants undertake. That is, it is possible that the participants had only started their process of change, which is not identified in the COPM re-evaluation (Law et al., 2019; Persson et al., 2004). Curtis et al. (2020) noted that although their participants did not meet the established threshold for improvement, they did not decline from baseline, suggesting a positive outcome for those living with a chronic condition. For people with LEoP the adaptation process can also be an ongoing process, if they experience a continuing decline due to the chronic condition (Nolvi et al., 2022; Thorén-Jönsson, 2001).

A comparison between the result from study II and the studies conducted by Davidson et al. (2009) and Curtis et al. (2020), shows that participants in study II demonstrated a larger mean change score for COPM performance than the other studies. Davidson et al. (2009) also reported higher percentages of participants experiencing improvements in both COPM performance and COPM satisfaction. This may be influenced by differences in rehabilitation approaches and participant characteristics. Even though all the three studies are based on rehabilitation programs following international guidelines and recommendation for interventions for people with LEoP, the structure of the rehabilitation varies. The rehabilitation program evaluated by Davidson et al. (2009) was mainly delivered as a group program focused on mobility issues and with many participants having prior rehabilitation experience. Consequently, their participants (Davidson et al., 2009) might have been better prepared to utilize the intervention and enact change, potentially explaining their higher change scores compared to participants in study II, who had not previously undergone interdisciplinary rehabilitation and represented a diverse range of unmet needs.

Despite having different numbers of participants, and to some extent different types of interventions, all three studies found that participants did not improve as much as expected and conclude that lifestyle interventions require longer term follow-ups.

Methodological considerations

This thesis comprises two studies with a retrospective design. Data was originally collected in a clinical context and registered into a clinical database. The database included 712 participants, who had received some kind of rehabilitation contact with the team during 2004-2015. The opportunity to conduct these studies was made possible thanks to this database. A strength was that the rehabilitation program utilized standardized and well-established instruments commonly used in both clinical rehabilitation and research, and therefore included in the database.

However, given that the two studies are built upon data from a database, there are some limitations to discuss.

A limitation is connected to how many participants that were included in the studies. Of the 712 people who received rehabilitation interventions, only 102 participants were included in the studies. There were different reasons for having to exclude many potential participants. Some were related to administration problems, and others were related to missing data for some individuals. For example, for 106 individuals only mean scores for COPM performance and COPM satisfaction were available and detailed information about their activity problems had not been registered. For another 74 individuals, the COPM had only been administered on admission and not at discharge. Despite the large number of potential participants that were excluded, the studies are among the larger papers on rehabilitation issues regarding activity and participation among people with LEoP (Davidson et al., 2009; Curtis et al., 2020). Still, clinical practice can learn from missing data in the database and in the future ascertain more complete data sets.

Data collected retrospectively can also lead to different types of missing data. For instance, in study I, there were missing data regarding RNL-I for seven participants. In one of the explorative analyses, only 47 of the 102 participants were included. This can be explained by the fact that the individual during the COPM interview not identified activities in all COPM subgroups. This is one of the challenges when using the COPM in research.

Another methodological consideration is that when several statistical analyses are made, there is an increased risk for Type 1 error. Often corrections for multiple testing are used, for example Bonferroni correction. Still, the Bonferroni correction is sensitive to Type II errors, meaning that it could fail to recognize significant associations even if they exit (Feise, 2002). We chose not use corrections for multiple testing, and therefore the result should be interpreted with caution.

In study II, the retrospective design did not enable a control group and the results reflect only the targeted sample. Thus, a comparison with individuals, who had not received comprehensive rehabilitation or no rehabilitation at all was not possible. Further, the included participants are homogenous in terms of their background. If participants with a more diverse background had been included in terms of age, ethnicity, and vocational situations, the results may have been altered. Further, there is currently a discussion regarding which thresholds that should be recommended to measure change (McColl et al., 2023).

The data from the COPM and the RNL-I were primarily collected to support the individual's rehabilitation process, i.e., the data was collected in a clinical context, and not for research purposes. It was the same rehabilitation professionals who conducted the assessments before and after rehabilitation and who also performed the interventions. It is possible that this may have influenced the outcomes regarding how the participants responded to the COPM at discharge. Moreover, despite being

an outcome measure the COPM was also administered as an important part of the individual's rehabilitation process where the individual had an opportunity to reflect upon his or her activity and participation, and to identify activities they find difficult to perform. Because the COPM is a semi-structured assessment tool, it can be slightly differently administered. During the time period between 2004-2015, several occupational therapists have been working in the team. It is therefore not ascertained that the COPM interview was administered in the same manner for all participants. For instance, due to different experience of using the COPM, which might have affected the result from the COPM interview (Enemark et al., 2021; Unsworth, 2001). Despite clear instructions on how data should be collected and registered in the database, it is difficult to verify that all data has been collected exactly in the same way for each individual.

Conclusion

In conclusion, the result from this thesis highlights the importance of using both the COPM and the RNL-I when assessing activity and participation among people with LEoP that are admitted to comprehensive rehabilitation. Both assessments offer valuable insights in, but cover different, aspects of activity and participation. At the same time, there may also be a need for additional assessments to provide a more comprehensive understanding of activity and participation in people with LEoP.

The results implies that comprehensive rehabilitation can change self-perceived activity and participation among people with LEoP, from admission to discharge. The change was manifested as both higher and lower ratings of COPM performance and COPM satisfaction suggesting participants are still in a process of change that is not yet completed. Thus, long-term follow ups are needed to measure and demonstrate changes in activity and participation.

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